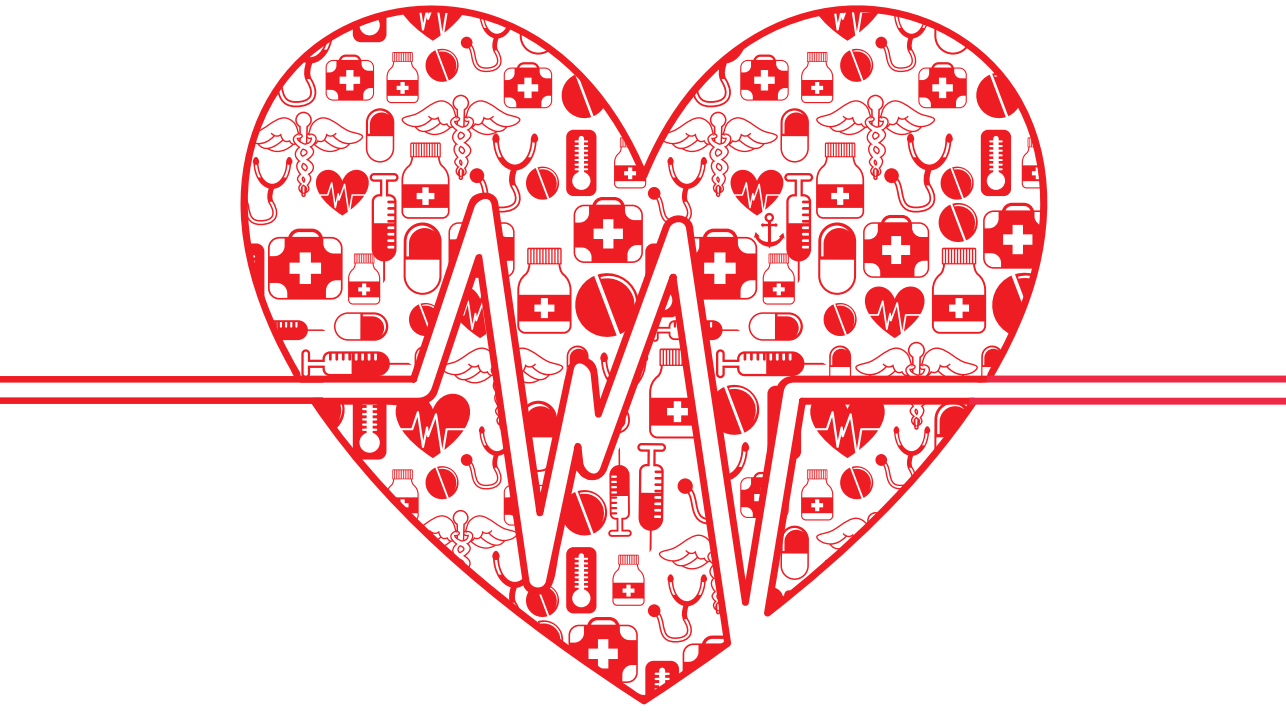
ASSESSING BARRIERS TO THE INVOLVEMENT OF EMERGENCY DEPARTMENTS IN ORGAN DONATION

CLAUDIA HELENA LOUISE MARCK



ASSESSING BARRIERS TO THE INVOLVEMENT OF EMERGENCY DEPARTMENTS IN ORGAN DONATION

CLAUDIA HELENA LOUISE MARCK

The research was funded by the Australian Organ and Tissue Authority and St Vincent's Hospital Melbourne.

ISBN: 978-94-6295-039-9
Author: Claudia Marck

Cover design: Proefschriftmaken.nl || Uitgeverij BOXPress
Printed by: Proefschriftmaken.nl || Uitgeverij BOXPress
Published by: Uitgeverij BOXPress, 's-Hertogenbosch

Assessing Barriers to the Involvement of Emergency Departments in Organ Donation

De rol van de afdeling spoedeisende hulp bij orgaandonatie

Proefschrift

Ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
op gezag van de
rector magnificus

Prof.dr. H.A.P. Pols

en volgens besluit van het College voor Promoties
De openbare verdediging zal plaatsvinden op
woensdag 14 januari 2015 om 13.30

door

Claudia Helena Louise Marck

geboren te Harderwijk

Promotiecommissie

Promotoren

Prof.dr. W. Weimar

Prof.dr. J.N.M. IJzermans

Overige leden

Prof.dr. J.J. van Busschbach

Prof.dr. J.L.C.M. van Saase

Prof.dr. H.W. Tilanus

Contents

Chapter 1

General introduction

Organ transplantation has become increasingly successful in terms of patient survival and is currently the best treatment option for patients with organ failure[1-3]. With living donor opportunities only being available for certain organs, most efforts are aimed to increase donation rates from deceased donors. In various countries, including the Netherlands and Australia the government has implemented reforms with an aim to increase the number of organ donations for life saving transplants. In this thesis the Australian approach is being analysed and compared to the management of organ donation in the Netherlands, and the involvement of ED clinicians in Australia is analysed in detail in order to find methods that can be used to optimize the donation rate.

Australia has historically had sub-optimal deceased donation rates and family consent rates compared to other countries in the developed world. Following the introduction of a national reform agenda in 2008 and the establishment of the DonateLife network in 2009 the number of organ donors has increased from 11.4 donors per million people in 2009 to 16.9 in 2013[4], a 48% increase. However, the number of people on the waiting list for an organ transplant has only decreased slightly from 1768 in 2009 to 1556 in 2013[5] and therefore the search for strategies to increase deceased donation continues.

Organ Donation after Death

Organ donation from deceased donors is firstly reliant on the community being willing to donate after death and giving consent for next of kin to donate after death. 98% of Australians agree that organ and tissue donation has the potential to save and improve lives but only 77% are generally willing to become organ and tissue donors[6]. Just over 6 million Australians are currently registered with the Australian Organ Donor Register (AODR)[7], with 99.9% registered as willing to donate. However whether or not a person is registered with the AODR, the next of kin generally makes the final decision, although this is legally not required[8]. Unfortunately, many Australians do not know the donation wishes of their family members and consent rates are currently around or below 60%[9].

Secondly, organ donation rates are highly dependent on hospital staff initiating the process by assessing donor eligibility, referring eligible patients, and discussing the topic with the next of kin[10,11]. For this reason, resources available, attitudes toward donation, and knowledge of the processes involved in OTD are critical factors which can contribute to optimal donation rates.

Missed potential donors

In 2010, 84% of organs were still donated by heart-beating brain dead patients[12]. A death audit of Victorian hospitals in 2006 showed that 21% of brain dead potential donors were either missed, or family consent was not requested[13]. Data from 2006-2008 has shown that in 10% of brain dead potential donors in Australia, families were not approached about donation[14]. In addition, there were 121 potential donors with imminent brain death for whom organ donation was also not raised with the next-of-kin. Of these patients 75 and 41 had treatment withdrawn in the ICU and ED respectively, before brain death occurred. Causes reported included: failure to recognise potential donors (predominantly in EDs), clinicians being unwilling to discuss brain death and organ donation with families prior to brain death, resource pressures, and patients of marginal medical suitability for organ

donation[14]. Thus, the failure to identify and/or refer potential donors by hospital staff contributes to sub-optimal donation rates. There is currently no data available on missed donors eligible for donation after circulatory death (DCD) although it is expected many potential DCD patients are not yet identified. Not all hospitals have implemented DCD pathways and some hospitals this is still in the implementation phase. With the adoption of the National Clinical Trigger in 2010, a national protocol aimed to assist hospital staff to identify and refer potential donors, the rates of missed potential donors should decrease. A retrospective audit of missed potential donors, which is reviewed at a hospital level with the clinicians involved will also help decrease the number of missed potential donors and these data can also guide further targeted strategies.

Healthcare professionals and organ donation

Healthcare professionals with a positive attitude toward organ and tissue donation have been shown to be more likely to elicit family consent for donation[16]. Several international studies have revealed that many healthcare professionals feel uncomfortable performing donation-related tasks such as approaching donor families, informing organ donor coordinators of potential donors, explaining brain death to family members, and providing support to the grieving family. The reasons for this discomfort appears to be related to age and/or educational status; younger and less experienced or knowledgeable health care professionals experience greater discomfort[17-19] as do those with a poor understanding of brain death[20-22]. Results from an international survey among almost 20,000 critical care staff in 11 countries, including Australia, showed that optimal donation rates were associated with support for donation, acceptance of the concept of brain death, confidence levels and average educational requirements with donation-related tasks[19].

Role of emergency clinicians in organ donation

An audit of missed potential donors in Australian hospitals revealed a substantial missed potential donor pool from EDs[14], a pattern which has also been recognized internationally[23]. End-of-life decisions regularly occur in the ED. Although the intensive care unit (ICU) might provide a more ideal environment for organ and tissue donation (OTD) related tasks, for patients with conditions thought to be non-survivable a decision is sometimes made that ICU admission is not indicated and end-of-life decisions and care occur in ED. Under these circumstances, the only opportunity for identification of a potential donor is by clarifying end-of-life decisions in the ED and then admission to ICU for consideration of potential organ donation. In addition, even when ICU admission is indicated for end of life decisions and care, transfer may take several hours and early identification of the potential for organ and tissue donation may facilitate timely referral, which can be crucial in rapidly deteriorating patients. Emergency clinicians may therefore be the primary instigators of donor referral, and the first point of contact for donor families in the initial process. ED clinicians, therefore, need to have awareness and understanding of organ donation so the opportunity for consideration of organ donation to be included in end-of-life decisions is not missed. Furthermore, international data suggests that referral of potential organ donors from the ED is associated with an increased likelihood of successful organ retrieval compared to inpatient units[24] it is essential to assess the barriers to OTD initiated in Australian EDs to optimize the national OTD rates.

Outline of the thesis

In this thesis barriers in Australian emergency departments to organ and tissue donation are assessed including attitudinal, knowledge and resource issues. Furthermore a more general overview of Australian and Dutch organ donation practices and rates will be presented and compared to identify potential areas of improvement. **Chapter two** will review personal beliefs of ED clinicians and how this affects their professional attitudes towards organ and tissue donation. **Chapter three** will show data on the organ and tissue donation related attitudes, education and practices of ED clinicians. **Chapter four** will assess resource barriers as reported by ED clinicians. **Chapter five** focuses on the knowledge of ED clinicians regarding brain death and related issues while knowledge and support of donation after cardiac death will be reviewed in **Chapter six. Chapter seven** discusses ED clinicians' knowledge and use of the Clinical Trigger, a tool to help identify potential organ donors. **Chapter eight** provides an overview of the differences and similarities in organ donation practices and rates between Australia and the Netherlands. **Chapter nine (the appendix)** is a report provided to the funding body, the Australian Organ and Tissue Authority, detailing all the findings. **Chapter ten, eleven** and **twelve** will provide a general discussion, and an English and Dutch summary of the previous chapters. **Chapter thirteen** shows my curriculum vitae and words of thanks.

References

1. Goh A. An analysis of liver transplant survival rates from the UNOS registry. *Clin Transpl.* 2008:19-34.
2. Gruessner AC, Sutherland DE. Pancreas transplant outcomes for United States (US) and non-US cases as reported to the United Network for Organ Sharing (UNOS) and the International Pancreas Transplant Registry (IPTR) as of June 2004. *Clin Transplant.* Aug 2005;19(4):433-455.
3. Meier-Kriesche HU, Ojo AO, Port FK, Arndorfer JA, Cibrik DM, Kaplan B. Survival improvement among patients with end-stage renal disease: trends over time for transplant recipients and wait-listed patients. *J Am Soc Nephrol.* Jun 2001;12(6):1293-1296.
4. DonateLife. DonateLife Australia website. 2010; www.donatelife.gov.au.
5. ANZOD. *Australia and New Zealand Organ Donation Registry 2011 report.* 2011.
6. AOTA. National Community Awareness Survey, Woolcott Research, for the Australian Organ and Tissue Authority. 2010.
7. AODR. *Australian Organ Donor Register Statistics.* 2010.
8. McCaughan G. Organ donation in Australia. *Intern Med J.* Aug 2010;40(8):603-604; author reply 604.
9. Opdam HI, Silvester W. Identifying the potential organ donor: an audit of hospital deaths. *Intensive Care Med.* Jul 2004;30(7):1390-1397.
10. Opdam HI, Silvester W. Potential for organ donation in Victoria: an audit of hospital deaths. *Med J Aust.* Sep 4 2006;185(5):250-254.
11. National Health and Medical Research Council, National Institute of Clinical Studies. Review of the National Organ Donation Collaborative. 2009

12. Lewis LM, Martin L, Hoffman T, Ruoff BE. Tissue and organ procurement in the emergency department setting. *Am J Emerg Med.* Jul 1993;11(4):347-349.
13. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA.* Jul 4 2001;286(1):71-77.
14. Akgün HS, Bilgin N, Tokalak I, Kut A, Haberal M. Organ donation: a cross-sectional survey of the knowledge and personal views of Turkish health care professionals. *Transplantation Proceedings.* 2003;35(4):1273-1275.
15. Bilgin N, Akgun HS. A focus on health care professionals in organ donation: a cross-sectional survey. *Transplantation Proceedings.* 2002;34(6):2445-2447.
16. Roels L, Spaight C, Smits J, Cohen B. Critical Care staffs' attitudes, confidence levels and educational needs correlate with countries' donation rates: data from the Donor Action® database. *Transplant International.* 2010;23(8):842-850.
17. Cohen J, Ami SB, Ashkenazi T, Singer P. Attitude of health care professionals to brain death: influence on the organ donation process. *Clin Transplant.* Mar-Apr 2008;22(2):211-215.
18. Rios A, Conesa C, Ramirez P, et al. Attitude survey of hospital workers in the surgical services toward living kidney donation. *Transplant Proc.* Nov 2005;37(9):3621-3625.
19. Schaeffner ES, Windisch W, Freidel K, Breitenfeldt K, Winkelmayer WC. Knowledge and attitude regarding organ donation among medical students and physicians. *Transplantation.* Jun 15 2004;77(11):1714-1718.
20. Aubrey P, Arber S, Tyler M. The organ donor crisis: the missed organ donor potential from the accident and emergency departments. *Transplant Proc.* May 2008;40(4):1008-1011.
21. Michael GE, O'Connor RE. The importance of emergency medicine in organ donation: successful donation is more likely when potential donors are referred from the emergency department. *Acad Emerg Med.* Sep 2009;16(9):850-858.

Chapter 2

Personal attitudes and beliefs regarding organ and tissue donation: a cross-sectional survey of Australian emergency department clinicians

Claudia H Marck, Tracey J Weiland, Sandra L Neate,

Bernadette B Hickey, and George A Jelinek

Progress in Transplantation 2012;22(3):317-22.

Abstract
Context: Resources are currently targeted at increasing organ and tissue donation rates from emergency departments in Australia. Health care professionals' beliefs and personal attitudes regarding organ and tissue donation are known to influence professional attitudes and practice.

Objective: To assess emergency department clinicians' general beliefs and personal attitudes toward organ and tissue donation, how general beliefs influence personal attitudes, and which demographic characteristics are related.

Design: A cross-sectional online survey, based on available literature and the validated and widely used Hospital Attitude Survey (DonorAction).
Participants: Data were collected from 811 Australian emergency department clinicians, invited to participate through the College of Emergency Nursing Australasia, and the Australasian College for Emergency Medicine.

Results: Most clinicians were very supportive of organ and tissue donation (962%), believed that organ and tissue donation can save lives (98.5%), and that organs and tissues will be allocated fairly (82.6%); however, 30.1% did not agree that organ and tissue donation can help the next of kin cope with grief. Holding positive general beliefs increased positive personal attitudes toward organ and tissue donation ($P < .001$). Most reported willingness to donate their own organs and tissues after death (90%) and give family consent for their children (79.6%) or adult family (86.6%) members to donate. Eighty-six percent had discussed their wishes with next of kin, but only 50.7% had registered on the Australian Organ Donor Register. Older clinicians, male clinicians, and clinicians of certain religious and cultural backgrounds were identified as having less positive general beliefs and personal attitudes.

Conclusion: Although Australian emergency department clinicians are generally positive toward organ and tissue donation, some groups could potentially benefit from education to change their beliefs and attitudes about organ and tissue donation further.

Introduction

For many people with end-stage organ failure, transplantation is the only hope for recovery. However, the increasing organ shortage results in many people dying while on waiting lists for surgery. Although Australia has a world-class reputation in terms of survival rates after transplant surgery, organ donor rates are lower than in other developed countries, despite recent attempts to address this problem.[1] Low family consent rates and failure of hospital staff to recognize and refer potential donors have been reported as some of the main reasons.[2,3]

In Australia, the recognition and referring of potential donors is the responsibility of hospital clinicians, as there are no in-house coordinators. Historically, organ and tissue donors are referred by staff in the intensive care unit (ICU), but in recent years a missed potential donor pool from the emergency department (ED) has been recognized in Australia[3] and internationally.[4] Furthermore, successful donation has been demonstrated to be more likely when donors are referred from the ED than when they are referred from inpatient units such as the ICU.[5] The Australian government has recently directed resources toward improving donation rates, including initiatives specifically aimed to optimize organ and tissue donation (OTD) initiated from the ED.[3]

General beliefs and personal attitudes of health care professionals toward OTD have been shown to influence professional attitudes and practice.[6,7] However, no data on this topic are currently available on Australian ED clinicians. In this study, part of a larger cross-sectional survey of Australian ED staff, we explored general beliefs as well as personal attitudes of ED staff toward OTD, and the association between them.

Methods

Instrument Development

The methods used in this study are described in detail elsewhere,[8] but briefly, the survey was developed by the project team, informed by the available literature. Components of the validated and commonly used Hospital Attitude Survey[9] were included in the survey with permission from DonorAction. A Delphi panel system with feedback from the project steering committee was used to ensure face validity of the draft survey. Staff members at St Vincent's Hospital in Melbourne were used to assess content validity, with 9 physicians and 10 nurses advised about the study and asked to rate survey items on a 4-point scale of relevance.[10] This assessment led to minor alteration of the survey. The final survey consisted of 133 items that required 15 minutes to complete. Survey items used graded responses with Likert scales or ordinal multicategory scales enabling quantitative analysis. Some qualitative responses were obtained by using open-ended questions. Approval for this study was obtained from the human research ethics committee at St Vincent's Hospital in Melbourne, Australia.

Procedure

An online survey of members of the College of Emergency Nursing Australasia (CENA) and the Australasian College for Emergency Medicine (ACEM) was conducted between March 21, 2011, and June 9, 2011 , by using the online tool SurveyMonkey. Members of ACEM and CENA were eligible to participate if they were currently working in an Australian ED. All 3995 eligible participants (1026 members of CENA and 2969 members of ACEM [1169 fellows and 1800 trainees]) were e-mailed an invitation to participate and a participant

information form outlining the study, participants' rights, and the anonymous nature of the survey. A hyperlink to the online questionnaire was included in the e-mail. Several reminder e-mails were distributed in the first 5 weeks, inviting participants to complete the survey if they had not already done so. It was possible to submit parts of the survey without completing the entire survey.

Sample Size

Assuming a 50% response distribution, sample size calculations showed that 351 ED clinicians were required to achieve a 5% margin of error and 95% confidence level.[11]

Data Analysis

Quantitative data were exported from the web based survey program to PASW Statistics 18.0 (IBM SPSS). For each survey item, summary statistics (either N, %, 95% CI, or mean [95% CI]) were calculated. As not all participants finished the entire survey, all percentages were adjusted to reflect the varying denominator due to missed items or non-completion. A Personal Attitudes Scale (PAS) was devised by summing 6 items (score from 0 to 6, Table 1) after verification of internal consistency of the scale with the Cronbach α. A univariate analysis of variance (ANOVA) was performed to explore main effects of non-dichotomous demographic variables (age, cultural background, religion, length of time living in Australia, and region of employment) simultaneously to minimize family-wise error rate. Post hoc Bonferroni adjustments (for multiple comparisons) were performed. Independent sample t tests were used to compare dichotomous demographics (sex and religiousness) and Bonferroni corrections were used with α set at 0.025.

Table 1 Personal Attitudes Scale items and responses (N=651)

Personal attitudes	Yes
* Would you donate some of your organs after death †	586, 90.0%
* Would you donate some of your tissues after death †	582, 89.4%
Have you registered your choice with the organ donor register	330, 50.7%
Have you informed your next of kin about your wishes concerning organ and tissue donation after your death	560, 86.0%
* Would you donate organs or tissues from an adult next of kin after his/her death	564, 86.6%,
* If you have children, or were to have children, would you donate his/her organs or tissues after death	518, 79.6%

* denotes items from the HAS [9]

† these two items were amalgamated in the HAS [9]

General beliefs toward OTD included 4 items (Table 2). Four separate independent sample t tests were used to compare effects of general beliefs (dichotomized) of OTD on PAS score. Bonferroni corrections were used in all instances with α set at 0.0125. Comparisons

between demographics and general beliefs related to OTD items were undertaken by using Chi-Square and Fisher exact test for 2 × 2 contingency tables. Two-tailed tests were used, and unless otherwise specified, α was set at 0.05.

Table 2 General beliefs of OTD and Interaction between general beliefs and personal attitudes

General beliefs of OTD			Personal Attitudes Scale		
		N, %	Mean Score	Range of score	Standard Deviation
* OTD can save lives	(strongly) disagree or neutral	10, 1.5%	1.71	0-5	2.06
	(strongly) agree	675, 98.5%	4.86	0-6	1.56
* OTD can help the next of kin cope with grief	(strongly) disagree or neutral	206, 30.1%	4.32	0-6	2.00
	(strongly) agree	479, 69.9%	5.03	0-6	1.35
* What is your general attitude on OTD	Oppose or don't know	24, 3.8%	1.63	0-6	1.64
	Support	611, 96.2%	4.95	0-6	1.46
I trust that organs and tissues will be allocated fairly	(strongly) disagree or neutral	113, 17.4%	3.50	0-6	2.24
	(strongly) agree	538, 82.6%	5.10	0-6	1.27

* denotes items from the HAS [9]

OTD = organ and tissue donation

Results

Demographics

The response rate was 20.3% overall, including 20.7% of all CENA members and 20.2% of ACEM members. As ACEM membership is compulsory for ED trainees and specialists, this reflects the actual percentage of Australian ED physicians who participated in the survey. CENA membership, however, is not obligatory and no data are currently available on the number of ED nurses working in Australia. Of the 811 participants, 434 participants (53.5%) were female. A total of 133 (16.4%) were between 21 and 30 years old, 347 (42.8%) 31 to 40 years old, 233 (28.7%) 41 to 50 years old, and 98 (12.1%) 51 years old or older. Most ED clinicians (512, 63.1%) reported an Australian or New Zealand background, followed by 148 (18.2%) of Western/Northern European and Northern American background, 40 (4.9%) of Central and East Asian background, 36 (4.4%) of Southern Asian background, 24 (3.0%) of Southern/Eastern European background, 18 (2.2%) of Middle Eastern, North African, Arab, and Jewish background, 17 (2.1%) of Southern/East African background,

and 16 (2.0%) of South American and Caribbean/Pacific Islander background. Most were born in Australia or had lived there for more than 20 years (548, 67.6%), 68 (8.4%) had lived in Australia between 10 and 20 years, and 195 (24.0%) had lived in Australia for fewer than 10 years. Almost half of the respondents reported being atheist or nonreligious (388, 47.8%), 331 (40.8%) were Christian or Catholic, 40 (4.9%) selected "other" or "prefer not to say," 33 (4.1%) were Buddhist or Hindu, and 19 (2.3%) were Muslim. Not taking into consideration ED clinicians who preferred not to disclose their religion (n = 17), 353 (44.5%) were not religious and 441 (55.5%) were. See Figure 1 for representation of respondents' state or territory of employment.

Figure 1 Respondents' states and territories of employment (N=811)VIC=Victoria, NSW= New South Wales, QLD= Queensland, WA= Western Australia, SA= South Australia, TAS=Tasmania, NT= Northern Territory, ACT= Australian Capital Territory

Personal Attitudes toward OTD

The vast majority of ED clinicians (90%) indicated that they would donate their own organs and tissues after death as well as their adult next of kin's (86.6%) or give family consent for (current or future) children's organ and tissues (79.6%; Table 1). Most (86%) had informed their next of kin about their OTD-related wishes; however, only around half the respondents (50.7%) had registered their wish with the Australian Organ Donor Register.

The Cronbach α of the PAS was good at 0.81. The mean score for all respondents on this scale was 4.82 (SD, 1.60; range, 0-6). A t test showed that female clinicians scored higher (and thus held more positive personal attitudes) than male clinicians did ($t = 3.2$, $P<.001$; Table 3), and that nonreligious or atheist ED clinicians scored higher than religious clinicians scored ($t=2.8$, $P= .006$). ANOVA revealed significant differences in the PAS score for age ($F(3,627) =5.8$, $P<.001$) and religion ($F(4,627)=6.7$, $P<.001$). Post-hoc tests showed that Buddhist or Hindu clinicians scored lower than nonreligious/atheist clinicians scored ($P =.002$), and Muslim clinicians scored lower than clinicians in all other religion groups scored (Buddhist/Hindu, $P= .023$; Christian/Catholic, $P< .001$; nonreligious/atheist and

other/prefer not to say category, all P< .009). Younger clinicians (31-40 years old) scored higher than older clinicians (≥51 years old, P=.028). ANOVA yielded no significant results for cultural background, region of employment, and length of time living in Australia.

General Beliefs on OTD

There was overwhelming support from ED clinicians (96.2%) for OTD in general, and almost all respondents (98.5%) agreed that OTD can save lives (Table 2). Most respondents (82.6%) trusted that organs and tissues will be allocated fairly. Although the majority (69.9%) agreed, more than a quarter (25.2%) were unsure whether OTD could help the next of kin cope with grief, and a small subgroup (4.9%) disagreed with this sentiment. The t tests also showed that those who believe that OTD can save lives (t=53,P< .001), OTD can help the next of kin cope with grief (t =4.5, P< .001), support the donation of organ and tissues for transplantation (t = 10.9, P< .001), and who trust that organs and tissues will be allocated fairly (t=7.4, P< .001) obtained a higher score on the PAS (Table 2).

Table 3 Personal attitudes according to demographics (N=651)

Demographics		Personal Attitudes Scale		
		Mean	Range	Standard Deviation
Gender *	male	4.59	0-6	1.72
	female	5.01	0-6	1.47
Age *	21-30	4.87	0-6	1.63
	31-40	4.99	0-6	1.37
	41-50	4.70	0-6	1.74
	51 and over	4.43	0-6	1.90
Religion *	Other and prefer not to say	4.03	0-6	1.96
	Not religious or atheist	5.09	0-6	1.29
	Christianity and Catholicism	4.81	0-6	1.67
	Buddhism and Hinduism	3.96	0-6	1.88
	Islam	2.43	0-5	2.06

*p<0.01

General beliefs were analyzed according to demographic groups (Table 4). Atheist or non-religious clinicians were more likely to support OTD for transplantation in general than were clinicians who indicated that they were religious (P = .049); males were less likely to agree that organs and tissues will be allocated fairly (P = .005); and clinicians of certain

cultural (Asian or Southern and Eastern European; P< .001) and religious (Buddhist, Hindu or Muslim; P= .012) backgrounds were less likely to agree that OTD can help the next of kin cope with grief (Table 4).

Table 4 General beliefs towards organ donation related to demographics

Demographics (N=685)		OTD can help the next of kin cope with grief	
		(strongly) disagree or neutral	(strongly) agree
Main cultural background **	Australian and New Zealand	123 (27.6)	323 (72.4)
	South American, Caribbean Islander and Pacific Islander	5 (38.5)	8 (61.5)
	Western and Northern European and Northern American	25 (21.7)	90 (78.3)
	Southern and Eastern Europe	12 (54.5)	10 (45.5)
	Middle Eastern, North African, Arab and Jewish	6 (40.0)	9 (60.0)
	Southern Asian	16 (57.1)	12 (42.9)
	Central and East Asian	16 (51.6)	15 (48.4)
	Southern and East African	3 (20.0)	12 (80.0)
Religion **	Other and prefer not to say	14 (42.4)	19 (57.6)
	Not religious or atheist	98 (29.7)	232 (70.3)
	Christianity and Catholicism	74 (26.1)	209 (73.9)
	Buddhism and Hinduism	13 (52.0)	12 (48.0)
	Islam	7 (50.0)	7 (50.0)

Demographics (N=635)		What is your general attitude on OTD	
		Support	Oppose or don't know
Religious *	Not religious/atheist	270 (98.2)	5 (1.8)
	Religious	333 (95.1)	17 (4.9)

Demographics (N=651)		I trust that organs and tissues will be allocated fairly	
	(strongly) disagree or neutral		(strongly) agree
	male	64 (22.2)	224 (77.8)
Gender **	female	49 (13.5)	314 (86.5)

* p<0.05, ** p≤0.01

OTD = organ and tissue donation

Discussion

Healthcare workers' attitudes toward OTD influence their professional behavior in requesting organ donation and the chances of a successful outcome.[7] Our study reveals that Australian ED clinicians are very supportive of OTD for transplantation in general and overwhelmingly hold positive beliefs about OTD. The smaller groups holding less positive views tended to be male and religious. A significant proportion of Australian ED clinicians are unsure about whether OTD can help the next of kin cope with grief, mainly clinicians of Southern and Eastern Europe and Asian background, and Buddhist, Hindu, and Muslim religions. Evidence suggests that not only does OTD not compromise the ability of next of kin to cope with grief, it might be beneficial for some.[2] It is important that ED staff are aware of this, as previous research has shown that health care professionals are more successful in initiating and supporting the process of OTD and therefore contributing to obtaining consent for OTD if they believe it will benefit the donor's family.[7]

Our results show that ED clinicians' general beliefs regarding OTD are closely related to their personal attitudes. Those who are supportive of OTD in general believe that OTD can save lives, that organs and tissues will be allocated fairly, and that OTD can help the next of kin cope with grief; they are generally more willing to donate themselves, give family consent, and communicate or register their wishes regarding OTD. The majority of ED staff hold very positive personal attitudes toward OTD; most are willing to donate and give family consent and have discussed their wish with next of kin. However, as reported in previous studies,[16,17] we found that this does not translate into formally registering their wishes on the Australian Organ Donor Register. Education about the positive effects of OTD, not only on organ and tissue recipients, but on the donor's family as well, may assist in reassuring ED clinicians and modifying professional behavior. As positive personal attitudes toward OTD correlate strongly with optimal donation rates,[6] such education may assist in improving rates of OTD from ED in Australia.

Demographic differences in personal attitudes to organ donation were mainly related to sex, age, religion, and cultural background. Males, older participants, Buddhists, Hindus, participants with an Asian or Mediterranean background, and especially Muslims seem less willing to donate their own or family members' organs and tissues and to communicate and register their wishes. These results appear to reflect attitudes of the broader Australian

population, as results of a recent study among Australian university students and their friends and relatives indicated that male, older, religious (especially Buddhist and Muslim) respondents had less favorable attitudes toward OTD.[8]

Further (qualitative) research could determine the specific issues that ED clinicians with particular demographics have regarding OTD. Although it is important to respect the personal views of ED clinicians, evidence suggests that attitudes are strongly affected by education.[6,7] Therefore, education addressing these issues directed to ED clinicians may aid in removing concerns and improving positive attitudes toward OTD. Additionally, as we know that Australian ED clinicians from certain cultural and religious backgrounds are less likely to have received voluntary education on OTD,[9] it might be beneficial to make OTD training compulsory for all ED clinicians, especially those trained overseas, by including it in their curriculum. This training is essential because in Australia there are no in-house organ procurement coordinators, and ED clinicians are responsible for recognizing and referring potential donors from the ED as well as introducing the subject to the next of kin.

Study Limitations

The response rate was low overall, but we received more than double the amount of responses needed according to our calculated sample size. Also, our response rate was considerably higher than in previous surveys of Australian ED clinicians.[20,21] However, it is important to note the risk of non-responder bias.

Certain items of the Hospital Attitude Survey were slightly amended to suit the online survey format, which, although not anticipated, could have affected the validity of the instrument. For purposes of statistical analyses, we summed items from the survey to construct the PAS, which has not previously been validated, as has been done before with other items from the Hospital Attitude Survey.[22]

Conclusion

The general beliefs of Australian ED clinicians affect their personal attitudes toward OTD. Those with positive general beliefs are more likely to report willingness to donate, and to give family consent, to have told next of kin of their wish, and to have registered their choice. Although Australian ED clinicians hold very positive general beliefs and personal attitudes toward OTD, some groups have attitudes that might be hindering optimal OTD rates. OTD education could change beliefs and attitudes about OTD further, particularly with respect to the impact of OTD on the next of kin.

Acknowledgments

The authors thank the steering committee members: Katherine Bowman, Dr Nicola Cunningham, Bernadine Dwyer, Dr Curtis Leacock, and Margaret Maslin.

Financial Disclosures

This study was supported by the Organ and Tissue Authority.

References

1. DonateLife, Australia, http://www.donatelife.gov.au. Accessed June 16, 2012.
2. Opdam HI, Silvester W. Potential for organ donation in Victoria: an audit of hospital deaths. Med J Australia. 2006;185(5):25O-254.
3. Louise Greene Consulting for The National Health and Medical Research Council National Institute of Clinical Studies. Review of the National Organ Donation Collaborative, Interim Report. May 2009. http://www.donatelife.gov.au/Media/docs / National%20Organ%20Donor%20Collabotative%20Interim%20Review-04666ca4-19dl-4b6b-86b9-b2939b04b08b-0.pdf. Accessed June 28, 2012.
4. Aubrey P, Arber S, Tyler M. The organ donor crisis: the missed organ donor potential from the accident and emergency departments. Transplant Proc. 2008;40(4):1008-1011.
5. Michael GE, O'Connor RE. The importance of emergency medicine in organ donation: successful donation is more likely when potential donors are referred from the emergency department. Acad Emerg Med. 2O09;16(9):850-858.
6. Roels L, Spaight C, Smits J, Cohen B. Critical care staffs' attitudes, confidence levels and educational needs correlate with countries' donation rates: data from the Donor Action® database. Transplant Int. 2010;23(8):842-850.
7. Siminoff LA, Arnold RM, Caplan AL. Health care professional attitudes toward donation: effect on practice and procurement. J Trauma. 1995;39(3):553-559.
8. Marck CH, Weiland TJ, Neate SL, Hickey BB, Jelinek GA. Assessing Barriers to Organ and Tissue Donation in Emergency Departments: Emergency Practice Innovation Centre, St Vincent's Hospital Melbourne; 2012. http://donatelifeforum .com.au/downloads/The_ABODE_study.pdf. Accessed June 27,2012.
9. Donor Action Foundation. The Hospital Attitude Survey, 1996. http://www.donoraction.org. Accessed March 21 , 2012.
10. Lynn MR. Determination and quantification of content validity. NursRes. 1986;35(6):382-385.
11. Raosoft. Sample Size Calculator, http://www.raosoft.com /samplesize.html. Accessed January 16, 2012.
12. Beard J, Ireland L, Davis N, Barr J. Tissue donation: what does it mean to families? Prog Transplant. 2002;12(l):42-48.
13. Cleiren MP, Van Zoelen AA. Post-mortem organ donation and grief: a study of consent, refusal and well-being in bereavement. Death Stud. 2002;26(10):837-849.
14. Bellali T, Papadatou D. Parental grief following the brain death of a child: does consent or refusal to organ donation affect their grief? Death Stud. 2006;30(10):883-917.
15. Merchant SJ, Yoshida EM, Lee TK, Richardson P, Karlsbjerg KM, Cheung E. Exploring the psychological effects of deceased organ donation on the families of the organ donors. Clin Transplant. 2008;22(3):341-347.
16. Chung CK, Ng CW, Li JY, et al. Attitudes, knowledge, and actions with regard to organ donation among Hong Kong medical students. Hong Kong Med J. 2008;14(4):278-285.
17. Sirois BC, Sears SF Jr, Marhefka S. Do new drivers equal new donors? An examination of factors influencing organ donation attitudes and behaviors in adolescents. JBehav Med. 2O05;28(2): 201-212.
18. Wakefield CE, Reid J, Homewood J. Religious and ethnic influences on willingness to donate organs and donor behavior: an Australian perspective. Prog Transplant. 2011;21(2): 161-168.

19. Jelinek GA, Marck CH, Weiland TJ, Neate SL, Hickey BB. Organ and tissue donation-related attitudes, education and practices of emergency department clinicians in Australia: a national survey. Emerg Med Australasia. 2012;24(3):244-250.
20. Sivakumar S, Weiland TJ, Gertdz MF, Knott J, Jelinek GA. Mental health related learning needs of clinicians working in Australian emergency departments: a national survey of self reported confidence and knowledge. Emerg Med Australasia. 2011;23(6):697-711.
21. Wong RE, Weiland TJ, Jelinek GA. Emergency clinicians' attitudes and decisions in patient scenarios involving advance directives [published online ahead of print October 19, 2011]. Emerg Med J. doi:10.1136/emermed-201 1-200287
22. Pugliese MR, Degli Esposti D, Venturoli N, et al. Hospital attitude survey on organ donation in the Emilia-Romagna region, Italy. Transplant Int. 2001;14(6):41 1-419.

Chapter 3

Organ and tissue donation-related attitudes, education and practices of emergency department clinicians in Australia

George A Jelinek, Claudia H Marck, Tracey J Weiland,

Sandra L Neate, and Bernadette B Hickey

Emergency Medicine Australasia 2012;24(3):244-50.

Abstract

Objective: The ED is emerging as a priority for efforts to improve rates of organ and tissue donation (OTD) in Australia, but little is known of ED clinicians' attitudes, education or practices in the area. We aimed to determine the attitudes and OTD-related educational background and practices of Australian ED clinicians.

Methods: This was a national cross-sectional survey of members of the Australasian College for Emergency Medicine (ACEM) and the College of Emergency Nursing Australasia (CENA); online questionnaire of 133 items, graded responses using Likert and ordinal multi-category scales, plus open-ended qualitative questions.

Results: Of 2969 ACEM members, 599 (20.2%) responded; of 1026 CENA members, 212 (20.7%) responded. Respondents were broadly representative of the membership, with male trainee specialists underrepresented. Most ED staff supported OTD, although many were not certain that facilitating OTD was their role, or that the ED was the right place to identify donors. Around a quarter of medical and nursing staff had received no education regarding OTD. Having received education was related to professional status, cultural background, place of work and years of experience, and was significantly associated with attitude towards OTD and whether staff participated in OTD-related tasks.

Conclusions: More education on OTD is needed and requested by ED clinicians in Australia, particularly on OTD after cardiac death, management of a donor, brain death and obtaining consent. Postgraduate curricula should reflect this need for more OTD-related education in emergency medicine and nursing.

Introduction

Health-care professionals with a positive attitude towards organ and tissue donation (OTD) are more likely to refer potential donors as well as elicit family consent for donation.[1,2] However, many health-care professionals feel uncomfortable performing donation-related tasks, such as approaching donor families, referring potential donors, explaining brain death to family members and providing support to the grieving family. The reasons for this discomfort appear to be related to age and/or educational status: younger and less experienced health-care professionals experience greater discomfort[3–5] as do those with poor knowledge.[6–8] Results from an international survey among almost 20 000 critical care staff in 11 countries, including Australia, showed that optimal donation rates were associated with support for donation, acceptance of the concept of brain death, confidence levels and some educational background in OTD-related tasks.[5]

An audit of missed potential donors in Australian hospitals revealed a substantial missed potential donor pool from EDs,[9] which has also been recognized internationally.[10] Emergency clinicians are often the primary instigators of donor referral, and the first point of contact for potential donor families. International data suggest that referral of potential organ donors from the ED is associated with an increased likelihood of successful organ retrieval compared with inpatient units.[11] In Australia, this has been recognized as a high priority with the introduction of the GIVE Trigger[9] into Australian EDs, a tool designed to optimize recognition and referral of potential donors. To assist in optimizing national OTD rates, we felt it important to assess the barriers to OTD initiated in Australian EDs. This study, part of a larger national study into OTD in Australia, aimed to assess attitudinal and educational barriers of ED clinicians to OTD, and the interaction between these factors.

Methods

Project oversight

The study was overseen by a steering committee, consisting of representatives from St. Vincent's Hospital Melbourne (SVHM), Melbourne, Australia, and an external member from DonateLife, and was chaired by the SVHM Co-Medical Director of Organ and Tissue Donation. The SVHM members comprised representatives from the ED, intensive care unit, hospital consultants and trainees, and a project officer. The committee held meetings throughout the project and maintained email contact to review the questionnaire design, pilot data collection, national data collection and data analysis phases.

Instrument design and development

Survey development was informed by available literature on organ donation with assistance from the steering committee. The survey included part of the Hospital Attitude Survey, a validated and widely used questionnaire to assess attitudes of hospital staff towards OTD developed by the Donor Action Program.[12] Face validity of the draft survey items was ensured through iterative feedback between steering committee staff using a Delphi panel system.

Pilot phase and survey refinement
Study design
Content validity was formally assessed during the pilot phase, using a cross-sectional survey of a sample of nurses and doctors working at SVHM ED.

Procedure
Participants of the pilot phase were requested to complete a survey wherein each survey item was rated according to relevance.[13] Participants were asked to provide free text comments regarding the wording and structure of items if they felt there were content areas that required further exploration, and about the survey generally.

Data analysis
Nine doctors and 10 nurses returned a completed survey. Participant responses using the four-point ordinal scales were used to calculate the content validity index of survey items and the instrument as a whole, as outlined by Lynn.[13] Participant comments about items and the instrument were considered by the researchers. As a result of the pilot, and consideration by the steering committee, the survey was slightly altered.

National cross-sectional survey
Study design
This was a cross-sectional survey of a national sample of nurses and doctors working in Australian EDs.

Participants
Eligible participants were fellows and trainees of the Australasian College for Emergency Medicine (ACEM) or members of the College for Emergency Nursing Australasia (CENA), working in an ED in Australia. The survey was sent to 3995 potential participants, comprising 2969 members of ACEM (1169 fellows and 1800 trainees) and 1026 members of CENA.

Survey
The final survey comprised 133 items. Graded responses using Likert and ordinal multicategory scales to enable quantitative statistical analysis were used. Open-ended questions were used to elicit qualitative responses.

Sample size
Assuming a 50% response distribution, 280 CENA and 341 ACEM members were required for a 5% margin of error and 95% confidence level.[14]

Procedure
The survey was sent electronically through ACEM and CENA. Fellows and trainees of the ACEM and members of the CENA were emailed an introductory email, which contained an invitation to participate, participant information and a hyperlink to the electronic questionnaire. Responses were collected over 11 weeks in early 2011. Several reminder emails were sent. The online survey package, 'Survey Monkey', was used for ease of response and respondent anonymity.

Participation in the survey was voluntary. Participants were advised that partial or full completion of the survey was taken as implied consent. Participants were able to withdraw from completing the questionnaire at any time; however, it was not possible to withdraw their data once they had submitted (part of) the questionnaire, as all data were non-identifiable.

Data analyses

Quantitative data were exported from the web-based survey program to pasw Statistics 18.0 (Chicago, IL, USA). For each survey item summary statistics (%, confidence interval, medians) were calculated for the sample, and by demographics, including staff type (e.g. nursing or medical), level and years working in EDs. Although descriptive analyses were undertaken, we also completed exploratory inferential analyses. For nominal data, comparisons between groups were undertaken using $\chi 2$, Fisher's exact test for 2×2 contingency tables. Mann–Whitney U- and Kruskall–Wallis tests were used for analyses of ordinal data. Qualitative data were summarized.

Ethics approval

The study was approved by the Human Research Ethics Committee of SVHM (protocol 154/10).

Results

Response rates and demographics

A total of 811 participants started the survey; 648 (79.9%) completed the full survey. Two participants were omitted because of data errors. Of 1026 invited CENA members, 212 (20.7%) started and 162 (15.8%) completed the survey; members from NSW were underrepresented, whereas Victorian members were overrepresented. CENA could not provide data on sex or age of members. Of 2969 invited ACEM members, 599 (20.2%) started and 486 (16.4%) completed the survey; members from Queensland and male trainees were significantly underrepresented, and fellows, both male and female, were overrepresented. The representation and demographics of the groups are listed in Tables 1 and 2.

Table 1. Representation of CENA and ACEM members according to jurisdiction, sex and member type

State or territory	CENA members in Australia	CENA members in survey	ACEM members in Australia	ACEM members in survey
NT	24 (2.3)	5 (2.4)	42 (1.4)	16 (2.7)
ACT	37 (3.6)	7 (3.3)	54 (1.8)	13 (2.2)
Tas.	36 (3.5)	8 (3.8)	74 (2.5)	25 (4.2)
SA	70 (6.8)	16 (7.5)	210 (7.1)	40 (6.7)
WA	98 (9.6)	16 (7.5)	325 (10.9)	69 (11.5)
Qld	198 (19.3)	26 (12.3)	698 (23.5)	104 (17.4)
NSW	265 (25.8)	37 (17.5)	814 (27.4)	154 (25.7)
Vic.	298 (29.0)	97 (45.8)	752 (25.3)	178 (29.7)
Male fellows			829 (27.9)	200 (33.5)
Female fellows			340 (11.5)	112 (18.8)
Male trainees			1078 (36.3)	137 (22.9)
Female trainees			722 (24.3)	148 (24.8)

Data are presented as n (%). ACEM, Australasian College for Emergency Medicine; CENA, College of Emergency Nursing Australasia.

Table 2. Demographical variables according to staff type

	ACEM	CENA
Median age in years (interquartile range)	38.0 (33–44)	41.1 (32–49)
Sex		
Female	262 (43.7)	172 (81.1)
Male	337 (56.3)	40 (18.9)
Duration of living in Australia		
Born in Australia	252 (42.1)	168 (79.2)
Less than 5 years	107 (17.9)	1 (0.5)
Between 5 and 10 years	83 (13.9)	4 (1.9)
Between 10 and 15 years	47 (7.8)	3 (1.4)
Between 15 and 20 years	16 (2.7)	2 (0.9)
Between 20 and 25 years	14 (2.3)	5 (2.4)
25 years or more	80 (13.4)	29 (13.7)

Type of hospital	ACEM	CENA
Major referral	344 (57.4)	104 (49.1)
Major regional/rural base	127 (21.2)	54 (25.5)
Urban district	118 (19.7)	52 (24.5)
Private hospital	10 (1.7)	2 (0.9)
Average work hours per week		
Less than 10	35 (5.8)	28 (13.2)
10–20	93 (15.5)	29 (13.7)
21–30	129 (21.5)	40 (18.9)
31 or more	342 (57.1)	115 (54.2)
Experience working in EDs in years		
0–5	177 (29.5)	49 (23.1)
6–10	158 (26.4)	66 (31.1)
11–15	121 (20.2)	38 (17.9)
16–20	68 (11.4)	23 (10.8)
21–25	47 (7.8)	24 (11.3)
26 or more	28 (4.7)	12 (5.7)
Staff position		
Other postgraduate qualification (masters)		19 (9.0)
ANUM		19 (9.0)
Other nurse		30 (14.1)
Grade 2 nurse		34 (16.0)
Postgraduate qualification in emergency or critical care		110 (51.9)
Other medical specialist	2 (0.3)	
Provisional trainee in emergency medicine	101 (16.9)	
Advanced trainee in emergency medicine	184 (30.7)	
FACEM	312 (52.1)	
Total	599 (73.9)	212 (26.1)

Data are presented as n *(%) unless stated otherwise. ACEM, Australasian College for Emergency Medicine; ANUM, Associate Nurse Unit Manager; CENA, College of Emergency Nursing Australasia; FACEM, Fellow of ACEM.*

Attitudes or beliefs about organ and tissue donation in the ED

Of 685 participants completing this section, almost all medical staff (98.8%) and nursing staff (97.7%) agreed that OTD can save lives. The majority of staff denied that OTD is something they just don't think about (73.7% medical, 67.8% nursing), and the majority agreed that facilitating OTD is a rewarding experience (70.4% medical, 66.7% nursing). Around half of staff (54.5% medical, 50.9% nursing) agreed that the costs of OTD are not

high compared with the benefits. The majority of medical (63.4%) and nursing (57.9%) staff disagreed with the statement 'facilitating OTD is not my role'. Medical and nursing staff were divided over the statement 'I feel obligated to offer the donor family the option of OTD', where 44.2% of medical staff disagreed and 39.3% were neutral, 35.1% of nursing staff disagreed and 46.2% were neutral. Most staff disagreed that 'the ED is not the right place to identify potential donors' (59.9% of medical staff and 67.7% of nursing staff).

Organ and tissue donation-related training or education

As respondents were asked to tick one or more responses, the percentages reported at each reply correspond to the proportion of the 785 respondents to this section per staff category. The modal response for both medical and nursing staff was that they had received departmental training (37.0% of medical and 38.8% of nursing staff); however, the second most common reply was that no education or training in regards to OTD had been received (29.2% of medical and 23.8% of nursing staff). The type of training received is shown in Figure 1.

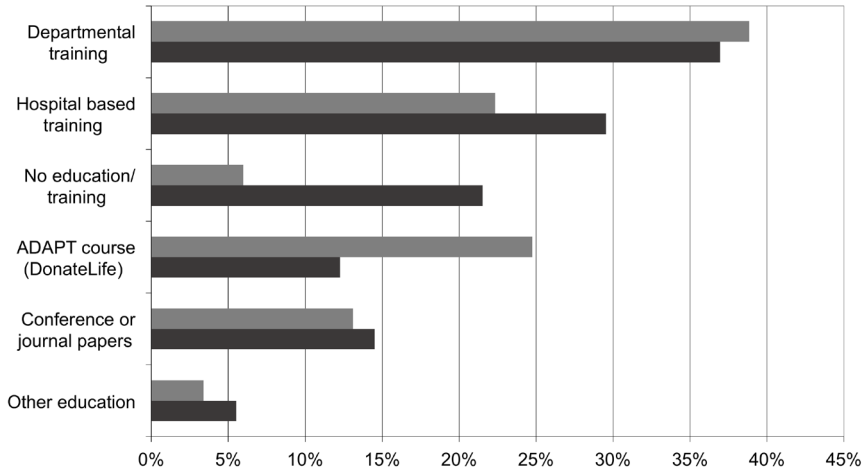


Figure 1. Percentage of (■) medical and (■) nursing staff according to organ and tissue donation-related training or education received. ADAPT, Australasian Donor Awareness Program.

Whether staff had received education or training regarding OTD was related to cultural background ($P < 0.01$); most Australians and New Zealanders had received education (n= 500, 76.4% educated), as had most Europeans and North Americans (n= 144, 69.4%), whereas fewer Asian (n= 70, 54.3%) and Middle Eastern (n= 17, 52.9%) participants had received education. Receiving education was also related to length of living in Australia ($P < 0.01$), with those living longer than 20 years or born in Australia highest (n= 531, 77.4% educated), compared with those living here 1–10 years (n= 189, 64.0%).

Religious background was associated strongly (P < 0.01) with whether or not clinicians had received education, with high percentages having received education among Christians (n= 320, 76.6%), atheists or those not religious (n= 379, 73.4%) and those who preferred not to say or other religion (n= 31, 71.0%), whereas fewer had received education about OTD among those identifying with Buddhism and Hinduism (n= 30, 40.0%) and Islam (n= 17, 41.2%). Years of experience in EDs were also relevant (P= 0.01), with those working 16–20 years the most likely to have received education (n= 91, 83.5%), and those working 0–5 years the least likely (n= 218, 66.1%).

Involvement with organ and tissue donation-related tasks

Of 785 participants completing this section, 28.7% had no experience with OTD-related tasks at all during the preceding calendar year. Identifying and caring for potential donors were the tasks most frequently experienced, but only 50% of staff had experience with this in the preceding calendar year. Obtaining consent for OTD was the least reported task (Fig. 2). Whether or not staff had experience with OTD-related tasks in the preceding year was related to sex, with men more likely (n= 361, 75.1% vs 68.2%, P= 0.04).

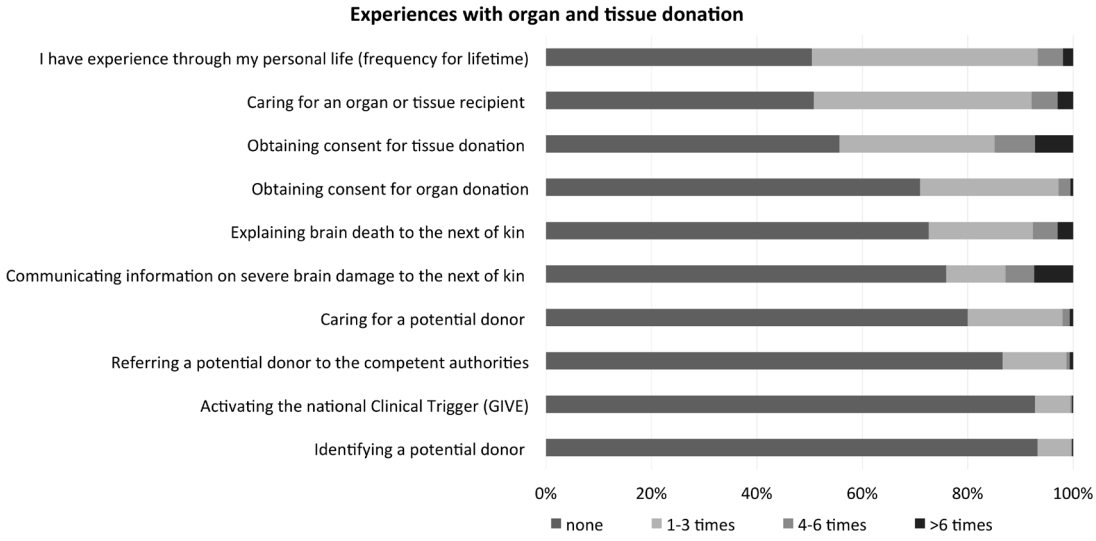


Figure 2. Percentage of respondents according to organ and tissue donation-related experience in the last calendar year.
GIVE, (potential donors who have) GCS of 5 or less, are Intubated, Ventilated and End of life care is considered for.

Experience with these tasks was also related to: region (P= 0.03), with Tasmanians the most likely (n= 33, 81.8%) and South Australians the least likely (n= 54, 59.3%); type of hospital (P < 0.01), with those working in major referral hospitals most likely (n= 431, 77.1%) versus those in urban district hospitals (166, 59.6%); and staff type (P < 0.01), with medical staff (n= 579, 78.4%) much more likely than nursing staff (n= 206, 51.5%).

Experience with OTD-related tasks in the previous year was also clearly related to whether or not respondents had received OTD-related education (P < 0.01), with those having received education (n= 569, 76.6%) more likely than those that did not (n= 216, 57.4%). Experience was also related to attitudes: clinicians who agreed or were neutral that facilitating OTD was not their role were less likely (n= 190, 35.4%) to have undertaken OTD-related tasks in the previous year than those disagreeing (n= 347, 64.6%) with this statement (P= 0.02).

Educational needs

The optional last question asked respondents to report any educational needs regarding OTD. Of 648 respondents finishing the survey, 499 (77.0%) responded. OTD after cardiac death was the most often selected area requiring education (79.8%), followed by clinical management of a donor (68.9%), brain death (66.9%), obtaining consent (66.5%), the use of the GIVE Trigger (64.7%), family issues in decision-making (60.1%), coordinating OTD in the hospital (56.7%), religious and cultural beliefs and OTD (56.3%), family grief counselling (47.7%), communication skills (45.1%), and other (6.6%).

Discussion

This study is the first national Australian study of the attitudes, educational background and practice of ED clinicians in OTD. It identifies a complex interaction between ED clinicians' status, experience, place of work, attitudes and educational background on OTD and their likelihood of being involved in OTD-related tasks in their day-to-day work. Virtually all ED clinicians, medical and nursing, affirm that OTD saves lives, and the majority feel their involvement is rewarding. However, a significant number of clinicians feel that facilitating OTD is not their role and that the ED is not the right place to identify donors, and are sceptical about the cost–benefits of OTD, despite evidence to the contrary.[15–19] Crucially, as in previous studies,[1,5,20] we have shown OTD-related education to be a key ingredient shaping attitudes and experience.

The data suggest that there are barriers to accessing this education and training. For the average experienced ED clinician in this study, living in Australia, of Australian background, and working in a major referral hospital, there did not appear to be great difficulty in accessing education, albeit with some regional differences. However, for those respondents originally from Asia and the Middle East, identifying with Buddhism, Hinduism or Islam, and relatively new to the ED, there appeared to be barriers to educational opportunities, which translated to lack of engagement with the process of OTD in day-to-day work. Further, education appears to shape attitudes; in turn, a belief that facilitating OTD is indeed the role of an ED clinician clearly influences the likelihood that the clinician will get involved with OTD. If rates of OTD are to improve in Australia, these barriers need to be addressed.

Fortunately, the great majority of ED clinicians appear to recognize that education is a key factor and desire more educational opportunities. There is clearly a need for relevant OTD authorities in Australia and their delegates in hospitals to make the process of OTD after cardiac death more easily understood by clinicians, to further support and disseminate information regarding the GIVE Trigger for EDs, and offer a variety of educational opportunities, particularly for overseas trained doctors and new staff in the ED. ED postgraduate curricula should reflect this need for more OTD-related education in emergency medicine and nursing.

Study limitations

The response rate overall was considerably higher than in previous surveys of this clinician cohort;[21,22] however, for the nursing cohort, it was below the calculated sample size. Additionally, the proportion of emergency nurses who are members of CENA is not known. The results might therefore lack generalizability for the nursing cohort. This response rate also affects the margin of error, thereby limiting the precision in some of the estimates made in this study.

Conclusions

Education about OTD is a key component in shaping the OTD-related attitudes and practice of clinicians working in Australian EDs. Our data suggest that providing more educational opportunities may assist in improving OTD rates from EDs in Australia.

Competing interests

This study was funded by a research grant from the Organ and Tissue Authority. GAJ is Editor Emeritus of Emergency Medicine Australasia, and TJW is a statistical consultant for Emergency Medicine Australasia.

References

1. Siminoff LA, Arnold RM, Caplan AL. Health care professional attitudes toward donation: effect on practice and procurement. J. Trauma 1995; 39: 553–9.
2. Siminoff LA, Gordon N, Hewlett J et al. Factors influencing families' consent for donation of solid organs for transplantation. JAMA 2001; 286: 71–7.
3. Akgün HS, Bilgin N, Tokalak I et al. Organ donation: a cross-sectional survey of the knowledge and personal views of Turkish health care professionals. Transplant. Proc. 2003; 35: 1273–5.
4. Bilgin N, Akgun HS. A focus on health care professionals in organ donation: a cross-sectional survey. Transplant. Proc. 2002; 34: 2445–7.
5. Roels L, Spaight C, Smits J et al. Critical Care staffs' attitudes, confidence levels and educational needs correlate with countries' donation rates: data from the Donor Action® database. Transpl. Int. 2010; 23: 842–50.
6. Cohen J, Ami SB, Ashkenazi T et al. Attitude of health care professionals to brain death: influence on the organ donation process. Clin. Transplant. 2008; 22: 211–15.
7. Rios A, Conesa C, Ramirez P et al. Attitude survey of hospital workers in the surgical services toward living kidney donation. Transplant. Proc. 2005; 37: 3621–5.

8. Schaeffner ES, Windisch W, Freidel K et al. Knowledge and attitude regarding organ donation among medical students and physicians. Transplantation 2004; 77: 1714–18.
9. National Organ Donation Collaborative N. Review of the national organ donation collaborative. 2009.
10. Aubrey P, Arber S, Tyler M. The organ donor crisis: the missed organ donor potential from the accident and emergency departments. Transplant. Proc. 2008; 40: 1008–11.
11. Michael GE, O'Connor RE. The importance of emergency medicine in organ donation: successful donation is more likely when potential donors are referred from the emergency department. Acad. Emerg. Med. 2009; 16: 850–8.
12. DonorAction. The Hospital Attitude Survey Copyright of Eurotransplant International Foundation (NL), Organizacion Nacional de Trasplantes (Spain), and the Partnership of Organ Donation (USA). 1996.
13. Lynn MR. Determination and quantification of content validity. Nurs. Res. 1986; 35: 382–5.
14. Raosoft. Sample size calculator.
15. Bellali T, Papadatou D. Parental grief following the brain death of a child: does consent or refusal to organ donation affect their grief? Death Stud. 2006; 30: 883–917.
16. Cleiren MP, Van Zoelen AA. Post-mortem organ donation and grief: a study of consent, refusal and well-being in bereavement. Death Stud. 2002; 26: 837–49.
17. Merchant SJ, Yoshida EM, Lee TK et al. Exploring the psychological effects of deceased organ donation on the families of the organ donors. Clin. Transplant. 2008; 22: 341–7.
18. Schnitzler MA, Lentine KL, Burroughs TE. The cost effectiveness of deceased organ donation. Transplantation 2005; 80: 1636–7.
19. Schnitzler MA, Whiting JF, Brennan DC et al. The life-years saved by a deceased organ donor. Am. J. Transplant. 2005; 5: 2289–96.
20. Collins TJ. Organ and tissue donation: a survey of nurse's knowledge and educational needs in an adult ITU. Intensive Crit. Care Nurs. 2005; 21: 226–33.
21. Sivakumar S, Knott J, Weiland TJ et al. Mental health related learning needs of clinicians working in Australian emergency departments: a nationwide survey of self-reported confidence and knowledge. Emerg. Med. Australas. 2011; 24: 697–711.
22. Wong R, Jelinek GA, Weiland TJ. Emergency clinicians' attitudes and decisions in patient scenarios involving advance directives. Emerg. Med. J. 2011; DOI: 10.1136/emergmed-2011-200287 2011

Chapter 4

Resource barriers to the facilitation of organ and tissue donation reported by Australian emergency clinicians

Claudia H Marck, George A Jelinek, Sandra L Neate,

Bernadine M Dwyer, Bernadette B Hickey, and Tracey J Weiland

Australian Health Review 2012 37(1) 60-65

Abstract
Objective: To explore emergency department clinicians' perceived resource barriers to facilitating organ and tissue donation (OTD).

Methods: A cross-sectional national online survey of Australian emergency department (ED) clinicians.

Results: ED clinicians reported a range of resource barriers that hinder the facilitation of OTD, most notably a lack of time to discuss OTD with a patient's family (74.6%). Those reporting more resource barriers had been less involved in OTD-related tasks. For example, those reporting a lack of time to assess a patient's suitability to be a potential donor had less experience with OTD-related tasks in the last calendar year than did those who reported that they often or always have enough time for this ($P < 0.01$). In addition, ED clinicians working in DonateLife network hospitals were more involved in OTD-related tasks ($P < 0.01$) and reported fewer resource shortages in the ED and the hospital overall.

Conclusions: Resource shortages hinder the facilitation of OTD in the ED and are related to decreased involvement in OTD-related tasks. In addition, ED clinicians working in DonateLife hospitals are more involved in OTD-related tasks and report fewer resource shortages overall. Addressing resource shortages and extending the DonateLife network could benefit OTD rates initiated from the ED.

Introduction

There is a global organ shortage that gravely affects the prognosis for patients with end-stage organ failure. In Australia, recent attempts to address this shortage have seen improvements in organ donation rates and a small decrease in the number of patients on waiting lists to receive an organ.[1,2] However, Australian organ donation rates are still well below those of other developed countries[3] and since waiting list mortality has increased, even a small increase in donation rates is critical in terms of lives and healthcare resources saved.[4–6] Similarly, tissue donation rates are not meeting demand.[7] One of the reasons for suboptimal rates of availability of organs and tissues is procurement failure, either as a result of health-care staff's failure to recognise or refer potential donors, or because family consent was not obtained.[8] Healthcare clinicians have an effect on whether or not family consent is obtained with several influencing factors being identified, including donor families' satisfaction with quality of care and attitude of staff.[9]

Emergency department (ED) clinicians are increasingly involved in organ and tissue donation (OTD), and have been identified as being essential in the early detection of potential donors.[10,11] In Australia, a 'clinical trigger' tool has been implemented to assist with the identification of potential donors, and to increase donor referral from the ED.[8] This tool and associated resources are designed to address the missed potential donor pool which has been recognised in EDs in Australia,[12,13] as well as internationally.[10] Reasons for procurement failure in Australian potential donors, as reported by hospital staff included: 'failure to recognise the patient as a potential donor (especially in EDs), clinicians being unwilling to discuss brain death and organ donation with families prior to brain death, and resource pressures'[8]. Potential donors identified in the ED are admitted to the intensive care unit (ICU) for further assessment and management, however immediate access to ICU beds is not always possible and the potential donor may need to be cared for in the ED until an ICU bed becomes available. Indeed, a recent study from the UK identifying barriers to OTD reported by ED clinicians noted a shortage of intensive care beds and limited resources with regards to physical space and workforce.[10]

Many Australian studies have reported worsening ED overcrowding and resource shortages with an adverse effect on patient care and satisfaction as well as on ED clinicians' work-related stress and satisfaction.[14–16] In recent years, the Organ and Tissue Authority (AOTA) has begun providing activity-based organ donation hospital support funding (ODHSF) to hospitals to ensure that any cost barriers surrounding organ donation, such as the need for additional beds and staff to care for potential donors, are removed. However, these funds become available retrospectively and are often transferred to general hospital revenue rather than directed to the department involved in OTD.[17]

It is possible that resource shortages may lead to suboptimal OTD rates due to failure to recognise or refer potential donors, discuss the potential for OTD, or medically support potential donors while waiting for a bed in ICU, however, this is unclear. This study, part of a larger national survey of ED clinicians, aimed to assess the resource barriers affecting the facilitation of OTD reported by Australian ED clinicians.

Methods

Instrument development

The methodology of this study has previously been described in detail.[18] Briefly, the survey was developed by the members of the project team, informed by available literature. A Delphi panel system with iterative feedback from members of the steering committee was used to ensure face validity of the draft survey. Staff members at St. Vincent's Hospital in Melbourne were involved in the pilot phase to assess content validity, with nine doctors and 10 nurses rating survey items on a 4-point scale of relevance according to a method previously described by Lynn[19]. This caused minor alteration to some of the survey items and the deletion of eight items. The final survey consisted of 133 items requiring ~15 min to complete. Survey items used graded responses with Likert scales or ordinal multicategory scales enabling quantitative analysis; open-ended questions were included to obtain additional data. The Human Research Ethics Committee at St. Vincent's Hospital Melbourne approved the study.

Procedure

We undertook a survey of members of the College of Emergency Nursing Australia (CENA) and the Australasian College for Emergency Medicine (ACEM) over 11 weeks from 21 March 2011 using the online tool SurveyMonkey.20 Members of ACEM and CENA currently working in an Australian ED were eligible to participate. All 3995 eligible participants (1026 members of CENA and 2969 members of ACEM (1169 fellows and 1800 trainees)) were emailed an invitation including a hyperlink to the online questionnaire, and a participant information form outlining the study, participant rights, and the anonymous nature of the survey. Multiple reminder emails were distributed in the first 5 weeks.

Sample size

The primary endpoint for this study was the frequencies reported for resource barriers. Assuming a 50% response distribution, we calculated that 351 ED clinicians were required to achieve a 5% margin of error and 95% confidence level.[21]

Data analysis

Quantitative data were exported from the web-based survey program to PASW Statistics 18.0 (Chicago, IL). For each survey item summary statistics were calculated and percentages were adjusted to reflect the varying denominator due to missed items or non-completion. Representation of membership per state, gender and membership type was calculated by comparing the confidence intervals (CI) of the percentages of all members of ACEM and CENA to the percentages of respondents to the survey. If the CI overlapped, we considered they were well represented.

Experience with OTD-related tasks in the last calendar year was measured over nine activities ranging from identifying a potential donor to explaining brain death to next of kin and obtaining consent for OTD. A total score for all items combined was computed by adding the rank of the frequencies of experiences (none, 1–3, 4–6, > 6) in the last calendar year together. Linear by linear chi-square tests were performed as exploratory analyses to investigate the relationship between resource barriers, hospital type, and experience with OTD-related tasks. Two tailed tests were used and unless otherwise specified α was set at 0.05.

Results

With 811 ED clinicians responding, response rate was 20.7% among CENA members, 15.8% among ACEM trainees, and 26.7% among ACEM fellows. The characteristics of the respondents have been described elsewhere,18 but in short, most states were well represented, with ACEM members from Queensland and CENA members from New South Wales under-represented, and Victorian CENA and ACEM members over-represented. Regarding membership type and gender, both male and female ACEM fellows were over-represented while male ACEM trainees were under-represented. Gender and seniority for CENA members not participating in the survey were unavailable. A total of 434 (53.5%) participants were female and 133 (16.4%) were aged 21–30 years, 347 (42.8%) 31–40 years, 233 (28.7%) 41–50 years and 98 (12.1%) were 51 years or older. The majority (448, 55.2%) were working in major referral hospitals, 181 (22.3%) in major regional or rural base hospitals, 170 (21.0%) in urban district hospitals and 12 (1.5%) in private hospitals.

Lack of time to assess whether a patient was a suitable potential donor, and to discuss OTD with the next of kin were reported to be significant barriers to the facilitation of OTD by most ED clinicians (Table 1). Almost three quarters of ED clinicians indicated that there were never or sometimes enough resources available in the ED to facilitate OTD while just over half reported there were never or sometimes enough resources available in the hospital. Furthermore, the majority of ED clinicians reported that ED overcrowding was often or always a barrier to facilitating OTD. Additional comments included that there was a lack of equipment (e.g. ventilators), beds and staff in the ED and that funding made available from the government to individual EDs to alleviate these resource shortages and facilitate organizing OTD had not been used for this purpose. A small minority reported that potential donors often or always took up too much time that could be spent on other patients.

Table 1 Resource barriers to the facilitation of organ and tissue donation

	Always	Often	Some-times	Never	Not applicable
I have enough time to discuss OTD with a patient's family	43 6.3%	82 12.0%	432 63.1%	79 11.5%	49 7.2%
There are enough resources in the ED to facilitate OTD	34 5.0%	123 18.0%	373 54.5%	136 19.9%	19 2.8%
I have enough time to assess whether a patient is suitable to be a potential donor	65 9.5%	159 23.2%	382 55.8%	34 5.0%	45 6.6%
There are enough resources in the hospital to facilitate OTD	84 12.3%	214 31.2%	307 44.8%	54 7.9%	26 3.8%
ED overcrowding is a barrier to facilitating OTD	121 17.7%	214 31.2%	272 39.7%	42 6.1%	36 5.3%
Facilitating OTD is difficult because the ICU is full	55 8.0%	156 22.8%	347 50.7%	59 8.6%	68 9.9%
Potential donors take up too much time which could be spent on other patients	26 3.8%	90 13.1%	352 51.4%	162 23.6%	55 8.0%

'Facilitating OTD is difficult because the intensive care unit (ICU) is often or always full', was a perceived barrier according to almost a third of staff. Additionally, some ED clinicians commented that their rural or remote hospital did not have access to an ICU, which made facilitating OTD difficult. Less than half of ED clinicians (329, or 45.0%) reported that they were willing to support a potential donor waiting on an ICU bed, regardless of resources required.

For additional analyses, responses for 'not applicable' were excluded. ED clinicians who reported more resource barriers overall had been less involved with OTD-related tasks in the last calendar year. Specifically, ED clinicians who reported that: they never or sometimes had enough time to assess whether a patient was suitable to be a potential donor ($P < 0.01$) or to discuss OTD with a patient's family ($P = 0.05$), and that there were never or sometimes enough resources in the hospital to facilitate OTD ($P < 0.01$) had significantly less experience with OTD-related tasks in the last calendar year. Involvement in OTD-related tasks was not found to be significantly related to reports that: potential donors often or always took up too much time that could be spent on other patients; there were never or sometimes enough resources in the ED to facilitate OTD; that ED overcrowding, or the ICU being full, were often or always barriers to OTD.

Most respondents (656, or 80.9%) indicated the hospital at which they mainly worked. Of the 128 hospitals listed, 71 hospitals were included in the DonateLife network and had staff employed specifically to assist with donation-related activities and develop donation-related education. Most (558, or 85.1%) ED clinicians worked in a DonateLife network hospital. They reported more often that there were often or always enough resources in the ED (26.0% v. 14.1%, $P = 0.02$) and the hospital (51.5% v. 15.4%, $P < 0.01$) to facilitate OTD, than did ED clinicians working in non-DonateLife network hospitals. There were no significant differences for any other resource barriers investigated in relation to DonateLife network hospital status or in relation to ED clinicians' levels of working experience (Table 2). ED clinicians working in DonateLife network hospitals had also been more involved in OTD-related tasks in the last calendar year ($P < 0.01$). This analysis was repeated for each hospital type, which showed that ED clinicians had been more involved with OTD-related tasks in the last calendar year if they were working in Major Regional or Rural Base ($P = 0.01$), and Urban District Hospitals ($P = 0.04$) that were part of the DonateLife network than had those not part of the DonateLife network. No significant effect was seen for ED clinicians working in Major Referral hospitals. All respondents working in Private hospitals were part of the DonateLife network and hence further analysis was not performed.

Table 2 Resource barriers stratified according to DonateLife network membership and working experience

		Part of DonateLife Network				Experience in Emergency Departments					
		No		Yes		0-10 years		11-20 years		≥20 years	
I have enough time to discuss OTD with a patient's family	Never/Sometimes	55	76.4%	361	81.1%	275	80.4%	172	82.7%	64	74.4%
	Often/Always	17	23.6%	84	18.9%	67	19.6%	36	17.3%	22	25.6%
There are enough resources in the ED to facilitate OTD	Never/Sometimes	**67**	**85.9%**	**344**	**74.0%**	263	73.3%	177	81.2%	69	77.5%
	Often/Always	**11**	**14.1%**	**121**	**26.0%**	96	26.7%	41	18.8%	20	22.5%
I have enough time to assess whether a patient is suitable to be a potential donor	Never/Sometimes	51	71.8%	279	61.9%	227	65.4%	147	70.3%	42	50.0%
	Often/Always	20	28.2%	172	38.1%	120	34.6%	62	29.7%	42	50.0%
There are enough resources in the hospital to facilitate OTD	Never/Sometimes	**66**	**84.6%**	**223**	**48.5%**	187	52.7%	123	57.2%	51	57.3%
	Often/Always	**12**	**15.4%**	**237**	**51.5%**	168	47.3%	92	42.8%	38	42.7%
ED overcrowding is a barrier to facilitating OTD	Never/Sometimes	36	49.3%	224	49.0%	165	47.4%	105	49.8%	44	48.9%
	Often/Always	37	50.7%	233	51.0%	183	52.6%	106	50.2%	46	51.1%
Facilitating OTD is difficult because the ICU is full	Never/Sometimes	33	55.0%	299	67.5%	220	65.9%	137	68.8%	49	58.3%
	Often/Always	27	45.0%	144	32.5%	114	34.1%	62	31.2%	35	41.7%
Potential donors take up too much time which could be spent on other patients	Never/Sometimes	57	80.3%	362	81.9%	273	80.3%	168	82.4%	73	84.9%
	Often/Always	14	19.7%	80	18.1%	67	19.7%	36	17.6%	13	15.1%

Results in bold are significant ($P < 0.05$).
ED, emergency department; ICU, intensive care unit; OTD, organ and tissue donation

Discussion

Australian studies have shown that around half of all missed potential donors have treatment withdrawn in EDs without OTD being considered or discussed with the family.[12,13] Resource shortages and ED overcrowding are well known issues in Australian EDs and sometimes caused by resource shortages elsewhere in the hospital.[15,22] However, until now it was unknown whether these issues affected the facilitation of OTD from the ED. Our results show that ED clinicians report several resource barriers to the facilitation of OTD, which could be inter-related, most notably a lack of time to assess patient's eligibility for OTD and to discuss OTD with the patient's family, as well as ED overcrowding and access block to ICU. The latter becomes an issue when, as found in this study, the majority of ED clinicians are not willing to medically support potential donors in ED while they await transfer to the ICU.

Our results showed that some of these resource shortages were directly related to the practice of ED clinicians regarding OTD-related tasks. Those that reported fewer barriers regarding lack of time and overall resources in the hospital, had been more involved in OTD-related tasks, implying that these resource shortages are a significant barrier to the facilitation of OTD from the ED. Although ICU and ED overcrowding were not found to be significantly related to practice (involvement with OTD-related tasks), overcrowding could influence an ED clinician's perception of lack of time to engage with OTD-related tasks. In addition, these results need to be seen in light of other factors related to involvement with OTD-related tasks, including having received OTD-related education, and attitudes of ED clinicians regarding whether or not facilitating OTD is their role.[23]

Although detailed figures are lacking, it has been suggested that having greater numbers of ICU beds per unit population is related to higher rates of deceased organ donation.[24–26] A US study showed that in the setting of ICU bed shortages, clinicians are often inclined to prioritize a gravely ill patient who is unlikely to benefit from ICU treatment over a potential organ donor.[27]

ED clinicians working in DonateLife network hospitals, having specified DonateLife employed staff in the hospital, reported fewer resource barriers in the ED and hospital overall. The presence of specialist OTD staff may have led to a perception of fewer resource barriers or may have, as intended, significantly reduced resource barriers. ED clinicians working in DonateLife network hospitals were more often involved in OTD-related tasks, which after controlling for hospital type still held for ED clinicians working in Major Regional or Rural Base, and Urban District Hospitals. This may be due to fewer resource barriers in hospitals with specialist staff, or potentially to the different culture around the facilitation of OTD engendered by these DonateLife clinicians. Also, hospitals not included in the DonateLife network might have fewer potential donors, which is why they might not have been included in the first place.

Overcrowding and access block appear to impede many functions in Australian EDs, culminating in increased overall mortality among patients admitted through more overcrowded departments.[15] Our study identifies OTD as another important function of EDs that may be compromised by overcrowding and access block, resulting in clinical staff having insufficient

time to assess patient suitability or even commence discussions about OTD with families. The implementation of National Emergency Access Targets (NEAT), if accompanied by genuine commitment by hospitals to change whole-of-hospital bed management strategies as in Western Australia, may potentially lead to decreased ED overcrowding and potential positive flow-on effects such as improved facilitation of OTD from EDs.[28] Addressing resource shortages in the ED, as well as those outside the ED affecting ED overcrowding, is a multifaceted and difficult task.[28] However, extending the DonateLife network to include more hospitals in Australia could be feasible and might decrease resource shortages in the ED specifically for the initiation of OTD as well as increase ED clinicians' involvement in OTD-related tasks. Assessing the number of potential donors in these non DonateLife network hospitals might indicate whether this is worthwhile.

Limitations

Although we received more than twice the number of responses needed according to our calculated sample size, the response rate was not high overall. However, our response rate was considerably higher than in previous surveys of the same population.29,30 As ACEM membership is mandatory for all ED specialists, 26.7% of all Australian ED specialists responded to our survey and are therefore particularly well represented. As CENA membership is not mandatory for ED nurses, and it is currently unknown how many ED nurses work in Australia, we cannot make assumptions about the generalisability of the nursing cohort.

Conclusion

ED clinicians report several resource barriers to the facilitation of OTD, most notably a lack of time, at least partly related to overcrowding and access block. ED clinicians reporting more resource barriers, and those working in non-DonateLife network hospitals were less involved in OTD-related tasks in the last calendar year. The presence of specialist OTD staff, a function of being part of a DonateLife network hospital, may result in a decreased perception of resource barriers in the ED and more engagement with OTD-related tasks by ED clinicians.

Acknowledgements

This study was supported by the Organ and Tissue Authority. We would also like to thank the steering committee members: Katherine Bowman, Dr Nicola Cunningham, Dr Curtis Leacock, and Margaret Maslin.

References

1. Australia and New Zealand Organ Donation Registry. Organ waiting list data. Available from: http://www.anzdata.org.au/anzod/v1/indexanzod.html [Verified 28 November 2011].
2. Australia and New Zealand Organ Donation Registry. Summary of Organ Donation statistics. Available from: http://www.anzdata.org.au/anzod/v1/indexanzod.html [Verified 28 November 2011].
3. Australia and New Zealand Organ Donation Registry. Australia and New Zealand Organ Donation Registry 2011 report, 2011. Available from: http://www.anzdata.org.au/anzod/ANZODReport/2011/ANZOD2011.pdf [Verified 17 September 2012].
4. Schnitzler MA, Lentine KL, Burroughs TE. The cost effectiveness of deceased organ donation. Transplantation 2005; 80: 1636–7.
5. Schnitzler MA, Whiting JF, Brennan DC, Lentine KL, Desai NM, Chapman W, et al The life-years saved by a deceased organ donor. Am J Transplant 2005; 5: 2289–96.
6. Prakoso E, Verran D, Dilworth P, Kyd G, Tang P, Tse C, et al Increasing liver transplantation waiting list mortality: a report from the Australian National Liver Transplantation Unit, Sydney. Intern Med J 2010; 40: 619–25.
7. Victorian Institute of Forensic Medicine. Annual report 2009/2010. Available from www.vifm.org/wp-content/uploads/2011/02/AR-2009-2010.pdf [Verified 28 November 2011].
8. Louise Greene Consulting for The National Health and Medical Research Council National Institute of Clinical Studies. Review of the National Organ Donation Collaborative, interim report, 2009. Available from: http://www.donatelife.gov.au/Media/docs/National%20Organ%20Donor%20Collabotative%20Interim%20Review-04666ca4-19d1-4b6b-86b9-b2939b04b08b-0.pdf [Verified 17 September 2012].
9. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. JAMA 2001; 286: 71–7.
10. Aubrey P, Arber S, Tyler M. The organ donor crisis: the missed organ donor potential from the accident and emergency departments. Transplant Proc 2008; 40: 1008–11.
11. Michael GE, O'Connor RE. The importance of emergency medicine in organ donation: successful donation is more likely when potential donors are referred from the emergency department. Acad Emerg Med 2009; 16: 850–8.
12. Opdam HI, Silvester W. Identifying the potential organ donor: an audit of hospital deaths. Intensive Care Med 2004; 30: 1390–7.
13. Opdam HI, Silvester W. Potential for organ donation in Victoria: an audit of hospital deaths. Med J Aust 2006; 185: 250–4.
14. Harris A, Sharma A. Access block and overcrowding in emergency departments: an empirical analysis. Emerg Med J 2010; 27: 508–11.
15. Sprivulis PC, Da Silva JA, Jacobs IG, Frazer AR, Jelinek GA. The association between hospital overcrowding and mortality among patients admitted via Western Australian emergency departments. Med J Aust 2006; 184: 208–12.
16. Forero R, Hillman K. Access block and overcrowding: a literature review. Prepared for the Australasian College for Emergency Medicine (ACEM): Simpson Centre for Health Services Research South Western Sydney Clinical School, University of New South Wales, 2008.

17. Australian Healthcare Associates. Organ and Tissue Donation Reform Package, mid-point implementation review report, 2011. Available from: http://www.donatelife.gov.au/media/docs/The_Authority/Mid-point_Implementation_Review_Final_Report.pdf
18. Marck CH, Weiland TJ, Neate SN, Hickey BB, Jelinek GA. Assessing barriers to organ and tissue donation in emergency departments. Final Report: St Vincent's Hospital Melbourne; 2012. Available from: http://donatelifeforum.com.au/downloads/The_ABODE_study.pdf [Verified 17 September 2012].
19. Lynn MR. Determination and quantification of content validity. Nurs Res 1986; 35: 382–386.
20. SurveyMonkey. SurveyMonkey.com, LLC Available from: www.surveymonkey.com
21. Raosoft. Sample size calculator. Available from: http://www.raosoft.com/samplesize.html [Verified 17 September 2012].
22. Fatovich DM, Nagree Y, Sprivulis P. Access block causes emergency department overcrowding and ambulance diversion in Perth, Western Australia. Emerg Med J 2005; 22: 351–4.
23. Jelinek GA, Marck CH, Weiland TJ, Neate SL, Hickey BB. Organ and tissue donation-related attitudes, education and practices of emergency department clinicians in Australia. Emerg Med Australas 2012; 24: .
24. Wight J, Jakubovic M, Walters S, Maheswaran R, White P, Lennon V. Variation in cadaveric organ donor rates in the UK. Nephrol Dial Transplant 2004; 19: 963–8.
25. Fabre J, Murphy P, Matesanz R. Presumed consent: a distraction in the quest for increasing rates of organ donation. BMJ 2010; 341: c4973.
26. Matesanz R. Factors influencing the adaptation of the Spanish Model of organ donation. Transpl Int 2003; 16: 736–41.
27. Kohn R, Rubenfeld GD, Levy MM, Ubel PA, Halpern SD. Rule of rescue or the good of the many? An analysis of physicians' and nurses' preferences for allocating ICU beds. Intensive Care Med 2011; 37: 1210–7.
28. Mountain D. Introduction of a 4-hour rule in Western Australian emergency departments. Emerg Med Australas 2010; 22: 374–8.
29. Sivakumar SWT, Gerdtz MF, Knott J, Jelinek GA. Mental health related learning needs of clinicians working in Australian emergency departments: A nationwide survey of self-reported confidence and knowledge. Emerg Med Australas 2011; 23: 697–711.
30. Wong R, Jelinek GA, Weiland TJ. Emergency clinicians' attitudes and decisions in patient scenarios involving advance directives. Emerg Med J 2012; 29: 720–724.

Chapter 5

Australian emergency doctors' and nurses' acceptance and knowledge regarding brain death: a national survey

Claudia H Marck, Tracey J Weiland, Sandra L Neate,

Bernadette B Hickey, and George A Jelinek

Clinical Transplantation 2012 26(3); E254–E260

Abstract
Healthcare staff's acceptance of brain death (BD) being a valid determination of death is essential for optimized organ and tissue donation (OTD) rates. Recently, resources to increase Australian OTD rates have been aimed at emergency departments (ED) as a significant missed donor potential was discovered.

A cross-sectional survey was conducted to assess Australian ED clinicians' acceptance and knowledge regarding BD. Most (86%) of the 599 medical and 212 nursing staff accepted BD, but only 60% passed a 5-item-validated BD knowledge tool. BD knowledge was related to the acceptance of BD. Accepting BD influenced attitudes toward OTD, including willingness to donate. BD acceptance and knowledge were related to education/training regarding OTD, years of experience in EDs, experience with OTD-related tasks, and increased perceived competence and comfort with OTD-related tasks. Of concern, more than half of respondents who did not pass the BD test reported feeling competent and comfortable explaining BD to next of kin; of respondents who had recent experience with this, more than a third failed the BD test.

Despite being generally positive toward OTD, Australian ED clinicians do not have a sound knowledge of BD. This may be hampering efforts to increase donation rates from the ED.

Introduction

Brain death (BD) in Australia requires irreversible cessation of all function of the brain[1] and is characterized by irreversible unresponsive coma, absence of brain-stem reflexes and lack of respiratory centre function[2]. Cardiopulmonary functions of brain-dead patients can be maintained with ventilation to allow time for BD testing or organ and tissue donation (OTD). In brain-dead patients, lack of cardio-respiratory support results in cessation of circulation within minutes; with support, 97% develop cardiac asystole within a week[3].

Australia's organ donation and family consent rates are far from optimal[4]. Having an understanding of BD positively influences attitudes of next of kin (NOK) toward OTD and could be essential for family consent[5-7]. Additionally, clinician acceptance of BD as a valid determination of death is related to optimal donation rates[8]. It is therefore critical that healthcare staff both understand and accept BD to convey accurate information to families.

Studies have shown substantial confusion, ambiguity, and lack of understanding about BD among health professionals, even among those who accept BD as being legally dead[9,10]. While there are data from other countries on knowledge and interpretation of BD by clinicians[11-13], there is currently no available literature on Australian clinicians. This is remarkable since any medical practitioner of over five yr standing is permitted to declare BD in most Australian States[2], and BD-related information is often communicated to NOK by treating Emergency Department (ED) or Intensive Care Unit (ICU) staff. Additionally, the Australasian College of Emergency Medicine (ACEM) has recently updated their policy on organ donation to include the statement: "Fellowship of ACEM should be included in government regulation as being a recognised critical care medical qualification that empowers the holder with the authority to perform the determination of BD. This is important in facilities with no intensive care specialists"[14], which underlines the importance of BD knowledge of ED physicians.

Most organ donation in Australia occurs after BD, as opposed to cardiac death or living donation[15]. Failure to identify and/or refer potential (brain-dead) donors by healthcare staff is a major cause of preventable procurement failure in Australia[4,16]. Historically, most resources have been aimed at ICU where most potential donors are recognized. However, donation may more often be successful when potential donors are referred from the ED[17]. The potential donor pool from the ED has been recognized internationally[18], in Australia receiving attention through the DonateLife "GIVE" Trigger initiative.

We assessed the acceptance and knowledge of BD among Australian ED doctors and nurses, and the associated effect on comfort levels and perceived competence in performing donation-related tasks. The study formed a part of a larger cross-sectional study of Australian emergency clinicians assessing barriers to OTD.

Methods

Instrument development

The survey was developed by the project team. A validated tool[19] consisting of five items to assess understanding of BD was included (Table 1), as well as components of the Hospital Attitude Survey (HAS), a validated questionnaire assessing attitudes of hospital staff toward OTD[20]. The HAS measures BD acceptance by asking participants to respond to: "BD is a valid determination of death" by selecting yes, no, or unsure. Face validity of the draft survey items was ensured through iterative feedback between steering committee staff using a Delphi panel system. Content validity was assessed using a sample of nine doctors and ten nurses from St. Vincent's Hospital Melbourne (SVHM), who were requested to rate the relevance of each item according to Lynn's method[21]. As a result of this validation phase, the survey was amended. The final survey comprised 133 items, taking approximately 15 min to complete. Items sought graded responses using Likert scales or ordinal multicategory scales. Open-ended questions elicited qualitative responses. Study approval was obtained from the Human Research Ethics Committee at SVHM.

Table 1. Brain death (BD) knowledge test (19) (n = 679)

5-item brain death knowledge test	**Correct response**	**N (%)**
Can someone who is brain-dead breathe without support of a breathing machine?	No	500 (73.6)
Can someone who is brain-dead ever wake up (recover)?	No	640 (94.3)
Will someone who is brain-dead react (grimace, move away or blink) if someone touches their eyeball?	No	542 (79.8)
Can a person be brain-dead even if the heart is still beating?	Yes	665 (97.9)
Is BD different from coma or a vegetative state?	Yes	619 (91.2)

Procedure

An online survey of members of the College of Emergency Nursing Australasia (CENA) and the ACEM, currently working in an Australian ED, was conducted between March and June 2011 using SurveyMonkey[22]. All 3995 eligible participants (1026 CENA and 2969 ACEM [1169 fellows and 1800 trainee specialists]) were emailed an invitation, a participant information form outlining the study and participant rights, and a hyperlink to the questionnaire. Reminder emails were distributed.

Sample size

Assuming a 50% response distribution, 280 CENA members (of 1026) and 341 ACEM members (of 2969) were calculated as being required to achieve a 5% margin of error and 95% confidence level[23].

Data analysis
Quantitative data were exported from SurveyMonkey to PASW Statistics 18.0 (Chicago, IL, USA). For each item, summary statistics (N %, or medians and interquartile range [IQR]) were calculated and compared by demographics. Percentages were adjusted to reflect varying denominators because of missed items or non-completion. Exploratory inferential analyses were conducted. Means were compared using t-test, and for nominal data, group comparisons using chi-square, linear by linear association, and two-sided Fisher's exact test for 2 × 2 contingency tables. Mann–Whitney U test was used for ordinal data. Alpha was set at .05, and two-tailed tests were used. Qualitative data were summarized thematically.

Results
Demographics
Response rates were 20.2% for ACEM and 20.7% for CENA. Of 811 respondents, 212 were nurses and 599 were medical staff (285 trainee specialists, 312 fellows, and two other medical specialists). Overall, 434 (53.5%) participants were women. Median age was 38 yr (IQR 32–46).

BD acceptance
The majority (85.5%, n = 578) of respondents accepted BD, agreeing that "BD is a valid determination of death," while 11% (n = 73) disagreed, and 4% (n = 25) replied "don't know." Respondents that replied "don't know" or "disagree" were asked to select one or more reasons; the majority selected "lack of information on BD" (52/98), "doubts on the scientific definition of BD" (36/98), "religious, personal or philosophical reasons" (13/98), "lack of trust in doctors' ability to diagnose BD" (13/98) and "other reasons" (12/98). "Other reasons" included the following: "the rare occasions of unexpected or unexplained recovery" (three nurses) and "you are not dead until your heart stops and you stop breathing" (three doctors).

The more years of experience in EDs ($p < 0.001$), the more likely respondents were to accept BD as a valid determination of death. Medical specialists were more likely to accept BD compared with trainee specialists and nursing staff (91.7% vs. 80.3% and 82.4% respectively, $p = 0.001$). BD acceptance was related to more positive personal attitudes toward OTD including willingness to donate organs and tissues after death (Table 2).

Additionally, BD acceptance was also related to perceived knowledge or competence to engage in OTD-related tasks (Table 3). No significant results were found for self-reported competence in obtaining consent for OTD. Of respondents who disagreed that BD is a valid determination of death or did not know, 35.9% of ED clinicians felt that they had the necessary knowledge or competence to explain BD to the NOK.

More respondents who accepted BD felt comfortable explaining BD to NOK (68.8% vs. 34.8%, $p < 0.001$), introducing organ (72.7% vs. 50.0%, $p < 0.001$) and tissue (70.7% vs. 44.6%, $p < 0.001$) donation to NOK, supporting or comforting grieving families (89.8% vs. 79.3%, $p = 0.008$), and referring a potential donor (71.3% vs. 46.9%, $p < 0.001$). No

significant results were found for comfort levels obtaining consent for OTD and BD acceptance. Of respondents who did not accept BD or did not know, 34.8% felt comfortable explaining BD to the NOK.

Table 2. Personal attitudes according to the acceptance of brain death (BD) of emergency department (ED) staff. N (%)

Personal attitudes		Brain death is a valid determination of death		
		Agree	Disagree or unsure	p value
What is your general attitude on OTD	Support	527 (86.7)	81 (13.3)	p = 0.003
	Oppose or don't know	15 (62.5)	9 (37.5)	
Would you donate some of your organs after death?	Yes	509 (87.3)	74 (12.7)	p = 0.007
	No or don't know	48 (73.8)	17 (26.2)	
Would you donate some of your tissues after death?	Yes	506 (87.4)	73 (12.6)	p = 0.005
	No or don't know	51 (73.9)	18 (26.1)	
Have you registered your choice with the organ donor register?	Yes	292 (88.8)	37 (11.2)	p = 0.042
	No or don't know	265 (83.1)	54 (16.9)	
Have you informed your next of kin (NOK) about your wishes concerning OTD after your death?	Yes	489 (87.6)	69 (12.4)	p = 0.005
	No or don't know	68 (75.6)	22 (24.4)	
Would you donate organs or tissues from an adult NOK after his/her death?	Yes	490 (87.3)	71 (12.7)	p = 0.019
	No or don't know	67 (77.0)	20 (23.0)	
If you have children, or were to have children, would you donate his/her organs or tissues after death?	Yes	457 (88.2)	61 (11.8)	p < 0.002
	No or don't know	100 (76.9)	30 (23.1)	

OTD, organ and tissue donation.

Table 3. Perceived competence with organ and tissue donation-related tasks according to the acceptance of brain death (BD). N (%)

I have the necessary competence or knowledge to:		Brain death is a valid determination of death		
		Agree N (%)	Disagree N (%)	p value
Explain BD to the next of kin	Yes	411 (72.5)	33 (35.9)	p < 0.001
	No	156 (27.5)	59 (64.1)	
Introduce the subject of organ donation	Yes	455 (80.2)	56 (60.9)	p < 0.001
	No	112 (19.8)	36 (39.1)	
Introduce the subject of tissue donation	Yes	436 (76.9)	53 (57.6)	p < 0.001
	No	131 (23.1)	39 (42.4)	
Obtain consent for organ donation	Yes	151 (26.6)	22 (23.9)	NS
	No	416 (73.4)	70 (76.1)	
Obtain consent for tissue donation	Yes	150 (26.5)	23 (25.0)	NS
	No	417 (73.5)	69 (75.0)	
Refer a potential donor	(Strongly) Disagree or neutral	203 (35.1)	54 (55.1)	p < 0.001
	(Strongly) Agree	375 (64.9)	44 (44.9)	
Identify a potential donor	(Strongly) Disagree or neutral	164 (28.4)	45 (45.9)	p = 0.001
	(Strongly) Agree	414 (71.6)	53 (54.1)	
Care for a potential donor	(Strongly) Disagree or neutral	204 (35.3)	58 (59.2)	p < 0.001
	(Strongly) Agree	374 (64.7)	40 (40.8)	

BD knowledge

Of respondents completing the BD knowledge test, 60.4% (410) correctly responded to all five test items and 39.6% (269) selected the incorrect response or "unsure" on one or more items (Table 1). Respondents who passed the knowledge test were more likely to accept BD than those who failed the test (93.9% vs. 72.6%, $p < 0.001$). Nursing staff and medical specialists were more likely to pass the knowledge test compared with trainee specialists (63.2%, 64.9%, and 52.8%, respectively, $p = 0.015$). The more experienced a respondent the more likely they were to pass the knowledge test ($p = 0.002$).

Respondents who passed the knowledge test were more likely to have informed their NOK about their own wishes concerning OTD compared with those who failed (89.1% vs. 81.3%, p = 0.005, N = 651). BD knowledge was not significantly related to general support for OTD, willingness to donate own organs or tissues after death, registering wishes, or consenting for OTD for adult NOK or (future) children.

BD knowledge was related to perceived knowledge or competence to engage in OTD-related tasks (Table 4), except obtaining consent for OTD. Of respondents who failed the knowledge test, 54.8% (142) felt that they had enough knowledge and competence to explain BD to NOK. This group consisted of 68 medical specialists, 55 trainee specialists, and 19 nurses.

Table 4. Perceived competence with organ and tissue donation-related tasks according to brain death (BD) knowledge. N (%)

I have the necessary competence or knowledge to		5-item brain death test		
		Pass	Fail	p value
Explain BD to the next of kin	Yes	305 (75.7)	142 (54.8)	p < 0.001
	No	98 (24.3)	117 (45.2)	
Introduce the subject of organ donation	Yes	325 (80.6)	188 (72.6)	p = 0.017
	No	78 (19.4)	71 (27.4)	
Introduce the subject of tissue donation	Yes	315 (78.2)	176 (68.0)	p = 0.004
	No	88 (21.8)	83 (32.0)	
Obtain consent for organ donation	Yes	110 (27.3)	64 (24.7)	NS
	No	293 (72.7)	195 (75.3)	
Obtain consent for tissue donation	Yes	110 (27.3)	64 (24.7)	NS
	No	293 (72.7)	195 (75.3)	
Refer a potential donor	(Strongly) Disagree or neutral	132 (32.2)	126 (46.8)	p < 0.001
	(Strongly) Agree	278 (67.8)	143 (53.2)	
Identify a potential donor	(Strongly) Disagree or neutral	103 (25.1)	106 (39.4)	p < 0.001
	(Strongly) Agree	307 (74.9)	163 (60.6)	
Care for a potential donor	(Strongly) Disagree or neutral	126 (30.7)	138 (51.3)	p < 0.001
	(Strongly) Agree	284 (69.3)	131 (48.7)	

More respondents passing the knowledge test felt comfortable explaining BD to NOK (71.5% vs. 52.5%, p < 0.001), introducing organ (73.9% vs. 62.5%, p = 0.002) and tissue (72.5% vs. 58.7%, p < 0.001) donation to NOK, supporting or comforting grieving families (90.8% vs. 84.2% p = 0.013), and referring a potential donor (73.2% vs. 59.5%, p< 0.001).

BD knowledge was not related to feeling comfortable obtaining consent for OTD. Of respondents who failed the knowledge test, 52.5% (136) felt comfortable explaining BD to the NOK.

Experience with OTD-related tasks
Experience with OTD-related tasks in the previous year was measured over nine activities ranging from identifying a potential donor to explaining BD to NOK and obtaining consent for OTD. A total score for all items combined was computed by adding the rank of the frequencies of experiences (none, 1–3, 4–6, >6) in the last calendar year together. Almost three-quarters had one or more OTD-related experiences in the last calendar year (560, 71.3%). Respondents who accepted BD ($p = 0.004$) and who passed the knowledge test ($p = 0.002$) had more experience with OTD-related tasks. 28.8% of respondents had explained BD to NOK at least once in the last year. Of those 196, 34.2% failed the knowledge test (35 medical specialists, 25 trainee specialists, and seven nurses) and 13.3% did not accept BD. Of respondents who had explained BD to NOK more than six times in the last year, almost half failed the knowledge test (45.5%, N = 10).

Education and or training regarding OTD
More than a quarter had not received any training or education about OTD (216, 27.5%). ED staff who had received training or education regarding OTD (e.g., hospital/department based or conferences) were more likely to accept BD (87.4% vs. 80.1%, $p = 0.025$) and to pass the knowledge test (64.1% vs. 49.7%, $p = 0.001$). More than half the participants completing the survey wanted to receive more education on BD. Of those 334 ED staff, 31% were nurses, 39% trainee specialists, and 30% medical specialists.

Discussion
Donation rates are related to the BD knowledge and understanding by NOK[5-7], and acceptance of BD as a valid determination of death by staff[8, 24]. To date, there has been little published on the association between staff knowledge of BD and OTD. ED staff members are pivotal in the early detection of potential organ and tissue donors, and providing information to NOK who consent to organ donation. Accepting BD appears essential for optimizing donation rates[8 ,24], and in our study, most medical (85.9%) and nursing (81.8%) ED staff accepted BD. This is slightly lower than previous figures (medical: 92.8%; nursing: 89.1%) (personal communication L. Roels, Linden, Belgium) from a similar international survey including Australian medical and nursing staff between 2006 and 2008[8, 24].

We have shown that accepting BD is related to increased support for OTD in general and personal attitudes toward OTD, including willingness to donate one's own or family's organs and tissues, and likelihood of registering and discussing one's wish. Accepting BD is also related to increased levels of perceived competence and comfort with OTD-related tasks like identifying, referring, and caring for a potential donor and introducing the subject of OTD and explaining BD to NOK.
A small minority of ED staff who did not accept BD reported doubts about the diagnosis of BD. The main reason reported was lack of information on BD. BD knowledge was indeed found to be related to accepting BD, which underscores the importance of education on BD during medical training.

Almost half the trainee specialists did not have sound knowledge of BD compared with just over one-third of medical specialists and nursing staff members. This is important because BD knowledge was significantly related to competence and comfort with OTD-related tasks like identifying, referring, and caring for a potential donor, and introducing the subject of OTD and explaining BD to NOK. Of concern, more than half the respondents who did not pass the BD knowledge test reported having the necessary competence or knowledge to explain BD to NOK, and feeling comfortable doing so. Further, more than a third of all respondents who had explained BD to NOK in the last year did not pass the test. These results raise concerns about lack of knowledge about BD and lack of awareness of this deficit and suggest that families of potential donors are frequently receiving explanations about BD from ED staff with limited ability to do so. This lack of knowledge and competence may affect family consent rates and thus hamper efforts to improve OTD rates in Australia and make it difficult for NOK to make sound end-of-life decisions and comprehend what is happening to their loved one; this increases the potential for decisions about OTD to be made based on inaccurate or misleading information, and for NOK to have long-term disquiet about these critically important choices.

Additionally, in light of the recent policy update of ACEM, which states that ED physicians should have the authority to determine BD in the absence of ICU specialists[14], our results show that many ED physicians lack the necessary knowledge about BD to undertake this responsibility without additional training. This highlights the need to include BD in the ED postgraduate curricula, as BD should only be determined by those who have solid knowledge and extensive training about BD.

Our data reinforce the wisdom of the current Australian approach where ED clinicians are not encouraged to formally obtain consent for OTD, but rather introduce the subject in a sensitive matter and refer the potential donor to the ICU or donor coordinator; it is not surprising that most ED clinicians in our study did not feel competent in obtaining consent as this is not and should not be expected of them.

Consistent with previous work[25], more than half the respondents indicated a desire for more education on BD. OTD education or training, as well as experience with OTD-related tasks, and number of years of experience in EDs increased BD acceptance as well as BD knowledge. This highlights the critical need for better education about BD for Australian emergency clinicians[8].

Limitations

The response rate for the nursing cohort was below the calculated sample size. This was despite the response rate in this study being considerably higher than in previous surveys of this cohort[26]. The specialist emergency medicine workforce, however, was particularly well represented. The results may therefore be more generalizable to emergency doctors than nurses.

Conclusion

This is the first study to examine BD knowledge and acceptance among ED staff. Higher rates of BD knowledge and acceptance increase competence and comfort with OTD-related tasks. The majority of ED staff accept BD as a valid determination of death. However, BD knowledge is poor, and ED staff, particularly emergency trainee specialists, seem insufficiently educated on BD to realize the full potential of facilitating OTD from the ED. More education, perhaps earlier in ED training, is required to improve BD knowledge to acceptable levels. This is likely to increase the acceptance of BD and facilitate improved rates of OTD initiated from the ED.

Acknowledgements

This research was supported by a grant from the Organ and Tissue Authority. We would like to thank the steering committee members for their contributions: Katherine Bowman, Dr. Nicola Cunningham, Bernadine Dwyer, Dr. Curtis Leacock, and Margaret Maslin.

Author contributions

CM was involved in the study design, data collection, statistics, data analysis/interpretation, and drafting of the article. TW, SN, BH, and GJ were involved in securing the funding, design of the study, and critical revision of the article.

References

1. Human Tissue Act 1982. Act no. 9860/1982, Version incorporating amendments as at 1 January 2010 [cited 2011 Aug 22]. Available from http://www.health.vic.gov.au/humantissue/htact.
2. Australian and New Zealand Intensive Care Society (ANZICS). The ANZICS Statement on Death and Organ Donation, 3.1 edn. Melbourne: ANZICS, 2010 [cited 2011 Aug 22] Available from http://www.anzics.com.au/death-and-organ-donation.
3. Hung TP, Chen ST. Prognosis of deeply comatose patients on ventilators. J Neurol Neurosurg Psychiatry 1995: 58: 75.
4. Louise Greene Consulting for The National Health and Medical Research Council National Institute of Clinical Studies. Review of the National Organ Donation Collaborative, interim report. May 2009.
5. Siminoff LA, Mercer MB, Arnold R. Families' understanding of brain death. Prog Transplant 2003: 13: 218.
6. Ormrod JA, Ryder T, Chadwick RJ, Bonner SM. Experiences of families when a relative is diagnosed brain stem dead: understanding of death, observation of brain stem death testing and attitudes to organ donation. Anaesthesia 2005: 60: 1002.

7. Franz HG, DeJong W, Wolfe SM et al. Explaining brain death: a critical feature of the donation process. J Transpl Coord 1997: 7: 14.
8. Roels L, Spaight C, Smits J, Cohen B. Critical care staffs' attitudes, confidence levels and educational needs correlate with countries' donation rates: data from the Donor Action® database. Transpl Int 2010: 23: 842.
9. White G. Intensive care nurses' perceptions of brain death. Aust Crit Care 2003: 16: 7.
10. Kim JR, Fisher MJ, Elliott D. Attitudes of intensive care nurses towards brain death and organ transplantation: instrument development and testing. J Adv Nurs 2006: 53: 571.
11. Harrison AM, Botkin JR. Can pediatricians define and apply the concept of brain death? Pediatrics 1999: 103: e82.
12. Erdogan O, Yücetin L, Tuncer M et al. Attitudes and knowledge of Turkish physicians about organ donation and transplantation. Transpl Proc 2002: 34: 2007.
13. Lima CX, Lima MVB, Cerqueira RG et al. Organ donation: cross-sectional survey of knowledge and personal views of Brazilian medical students and physicians. Transpl Proc 2010: 42: 1466.
14. Australasian College of Emergency Medicine (ACEM). Policy on Organ Donation, P34. ACEM, 2011 [cited 2012 Jan 24] Available from http://www.acem.org.au/media/policies_and_guidelines/111012_P34_Policy_on_Organ_Donation.pdf.
15. Excell L, Hee K, Russ G eds. ANZOD Registry Report 2011. Adelaide, South Australia: Australia and New Zealand Organ Donation Registry, 2011.
16. Opdam HI, Silvester W. Potential for organ donation in Victoria: an audit of hospital deaths. Med J Aust 2006: 185: 250.
17. Michael GE, O'Connor RE. The importance of emergency medicine in organ donation: successful donation is more likely when potential donors are referred from the emergency department. Acad Emerg Med 2009: 16: 850.
18. Aubrey P, Arber S, Tyler M. The organ donor crisis: the missed organ donor potential from the accident and emergency departments. Transplant Proc 2008: 40: 1008.
19. Tawil I, Marinaro J, Brown LH. Development and validation of a tool for assessing understanding of brain death. Prog Transplant 2009: 19: 272.
20. DonorAction. The Hospital Attitude Survey Copyright of Eurotransplant International Foundation (NL), Organizacion Nacional de Trasplantes (Spain), and the Partnership of Organ Donation (USA). DonorAction, 1996.
21. Lynn MR. Determination and quantification of content validity. Nurs Res 1986: 35: 382.
22. SurveyMonkey, LLC. Palo Alto, California, USA. Copyright 1999-2011 [cited 2011 Aug 22]. Available from: http://www.surveymonkey.com.
23. Raosoft. Sample size calculator. [cited 2011 Aug 22]. Available from: http://www.raosoft.com/samplesize.html.
24. Cohen J, Ami SB, Ashkenazi T, Singer P. Attitude of health care professionals to brain death: influence on the organ donation process. Clin Transplant 2008: 22: 211.
25. Pont Castellana T, Masnou Burrallo N, Gracia Gonzalo RM et al. Health care professionals: what do they know about organ donation? Prog Transplant 2008: 18: 141.
26. Sivakumar SWT, Gerdtz MF, Knott J, Jelinek GA. Mental health related learning needs of clinicians working in Australian emergency departments: a nationwide survey of self-reported confidence and knowledge. Emerg Med Australas 2011: 24: 697

Chapter 6

Donation after Cardiac Death: are Australian emergency clinicians supportive?

Claudia H Marck, Sandra L Neate, Tracey J Weiland,

Bernadette B Hickey, and George A Jelinek

Internal Medicine Journal, 2013; 43: 816–819.

Abstract
To improve organ donation processes and outcomes, many Australian hospitals have introduced donation after cardiac death (DCD) following the 2010 publication of the National Protocol for DCD. As emergency clinicians play a significant role in identifying potential DCD donors, it is critical to assess their support and knowledge. Although many support DCD, most are unaware of the protocol or procedures regarding DCD. Education is needed and desired by many emergency clinicians.

Introduction

Improving organ and tissue donation (OTD) processes and organ donation rates for the purposes of transplantation has been a topic of major interest worldwide and a focus of the Australian Government since 2007.[1] In Australia, organ donation most commonly occurs in deceased donors following the determination of brain death (donation after brain death or DBD). There has been a renewed interest in donation after cardiac death (DCD), historically the first method of donation prior to the availability of advanced cardiorespiratory support.[2] This interest has resulted from a desire to provide an alternative pathway to donation to fulfil the wishes of individuals wishing to donate organs when DBD is not possible or appropriate, and to increase the availability of organs and tissues for transplantation.[3]

In 2010, the Australian Organ and Tissue Authority published a national protocol for DCD.[3] The protocol highlights that DCD is often logistically complex due mainly to the need to retrieve organs in a time critical manner following the cessation of circulation. DCD only occurs in Australia in the controlled situation of death following withdrawal of cardiorespiratory support in intensive care units (ICU). However, controlled DCD may still raise specific ethical issues, such as perceived conflicts of interest surrounding the withdrawal of cardiorespiratory support. The decision to withdraw cardiorespiratory support is taken independently of, and prior to, any consideration of the potential for DCD.

The reintroduction of DCD increases the number of patients who may be suitable for deceased donation beyond those who progress to brain death to include patients with other organ failures. While DBD and DCD are, in Australia, organised from the ICU, many end-of-life and withdrawal or limitation of treatment decisions regularly occur in the emergency department (ED).[4, 5] ED clinicians, therefore, need to have awareness and understanding of DCD so the opportunity for consideration of DCD to be included in end-of-life decisions is not missed. As part of a cross-sectional survey of Australian ED clinicians on the barriers to OTD, we aimed to collect data on their knowledge and support regarding DCD.

The methods have been described in detail elsewhere,[6, 7] but in short the survey was constructed based on available literature and iterative feedback from the steering committee. A pilot study was conducted at St Vincent's Hospital in Melbourne (SVHM), and the final survey took approximately 15–20 min to complete and was approved by the Human Research Ethics Committee of SVHM. Of the 133 items of the larger survey, nine were relevant to the study described here. A total of 3995 members of the Australasian College for Emergency Medicine (ACEM) and College of Emergency Nursing Australasia (CENA) was invited by email to take part in an online survey in early 2011. Knowledge and attitudes regarding DCD were assessed by rating agreement with statements regarding DCD on a 5-point scale. These results were collapsed into three categories – (strongly) agree, neutral and (strongly) disagree – and for further data analysis collapsed into binary responses (strongly disagree, disagree and neutral vs agree and strongly agree). Free-text comments regarding the opinions of DCD could also be made. These comments were categorised into common themes identified by two researchers, and discussed until consensus was reached. Quantitative data were analysed using Pearson's Chi-squared test or Fisher's exact tests in Predictive Analytic Software (Version 18.0; spss Inc., Chicago, IL, USA).

As not all respondents answered all sections of the survey, results reported include only those respondents completing items in the survey relating to DCD.

Results

Response rates were 16.4% for ACEM and 15.7% for CENA members, and included 222 emergency medicine trainees, 265 emergency physicians and 161 nurses. Respondents could report the hospital in which they worked, of those that did the majority (86.0%, 461) worked in DonateLife Network hospitals, that is those having DonateLife-supported, hospital-based medical and nurse donation specialists. Most staff (74.2%, 481) had one or more experiences with OTD-related tasks, including identifying, referring or caring for potential donors during the preceding calendar year. However, 26.7% (173) had not received any education regarding OTD, such as attending departmental information sessions, conference sessions, on-the-job training or reading articles regarding OTD.

A minority of emergency clinicians had any knowledge of the processes involved in DCD. Less than one-third of ED clinicians (31.9%, 207) agreed with the statement 'I am familiar with the processes involved with OTD after cardiac death', while 19.3% (125) were neutral and 48.8% (316) disagreed. Less than a quarter (22.7%, 147) agreed with the statement 'I am aware of the national policy on OTD after cardiac death', with 23.3% (151) responding neutral and 54.0% (350) disagreeing.

When asked whether supportive of OTD after cardiac death, 71.0% (460) agreed, while 25.6% (166) were neutral and 3.4% (22) disagreed. Analysis of factors contributing to knowledge and attitudes towards DCD showed that having received education regarding OTD, having had any experience with OTD-related tasks, staff type and working in a hospital that was part of the DonateLife Network were related (Table 1).

Table 1. Knowledge and attitude regarding donation after cardiac death according to demographics (N, %)

	I am familiar with the processes involved with OTD after cardiac death		I support OTD after cardiac death		I am aware of the national policy on OTD after cardiac death	
	(strongly) disagree or neutral	(strongly) agree	(strongly) disagree or neutral	(strongly) agree	(strongly) disagree or neutral	(strongly) agree
Non DonateLife hospital	55, 73.3%	20, 26.7%	26, 34.7%	49, 65.3%	66, 88.0%	9, 12.0%
DonateLife hospital	301, 65.3%	160, 34.7%	122, 26.5%	339, 73.5%	345, 74.8%	116, 25.2%
Fisher's exact	NS		NS		P=0.012	
Nursing staff	105, 65.2%	56, 34.8%	51, 31.7%	110, 68.3%	124, 77.0%	37, 23.0%
Medical trainee	170, 76.6%	52, 23.4%	64, 28.8%	158, 71.2%	188, 84.7%	34, 15.3%
Medical specialist	166, 62.6%	99, 37.4%	73, 27.5%	192, 72.5%	189, 71.3%	76, 28.7%
Pearson's Chi-Squared	P=0.003		NS		P=0.002	
No OTD education	150, 86.7%	23, 13.3%	62, 35.8%	111, 64.2%	160, 92.5%	13, 7.5%
Had OTD education	291, 61.3%	184, 38.7%	126, 26.5%	349, 73.5%	341, 71.8%	134, 28.2%
Fisher's exact	P<0.001		P=0.024		P<0.001	
No OTD experience	138, 82.6%	29, 17.4%	62, 37.1%	105, 62.9%	147, 88.0%	20, 12.0%
Had OTD experience	303, 63.0%	178, 37.0%	126, 26.2%	355, 73.8%	354, 73.6%	127, 26.4%
Fisher's exact	P<0.001		P=0.010		P<0.001	

OTD, organ and tissue donation.

There were 37 free-text responses provided following the statement 'My opinion on OTD after cardiac death is…' These comments were categorised into five categories: positive, negative, ethical concerns, logistical concerns and not enough knowledge (Table 2).

Table 2. Free-text comments regarding donation after cardiac death

Theme	n†	Example
Positive	19	'A good thing as it can make more life saving or life improving organ/tissues available'.
Insufficient knowledge	9	'Something I know nothing about'.
Logistical concerns	8	'Logistically challenging. Often difficult to facilitate due to timeline uncertainty for families given logistical complexities'.
Ethical concerns	6	'I struggle with this ethically. I think it is a fine line often and have heard stories of death needing to be 'facilitated' quite quickly due to the time frames required. I would struggle with that if I were the treating doctor – I have even heard people say it seems something like euthanasia. Glad I am not an intensivist dealing with this'.
Negative	4	"Usually a waste of time"

†There were 37 free-text comments, 9 were categorised under two themes.

From the 648 respondents completing the full survey, 77% (499) indicated they desired further education about OTD, and 79.8% (398) of those specifically selected DCD as a topic for further education, making it the most selected topic for further education (61.4% of the total).

The launch of the national DCD protocol, in unison with DCD pathways being developed and implemented in many Australian hospitals, is part of a major effort to increase organ donation rates in Australia.[3, 8] However, little is known about Australian healthcare staff knowledge and support regarding DCD. Our results showed that the majority of respondents are not familiar with the processes or policies regarding DCD. In particular, emergency medicine trainees, those working in hospitals not part of the DonateLife Network and those without education or experience with OTD-related tasks, are more often unaware of the processes or the national protocol regarding DCD. The proportion of ED clinicians unfamiliar with DCD procedures and protocol may, in fact, be larger, as our results may underestimate this proportion due to low response rate and responder bias, or a potential perceived social desirability of reporting knowledge. The proportion of staff supportive of DCD (71.0%) is consistent with studies examining attitudes towards DCD in US critical care staff.[9, 10]

Of interest, respondents were less supportive of DCD compared with the proportion supportive of OTD for transplantation in general (which was 96.2%, as assessed in the larger study of the same cohort).[11] This lower rate of support for DCD is consistent with other studies finding less comfort and knowledge regarding DCD compared with DBD.[12]

Although the majority were supportive of DCD, those who had not received any education regarding OTD and those without any experience of OTD were less supportive than those with some knowledge and experience. This is consistent with studies reporting that a lack of

knowledge and familiarity among healthcare staff regarding DCD can lead to misconceptions or negative attitudes.[13] Educational sessions were shown to increase the support and knowledge regarding DCD in the US.[12]

Although most free-text comments regarding DCD were positive remarks, they revealed that some respondents had ethical concerns regarding the issues surrounding withdrawal of cardiorespiratory support. These concerns have also been identified in other studies looking at healthcare staff attitudes towards DCD.[10, 14] Ethical concerns regarding end-of-life decision-making and the withdrawal of cardiorespiratory support are also acknowledged in the protocol.[3] Education relating to the process of DCD may reassure emergency clinicians that, in Australia, DCD will only occur in controlled circumstances in the ICU. However, it is important for emergency clinicians' concerns to be acknowledged and discussed as part of the ongoing international debate.

Other themes expressed in the free-text comments related to logistical issues and insufficient knowledge. Although logistical issues regarding DCD are inherent to the process, most of the process occurs in the ICU, and the identification of potential donors in the ED should not generally add significantly to the burden of clinical care in the ED. However, emergency clinicians have complex roles and heavy workload, and adding new dimensions of care adds to workload issues.

Finally, our results showed that the majority of ED clinicians desired additional education on the topic of DCD, implying support for the introduction of DCD pathways in Australian hospitals, although much work remains to be done educating staff about DCD.

DCD is a process with which the majority of respondents were unfamiliar and had not experienced personally. Those who have received specific education and have had experience with OTD show a higher rate of support for the process of DCD. For those involved in OTD education and processes, it is critical to engage with emergency clinicians to increase acceptance and understanding of DCD, so that patients in the ED who may be potential DCD donors are identified and their families provided with the opportunity to consider DCD.

References

1. Louise Greene Consulting for The National Health and Medical Research Council National Institute of Clinical Studies. Review of the National Organ Donation Collaborative, interim report. May 2009.
2. Linden PK. History of solid organ transplantation and organ donation. Crit Care Clin 2009; 25: 165–184. ix.
3. Australian Organ and Tissue Donation and Transplantation Authority. National protocol for donation after cardiac death, July 2010. [cited 2012 Jul 9]. Available from URL: http://www.donatelife.gov.au/Media/docs/DCD%20protocol%20020311-0e4e2c3d-2ef5-4dff-b7ef-af63d0bf6a8a-1.PDF

4. Tardy B, Venet C, Zeni F, Berthet O, Viallon A, Lemaire F et al. Death of terminally ill patients on a stretcher in the emergency department: a French speciality? Intensive Care Med 2002; 28: 1625–1628.
5. Le Conte P, Riochet D, Batard E, Volteau C, Giraudeau B, Arnaudet I et al. Death in emergency departments: a multicenter cross-sectional survey with analysis of withholding and withdrawing life support. Intensive Care Med 2010; 36: 765–772.
6. Jelinek GA, Marck CH, Weiland TJ, Neate SL, Hickey BB. Organ and tissue donation-related attitudes, education and practices of emergency department clinicians in Australia. Emerg Med Australas 2012; 24: 244–250.
7. Marck CH, Weiland TJ, Neate SL, Hickey BB, Jelinek GA. Australian emergency doctors' and nurses' acceptance and knowledge regarding brain death: a national survey. Clin Transplant 2012; 26: E254–260.
8. Coulson TG, Pilcher DV, Graham SM, Snell GI, Levvey BJ, Philpot S et al. Single-centre experience of donation after cardiac death. Med J Aust 2012; 197: 166–169.
9. Keenan SP, Hoffmaster B, Rutledge F, Eberhard J, Chen LM, Sibbald WJ. Attitudes regarding organ donation from non-heart-beating donors. J Crit Care 2002; 17: 29–36. Discussion 7–8.
10. Hart JL, Kohn R, Halpern SD. Perceptions of organ donation after circulatory determination of death among critical care physicians and nurses: a national survey. Crit Care Med 2012; 40: 2595–2600.
11. Marck CH, Weiland TJ, Neate SL, Hickey BB, Jelinek GA. Personal attitudes and beliefs regarding organ and tissue donation: a cross-sectional survey of Australian emergency department clinicians. Prog Transplant 2012; 22: 317–322.
12. Mathur M, Taylor S, Tiras K, Wilson M, Abd-Allah S. Pediatric critical care nurses' perceptions, knowledge, and attitudes regarding organ donation after cardiac death. Pediatr Crit Care Med 2008; 9: 261–269.
13. D'Alessandro AM, Peltier JW, Phelps JE. An empirical examination of the antecedents of the acceptance of donation after cardiac death by health care professionals. Am J Transplant 2008; 8: 193–200.
14. DuBois JM, Anderson EE. Attitudes toward death criteria and organ donation among healthcare personnel and the general public. Prog Transplant 2006; 16: 65–7

Chapter 7

Australian emergency clinicians' perceptions and use of the GIVE Clinical Trigger for identification of potential organ and tissue donors.

Sandra L Neate, Claudia H Marck, Tracey J Weiland, Nicola Cunningham, Bernadette B Hickey, Bernadine M Dwyer, and George A Jelinek

Emergency Medicine Australasia 2012;24(5):501-09.

Abstract

Objectives: In 2010 the Australian Organ and Tissue Authority introduced a nationally consistent indicator, the GIVE Clinical Trigger, for early identification of potential organ and tissue donors in EDs and intensive care units. This national survey of emergency clinicians aimed to assess emergency clinicians' perceptions and use of the Trigger.

Methods: National cross-sectional survey of Australasian College for Emergency Medicine (ACEM) fellows and trainees and members of the College of Emergency Nursing Australia (CENA); online questionnaire; 12 items addressing implementation of the GIVE Trigger; graded and free-text responses.

Results: Five hundred and ninety-nine (20.2%) of 2969 ACEM members and 212 (20.7%) of 1026 CENA members responded. Four hundred and seventy-four respondents (62.7%) were familiar with the Trigger; 472 (63.8%) agreed it was easy to recognise patients who activated the Trigger; 490 (64.9%) had sufficient time to use the Trigger; 511 (67.7%) felt they had the necessary competence and knowledge to identify a potential donor; 464 (61.5%) felt competent and 501 (66.4%) felt comfortable referring a potential donor when identified. Overall 587 (77.7%) ED clinicians supported the use of the Trigger, but most (587 [77.7%]) perceived barriers to its use; 628 (80%) had never activated the Trigger and 557 (71%) had never referred a potential donor to relevant authorities.

Conclusion: Most Australian emergency clinicians are familiar with and support the GIVE Clinical Trigger, and feel they have the necessary skills to use the Trigger; however, most perceive barriers to its use and have not yet used the Trigger.

Introduction

Australia has a world-class reputation in organ transplantation but has a low organ donation rate compared with other developed nations,[1] at 14.9 donors per million population in 2011.[2] Health professional engagement is essential to improved organ and tissue donation (OTD) rates as clinician attitudes, identification and referral of potential donors, and ability to discuss OTD with families are critical to successful donation.[3-6]

Australian data from the 2006–2009 National Organ Donation Collaborative (NODC)[7] identified significant numbers of missed potential donors, with 10% of patients with established brain death and substantial numbers with imminent brain death either not identified as potential donors or organ donation was not raised with the next-of-kin. Of patients with imminent brain death, significant numbers had treatment withdrawn in intensive care units (ICUs) and EDs before brain death developed.[7] Causes reported included failure to recognise potential donors (predominantly in EDs), clinician unwillingness to discuss organ donation with families before brain death, resource pressures and marginal medical suitability for OTD.[7] UK data support the premise that potential donors have been missed in ED populations.[8] US data support improved rates of organ retrieval following ED referral versus inpatient referral.[9]

In July 2008 the Australian Government funded a national reform package, A World's Best Practice Approach to Organ and Tissue Donation for Transplantation, informed by findings from the NODC. Nine key measures were implemented (Table 1), the first two of relevance to this study. The first was the development of a new national authority and a network of OTD agencies.[10] In 2009 the Organ and Tissue Authority (The Authority) was established to deliver a nationally coordinated approach to OTD and establish and operate a national network of OTD agencies, known as DonateLife Agencies.[11]

Table 1. The nine measures of the national reform agenda

Measure	Description
1	A new national approach and system – a national authority and network of organ procurement organisations
2	Specialist hospital staff and systems dedicated to organ donation
3	New funding for hospitals
4	National professional awareness and education
5	Coordinated ongoing community awareness and education
6	Support for donor families
7	Safe, equitable and transparent national transplantation process
8	National eye and tissue donation and transplantation
9	Additional national initiatives, including living donation programmes

The second key measure was the employment of hospital-based specialist medical and nursing staff dedicated to OTD across selected private and public hospitals,[12] and the implementation of a nationally consistent Clinical Trigger for identification of potential donors in EDs and ICUs. The GIVE Clinical Trigger (GIVE Trigger/The Trigger) aims to identify patients less than 80 years who have a Glasgow Coma Scale (GCS) score equal to or less than 5 from an irrecoverable brain injury (G), are intubated (I), ventilated (V) and in whom end-of-life discussions (E) have concluded that palliative care is planned.[12] There are no medical conditions that preclude activation of the Trigger. When a potential donor is identified via the GIVE Trigger criteria, referral from ED to ICU occurs via responses individualised in each hospital.

The GIVE Trigger was endorsed by the Australasian College for Emergency Medicine (ACEM), Australian and New Zealand Intensive Care Society, the College of Intensive Care Medicine and the Australian College of Critical Care Nurses. In November 2009 the GIVE Trigger was launched by the President of ACEM and the National Medical Director of The Authority. In early 2010 the GIVE Trigger was implemented in all DonateLife-affiliated hospitals. Hospital-based specialist staff provided education in EDs, ICUs and hospital-wide to facilitate implementation of The Trigger.

Our national survey of emergency doctors and nurses aimed, in part, to assess familiarity with and comfort using the GIVE Trigger 15–18 months after its introduction and to identify barriers faced by clinicians responsible for identifying and referring potential donors.

Methods

Instrument development

The methods have been previously described in detail;[13] however, in brief, the survey was developed by the project team, with a steering committee providing feedback to ensure face validity. A pilot study of emergency clinicians at St Vincent's Hospital, Melbourne, Australia, assessed content validity, using Lynn's method.[14] The final survey comprised 133 items requiring graded responses, including 12 items addressing the GIVE Trigger. Components of the validated Hospital Attitude Survey[15] were included with permission (DonorAction). Free-text answers provided qualitative responses.

Approval for the study was obtained from the Human Research Ethics Committee at St Vincent's Hospital Melbourne.

Procedure

This online survey of 3995 potential participants comprising all trainees (n = 1800) and Fellows (n = 1169) of ACEM and members (n = 1026) of College of Emergency Nursing Australia (CENA) currently working in Australian EDs was conducted between 21 March and 9 June 2011.

Data analysis

Data were collected using the online survey package SurveyMonkey. For item summary statistics (n, %, 95% confidence intervals [CI], means [95% CI] or medians [interquartile range]) were calculated using Predictive Analytics SoftWare statistics 18.0 (SPSS, Chicago, IL, USA). $\chi 2$ linear-by-linear association for ordinal data, and Fisher's exact test were undertaken. Alpha was set at 0.05 and two-tailed tests were used. 'Strongly agreed' and 'agreed' categories were combined to indicate agreement. 'Neutral' responses were combined with 'disagreed' and 'strongly disagreed' except when the response was to a negative statement when 'neutral' was then combined with 'agreed' and 'strongly agreed'.

Results

Of the 3995 members of ACEM and CENA invited to participate, 811 started the survey, 755 completed the section on the GIVE Trigger (93.1% of all respondents) and 648 completed the whole survey. As respondent numbers varied, percentages were adjusted for number of respondents for each item.

Complete sample demographics have previously been described in detail.[13, 16] A total of 212 (20.7%) CENA members and 599 (20.2%) ACEM members responded.

Fellows of ACEM comprised the greatest number of respondents (312, 38.4%), followed by ACEM advanced trainees (184, 22.6%), CENA members with critical care postgraduate qualifications (110, 13.5%), ACEM provisional trainees (101, 12.4%), other nursing (102, 12.6%) and other medical specialists (2, 0.01%). The majority of nursing (115, 54.2%) and medical respondents (335, 55.9%) had fewer than 10 years' ED experience.

Regional representation within the sample (Fig. 1) reasonably reflected the demographics of CENA and ACEM with slight overrepresentation of clinicians from Victoria. Most respondents worked in major referral hospitals (448, 55.2%), followed by major regional (181, 22.3%), urban district (170, 21.0%) and private hospitals (12, 1.5%). Respondents could identify their major place of employment. One hundred and twenty-eight hospitals were listed by 656 respondents, 71 of which were part of the DonateLife Network. Of all respondents, 88.7% doctors and 76.1% of nurses worked in DonateLife Network hospitals.

As previously reported,[16] 50 (23.8%) nurses and 175 (29.2%) doctors reported no prior education or training in OTD, whereas 106 (51.5%) nurses and 454 (78.4) doctors reported having experience with OTD-related tasks during the preceding year.

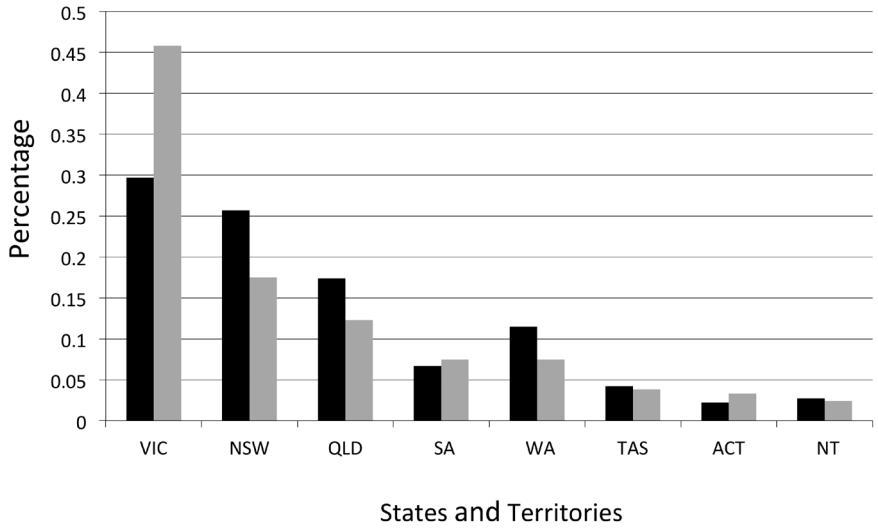


Figure 1. Representation of medical and nursing staff participants according to jurisdiction. ACT, Australian Capital Territory; NSW, New South Wales; NT, Northern Territory; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia. (■) Medical staff; (■) nursing staff.

GIVE Trigger

The section relating to the GIVE Trigger was completed by 755 participants. Most respondents (474, 62.7%, 95% CI 59.3–66.2) agreed with the statement, 'I am familiar with the Clinical Trigger'. Familiarity with the Trigger was related to region of employment ($P < 0.001$), with rates ranging from 48.7% (95% CI 37.8–59.7; Western Australian) to 74.8% (95% CI 69.8–80.3; Victoria). Familiarity varied with hospital type ($P = 0.02$), with greatest rates in major referral (276, 66.3%, 95% CI 61.7–70.7) and private hospitals (9, 90.0%, 95% CI 57.4–99.9), and slightly lower rates in major regional/rural and urban hospitals (96, 56.8%, 95% CI 49.3–64.0 and 93, 58.1%, 95% CI 50.4–65.5, respectively). Clinicians from hospitals previously associated with the NODC and those with dedicated specialist staff (affiliated with DonateLife) had the highest rates of Trigger familiarity (218, 70.1%, 95% CI 64.8–74.9 and 141, 65.6%, 95% CI 59.0–71.6, respectively). Clinicians from hospitals without NODC or DonateLife affiliation had significantly lower rates of familiarity (40, 40.4%, 95% CI 34.2–54.2; $P < 0.001$). Familiarity also varied with having received OTD-related education (74.9%, 95% CI 71.1 vs 29.4%, 95% CI 23.4–36.0; $P < 0.001$) and having OTD-related experience in the preceding year (67.3%, 95% CI 63.3–71.1 vs 50.7%, 95% CI 44.0–57.5; $P < 0.001$).

Four hundred and seventy-two (63.8%, 95% CI 60.1–67.2) respondents agreed that it was easy to recognise patients who activated the GIVE Trigger. This was related to staff type ($P < 0.001$); 146 (55.3%, 95% CI 49.3–61.2) trainee emergency physicians agreed, compared with 117 (60.9%, 95% CI 53.9–67.6) nurses and 219 (73.2%, 95% CI 68.0–78.0) emergency physicians. Ease of recognition was related to years of ED experience ($P < 0.001$; Fig. 2), having received OTD education (71.7%, 95% CI 67.8–75.3 vs 42.3%, 95% CI 37.7–49.2

who had not received OTD education; P < 0.001), and having experience with OTD-related tasks in the preceding year (69.2%, 95% CI 65.2–72.9 vs 49.8%, 95% CI 43.0–56.5 of those who had no OTD experience; P < 0.001). Those working in hospitals with a history of NODC collaboration/DonateLife Network affiliation more often found it easy to recognise potential donors (362, 68.8%, 95% CI 64.7–72.6) compared with those working in other hospitals (49, 53.8%, 95% CI 43.7–63.7; P < 0.005).

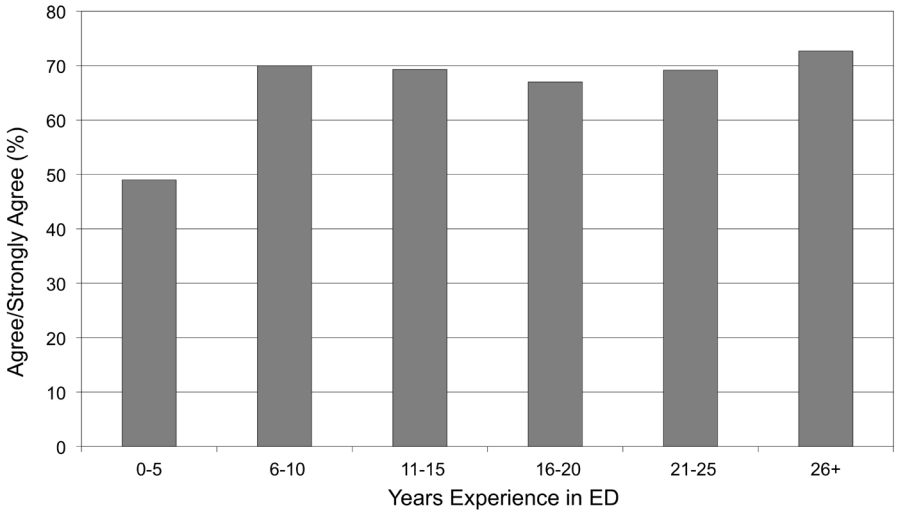


Figure 2. Ease of using the Trigger according to years of experience.

The majority of ED clinicians (490, 64.9%, 95% CI 61.4–68.2) felt they had sufficient time to activate the Trigger/identify a potential donor; this was related to jurisdiction, staff type, OTD education and OTD experience (Table 2).

Most ED clinicians (511, 67.7%, 95% CI 64.3–70.9) also felt they had the necessary competence and knowledge to identify a potential donor via the GIVE Trigger. Perceived competence and knowledge increased continuously according to years of experience (P < 0.001) from 103 (50.0%, 95% CI 43.2–56.8) clinicians with fewer than 5 years' experience to 27 of 33 clinicians with greater than 25 years' experience. It was also related to staff type (118, 61.5%, 95% CI 54.4–68.1 of nursing staff; 157, 59.5%, 95% CI 53.5–65.2 of trainees and 236, 78.9%, 95% CI 73.9–83.2 of medical specialists; P < 0.001), OTD education (412, 74.4%, 95% CI 70.1–77.8 vs 99, 49.3%, 95% CI 42.4–56.1 of those without OTD education; P < 0.001), having had actual experience with OTD-related tasks (392, 71.5%, 95% CI 67.6–75.2 vs 119, 57.5%, 95% CI 50.7–64.0 of those without experience; P < 0.001) and hospital affiliation (140, 65.1%, 95% CI 58.5–71.2 of those working in DonateLife hospitals vs 229, 73.6%, 95% CI 68.5–78.2 of those working in NODC hospitals vs 55, 60.4%, 95% CI 50.2–69.9 of those working in non-affiliated hospital; P = 0.02).

Table 2. Time to use the Trigger according to demographics [number (%; 95%CI)]

Demographics		I don't have time to use the Clinical Trigger/identify potential donors		
		(strongly) disagree	(strongly) agree or neutral	P
Jurisdiction	VIC	192 (74.4; 68.8-79.4)	66 (25.6;20.6-31.3)	P<0.001
	NSW	99 (56.6;49.2-63.7)	76 (43.4;36.3-50.8)	
	QLD	83 (66.4;57.7-74.1)	42 (33.6;25.9-42.3)	
	SA	23 (44.2;31.6-57.7)	29 (55.8;42.3-68.4)	
	WA	44 (57.9;46.7-68.4)	32 (42.1;31.6-53.3)	
	TAS	20 (63;45-77)	12 (38;23-54)	
	ACT	15 (83;60-95)	3 (17;5-40)	
	NT	14 (74;51-89)	5 (26;11-49)	
Staff type	Nursing	112 (58.3;51.3-65.1)	80 (41.7;34.9-48.7)	P=0.023
	ACEM trainee	168 (63.6;57.7-69.2)	96 (36.4;30.8-42.3)	
	ACEM specialist	210 (70.2;64.8-75.1)	89 (29.8;24.9-35.2)	
Training or education in OTD	No	114 (56.7;49.8-63.4)	87 (43.3;36.6-50.2)	P=0.05
	Yes	376 (67.9;63.9-71.6)	178 (32.1;28.4-36.1)	
OTD experience in the last calendar year	No	119 (57.5;50.7-64.0)	88 (42.5;36.0-49.3)	P=0.09
	Yes	371 (67.7;63.7-71.5)	177 (2.3;28.5-36.3)	

ACT, Australian Capital Territory; CI, confidence interval; NSW, New South Wales; NT, Northern Territory; OTD, organ and tissue donation; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia.

Most ED clinicians felt competent (464, 61.5%, 95% CI 57.9–64.9) and comfortable (501, 66.4%, 95% CI 62.9–69.6) referring an identified potential donor to an appropriate person or authority. Both comfort and perceived competence were related to region, staff type, experience in EDs, OTD experience and education and hospital affiliation (Table 3).

Table 3. Comfort and competence to refer a potential donor according to demographics [number (%; 95%CI)]

Demographics		I feel comfortable to refer a potential donor	I have the necessary competence and knowledge to refer a potential donor
		(strongly) agree	(strongly) agree
Staff type	Nursing	**103 (53.6;46.6-60.6)**	**84 (43.8;36.9-50.8)**
	ACEM trainee	**162 (61.4;33.0-44.6)**	**141 (53.4;47.4-59.3)**
	ACEM specialist	**236 (78.9;73.9-83.2)**	**239 (79.9;75.0-84.1)**
Years of experience working in EDs	0-5	**100 (48.5;41.8-55.3)**	**85 (41.3;34.8-48.1)**
	6-10	**147 (70.0;63.5-75.8)**	**140 (66.7;60.0-72.7)**
	11-15	**115 (75.2;67.7-81.4)**	**109 (71.2;63.6-77.8)**
	16-20	**63 (71.6;61.4-80.0)**	**62 (70.5;60.2-79.0)**
	21-25	**51 (78.5;66.9-86.8)**	**43 (66.2;54.0-76.5)**
	26 or more	**25 (76;61-89)**	**25 (76;61-89)**
OTD Education	no	**105 (52.2;45.4-59.0)**	**84 (41.8;35.2-48.7)**
	yes	**396 (71.5;67.6-75.1)**	**380 (68.6;64.6-72.3)**
Experience with OTD	No	**116 (56.0;49.2-62.6)**	**91 (44.0;37.4-50.8)**
	Yes	**385 (70.3;66.3-73.9)**	**373 (68.1;64.1-71.8)**
Hospital affiliation	Non DonateLife hospital	*52 (57.1;46.9-66.8)*	**41 (45.1;35.2-55.3)**
	DonateLife hospital	*143 (66.5;60.0-72.5)*	**133 (61.9;55.2-68.1)**
	NODC hospital	*222 (71.4;66.1-76.1)*	**211 (67.8;58.8-69.4)**
Region	VIC	**194 (75.2;69.6-80.1)**	
	NSW	**112 (64.0;56.7-70.8)**	
	QLD	**71 (56.8;48.0-65.2)**	
	SA	**25 (48;35-61)**	
	WA	**55 (72.4;61.4-81.2)**	
	TAS	**20 (63;45-77)**	
	ACT	**13 (72;49-88)**	
	NT	**11 (58;36-77)**	

Bold, P ≤ 0.001. Italics, P < 0.05. ACT, Australian Capital Territory; CI, confidence interval; NODC, National Organ Donation Collaborative; NSW, New South Wales; NT, Northern Territory; OTD, organ and tissue donation; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia.

Other than age less than 80 years and the low GCS being from an irrecoverable brain injury, there are no preconditions to Trigger activation. In particular, there are no medical conditions precluding Trigger activation. Respondents were asked whether certain medical conditions would prevent their activating the Trigger. Both medical and nursing staff were very conservative with respect to referring patients with specific medical conditions (Table 4).

Although the majority of staff were familiar with the Trigger before the survey, the survey was also used as an opportunity to provide education regarding the Trigger. Following this, 587 (77.7%, 95% CI 74.6–80.6) ED clinicians supported the use of the Trigger. Rates of support were related to region, with lowest rates of support in Tasmania (20/32, 63%, 95% CI 45–77) up to the highest rates in Victoria (235, 91.1%, 95% CI 86.9–94.0; P < 0.001), staff type (nursing staff 155, 80.7%, 95% CI 74.5–85.7 vs medical trainees 191, 72.3%, 95% CI 66.7–77.4 vs medical specialists 241, 80.6%, 95% CI 75.7–84.7; P = 0.03) and having received education (455, 82.1%, 95% CI 78.7–85.1 vs 132, 65.7%, 95% CI 58.9–71.9 without OTD education; P < 0.001). Most staff disagreed with the statement that the ED is not the right place to identify potential donors (337, 59.9%, 95% CI 55.8–63.8 medical and 130, 67.7%, 95% CI 60.8–73.9 nursing). However, a large proportion of staff (587, 77.7%, 95% CI 72.2–78.3) perceived barriers to the identification of potential donors in the ED (Table 5), including time and ED overcrowding, with fewer nursing staff (134, 69.8%, 95% CI 63.0–75.9) perceiving barriers than emergency physicians (222, 74.2%, 95% CI 69.0–78.9). Two hundred and thirteen (80.7%, 95% CI 75.5–85.0) emergency trainees perceived barriers to the identification of potential donors in the ED.

Table 4. Referring potential donors with medical conditions [number (%; 95%CI)]

Would you refer a patient who activated the Trigger and has the following medical condition?	Yes	No	Unsure
Overwhelming sepsis	170 (23.3;20.3-26.5)	409 (56.0;52.3-59.5)	152 (20.8;18.0-23.9)
Metastatic cancer	137 (18.7;16.1-)	495 (67.7;64.2-71.0)	99 (13.5;11.3-16.2)
Hepatitis	230 (31.5;28.2-34.9)	381 (52.1;48.1-55.7)	120 (16.4;13.9-19.3)
HIV	93 (12.7;10.5-15.3)	546 (74.7;71.4-77.7)	92 (12.6;10.4-15.2)
Current IV drug use	229 (31.3; 28.1-34.8)	346 (47.3;43.7-51.0)	156 (21.3;18.5-24.5)
Multiple sclerosis	396 (54.2;50.6-57.8)	140 (19.2;16.5-22.2)	195 (26.7;23.6-30.0)
Meningococcal infection	163 (22.3;19.4-25.5)	414 (56.6;53.0-60.2)	154 (21.1;18.3-24.2)
Tuberculosis	163 (22.3;19.4-25.5)	406 (55.5;51.9-59.1)	162 (22.2;19.3-25.3)
Neurological disease	471 (64.4;60.9-67.8)	106 (14.5;12.1-17.3)	154 (21.1;18.3-24.2)
Age >80 years	281 (38.4;35.0-42.0)	313 (42.8;39.3-36.4)	137 (18.7;16.1-21.7)

CI, confidence interval.

Table 5. Barriers to identifying potential donors according to demographics [number (%; 95%CI)]

Demographics		I perceive no barriers to the identification of potential donors	P value
		(strongly) agree	
Region	VIC	74 (28.7;23.5-34.5)	P=0.012
	NSW	50 (28.6;22.4-35.7)	
	QLD	20 (16.0;10.5-23.5)	
	SA	7 (13.5;6.4-25.6)	
	WA	21 (27.6;18.8-38.6)	
	TAS	5 (16;6-32)	
	ACT	7 (39;20-62)	
	NT	2 (11;1-32)	
Staff type	Nursing	58 (30.2;24.1-37.1)	P=0.024
	ACEM trainee	51 (19.3;15.0-24.5)	
	ACEM specialist	77 (25.8;21.1-31.0)	
Years of experience in EDs	0-5	36 9 (17.5;14.3-25.7)	P=0.001
	6-10	53 (25.2;19.8-31.5)	
	11-15	37 (24.2;18.1-31.6)	
	16-20	26 (29.5;20.0-38.2)	
	21-25	20 (30.8;20.8-42.9)	
	26 or more	14 (42;27-59)	
OTD education	No	37 (18.4;13.6-24.4)	P=0.017
	Yes	149 (26.9;23.4-30.7)	

ACT, Australian Capital Territory; CI, confidence interval; NSW, New South Wales; NT, Northern Territory; OTD, organ and tissue donation; QLD, Queensland; SA, South Australia; TAS, Tasmania; VIC, Victoria; WA, Western Australia.

Three hundred and ninety-six (50.4%, 95% CI 47.0–53.9) respondents had never identified a potential donor, 628 (80%, 95% CI 77.1–82.7) had never activated the Trigger, 557 (71%, 95% CI 67.7–74.0) had never referred a potential donor to the relevant authorities, and 232 (33.9%, 95% CI 30.4–37.5) did not know who to contact to initiate referral of a potential donor in the ED.

Eighty-five (11.2%) respondents provided free-text responses to the statement 'I don't use the Clinical Trigger because …' Sixteen (2.1%) had not heard of the Trigger before the survey and another 10 (1.3%) stated they had heard of the Trigger but had received no education or training about the Trigger. Other themes expressed were lack of time and other pressures in the ED, lack of exposure to a relevant patient population and not knowing whom to contact. A small number of respondents indicated a reluctance to raise the issue of OTD in the ED because of a perceived conflict of interest; that is, the patient's family might perceive that the ED is not providing all care possible. Box 1 provides a sample of responses.

Box 1.
Some free-text responses to 'I don't use the Clinical Trigger because':

I presume someone else (more senior) will do this;

Didn't know it existed; I had not been aware of the Trigger until now;

Lack of time, training in triggers and confidence in appropriate referrals

I find it inappropriate in paediatric emergency care;

It compromises patient care and leads to a hasty decision to stop treatment;

ED is not the right place but ICU is; the focus in ED is on immediate care, not organ donation;

I work in a rural/small hospital where critically ill patients are transferred out;

The ACEM Policy on Organ Donation does not support it.

It is unethical to change management in any way without requesting permission from the family.

Forty-two (5.6%) respondents provided free-text responses to the statement 'I don't support the Clinical Trigger because …' Fourteen (1.9%) provided a response where the theme was that the ED is not the right place for identification of donors. A sample of reasons given included not enough time, that families require more time to come to decisions about OTD than can be provided in the ED, 'keeping potential donors alive' just for OTD, and the use of resources to support a potential donor when another person might benefit from those resources.

Discussion

Fifteen to 18 months after the introduction of the GIVE Clinical Trigger to Australian EDs the majority of emergency clinicians surveyed were familiar with and supported the Trigger for the early identification of potential organ and tissue donors in the ED. Most respondents felt they had sufficient knowledge and competence to identify and refer potential donors and felt comfortable to do so. It is notable, however, that emergency medicine trainees reported less ease of recognition of potential donors, less time to use the Trigger, less perceived competence and knowledge and less comfort referring identified potential donors than their more senior colleagues. As trainees frequently represent the greatest numbers of staff on any given shift, it appears important to focus educational efforts towards trainees, particularly with respect to core knowledge, such as brain death and the lack of medical exclusions to Trigger activation, and to potentially include OTD as part of the Fellowship curriculum. Workload issues for trainees, including after-hours support, might be equally relevant but more difficult to address.

We suggest that education on advanced communication skills, end-of-life discussions and end-of-life care be focused on emergency specialists, as they will usually be leading the management of these critically ill patients. This might represent an opportunity for specialist staff for clinical leadership and to provide mentoring of trainees in challenging areas of the specialty.

The Trigger is designed to identify all potential donors less than 80 years of age with an irreversible brain injury, independent of presenting or pre-existing medical conditions. The simplicity of the Trigger aims to encourage referral of all potential donors and to relieve clinicians of the need to exhaustively investigate a patient's medical history and determine whether such conditions preclude donation. Although HIV and metastatic cancer, for example, would frequently preclude OTD, activation of the Trigger is desirable to allow verification and full consideration of the facts surrounding each case. Despite the simplicity of the Trigger, over 50% of clinicians would not have referred six of the eight listed medical conditions in our survey. Patients with the listed conditions might be considered as potential donors in certain circumstances and might have some, if not all, organs and tissues suitable for transplantation. It is possible that clinicians assume that, with no exclusions listed, they must still make decisions regarding potential exclusions. An alternative explanation is that clinicians might have concerns that referral of all patients will result in increased workload and increased distress for families (if referrals are made and donation does not eventuate). It is possible that the inclusion of one to two exclusions (such as HIV and metastatic cancer) might in fact assist clinicians.

Some free-text responses indicated potential knowledge deficits, especially those which indicated that respondents had neither heard of nor received education regarding the Trigger, emphasising the need for further education. It is possible that more subtle knowledge deficits led to comments, such as the Trigger compromising patient care and hastening decisions to stop treatment. Personal and professional values might play a role in individuals' opinions regarding the time required to determine when active management should change to end-of-life care. However, the Trigger stipulates that end-of-life decisions must have been independently and previously made before activation of the Trigger and

the need for decoupling of the decision to commence end-of-life care and the activation of the Trigger needs to be emphasised to help alleviate these ethical concerns of the treating clinicians.
Other free-text responses expressed that ICU was a more appropriate place for identification of potential donors. ICU might provide a more ideal environment for OTD-related discussions, and admission to ICU, followed by later activation of the Trigger in ICU, might give clinicians a greater sense of certainty that full assessment, before end-of-life decisions having been made, has occurred. However, under some circumstances, patients with severe illness or injuries might not be admitted to ICU if prognosis is that the condition is not survivable. The Trigger is designed specifically to identify patients where ICU admission would not otherwise be indicated, because of the decision to provide end-of-life care. Under these circumstances, the only opportunity for identification of a potential donor is by clarifying end-of-life decisions in the ED and then admission to ICU for consideration of potential organ donation. Results reported elsewhere[17] found that 96.2% of clinicians were very supportive of OTD in general, 98.5% believed that OTD can save lives and 90% expressed a willingness to donate their own organs and tissues after death. Given this level of general support for OTD, it appears unlikely that attitudes towards identification of donors in the ED stem from a lack of support for OTD.

Other concerns, such as ACEM not supporting the Trigger, can be allayed by emphasising the clear support and endorsement of the Trigger by ACEM.

Despite an overall familiarity with the Trigger of 62.7%, significant numbers of clinicians had not had personal experience with the Trigger and did not know who first to contact in the event of identifying a potential donor, even though the Trigger includes a referral pathway individualised to each hospital. Of concern, significant numbers perceived barriers to identification of potential donors in the ED despite the introduction of specialised OTD staff and other supports facilitated by DonateLife. DonateLife provides activity-based funding to assist in alleviating cost-related pressures incurred while identifying and supporting a potential donor. However, ED overcrowding remains an important barrier to donor identification, as it does to many other facets of contemporary emergency medicine practice.[13] The introduction of national emergency access targets in 2012 might assist in easing this pressure.

Limitations
The relatively low response rate introduces potential bias as those with an interest in OTD might have been the most likely respondents. Therefore, our results might not accurately reflect the views of all emergency clinicians. However, as ACEM requires membership from all trainees and fellows, the group of emergency doctors invited to participate represents all doctors training or specialised in emergency medicine in Australia, which constitutes the bulk of the emergency medical workforce. Membership of CENA is not compulsory, therefore the extent to which CENA membership is representative of Australian emergency nurses is not known; hence our results might not be generalisable to this cohort. The overrepresentation of Victorian respondents might be explained by the authors being from a

Victorian hospital and that a reminder notice was sent from the president of CENA to Victorian members. The lower representation of trainees in emergency medicine limits the generalisability of our results for this cohort.

Conclusion

Although emergency clinicians are generally familiar with and support the GIVE Trigger for identification of potential organ and tissue donors from the ED, and generally express comfort and competence with respect to identification and referral of potential donors, these characteristics vary significantly with staff type, seniority, education and experience. Significant numbers of clinicians had never experienced use of the Trigger or identified a potential donor and significant numbers perceived barriers to the identification of potential donors in the ED. Ongoing education regarding the broad nature and lack of exclusions to Trigger activation might assist in the more effective implementation of the Trigger and, hence, optimise rates of OTD in Australia.

Acknowledgements

This study was funded by a grant from the Organ and Tissue Authority. We wish to acknowledge the steering committee, and the Organ and Tissue Authority for funding and advice.

Competing interests

GAJ is Emeritus Editor of Emergency Medicine Australasia; TJW is a statistical consultant to Emergency Medicine Australasia.

References

1. DonateLife. Facts and statistics: Organ and Tissue Authority. Available from URL: http://www.donatelife.gov.au/discover/facts-a-statistics [Accessed 30 August 2012].
2. ANZOD. Monthly Report on Deceased Organ Donation in Australia December 2011. 2011.
3. McCaughan G. Organ donation in Australia. Intern. Med. J. 2010; 40: 603–604; author reply 604.
4. Opdam HI, Silvester W. Potential for organ donation in Victoria: an audit of hospital deaths. Med. J. Aust. 2006; 185: 250–254.
5. Siminoff LA, Arnold RM, Caplan AL. Health care professional attitudes toward donation: effect on practice and procurement. J. Trauma 1995; 39: 553–559.
6. Roels L, Spaight C, Smits J, Cohen B. Critical Care staffs' attitudes, confidence levels and educational needs correlate with countries' donation rates: data from the Donor Action® database. Transpl. Int. 2010; 23: 842–850.
7. National Health and Medical Research Council, Studies NIoC. Review of the National Organ Donation Collaborative. 2009.
8. Aubrey P, Arber S, Tyler M. The organ donor crisis: the missed organ donor potential from the accident and emergency departments. Transplant. Proc. 2008; 40: 1008–1011.

9. Michael GE, O'Connor RE. The importance of emergency medicine in organ donation: successful donation is more likely when potential donors are referred from the emergency department. Acad. Emerg. Med. 2009; 16: 850–858.
10. DonateLife. World's best practice reform package: Measure 1: Organ and Tissue Authority. Available form URL: http://www.donatelife.gov.au/the-authority/national-reform-agenda-/nine-measures/1468-measure-1 [Accessed 30 August 2012].
11. DonateLife. World's best practice reform package: Organ and Tissue Authority. Available form URL: http://www.donatelife.gov.au/the-authority/national-reform-agenda-%20[Accessed 30 August 2012].
12. DonateLife. World's best practice reform package: Measure 2: Organ and Tissue Authority. Available form URL: http://www.donatelife.gov.au/the-authority/national-reform-agenda-/nine-measures/501-measure-2 [Accessed 30 August 2012].
13. Marck CH, Weiland TJ, Neate SL, Hickey BB, Jelinek GA. Assessing Barriers to Tissue Donation in Emergency Departments. Report to Commonwealth of Australia, Organ and Organ and Tissue Authority 2012. 2012.
14. Lynn MR. Determination and quantification of content validity. Nurs. Res. 1986; 35: 382–385.
15. DonorAction. The Hospital Attitude Survey Copyright of Eurotransplant International Foundation (NL), Organizacion Nacional de Trasplantes (Spain), and the Partnership of Organ Donation (USA). 1996.
16. Jelinek GA, Marck CH, Weiland TJ, Neate SL, Hickey BB. Organ and tissue donation-related attitudes, education and practices of emergency department clinicians in Australia. Emerg. Med. Australas. 2012; 24: 244–250.
17. Marck CH, Weiland TJ, Neate SL, Hickey BB, Jelinek GA. Personal attitudes and beliefs regarding organ and tissue donation: a cross-sectional survey of Australian emergency department clinicians. Prog. Transplant., in press.

Chapter 8

Comparing organ donation practices and rates between Australia and the Netherlands to detect best practices and areas for improvement

Claudia H Marck, Nichon Jansen, Sandra L Neate, Bernadine M Dwyer,

Frank van Haren, Willem Weimar, and Jan IJzermans

Organs, Tissues and Cells (in press)

Abstract
Improving deceased organ donation rates is a priority worldwide. Australia and the Netherlands are developed countries that have historically had similar donation outcomes, but varying attitudes and practices make comparison of interest, as opportunities may exist to learn from each other. For example, Australia has successfully implemented a reform to increase donation and transplantation rates in 2009, whereas Dutch rates have only slightly increased following the implementation of a similar government plan in 2008. While 30-40% have registered their wish regarding donation in both countries, more than 10% of the Dutch population registered unwilling to donate, compared to only 0.1% in Australia. Differences exist in donation after circulatory death (DCD) practices and rates, with Australia implementing DCD pathways in hospitals in recent years. Emergency department (ED) clinicians in Australia are increasingly involved in donor recognition and referral, whereas the number of potential donors in Dutch EDs is unknown and Dutch ED clinicians have minimal involvement in donor identification and referral. In both countries potential donors are still missed, but comparisons are made difficult as data collection and reporting methods differ. There are significant areas of lack of data, such as potential DCD numbers in Australia and potential donors transiting the ED in the Netherlands. Assessing these potential donor pools may help increase organ donation rates. Comparing practices and outcomes between countries can be a useful method to detect effective practices in each country and identify areas for improvement, and this may be further facilitated by applying international data collection and reporting standards.

Background

The shortage of deceased organ donors leads to patients dying on the waiting list for transplantation. This unacceptable situation is the incentive for most countries to continue searching for new ways to improve donor rates. Both the Netherlands and Australia have had historically comparable deceased donation rates which are significantly lower than many other developed countries (figure 1) and major efforts have been made in both countries to increase donation rates in the last five years. This article seeks to compare and contrast policies and practices in these countries and to identify areas where there may be potential to learn from the other countries' practices which could assist with improving donation rates. It comprises an overview of deceased organ donation rates in the Netherlands and Australia, and compares the practices related to obtaining consent, pathways of donation and reporting on (potential) donation rates. Furthermore, it is hypothesized that emergency departments (EDs) play an important role in the identification and referral of potential donors. Donation after circulatory death (DCD) occurs with increasing frequency in both countries and, due to the time pressures involved in the DCD process, timely referral is of the essence. Patients with a poor prognosis who may be eligible to donate are often first seen by an ED clinician and end-of-life decisions are frequently made in ED. Therefore, the involvement of the emergency department (ED) in these two industrialized Western countries will be explored and compared in order to detect and learn from their practices.

Comparing donation rates and outcomes

Both the Netherlands and Australia have been steadily increasing rates of donation and numbers of transplant recipients although Australia's relative increase has been larger. In the Netherlands in the last 5 years the number of donation after circulatory death (DCD) donors has overtaken the number of donation after brain death (DBD) donors, which impacts negatively on the number of transplant recipients, as fewer organs can generally be retrieved from DCD donors compared to DBD donors. In Australia the proportion of DCD to DBD donors is increasing but still equates to less than a quarter of all donors (figure 2). Although the re-implementation of DCD pathways and protocols is still in the early stages in Australia, DCD has provided Australia with an expansion of the donor pool and this is expected to increase further as the process is optimized, importantly without decreasing the number of DBD donors[1,2]. As the two countries' demographics and geography differ, there may be an inherent difference in the potential donor pool. Comparing outcomes between countries is further challenged due to differences in practices and laws[3], population demographics, and variations in data collection and reporting methods. Also, differences are found between data reported by the websites of The International Registry on Organ Donation and Transplantation (IRODAT), and the annual performance reports from the Dutch Transplant Foundation (Nederlandse Transplantatie Stichting, NTS) and the Australian Organ and Tissue Authority (OTA) for donation rates per million population (PMP) (Table 1). Although outside the scope of this article, it should be taken into account that both countries, but especially the Netherlands, is investing large efforts into living donation, which affects waiting list data considerably.

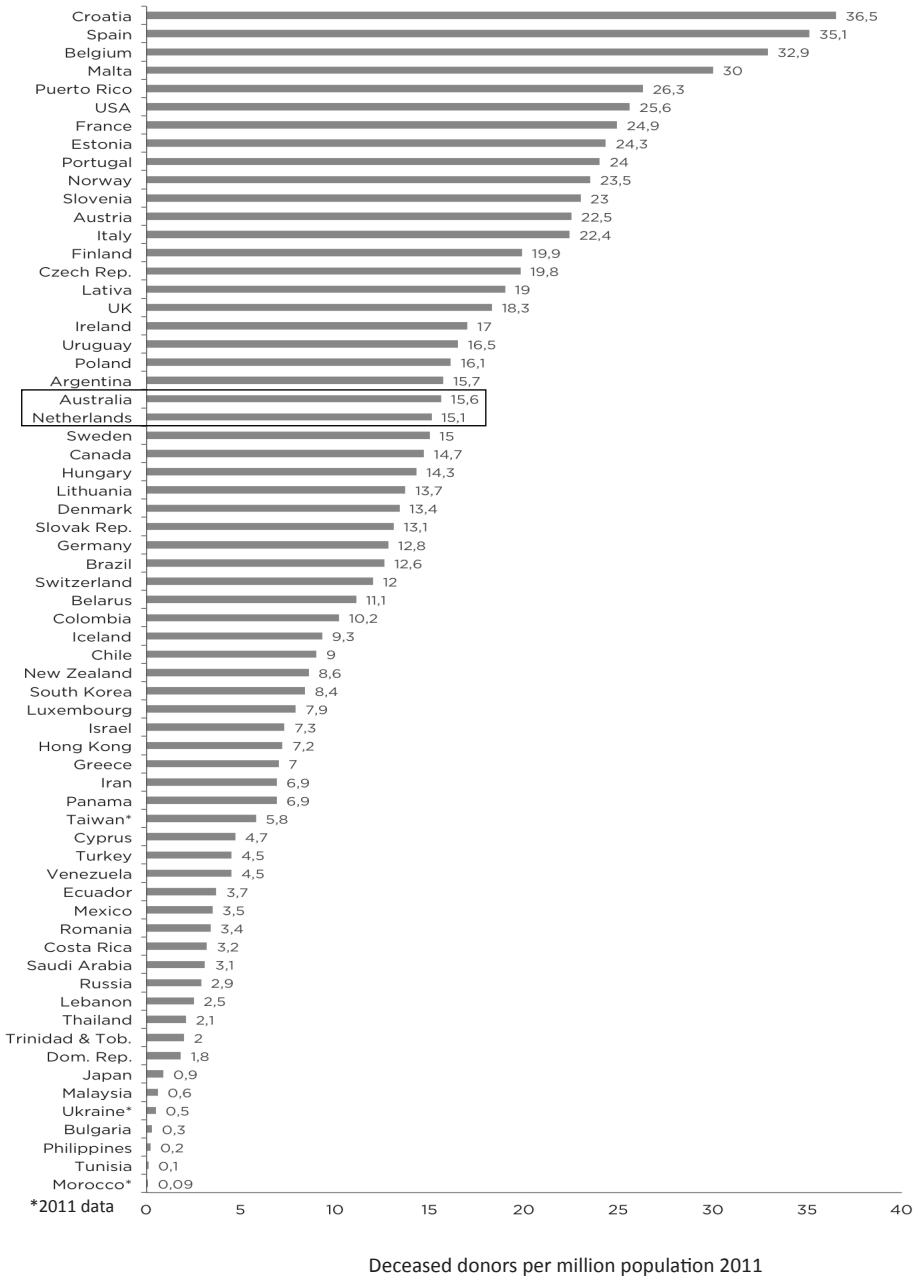


Figure 1. 2011 worldwide deceased donation rates per million population from The International Registry on Organ Donation and Transplantation[38] (permission granted by IRODAT to reproduce the figure)

Table 1 Deceased organ donation and transplantation data

	the Netherlands					Australia				
	2009	2010	2011	2012	2013	2009	2010	2011	2012	2013
Number of deceased organ donors~	215	216	221	252	255	247	309	337	354	391
Number of transplant recipients	634	643	672	746	703	808	943	1009	1053	1122
Transplant recipients per donor	2.9	3.0	3.0	3.0	2.8	3.3	3.1	3.0	3.0	2.9
Donors per million population (IRODAT)	13.0	13.0	13.2	15.1	15.3	11.3	14.0	15.1	15.6	16.9
Donors per million population (NTS/OTA)	13.8	13.7	13.6	15.3	15.2	11.4	14.0	15.1	15.6	16.9
People on waiting list^	1288	1300	1311	1286	1149	1768	1663	1614	1536	1556

Dutch data from Nederlandse Transplantatie Stichting (NTS)[10,39], The International Registry of Organ Donation and Transplantation (IRODAT)[40], and Centraal Bureau voor de Statistiek[41] Australian data from Australia and New Zealand Organ Donation Registry (ANZOD Registry) [42-44] and Organ and Tissue Authority [45,46]

^ Waiting list data from December 2013 for both countries

~ The Netherlands defines deceased organ donors as donors of which at least one organ is transplanted; Australia defines organ donors as those who underwent organ retrieval surgery regardless of whether any organs were actually retrieved or transplanted. Donors who did not have organs transplanted: six in 2009 and 2010, five in 2011, 12 in 2012 and no data is available yet for 2013.

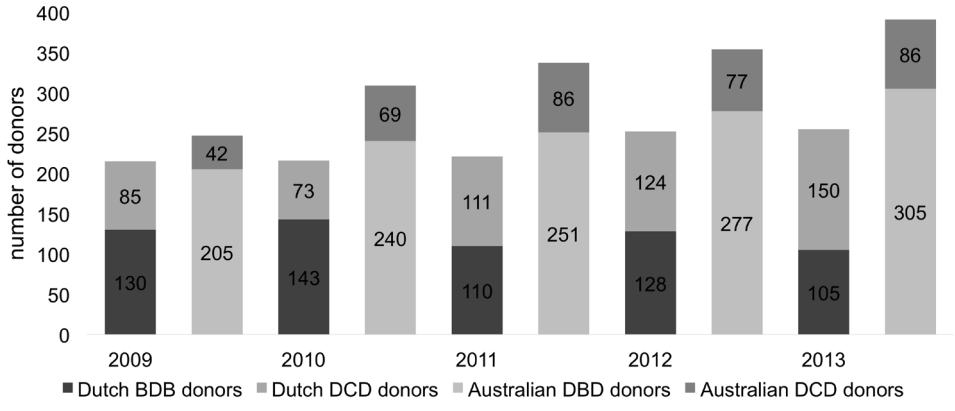


Figure 2. Organ donation rates

Organisation

In Australia the commonwealth government funded OTA (also known as DonateLife), was established under the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008*[4] in 2009 and was allocated $AUD151 million to develop and implement a National Reform Agenda over the following 4 years. The purpose of the OTA is: "to establish - in partnership with states, territories, clinicians, consumers and the community - a nationally coordinated approach to organ and tissue donation for transplantation"[5]. Although there are national guidelines and protocols regarding deceased organ and tissue donation, every state and territory has its own laws to regulate organ and tissue transplantation. The OTA employs 93 staff in eight specialist "DonateLife" agencies and in addition employs 162 medical and nurse donation specialists (DS) within 72 hospitals in Australia, who mostly work in these roles part time while also employed by hospitals in a clinical nursing or medical role[6]. Given the geography of Australia, there are smaller rural and remote hospitals that do not have affiliations with the OTA, however most hospitals with a significant potential donor pool have at least one DS. Hospital based DSs provide education for staff in various hospital departments on the use and implementation of the national "Clinical Trigger" tool (Figure 3)[7] which assists staff to identify and refer potential donors thereby ensuring that all potential donors are identified and their next of kin, usually a family member or partner (hereafter called family) is provided with an opportunity to discuss organ donation. These DSs have been trained in family donation conversations and are often the point of contact for hospital staff to assist them with conversations with the family of a potential donor. The College of Intensive Care Medicine has included Family Donation Conversation training as part of the mandatory training programme for intensive care trainees. In most states, when a potential donor is identified and it seems likely that consent for organ donation will be obtained, the DS contacts a coordinator from the local DonateLife agency who attends the donor hospital to organize the donation and transplantation. More recently there has been a move towards, and a trial of, a collaborative request model where the coordinator will become involved earlier and play a significant role in the planning of and participation in the family donation conversation.

The NTS, the organisation responsible for coordinating organ donation and transplantation in the Netherlands, came into existence one year before the Dutch organ and tissue donation act was implemented in 1998. In 2008 a governmental program "Master Plan Organ Donation" was launched in order to increase the number of organ donors and a number of organisational changes were implemented. First, hospitals were clustered; one large hospital together with a number of smaller hospitals, and within the cluster local donation coordinators were employed. Donation coordinators provide education to medical professionals including training in donation related communication with family and register all hospital deaths in order to monitor the entire process from donor identification to donor referral. All organ donation procedures in Dutch hospitals are facilitated by transplant coordinators, who attend the donor hospital as soon as the relatives provide consent or authorization for donation. These coordinators are also involved in providing education, data collection and reporting. Secondly, in these clusters, donation intensive care physicians were appointed in the intensive care units (ICUs) to facilitate organ donation. The donation intensive care physicians evaluate all organ donation requests within their cluster, by the use of a questionnaire, to find out the strengths and weaknesses within the consent process. Thirdly, regional

self-supporting organ retrieval teams were appointed to retrieve organs for transplantation, without having to rely on the operating team of a local donor hospital. These organisational changes have now been rolled out nationally and will be evaluated at end of 2014.

Practices

The Netherlands currently carries out DBD and DCD including uncontrolled DCD (uDCD) Maastricht category 1 in a pilot setting (circulatory death outside the hospital), uDCD category 2 (circulatory death inside the hospital when resuscitation is not successful), controlled DCD (cDCD) category 3 (anticipated circulatory death in hospital) and 4 (circulatory arrest in a brain-dead donor)[8]. Australia does not perform uDCD and not all hospitals offer controlled DCD pathways. Potential DCD donors in hospitals without DCD pathways are either transferred to other hospitals if feasible, or are unable to donate organs. This applies also to potential organ donors if they are located in a remote area where some hospitals or clinics may not have an ICU. In addition to these geographic and logistic challenges, Australia's criteria for donor age, and maximum time from withdrawal of respiratory support to circulatory arrest to allow for transplantation are currently stricter than the Dutch criteria and this can have a significant impact on the number of potential and actual donors and transplantation outcomes.

Reporting systems

In Australia, donation specialists retrospectively review all deaths occurring in the 72 hospitals in the DonateLife network and complete monthly reports on the number and characteristics of potential donors identified, referred, and missed, the so called "DonateLife audit". This includes all deaths in those aged between 28 days and 80 years occurring in, or within 24 hours of leaving, the ED or ICU and all other patients for whom organ donation was considered[9]. Within the hospital, and at jurisdictional DonateLife meetings, these data are reviewed and discussed, with a focus on ensuring minimization of missed donors and improving potential donor identification and consent procedures. These data are also collected by the OTA on a national level. Although data on all potential donors is collected in the audit, data published in the yearly performance report of the OTA only includes approximate figures as rates of consent to donation and conversion (actual organ donors/all potential donors) are calculated using only data from donors with confirmed or probable brain death, and does not include those with imminent brain death, or potential DCD donors due to OTA's concerns about accurately and objectively identifying potential DCD or imminent brain death donors via the audit tool.

In the Netherlands a similar reporting system records all hospital deaths through physician completed documentation including a donation form. Dutch donation coordinators and transplant coordinators review these forms in all 95 hospitals (this includes all Dutch hospitals except private clinics and cancer centres). Collected data are entered in the 'Dutch Deceased Registration Donors' (Nederlandse Overledenen Registratie Donoren, NORD), an application developed by the NTS. These data provide information about deceased patients and potential donation opportunities. In addition, a more comprehensive assessment on medical records of deceased patients in ICUs from 92 hospitals is carried out to

identify barriers to organ donation. It is estimated that around 99% of potential donors are identified in the ICUs of Dutch hospitals based on data from the additional medical record review[10].

Organ Donation Register

Although a topic of discussion in both countries, presumed consent (an opt-out system) has not been adopted in either country. While the Dutch are able to register their wish regarding donation from the age of 12[11], Australians are able to register intent at age 16 and consent at age 18[12]. While both have the option to register their wish to donate or to not donate, and specify organs and tissues they wish to donate, the Dutch also have the additional option to defer this decision to the family (which is the default in both countries when someone is not registered) or another specified person. A striking difference between these countries is that, while 30-40% of the population are registered on the organ donor register in both countries, the proportion of people registered as not willing to donate in the Netherlands is 100 fold higher compared to Australia (table 2).

Table 2 Organ donor registration data

	the Netherlands			Australia		
	N	Of all registered	Of population	N	Of all registered	Of population
Registered	5,771,382	100%	39.6%	6,009,246	100%	32.5%
Wish to donate^	3,485,914	60.4%	23.9%	5,986,276	99.6%	32.4%
Wish not to donate	1,581,359	27.4%	10.8%	22,970	0.4%	0.1%
Family to decide	704,109	12.2%	4.8%	N/A	N/A	N/A

^ Registered wish to donate at least one organ or tissue

Dutch donor registration data on 31-12-201347, Population data on 1-1-2014 (14,589,608 people ≥ 12 years)48 Australian data from 31-4-201412. Population data on 30-6-2013 (18,480,406 ≥ 16 years, best available data). In 2005 the Australian organ donation register changed from registering "intentions to donate" to "valid consent to donate". This table shows combined number of intent and valid consent.

Although it is encouraged, it is not yet routine practice in all Australian states and territories to check the Australian organ donor register (AODR) before a request is made to the family for consent and there is no national data available regarding how frequently and when the AODR is checked. Recent Victorian audits revealed that the register was checked in 50%-85% of cases and that checking the register was associated with a higher consent rate[13] (Marck et al, in press). It is possible, however, that this association may reflect, depending on whether the register was checked before or after the request, that those who have consented have then had the register checked following conversations with the

family. In the Netherlands, legislation mandates that the donor register is checked for every potential donor and documentation regarding organ or tissue donation is completed for every deceased patient.

In Australia as well as in the Netherlands, registration on the ODR is legally recognised as consent or non-consent, for people aged over 16 (in the Netherlands) or 18 (in Australia), however confirmation that this wish has not changed since registration is usually requested from families. In most cases, families adhere to the legal consent or non-consent as recorded on the ODR. However, the practice in both countries is not to proceed with donation if the family has serious objections even after consultations with specialists, as there is concern about the impact of proceeding against the family's wishes[14] (Table 3).

Table 3. Consultation of the Donor Register and family consent rate for recognized potential organ donors in 2013 in the Netherlands

Category	N	%	Family approached		Family consent rate
Register not checked	110	13%	542	94%	34%
Register checked but outcome unknown	7	1%			
Not registered	394	46%			
Registered that family is to decide	64	8%			
Registered as not willing to donate	115	13%	(family not approached)		
Registered as willing to donate	163	19%	162	99%	94%
Total	853	100%	704	95%	48%

Adapted from NTS annual report 2013[10] including all identified DBD and DCD (only from hospitals with a DCD protocol) potential donors on a ventilator from 92 intensive care units

Family consent and donor conversion rates

In Australia, only data on potential donors who were confirmed or suspected brain dead are included in reports. In 2013, 4% of potential donors were missed, and there was an approximate consent rate (rate at which families of potential donors consent) of 61% and conversion rate (the rate at which potential donors become actual donors) of 54%[15]. These data are estimates and, due to concerns regarding consistency in methods of data collection and reporting between jurisdictions, it is not possible to obtain data on other potential donors. In Australia the DonateLife audit registers those registered on the AODR as 'not willing to donate' as a non-consent, but this is a rare occurrence and only minimally affects

consent rates. Given imminent brain death and DCD potential donors are not taken into account in the reported consent and conversion rates, it is likely that consent and conversion rates across the whole donor pool may be lower (Marck et al, in press).

Dutch data from 2013 shows that only 10 of 863 (1%) potential donors in ICUs were missed, the organ donation register was checked in 87% of identified cases and when registered objection was lacking, donation was discussed with the family in 95% of cases (Table 3)[10]. Although consent is legally not required for those registered as willing to donate in the Netherlands, in 6% of these cases the family objected to organ donation and donation did not proceed. The consent rate of 48% ultimately gave rise to a conversion rate of 30%[10]. Although it is difficult to compare these rates due to the differences in definitions of potential and actual donors (Table 1), the overall Dutch family consent rate of 48% in 2013 seems lower than the Australian consent rate of 53-61%, which is again lower than the target set by OTA to obtain family consent in 75% of all potential donors. Equally, the conversion rates seemed lower for the Netherlands (30%), compared to Australia (34%-50%), again lower than the targets set by the OTA (50% for DCD and 70% for DBD donors).

Potential donor pool and involvement of emergency departments

Despite many initiatives, there may still be room for improvement regarding deceased donation rates. One of these areas is donor recognition in the ED. Traditionally, organ donation occurs from the ICU, however the ED can play an important role in the early identification of potential organ donors, for both potential DCD donors and DBD donors. This was first mentioned in the literature in 1977[16] but the ED has only in the last decade received more serious recognition as a source of potential organ donors around the world including the USA [17] UK [18-20], Brazil[21], Turkey[22], Canada[23], and Australia[24,25]. Although some indicate the potential donor pool in ED may be small, any increase in donor recognition would make a significant difference to donation rates[20]. In addition, referral from the ED may have a higher success to organ retrieval rate compared to other inpatient units including the ICU[26]. Two audits performed in 2004 and 2006 in Australia showed that there was a missed potential donor pool in EDs[24,25] and a recent audit showed that 13% of potential donors were identified in ED (Marck et al, in press) indicating that the ED plays a small but significant role in donor identification in Australia.

Data from the NORD have the potential to provide valuable information regarding the potential donor pool identified in, and referred from, EDs in the Netherlands, however no reports detailing this are currently available[27]. There are few missed donors from Dutch ICUs, however, preliminary data indicates that not all potential organ donors are identified in EDs in the Netherlands [28].

As it became clear in Australia that there was a missed potential donor pool in EDs[24,25], the Australian government aimed resources at improving identification of potential donors in EDs by implementing a Clinical Trigger nationwide. This tool assists clinicians in EDs and ICUs to identify and refer potential donors. The Trigger (Figure 3), including the referral details for that specific hospital is depicted on posters in the ICU and ED, and many staff members carry a plasticised card. There are several Australian hospitals where emergency physicians have been trained by the OTA to communicate with families and other health

clinicians regarding organ donation, and are appointed as a DS to raise awareness regarding organ (and tissue) donation. Potential donors that were missed in ED are identified retrospectively by the DonateLife audit and this information is used to assist in giving feedback to those clinicians involved. A recent study showed that 63% of ED clinicians were familiar with the clinical trigger and that 78% supported the use of this Trigger in the ED[29].

Figure 3. Clinical Trigger

In the Netherlands, the numbers of organ donors going from the ED directly to theatre for organ retrieval are small, and are only uDCD donors (category 2, or category 1 in a pilot setting). It has only recently been nationally recognised that perhaps not all potential DCD and DBD donors, who are generally referred to ICU before organ retrieval, are identified in the ED. Because there are no donation specialists working in the ED, clinical staff working have the responsibility for potential donor identification and referral to ICU. There are no Dutch equivalents to the Australian Clinical Trigger for use in ED. Several projects and initiatives are currently being undertaken to analyse end of life care decisions that may have an impact on the possibilities for organ donation in the Netherlands. In the Netherlands ICU and ED doctors are trained in 'Communication about Donation', to facilitate medical professionals raising the subject of donation and assisting the family in the decision-making process.

The Netherland is a frontrunner in the area of controlled DCD in the ICU, the southern region is particularly active in this area as they have been practising both uncontrolled and controlled DCD for over 25 years. As uDCD donors are often identified in ED, they have had longstanding connections with ED staff. This area of the Netherlands also had the highest donation rate PMP in 2013, 30.2 compared to 15.2 nationally[10]. This area is involved in several pilot studies and projects involving the ED with the aim of maximising the opportunities with regard to the potential donor pool. Some of the hospitals involved

have now employed dedicated staff to educate and raise awareness among ED clinicians regarding DCD, and assist if a potential donor is identified in ED. The final results of this pilot have not been yet published [30].

A national survey carried out in Australia in 2011 in over 800 Australian ED clinicians, showed that many had been involved in organ donation related tasks and most felt comfortable and competent doing so, however barriers were identified regarding available resources as well as knowledge about eligibility, brain death and DCD. Most importantly, having received some education regarding organ donation was related to having more knowledge and more positive attitudes, and a large majority indicated a need and desire for further education[29,31-34]. These data have informed further education programs. While in Australia emergency medicine was recognized in 1993 as a formal specialty, in the Netherlands this is a relatively new specialty only formally recognized in 2008[35]. Therefore medical staff working in Dutch EDs were from a variety of medical specialties. Little data is currently available about the Dutch ED clinicians' involvement, attitudes, knowledge and perceived barriers to organ and/or tissue donation. The authors of a qualitative report with Dutch medical specialists from several disciplines (other than the ED) recommend further assessment of the role and the number of potential donors in the ED and indicate that ethical barriers are likely to play a role[27]. Awareness and willingness of staff to be involved in organ donation is crucial for complex interactions where time is of the essence[27,30]. Intensive care medical staff receive (mandatory) training to assist with communication with donor families in both countries, and although it is available to ED staff, their involvement in formal training has thus far been less common and largely driven by advocates.

Discussion and conclusion

The comparison between Australia and the Netherlands in deceased organ donation practices and rates show that organisational structures are generally similar. However significant differences between the two systems exist. While Australia's rates of DBD and DCD donation have both increased in recent years and are expected to increase further, the slight increase in the Netherlands has been at the expense of DBD (the preferred pathway). Best practices that have been identified are 1) the recent efforts made in Australia to improve donor recognition and referral from EDs, including the Clinical Trigger tool that assists clinicians to recognize donors. 2) the inclusion of the DCD pathway in all Dutch hospitals, and 3) the inclusion of all potential donors in audits and reports which currently does not occur in either country; while the Netherlands doesn't collect or report data on potential donors in EDs, Australia doesn't report data on missed DCD or imminent brain dead donors.

In the Netherlands, assessing the potential donor pool in EDs may elucidate whether it is worthwhile to invest efforts to increase the involvement of EDs. Improving donor recognition and referral from the ED may increase donation rates as potential donors may arrive via the ED, especially in the Netherlands where (controlled and uncontrolled) DCD is a common practice. As the number of identified and referred potential donors increases and potential donors are identified earlier, higher success rate for donation and transplantation

may result. Assessing Dutch ED clinicians' attitudes and knowledge regarding the identification and referral of potential donors would be warranted as significant barriers may exist and need to be overcome to improve the involvement of ED staff.

In Australia, it is expected that a proportion of potential DCD donors are currently missed as DCD pathways have not yet been implemented in all Australian hospitals, however, these data are not reported currently. These data could help to further assess if and where the implementation of DCD pathways may be warranted to increase donation rates.

Central to all these considerations is the need for applying a more uniform international standard that defines categories of potential donors, missed and actual donors, and criteria for collecting, registering and publishing these data are necessary to be able to compare between countries and identify areas for improvement, or set targets[36,37]. Although these limitations currently impede the ability to directly compare family consent and conversion rates, in this study it seems that the Dutch family consent and conversion rates may be lower. Furthermore, a significant proportion of Dutch people are registered on the ODR as not willing to donate, while this proportion is negligible in Australia. This may reflect a difference in public attitudes towards deceased donation that may affect consent and donation rates. Although beyond the scope of this study, this remarkable difference in organ donor registrations between Australia and the Netherlands deserves further study.

References

1. Opdam H. The rise and rise of donation after cardiac death: a solution to the shortfall in organs for transplantation? *Crit Care Resusc.* Mar 2013;15(1):3-4.
2. Sampson BG, O'Callaghan GP, Russ GR. Is donation after cardiac death reducing the brain-dead donor pool in Australia? *Crit Care Resusc.* Mar 2013;15(1):21-27.
3. Winters D. Comparing Organ Donation Practices and Rates. *Progress in Transplantation.* 06/01/ 2008;18(2):73-73.
4. Australian Government. Australian Organ and Tissue Donation and Transplantation Authority Act 2008 2008; http://www.comlaw.gov.au/Details/C2008A00122.
5. DonateLife. DonateLife Australia website. 2010; www.donatelife.gov.au.
6. The Australian Organ and Tissue Donation and Transplantation Authority. *Annual Report 2012–13.* 2013.
7. Australian Organ and Tissue Authority. *Clinical Trigger Information Update.* 2009.
8. Kootstra G, Daemen JH, Oomen AP. Categories of non-heart-beating donors. *Transplant Proc.* Oct 1995;27(5):2893-2894.
9. Australian Organ and Tissue Authority. *DonateLife Audit Guide V1.2.0.* 2013.
10. Nederlandse Transplantatie Stichting. *Cijferbijlage 2013.* 2014.
11. Ministerie van Volksgezondheid Welzijn en Sport. Donorregister. 2014; https://www.donorregister.nl/organisatie/cijfers/registraties/default.aspx.
12. AODR. *Australian Organ Donor Register Statistics.* 2014.
13. Stephens HO, Pilcher DV, Opdam HI. The impact of checking the Australian Organ Donor Register on family consent rates. *Med J Aust.* Oct 21 2013;199(8):536-538.

14. Bramstedt KA. Family refusals of registered consents: the disruption of organ donation by double-standard surrogate decision-making. *Intern Med J.* Feb 2013;43(2):120-123.
15. Australian Government Organ and Tissue Authority. Performance report 2013. 2014.
16. Gennrich JM. The emergency physician and organ donation. *JACEP.* Jan 1977;6(1):21-25.
17. Henderson SO, Chao JL, Green D, Leinen R, Mallon WK. Organ procurement in an urban level I emergency department. *Ann Emerg Med.* Apr 1998;31(4):466-470.
18. Aubrey P, Arber S, Tyler M. The organ donor crisis: the missed organ donor potential from the accident and emergency departments. *Transplant Proc.* May 2008;40(4):1008-1011.
19. Reed MJ, Lua SB. Uncontrolled organ donation after circulatory death: potential donors in the emergency department. *Emerg Med J.* May 25 2013.
20. Blackstock M, McKeown DW, Ray DC. Controlled organ donation after cardiac death: potential donors in the emergency department. *Transplantation.* May 15 2010;89(9):1149-1153.
21. Dell Agnolo CM, de Freitas RA, Toffolo VJ, et al. Causes of organ donation failure in Brazil. *Transplant Proc.* Oct 2012;44(8):2280-2282.
22. Ergin M, Karaman L, Demircan A, Dalgic A. Potential organ donor concept is developing in emergency departments: Gazi University Hospital experience. *Transplant Proc.* Jan-Feb 2008;40(1):39-41.
23. Kutsogiannis DJ, Asthana S, Townsend DR, Singh G, Karvellas CJ. The incidence of potential missed organ donors in intensive care units and emergency rooms: a retrospective cohort. *Intensive Care Med.* Aug 2013;39(8):1452-1459.
24. Opdam HI, Silvester W. Potential for organ donation in Victoria: an audit of hospital deaths. *Med J Aust.* Sep 4 2006;185(5):250-254.
25. Opdam HI, Silvester W. Identifying the potential organ donor: an audit of hospital deaths. *Intensive Care Med.* Jul 2004;30(7):1390-1397.
26. Michael GE, O'Connor RE. The importance of emergency medicine in organ donation: successful donation is more likely when potential donors are referred from the emergency department. *Acad Emerg Med.* Sep 2009;16(9):850-858.
27. R. Coppen, K.T. Paul, C.C.J. Avezaat, et al. *Praktijken van Orgaandonatie in Nederlandse ziekenhuizen. Een studie in het kader van het Masterplan Orgaandonatie.* 2011.
28. ACCORD. *EU Joint Action: Achieving Comprehensive Coordination in ORgan Donation throughout the European Union. Interim report March 2014.* 2014.
29. Neate S, Marck CH, Weiland TJ, et al. Australian emergency clinicians' perceptions and use of the GIVE Clinical Trigger for identification of potential organ and tissue donors. *Emerg Med Australas.* Oct 2012;24(5):501-509.
30. Swinkels E. het Masterplan Orgaandonatie in Maastricht: ervaringsverhaal van de spoedeisende hulp. *Transparant.* Vol 532012:10-11.
31. Jelinek GA, Marck CH, Weiland TJ, Neate SL, Hickey BB. Organ and tissue donation-related attitudes, education and practices of emergency department clinicians in Australia. *Emergency Medicine Australasia.* 2012:no-no.
32. Marck CH, Jelinek GA, Neate SL, Dwyer BM, Hickey BB, Weiland TJ. Resource Barriers to the Facilitation of Organ and Tissue Donation in Australian Emergency Departments. *Australian Health Review.* 2012;submitted.
33. Marck CH, Neate SL, Weiland TJ, Hickey BB, Jelinek GA. Donation after cardiac death: are Australian emergency clinicians supportive? *Intern Med J.* Jul 2013;43(7):816-819.

34. Marck CH, Weiland TJ, Neate SL, Hickey BB, Jelinek GA. Australian emergency doctors' and nurses' attitudes and knowledge regarding brain death: A national survey. 2012.
35. Gaakeer MI, van den Brand CL, Bracey A, van Lieshout JM, Patka P. Emergency medicine training in the Netherlands, essential changes needed. *International journal of emergency medicine.* 2013;6(1):19.
36. Jansen NE, de Groot YJ, van Leiden HA, Haase-Kromwijk BJ, Kompanje EJ, Hoitsma AJ. Imprecise definitions of starting points in retrospectively reviewing potential organ donors causes confusion: call for a reproducible method like 'imminent brain death'. *Transpl Int.* Aug 2012;25(8):830-837.
37. Roels L, Spaight C, Smits J, Cohen B. Critical Care staffs' attitudes, confidence levels and educational needs correlate with countries' donation rates: data from the Donor Action® database. *Transplant International.* 2010;23(8):842-850.
38. Manyalich M. PB, Gómez M.P. Worldwide Actual Deceased Organ Donation 2012 (pmp)- International Registry in Organ Donation and Transplantation – IRODaT. 2013.
39. Nederlandse Transplantatie Stichting. *Cijferbijlage bij het jaarverslag van de Nederlandse Transplantatie Stichting 2012.* 2013.
40. The International Registry of Organ Donation and Transplantation. *Facts For Health Professionals - Netherlands.* 2013.
41. Centraal Bureau voor de Statistiek (CBS). Bevolking en bevolkingsontwikkeling; per maand, kwartaal en jaar. 2013.
42. Delmonico FL, Sheehy E, Marks WH, Baliga P, McGowan JJ, Magee JC. Organ donation and utilization in the United States, 2004. *Am J Transplant.* Apr 2005;5(4 Pt 2):862-873.
43. Australia and New Zealand Organ Donation Registry. *Waiting list data.* 2013.
44. Leonie Excell, Violet Marion, Kylie Hurst, Graeme Russ. *Australia and New Zealand Organ Donation Registry 2012 Report.* 2013.
45. Australian Government Organ and Tissue Authority. June 2013 Performance Update. 2013.
46. Australian Government Organ and Tissue Authority. Performance Report 2012. 2013.
47. Ministerie van Volksgezondheid Welzijn en Sport. Donorregister, Registraties per 31 juli 2013. 2013; http://www.donorregister.nl/organisatie/cijfers/registraties/default.aspx. Accessed 26-08-2013.
48. Centraal Bureau voor de Statistiek (CBS). Bevolking per maand; leeftijd, geslacht, herkomst, generatie. 03-06-2014 2014.

Chapter 9

Appendix

Assessing Barriers to Organ and Tissue Donation in Emergency Departments

FINAL REPORT to Commonwealth of Australia,

Organ and Tissue Authority

2012

Claudia H Marck, Tracey J Weiland, Sandra L Neate,

Bernadette B Hickey, and George A Jelinek

9

Contact information

This research project was funded by the Organ and Tissue Authority and carried out by the Emergency Practice Innovation Centre (EPIcentre) at St Vincent's Hospital in Melbourne.

Please direct any communication to:

Ms Claudia Marck: 03 9288 2793, claudia.marck@svhm.org.au or
Professor George Jelinek: 03 9288 2788, george.jelinek@svhm.org.au
EPIcentre, St Vincent's hospital
35 Victoria Parade
Fitzroy VIC 3065

Table of Contents

List of abbreviations

ACEM Australasian College for Emergency Medicine
ABODE Assessing Barriers to Organ Donation in Emergency
BD Brain Death
CENA College of Emergency Nursing Australasia
ED Emergency Department
EPIcentre Emergency Practice Innovation Centre
HMD Hospital Medical Director
ICU Intensive Care Unit
OTD Organ and Tissue Donation
OTA Organ and Tissue Authority
SVHM St Vincent's Hospital Melbourne

Project team

The Assessing Barriers to Organ Donation in Emergency (ABODE) study was conducted by St. Vincent's Hospital Melbourne, and overseen by a Steering Committee.

The Project Team included:

Ms Claudia Marck - ABODE Project Officer, Emergency Practice Innovation Centre (EPIcentre), St. Vincent's Hospital Melbourne (SVHM). Ms Marck participated in questionnaire design, conducted data collection, managed recruitment and databases, statistical analyses, and drafted the final report.

Dr Tracey Weiland - Principal Investigator, EPIcentre, SVHM. Dr Weiland participated in the study design and statistical analyses and participated in the editing of the final report.

Prof. George Jelinek - Professorial Fellow, EPIcentre, SVHM. Professor Jelinek provided advice regarding the content of interview questions, study implementation, data analysis and editing of the final draft of the report.

Dr Sandra Neate - Hospital Medical Director (HMD) of Organ and Tissue Donation, Emergency Department, SVHM. Dr Neate provided advice regarding the content of interview questions and study implementation.

Dr Bernadette Hickey - HMD of Organ and Tissue Donation, Intensive Care Unit, SVHM. Dr Hickey provided advice regarding the content of interview questions and study implementation.

The Steering Committee members included the project team members above and:

Bernadine Dwyer - Clinical Manager, DonateLife Victoria.
Katherine Bowman – Nurse Manager, Emergency Department, SVHM
Dr Nicola Cunningham – Physician, Emergency Department, SVHM
Margaret Maslin - Nurse Manager, Emergency Department, SVHM
Dr Curtis Leacock - Registrar, Emergency Department, SVHM.

Acknowledgements
We would like to thank the members of the steering committee who have occasionally dedicated personal time for regular meetings. We would also like to thank all the respondents from ACEM and CENA as well as the staff members from St Vincent's Hospital in Melbourne who participated in the pilot phase or online survey.

We are grateful to the Organ and Tissue Authority for funding this study and are looking forward to collaborating in the future.

Executive summary
Since recent resources have been aimed at improving organ and tissue donation (OTD) rates initiated from the emergency department (ED), this study aimed to identify the barriers perceived by emergency clinicians to facilitating OTD from the ED, their attitudes to OTD, and familiarity with processes regarding OTD including the recently introduced Clinical Trigger. A cross-sectional national survey was carried out in the first half of 2011 and resulted in over 800 ED clinicians participating.

Results show that the majority of ED clinicians have had involvement with OTD related tasks in the last calendar year. Most have received some form of OTD related education but an overwhelming majority desired additional education.

Just over a third of ED clinicians were not familiar with the Clinical Trigger, however after providing a description of the Trigger in the survey, more than three quarters reported supporting the Trigger. Despite the positive attitude towards the Trigger, three quarters report that they perceive barriers to identifying potential donors. Reported barriers to facilitate OTD include lack of time, and ED overcrowding. In addition, results show that ED clinicians are conservative when it comes to referring patients with a variety of medical conditions as they are unsure about exclusion criteria. Overall, there is also a poor understanding of the legal and coronial processes involved with OTD among ED clinicians.
Although most ED clinicians accept brain death (BD) as a valid determination of death, only just over half pass the 5 item BD knowledge test. Literature shows that the next of kin's understanding of BD is critical for family consent. Of concern, of ED clinicians who failed this test, the majority felt comfortable and competent enough to explain BD to the next of kin. In fact, a fifth had explained BD to the next of kin in the last calendar year, and of those ED clinicians more than a third failed the test and were thus not optimally equipped for this task.

Around three quarters of medical and half of nursing clinicians feel comfortable and competent about OTD related tasks but this proportion drops to a third when it comes to obtaining consent for OTD. OTD related experience and education as well as BD knowledge and acceptance are related to increased comfort and perceived competence levels of ED clinicians, except for obtaining consent. Many ED clinicians are unsure about the cost benefit of OTD in terms of resources as well as burden/benefit for the next of kin.

Almost all ED clinicians support organ and tissue donation in general, report willingness to donate their own organs and tissues after death, and consent for OTD of family members. Most ED clinicians had discussed their OTD wish with loved ones but only around half had registered with the organ donor register. Most ED clinicians support OTD after cardiac death, although there is less support than for OTD in general, and less than half are familiar with the processes around it.
Cultural and religious barriers were identified when it comes to receiving OTD education, support of the Trigger, and support of OTD in general or after cardiac death, willingness to donate, communicate/register their wish, and willingness to give family consent. It seems that especially Asian, Mediterranean, Buddhist, Hindu and Muslim ED clinicians perceive more barriers to OTD although the reasons are unclear.

Most importantly, having received any type of OTD related education was found to be related to having more knowledge and more positive attitudes to OTD as well as more involvement in OTD related tasks.

We recommend that education regarding OTD becomes part of the curriculum of ED clinicians' education and that it focuses on the key areas identified in this study.

1. Introduction

St. Vincent's Hospital Melbourne was contracted in June 2010 by the Commonwealth of Australia's Organ and Tissue Authority (OTA) to conduct an Assessment of Barriers to Organ and tissue Donation in the Emergency departments (ABODE) of Australia. Using a cross-sectional national survey, the ABODE study sought to identify the barriers perceived by emergency staff to increasing the number of organ and tissue donors originating from emergency departments (EDs) in Australia.

The OTA has initiated a recent roll out of resources aimed at increasing OTD rates that are targeted towards EDs and staff. Among these resources is the National Clinical Trigger: a checklist to help hospital staff appropriately identify all potential donors and consequently contact the appropriate staff member to initiate the process. Concerns about the increased workload related to support of the potential donor may affect attitudes to organ and tissue donor identification from the ED. For these reasons determination of attitudes towards and the barriers to OTD, and barriers to uptake of the National Clinical Trigger, from the perspective of emergency clinicians was required.

Specific aims of the ABODE study were to build a national evidence base regarding the barriers to organ donation initiated at EDs, including:

» 1 Assessment of the current processes and resources for organ and tissue donation initiated in the ED following the introduction of the National Clinical Trigger.
» 2 Assessment of the process-related barriers to the use of the National Clinical Trigger in the ED.
» 3 Identification of current clinician's knowledge and educational deficits and learning needs regarding organ and tissue donation processes.
» 4 Identification of ED clinicians' perceived skills in communicating relevant organ and tissue donation related issues to the donor family.
» 5 Identification of ED clinicians' perceptions and assumptions of donor families' understanding and beliefs about relevant legislation, donor eligibility, and processes related to organ and tissue donation.
» 6 Identification of ED clinicians' attitudinal barriers to organ and tissue donation initiated at the ED.
» 7 Identification of perceived workload and resource barriers to the identification of potential donors and the willingness to medically support potential donors until Intensive Care facilities become available.

While the survey itself is likely to have increased awareness by ED clinicians of organ and tissue donation, a key outcome of the study is the following report outlining the process undertaken, literature review, methodology, results and recommendations designed to target identified barriers to organ and tissue donation initiated at emergency departments.

2. Literature overview

Organ transplantation has become increasingly successful in terms of patient survival and is currently the best treatment option for patients with organ failure[1-3]. However, the need for organ donors has become more urgent in recent years, with waiting lists for organ transplants growing globally. Health professionals can play a pivotal role in redressing this important public health issue since they are typically involved in identifying potential donors and communicating with potential donor families.

In terms of successful transplant outcomes, Australia has a world class reputation[4]. With living donor opportunities only being available for certain organs and tissues, most efforts are aimed to increase donation rates from deceased donors. Unfortunately, Australia has suboptimal posthumous donation, and family consent rates compared to other countries in the developed world, 13.8 donors per million people in 2010[5]. On average 1700 Australians are on the waiting list at any time, many dying without receiving a transplant[4].

2. 1. Organ and Tissue Donation after Death

Organ and tissue donation from deceased donors is firstly reliant on community members being willing to be a donor after death and giving consent for their next of kin to donate after death. 98% of Australians agree that organ and tissue donation has the potential to save and improve lives but only 77% are generally willing to become organ and tissue donors[6]. Almost 4.3 million Australians are currently registered with the Australian Organ Donor Register (AODR)[7], however increases in registrations have not lead to increases in OTD rates. In Australia, whether or not a person is registered with the AODR, the next of kin needs to consent for donation to proceed. Unfortunately, 40% of Australians do not know the donation wishes of their loved ones and only 58% of Australian families give consent for organ and tissue donation to proceed[4]. More work is needed to raise public awareness.

Secondly, OTD rates are highly dependent on healthcare professionals initiating the process by assessing donor eligibility, referring eligible patients, and discussing the topic with the next of kin[8, 9]. For this reason, resources available, attitudes toward donation, and knowledge of the processes involved in OTD are critical.

2. 2. Missed potential donors

A major cause of preventable procurement failure in Australia is the failure to identify and/or refer potential donors by healthcare staff. In 2010, 84% of organs were donated by heart-beating brain dead patients[5]. A death audit of Victorian hospitals in 2006 shows that 21% of brain dead potential donors were either missed, or family consent was not requested[10]. Data from 2006-2008 has shown that in 10% of brain dead potential donors in Australia, families were not approached about donation[11]. In addition, there were 121 potential donors with imminent brain death for whom organ donation was also not raised with the next-of-kin. Of these patients 75 and 41 had treatment withdrawn in the ICU and ED respectively, before brain death occurred. Causes reported included: failure to recognise potential donors (predominantly in EDs), clinicians being unwilling to discuss brain death and organ donation with families prior to brain death, resource pressures, and patients of marginal medical suitability for organ donation[11]. With the adoption of the National Clinical Trigger in 2010, a national protocol for identifying and referring potential donors,

the rates of missed potential donors should decrease. However, the provision of procurement systems within emergency departments internationally has not always translated to an increase in donation rates because of failure of clinicians to approach potential donor families[12].

2. 3. Healthcare professionals and organ donation

Healthcare professionals with a positive attitude toward organ and tissue donation have been shown to be more likely to elicit family consent for donation[13]. Several international studies have revealed that many healthcare professionals feel uncomfortable performing donation-related tasks such as approaching donor families, informing organ donor coordinators of potential donors, explaining brain death to family members, and providing support to the grieving family. The reasons for this discomfort appears to be related to age and/or educational status; younger and less experienced or knowledgeable health care professionals experience greater discomfort[14-16] as do those with a poor understanding of brain death[17-19]. Results from an international survey among almost 20,000 critical care staff in 11 countries, including Australia, showed that optimal donation rates were associated with support for donation, acceptance of the concept of brain death, confidence levels and average educational requirements with donation-related tasks[16].

2. 4. Role of emergency clinicians in organ donation

An audit of missed potential donors in Australian hospitals revealed a substantial missed potential donor pool from EDs[11], a pattern which has also been recognized internationally[20]. Emergency clinicians will be the primary instigators of donor referral, and will be the first point of contact for donor families in the initial process. Since international data suggests that referral of potential organ donors from the ED is associated with an increased likelihood of successful organ retrieval compared to inpatient units[21] it is essential to assess the barriers to OTD initiated in Australian EDs to optimize the national OTD rates.

The study presented aimed to assess barriers to organ and tissue donation initiated in Australian emergency departments including procedural, attitudinal, knowledge and resource barriers.

3. Methodology

3. 1. Project Oversight

The ABODE study was conducted by St. Vincent's Hospital Melbourne, and overseen by a Steering Committee.

The committee held four meetings throughout the project and maintained email contact to review the questionnaire design, pilot data collection, national data collection and data analysis phases.

3. 2. Instrument Design and Development

The survey was developed by Ms Marck, informed by available literature on organ donation and with assistance from the project team. A validated tool consisting of 5 items to assess understanding of brain death[22] was included in the survey, as well as part of the Hospital Attitude Survey (HAS), a validated and widely used questionnaire to assess attitudes of hospital staff towards organ and tissue donation developed by the Donor Action Program[23]. Face validity of the draft survey items was ensured through iterative feedback between steering committee staff using a Delphi panel system.

3. 3. Pilot phase and survey refinement

3. 3. 1. Study design

Content validity was formally assessed during the pilot phase by surveying a sample of ED clinicians.

3. 3. 2. Participants

Eligible participants were all nurses and doctors working in the Emergency Department at St. Vincent's Hospital (Melbourne).

3. 3. 3. Survey

The pilot survey consisted of 141 items. On the paper-based survey, each item featured a specified place where participants were asked to rate the item according to relevance on a 4 point scale. Text boxes were provided as well to enable provision of comments regarding the wording and structure of items, content areas that required further exploration, and about the survey generally. Completion of the pilot survey took approximately 20 minutes.

3. 3. 4. Procedure

Participants of the pilot phase were advised of the nature of the study, issued with a participant information form and requested to complete the survey. Participants were provided with both the online survey and a paper-based version of the online survey for reference. The paper surveys were returned to a return box placed in the ED where they were collected by Ms Marck.

3. 3. 5. Data analysis

Nine doctors and 10 nurses returned a completed survey. Participant responses using the four-point ordinal scales were used to calculate the content validity index of survey items and the instrument as a whole, as outlined by Lynn[24]. Participant comments about items and the instrument were considered by the researchers. As a result of the pilot phase of the study, and careful consideration by the steering committee, the survey was slightly altered.

3. 4. National Cross-sectional Survey

3. 4. 1. Study design

The ABODE study has addressed the research questions by means of a cross-sectional survey of a national sample of nurses and doctors working in Australian Emergency Departments.

3. 4. 2. Participants

Participants eligible to complete the survey were Fellows, Provisional or Advanced Trainees of the Australasian College for Emergency Medicine (ACEM) or members of the College for Emergency Nursing Australasia (CENA), working in an ED in Australia. The survey was sent out to 3995 potential participants. This included 1026 members of CENA and 2969 members of ACEM (1169 fellows and 1800 trainees).

3. 4. 3. Survey

The final survey comprised 133 items and took approximately 15-20 minutes to complete. Graded responses using Likert scales and ordinal multi-category scales to enable quantitative statistical analysis were used. Open-ended questions were also used to elicit qualitative responses. We have included a validated tool to assess understanding of brain death[22] in the survey as well as part of a validated and widely used questionnaire to assess attitudes of hospital staff towards organ and tissue donation[23].

3. 4. 4. Procedure

The survey was sent electronically to nurses and emergency medical specialists and trainees via their professional bodies, CENA, and ACEM respectively. Fellows and Advanced Trainees of the ACEM and members of the CENA were emailed an introductory email, which contained an invitation to participate, and an attachment of a participant information form outlining the study and participant rights. A hyperlink to the electronic questionnaire was included in the email, and responses were collected over a period of 11 weeks. CENA sent the initial email on the 22nd of March 2011 and sent out weekly reminders for the first 3 weeks followed by a last reminder 5 weeks after the initial invitation. ACEM sent the initial email on the 21st of March 2011 and sent out a reminder one and five weeks after the initial invitation. The online data collection was closed on the 9th of June 2011 but the last survey data was received on the 6th of June. The online survey package, "Survey Monkey", was used as it has been found to yield a good response rate while maintaining respondent anonymity. Participation in the survey was voluntary, and participants were advised that partial or full completion of the survey was taken as implied consent. Participants were able to withdraw from completing the questionnaire at any time, however it was not possible to withdraw their data once they had submitted the questionnaire, as all data was non-identifiable.

3. 4. 5. Data analyses

Quantitative data was exported from the web-based survey program to PASW Statistics 18.0. For each survey item summary statistics (%, CI, medians) were calculated for the entire sample, and by demographics including staff type (e.g. nursing or medical), level, and years working in emergency departments. While descriptive analyses were undertaken we also completed exploratory inferential analyses. For nominal data, comparisons between groups were undertaken using Chi Square, Fisher's Exact for 2X2 contingency tables. Mann Whitney U and Kruskall Wallis tests were used for analyses of ordinal data. Qualitative data were summarized.

3. 5. Ethical consideration

This study was approved by St Vincent's Human Ethics Research Committee (protocol 154/10).

4. Results

4. 1. Overall Response Rates

811 participants started the survey with 648 completing the full survey. Two participants were omitted and are not included in these numbers, the first one because it was a double entry and the other because of obvious disingenuous replies.

4. 1. 1. Nursing staff (CENA members)

Of invited CENA members 212 (20.7%) started the survey and 162 (15.8%) completed the survey. There was a fairly good representation of CENA members per state as can be seen in Table 1 Representation of CENA members according to state or territory. Members from NSW were underrepresented while Victorian members were overrepresented in the survey. CENA could not provide us with data on gender or age of members.

Table 1 Representation of CENA members according to state or territory; percentages (95% confidence interval)

State or territory	CENA members	CENA members in survey
NT	2.3% (1.6-3.5)	2.4% (0.9-5.6)
ACT	3.5% (2.6-4.9)	3.3% (1.5-6.8)
TAS	3.6% (2.5-4.8)	3.8% (1.8-7.3)
SA	6.8% (5.4-8.5)	7.5% (4.6-12.0)
WA	9.6% (7.9-11.5)	7.5% (4.6-12.0)
QLD	19.3% (17.0-21.8)	12.3% (8.5-17.4)
NSW	25.8% (23.2-28.6)	17.5% (12.9-23.2)
VIC	29.0% (26.4-31.9)	45.8% (39.2-52.5)

4. 1. 2. Medical staff (ACEM members)

Of invited ACEM members 599 (20.2%) started the survey and 486 (16.4%) completed the survey. Since all ED fellows and trainees are required to be a member of ACEM, the response rates show that 26.7% of all Australian Emergency Fellows, and 15.8% of all Australian Emergency Trainees have taken part in our survey. There was a good representation of ACEM members per state as can be seen in Table 2, although members from Queensland were underrepresented. ACEM also provided data on gender and type of member (fellow or trainee), see Table 3. Male and female fellows are overrepresented in our sample, while male trainees are underrepresented. Since all ED fellows and trainees are required to be a member of ACEM, the response rates show that 26.7% of all Australian Emergency Fellows, and 15.8% of all Australian Emergency Trainees have taken part in our survey.

Table 2 Representation of ACEM members according to state or territory; percentages (95% confidence interval)

State or territory	ACEM members	ACEM members in survey
NT	1.4% (1.0-1.9)	2.7% (1.6-4.3)
ACT	1.8% (1.4-2.4)	2.2% (1.2-3.7)
TAS	2.5% (2.0-3.1)	4.2% (2.8-6.1)
SA	7.1% (6.2-8.1)	6.7% (4.9-9.0)
WA	10.9% (9.9-12.1)	11.5% (9.2-14.4)
QLD	23.5% (22.0-25.1)	17.4% (14.5-20.6)
NSW	27.4% (25.8-29.1)	25.7% (22.4-29.4)
VIC	25.3% (23.8-26.9)	29.7% (26.2-33.5)

Table 3 Representation of ACEM members and survey participants according to member type and gender

		ACEM	Survey
Fellows	Male	27.9% (26.3-29.6)	33.4% (29.8-37.4)
	Female	11.5% (10.4-12.7)	18.7% (15.8-22.1)
Trainees	Male	36.3% (34.6-38.1)	22.9% (19.8-26.5)
	Female	24.3% (22.8-25.9)	24.7% (21.5-28.4)

4. 2. Demographics

Demographics are reported for all participants (N=811) including those who did not complete the entire survey.

4. 2. 1. Gender

Overall, 434 (53.5%) participants were female. Among medical staff 262 (43.7%) participants were female and among nursing staff 172 (81.1%) were female.

4. 2. 2. Age

Overall, the median age of all participants was 38 years (IQR 32-46). Among medical staff, the median age was 38.0 (IQR 33-44) years. Among nursing staff the median age was 41.1 years (IQR 32-49).

4. 2. 3. Cultural background

In Table 4 an overview is given of the participants' cultural backgrounds. Of note, is that 88.2% of nursing staff had an Australian background whereas only 50.1% of medical staff had an Australian cultural background. Whereas 24.9% of medical staff had a European background, only 7.6% of nursing staff had a European background. Similarly, 12.5% of medical staff had an Asian background whereas only 0.5% of nursing staff had an Asian background.

Table 4 Number (percentage) of medical and nursing staff according to main cultural background

Main Cultural background	Medical staff	Nursing staff	Total
Australian	300 (50.1)	187 (88.2)	487 (60.0)
British and Irish	100 (16.7)	10 (4.7)	110 (13.6)
Southern Asian	36 (6.0)	0 (0.0)	36 (4.4)
Chinese, Central and North East Asian	25 (4.2)	1 (.5)	26 (3.2)
New Zealand	23 (3.8)	2 (.9)	25 (3.1)
Western European	23 (3.8)	1 (.5)	24 (3.0)
Southern and East African	16 (2.7)	1 (.5)	17 (2.1)
Southern Europe	10 (1.7)	4 (1.9)	14 (1.7)
South-East Asian	14 (2.3)	0 (0.0)	14 (1.7)
South American and Caribbean Islander	11 (1.8)	0 (0.0)	11 (1.4)
(South) Eastern European	9 (1.5)	1 (0.5)	10 (1.2)
Other North African and Middle Eastern	8 (1.3)	1 (0.5)	9 (1.1)
Arab	7 (1.2)	1 (0.5)	8 (1.0)
Northern European	7 (1.2)	0 (0.0)	7 (0.9)
North American	6 (1.0)	1 (0.5)	7 (0.9)
Pacific Islander	3 (0.5)	2 (0.9)	5 (0.6)
Jewish	1 (0.2)	0 (0.0)	1 (0.1)
Total	**599 (100.0)**	**212 (100.0)**	**811 (100.0)**

4. 2. 4. Duration of living in Australia

Figure 1 Percentage of medical and nursing staff according to duration of living in Australia shows the duration of living in Australia per staff type. Of all medical staff, 42.1% was born in Australia as opposed to 79.2% of nursing staff. Accordingly, a much larger proportion of medical staff had lived in Australia shorter than 20 years compared to nursing staff, and 17.9% of medical staff had lived in Australia shorter than 5 years (Appendix B Table 26).

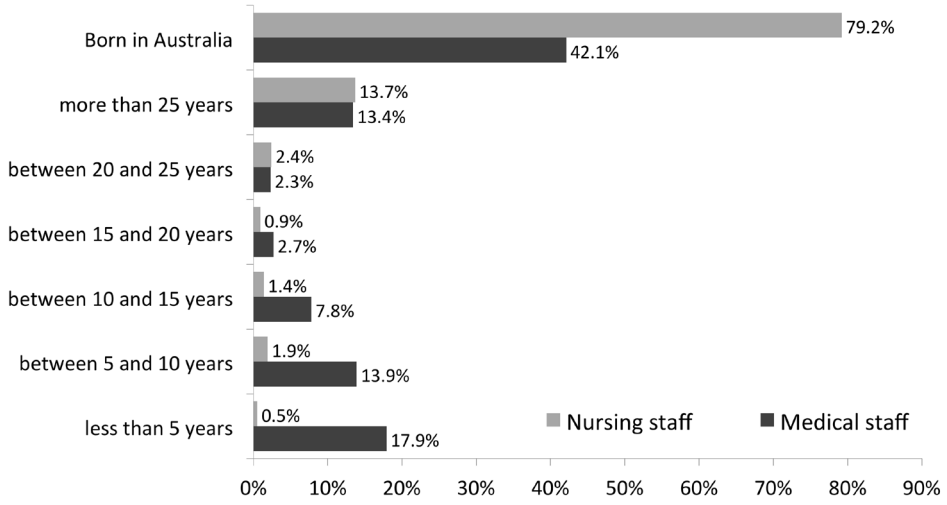


Figure 1 Percentage of medical and nursing staff according to duration of living in Australia

4. 2. 5. Religion

Figure 2 shows religion per staff type. More medical staff were not religious, or atheist compared to nursing staff (47.4% vs. 36.1% FET, $p<0.01$). The majority of nursing staff was Christian or Catholic (Appendix B Table 27).

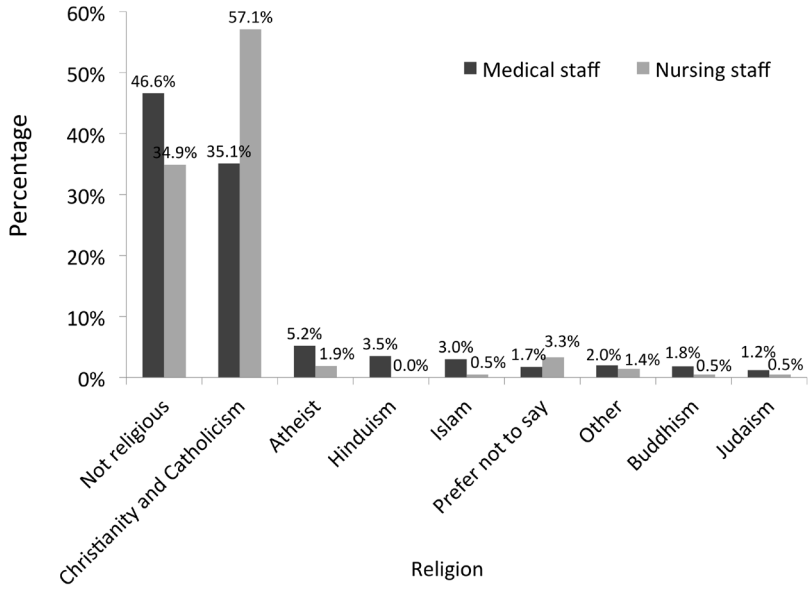


Figure 2 Percentage of medical and nursing staff according to religion

4. 2. 6. Region of employment

Figure 3 shows the proportions of medical and nursing staff according to state or territory where they were employed. The state where the most participants were employed was Victoria (45.8% of nursing staff and 29.7% of medical staff). The Victorian executive director sent out one of the CENA reminder emails to all their members, this may explain the relative large proportion of nursing staff employed in Victoria (Appendix B Table 28).

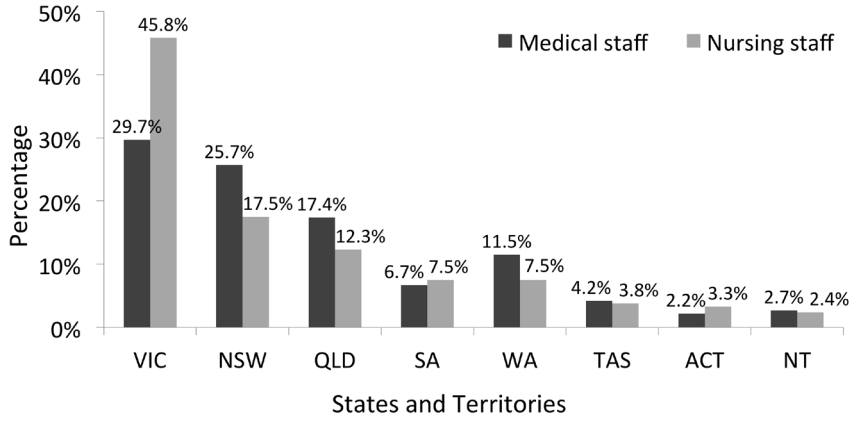


Figure 3 Percentage of medical and nursing staff according to region of employment

4. 2. 7. Type of hospital of employment

Figure 4 shows the proportion of medical and nursing staff according to the type of hospital they mainly worked at. Most participants (57.4% of medical staff and 49.1% of nursing staff) were employed at a major referral hospital whereas only a very small proportion was working at a private hospital (Appendix B Table 29).

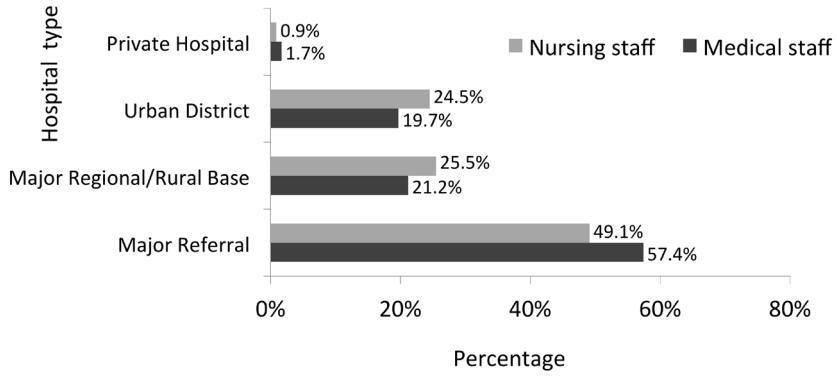


Figure 4 Percentage of medical and nursing staff according to type of hospital of employment

4. 2. 8. Average work hours per week

Figure 5 shows the proportion of medical and nursing staff according to the average working hours per week. The majority of both medical (57.1%) and nursing staff (54.2%) worked 31 hours or more per week on average (Appendix B Table 30).

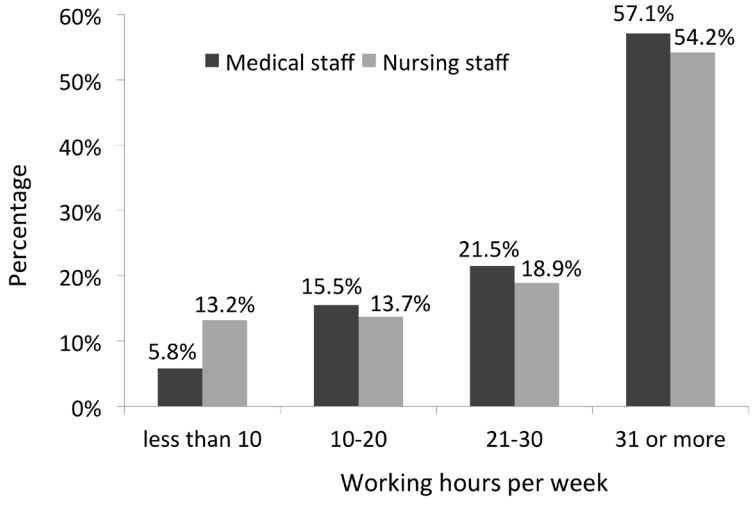


Figure 5 Percentage of medical and nursing staff according to working hours per week

4. 2. 9. Experience/years of employment in the ED

Figure 6 shows the proportion of medical and nursing staff according to years of employment in EDs. The majority of both medical (55.9%) and nursing staff (54.2%) had been working in EDs for less than 10 years (Appendix B Table 31).

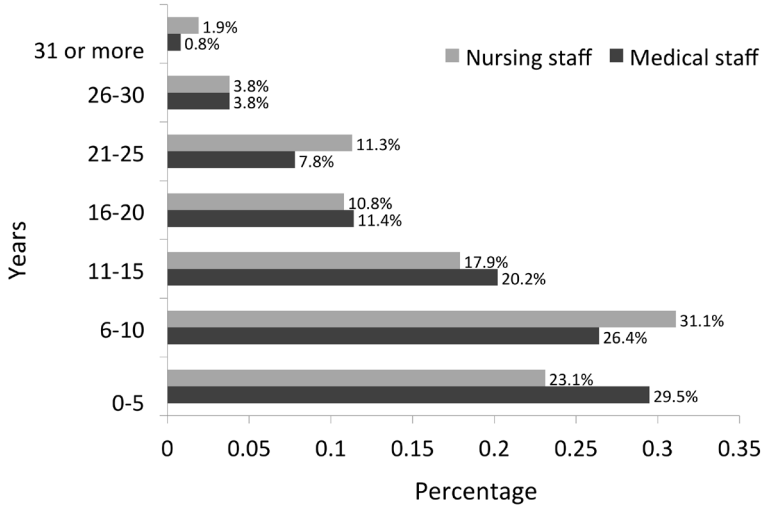


Figure 6 Percentage of medical and nursing staff according to years of employment in the ED

4. 2. 10. Staff type

Figure 7 shows the number of medical and nursing staff according to staff type. The largest proportion of participants of the survey were fellows of ACEM, followed by advanced

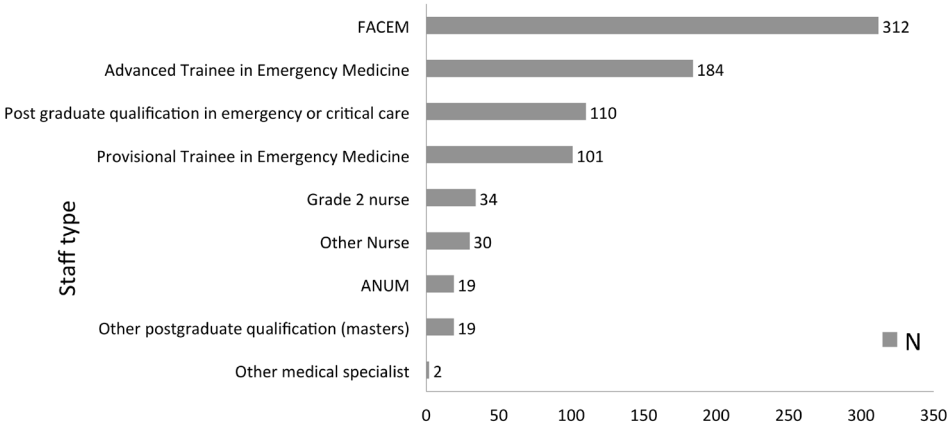


Figure 7 Number of respondent per staff type

4. 2. 11. DonateLife Network

Respondents had the option of listing in which hospital they mainly worked. 128 hospitals were listed by 656 respondents, including 71 hospitals that are part of the DonateLife Network. 85.1% (558) respondents worked in DonateLife Network Hospitals (88.7% of medical staff and 76.1% of nursing staff).

4. 3. Main Findings

Main findings are reported for all respondents that finished that section of items. So although the demographic items all had 811 respondents for each item, this number will gradually decline as 648 participants completed the whole survey. For some items additional analyses were performed to compare groups according to all demographics listed above as well as OTD related training and education and OTD related experience, and only significant results were reported. To enable such analysis, for some demographic items, categories were collapsed as can be seen in the referenced additional tables.

4. 3. 1. Organ and tissue donation related training or education

This section was completed by 785 participants. Figure 8 shows the proportion of medical and nursing staff according to OTD related training or education. Since respondents were asked to tick one or more responses, the percentages reported at each reply correspond to the proportion of respondents per staff category. The modal response for both medical and nursing staff was that they had received departmental training (37.0% of medical staff and 38.8% of nursing staff), however, the second most common reply was that no education or training in regards to OTD had been received (29.2% of medical staff and 23.8% of nursing staff). Whether or not staff had received education or training related to OTD was related to cultural background ($p<0.01$), length of living in Australia ($p<0.01$), religion ($p<0.01$), and years of experience in EDs ($p=0.01$) (Appendix B Table 32). Noteworthy, having received education related to OTD was not significantly related to whether the ED clinician worked in a DonateLife Network Hospital.

The "other education" category included: *training in a previous role (in ICU or overseas); being employed by DonateLife; education during med school or post graduate course; and in-services on G.I.V.E., from DonateLife educator, or by donor coordinator.*

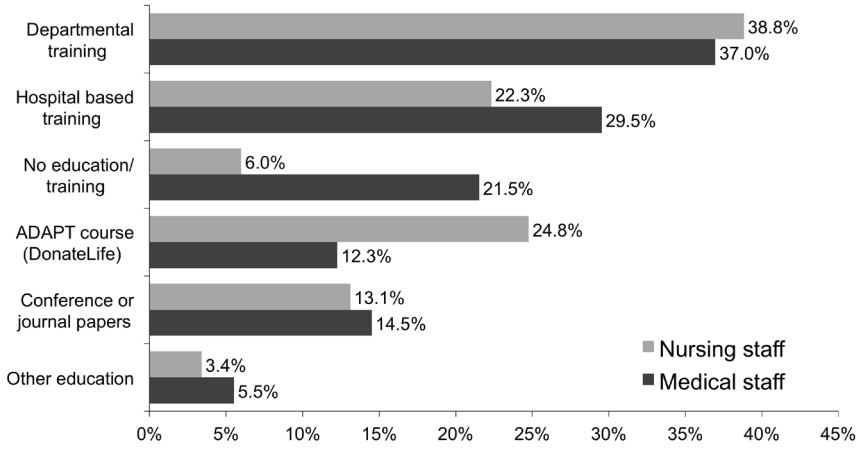


Figure 8 Percentage of medical and nursing staff according to organ and tissue donation related training or education received

4. 3. 2. Involvement with organ and tissue donation related tasks

This section was completed by 785 participants. Figure 9 shows ED clinicians' experience with organ and tissue related tasks in the last calendar years, and lifetime personal experience. The following results do not include personal lifetime experience. 28.7% of all staff had no experience with OTD related tasks at all during the last calendar year (48.5% of nursing staff and 21.6% of medical staff). Identifying and caring for potential donors were the most experienced tasks but only 49.6% of staff had experience with this in the last calendar year. Obtaining consent for organ and tissue donation was the least reported task (6.8%)(Appendix B Table 33). Whether or not staff had experience with OTD related tasks in the last year was related to gender ($p=0.04$), region ($p=0.03$), type of hospital ($p<0.01$), staff type ($p<0.01$), working in a DonateLife Network hospital ($p<0.01$), and whether or not they had received OTD related education ($p<0.01$) (Appendix B Table 34).

"Other experience with organ and tissue donation" included: *caring for potential donors or transplant while working in ICU or overseas; being employed by DonateLife; or being a registered donor and having family discussions about it.*

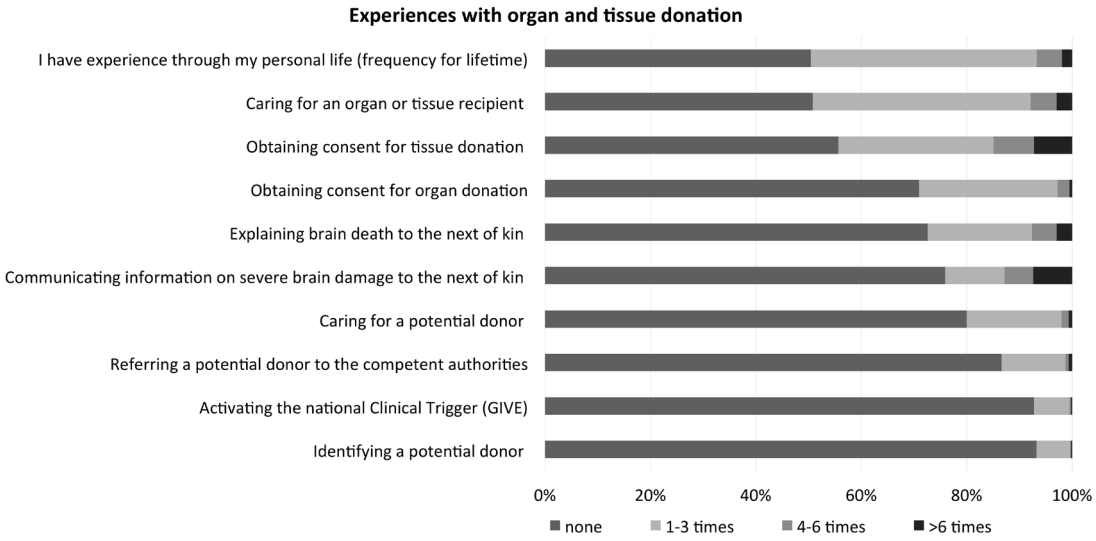


Figure 9 Percentage of respondents according to organ and tissue donation related experience in the last calendar year

4. 3. 3. National Clinical Trigger

This section was completed by 755 participants. Most medical (62.3%) and nursing staff (64.1%) (strongly) agreed with the statement, "*I am familiar with the Clinical Trigger*" (Table 5), which was related to region ($p<0.01$), type of hospital ($p=0.02$), working in a DonateLife Network Hospital ($p<0.01$), having received OTD related education ($p<0.01$) and having OTD related experience in the last year ($p<0.01$) (Appendix B Table 35). Similar proportions (64.8% and 60.9%) also found it easy to recognize patients that fulfil the criteria of the trigger. When it comes to referring a potential donor or notifying a transplant coordinator, more medical staff felt competent (67.5%) and comfortable (70.7%) doing these tasks compared to nursing staff (43.8% and 53.6% respectively). The majority of staff felt they had enough time (67.1% of medical staff and 58.3% of nursing staff) and knowledge/competence to identify a potential donor (69.8% of medical staff and 61.5% of nursing staff). Most staff (strongly) disagreed with the statement that the ED is not the right place to identify potential donors (59.9% of medical staff and 67.7% of nursing staff) although a large proportion of staff perceived barriers to the identification of potential donors (48.5% of medical staff and 44.3% of nursing staff). Perceiving barriers to the identification of potential donors was related to younger age ($p<0.01$), shorter duration of living in Australia ($p<0.01$), religion ($p=0.05$), region of employment ($p=0.01$), staff type ($p=0.03$), having less experience working in EDs in years ($p<0.01$), and having received training related to OTD ($p=0.02$)(Appendix B Table 36). An optional open ended question was included stating "I don't use the Clinical Trigger because" which evoked the following (84) responses (summarized):

I had not heard of the trigger before; I had heard of the trigger before but forgotten about it; I'm too junior; I haven't seen any patients fulfilling the criteria; I presume someone else (more senior) will do this; I find it inappropriate in paediatric emergency care; it compromises patient care and leads to a hasty decision to stop treatment; ED is not the right place but ICU is; the focus in ED is on immediate care, not organ donation; I work in a rural/small hospital where critically ill patients are transferred out, the ACEM Policy on Organ Donation does not support it.

Table 5 Number (percentage) of medical and nursing staff according to National Clinical Trigger items

Barriers to the use of the Clinical Trigger		(strongly) disagree	neutral	(strongly) agree
I am familiar with the Clinical Trigger	Medical	151 (26.8)	61 (10.8)	351 (62.3)
	Nursing	50 (26.0)	19 (9.9)	123 (64.1)
I find it easy to recognize patients that fulfil the criteria of the Clinical Trigger	Medical	67 (11.9)	131 (23.3)	365 (64.8)
	Nursing	37 (19.3)	38 (19.8)	117 (60.9)
I have the necessary competence and knowledge to refer a potential donor	Medical	82 (14.6)	101 (17.9)	380 (67.5)
	Nursing	59 (30.7)	49 (25.5)	84 (43.8)
I feel comfortable notifying a transplant coordinator or the appropriate person when a potential donor is identified	Medical	82 (14.6)	83 (14.7)	398 (70.7)
	Nursing	54 (28.1)	35 (18.2)	103 (53.6)
I don't have time to use the Clinical Trigger/identify potential donors	Medical	378 (67.1)	119 (21.1)	66 (11.7)
	Nursing	112 (58.3)	63 (32.8)	17 (8.9)
I have the necessary competence and knowledge to identify a potential donor	Medical	72 (12.8)	98 (17.4)	393 (69.8)
	Nursing	36 (18.8)	38 (19.8)	118 (61.5)
I think the ED is not the right place to identify potential donors	Medical	337 (59.9)	110 (19.5)	116 (20.6)
	Nursing	130 (67.7)	24 (12.5)	38 (19.8)
I perceive no barriers to the identification of potential donors	Medical	273 (48.5)	162 (28.8)	128 (22.7)
	Nursing	85 (44.3)	49 (25.5)	58 (30.2)

Table 6 shows that the vast majority of respondents supported the use of the Clinical Trigger in the ED (76.7% of medical staff and 80.7% of nursing staff) after explanation of the Clinical Trigger in the survey; however there was still a significant proportion that were unsure or unsupportive (23.3% of medical staff and 19.3% of nursing staff). Support of the Trigger was related to religion ($p<0.01$), region ($p<0.01$), average hours of work per week ($p=0.02$), and whether or not OTD education was received ($p<0.01$), (Appendix B Table 37).

Comments of the staff members not supportive of the Clinical Trigger (42) included: *ED is not the place to begin identifying patients who may be potential donors, it is too chaotic and there is not enough time or bedspace; I feel the ICU is a better environment to discuss this with*

the family, they have support staff better equipped for raising these discussions; Not appropriate for all ED's, maybe metro or trauma ED's, others might not have the resources like support staff or senior staff ; I am not educated enough; I have ethical issues with this.

Table 6 Number (percentage) of medical and nursing staff according to support of the National Clinical Trigger

Support of the Clinical Trigger		Yes	Unsure	No
Do you support the use of the National Clinical Trigger in the ED?	Medical	432 (76.7)	97 (17.2)	34 (6.0)
	Nursing	155 (80.7)	29 (15.1)	8 (4.2)

4. 3. 4. Referring and medically supporting potential donors

This section was completed by 731 participants. Table 7 shows responses to an item asking ED clinicians whether they would refer a patient who activates the trigger and has a medical condition for OTD. The majority of these medical conditions do not preclude eligibility for OTD except HIV and metastatic cancer. As can be seen in the table, both medical and nursing staff were very conservative when it comes to referring patients with a medical condition, the majority would not refer, or were unsure whether to refer patients with overwhelming sepsis, metastatic cancer, hepatitis, HIV, current IV drug use, meningococcal infection, tuberculosis, and age over 80 years.

Table 7 Number (percentage) of medical and nursing staff according to items about referring potential donors

Would you refer a patient for OTD who activates the trigger and has the following medical condition:		Yes	No	Unsure
Overwhelming sepsis	Medical	129 (23.7)	331 (60.7)	85 (15.6)
	Nursing	41 (22.0)	78 (41.9)	67 (36.0)
Metastatic cancer	Medical	104 (19.1)	382 (70.1)	59 (10.8)
	Nursing	33 (17.7)	113 (60.8)	40 (21.5)
Hepatitis	Medical	185 (33.9)	280 (51.4)	80 (14.7)
	Nursing	45 (24.2)	101 (54.3)	40 (21.5)
HIV	Medical	70 (12.8)	417 (76.5)	58 (10.6)
	Nursing	23 (12.4)	129 (69.4)	34 (18.3)
Current IV drug use	Medical	181 (33.2)	258 (47.3)	106 (19.4)
	Nursing	48 (25.8)	88 (47.3)	50 (26.9)
Multiple sclerosis	Medical	321 (58.9)	92 (16.9)	132 (24.2)
	Nursing	75 (40.3)	48 (25.8)	63 (33.9)

Meningococcal infection	Medical	129 (23.7)	323 (59.3)	93 (17.1)
	Nursing	34 (18.3)	91 (48.9)	61 (32.8)
Tuberculosis	Medical	127 (23.3)	317 (58.2)	101 (18.5)
	Nursing	36 (19.4)	89 (47.8)	61 (32.8)
Neurological disease	Medical	378 (69.4)	69 (12.7)	98 (18.0)
	Nursing	93 (50.0)	37 (19.9)	56 (30.1)
Age >80 years	Medical	230 (42.2)	218 (40.0)	97 (17.8)
	Nursing	51 (27.4)	95 (51.1)	40 (21.5)
I refer every patient who activates the Trigger for potential OTD	Medical	100 (18.3)	334 (61.3)	111 (20.4)
	Nursing	40 (21.5)	82 (44.1)	64 (34.4)

Table 8 shows responses to items about medically supporting potential donors in the ED. Supporting potential donors would ideally occur in the ICU, but often an ICU bed is not (immediately) available and potential donors need to be cared for in ED until an ICU bed becomes available. 45% of medical staff and 59.7% of nursing staff indicated willingness to support a potential donor waiting on an ICU bed, even if someone else needed the resuscitation bay, and 39.8% of medical staff and 60.2% of nursing staff indicated willingness to support a potential donor waiting on an ICU bed, regardless of resources required. The majority (strongly) agreed that providing care to a potential organ donor would be rewarding (70.1% of medical staff and 76.9% of nursing staff) and that they were competent enough to care for a potential donor (60.7% of medical staff and 54.3% of nursing staff).
The following optional open ended item was included: *"I don't feel completely comfortable providing medical support to a potential donor because"* which evoked the following (94) responses (summarized):

Cynicism as how the waiting list for organ donors is manipulated to suit politicians/ VIPs. It is also tempered by looking after several liver transplant pts who are back on alcohol/ IVDU; Happy to clinically provide support, but resources within ED are inadequate even for salvageable patients, so to enable support, must provide resources to ED; I wonder about techniques such as cooling, remote ischemic conditioning, tight glycaemic control that may promote the health of the donor tissues-are we doing enough?; Insufficient knowledge about care required; Not at the expense of living patients who require urgent care; Our ED is stretched beyond capacity every day caring for the living: major bed block issues and constant resuscitation bay pressures, nurse and doctor shortages, we do not have the resources to care for potential donors.

Table 8 Number (percentage) of medical and nursing staff according to items on medically supporting potential donors

Medically supporting potential donors in the ED until ICU facilities become available		(strongly) disagree	neutral	(strongly) agree
I am unwilling to support a potential donor waiting on an ICU bed if someone else needs the resuscitation bay	Medical	245 (45.0)	93 (17.1)	207 (38.0)
	Nursing	111 (59.7)	31 (16.7)	44 (23.7)
I am willing to support a potential donor waiting on an ICU bed, regardless of resources required	Medical	213 (39.1)	115 (21.1)	217 (39.8)
	Nursing	33 (17.7)	41 (22.0)	112 (60.2)
Providing care to a potential organ donor would be rewarding	Medical	34 (6.2)	129 (23.7)	382 (70.1)
	Nursing	4 (2.2)	39 (21.0)	143 (76.9)
I have the necessary competence and knowledge to care for a potential donor	Medical	89 (16.3)	125 (22.9)	331 (60.7)
	Nursing	47 (25.3)	38 (20.4)	101 (54.3)

4. 3. 5. Knowledge of the processes involved in OTD

This section was completed by 685 participants. The majority of medical and nursing staff were aware of who to contact to refer a potential donor (69.1% of medical staff and 57.3% of nursing staff), and the formal guidelines for declaring brain death (59.9% of medical staff and 62.0% of nursing staff), obtaining consent for organ donation (59.9% of medical staff and 59.6% of nursing staff), and tissue donation (58.8% of medical staff and 58.5% of nursing staff) in their hospital (Table 9).

Table 9 Number (percentage) of medical and nursing staff according to knowledge of the processes involved in OTD

Knowledge of the processes involved in OTD		(strongly) disagree	neutral	(strongly) agree
I know who to contact to refer a potential donor	Medical	112 (21.8)	47 (9.1)	355 (69.1)
	Nursing	52 (30.4)	21 (12.3)	98 (57.3)
Our hospital has formal guidelines for declaring brain death	Medical	44 (8.6)	162 (31.5)	308 (59.9)
	Nursing	17 (9.9)	48 (28.1)	106 (62.0)
Our hospital has formal guidelines for obtaining consent for organ donation	Medical	40 (7.8)	166 (32.3)	308 (59.9)
	Nursing	19 (11.1)	50 (29.2)	102 (59.6)
Our hospital has formal guidelines for obtaining consent for tissue donation	Medical	39 (7.6)	173 (33.7)	302 (58.8)
	Nursing	18 (10.5)	53 (31.0)	100 (58.5)

4. 3. 6. Availability of resources to facilitate OTD

This section was completed by 685 participants. Availability of resources can impact the facilitation of OTD from the ED (Table 10). Only about a third of staff reported they often or always have the time to assess whether a patient is suitable to be a potential donor (32.6% of medical staff and 32.7% of nursing staff). Less than a fifth of staff members reported they often or always have enough time to discuss OTD with a patient's family (18.7% of medical staff and 16.9% of nursing staff). A patient's family's inability to speak English is often or always a barrier according to more than a third of staff (41.6% of medical staff and 36.3% of nursing staff). Absence of patient's family or partner is often or always a barrier to OTD according to 41.5% of medical staff and 43.9% of nursing staff. The ICU being full was perceived to be a barrier to facilitating OTD according to 31.3% of medical staff and 29.3% of nursing staff. The majority of medical staff (52.4%), and 38.6% of nursing staff, reported that ED overcrowding to be often/always a barrier to facilitating OTD. Only a small proportion indicated that potential donors often/always take up too much time which could be spent on other patients (18.3% of medical staff and 12.8% of nursing staff). Almost three quarters indicated that there was never/sometimes enough resources available in the ED to facilitate OTD (76.3% of medical staff and 68.4% of nursing staff), while just over half reported there were never/sometimes enough resources available in the hospital (52.1% of medical staff and 54.4% of nursing staff).

The following optional item was included: "*Other resource barriers to facilitate OTD are...*" which evoked the following (44) responses (summarized):

My experience suggests that ED staff raising donation has been frowned on by ICU staff; Religious beliefs of some intensivists; ICU is always full, never has availability; social worker availability, bed availability, ICU unwilling to accept, nursing staff shortages, equipment shortages - ED ventilators for example; Reluctance to approach family - too early in grieving process?; We have been told the resources will be there if donation is appropriate but I have never seen extra resources put in place in ED to cover for such a situation; If using the trigger meant you got help from ICU and bed management quicker, and assistance to care for that pt (as is postulated to be available but never is), an ED Dr may use the trigger more, versus extubate in ED.

Table 10 Number (percentage) of medical and nursing staff according to items on availability of resources to facilitate OTD

Resources available in the ED to facilitate OTD	Staff type	Never	Some-times	Often	Always	Not applicable
I have enough time to assess whether a patient is suitable to be a potential donor	Medical	23 (4.5)	308 (59.9)	120 (23.3)	48 (9.3)	15 (2.9)
	Nursing	11 (6.4)	74 (43.3)	39 (22.8)	17 (9.9)	30 (17.5)
A patient's family's inability to speak English is a barrier to OTD	Medical	24 (4.7)	261 (50.8)	158 (30.7)	56 (10.9)	15 (2.9)
	Nursing	12 (7.0)	83 (48.5)	41 (24.0)	21 (12.3)	14 (8.2)
I have enough time to discuss OTD with a patient's family	Medical	59 (11.5)	340 (66.1)	63 (12.3)	33 (6.4)	19 (3.7)
	Nursing	20 (11.7)	92 (53.8)	19 (11.1)	10 (5.8)	30 (17.5)
Absence of patient's family or partner is a barrier to OTD	Medical	13 (2.5)	271 (52.7)	131 (25.5)	82 (16.0)	17 (3.3)
	Nursing	4 (2.3)	74 (43.3)	34 (19.9)	41 (24.0)	18 (10.5)
Facilitating OTD is difficult because the ICU is full	Medical	44 (8.6)	275 (53.5)	120 (23.3)	41 (8.0)	34 (6.6)
	Nursing	15 (8.8)	72 (42.1)	36 (21.1)	14 (8.2)	34 (19.9)
ED overcrowding is a barrier to facilitating OTD	Medical	21 (4.1)	204 (39.7)	170 (33.1)	99 (19.3)	20 (3.9)
	Nursing	21 (12.3)	68 (39.8)	44 (25.7)	22 (12.9)	16 (9.4)
Potential donors take up too much time which could be spent on other patients	Medical	100 (19.5)	289 (56.2)	73 (14.2)	21 (4.1)	31 (6.0)
	Nursing	62 (36.3)	63 (36.8)	17 (9.9)	5 (2.9)	24 (14.0)
There are enough resources in the ED to facilitate OTD	Medical	95 (18.5)	297 (57.8)	96 (18.7)	19 (0.7)	7 (1.4)
	Nursing	41 (24.0)	76 (44.4)	27 (15.8)	15 (8.8)	12 (7.0)
There are enough resources in the hospital to facilitate OTD	Medical	32 (6.2)	236 (45.9)	176 (34.2)	58 (11.3)	12 (2.3)
	Nursing	22 (12.9)	71 (41.5)	38 (22.2)	26 (15.2)	14 (8.2)

4. 3. 7. Attitudes or beliefs about OTD in the ED

This section was completed by 685 participants. Almost all medical staff (98.8%) and nursing staff (97.7) (strongly) agreed that OTD can save lives. The majority of staff denied that OTD was something they just don't think about (73.7% of medical staff and 67.8% of nursing staff). The majority agreed that OTD can help the next of kin cope with grieve (70.0% of medical staff and 69.6% of nursing staff) and that facilitating OTD is a rewarding experience (70.4% of medical staff and 66.7% of nursing staff). Just over half of staff (54.5% of medical staff and 50.9% of nursing staff) (strongly) agreed with the statement that the costs of OTD are not high compared to the benefits. The majority of medical (63.4%) and nursing (57.9%) staff (strongly) disagreed with the statement "*facilitating OTD is not my role*" and this was related to gender ($p=0.03$), region ($p<0.01$) and having experience with OTD in the last calendar year ($p=0.02$)(Appendix B Table 38). Medical and nursing staff were divided over the following statement "*I feel obligated to offer the donor family the option of OTD*" where 44.2% of medical staff (strongly) disagreed and 39.3% replied neutral, 35.1% nursing staff (strongly) disagreed and 46.2% replied neutral (Table 11).

Table 11 Number (percentage) of medical and nursing staff according to attitudes or beliefs about OTD in the ED

Your attitudes or beliefs about OTD in the ED		(strongly) disagree	neutral	(strongly) agree
OTD can save lives	Medical	1 (0.2)	5 (1.0)	508 (98.8)
	Nursing	0 (0.0)	4 (2.3)	167 (97.7)
OTD is something I just don't think about	Medical	379 (73.7)	81 (15.8)	54 (10.5)
	Nursing	116 (67.8)	29 (17.0)	26 (15.2)
OTD can help the next of kin cope with grief	Medical	7 (1.4)	147 (28.6)	360 (70.0)
	Nursing	6 (3.5)	46 (26.9)	119 (69.6)
Facilitating OTD is a rewarding experience	Medical	10 (1.9)	142 (27.6)	362 (70.4)
	Nursing	4 (2.3)	53 (31.0)	114 (66.7)
The costs of OTD are not high compared to the benefits	Medical	42 (8.2)	192 (37.4)	280 (54.5)
	Nursing	19 (11.1)	65 (38.0)	87 (50.9)
Facilitating OTD is not my role	Medical	326 (63.4)	130 (25.3)	58 (11.3)
	Nursing	99 (57.9)	43 (25.1)	29 (17.0)
I feel obligated to offer the donor family the option of OTD	Medical	90 (17.5)	197 (38.3)	227 (44.2)
	Nursing	32 (18.7)	79 (46.2)	60 (35.1)

4. 3. 8. Knowledge and attitude towards brain death

This section was completed by 679 participants. A validated 5 item tool to assess understanding of brain death (BD) was incorporated into the survey (22). Table 12 shows the result of the test items. 59.4% of all medical staff answered all 5 items correctly where a slightly higher 63.2% of nursing staff passed this test. Passing the BD test was related to age ($p=0.04$), average hours work per week ($p<0.01$), years of experience in EDs ($p<0.01$), whether or not OTD related education was received ($p<0.01$) and whether or not someone had any experience with OTD related tasks in the last calendar year ($p=0.02$) (Appendix B Table 39).

Table 12 Number (percentage) of medical and nursing staff according to items on the brain death test

Brain Death knowledge test		Correct answer	Incorrect or unsure
Can someone who is brain dead breathe without support of a breathing machine?	Medical	368 (72.4)	140 (27.6)
	Nursing	132 (77.2)	39 (22.8)
Can someone who is brain dead ever wake up (recover)?	Medical	482 (94.9)	26(5.1)
	Nursing	158 (92.4)	13 (7.6)
Will someone who is brain dead react (grimace, move away or blink) if someone touches their eyeball?	Medical	400 (78.7)	108 (21.3)
	Nursing	142 (83.0)	29 (17.0)
Can a person be brain dead even if the heart is still beating?	Medical	503 (99.0)	5 (1.0)
	Nursing	162 (94.7)	9 (5.3)
Is brain death different from coma or a vegetative state?	Medical	461 (90.7)	47 (9.3)
	Nursing	158 (92.4)	13 (7.6)
		Pass	Fail
5 items brain death test	Medical	302 (59.4)	206 (40.6)
	Nursing	108 (63.2)	63 (36.8)

Two thirds of ED clinicians (67.3% of medical staff and 66.1% of nursing staff) reported that they were aware of the clinical signs of imminent brain death (Table 13).

Table 13 Number (percentage) of medical and nursing staff according to awareness of imminent brain death

Imminent brain death		Yes	No	Unsure
Are you aware of the clinical signs of imminent brain death?	Medical	342 (67.3)	55 (10.8)	111 (21.9)
	Nursing	113 (66.1)	21 (12.3)	37 (21.6)

The majority of ED clinicians agreed with the statement that "*brain death is a valid determination of death*" (86.6% of medical staff and 82.4% of nursing staff) (Of concern, of 196 ED clinicians who had explained BD to the next of kin in the last calendar year, 34.2% failed the knowledge test (35 medical specialists, 25 trainee specialists and 7 nurses) and 13.3% did not accept BD as a valid determination of death.

Table 14). Whether clinicians agreed with this statement was related to longer length of living in Australia ($p=0.02$), fewer average work hours per week ($p=0.01$), staff type ($p<0.01$), more years of experience in EDs ($p<0.01$), and having received OTD related education

(p=0.03)(Appendix B Table 40). Clinicians that replied "don't know' (9.3% of medical staff and 15.3% of nursing staff) or "disagree" (4.2% of medical staff and 2.4% of nursing staff) were asked to further elaborate and the following reasons were selected (some participants selected two or more options): Lack of information on brain death; Doubts on the scientific definition of brain death; Religious, personal or philosophical reasons; Lack of trust in doctors' ability to diagnose brain death, and Other (Table 14).

"Other" includes: *Death in my opinion implies that the heart has stopped irrespective of brain death; Death is a consequence (and not concomitance) of brain death. And you can't pronounce somebody dead (in the medicolegal sense) while they still have a pulse; The rare occasions of unexpected recovery; Validity is determined by the individual patient and their family, not my opinion. Therefore validity will differ in each case; Defining death as anything other than the physiologically unreactive state following cardio-respiratory arrest is philosophical sophistry. It is more honest to admit that we allow people who are not quite dead to be killed in order to facilitate organ transplant.*

Of concern, of 196 ED clinicians who had explained BD to the next of kin in the last calendar year, 34.2% failed the knowledge test (35 medical specialists, 25 trainee specialists and 7 nurses) and 13.3% did not accept BD as a valid determination of death.

Table 14 Number (percentage) of medical and nursing staff according to attitude towards brain death

Attitude towards brain death		Agree	Don't know	Disagree
Brain death is a valid determination of death	Medical	438 (86.6)	47 (9.3)	21 (4.2)
	Nursing	140 (82.4)	26 (15.3)	4 (2.4)
	Total	578 (86)	73 (11)	25 (4)

You have replied "disagree" or "don't know", is this due to: (one or more replies)	Medical N=68 (13.5)	Nursing n=30 (17.7)
Lack of information on brain death	35 (51.5)	17 (56.7)
Doubts on the scientific definition of brain death	28 (41.2)	8 (26.7)
Religious, personal or philosophical reasons	10 (14.7)	3 (10.0)
Lack of trust in doctors' ability to diagnose brain death	8 (11.8)	5 (16.7)
Other	8 (11.8)	4 (13.3)

4. 3. 9. Understanding of the legal processes in OTD

This section was completed by 669 participants. When organizing OTD there may be legal processes involved. Table 15 shows responses to related items. Around half of respondents (58.4% of medical staff and 48.5% of nursing staff) (strongly) agreed with the statement "*I am familiar with the Coroner's process*" whereas a slightly larger proportion (strongly) agreed to the statement "*I know how to access information about the Coroner's process*" (67.1% of medical staff and 57.7% of nursing staff). Respondents were more divided over the statement "*A cause of death that is reportable to the Coroner precludes OTD*"; 50.7% of medical staff (strongly) disagreed whereas neutral was the most chosen reply for nurses (42.3%).

Less than half (49%) of medical staff reported feeling comfortable explaining the Coroner's process to the donor family whereas only 31% of nursing staff reported feeling comfortable. Close to half (46.3% of medical staff and 48.8% of nursing staff) of respondents were not familiar with the local legislation on OTD and only just over a third of respondents knew how to access this information (35.5% of medical staff and 37.5% of nursing staff). More than half of the respondents reported not feeling comfortable explaining local legislation on OTD to the donor family (56.0% of medical staff and 57.1% of nursing staff).

Table 15 Number (percentage) of medical and nursing staff according to items on legal processes in OTD

Your understanding of the legal processes in OTD		(Strongly) disagree	Neutral	(Strongly) agree
I am familiar with the Coroner's process	Medical	121 (24.1)	88 (17.5)	293 (58.4)
	Nursing	49 (29.3)	37 (22.2)	81 (48.5)
A cause of death that is reportable to the Coroner precludes OTD	Medical	254 (50.7)	151 (30.1)	96 (19.2)
	Nursing	55 (32.7)	71 (42.3)	42 (25.0)
I know how to access information about the Coroner's process	Medical	80 (16.0)	85 (17.0)	336 (67.1)
	Nursing	38 (22.6)	33 (19.6)	97 (57.7)
I feel comfortable explaining the Coroner's process to the donor family	Medical	141 (28.1)	115 (22.9)	246 (49.0)
	Nursing	73 (43.5)	43 (25.6)	52 (31.0)
I am familiar with local legislation on OTD	Medical	232 (46.3)	159 (31.7)	110 (22.0)
	Nursing	82 (48.8)	53 (31.5)	33 (19.6)
I know how to access information about local legislation on OTD	Medical	196 (39.0)	128 (25.5)	178 (35.5)
	Nursing	74 (44.0)	31 (18.5)	63 (37.5)
I feel comfortable explaining local legislation on OTD to the donor family	Medical	280 (56.0)	141 (28.2)	79 (15.8)
	Nursing	96 (57.1)	43 (25.6)	29 (17.3)

4. 3. 10. Communicating relevant OTD related issues to the donor family

This section was completed by 662 participants. Communicating relevant OTD related issues to the donor family is something that many ED clinicians would experience often (Figure 9 Percentage of respondents according to organ and tissue donation related experience in the last calendar year). 74.0% of medical staff felt they had the necessary competence or knowledge to explain brain death to the next of kin against only 48.2% of nursing staff. Similarly, 84.7% of medical staff felt they have the necessary competence or knowledge to introduce the subject of organ donation and 81.3% for tissue donation against 56% and 53% of nursing staff respectively. The majority felt like they did not have the necessary competence or knowledge to obtain consent for organ or tissue donation (67.9% for medical staff and 91% for nursing staff).

Table 16 Number (percentage) of medical and nursing staff according to items on competency in communicating with the donor family

Do you feel you have the necessary competence or knowledge to:		Yes	No
Explain brain death to the next of kin	Medical	367 (74.0)	129 (26.0)
	Nursing	80 (48.2)	86 (51.8)
Introduce the subject of organ donation	Medical	420 (84.7)	76 (15.3)
	Nursing	93 (56.0)	73 (44.0)
Introduce the subject of tissue donation	Medical	403 (81.3)	93 (18.8)
	Nursing	88 (53.0)	78 (47.0)
Obtain consent for organ donation	Medical	159 (32.1)	337 (67.9)
	Nursing	15 (9.0)	151 (91.0)
Obtain consent for tissue donation	Medical	159 (32.1)	337 (67.9)
	Nursing	15 (9.0)	151 (91.0)

Table 17 summarizes the results of items on comfort in communicating with donor families. More than two thirds (71.2%) of medical staff felt comfortable explaining brain death to the next of kin against only 42.8% of nursing staff. Similarly, three quarters of medical staff felt comfortable introducing the subject of organ donation (75.8%) and tissue donation (73.0%) against half of nursing staff (50.6% and 49.4% respectively). The majority did not feel comfortable obtaining consent for organ or tissue donation (57.7% and 58.1% for medical staff and 51.2% for both for nursing staff). The majority felt comfortable approaching families that are visibly distressed (76.6% of medical staff and 75.9% of nursing staff) as well as supporting grieving families (89.1% of medical staff and 85.5% of nursing staff).

Of note, of ED clinicians who failed the BD knowledge test, 54.8% felt they had enough knowledge and competence, and 52.5% felt comfortable to explain BD to the next of kin.

Table 17 Number (percentage) of medical and nursing staff according to items on comfort in communicating with the donor family

Do you feel comfortable in the following situation:		Yes	No	No involvement
Explaining brain death to the next of kin	Medical	353 (71.2)	90 (18.1)	53 (10.7)
	Nursing	71 (42.8)	45 (27.1)	50 (30.1)
Introducing the subject of organ donation	Medical	376 (75.8)	85 (17.1)	35 (7.1)
	Nursing	84 (50.6)	42 (25.3)	40 (24.1)
Introducing the subject of tissue donation	Medical	362 (73.0)	96 (19.4)	38 (7.7)
	Nursing	82 (49.4)	45 (27.1)	39 (23.5)
Obtaining consent for organ donation	Medical	127 (25.6)	286 (57.7)	83 (16.7)
	Nursing	16 (9.6)	85 (51.2)	65 (39.2)
Obtaining consent for tissue donation	Medical	127 (25.6)	288 (58.1)	81 (16.3)
	Nursing	16 (9.6)	85 (51.2)	65 (39.2)
Approaching families that are visibly distressed	Medical	380 (76.6)	108 (21.8)	8 (1.6)
	Nursing	126 (75.9)	28 (16.9)	12 (7.2)
Supporting/comforting grieving families	Medical	442 (89.1)	42 (8.5)	12 (2.4)
	Nursing	142 (85.5)	13 (7.8)	11 (6.6)

Since Australia is a multicultural country it is very likely that the medical or nursing staff have a different religion or come from a different culture then the potential donor family. Table 18 summarizes the response to items exploring whether ED clinicians felt comfortable communicating about OTD with families from same or different culture and religion. The modal response for medical staff was that they felt comfortable in all situations, whether a donor family has the same or different religion or culture to them. Nursing staff often indicated that they were unsure or that these situations were not applicable to them, except when the donor family has the same culture, this is when half of nursing staff (50%) felt comfortable communicating OTD related issues, which was also the situation in which the most medical staff indicated to be comfortable (65.1%).

The following optional item was included: "I feel uncomfortable communicating to potential donor families because" which evoked the following (52) responses (summarized):

I am not experienced enough with the process/don't have enough knowledge and would be concerned I could not adequately answer their questions; It should be someone detached from intimate decisions of clinical care to prevent a potential conflict of interest; often when patients come to ED, their families don't expect them to die. So, when I am the messenger of bad news (i.e. ICH - pt will have bad outcome), family has to deal with that shock first. Organ donation is not yet something that is generally accepted in the public, hence it is hard to breach that subject with grieving family in ED. If it was something that Australia as a nation accepted as something we just did for each other, something positive that saves other people's lives, it would

be easier to discuss it. Eg. I have told my family over and over again that I want all my organs and everything donated. Still my family is a bit reluctant about all this and doesn't want to discuss death in general. I hope they won't override my wishes but I know that they could the way our legislation works at present.

Table 18 Number (percentage) of medical and nursing staff according to communicating with cultural/religious donor families

I feel comfortable communicating about OTD with the potential donor family when:		Yes	No	Unsure/ Not applicable
the family has the same religion as mine	Medical	253 (51.0)	36 (7.3)	207 (41.7)
	Nursing	71 (42.8)	22 (13.3)	73 (44.0)
the family has a different religion to mine	Medical	245 (49.4)	53 (10.7)	198 (39.9)
	Nursing	65 (39.2)	29 (17.5)	72 (43.4)
the family comes from the same culture as mine	Medical	323 (65.1)	42 (8.5)	131 (26.4)
	Nursing	83 (50.0)	23 (13.9)	60 (36.1)
the family comes from a different culture to mine	Medical	268 (54.0)	77 (15.5)	151 (30.4)
	Nursing	66 (39.8)	34 (20.5)	66 (39.8)
I feel uncomfortable in all these situations because I don't support OTD	Medical	7 (1.4)	365 (73.6)	124 (25.0)
	Nursing	4 (2.4)	104 (62.7)	58 (34.9)

When it comes to the right time to approach potential donor families, more than a third of medical staff reported to be uncertain about this (35.8%), whereas also more than third reported they are not uncertain (37.3%). The modal response for nursing staff is that they are uncertain (41.4%). The majority of both medical and nursing staff (strongly) agreed that families with certain cultural or religious backgrounds are not supportive of OTD. We further elaborate on that below where the free text comments are discussed. Respondents had mixed responses to the statement "*Families with certain socioeconomic status are supportive of OTD*" the modal response of medical staff was neutral (42.2%) where close to half of the nursing staff (strongly) disagreed with the statement (45.1%). More than three quarters of respondents (strongly) disagreed that families are not supportive of OTD of young patients (78.4% of medical staff and 75.9% of nursing staff). More than two thirds of respondents did not think that they could predict whether families will be supportive of OTD (72.7% of medical staff and 66.0% of nursing staff).

The following optional item was included: "*Which type of families (if any) you think are likely to not support OTD*" which evoked the following (44) responses (summarized):
Families who have not been treated with respect and consultation from the outset of their loved ones injury/accident/illness; Japanese, Australian indigenous, Jehovah's witness; large families - often no consensus; strongly religious people of catholic, orthodox Christians, Muslims,

Buddhist backgrounds; Those marginalised groups (low SES) who may not perceive that they are truly included in the broader society; working/underclass families who perceive that they are not included into mainstream society.

Table 19 Number (percentage) of medical and nursing staff according to items on approaching potential donor families

Approaching potential donor families		(Strongly) disagree	Neutral	(Strongly) agree
I'm uncertain what the right time is to approach families	Medical	183 (37.3)	132 (26.9)	176 (35.8)
	Nursing	59 (36.4)	36 (22.2)	67 (41.4)
Families with certain cultural/religious backgrounds are not supportive of OTD	Medical	68 (13.8)	116 (23.6)	307 (62.5)
	Nursing	31 (19.1)	41 (25.3)	90 (55.6)
Families with certain socioeconomic status are supportive of OTD	Medical	187 (38.1)	207 (42.2)	97 (19.8)
	Nursing	73 (45.1)	63 (38.9)	26 (16.0)
Families are not supportive of OTD of young patients	Medical	385 (78.4)	96 (19.6)	10 (2.0)
	Nursing	123 (75.9)	34 (21.0)	5 (3.1)
I can predict whether families will be supportive of OTD	Medical	357 (72.7)	119 (24.2)	15 (3.1)
	Nursing	107 (66.0)	53 (32.7)	2 (1.2)

This section was completed by 653 participants. Staff's perceptions of donor families' attitudes are summarized in Table 20. The majority (strongly) agreed with the statement that donor families find it useful to talk about end of life decisions (71.9% of medical staff and 66.7% of nursing staff). The modal response to the statement "donor families don't understand brain death" was (strongly) agree (38.7% of medical staff and 54.9% of nursing staff). It seems like respondents did not have strong opinions on most other items as their responses are quite divided and often neutral.

Table 20 Number (percentage) of medical and nursing staff according to beliefs about donor families

In general, I think donor families:		(Strongly) disagree	Neutral	(Strongly) agree
find it uncomfortable to discuss processes related to OTD	Medical	174 (35.4)	177 (36.0)	140 (28.5)
	Nursing	52 (32.1)	67 (41.4)	43 (26.5)
find it useful to talk about end of life decisions	Medical	24 (4.9)	114 (23.2)	353 (71.9)
	Nursing	9 (5.6)	45 (27.8)	108 (66.7)
don't understand brain death	Medical	121 (24.6)	180 (36.7)	190 (38.7)
	Nursing	30 (18.5)	43 (26.5)	89 (54.9)
are usually too upset to make a decision about OTD	Medical	217 (44.2)	173 (35.2)	101 (20.6)
	Nursing	55 (34.0)	65 (40.1)	42 (25.9)
think that the processes related to OTD are too complicated	Medical	130 (26.5)	267 (54.4)	94 (19.1)
	Nursing	37 (22.8)	95 (58.6)	30 (18.5)
find it useful to talk about the eligibility for OTD	Medical	28 (5.7)	229 (46.6)	234 (47.7)
	Nursing	12 (7.4)	77 (47.5)	73 (45.1)
are usually too upset to discuss eligibility related to OTD	Medical	200 (40.7)	219 (44.6)	72 (14.7)
	Nursing	52 (32.1)	74 (45.7)	36 (22.2)
don't understand legislation related to OTD	Medical	34 (6.9)	183 (37.3)	274 (55.8)
	Nursing	8 (4.9)	66 (40.7)	88 (54.3)
care about legislation related to OTD	Medical	137 (27.9)	256 (52.1)	98 (20.0)
	Nursing	30 (18.5)	88 (54.3)	44 (27.2)
have easy access to legislation related to OTD	Medical	251 (51.1)	220 (44.8)	20 (4.1)
	Nursing	64 (39.5)	81 (50.0)	17 (10.5)

4. 3. 11. Personal attitudes and beliefs about OTD

This section was completed by 635 participants. Almost all respondents supported organ and tissue donation in general (96.4% of medical staff and 95.7% of nursing staff, Table 21). This was related to whether or not the participant was religious (p=0.05)(Appendix B Table 41).

Table 21 Number (percentage) of medical and nursing staff according to general attitude about OTD

General attitude about OTD		Support	Don't know	Oppose
What is your general attitude to donation of organs and tissues for transplants?	Medical	457 (96.4)	15 (3.2)	2 (0.4)
	Nursing	154 (95.7)	5 (3.1)	2 (1.2)
	Total	611(96.2)	20 (3.2)	4 (0.6)

Table 22 summarizes the personal attitudes about OTD. The overwhelming majority of respondents reported willingness to donate their own organs (90% of medical staff and 90.1% of nursing staff) and tissues (89.2% of medical staff and 90.1% of nursing staff) after death. Willingness to donate own organs and tissues was related to younger age ($p<0.01$) and religion ($p<0.01$) (Appendix B Table 42). Most respondents had also informed their next of kin about their wishes (84.0% of medical staff and 92.0% of nursing staff) however, only 47.2% of medical staff and 61.1% of nursing staff had registered their choice. Having registered and communicated OTD wish was related to female gender ($p<0.01$), younger age ($p<0.01$), cultural background ($p<0.01$), longer length of living in Australia ($p<0.01$), religion ($p<0.01$), type of hospital ($p=0.02$), staff type ($p<0.01$), shorter experience in years in EDs ($p=0.04$), and having received OTD education ($p=0.03$) (Appendix B Table 43). The majority also reported willingness to donate organs or tissues from their adult next of kin (87.1% of medical staff and 85.2% of nursing staff) and children (81.6% of medical staff and 73.5% of nursing staff) after their death. Willingness to give family consent was related to cultural background ($p<0.01$) and religion ($p<0.01$) (Appendix B Table 44).

Table 22 Number (percentage) of medical and nursing staff according to personal attitude about OTD

Personal attitudes about OTD		Yes	No	Unsure
Would you donate some of your organs after death?	Medical	440 (90.0)	20 (4.1)	29 (5.9)
	Nursing	146 (90.1)	9 (5.6)	7 (4.3)
Would you donate some of your tissues after death?	Medical	436 (89.2)	23 (4.7)	30 (6.1)
	Nursing	146 (90.1)	9 (5.6)	7 (4.3)
Have you registered your choice with the organ donor register (through Medicare, not on your driver's license)?	Medical	231 (47.2)	221 (45.2)	37 (7.6)
	Nursing	99 (61.1)	52 (32.1)	11 (6.8)
Have you informed your next of kin about your wishes concerning OTD after your death?	Medical	411 (84.0)	70 (14.3)	8 (1.6)
	Nursing	149 (92.0)	9 (5.6)	4 (2.5)
Would you donate organs or tissues from an adult next of kin after his/her death?	Medical	426 (87.1)	14 (2.9)	49 (10.0)
	Nursing	138 (85.2)	8 (4.9)	16 (9.9)
If you have children, or were to have children, would you donate his/her organs or tissues after death?	Medical	399 (81.6)	16 (3.3)	74 (15.1)
	Nursing	119 (73.5)	7 (4.3)	36 (22.2)

Table 23 summarizes the responses to items on personal beliefs about OTD. Only a small proportion of staff wanted their body intact for the life after death (2.5% of medical staff and 5.6% of nursing staff). An even smaller proportion did not want to be a donor because it is against their religious beliefs (0.8% of medical staff and 0.6% of nursing staff) or because they don't trust the diagnosis of brain death (1.0% of medical staff and 1.9% of nursing staff). The majority of respondents trusted that organs and tissues would be allocated fairly (81.2% of medical staff and 87.0% of nursing staff) and wanted to receive an organ from someone who died if they needed one (84.3% of medical staff and 79.6% of nursing staff).

Table 23 Number (percentage) of medical and nursing staff according to personal beliefs about OTD

Personal beliefs about OTD		(strongly) disagree	neutral	(strongly) agree
I want my body to be intact for the life after death	Medical	432 (88.3)	45 (9.2)	12 (2.5)
	Nursing	130 (80.2)	23 (14.2)	9 (5.6)
I don't want to be a donor because it is against my religious beliefs	Medical	473 (96.7)	12 (2.5)	4 (0.8)
	Nursing	155 (95.7)	6 (3.7)	1 (0.6)
I don't want to be a donor because I don't trust the diagnosis of brain death	Medical	465 (95.1)	19 (3.9)	5 (1.0)
	Nursing	153 (94.4)	6 (3.7)	3 (1.9)
I trust that organs and tissues will be allocated fairly	Medical	23 (4.7)	69 (14.1)	397 (81.2)
	Nursing	5 (3.1)	16 (9.9)	141 (87.0)
I would want to receive an organ from someone who died if I needed one	Medical	20 (4.1)	57 (11.7)	412 (84.3)
	Nursing	12 (7.4)	21 (13.0)	129 (79.6)

4. 3. 12. Knowledge and attitudes regarding OTD after cardiac death

This section was completed by 648 participants. OTD after cardiac death was slowly being rolled out across hospitals in Australia during the time of the survey. Table 24 summarizes responses to items about OTD after cardiac death. About half of the respondents were not familiar with the processes involved with OTD after cardiac death (49.3% of medical staff and 47.2% of nursing staff), and were unaware of the national policy on this (54.4% of medical staff and 52.8% of nursing staff). The majority (71.9% of medical staff and 68.3% of nursing staff) supported OTD after cardiac death, although there seemed to be less support for this than for organ donation in general. Support of OTD after cardiac death was related to main cultural background ($p<0.01$), religion ($p<0.01$), having received OTD related training ($p=0.02$) and experience with OTD in last year ($p=0.01$) (Appendix B Table 45). The following optional item was included: "*My opinion on OTD after cardiac death is*" which evoked the following (37) responses (summarized):

A good thing as it can make more life-saving or life improving organ/tissues available; I consider there is potential for real or perceived conflict for the doctor's intentions in seeking withdrawal of life support and then seeking permission for OTD after cardiac death. I do not consider there are satisfactory processes in place to avoid this potential or actual problem; I struggle with this ethically. I think it is a fine line often and have heard stories of death needing to be "facilitated" quite quickly due to the time frames required. I would struggle with that if I were the treating doctor - I have even people say it seems something like euthanasia. Glad I am not an intensivist dealing with this; that it may require a degree of harm, prolonged suffering, invasive techniques to maintain the organs for transplant that contradicts my responsibility to my own patient to want the best course of treatment for them and to minimize suffering. I don't know that the general members of public understand the actual physical processes of keeping a cardiac death patient alive to give informed consent as NOK. I am personally undecided about the ethics of prolonging someone's life to then withdraw cardiovascular support intraoperatively after transferring life-saving organs to another person, in the situation of a cardiac-death patient rather than a brain-dead patient. This relies partly on the consideration of a cardiac death patient as a potential cardiac donation recipient. I have no ethical reservations with organ donation post-mortem (such as bone marrow, cornea) in cardiac death patients as this should not alter their peri-mortem treatment; that it is not kosher; I didn't realise that OTD after cardiac death is now an option in Australia. I fully support it.

Table 24 Number (percentage) of medical and nursing staff according to knowledge and attitudes regarding OTD after cardiac death

Knowledge and attitudes regarding OTD after cardiac death		(strongly) disagree	neutral	(strongly) agree
I am familiar with the processes involved with OTD after cardiac death	Medical	240 (49.3)	96 (19.7)	151 (31.0)
	Nursing	76 (47.2)	29 (18.0)	56 (34.8)
I support OTD after cardiac death	Medical	14 (2.9)	123 (25.3)	350 (71.9)
	Nursing	8 (5.0)	43 (26.7)	110 (68.3)
I am aware of the national policy on OTD after cardiac death	Medical	265 (54.4)	112 (23.0)	110 (22.6)
	Nursing	85 (52.8)	39 (24.2)	37 (23.0)

4. 3. 13. Educational needs

The last question of the survey was optional and asked respondents to report any educational needs regarding OTD; this is summarized in Table 25. From the 648 respondents that finished the entire survey, 499 respondents (77%) responded to this optional item about additional education on OTD related subjects. OTD after cardiac death was the most often selected (398). "Other" included: *coordinating OTD from a rural centre; exclusion criteria for donation; legal aspects; The cost-benefit analysis of the organ/tissue transplant program. Do other vulnerable people miss out (e.g. psychiatric services) because of resources applied to OTD?; Coroner issues; All of the above, but limitation would be time to attend; A short refresher program every year or two would be good.*

Table 25 Number of medical and nursing staff according to educational needs

Would you like to receive education regarding OTD in any of the following areas? Tick any that apply	Medical	Nursing	Total
OTD after cardiac death	286 (59)	112 (70)	398
Clinical management of a donor	246 (51)	98 (61)	344
Brain death	230 (47)	104 (65)	334
Obtaining consent for OTD	243 (50)	89 (55)	332
The use of the Clinical Trigger	231 (47)	92 (57)	323
Family issues in decision making	201 (41)	99 (61)	300
Coordinating the OTD process in the hospital	199 (41)	84 (52)	283
Religious and cultural beliefs on OTD	193 (40)	88 (55)	281
Family grief counselling	151 (31)	87 (54)	238
Communication skills	138 (28)	87 (54)	225
Other (please specify)	21 (4)	12 (7)	33

4. 4. Additional comments

We received the following comments in response to the survey (summarized):

"I know from personal discussions with Drs for non referred (but appropriate) patients, in this dept, the main issues seem to be clinical pressures which lead to a lack of time to spend with the families and also failure to recall trigger i.e. "I forgot" , and difficult family dynamics, including aggression, in the ED."

"Often when it becomes clear that a patient's condition has put them in a position where they qualify for organ donation the staff in the ED have been making a huge effort to prevent that as being the outcome - ie, they have been actively trying to improve the patient's condition, and sometimes for quite a while. It is not unusual for the staff to be physically, mentally and emotionally quite exhausted afterwards. I doubt that staff that are in this state are the most appropriate to approach grieving families, from the point of view of either of the parties."

"I have noticed an increasing amount of locums working at my hospital; in fact the majority of FACEMS on any day are locums. I'm afraid they will miss out on OTD education as hospital based education sessions are rarely if ever attended by locums, many of whom either see it as their role or may be specifically employed on certain days to free the fulltime staff for teaching meetings. But locums are over-represented at weekends/evenings when there are fewer people around to ask for advice on such subjects – but when there is often more trauma, traditionally one of the sources for OTD donors."

"We need more education directed to rural centres and SPECIFICALLY giving us information to help relatives. Does the body, or the retrieval team do the travelling (probably depends on local theatre, distance etc.) If the body travels, who is responsible for sending back for local

funeral, who pays? IF I do a ton of investigations or treatment clearly NOT for the direct benefit of a donor (HIV Hep, heck, the ICU admission)how can I ensure that the pt isn't billed, - particular problem if they were labelled private or compensable and the carrier correctly rejects claims! Remembering that some of these will as a result of such tests be rejected. In a city I can leave all this to the transplant liaison nurse/facilitator."

"It is paramount to identify potential donors as soon as possible, this usually means in the ED. But from a pragmatic perspective, it is not necessary for a busy ED doctor to continue being extensively involved in ongoing consent, bereavement issues etc. The transplant co-ordinator/ team is there for this purpose and identified patients should swiftly move onto ICU. But from personal experience, I would say a majority of identified donor patients remain in the ED intubated/ventilated and using staff and equipment resources while the transplant co-ordinators go to and fro leaving either the ED team or sometimes ICU team in limbo. The vast majority of potential donors I have been involved with did not go onto the retrieval stage after several hours in ED. I continue to support the process however, since one successful retrieval can end the misery for several recipients."

5. Main findings and implications

» Almost 30% of ED clinicians had not had any education/training about OTD and 77% selected one or more items on which they desired to receive additional education.
» Three quarters of ED clinicians had one or more experiences with OTD related tasks during the last calendar year and those that had received some form of OTD education were significantly more often involved in OTD related tasks.
» Just over 60% of ED clinicians were familiar with the National Clinical Trigger whereas almost 80% said they support it (after it was explained in the survey).
» Knowledge about eligibility for potential donors and excluding medical conditions was poor; ED clinicians were very conservative when it came to referring patients with a variety of medical conditions.
» ED overcrowding, and lack of time to discuss OTD with next of kin were the most often reported resource barriers for facilitating OTD by of ED clinicians
» Although around 85% of ED clinicians accepted BD as a valid determination of death, only around 60% passed the 5 item BD knowledge test.
» There was an overall poor understanding of the legal processes involved with OTD among ED clinicians.
» Around 75% of medical ED clinicians and 50% of nursing ED clinicians reported feeling comfortable and competent about explaining BD, introducing OTD and comforting grieving families but this proportion dropped to 30% when it came to obtaining consent for OTD.
» Of concern, of ED clinicians who failed the BD knowledge test, 54.8% felt they had enough knowledge and competence, and 52.5% felt comfortable to explain BD to the next of kin. Of the 20% who had explained BD to the next of kin in the last calendar year, more than 35% failed the BD test.
» OTD related experience and education as well as BD knowledge and acceptance were related to increased comfort and perceived competence levels of ED clinicians, except for obtaining consent.
» Whereas 96.2% of ED clinicians supported OTD in general, a somewhat smaller proportion, around 70% of ED clinicians supported OTD after cardiac death, and fewer than 50% were familiar with the processes around it.
» Almost all ED clinicians indicated willingness to donate their own organs (90%), and their tissues after death (89.4%) and around 85% of ED clinicians had discussed their OTD wish with loved ones but only around 50% had registered with the organ donor register. The majority of ED clinicians reported willingness to consent for OTD for adult next of kin (86.6%) or (future) children (79.6%).
» Cultural/religious barriers existed for some items: support of the trigger and of OTD in general or after cardiac death, willingness to donate, communicate/register their wish, and willingness to give family consent.

6. Study strengths and limitations

Respondents to this survey represented 26.7% of Australian Fellows and 15.8% of Trainees of ACEM and overall, more than 20% of the Australian Emergency Physician workforce has taken part in this study. Therefore these results are highly representative of the attitudes, knowledge and perceptions of Australian ED doctors. Since the member body for emergency nursing (CENA) does not have mandatory membership, we have captured a smaller proportion of ED nurses compared to doctors. This study might reflect more the opinions of those nurses that have become a member of CENA.

The results of this survey present a comprehensive current overview of ED clinicians' perceived barriers to OTD organized from the ED. This report is therefore essential material for informing strategies to overcome these barriers and increase donation rates initiated from the ED.

7. Recommendations

The results of this study make it clear that those ED clinicians who had received education related to OTD had better knowledge, more positive attitudes towards OTD, and more involvement in OTD related tasks. This effect was seen even if this education only consisted of reading journal articles or attending conference sessions regarding OTD.

Therefore it is essential that OTD related education becomes an essential part of the curriculum of the ED clinicians. Results showed that some cultural and religious groups were more likely than others to have received OTD education and we have also noted the comment made by an ED doctor that a large proportion of ED clinicians are locum doctors who would not benefit from hospital or departmental training. Therefore we find it important that this education is provided at an early stage in the clinicians' career and that it becomes a mandatory and ingrained part of their education.

We believe this education program should focus on

» The early detection of all potential donors, including exclusion criteria
» Processes involved with OTD after brain death and cardiac death
» Knowledge and acceptance of brain death
» Legislation regarding OTD
» Communication with next of kin regarding the possibility of OTD
» Caring clinically for potential donors
» Cultural and religious aspects regarding OTD
» Burden/benefit of OTD for the health system and the next of kin

Ideally, potential donors should, once identified be moved to ICU as quickly as possible. However in reality this is not always possible. Results showed that although ED clinicians are willing to be involved with identifying and referring potential donors, obtaining consent for OTD was something ED clinicians did not feel comfortable with or competent to do and many did not feel competent to care for potential donors. Combined with reported time constraints and ED overcrowding, this makes the ED an unsuitable environment to discuss or obtain consent. It should be made clear to ED clinicians that although they play a vital part in identifying and referring potential donors, obtaining consent for OTD is not their role.

Additionally, individual hospitals should continue to educate their staff on the Clinical Trigger, stipulate that every potential donor should be referred, and provide specific instructions on how to refer these potential donors.

Appendix A: the abode survey

Assessing Barriers to Organ Donation in Emergency

1. Demographics

Thank you for taking the time to fill in this anonymous survey. Please don't use the "previous" button in your browser; you can navigate by using the "prev" and "next" buttons on the bottom of each page.

1. What is your gender:

- ◯ male
- ◯ female

2. What is your age:

3. What is your main cultural background:

- ◯ Australian
- ◯ New Zealand
- ◯ Pacific Islander
- ◯ British
- ◯ Irish
- ◯ Western European
- ◯ Northern European
- ◯ Greek
- ◯ Italian
- ◯ Other Southern European
- ◯ South Eastern European
- ◯ Eastern European
- ◯ Arab
- ◯ Jewish
- ◯ Other North African and Middle Eastern
- ◯ Mainland South-East Asian
- ◯ Maritime South-East Asian
- ◯ Chinese Asian
- ◯ Other North-East Asian
- ◯ Southern Asian
- ◯ Central Asian
- ◯ North American
- ◯ South American
- ◯ Central American
- ◯ Caribbean Islander
- ◯ Central and West African
- ◯ Southern and East African
- ◯ Other (please specify)

4. How long have you been living in Australia:

- ◯ Born in Australia
- ◯ less than 5 years
- ◯ between 5 and 10 years
- ◯ between 10 and 15 years
- ◯ between 15 and 20 years
- ◯ between 20 and 25 years
- ◯ more than 25 years

5. Your religion:

- ◯ Not religious
- ◯ Prefer not to say
- ◯ Christianity
- ◯ Jehovah's Witness
- ◯ Buddhism
- ◯ Islam
- ◯ Hinduism
- ◯ Sikhism
- ◯ Judaism
- ◯ Confucianism
- ◯ Shintoism
- ◯ Taoism
- ◯ Atheist
- ◯ Other (please specify)

6. Region in which you perform most of your Emergency Care:

- ◯ VIC
- ◯ NSW
- ◯ QLD
- ◯ SA
- ◯ WA
- ◯ TAS
- ◯ ACT
- ◯ NT

7. Type of hospital in which you perform most of your Emergency Care:

- ◯ Major Referral
- ◯ Major Regional/Rural Base
- ◯ Urban District
- ◯ Private Hospital

8. Which hospital do you mainly work at?
(Optional. Reminder: this survey is anonymous. In addition, the identity of your hospital will not be disclosed in any publication.)

Other (please specify hospital name and state)

9. Average hours per week you work clinically in an Emergency Department (ED):

- ◯ less than 10
- ◯ 10-20
- ◯ 21-30
- ◯ 31 or more

10. Your current staff position:

- ◯ Grade 2 nurse
- ◯ Post graduate qualification in emergency or critical care
- ◯ Other postgraduate qualification (masters)
- ◯ ANUM
- ◯ Provisional Trainee in Emergency Medicine
- ◯ Advanced Trainee in Emergency Medicine
- ◯ FACEM
- ◯ Other (please specify)

11. How many years have you have worked in EDs:

2. Experience and education related to organ and tissue donation (OTD)

Organ and tissue donation will be referred to as OTD

12. Have you received training or education in OTD (organ and tissue donation)? Please tick one or more of the following:

- ☐ No
- ☐ Yes, departmental training
- ☐ Yes, hospital based training
- ☐ Yes, The Australian Donor Awareness Programme (ADAPT)
- ☐ Yes, I have attended a conference session or have read journal articles about OTD
- ☐ Yes, provided by (please specify)

13. Please indicate the number of cases you were involved in the last calendar year in:

	none	1-3	4-6	>6
Identifying a potential donor	◯	◯	◯	◯
Activating the national Clinical Trigger (GIVE)	◯	◯	◯	◯
Referring a potential donor to the competent authorities	◯	◯	◯	◯
Caring for a potential donor	◯	◯	◯	◯
Communicating information on severe brain damage to the next of kin	◯	◯	◯	◯
Explaining brain death to the next of kin	◯	◯	◯	◯
Obtaining consent for organ donation	◯	◯	◯	◯
Obtaining consent for tissue donation	◯	◯	◯	◯
Caring for an organ or tissue recipient	◯	◯	◯	◯
I have experience with organ donation or transplants through my personal life (family, friends or self) indicate frequency for lifetime	◯	◯	◯	◯

Other (please specify the activity and frequency)

3. Barriers to the use of the national Clinical Trigger in the ED

The national Clinical Trigger (the G.I.V.E. protocol) was implemented nationally in 2010 by The Australian Organ and Tissue Authority. The Trigger is activated when a patient fulfils the following criteria:
- a Glasgow coma scale (GCS) rating that is 5 or below
- patient is Intubated
- patient is Ventilated
- End of life care is considered

When the Trigger is activated, the next step is to refer the potential donor to the appropriate person. Every hospital has a different trigger response. It can be contacting a staff member in your hospital specifically employed to facilitate OTD (Organ and Tissue Donation), the ICU consultant, or someone from DonateLife who will coordinate the process.

14. Barriers to the use of the Trigger and identification of potential donors in the ED:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I am familiar with the Clinical Trigger	◯	◯	◯	◯	◯
I find it easy to recognize patients that fulfil the criteria of the Clinical Trigger	◯	◯	◯	◯	◯
I have the necessary competence and knowledge to refer a potential donor	◯	◯	◯	◯	◯
I feel comfortable notifying a transplant coordinator or the appropriate person when a potential donor is identified	◯	◯	◯	◯	◯
I don't have time to use the Clinical Trigger/identify potential donors	◯	◯	◯	◯	◯
I have the necessary competence and knowledge to identify a potential donor	◯	◯	◯	◯	◯
I think the ED is not the right place to identify potential donors	◯	◯	◯	◯	◯
I perceive no barriers to the identification of potential donors	◯	◯	◯	◯	◯

I don't use the Clinical Trigger because of other reasons (please specify)

15. Do you support the use of the National Clinical Trigger (GIVE) in the ED?

◯ Yes

◯ Unsure

◯ No, because (please specify)

4. Referring and medically supporting potential donors

16. Would you refer a patient with the following medical condition for OTD if he/she activated the Trigger?

	Yes	No	Unsure
Overwhelming sepsis	◯	◯	◯
Metastatic cancer	◯	◯	◯
Hepatitis	◯	◯	◯
HIV	◯	◯	◯
Current IV drug use	◯	◯	◯
Multiple sclerosis	◯	◯	◯
Meningococcal infection	◯	◯	◯
Tuberculosis	◯	◯	◯
Neurological disease	◯	◯	◯
Age >80 years	◯	◯	◯
I refer every patient who activates the Trigger for potential OTD	◯	◯	◯

17. Your opinion about medically supporting potential donors in the ED until ICU facilities become available:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I am unwilling to support a potential donor waiting on an ICU bed if someone else needs the resuscitation bay	◯	◯	◯	◯	◯
I am willing to support a potential donor waiting on an ICU bed, regardless of resources required	◯	◯	◯	◯	◯
Providing care to a potential organ donor would be rewarding	◯	◯	◯	◯	◯
I have the necessary competence and knowledge to care for a potential donor	◯	◯	◯	◯	◯

(Optional) If you do not feel completely comfortable about providing medical support to a potential donor, please specify the reasons

5. Processes and resources for OTD after brain death in the ED

The following questions refer to the emergency department at which you undertake most of your clinical work.

18. Your knowledge of the processes involved in OTD:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I know who to contact to refer a potential donor	◯	◯	◯	◯	◯
Our hospital has formal guidelines for declaring brain death	◯	◯	◯	◯	◯
Our hospital has formal guidelines for obtaining consent for organ donation	◯	◯	◯	◯	◯
Our hospital has formal guidelines for obtaining consent for tissue donation	◯	◯	◯	◯	◯

19. Availability of resources to facilitate OTD:

	Never	Sometimes	Often	Always	Not applicable
I have enough time to assess whether a patient is suitable to be a potential donor	◯	◯	◯	◯	◯
A patient's family's inability to speak English is a barrier to OTD	◯	◯	◯	◯	◯
I have enough time to discuss OTD with a patient's family	◯	◯	◯	◯	◯
Absence of patient's family or partner is a barrier to OTD	◯	◯	◯	◯	◯
Facilitating OTD is difficult because the ICU is full	◯	◯	◯	◯	◯
ED overcrowding is a barrier to facilitating OTD	◯	◯	◯	◯	◯
Potential donors take up too much time which could be spent on other patients	◯	◯	◯	◯	◯
There are enough resources in the ED to facilitate OTD	◯	◯	◯	◯	◯
There are enough resources in the hospital to facilitate OTD	◯	◯	◯	◯	◯

(Optional) Other resource barriers to facilitate OTD are:

20. Your attitudes or beliefs about OTD in the ED:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
OTD can save lives	◯	◯	◯	◯	◯
OTD is something I just don't think about	◯	◯	◯	◯	◯
OTD can help the next of kin cope with grief	◯	◯	◯	◯	◯
Facilitating OTD is a rewarding experience	◯	◯	◯	◯	◯
The costs of OTD are not high compared to the benefits	◯	◯	◯	◯	◯
Facilitating OTD is not my role	◯	◯	◯	◯	◯
I feel obligated to offer the donor family the option of OTD	◯	◯	◯	◯	◯

6. Knowledge regarding brain death

21. Your knowledge and attitude towards brain death:

	Yes	No	Unsure
Are you aware of the clinical signs of imminent brain death?	◯	◯	◯
Can someone who is brain dead breathe without support of a breathing machine?	◯	◯	◯
Can someone who is brain dead ever wake up (recover)?	◯	◯	◯
Will someone who is brain dead react (grimace, move away or blink) if someone touches their eyeball?	◯	◯	◯
Can a person be brain dead even if the heart is still beating?	◯	◯	◯
Is brain death different from coma or a vegetative state?	◯	◯	◯

22. Brain death is a valid determination of death

◯ Disagree

◯ Don't know

◯ Agree

7. Knowledge regarding legal processes of OTD after brain death

23. You have replied "disagree" or "don't know" to the previous question (Brain death is a valid determination of death), is this due to:

Tick one or more boxes

☐ lack of information on brain death

☐ doubts on the scientific definition of brain death

☐ religious, personal or philosophical reasons

☐ lack of trust in doctors' ability to diagnose brain death

☐ Other (please specify)

24. Your understanding of the legal processes in OTD:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I am familiar with the Coroner's process	◯	◯	◯	◯	◯
A cause of death that is reportable to the Coroner precludes OTD	◯	◯	◯	◯	◯
I know how to access information about the Coroner's process	◯	◯	◯	◯	◯
I feel comfortable explaining the Coroner's process to the donor family	◯	◯	◯	◯	◯
I am familiar with local legislation on OTD	◯	◯	◯	◯	◯
I know how to access information about local legislation on OTD	◯	◯	◯	◯	◯
I feel comfortable explaining local legislation on OTD to the donor family	◯	◯	◯	◯	◯

8. Communicating relevant OTD related issues to the potential donor family/nex...

Donor family and next of kin are used interchangeable and includes spouse, partner, guardian, carer, and any family members of the (potential) donor.

25. Do you feel you have the necessary competence or necessary knowledge to:

	Yes	No
Explain brain death to the next of kin	◯	◯
Introduce the subject of organ donation	◯	◯
Introduce the subject of tissue donation	◯	◯
Obtain consent for organ donation	◯	◯
Obtain consent for tissue donation	◯	◯

26. Do you feel comfortable in the following situations?

	Yes	No	No involvement
Explaining brain death to the next of kin	◯	◯	◯
Supporting/comforting grieving families	◯	◯	◯
Introducing the subject of organ donation	◯	◯	◯
Introducing the subject of tissue donation	◯	◯	◯
Obtaining consent for organ donation	◯	◯	◯
Obtaining consent for tissue donation	◯	◯	◯
Approaching families that are visibly distressed	◯	◯	◯

27. I feel comfortable communicating about OTD with the potential donor family when:

	Yes	No	Unsure/ Not applicable
the family has the same religion as mine	◯	◯	◯
the family has a different religion to mine	◯	◯	◯
the family comes from the same culture as mine	◯	◯	◯
the family comes from a different culture to mine	◯	◯	◯
I feel uncomfortable in all these situations because I don't support OTD	◯	◯	◯

(Optional) I feel uncomfortable communicating about OTD to potential donor families because (please specify)

9. Approaching donor families and their understanding and beliefs related to O...

Donor family and next of kin are used interchangeable and includes spouse, partner, guardian, carer, and any family members of the (potential) donor.

28. Your attitudes or beliefs about approaching families to discuss OTD:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I'm uncertain what the right time is to approach families	◯	◯	◯	◯	◯
Families with certain cultural/religious backgrounds are not supportive of OTD	◯	◯	◯	◯	◯
Families with certain socioeconomic status are supportive of OTD	◯	◯	◯	◯	◯
Families are not supportive of OTD of young patients	◯	◯	◯	◯	◯
I can predict whether families will be supportive of OTD	◯	◯	◯	◯	◯

(Optional) Please specify which type of families (if any) you think are likely to not support OTD

29. Donor families' understanding and beliefs about processes related to OTD:

In general, donor families:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
find it uncomfortable to discuss processes related to OTD	◯	◯	◯	◯	◯
find it useful to talk about end of life decisions	◯	◯	◯	◯	◯
don't understand brain death	◯	◯	◯	◯	◯
are usually too upset to make a decision about OTD	◯	◯	◯	◯	◯
think that the processes related to OTD are too complicated	◯	◯	◯	◯	◯
find it useful to talk about the eligibility for OTD	◯	◯	◯	◯	◯
are usually too upset to discuss eligibility related to OTD	◯	◯	◯	◯	◯
don't understand legislation related to OTD	◯	◯	◯	◯	◯
care about legislation related to OTD	◯	◯	◯	◯	◯
have easy access to legislation related to OTD	◯	◯	◯	◯	◯

Assessing Barriers to Organ Donation in Emergency

10. Personal attitudes and beliefs about OTD

Please remember that this survey is anonymous.

30. What is your general attitude to donation of organs and tissues for transplants?

◯ Support ◯ Oppose ◯ Don't know

31. Your willingness to donate

	Yes	No	Unsure
Would you donate some of your organs after death?	◯	◯	◯
Would you donate some of your tissues after death?	◯	◯	◯
Have you registered your choice with the organ donor register (through Medicare, not on your driver's license)?	◯	◯	◯
Have you informed your next of kin about your wishes concerning OTD after your death?	◯	◯	◯
Would you donate organs or tissues from an adult next of kin after his/her death?	◯	◯	◯
If you have children, or were to have children, would you donate his/her organs or tissues after death?	◯	◯	◯

32. Your personal attitudes or beliefs about OTD:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I want my body to be intact for the life after death	◯	◯	◯	◯	◯
I don't want to be a donor because it is against my religious beliefs	◯	◯	◯	◯	◯
I don't want to be a donor because I don't trust the diagnosis of brain death	◯	◯	◯	◯	◯
I trust that organs and tissues will be allocated fairly	◯	◯	◯	◯	◯
I would want to receive an organ from someone who died if I needed one	◯	◯	◯	◯	◯

11. OTD after cardiac death and Educational needs on OTD related issues

So far we have asked questions about OTD in general or OTD after brain death as this is the most common in Australia. DonateLife has just published a national policy on donation after cardiac death to promote this across Australia.

33. Your knowledge and attitudes regarding OTD after cardiac death:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I am familiar with the processes involved with OTD after cardiac death	◯	◯	◯	◯	◯
I support OTD after cardiac death	◯	◯	◯	◯	◯
I am aware of the national policy on OTD after cardiac death	◯	◯	◯	◯	◯

(OPTIONAL) My opinion on OTD after cardiac death is

34. Would you like to receive education regarding OTD in any of the following areas? (please note that this is an anonymous survey and therefore education will not be tailored to individual learning needs)

Tick any that apply

- ☐ The use of the Clinical Trigger
- ☐ Family issues in decision making
- ☐ Family grief counselling
- ☐ Obtaining consent for OTD
- ☐ Communication skills
- ☐ Clinical management of a donor
- ☐ Coordinating the OTD process in the hospital
- ☐ Brain death
- ☐ Religious and cultural beliefs on OTD
- ☐ OTD after cardiac death
- ☐ Other (please specify)

Appendix B: figures and tables

Table 26 Number (percentage) of medical and nursing staff according to duration of living in Australia

How long have you been living in Australia:		Medical staff	Nursing staff	Total
Born in Australia	N	252	168	420
	%	42.1%	79.2%	51.8%
less than 5 years	N	107	1	108
	%	17.9%	.5%	13.3%
between 5 and 10 years	N	83	4	87
	%	13.9%	1.9%	10.7%
between 10 and 15 years	N	47	3	50
	%	7.8%	1.4%	6.2%
between 15 and 20 years	N	16	2	18
	%	2.7%	.9%	2.2%
between 20 and 25 years	N	14	5	19
	%	2.3%	2.4%	2.3%
more than 25 years	N	80	29	109
	%	13.4%	13.7%	13.4%
Total	N	599	212	811
	%	100.0%	100.0%	100.0%

Table 27 Number (percentage) of medical and nursing staff according to religion

Religion		Medical staff	Nursing staff	Total
Not religious	N	279	74	353
	%	46.6%	34.9%	43.5%
Christianity and Catholicism	N	210	121	331
	%	35.1%	57.1%	40.8%
Atheist	N	31	4	35
	%	5.2%	1.9%	4.3%
Hinduism	N	21	0	21
	%	3.5%	.0%	2.6%
Islam	N	18	1	19
	%	3.0%	.5%	2.3%
Prefer not to say	N	10	7	17
	%	1.7%	3.3%	2.1%
Other (see below)	N	12	3	15
	%	2.0%	1.4%	1.8%
Buddhism	N	11	1	12
	%	1.8%	.5%	1.5%
Judaism	N	7	1	8
	%	1.2%	.5%	1.0%
Total	N	599	212	811
	%	100.0%	100.0%	100.0%

Other consists of (N=2 or less): Confucianism, Agnostic, Baha'i Faith, Secular humanist, Henotheist, Jainism, Jedi, Kashmir Shaivism, Latter Day Saint (Mormon), New age, metaphysical, non-denominational, and Vaisnavism

Table 28 Number (percentage) of medical and nursing staff according to region of employment

Region in which you perform most of your Emergency Care:		Medical staff	Nursing staff	Total
VIC	N	178	97	275
	%	29.7%	45.8%	33.9%
NSW	N	154	37	191
	%	25.7%	17.5%	23.6%
QLD	N	104	26	130
	%	17.4%	12.3%	16.0%
WA	N	69	16	85
	%	11.5%	7.5%	10.5%
SA	N	40	16	56
	%	6.7%	7.5%	6.9%
TAS	N	25	8	33
	%	4.2%	3.8%	4.1%
NT	N	16	5	21
	%	2.7%	2.4%	2.6%
ACT	N	13	7	20
	%	2.2%	3.3%	2.5%
Total	N	599	212	811
	%	100.0%	100.0%	100.0%

Table 29 Number (percentage) of medical and nursing staff according to type of hospital of employment

Type of hospital in which you perform most of your Emergency Care:		Medical staff	Nursing staff	Total
Major Referral	N	344	104	448
	%	57.4%	49.1%	55.2%
Major Regional/Rural Base	N	127	54	181
	%	21.2%	25.5%	22.3%
Urban District	N	118	52	170
	%	19.7%	24.5%	21.0%
Private Hospital	N	10	2	12
	%	1.7%	.9%	1.5%
Total	N	599	212	811
	%	100.0%	100.0%	100.0%

Table 30 Number (percentage) of medical and nursing staff according to average working hours per week

Average hours per week you work clinically in an ED:		Medical staff	Nursing staff	Total
less than 10	N	35	28	63
	%	5.8%	13.2%	7.8%
10-20	N	93	29	122
	%	15.5%	13.7%	15.0%
21-30	N	129	40	169
	%	21.5%	18.9%	20.8%
31 or more	N	342	115	457
	%	57.1%	54.2%	56.4%
Total	N	599	212	811
	%	100.0%	100.0%	100.0%

Table 31 Number (percentage) of medical and nursing staff according to years of experience in the ED

How many years have you worked in EDs		Medical staff	Nursing staff	Total
0-5	N	177	49	226
	%	29.5%	23.1%	27.9%
6-10	N	158	66	224
	%	26.4%	31.1%	27.6%
11-15	N	121	38	159
	%	20.2%	17.9%	19.6%
16-20	N	68	23	91
	%	11.4%	10.8%	11.2%
21-25	N	47	24	71
	%	7.8%	11.3%	8.8%
26-30	N	23	8	31
	%	3.8%	3.8%	3.8%
31 or more	N	5	4	9
	%	.8%	1.9%	1.1%
Total	N	599	212	811
	%	100.0%	100.0%	100.0%

Table 32 OTD training according to demographics

Have you received training or education in OTD (organ and tissue donation)?		No		Yes	
Main cultural background	Australian and New Zealand	118	23.6%	382	76.4%
	South American and Caribbean Islander and Pacific Islander	5	31.3%	11	68.8%
	Western and Northern European and Northern American	44	30.6%	100	69.4%
	Southern and Eastern Europe	5	22.7%	17	77.3%
	Arab, Jewish and other North African and Middle Eastern	8	47.1%	9	52.9%
	Southern Asian	17	51.5%	16	48.5%
	Chinese, Central and East Asian	15	40.5%	22	59.5%
	Southern and East African	4	25.0%	12	75.0%
How long have you been living in Australia	1-10 years	68	36.0%	121	64.0%
	10-20 years	28	43.1%	37	56.9%
	Longer than 20 years or born in Australia	120	22.6%	411	77.4%
Your religion:	Other and prefer not to say	9	29.0%	22	71.0%
	Not religious or atheist	101	26.6%	278	73.4%
	Christianity and Catholicism	75	23.4%	245	76.6%
	Buddhism and Hinduism	18	60.0%	12	40.0%
	Islam	10	58.8%	7	41.2%
	Judaism	3	37.5%	5	62.5%
How many years have you worked in EDs	0-5	74	33.9%	144	66.1%
	6-10	62	28.4%	156	71.6%
	11-15	39	25.0%	117	75.0%
	16-20	15	16.5%	76	83.5%
	21-25	17	25.8%	49	74.2%
	26 or more	9	25.0%	27	75.0%

Table 33 Percentage of medical and nursing staff according to experience with organ and tissue donation

Experience with organ and tissue donation		none	1-3	4-6	>6
Identifying a potential donor	medical	43.2%	49.6%	4.8%	2.4%
	nursing	70.9%	23.8%	4.9%	.5%
Activating the national Clinical Trigger (GIVE)	medical	76.3%	21.4%	1.4%	.9%
	nursing	90.3%	8.3%	1.5%	.0%
Referring a potential donor to the competent authorities	medical	64.9%	32.0%	2.4%	.7%
	nursing	87.9%	10.2%	1.9%	.0%
Caring for a potential donor	medical	46.1%	45.3%	5.4%	3.3%
	nursing	64.1%	30.1%	3.9%	1.9%
Communicating information on severe brain damage to the next of kin	medical	45.1%	36.1%	9.7%	9.2%
	nursing	85.4%	10.7%	1.9%	1.9%
Explaining brain death to the next of kin	medical	66.7%	24.4%	5.5%	3.5%
	nursing	89.3%	6.8%	2.4%	1.5%
Obtaining consent for organ donation	medical	91.2%	8.3%	.2%	.3%
	nursing	99.0%	1.0%	.0%	.0%
Obtaining consent for tissue donation	medical	91.0%	8.3%	.3%	.3%
	nursing	97.6%	2.4%	.0%	.0%
Caring for an organ or tissue recipient	medical	72.7%	11.6%	7.1%	8.6%
	nursing	85.0%	10.2%	1.0%	3.9%
I have experience through my personal life (frequency for lifetime)	medical	88.8%	10.0%	.7%	.5%
	nursing	80.6%	18.0%	.5%	1.0%

Table 34 OTD professional experience in the last calendar year according to demographics

Have you had experience with OTD related tasks in the last calendar year		No		Yes	
Gender:	male	90	24.9%	271	75.1%
	female	135	31.8%	289	68.2%
Region in which you perform most of your Emergency Care:	VIC	91	34.0%	177	66.0%
	NSW	39	21.3%	144	78.7%
	QLD	34	26.2%	96	73.8%
	SA	22	40.7%	32	59.3%
	WA	22	27.8%	57	72.2%
	TAS	6	18.2%	27	81.8%
	ACT	4	22.2%	14	77.8%
	NT	7	35.0%	13	65.0%
Type of hospital in which you perform most of your Emergency Care:	Major Referral	96	22.3%	335	77.7%
	Major Regional/Rural Base	58	32.8%	119	67.2%
	Urban District	67	40.4%	99	59.6%
	Private Hospital	4	36.4%	7	63.6%
Staff type	Medical staff	125	21.6%	454	78.4%
	Nursing staff	100	48.5%	106	51.5%
DonateLife network	DonateLife network hospital	132	24.3%	411	75.7%
	Other hospital	44	45.8%	52	54.2%
Have you received training or education in OTD?	no	92	42.6%	124	57.4%
	yes	133	23.4%	436	76.6%

Table 35 Familiarity with the trigger according to demographics

I am familiar with the Clinical Trigger		(strongly) disagree or neutral		(strongly) agree	
Region in which you perform most of your Emergency Care:	VIC	65	25.2%	193	74.8%
	NSW	79	45.1%	96	54.9%
	QLD	53	42.4%	72	57.6%
	SA	17	32.7%	35	67.3%
	WA	39	51.3%	37	48.7%
	TAS	13	40.6%	19	59.4%
	ACT	6	33.3%	12	66.7%
	NT	9	47.4%	10	52.6%
Type of hospital in which you perform most of your Emergency Care:	Major Referral	140	33.7%	276	66.3%
	Major Regional/Rural Base	73	43.2%	96	56.8%
	Urban District	67	41.9%	93	58.1%
	Private Hospital	1	10.0%	9	90.0%
DonateLife network hospital	DonateLife Network hospital	167	31.7%	359	68.3%
	Other hospital	51	56.0%	40	44.0%
Have you received training or education in OTD?	No	142	70.6%	59	29.4%
	yes	139	25.1%	415	74.9%
Have you had experience with OTD related tasks in the last calendar year	No	102	49.3%	105	50.7%
	Yes	179	32.7%	369	67.3%

Table 36 I perceive no barriers to the identification of potential donors according to demographics

I perceive no barriers to the identification of potential donors		(strongly) disagree or neutral		(strongly) agree	
Age	21-30	101	83.5%	20	16.5%
	31-40	254	76.5%	78	23.5%
	41-50	156	71.9%	61	28.1%
	51 and over	58	68.2%	27	31.8%
How long have you been living in Australia	1-10 years	151	83.0%	31	17.0%
	10-20 years	47	73.4%	17	26.6%
	Longer than 20 years or born in Australia	371	72.9%	138	27.1%
religion	Other and prefer not to say	32	86.5%	5	13.5%
	Not religious or atheist	276	76.0%	87	24.0%
	Christianity and Catholicism	225	72.6%	85	27.4%
	Buddhism and Hinduism	20	69.0%	9	31.0%
	Islam	16	100.0%	0	.0%
Region in which you perform most of your Emergency Care:	VIC	184	71.3%	74	28.7%
	NSW	125	71.4%	50	28.6%
	QLD	105	84.0%	20	16.0%
	SA	45	86.5%	7	13.5%
	WA	55	72.4%	21	27.6%
	TAS	27	84.4%	5	15.6%
	ACT	11	61.1%	7	38.9%
	NT	17	89.5%	2	10.5%
How many years have you worked in EDs	0-5	170	82.5%	36	17.5%
	6-10	157	74.8%	53	25.2%
	11-15	116	75.8%	37	24.2%
	16-20	62	70.5%	26	29.5%
	21-25	45	69.2%	20	30.8%
	26 or more	19	57.6%	14	42.4%
Have you received training or education in OTD?	no	164	81.6%	37	18.4%
	yes	405	73.1%	149	26.9%

Table 37 Support of the trigger according to demographics

Do you support the use of the National Clinical Trigger (GIVE) in the ED?		Yes		No or unsure	
Religion:	Other and prefer not to say	17	58.6%	12	41.4%
	Not religious or atheist	289	79.6%	74	20.4%
	Christianity and Catholicism	244	78.7%	66	21.3%
	Buddhism and Hinduism	17	58.6%	12	41.4%
	Islam	12	75.0%	4	25.0%
	Judaism	8	100.0%	0	.0%
Region in which you perform most of your Emergency Care:	VIC	235	91.1%	23	8.9%
	NSW	124	70.9%	51	29.1%
	QLD	89	71.2%	36	28.8%
	SA	35	67.3%	17	32.7%
	WA	58	76.3%	18	23.7%
	TAS	20	62.5%	12	37.5%
	ACT	14	77.8%	4	22.2%
	NT	12	63.2%	7	36.8%
Average hours per week you work clinically in an ED:	less than 10	46	80.7%	11	19.3%
	10-20	96	85.7%	16	14.3%
	21-30	129	80.1%	32	19.9%
	31 or more	316	74.4%	109	25.6%
Have you received training or education in OTD?	no	132	65.7%	69	34.3%
	yes	455	82.1%	99	17.9%

Table 38 Facilitating OTD is not my role according to demographics

Facilitating OTD is not my role		(strongly) disagree		(strongly) agree or neutral	
What is your gender:	male	205	66.6%	103	33.4%
	female	220	58.4%	157	41.6%
Region in which you perform most of your Emergency Care:	VIC	175	73.2%	64	26.8%
	NSW	100	62.9%	59	37.1%
	QLD	56	51.4%	53	48.6%
	SA	21	47.7%	23	52.3%
	WA	36	51.4%	34	48.6%
	TAS	14	48.3%	15	51.7%
	ACT	15	88.2%	2	11.8%
	NT	8	44.4%	10	55.6%
Have you had experience with OTD related tasks in the last calendar year	No	95	54.3%	80	45.7%
	Yes	330	64.7%	180	35.3%

Table 39 Brain death knowledge according to demographics

5 items brain death test		Pass		Fail	
Age	21-30	63	57.3%	47	42.7%
	31-40	168	56.0%	132	44.0%
	41-50	130	67.4%	63	32.6%
	51-60	46	63.9%	26	36.1%
	61 and over	3	75.0%	1	25.0%
Average hours per week you work clinically in an ED:	less than 10	37	74.0%	13	26.0%
	10-20	70	67.3%	34	32.7%
	21-30	88	59.1%	61	40.9%
	31 or more	215	57.2%	161	42.8%
Staff type	Nursing	108	63.2%	63	36.8%
	Medical trainee	121	52.8%	108	47.2%
	Medical specialist	181	64.9%	98	35.1%
How many years have you worked in EDs	0-5	93	51.7%	87	48.3%
	6-10	110	58.8%	77	41.2%
	11-15	93	63.7%	53	36.3%
	16-20	53	70.7%	22	29.3%
	21-25	42	66.7%	21	33.3%
	26 or more	19	67.9%	9	32.1%
Have you received training or education in OTD?	no	88	49.7%	89	50.3%
	yes	322	64.1%	180	35.9%

Table 40 Acceptance of brain death according to demographics

Brain death is a valid determination of death		Agree		Disagree or unsure	
How long have you been living in Australia	1-10 years	122	80.3%	30	19.7%
	10-20 years	47	82.5%	10	17.5%
	Longer than 20 years or born in Australia	409	87.6%	58	12.4%
Average hours per week you work clinically in an ED:	less than 10	44	88.0%	6	12.0%
	10-20	95	91.3%	9	8.7%
	21-30	131	89.7%	15	10.3%
	31 or more	308	81.9%	68	18.1%
Staff type	Nursing	140	82.4%	30	17.6%
	Medical trainee	184	80.3%	45	19.7%
	Medical specialist	254	91.7%	23	8.3%
How many years have you worked in EDs	0-5	138	76.7%	42	23.3%
	6-10	158	84.5%	29	15.5%
	11-15	134	93.1%	10	6.9%
	16-20	65	87.8%	9	12.2%
	21-25	58	92.1%	5	7.9%
	26 or more	25	89.3%	3	10.7%
Have you received training or education in OTD?	no	141	80.1%	35	19.9%
	yes	437	87.4%	63	12.6%

Table 41 General attitude on OTD according to demographics

What is your general attitude on OTD		Support		Oppose or don't know	
Religiosity	not religious	270	98.2%	5	1.8%
	religious	333	95.1%	17	4.9%

Table 42 Willingness to donate according to demographics

Are you willing to donate your organs and tissues after death		Yes		No	
Age	21-30	95	88.8%	12	11.2%
	31-40	266	92.7%	21	7.3%
	41-50	161	87.0%	24	13.0%
	51-60	54	78.3%	15	21.7%
	61 and over	2	66.7%	1	33.3%
Religion:	Other and prefer not to say	16	66.7%	8	33.3%
	Not religious or atheist	288	92.6%	23	7.4%
	Christianity and Catholicism	239	88.5%	31	11.5%
	Buddhism and Hinduism	19	79.2%	5	20.8%
	Islam	8	57.1%	6	42.9%
	Judaism	8	100.0%	0	.0%

Table 43 Communication about own wish according to demographics

Have you registered and communicated your wish		yes both		no or unsure	
Gender	male	111	38.5%	177	61.5%
	female	213	58.7%	150	41.3%
Age	21-30	64	59.8%	43	40.2%
	31-40	146	50.9%	141	49.1%
	41-50	88	47.6%	97	52.4%
	51-60	26	37.7%	43	62.3%
	61 and over	0	.0%	3	100.0%

Main cultural background	Australian and New Zealand	237	55.8%	188	44.2%
	South American and Caribbean Islander and Pacific Islander	6	54.5%	5	45.5%
	British and Irish	44	51.8%	41	48.2%
	Western and Northern European and Northern American	7	26.9%	19	73.1%
	Southern and Eastern Europe	6	28.6%	15	71.4%
	Arab, Jewish and other North African and Middle Eastern	1	6.7%	14	93.3%
	South-East Asian	2	22.2%	7	77.8%
	Southern Asian	7	28.0%	18	72.0%
	Chinese, Central and North East Asian	9	45.0%	11	55.0%
	Southern and East African	5	35.7%	9	64.3%
How long have you been living in Australia	1-10 years	52	35.4%	95	64.6%
	10-20 years	27	48.2%	29	51.8%
	Longer than 20 years or born in Australia	245	54.7%	203	45.3%
Religion	Other and prefer not to say	7	29.2%	17	70.8%
	Not religious or atheist	167	53.7%	144	46.3%
	Christianity and Catholicism	141	52.2%	129	47.8%
	Buddhism and Hinduism	6	25.0%	18	75.0%
	Islam	0	.0%	14	100.0%
	Judaism	3	37.5%	5	62.5%
Type of hospital in which you perform most of your Emergency Care:	Major Referral	200	54.2%	169	45.8%
	Major Regional/Rural Base	69	48.3%	74	51.7%
	Urban District	52	38.8%	82	61.2%
	Private Hospital	3	60.0%	2	40.0%
Staff type	Medical staff	227	46.4%	262	53.6%
	Nursing staff	97	59.9%	65	40.1%
How many years have you worked in EDs	0-5	92	52.6%	83	47.4%
	6-10	91	51.7%	85	48.3%
	11-15	76	54.3%	64	45.7%
	16-20	29	39.7%	44	60.3%
	21-25	26	42.6%	35	57.4%
	26 or more	10	38.5%	16	61.5%
Have you received training or education in OTD?	no	74	42.8%	99	57.2%
	yes	250	52.3%	228	47.7%

Table 44 Willingness to give family consent according to demographics

Would you consent for family member		Yes		No or unsure	
Main cultural background	Australian and New Zealand	339	79.8%	86	20.2%
	South American and Caribbean Islander and Pacific Islander	10	90.9%	1	9.1%
	British and Irish	72	84.7%	13	15.3%
	Western and Northern European and Northern American	18	69.2%	8	30.8%
	Southern and Eastern Europe	15	71.4%	6	28.6%
	Arab, Jewish and other North African and Middle Eastern	8	53.3%	7	46.7%
	South-East Asian	7	77.8%	2	22.2%
	Southern Asian	12	48.0%	13	52.0%
	Chinese, Central and North East Asian	12	60.0%	8	40.0%
	Southern and East African	10	71.4%	4	28.6%
Your religion:	Other and prefer not to say	15	62.5%	9	37.5%
	Not religious or atheist	258	83.0%	53	17.0%
	Christianity and Catholicism	205	75.9%	65	24.1%
	Buddhism and Hinduism	14	58.3%	10	41.7%
	Islam	5	35.7%	9	64.3%
	Judaism	6	75.0%	2	25.0%

Table 45 Support of OTD after cardiac death according to demographics

I support OTD after cardiac death		(strongly) disagree or neutral		(strongly) agree	
Main cultural background	Australian and New Zealand	119	28.1%	304	71.9%
	South Pacific Islander American and Caribbean Islander and	2	20.0%	8	80.0%
	Western and Northern European and Northern American	25	22.5%	86	77.5%
	Southern and Eastern Europe	7	33.3%	14	66.7%
	Arab, Jewish and other North African and Middle Eastern	12	80.0%	3	20.0%
	Southern Asian	10	40.0%	15	60.0%
	Chinese, Central and East Asian	9	31.0%	20	69.0%
	Southern and East African	4	28.6%	10	71.4%
Your religion:	Other and prefer not to say	8	33.3%	16	66.7%
	Not religious or atheist	74	23.9%	236	76.1%
	Christianity and Catholicism	82	30.6%	186	69.4%
	Buddhism and Hinduism	10	41.7%	14	58.3%
	Islam	12	85.7%	2	14.3%
	Judaism	2	25.0%	6	75.0%
Have you received training or education in OTD?	no	62	35.8%	111	64.2%
	yes	126	26.5%	349	73.5%
Have you had experience with OTD related tasks in the last calendar year	No	62	37.1%	105	62.9%
	Yes	126	26.2%	370	73.8%

References

1. Goh A. An analysis of liver transplant survival rates from the UNOS registry. Clin Transpl. 2008:19-34.
2. Gruessner AC, Sutherland DE. Pancreas transplant outcomes for United States (US) and non-US cases as reported to the United Network for Organ Sharing (UNOS) and the International Pancreas Transplant Registry (IPTR) as of June 2004. Clin Transplant. 2005 Aug;19(4):433-55.
3. Meier-Kriesche HU, Ojo AO, Port FK, Arndorfer JA, Cibrik DM, Kaplan B. Survival improvement among patients with end-stage renal disease: trends over time for transplant recipients and wait-listed patients. J Am Soc Nephrol. 2001 Jun;12(6):1293-6.
4. DonateLife. DonateLife Australia website. 2010; Available from: www.donatelife.gov.au.
5. Excell L, Hee K, Russ G, editors. ANZOD Registry Report 2011. Australia and New Zealand Organ Donation Registry, Adelaide, South Australia. 2011
6. Australian Organ and Tissue Authority. National Community Awareness Survey, Woolcott Research, for the Australian Organ and Tissue Authority. 2010.
7. Australian Organ Donor Register Statistics 2011. Available at www.medicareaustralia.gov.au/provider/patients/aodr/stats.jsp
8. McCaughan G. Organ donation in Australia. Intern Med J. 2010 Aug;40(8):603-4; author reply 4.
9. Opdam HI, Silvester W. Identifying the potential organ donor: an audit of hospital deaths. Intensive Care Med. 2004 Jul;30(7):1390-7.
10. Opdam HI, Silvester W. Potential for organ donation in Victoria: an audit of hospital deaths. Med J Aust. 2006 Sep 4;185(5):250-4.
11. Louise Greene Consulting for The National Health and Medical Research Council National Institute of Clinical Studies. Review of the National Organ Donation Collaborative, interim report. May 2009.
12. Lewis LM, Martin L, Hoffman T, Ruoff BE. Tissue and organ procurement in the emergency department setting. Am J Emerg Med. 1993 Jul;11(4):347-9.
13. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. JAMA. 2001 Jul 4;286(1):71-7.
14. Akgün HS, Bilgin N, Tokalak I, Kut A, Haberal M. Organ donation: a cross-sectional survey of the knowledge and personal views of Turkish health care professionals. Transplantation Proceedings. 2003;35(4):1273-5.
15. Bilgin N, Akgun HS. A focus on health care professionals in organ donation: a cross-sectional survey. Transplantation Proceedings. 2002;34(6):2445-7.
16. Roels L, Spaight C, Smits J, Cohen B. Critical Care staffs' attitudes, confidence levels and educational needs correlate with countries' donation rates: data from the Donor Action® database. Transplant International. 2010;23(8):842-50.
17. Cohen J, Ami SB, Ashkenazi T, Singer P. Attitude of health care professionals to brain death: influence on the organ donation process. Clin Transplant. 2008 Mar-Apr;22(2):211-5.
18. Rios A, Conesa C, Ramirez P, Galindo PJ, Fernandez OM, Rodriguez MM, et al. Attitude survey of hospital workers in the surgical services toward living kidney donation. Transplant Proc. 2005 Nov;37(9):3621-5.

19. Schaeffner ES, Windisch W, Freidel K, Breitenfeldt K, Winkelmayer WC. Knowledge and attitude regarding organ donation among medical students and physicians. Transplantation. 2004 Jun 15;77(11):1714-8.
20. Aubrey P, Arber S, Tyler M. The organ donor crisis: the missed organ donor potential from the accident and emergency departments. Transplant Proc. 2008 May;40(4):1008-11.
21. Michael GE, O'Connor RE. The importance of emergency medicine in organ donation: successful donation is more likely when potential donors are referred from the emergency department. Acad Emerg Med. 2009 Sep;16(9):850-8.
22. Tawil I, Marinaro J, Brown LH. Development and validation of a tool for assessing understanding of brain death. Prog Transplant. 2009 Sep;19(3):272-6.
23. DonorAction. The Hospital Attitude Survey Copyright of Eurotransplant International Foundation (NL), Organizacion Nacional de Trasplantes (Spain), and the Partnership of Organ Donation (USA). 1996.
24. Lynn MR. Determination and quantification of content validity. Nurs Res. 1986 Nov-Dec;35(6):382-5.

Chapter 10

Conclusion

Conclusion

This is the first national comprehensive study of ED clinicians' involvement, knowledge, attitudes and learning needs regarding organ and tissue donation. It has revealed ED clinicians' regular involvement in the care and identification of potential donors, as well as barriers and enablers that can further guide educational efforts and the use of the Clinical Trigger in ED to maximize the identification and referral of potential donors. The main finding is that education regarding OTD and its general benefits to society, is associated with support for OTD in general, and knowledge, involvement and perceived comfort and competence regarding OTD-related tasks. OTD education is not a mandatory component of ED medical or nursing education, and it is currently dependent on the willingness of the ED clinicians to invest time in educating themselves, or on a clinical champion in the department to provide departmental education sessions, as only few EDs have dedicated DonateLife employed staff. Although most indicated a desire for further education, ED clinicians with a non-Australian background or with certain religious backgrounds seemed to perceive barriers to receiving education. A lack of education, or knowledge, about brain death, the use of the Clinical Trigger, and DCD protocols and procedures were other specific barriers that were identified in this thesis. The college of emergency physicians in Australia states that ED physicians should be able to determine brain death in the absence of intensive care physicians. Our results show that many ED physicians, especially junior doctors, are not equipped to do so and will require additional training to understand brain death criteria and diagnosis. The recent implementation of DCD pathways will continue further and as staff becomes more familiar, the support and involvement is likely to improve. Many clinicians were familiar with the Clinical Trigger after it was introduced one and a half years before the survey. The simplicity of the Clinical Trigger may have benefits, but one of the disadvantages is that clinicians seem to make their own judgements regarding in- and exclusion criteria for OTD thereby limiting the referral of potential donors. Further education, or the inclusion of some simple criteria may assist the further uptake and appropriate use of the Clinical Trigger. Furthermore, a lack of time to perform certain tasks and access block to ICU can create problems when potential donors who need to be transferred to ICU are waiting in ED and take up valuable resources while critically ill patients have to wait to be seen. A recently implemented whole-of-hospital change in Australia that stimulates patient flow aims to improve problems associated with this access block but workload in ED will remain high and prioritizing patients is not an easy task. Overall, education is crucial and the inclusion of OTD related education in the curriculum of ED clinicians may have a wide range of benefits for the involvement and support of ED clinicians.

There has not been any formal involvement of ED clinicians in OTD-related tasks in the Netherlands and data is lacking to assess the efficacy of investing efforts and resources in this area. Lastly, there are no international standards for data collection and reporting of potential and actual organ donors and this hinders comparison of best practice and areas for improvement between countries. Nevertheless, we have revealed some interesting differences in public support and willingness to register on the organ donor register which deserve further attention.

Study limitations

Although the response rate for the survey was low overall, but considerably higher than in previous surveys of this same cohort of Australian ED clinicians, it yielded a large number of respondents. Still, this response rate may affect the margin of error, thereby limiting the precision in some of the estimates. The relatively low response rate also introduces potential responder bias as those with an interest in OTD might have been the most likely respondents. Therefore, the results might not accurately reflect the views of all emergency clinicians. College membership is mandatory for all ED specialists, therefore we can deduct that 26.7% of all Australian Emergency Fellows, and 15.8% of all Australian Emergency Trainees have taken part in our survey and ED physicians are therefore reasonably well represented. As college membership is not mandatory for ED nurses, and it is currently unknown how many ED nurses work in Australia we cannot estimate the proportion who took part in the survey. The results may therefore be more generalizable to emergency doctors than nurses. Certain items of the Hospital Attitude Survey were incorporated in this thesis. For purposes of statistical analyses, we summed items from the survey to construct a scale (Personal Attitude Scale), as has been done before with other items from the Hospital Attitude Survey but has not previously been validated. Comparing organ donation rates between the Netherlands and Australia was hindered by international standards of data collection and reporting but all efforts were made to ensure the limitations were made clear and conclusions were drawn with these limitations in mind.

Further directions

Many hospitals in Australia have now adopted donation after circulatory death (DCD) pathways to maximize the potential donor pool although there are still improvements to be made here in terms of number of hospitals offering this pathway and staff knowledge and support. Intensive care units (ICUs) nationally have incorporated strategies to maximize potential donor identification including education sessions, trigger tools, and organ donation advocates or specialists among staff. Communication workshops organized by DonateLife are mandatory for intensive care doctors and assist in conversations with donor families. Although not mandatory for ED staff, they are encouraged to participate in these workshops. It seems that strategies to optimize engagement of ICU staff in OTD are currently fully exploited. The data presented in this thesis revealed that ED staff can further benefit from targeted education to overcome the barriers identified and this has already resulted in several education sessions for ED clinicians. The number of organ donors missed in EDs is currently unknown and may be relatively small, however, each organ donor can save and improve the lives of many. To maximize the donor potential ED clinicians need to be supportive and have the knowledge and skills to be involved in the identification and referral of potential donors. National data collected through the DonateLife audit on every hospital death can provide insight into the number of missed and referred donors in ED and guide assessments of whether it is worthwhile putting more resources and educational efforts into the involvement of ED clinicians in identifying and referring potential donors. Furthermore these data could provide insight on whether family consent rates from those referred from ED differ from those referred from ICU, and can guide further communication strategies with donor families. However, these data are still not publically available due to stakeholder concerns around consistency in data collection. It is crucial that these data become available to further guide strategies to optimize donation rates. Also, the definitions

and categories of potential donors that are reported, e.g. confirmed or suspected brain dead donor, imminent brain death, DCD donor, are not internationally consistent and this hinders international comparisons to identify best practice and areas for improvement. International standards for data collection and reporting are warranted.

Despite many initiatives and effort made to increase organ donation rates, still people on the waiting list die every year while waiting for an organ and therefore the search for new strategies has to continue. Although there is public support for organ donation, family consent rates in the Netherlands and Australia are lower than seen in other developed countries. Little research has been undertaken in these countries to assess factors involved in donor families' decision making to provide consent for organ donation, and in some instances, to overturn a registered decision of a family member regarding organ donation wishes. Also it is unclear why the proportion of people who register their wish not to donate is 100 fold higher in the Netherlands compared to Australia and qualitative research is needed to further elucidate this. Communication strategies and public awareness campaigns are largely informed by international literature, however, large differences between countries may exist and local data could further guide optimal strategies to inform families about organ donation. It seems that much can be gained from increasing family consent rates and this will be the next challenge in the battle to increase donation rates.

Chapter 11

English Summary

Efforts are being made all over the world to increase deceased donation rates and thereby enabling more lifesaving organ transplants and improving many more lives through tissue transplantation. As the Australian government developed a national reform to boost deceased organ and tissue donation (OTD) rates, it was clear that potential organ donors were missed in the emergency departments (EDs). Some patients with conditions thought to be non-survivable may not be referred to the intensive care unit (ICU) as the decision is made to provide end-of-life care in ED. The only opportunity for identification of a potential donor in this case lies with ED clinicians. In addition, for patients who are waiting to be transferred to ICU, early identification of the potential for organ and tissue donation may facilitate timely referral to the donation coordinator, which can be crucial in rapidly deteriorating patients, and therefore early identification of potential organ and tissue donors in ED is desirable. The national reform introduced in 2009 in Australia included several measures including Donation after cardiac death (DCD) protocols and pathways, and a national Clinical Trigger to assist clinicians with the identification and referral which was implemented in EDs nationally, in many hospitals accompanied by education sessions provided by local donation specialists. This thesis identified the barriers and enablers perceived by emergency clinicians to facilitating OTD from the ED, their attitudes to OTD, and familiarity with processes regarding OTD including the recently introduced Clinical Trigger.

About half of ED clinicians surveyed had had involvement in identifying or caring for potential donors in the preceding calendar year indicating an important need for assessing the barriers and enablers they perceive to their involvement in OTD related tasks. Results from a large international survey show that ED clinicians' are generally very supportive of OTD, and that their general beliefs regarding OTD are closely related to their personal attitudes. Those who believe that OTD can save lives, that organs and tissues will be allocated fairly, and that OTD can help the next of kin cope with grief; are generally more willing to donate themselves, give family consent, and communicate or register their wishes regarding OTD. Although most indicated a willingness to donate, only half had registered their wishes on the Australian Organ Donor Register, indicating that willingness to donate does not always translate into formally registering. A significant proportion of Australian ED clinicians are unsure about the cost benefit of OTD as well as whether OTD can help the next of kin cope with grief, mainly clinicians of Asian and Mediterranean background, and Buddhist, Hindu, and Muslim religions. Males, older participants, Buddhists, Hindus, participants with an Asian or Mediterranean background, and especially Muslims seem less willing to donate their own or family members' organs and tissues and to communicate and register their wishes (Chapter 2). In line with this, those respondents originally from Asia and the Middle East, identifying with Buddhism, Hinduism or Islam, and relatively new to the ED, more often indicated having received less or no education related to OTD and a lack of engagement with the process of OTD in day-to-day work. Most ED staff supported OTD, although many were not certain that facilitating OTD was their role, or that the ED was the right place to identify donors. Around three quarters of medical and half of nursing clinicians felt comfortable and competent about OTD related tasks but this proportion dropped to a third when asked about obtaining consent for OTD. Our data reinforce the wisdom of the current Australian approach where ED clinicians are not encouraged to formally obtain consent for OTD, but rather introduce the subject in a sensitive matter and refer the potential donor to the ICU or donor coordinator. It is not surprising that most ED clinicians

in our study did not feel competent in obtaining consent as this is not and should not be expected of them. Crucially, we have shown OTD-related education to be a key ingredient shaping attitudes and experience as this was related to having more knowledge and more positive attitudes to OTD as well as more involvement in OTD related tasks. Fortunately, the great majority of ED clinicians appear to recognize that education is a key factor and desire more educational opportunities (Chapter 3).

ED clinicians report several resource barriers to the facilitation of OTD, most notably a lack of time, at least partly related to overcrowding and access block to ICU. The latter becomes an issue when, as found in this study, the majority of ED clinicians are not willing to medically support potential donors in ED while they await transfer to the ICU. ED clinicians reporting more resource barriers, and those working in non-DonateLife network hospitals were less involved in OTD-related tasks in the last calendar year. The presence of specialist OTD staff, a function of being part of a DonateLife network hospital, may result in a decreased perception of resource barriers in the ED and more engagement with OTD-related tasks by ED clinicians. Also, hospitals not included in the DonateLife network might have fewer potential donors, which is why they might not have been included in the first place (Chapter 4).

The first study to examine brain death knowledge and acceptance among ED staff showed that knowledge about brain death is poor among ED staff, particularly emergency trainee specialists. Only just over half of all ED clinicians passed a validated five item brain death knowledge test. Most medical and nursing staff accepted that brain death is a valid determination of death, but a small minority of ED staff who did not accept this reported doubts about the diagnosis of brain death, the main reason was lack of knowledge. Knowledge about brain death, was indeed found to be related to accepting brain death, and to competence and comfort with OTD-related tasks which underscores the importance of education on brain death during medical training. Of concern, of ED clinicians who failed this test, the majority felt comfortable and competent enough to explain brain death to a patient's family. In fact, a fifth had explained brain death in the preceding year, and of those ED clinicians more than a third failed the test and were thus not optimally equipped for this task. The college of emergency physicians in Australia is of the opinion that ED physicians should be able to determine brain death in the absence of intensive care physicians. Our results show that many ED physicians, especially junior doctors, are not equipped to do so and may require additional training. OTD education or training was related to increased acceptance and knowledge regarding brain death, and more than half the respondents indicated a desire for more education on this topic (Chapter 5).

The recent implementation of a national DCD protocol accompanied the introduction of DCD pathways in most large hospitals in Australia. The majority of ED clinicians were unfamiliar and had no experience with DCD processes. Those who had received specific education showed a higher rate of support for the process of DCD although support overall was lower than for OTD in general. Free-text comments regarding DCD were mostly positive, however they revealed that some respondents had ethical concerns regarding the issues surrounding withdrawal of cardiorespiratory support. The majority of ED clinicians

desired additional education on the topic of DCD, implying support for the introduction of DCD pathways in Australian hospitals, although much work remains to be done educating staff about DCD (Chapter 6).

The Clinical Trigger was designed to identify all potential donors less than 80 years of age with an irreversible brain injury, independent of presenting or pre-existing medical conditions. The simplicity of the Trigger aims to encourage referral of all potential donors and to relieve clinicians of the need to exhaustively investigate a patient's medical history and determine whether such conditions preclude donation. Just over a third of ED clinicians were not familiar with the Clinical Trigger, however, after providing a description, more than three quarters reported support for the use of the Trigger. Despite this, significant numbers of clinicians had not had personal experience with the Trigger and did not know who first to contact in the event of identifying a potential donor, even though the Trigger includes a referral pathway individualised to each hospital. Of concern, significant numbers perceived barriers to identification of potential donors in the ED despite the introduction of specialised OTD staff and other supports facilitated by DonateLife. Despite, or maybe because of the simplicity of the Trigger, over half would not have referred patients with six of the eight listed medical conditions in our survey. Some free-text responses indicated potential knowledge deficits, especially those which indicated that respondents had neither heard of nor received education regarding the Trigger, emphasising the need for further education (Chapter 7).

As the number of identified and referred potential donors increases, potential donors are identified earlier, and communication with donor families is further optimized, higher success rate for donation and transplantation may result in Australia. In the Netherlands there have not been any national initiatives to involve the ED in the identification process of potential donors, apart from individual hospitals implementing pilot projects. It is currently not known what the potential donor pool is in EDs and whether it is worthwhile to invest efforts into increasing the involvement of EDs. Collection and evaluation of these data could guide the implementation of further protocols to maximize organ donor identification and referral. It is also not known how comfortable or competent Dutch ED clinicians are about being involved in the identification and referral of potential donors and it is critical to assess the barriers which need to be overcome to improve the involvement of ED staff in the identification and referral of potential organ donors. Australia and the Netherlands have historically had similar donation outcomes; whereas Australia has successfully implemented a reform to increase donation and transplantation rates in 2009, Dutch rates have only slightly increased following the implementation of a similar government plan in 2008. There are significant differences in practices between the Netherlands and Australia in terms of donor recognition and referral from EDs, and uncontrolled DCD, as well as willingness in the community to register or consent for organ donation. For both the Netherlands and Australia there is room for improvement in terms of minimizing missed potential donors, maximizing consent and donation rates, and improved data collection and reporting may assist with this goal. International standards with regards to identifying and reporting (potential) organ donation rates are currently not applied, and are needed to facilitate the comparison of best practices and areas for improvement (Chapter 8).

Many strategies to optimize the identification and referral of potential organ donors have been developed and implemented in clinical settings throughout Australia and this has paid off. However, when provided with the opportunity to consent for organ donation for a family member, many Australian families still say no. Family consent rates have largely been unchanged and this is now thought to be the biggest barrier to further increasing organ donation rates and little research has been done in this area. Further research should assess the reasons for the currently sub-optimal family consent rates to inform strategies to further increase organ donation rates.

Chapter 12

Nederlandse samenvatting

Over de hele wereld worden inspanningen geleverd om het aantal orgaan- en weefseldonaties te verhogen, zodat mensenlevens gered of verbeterd kunnen worden door middel van orgaan- en weefsel transplantaties. Terwijl in opdracht van de Australische regering een nationaal hervormingsprogramma werd ontwikkeld om het aantal orgaan-en weefseldonaties na overlijden te verhogen, werd het duidelijk dat potentiële orgaandonoren werden gemist op de afdeling spoedeisende hulp (SEH) in ziekenhuizen. Niet alle patiënten met een infauste prognose worden overgeplaatst naar de afdeling intensive care (IC), soms wordt de beslissing genomen om palliatieve zorg te verlenen op de SEH. De enige mogelijkheid voor de identificatie van een potentiële donor in dit geval ligt bij het SEH personeel. Zelfs voor patiënten die wel worden overgeplaatst naar de IC kan vroegtijdige identificatie van een mogelijke orgaan-en weefseldonor tijdige doorverwijzing naar de donatie coördinator vergemakkelijken. Dit kan cruciaal zijn in snel verslechterende patiënten, en daarom is het doorverwijzen van potentiële donoren vanuit de SEH in een vroeg stadium wenselijk. Het nationale hervormingsprogramma dat werd geïntroduceerd in 2009 in Australië bevatte verschillende maatregelen, waaronder de herintroductie van een landelijk non-heartbeating protocol, en een nationale Klinische Trigger om clinici op de SEH te helpen met de identificatie en verwijzing van orgaandonoren. De Klinische Trigger werd ingevoerd op nationaal niveau, in veel ziekenhuizen vergezeld door educatieve sessies verzorgd door lokale donatie specialisten.

Dit proefschrift identificeerde de barrières, en factoren die het SEH artsen en verpleegkundigen vergemakkelijken om orgaan- en weefsel donatie in gang te zetten vanuit de SEH, en evalueerde hun houding ten opzichte van orgaan- en weefsel donatie. Tevens werd hun kennis over processen voor orgaan- en weefseldonatie waaronder de onlangs geïntroduceerde Klinische Trigger gemeten. Ongeveer de helft van de ondervraagde SEH clinici gaven aan dat zij in het voorafgaande kalenderjaar betrokken waren geweest bij het identificeren van, of de zorg voor, potentiële donoren. Dit geeft de noodzaak aan om vast te stellen welke factoren hun betrokkenheid bij orgaan- en weefseldonatie gerelateerde taken makkelijker of moeilijker maken.

Resultaten uit een groot nationaal onderzoek laten zien dat SEH clinici over het algemeen een zeer positieve houding hebben tegenover orgaan- en weefseldonatie, en dat hun algemene opvattingen met betrekking tot orgaan- en weefseldonatie nauw verwant zijn aan hun persoonlijke opvattingen. Degenen die geloven dat orgaandonatie levens kan redden, dat organen en weefsels eerlijk zullen worden toegewezen, en dat donatie de nabestaanden kan helpen omgaan met het rouwproces, zijn over het algemeen zelf meer bereid om donor te worden, om toestemming te geven voor orgaandonatie voor een familielid, en om hun wensen ten aanzien van orgaan- en weefseldonatie te communiceren of te registreren. Hoewel de meesten aanduidden bereid te zijn om orgaandonor te worden, was slechts de helft geregistreerd bij het Australische Orgaandonor Register, wat aangeeft dat de bereidheid om te doneren niet altijd vertaald wordt in formele registraties. Een aanzienlijk deel van de Australische SEH clinici zijn onzeker over de balans tussen kosten en baten van orgaan- en weefseldonatie in het algemeen, en of donatie de nabestaanden te helpen omgaan met verdriet. Dit geldt voornamelijk voor personeel van Aziatische en mediterrane achtergrond, en met boeddhistische, hindoeïstische en islamitische religies. Mannen, oudere respondenten, boeddhisten, hindoes, personeel met een Aziatische of mediterrane achtergrond, en vooral

moslims lijken minder bereid zijn om hun eigen familie of organen van leden en weefsels doneren en hun wensen te communiceren en te registreren (hoofdstuk 2). Ook hadden respondenten oorspronkelijk uit Azië en het Midden-Oosten, boeddhisten, hindoes en moslims, en zij die relatief kort bij de SEH werkten, minder vaak onderwijs gerelateerd aan orgaan- en weefseldonatie ontvangen en gaven zij aan minder vaak betrokken te zijn bij het proces van orgaan- en weefseldonatie in hun dagelijkse werk. Het grootste gedeelte van het SEH personeel gaf aan positief tegenover orgaan- en weefseldonatie te staan, hoewel velen niet zeker waren dat het faciliteren van orgaan- en weefseldonatie hun rol is, of dat de SEH de juiste plek is om donoren te identificeren. Ongeveer driekwart van het medische personeel en de helft van het verplegend personeel voelde zich comfortabel en bekwaam in het uitvoeren van orgaan- en weefseldonatie gerelateerde taken, maar dit aandeel daalde naar een derde wanneer gevraagd werd naar het verkrijgen van toestemming van de nabestaanden voor orgaan- en weefseldonatie. Deze resultaten steunen de huidige Australische aanpak waarbij SEH personeel niet wordt aangemoedigd om de nabestaanden om toestemming te vragen voor orgaan- en weefseldonatie, maar liever om het onderwerp voorzichtig in te leiden en door te verwijzen naar de IC of de donorcoördinator. Het is niet verwonderlijk dat de meeste SEH clinici in onze studie zich niet bevoegd voelden om de nabestaanden om toestemming te vragen, aangezien dit ook niet van hen wordt verwacht. We hebben aangetoond dat orgaan- en weefseldonatie-gerelateerd onderwijs een cruciale rol speelt bij het vormgeven van attitudes en betrokkenheid, aangezien het is gerelateerd aan het hebben van meer kennis en meer positieve houding ten opzichte van orgaan- en weefseldonatie evenals meer betrokkenheid bij orgaan- en weefseldonatie-gerelateerde taken. De overgrote meerderheid van de SEH artsen erkende dat onderwijs een belangrijke factor is, zij gaven aan meer educatie mogelijkheden te willen (Hoofdstuk 3).

SEH clinici melden verschillende belemmerende factoren die te maken hebben met een gebrek aan middelen voor het faciliteren van orgaan- en weefseldonatie, in het bijzonder een gebrek aan tijd. Dit houdt gedeeltelijk verband met een teveel aan patiënten in de SEH door een gebrek aan beschikbare bedden op overige afdelingen en in het bijzonder de IC. Dit laatste wordt een probleem wanneer, zoals in dit onderzoek, de meerderheid van het SEH personeel aangeeft niet bereid te zijn om potentiële donoren die wachten op overplaatsing naar de IC op de SEH medisch te ondersteunen. SEH artsen die meer gebrek aan middelen (voornamelijk tijd) rapporteerden, en degenen die werkzaam waren in een ziekenhuizen verbonden aan DonateLife waren minder vaak betrokken bij orgaan- en weefseldonatie-gerelateerde taken in het afgelopen kalenderjaar. De aanwezigheid van gespecialiseerd donatiepersoneel in ziekenhuizen die verbonden zijn bij DonateLife kan resulteren in een verminderde perceptie van gebrek aan middelen in de SEH en meer betrokkenheid bij orgaan- en weefseldonatie-gerelateerde taken door SEH personeel. Ook kan het zijn dat ziekenhuizen die minder potentiële donoren krijgen om die reden niet verbonden zijn aan DonateLife (Hoofdstuk 4).

De eerste studie die kennis en acceptatie met betrekking tot hersendood onder SEH personeel onderzocht, toonde aan dat hun kennis over hersendood gebrekkig is, met name onder specialisten in opleiding. Slechts iets meer dan de helft van alle SEH clinici beantwoorde de vijf vragen van een gevalideerde vragenlijst over hersendood op de juiste manier. De meerderheid van het SEH personeel aanvaardde dat hersendood een geldige en wettige bepaling

van de dood is, maar een kleine minderheid van de SEH-medewerkers accepteerde dit niet en meldde dat zij twijfels hadden over de diagnose van hersendood, met als belangrijkste reden een gebrek aan kennis. Kennis over hersendood bleek inderdaad verband te houden met zowel het accepteren van hersendood, als met gerapporteerde bekwaamheid en comfort met orgaan- en weefseldonatie-gerelateerde taken, wat het belang van onderwijs over hersendood tijdens de medische opleiding verder onderstreept. Verontrustend was dat de meerderheid van artsen en verpleegkundigen die niet door de test kwamen zich comfortabel en bekwaam genoeg voelde om hersendood uit te leggen aan de familie van een patiënt. Sterker nog, een vijfde van het SEH personeel zei dat zij in het voorafgaande jaar hersendood hadden uitgelegd aan familie van patiënten, en van hen kwam meer dan een derde niet door de test en waren dus niet bevoegd voor deze taak. De vereniging van SEH artsen in Australië stelt zich op het standpunt dat SEH artsen in staat zouden moeten zijn om hersendood vast te stellen, als IC artsen niet beschikbaar zijn. Onze resultaten tonen aan dat veel SEH artsen, vooral specialisten in opleiding, hier niet voor uitgerust zijn en dat zij mogelijk extra training nodig hebben. Onderwijs over orgaan- en weefseldonatie was gerelateerd aan grotere acceptatie en kennis over hersendood, en meer dan de helft van de respondenten gaf aan behoefte te hebben aan meer onderwijs over dit onderwerp (Hoofdstuk 5).

De recente invoering van een nationale non-heartbeating donatie protocol heeft de invoering van non-heartbeating donatie trajecten in de meeste grote ziekenhuizen in Australië bevorderd. De meerderheid van de SEH clinici gaf aan niet bekend te zijn, en geen ervaring te hebben, met non-heartbeating donatie processen. Degenen die educatieve sessies over orgaandonatie hadden gevolgd vertoonden een hogere mate van de steun voor het proces van non-heartbeating donatie, hoewel dit in zijn geheel lager was dan voor orgaan- en weefseldonatie in het algemeen. Commentaar betreffende non-heartbeating donatie was overwegend positief, maar sommige respondenten uitten ethische bezwaren omtrent het stopzetten van beademing apparatuur. De meerderheid van de SEH clinici wenste extra onderwijs op het gebied van non-heartbeating donatie, hetgeen impliceert dat er steun is voor de invoering van non-heartbeating donatie trajecten in Australische ziekenhuizen, hoewel er nog veel werk te doen is om personeel op te leiden (Hoofdstuk 6).

De Klinische Trigger is ontworpen om alle potentiële donoren jonger dan 80 jaar met onomkeerbare hersenschade te identificeren, onafhankelijk van bestaande medische aandoeningen. De eenvoud van de Trigger is erop gericht om doorverwijzing van alle potentiële donoren aan te moedigen en personeel te ontzien van de noodzaak om de medische geschiedenis van een patiënt te onderzoeken om te bepalen of er contra indicatie voor donatie bestaan. Iets meer dan een derde van het SEH personeel was niet bekend met de Klinische Trigger, echter, na het verstrekken van een beschrijving, gaf meer dan driekwart aan het gebruik van de Trigger te steunen. Toch had een aanzienlijk aantal geen persoonlijke ervaring met de Trigger en wist in geval van het identificeren van een potentiële donor niet met wie contact op te nemen, ook al bevat de Trigger voor elk ziekenhuis afzonderlijk gegevens van een contactpersoon. Een aanzienlijk aantal gaf aan dat er barrières waren bij de identificatie van potentiële donoren in de SEH, ondanks de invoering van donatie specialisten in ziekenhuizen door DonateLife. Ondanks, of misschien vanwege de eenvoud van de Trigger, gaf meer dan de helft aan dat zij patiënten met zes van de acht genoemde medische

aandoeningen niet door zouden verwijzen voor donatie. Sommige reacties duidden op een tekort aan kennis, en het feit dat niet iedereen bekend was met de Trigger, of er nooit informatie over hadden ontvangen benadrukte de noodzaak voor meer scholing (Hoofdstuk 7). Naarmate het aantal geïdentificeerde en doorverwezen potentiële donoren toeneemt, potentiële donoren eerder worden geïdentificeerd, en de communicatie met donor families verder wordt geoptimaliseerd, stijgt het aantal donaties en transplantaties in Australië. In Nederland zijn er tot nu toe geen nationale initiatieven geweest om de SEH te betrekken bij de identificatie van potentiële donoren, afgezien van het uitvoeren van proefprojecten in enkele ziekenhuizen. Het is momenteel niet bekend wat het donor potentieel is op SEH afdelingen landelijk en of het de moeite waard is om inspanningen te investeren in het vergroten van de betrokkenheid van de SEH. Het verzamelen en evalueren van deze gegevens is cruciaal voor de eventuele ontwikkeling en implementering van verdere protocollen om orgaandonoren te identificeren en door te verwijzen vanaf de SEH. Het is tevens niet bekend hoe comfortabel of bekwaam Nederlandse SEH artsen en verpleegkundigen zich voelen over eventuele betrokkenheid bij de identificatie en doorverwijzing van potentiële donoren. Het is belangrijk om erachter te komen welke barrières moeten worden overwonnen als de betrokkenheid van het SEH personeel bij de identificatie en doorverwijzing van potentiële orgaandonoren verhoogd zal worden.

Australië en Nederland hadden in het verleden vergelijkbare aantallen orgaandonoren; terwijl Australië met succes een hervormingsprogramma heeft geïmplementeerd in 2009 om het aantal donaties en transplantaties te verhogen, zijn de aantallen donaties en transplantaties in Nederland slechts licht gestegen na de invoering van een soortgelijke hervorming in 2008. Er zijn significante verschillen tussen Nederland en Australië als het gaat om herkenning en verwijzing van donoren vanaf de SEH, ongecontroleerde non-heartbeating donatie, evenals de bereidheid onder de bevolking om te registreren of toestemming te geven voor orgaandonatie. Voor zowel Nederland als Australië is er ruimte voor verbetering op het gebied van het minimaliseren van gemiste potentiële donoren, het maximaliseren van orgaan- en weefseldonaties en van toestemming van nabestaanden, en verbeterde gegevensverzameling en rapportering kunnen helpen met dit doel. Internationale normen met betrekking tot het identificeren en rapporteren van (potentiële) orgaandonaties worden momenteel niet toegepast, maar zijn wel nodig om de vergelijking van werkwijzen en verbeterpunten te vergemakkelijken (Hoofdstuk 8).

Er zijn veel strategieën ontwikkeld en doorgevoerd om de identificatie en doorverwijzing van potentiële orgaandonoren te optimaliseren in Australische ziekenhuizen en dit heeft zijn vruchten afgeworpen. Echter, wanneer om toestemming voor orgaandonatie voor een familielid wordt gevraagd, zeggen veel Australische nabestaanden nog steeds nee. Het aantal nabestaanden dat toestemming geeft is in de afgelopen jaren grotendeels ongewijzigd gebleven en momenteel wordt gedacht dat dit de grootste barrière is voor een verdere verbetering van het aantal orgaandonaties, en er wordt op dit gebied weinig onderzoek gedaan. Verder onderzoek is nodig om te onderzoeken wat de redenen zijn voor het lage aantal toestemmingen van nabestaanden om zo strategieën te kunnen ontwikkelen om verdere toename van het aantal orgaan- en weefseldonaties mogelijk te maken.

Chapter 13

Curriculum Vitae and Words of thanks

Curriculum Vitae

Claudia Helena Louise Marck

claudia.marck@svha.org.au || +61 (0) 449 946 932

Biography

On November 5th 1982 Claudia was born in Harderwijk, the Netherlands where she grew up and finished her primary and high school. In 2001 she started her Bachelor's degree in Psychology at the Utrecht University. She went on to do a Master's degree in Clinical Psychology for which she completed a research project on obsessive compulsive behaviour under supervision of Professor van den Hout for whom she kept working as a research assistant afterwards. She also finished a clinical internship at the Military Hospital in Utrecht and wrote a thesis on trauma under supervision of Dr Rademaker and Professor Kleber. She later returned there for a research project when she started her research Master's degree in Neuroscience under the supervision of Dr Geuze. In her second year of this degree she left for Melbourne, Australia to research the effects of cannabis use on memory at the Melbourne Neuropsychiatry Centre under supervision of Dr Seal. After obtaining her Master's degree in Neuroscience she returned to Melbourne where she started working in youth mental health research at Melbourne University and Victoria University. A change to a research assistant job at the Emergency Practice Innovation Centre at St Vincent's Hospital Melbourne was made in October 2010, where she has worked since. She works here with a team of clinicians and researchers on a variety of areas but her main area of interest has been organ donation. She carried out a government funded study to assess barriers to organ donation in emergency departments and these data gave rise to most of the papers in this thesis. At the start of 2012 she started her external PhD at Erasmus University under the supervision of Professor Weimar and Professor IJzermans. While finishing her thesis, she was able to continue her work in this field part-time when she, together with her colleagues, was successful in obtaining funding to qualitatively study experiences and decision making in families of potential organ donors. Other areas of research she is involved in are care for palliative patients and lifestyle interventions in people with multiple sclerosis, while she is also completing a Diploma of Management at Swinburne University. In 2015 she will continue to work at the EPIcentre as a Research Fellow and she is excited about all the opportunities that lie ahead!

Academic qualifications

2014 - present	**Diploma of Management** *Swinburne University, Melbourne, Australia*
2012 – present	**PhD Candidate** *Erasmus Medical Centre, Rotterdam, the Netherlands*
2006-2009	**MSc Neuroscience** *Prestigious Research Master Program Neuroscience and Cognition* *Utrecht University, Life Sciences, The Netherlands*
2004-2006	**MSc Clinical Psychology** *Utrecht University, Social Sciences, The Netherlands*
2001-2004	**BSc Psychology** *Utrecht University, Social Sciences, The Netherlands*

Awards

2014	**Professor Anthony d'Apice Award for best senior investigator oral presentation** *Aikenhead Centre for Medical Discovery Research Week*	**Aikenhead Centre for Medical Discovery** AU$1,000
2013	**Young Investigator Award** *International Society of Organ Donation and Procurement*	**The Transplant Society** US$750
2012	**Travel award** *To fund travel to the TTS conference in Berlin*	**Organ and Tissue Authority** AU$3,000
2008	**Travel award** *To assist with travel to research internship in Melbourne*	**Utrecht University** €250
2008	**Travel award** *To assist with travel to research internship in Melbourne*	**Hersenstichting** €750

Participation at conferences and scientific meetings

Associations of physical activity with health outcomes in a large international sample of people with multiple sclerosis **Aikenhead Centre for Medical Discovery Research Week. Melbourne, Australia 2014**	Senior Investigator Oral Presentation
Conversations about Organ Donation Experiences and Decisions **Victorian DonateLife Professional Development Meeting. Melbourne, Australia 2014**	Invited Oral Presentation
Associations of physical activity with health outcomes in a large international sample of people with MS **Rehabilitation In Multiple Sclerosis (RIMS), Brighton, UK 2014**	Oral and Poster Presentation
Characteristics and preliminary determinants of family consent regarding organ donation from 4 Melbourne hospitals **International Society of Organ Donation and Procurement. Sydney, Australia 2013**	Oral Presentation (unable to attend)
Donation after cardiac death: are Australian emergency clinicians supportive? **Aikenhead Centre for Medical Discovery Research Week. Melbourne, Australia 2013**	Poster Presentation
Is the ED the right place to die? Exploring opportunities to improve care for patients with advanced cancer. **Annual Scientific Meeting of the Australasian College of Emergency Medicine. Broome, Australia 2011**	Oral Presentation (unable to attend)
Personal attitudes and beliefs regarding organ and tissue donation: a cross-sectional survey of Australian emergency department clinicians. *Donation after cardiac death: are Australian emergency clinicians supportive?* **European Society for Organ Transplantation. Rotterdam, the Netherlands 2013**	2 Oral Presentations
Assessing Barriers to Organ and Tissue Donation in Australian Emergency Departments **International Congress of The Transplantation Society. Berlin, Germany 2012**	Oral presentation
Australian emergency clinicians' acceptance and understanding of brain death: a national survey **St Vincent's Health Research Week. Melbourne, Australia 2012**	Moderated poster presentation

Assessing barriers to organ and tissue donation organised from the emergency department: a national cross-sectional survey	Invited oral presentation
Annual DonateLife Forum. Brisbane, Australia 2012	
Assessing barriers to organ and tissue donation organised from the emergency department: a national cross-sectional survey	Oral presentation
Hospital Grand Rounds at St Vincent's Hospital. Melbourne, Australia 2011	
Assessing barriers to organ and tissue donation organised from the emergency department: a national cross-sectional survey	Invited oral presentation
Victorian DonateLife Professional Development meeting. Melbourne, Australia 2011	
Assessing barriers to organ and tissue donation organized from the emergency department: a national cross-sectional survey	Oral presentation
Annual Scientific Meeting of the Australasian College of Emergency Medicine. Sydney, Australia 2011	
Human brain mapping, Melbourne, Australia 2008	Participation

Publications

Published/In press

1. **Marck CH**, Jansen N, Neate SL, Dwyer B, van Haren F, Weimar W, IJzermans J. Comparing organ donation practices and rates between Australia and the Netherlands. *Organs, Tissues and Cells* (in press)
2. Weiland TJ, Jelinek GA, **Marck CH**, Hadgkiss EH, van der Meer DM, Pereira NG, Taylor KL. Clinically significant fatigue: Prevalence and associated factors in an international sample of adults with multiple sclerosis recruited via the internet. *PLoS ONE* (in press)
3. **Marck CH,** Neate SL, Skinner M, Dwyer B, Hickey B, D'Costa R, Weiland TJ, Jelinek GA. Factors relating to consent for organ donation: prospective data on potential organ donors. *Internal Medicine Journal* 2014 Nov 5 (Epub ahead of print)
4. Neate SL, **Marck CH**, Skinner M, Dwyer B, McGain F, Weiland TJ, Hickey BB, Jelinek GA. Understanding Australian families' organ donation decisions. *Anaesthesia and Intensive Care* (in press)
5. Taylor KL, Hadgkiss EJ, Jelinek GA, Weiland TJ, Pereira NG, **Marck CH** and van der Meer DM. Lifestyle factors, demographics and medications associated with depression risk in an international sample of people with multiple sclerosis. *BMC Psychiatry* (in press)
6. Levin A, Hadgkiss EJ, Weiland TJ, **Marck CH**, van der Meer DM, Pereira NG, and Jelinek GA. Can meditation influence quality of life, depression and disease outcome in multiple sclerosis? Findings from a large international web-based study. *Behavioural Neurology* (in press)

7. Weil J, Weiland TJ, Lane H, Jelinek GA, Boughey M, **Marck CH**, Philip J. What's in a name? An exploration of what is understood by 'palliative care' in the emergency department. *Palliative Medicine* (in press)
8. **Marck CH**, Hadgkiss EJ, Weiland TJ, van der Meer DM, Pereira NG and Jelinek GA. Physical activity and associated levels of disability and quality of life in people with multiple sclerosis: a large international survey. *BMC Neurology* 2014; 12;14:143.
9. Hadgkiss EJ, Jelinek GA, Weiland TJ, Pereira NG, **Marck CH**, van der Meer DM. The association of diet with quality of life, disability and relapse rate in an international sample of people with multiple sclerosis. *Nutritional Neuroscience* 2014; Epub ahead of print
10. Jelinek GA, **Marck CH**, Weiland TJ, Philip J, Boughey M, Weil J, Lane H. "Better Pathways of Care": Suggested improvements to the emergency department management of people with advanced cancer. *Journal of Palliative Care* 2014; 30(2):83-9
11. Lane H, Weil J, Jelinek GA, Boughey M, **Marck CH**, Weiland TJ, Haydon A, Philip J. Ideal care and the realities of practice: interdisciplinary relationships in the management of advanced cancer patients in the emergency department. *Supportive Care and Cancer* 2014;22(4):1029-35
12. **Marck CH**, Weil J, Lane H, Weiland TJ, Philip J, Boughey M, Jelinek GA. Care of the dying patient in the emergency department: findings from a national survey of Australian emergency department clinicians. *Intern Med J 2014; 44(4):326-8*
13. Weiland TJ, Hadgkiss EJ, Jelinek GA, Pareira N, **Marck CH**, van der Meer DM. The association of alcohol consumption and smoking with quality of life, disability and disease activity in an international sample of people with multiple sclerosis. *J Neurol Sci 2014*;336(1-2):211-19
14. Neate SL, **Marck CH**, Weiland TJ, Hickey BB, Jelinek GA. Author Reply: Doctor knowledge and attitudes to donation after cardiac death. *Int Med J* 2013;43(12):1351.
15. Weiland TJ, **Marck CH**, Jelinek GA, Neate SL, Hickey BB. Attitudes of Australian emergency department clinicians toward organ and tissue donation: an analysis of cultural and religious influences. *Prog Transplant* 2013;23(3):278-89
16. Jelinek GA, Hadgkiss EJ, , Weiland TJ, Pareira N, **Marck CH,** van der Meer DM. Association of fish consumption and omega 3 supplementation with quality of life, disability and disease activity in an international cohort of people with multiple sclerosis. *Int J Neurosci.* 2013;123(11):792-800
17. Hadgkiss EJ, Jelinek GA, Weiland TJ, Pareira N, **Marck CH**, van der Meer DM. Methodology of an International Study of People with Multiple Sclerosis Recruited through Web 2.0 Platforms: Demographics, Lifestyle and Disease Characteristics. *Neurol Res Int*. 2013;2013:580596
18. Jelinek GA, **Marck CH**, Weiland TJ, Philip J, Boughey M, Weil J, Lane H. Caught in the middle: Tensions around the emergency department care of people with advanced cancer. *Emerg Med Australas* 2013;25(2):154-160
19. **Marck CH**, Neate SL, Weiland TJ, Hickey BB, Jelinek GA. Donation after Cardiac Death: are Australian emergency clinicians supportive? *Int Med J* 2012;43(7):816-819
20. McCann TV, Lubman DI, Cotton SM, Murphy B, Crisp K, Catania L, **Marck C**, Gleeson JF. A Randomized Controlled Trial of Bibliotherapy for Carers of Young People with First-Episode Psychosis. *Schizophr Bull.* 2012;39(6):1307-17.

21. Neate SL, **Marck CH**, Weiland TJ, Cunningham N, Hickey BB, Dwyer BM, Jelinek GA. Australian emergency clinicians' perceptions and use of the GIVE Clinical Trigger for identification of potential organ and tissue donors. *Emerg Med Australas* 2012;24(5):501-09.
22. **Marck CH**, Jelinek GA, Neate SL, Dwyer BM, Hickey BB, Weiland TJ. Resource barriers to the facilitation of organ and tissue donation reported by Australian emergency clinicians. *Aust Health Rev* 2012; 37(1) 60-65
23. **Marck CH**, Weiland TJ, Neate SL, Hickey BB, Jelinek GA. Personal attitudes and beliefs regarding organ and tissue donation: a cross-sectional survey of Australian emergency department clinicians. *Prog Transplant* 2012;22(3):317-22.
24. **Marck CH**, Weiland TJ, Neate SL, Hickey BB, Jelinek GA. Australian emergency doctors' and nurses' acceptance and knowledge regarding brain death: a national survey. *Clin Transplant* 2012;26(3):E254-60.
25. Jelinek GA, **Marck CH**, Weiland TJ, Neate SL, Hickey BB. Organ and tissue donation-related attitudes, education and practices of emergency department clinicians in Australia. *Emerg Med Australas* 2012;24(3):244-50.
26. van den Hout M, Kindt M, Luigjes J, **Marck C**. Compulsive perseveration: empirical criticism on the mood-as-input model. Behav Res Ther. 2007;45(6):1221-30.

Reports

27. **Marck CH**, Weiland TJ, Neate SL, Hickey BB, Jelinek GA. Assessing Barriers to Organ and Tissue Donation in Emergency Departments. Final Report to Commonwealth of Australia, Organ and Tissue Authority. 2011
28. Hadgkiss EJ, Lethborg C, Al-Mousa A, **Marck CH.** Asylum Seeker Health and Wellbeing. Scoping study. Commissioned by St Vincent's Health Australia. September 2012

Submitted

29. Weiland TJ, Lane H, Jelinek GA, **Marck CH**, Weil J, Boughey M, Philip J. Managing the advanced cancer patient in the Australian Emergency Department Environment: Findings from a national survey of emergency department clinicians. *(Submitted)*
30. GA Jelinek, **CH Marck**, J Weil, H Lane, J Philip, M Boughey, TJ Weiland. Skills, expertise and role of Australian emergency clinicians in caring for people with advanced cancer. *(Submitted)*
31. Hadgkiss EJ, Jelinek GA, Taylor KL, **Marck CH**, van der Meer DM, Pereira NG, Weiland TJ. Engagement in a program promoting lifestyle modification is associated with better patient-reported outcomes for people with MS. *(Submitted)*
32. Jelinek GA, Weiland TJ, Hadgkiss EJ, **Marck CH**, Pereira N, van der Meer DM. Medication use in a large international sample of people with multiple sclerosis: associations with quality of life, relapse rate and disability. *(Submitted)*
33. **Marck CH**, Neate SL, Skinner MR, Dwyer BM, Hickey BB, Radford ST, Weiland TJ, Jelinek GA. Potential organ donor families' reflections on communication, processes and donation outcomes. (Submitted)

Words of thanks

During a coffee break at a conference in Brisbane in 2012, while I was preparing to present later in the day, I met emergency physician and donation specialist Dr Martin Dutch who asked me about my research. As soon as he heard my name, he showed me he was carrying around my (lengthy) report on all the findings (chapter 9), which he told me he was using as a handbook to guide his education sessions to his fellow emergency clinicians on organ donation. I have since had many people around Australia contacting me to say the research has guided their education sessions to emergency staff. I was so proud to see that our recommendations were used to educate emergency clinicians, I knew we had to try and publish these results. I am grateful to be able to do work that makes a positive impact and work with people who are passionate about helping others.

2013 was the year I would originally finish my PhD, instead it became a year filled with sadness and grief, when my dad became sick and passed away. But this year was also filled with love and support. I am thankful for the time and freedom I was given by my supervisors in the Netherlands, and my work in Melbourne, to spend as much time possible with my dad and put everything else on hold. I received so much support from everyone around me that it overwhelmed me and I am truly grateful for this.

"Family faces are magic mirrors. Looking at people who belong to us, we see the past, present, and future." - Gail Lumet Buckley

Now I am finishing what I started, I want to firstly thank my dad, who I miss every day, for encouraging me to "always try your best" while also enjoying life to the fullest, I know he would have been proud. I am still adjusting to a life without him, yet he is everywhere all the time. Mum, both you and dad have given me all the opportunities I could have wished for in life and you always love me unconditionally. You have also given me 4 siblings, which I wasn't always happy with when I had to share the tv with them but I now that I have my own tv I am very happy with. Lau, thanks for letting me stay at your house so often. You are such a great mum to those cheeky boys and I admire your ability to function with your level of sleep deprivation, without complaining ever. Paulie, I am glad you are finally a CEO, even if at this moment you are only ordering yourself around. You are a great help to everyone and a rock in the family, just remember to take good care of yourself too. Mien, you are suddenly grown up, organized and a house owner! But you still refuse to buy clothes over 5 euros and I am proud of how you make those choice that are very you. I am looking forward to staying over in your beautiful apartment soon. Mau, I can always rely on you to pick me up from Schiphol airport (although preferably after midday). You are funny, easy going and are always able to cheer others up and I really enjoy seeing you as uncle Kip. Going back to study was not an easy choice but I hope you will enjoy it and it will open up new opportunities that you will love. You are simply the best siblings in the world, and Nils I could not wish for a better brother (not) in law, you are such an amazing dad to my nephews. Mart, you're the cutest and cheekiest toddler in the world, and you and chubby adorable baby Lenn make me the proudest auntie. Thanks for always having lots of energy to play with me and making me smile. Also thanks to my uncles and aunties Klaas, Dieuwke, Quintus, Herman, Nel, Frans and Bert for supporting me and feeding me fantastic meals. Emy, I am glad you were there with us in hard times, thanks for your good care.

"Friendship improves happiness and abates misery, by the doubling of our joy and the dividing of our grief" - Marcus Tullius Cicero

My paranimphen, Judy and Haike, thanks for your help with organizing me (I never thought I would say this)! Jude, since we met on our first day in uni our lives have run strangely parallel to each other and we have shared so much now, I cannot imagine my life without you. Currently we live continents apart but we still chat for hours and hours and to me it always feels the same, whether we meet up in Amsterdam, Barcelona, Melbourne, or Bangkok. I'm curious to see what is next after completing our PhD's pretty much at the same time. Haik, my other travel buddy, but also old roomie and neurohartsie, it is great to see you so happy with Sylco! You are both fantastic people, very caring and fun and I am looking forward to many more trips, long chats and fun nights with you. Without you Haik, this PhD would not have happened!

Annie, we've been friends so long you feel like a sister (me being the responsible one). You are very loyal, thoughtful and you always try to get the most out of life. I think you're the only person I know who goes on holiday more often than me and I'm glad we're still going on a lot of those holidays together. Shanti, friends since day one in high school, and I am so happy we never lost touch even though we have never lived close to each other. We have both moved continents for love and stay in close contact regardless of where we are. I would love to visit you in Colombia, but until then we will have to time our trips to Amsterdam so we can still have long dinners with wine and chocolate now and then. Anne, old roomie, it's always good to catch up in your beautiful house and see your boys. You are doing a million things at the same time but I know where to find you for support or good wine, or both. The Harderwijk club: Mariek, Es, Cor, Jen, Harrie, Jan, Tinus, my oldest friends, our long chats over dinners and drinks, although not occurring as often as in high school, are still very valuable to me and I hope we will still be doing this when we're 90! Wilco, you're a great friend and I always call on you when I need a devil's advocate. Cas and Wien, you are such a great team, Tess is so lucky to have you as parents! And I am lucky to have you as friends, I am looking forward to staying in your new house. Also Lianne, Jolande, Annemarie, Noortje and many others have proven to be great friends through mostly good but also sad times and this means the world to me. Many of you I have known for over 15 years, and I hope our friendship will remain despite the more than 15,000 kilometres between us.

As for my Australian friends: thanks Vale, Cali, Mario, Dario (Nachooooo), Natalia, Antonio, you have been very supportive and positive influences especially in the last year, and we have had some really awesome times together! I am looking forward to more of the Thailand kind of trips, and to celebrating milestones together. The "Dutchies in Melbourne" who are always supportive and up for traveling, dress up parties, playing giant Djenga, or brunch at the Pelican: Vanessa, Martin, Mark, Astrid, Camille, Menno, Jelmer, Khanh-Linh, Laurens and Rachel, you guys are awesome and have made Melbourne feel more like home to me in the past 6-7 years! My other Aussie friends without whom Melbourne would not be the place to be: Karissa, Tim, Cat, Andrew, Danijela, Laura, and Sarah I am very happy to be able to hang out with you guys!

Em, Dania, Keryn and many others who work or worked at the EPIcentre, aka the pink office, in Melbourne: you guys are all fun, fantastic, inspiring and truly wonderful. Sandy I love working with you and I hope there is still more research to do together. Thanks to you, Bern, Bernie and Michelle for educating me on all things organ donation related. A very special and big thanks to Tracy and George for their support over the last few year, this thesis would not be here if it wasn't for you. You are big inspirations to me and you have changed the way I think and live.

Thanks to my PhD supervisors who welcomed this clueless Dutch girl living down under and very unfamiliar to the Dutch PhD system into their offices many times for long discussions. Professors Willem Weimar and Jan IJzermans, thank you for your guidance and help in navigating me through this process. Thanks also to Saida, Emma and others at the Erasmus MC who have helped me get to this point, you have been very supportive and I am grateful for your help. Thanks to Professors van Busschbach, van Saase en Tilanus for being part of the thesis committee.

Last, but not least, I thank Mu for his motivational speeches, hugs, sense of humour, and creativity for solving problems that helped me to progress my thesis whenever I was struggling for time, energy or motivation, thanks for your love and support monkey.