

Policy Document

Organ and Tissue Donation

(2022)

Position Statement

AMSA believes that:

1. Organ and tissue transplantation is an effective, economical treatment for a number of conditions and is a crucial modality for improving patient health;
2. There is significant potential to increase the current organ and tissue donation rate in Australia;
3. The rate of organ donation in Australia would be significantly increased by adopting:
 - a. A 'soft opt-out' model of consent, whereby consent is presumed unless otherwise documented by the patient or by the next of kin;
 - b. A system of mandatory choice, in which individuals' decisions upon organ donation would be made upon the registration or renewal of official documentation, including but not limited to driver's licence registration, passport registration and voting. The decision of the individual may include the option to defer choosing.
4. Organ and tissue donation should be centred on the following ethical principles (based on NHMRC [8] and WHO [78] guidelines):
 - a. Donation is altruistic;
 - b. The donor must consent to the removal of their organs and tissues; if no prior wishes have been recorded then the family must consent;
 - c. The choice not to donate is to be respected, including the right to change a donation choice;
 - d. The needs of the donor take precedence over organ procurement;
 - e. Organs and tissues are allocated fairly, without regard to gender, ethnicity, religion, sexual identity or lifestyle, except where this may reduce the likelihood of a positive outcome;
 - f. The recipient consents to transplantation;
 - g. The privacy and confidentiality of donors and recipients is respected;
 - h. In the case of deceased donation, death has occurred following irreversible cessation of brain function or circulation of blood;
 - i. There is a separation of roles between the teams involved in caring for the donor and the recipient;



Head Office

A Level 1,
39 Brisbane Avenue,
Barton, ACT 2600

Postal Address

PO Box 6099,
Kingston, ACT 2604

ABN:

67079 544 513

Email:

info@amsa.org.au

Website:

www.amsa.org.au

- j. There are to be no practises of advertising, soliciting, or brokering for the purpose of transplant commercialism, organ trafficking, or transplant tourism.
- 5. Australia should invest in improved research and development around organ transplants and future technologies.

Policy Points

AMSA calls upon:

1. The Federal Government to:
 - a. Adopt a 'soft opt-out' model in regards to organ donation;
 - b. Adopt a mandatory consent model, in which individuals (with full capacity for consent) are required to record their personal preferences regarding organ donation during registration and renewal of public and government documentation including but not limited to passport registration and driver's licence registration. This may include the decision to abstain or defer deciding;
 - c. Adopt a system that allows for the renewal or change in personal decisions regarding organ donation during future registration and at every renewal of government documentation;
 - d. Ensure widespread awareness of changes to the model of donation through public awareness campaigns, making sure that any shifts in model are not made unless there is universal Australian awareness of the new model;
 - e. Continue to support the efforts of DonateLife in:
 - i. Increasing awareness about the benefits of organ donation for individuals and the community through targeted public campaigns;
 - ii. Encouraging people to consider their willingness to register for organ tissue and bone marrow donation as living donors;
 - iii. Encouraging family discussions of relatives' intentions regarding organ and tissue donation;
 - iv. Having targeted campaigns towards a diverse range of populations, including older adults, Aboriginal and Torres Strait Islander Peoples and culturally and linguistically diverse subpopulations;
 - v. Encouraging more grass-roots community campaigns to increase discussion and education regarding organ donation.
 - f. Increase funding into emerging organ and tissue transplant research and technologies, facilities and community outreach and education programs
 - g. Increasing the number of doctors, clinicians and allied health workers; including but not limited to nurses, social workers,

Aboriginal liaisons, working within Donate Life's administration, management and outreach programs;

- h. Collect and retrieve data regarding the involvement of Australian citizens in overseas organ transplantation to assess and mitigate possible cases of organ trafficking;
- i. Increase collaboration with Australasian partner health systems in joining organ donor and recipient pools, as has been done with the living kidney donation program with New Zealand.

2. Australian Red Cross to:

- a. Prioritise cultural sensitivity in the blood donation process, by;
 - i. Ensuring options for donors with personal or religious preferences to donate in private, modest areas which are compatible with their views;
 - ii. Encouraging greater staff hires from ethnically and linguistically diverse backgrounds;
 - iii. Holding cultural sensitivity training for all employees to allow a safe and comfortable space for all individuals to donate;
 - iv. Disseminating promotional material, as well as the donor questionnaire in different languages, especially targeted towards linguistically diverse populations from which a significantly greater amount of blood donations are required;
 - v. Promoting discussion and collaboration with community leaders of linguistically and culturally diverse groups, to better understand their concerns, values and beliefs regarding organ donation and mitigate barriers to donating;
- b. Increase the amount of mobile donation centres available to be deployed in workplaces, universities and other similar communal places;
- c. Communicate with diverse communities to increase awareness about the donation process, eligibility, the shortage of blood and the dire need for blood donors;
- d. Clearly communicate with donors the reason for their blood donation deferral, so as to not cause misinformation to spread within communities;
- e. Run public campaigns informing citizens of the need to eat and drink before donating blood.

3. Australian Medical and Allied Health schools:

- a. Increase curriculum content surrounding organ and tissue donation including but not limited to, ethical issues, cultural concerns, transplant legislation and present Australian systems
- b. Increase communication skills teaching upon discussing organ donation with patients and families, and the need to provide a

culturally safe discussion about the relevant issues and concerns to organ donation.

4. The Australian Medical Students' Association and Medical Societies:
 - a. Continue to encourage medical students to consider donating organs or tissues through initiatives such as Vampire Cup;
 - b. Support and participate in educational and promotional campaigns that advocate for organ donation, such as DonateLife week.

5. State and Territory Health Departments and Hospital and Health Services:
 - a. Create a supportive environment for families to make their organ donation decisions, if the potential donor's family members have not made their wishes clear;
 - b. Adopt Donate Life's Best Practice Guidelines for Offering Organ and Tissue Donation;
 - c. Increase the number of staff trained as donation specialists under DonateLife's program, particularly those part of ED and ICU multidisciplinary teams;
 - d. Encourage the donation team to discuss the approach to the donation conversation and the needs of the family before offering organ and tissue donation in a sensitive manner;
 - e. Encourage post-donation conversation meetings with the donation team to review the conversation with the family and/or donor and the approach for communication.



Background

Organ and tissue transplantation are life-saving treatments for a range of illnesses. Organs and tissues may be donated from living or deceased donors. One deceased donor may improve the lives of more than ten people living with disabling diseases by donating organs such as: kidneys, liver, lungs, heart, pancreas and eyes; or tissues such as: skin, musculoskeletal and cardiac tissues [1].

The central organisation for organ and tissue donation in Australia is the national DonateLife Network. Established by Australian state and federal governments in 2009, it sets standards, allocates organs and supports local retrieval arrangements [2]. In Australia, in 2020, 1270 organs were received from 463 deceased organ donors with 10,817 tissue donations received from 3,018 tissue donors [3]. Whilst the number of deceased organ donors has increased by 87% since 2009 [1], the number of Australians waiting to receive an organ transplant is still much higher than the number of organs available, with 1,864 people waiting for an organ transplant as of January 2022 [4].

Waiting times for donations vary between different organs. Those needing a kidney transplant wait for an average of 2.5 years, but may take up to 7 years in some cases [5]; whereas heart or liver transplants may have patients waiting upwards of 9 months [6].

For deceased donation to be possible, brain or circulatory death must occur under specific circumstances which maintain sufficient organ function [7]. In 2020, around 2% of deaths from hospitals were suitable for donation to be considered [1]. Following death, requests for organ donation are made to the family, who make the final decision based on the deceased's known wishes, or their values and beliefs if the wishes are unknown. 58% family consent rate was recorded among deceased donors who were considered for organ donation and had previously consented [1]. In 2020, 89% of families agreed to donation when the deceased was registered as a donor on the Australian Organ Register. When the deceased was not registered, 66% of families agreed to donation if there was prior acknowledgement of the deceased donor's wishes. When the wishes of the deceased donor wasn't known, 44% of families gave consent to donation. [1]

Living organ donation is a way to increase the availability of organs, with kidneys and partial livers being the more common living transplants in Australia [8]. Living organ donors can be categorised mainly into directed and non-directed donors. Directed donors refers to those donating to someone the donors have a relationship with, including but not limited to families, relatives, partners and friends [9]. The guidelines state that the motives for directed living organ donors are investigated to ensure the donation is purely voluntary without family or peer pressure [8].

Non-directed donors refer to those donating to someone without any genetic or emotional relationships [10]. Unlike the deceased organ donation where there is a system for registration, non-directed living organ donors often require referrals to the transplant unit at public hospitals [11]. Apart from compatibility with patients on the transplant waiting list, the living donors' medical, psychological and social well-being are assessed by health professionals having no relationships with the transplant recipient [12]. Anonymity between non-directed living donors and transplant recipients is maintained [11], as to avoid potential abuse or financial conflicts in the future [8].

Ethical Principles of Organ Donation

Due to the complex concerns and issues that pertain to both recipients and donors, organ donation presents itself with many serious ethical questions and considerations. Despite the serious debate on the facets of this topic, the consensus amongst bioethicists posits organ donation to be a voluntary and altruistic process, with the allocation of organs being a fair and just process which distributes based upon recipient needs, free from any financial reward. [67,68]. The standard principles of medical ethics such as confidentiality, beneficence, non-maleficence and family consent are also accepted [68]. In the face of global issues such as organ trafficking, it follows that, no matter what system of organ donation, ethical

principles that respect the rights, values, beliefs and privacy of both donors and recipients are followed.

Donation Policy Systems and models of consent

The process by which organ and tissue donation occurs is governed differently across the globe. However, there are two systems by which most fall under, and 2 consent models that can be chosen. For instance, the government may decide that the 'default' for its constituents is that organ donation does not occur unless an individual 'opts-in'. Alternatively a government can decide that organ donation from its constituents *will* occur unless an individual 'opts-out'. These are the two organ donation systems. In conjunction with this, a government will also decide if an individual's choice to donate, or the choice not to donate, can be overturned by their family in the event that organ donation is a possibility. This is known as 'hard' or 'soft' consent, depending on whether the individual's choice is the only guiding decision or if the family's consent is final, respectively. See Table 1 in Appendix for summarised information on the systems of consent and donation.

Consent models

Soft Consent

Regardless of the donation policy system, in countries that have adopted a 'soft' consent model, donation cannot take place without the involvement and consent of family members [13]. In countries that adopt the 'opt-in' systems, there may be a legal requirement for the family to authorise the donation. However, in countries such as Australia, seeking the consent of the families may not be a legal requirement, but is a best practice convention that is routinely observed [30]. In practice, this means that the family of the deceased person can revoke their consent to organ donation, regardless of their decision to 'opt-in'. Alternatively, in countries that adopt the 'opt-out' system, a soft consent model may see family members approached to ensure that the potential donor wished to opt-out but didn't get a chance to [13].

Hard Consent

By contrast, in countries that have adopted a 'hard' consent model, the choice and preference of an individual on becoming an organ donor given while they were alive is the prime focus. Thereby, this model assumes that there is no role of families to play in this process. For instance, in countries that have adopted an 'opt-out' system, organs can be transplanted from anyone who has not registered their express opposition to donation, without the need for consent from family members [22]. Whereas, in countries and regions that have adopted an 'opt-in' system, family consent is not required from individuals that have consented, and 'opted-in', to organ transplantation.

Ethics of Family Involvement in the 'Hard' and 'Soft' Consent Models



When considering both hard and soft consent models, consideration must be given to the ethical discussions of family role and individual autonomy. As the role of the family is culturally, socially and personally dependent one, significant debate exists amongst bioethicists around the world upon the ethics of this issue [88]. However in cases when the wishes of the individual were not made clear in their lifetime, it is generally accepted by bioethicists that the family and next-of-kin are the best individuals to make the posthumous decisions [88]. The area of debate, however, has been the family's ability to veto the decisions of the individual when they were made clear within their lifetime. Within recent years, the family veto power over an individual decision to become a posthumous donor has been controversial, due to the potential abrogation of the individual's autonomy over their decision [89]. There has furthermore been debate about the role of family decisions, in cases when the individual didn't have close connections with their genetic family.

However 'hard consent' models have been strongly criticised for their potential to create 'unwilling donors', especially for individuals of low-socioeconomic status or low health literacy, who are unaware of the shifts in law. This may present considerable issues especially in the initial implementation of this model, when there may not be widespread awareness of this model. Furthermore, there are ethical concerns about the levels of trust in the medical establishment as families find themselves no longer able to represent the wishes of their loved ones in moments of immense distress [88]. This distrust was seen in the Brazilian implementation of the hard consent model (see Ethical considerations of Opt-out models below) [85]. The immense importance of trust in the medical establishment can be seen through the results of the Spanish model (see Spanish Model below).

Mandatory Choice

This policy requires that individuals make a decision on their preference on becoming an organ donor or not. This is often enforced when applying for a driver's licence or other official government document [13,23]. Such a choice can be made in either 'opt-in' or 'opt-out' policy systems, and can be applied in 'soft consent' or 'hard consent' models. Some research suggests that options may also include deferring their choice, either for a period of time, or to defer their decision to relatives at the necessary time [24,25].

This system has the benefit of bypassing the family consent barrier, which can sometimes create discrepancies between the wishes of the donor and the final result, especially when the wish of the individual wasn't known before they passed away [81]. Furthermore, it moves the decision making process from a stressful environment to a relaxed one, and it helps nurture public discourse upon the issue (see Spanish model below), as every individual is forced to consider it. It ensures that autonomy is maintained at the highest standard.

This policy has received support from a number of governments and organisations, such as in New Zealand and the American Medical Association [13,23–25]. It has been implemented in several countries and states, most prominent in the UK in 2011,

and in Illinois in 2006 [81,82]. The implementation in Illinois saw an increase of donor rates from 38% to 60% [83].

Opt-In

In an 'opt-in' system, individuals are required to register or express their explicit desire to be an organ donor, often having to register through government organisation. Sometimes known as an "express consent" or "explicit consent" policy [13,14], the nature of this policy often results in a discrepancy between the number of individuals who are "willing" to donate an organ, and those that complete the registration process [15,26]. Some of the barriers that lead to this discrepancy include language barriers, misinformation and lack of communication.

Some view this policy system as being unsuitable in countries whereby the need for organ donations is far surpassing the ability to supply organs suitable for transplantation [16]. While this system affords autonomy of the donor autonomy, reducing rates of apathy amongst would-be donors may improve donation registration rates. Countries and regions that adopt this system include Australia, Brazil, Canada, Cuba, Denmark, Germany, Guatemala, Hong Kong, Ireland, Israel, Japan, Malaysia, Mexico, The Netherlands, New Zealand, Taiwan, UK, USA [22].

Opt-out

In an 'opt-out' system, consent to donating organs is presumed unless an objection has been registered, and this decision is recorded in a national register for if organ donation eventuates [13]. This system is also sometimes known as "presumed consent". This system addresses the discrepancy between the majority of individuals who wish to donate and the minority who register. While 76% of Australians are willing to be organ donors, only 36% are registered to be organ donors [2]. This discrepancy has been attributed to factors such as reluctance or ambivalence to sign up and fears of confronting one's own death [90]. Several international studies have shown increases in donor rates of 25-30% following transition to an opt-out system [17-19]. However, the observed increase in donation rates cannot be isolated from confounding factors such as increased awareness of organ donation surrounding the transition from opt-in to opt-out, and other concurrent legislative changes [20]. Nevertheless, when accounting for these factors and other covariates, such as Gross Domestic Product (GDP), road traffic accident mortality, hospital beds, and percentage of religious groups, it has been illustrated that countries with opt-out models of consent have statistically greater total number of kidney and liver donations compared to opt-in countries [17]. Reviews by the state governments of Western Australia [27], Queensland [27], and Tasmania [28] have highlighted the benefits of an opt-out model but have been reticent in their support, citing concerns of resistance from a minority of the community, or inadequate evidence of benefit. In Victoria, following a trial by the Royal Melbourne Hospital, health services have adopted a policy of 'automatic assessment', whereby all patients nearing the end of life are referred to DonateLife specialists to be assessed as to whether they are suitable organ donors, regardless of their status on the donation register. If deemed suitable, doctors will approach the patient and their family to discuss organ donation prior to their death. The



Victorian Government expects a 10% increase in donors as a result of this policy [30]. Countries that adopt this system include Argentina, Belgium, Bulgaria, Columbia, Croatia, Finland, France, Greece, Italy, Poland, Portugal, Russia, Singapore, Spain, Sweden [22].

Ethical Considerations of Opt-out Models

Implementation of opt-out models, however, presents several ethical concerns, most prominently regarding consent. Through the assumption that the individual is a donor, there may present issues regarding the real intent, autonomy and consent of the individual, especially if the individual was unaware of the system [84]. This issue may particularly affect individuals with lower health literacy rates, and lower socio-economic statuses. There may also be issues regarding trust of the medical profession. For example, the implementation of a hard opt-out system in Brazil in 1997 created fear and distrust of the organ donation process and with the medical profession in general. This led to its abolishment 18 months later [85]. The failure of the Brazilian model, however, cannot be entirely attributed to the opt-out system, but also due to the lack of familial consent and involvement as a 'hard consent' model, lack of public discussion and lack of public identification systems and records in Brazil, which lead many Brazilians (especially from low socio-economic backgrounds) to assume that their autonomy and consent would be violated [85]. Thus the implementation of an opt-out model must ensure wide-spread awareness to be successful and must have mechanisms (such as the concurrent implementation of mandatory choice) to ensure that the autonomy and rights of the individual are maintained.

Spanish Model

Often considered the "gold standard" of organ donation, Spain's model, which utilises a soft opt-out model, has a structured, yet holistic approach. The model begins with a dedicated organisation being charged with identification of a potential donor [32], confirmation of their suitability for donation, careful management and care of the donor in order to ensure donor suitability, and considers family consent as a pillar of the model. In a review of this model, it was noted that an important element is having specialised medical doctors, who have an in-depth understanding of the biopsychosocial elements of transplant medicine, in the position of donor coordinator. In this way, the Spanish model is able to more efficiently and effectively find the individuals who may be more suitable for donation. In Australia, the role of donor coordinators is typically carried out by non-medical officers. Though these officers are extensively experienced and are often well-renowned for their professional excellence, there are some key issues they face regarding support resources and education opportunities (discussed in the Role of Education in Organ Donation). Another difference includes the involvement and rigorous education of intensive care doctors as key members of this process, as these training methods, combined with clinician delivery, is integral in the approach of family members in the process of mourning [31, 32]. Furthermore, a striking feature of the Spanish model has been the immense public outreach performed by the Spanish Organ Donor Donor Service. There is a coordinated national effort to communicate to the

media, public and medical profession with ongoing proactive messaging and easily available information on the topic. This has led to high rates of trust in the Spanish Medical system [86]. The adoption of this model has proved successful for several other nations and states, most prominently in Italy which saw a 10% increase in organ donation rates after the implementation of this policy [87].

Current Australian Model

Currently, Australia uses a soft opt-in approach in organ and tissue donations, where people are non-donors by default upon death [38]. People aged 16 or above can express their preferences of becoming an organ and tissue donor by registering with the Australian Organ Donor Register, the only place where the decision is officially recorded [39]. The registration can be done online through their Medicare account, or filling out the Australian Organ Donor Register Form [40]. As of December 2021, the Australia Organ Donor Register recorded 4,293,118 intent registrations, with 3,070,295 of those (71.5%) completed the legal and consent process [41,42]. These rates of organ donation, which lag behind the success of other countries, have often been attributed to the use of the 'opt-in' system [90].

International Collaborative Models

A moment of consideration must be given to the emergence of organ transplant collaborative drives. Examples of these groups include ScandiaTransplant, an international collaborative effort in organ transplantation exchange between Finland, Sweden, Norway, Denmark, Estonia and Iceland founded in 1969 [33]; Founded in 1984, Eurotransplant, organises the collection and allocation of donated organs in Austria, Belgium, Croatia, Germany, Hungary, Luxembourg, the Netherlands and Slovenia [33]; United Network for Organ Sharing (UNOS), an organ procurement and transplant network that was established in the United States of America in 1984 [34].

The Australian and New Zealand Paired Kidney Exchange program (ANZKXP), established in 2019, aimed at increasing the chance of success in compatibility-matching by expanding the database to include living donors and recipients from both Australia and New Zealand [35]. In situations where the living donor is unable to proceed with transplantation due to incompatibility, the program will search the database for another pairing of living donor and recipients. Then, the living donors are swapped so that a compatible transplantation can take place [36]. In 2021, there were 202 living kidney donors in Australia; 162 of which are directed donations and 38 out of the 40 non-directed donations are recruited from the ANZKXP [37]. While ANZKXP represents an exciting opportunity for Australian citizens on a kidney transplant waitlist, sustained success remains to be seen in the future.

Blood and Bone marrow

Blood donation



Blood consists of four main components – Red blood cells (RBCs), white blood cells (WBCs), plasma and platelets [43]. RBCs, plasma and platelets are donated and collected at Australian Red Cross Lifeblood centres, while those who need stem cells/WBCs need a bone marrow donation through the Australian Bone Marrow Donor Registry (ABMDR) [35].

Transfusions of RBCs have many uses – they're often given to anaemic patients, patients undergoing surgeries or traumas, or to pregnant individuals and young children [45]. Plasma can be used in 18 different ways, for patients with severe burns, to brain disorders, to liver disease [46]. Platelet transfusions are used to stop spontaneous bleeding in chemotherapy patients, for example, or to stop bleeding during surgery or after major trauma [47].

The need for blood donation

Australia needs more than 1.7 million donations annually to meet demand – which amounts to 3 donations every minute [48]. An average blood donation is 470ml – both for whole blood donation (RBCs) or plasma/platelet donation – and within 48hrs, the donor's original blood volume is fully restored. However, despite the dire need for blood donations and the safety of the process, there is still unmet demand due to the shortage of blood donors.' [48]

Within Australia's diverse ethnic population, there is a large phenotypic variety in blood groups. While the ABO system (blood types A, B, AB or O) and the Rh type system (positive or negative) makes up the common phenotyping of blood groups (for example, O-), phenotypic variation has evolved in response to genetic adaptation to protect certain human populations from infectious disease [49]. For example, certain population groups from West Africa with Fy(AB-) blood phenotype have protection against the *P. vivax* strain of malaria. For most optimal outcomes, the blood transfused to patients should match as closely as possible, their own blood type [49]. While matching the ABO system and Rh system is usually enough, for those who require frequent transfusions, such as patients with anaemia and thalassemia, outcomes are improved if the blood is matched on the basis of phenotype – otherwise there is a risk of alloimmunisation, which is an immune response due to the exposure of foreign antigens in transfused blood [49]. For example, sickle cell anaemia is more prevalent among sub-Saharan Africans, and therefore for repeated blood donations, the optimal blood donor would be someone of a similar ethnic background who would likely have the same phenotype as the recipient [48, 49]. It is therefore necessary to prioritise the recruitment of ethnically diverse blood donors to address the blood shortage [49].

Despite different socio-cultural factors in various ethnic groups, it has been found that motivators and barriers to donating blood are similar among the minority groups sampled. [49].

Motivators for blood donation

When regular blood donors were asked about their motivations for blood donation, the most frequently cited reason was the simple desire to help others, whether it be steeped in humanitarianism and altruism as it relates to public service, or feeling a moral obligation and duty to donate blood – whether this arose from personal values, or religious convictions [50]. Donors knowing someone who required blood transfusions, or having friends and family with medical knowledge about the need for blood donations also bolstered their motivation to donate. It was also found that

convenience was a significant factor in donors' motivation to donate [50]. Having an organised group with whom to donate, such as organised by their place of employment, or regularly seeing a mobile donation unit for example at the gym, as well as targeted marketing such as reminder messages to come back and donate were all factors which increased donor motivation and capacity to donate. Furthermore, the reputation of the Red Cross as a well-known and respected organisation was a driving factor for the inclination to donate [50].

This is summarised in Table 2 of the Appendix.

Barriers to blood donation

Barriers to blood donation for ethnic minorities can come from medical mistrust and misunderstanding. A common misunderstanding occurs when a donor's blood donation is deferred, and the reason for their deferment isn't adequately explained to them [50]. The belief that their deferment is due to their ethnic background can lead others in their community to believe that they're not able to donate blood either, which is never the case [50]. Some Sub-Saharan African immigrants and African American immigrants who were interviewed believed that their blood was unwanted, or later discarded out of fear that their blood carried viruses such as HIV, which deterred them from wanting to donate [50].

Another deterrent for certain groups was having to book an appointment at the Red Cross blood service [50]. According to one interviewee, in Indonesia, it's far more commonplace to walk in for an appointment, than to commit to a time weeks in advance. Thus when turned around at a walk-in attempt at a blood donation centre, these potential donors would be unlikely to attempt to donate blood again [50].

Furthermore, to create a more inclusive environment, interviewees cited their desire to see staff from their own ethnic background at the Lifeblood centres, as well as donors with their skin colour on the advertising pamphlets. Interviewees also suggested that marketing materials should be less scientific and jargon heavy [50]. Rather, they should focus on the emotional stories and images from people from their communities who have received blood and the difference it has made to their lives. This marketing material would include not only pamphlets and advertising campaigns, but having LifeBlood staff directly come in and engage with these minority communities [50].

Another significant barrier was the cultural need for privacy for females from certain backgrounds. For example, one interviewee noted that Pacific Islander women might find it embarrassing to lie down in public, and a Muslim interviewee mentioned that a woman baring her arm in public would go against her faith [50]. Given that Lifeblood centres are arranged in such a way that all the donation chairs are in full view of other donors, this would render the service inaccessible for potential donors of certain ethnic backgrounds [50].

These barriers are summarised in Table 3 of the Appendix.

Bone Marrow donation

Bone marrow is the spongy material found in the centre of most bones which contains *stem cells* – cells which divide to form other types of cells: in this case, RBCs, WBCs and platelets [51]. Some medical conditions like blood cancers or medical treatments such as chemotherapy can damage patients' stem cells, meaning their body isn't able to autonomously produce these blood cells [52]. In these situations, patients require a donor whose HLA markers (Human Leukocyte

Antigen- a set of unique cell markers) match their own. Oftentimes, siblings from the same parents are the best match, but otherwise a donor with a similar ethnic background is most likely to be a match; indeed, 70% of people need to find an unrelated donor. It is therefore crucial for the Australian Bone Marrow Donation Registry to have donors from a variety of ethnic backgrounds – currently, 80% of donors are of Caucasian background, meaning that there is a critical need for increased ethnic and cultural diversity within the registry [53].



Role of Education in Organ Donation

The education of health professionals and medical students on the issue of organ and tissue donation is vital for its efficiency and effectiveness. While 78% of the Australian population support organ and tissue donation, only 60% consent to it [56]. Though this may reflect an issue within the donation process at the level of gaining consent, it may also be reflective of those who support organ and tissue donation but do not want to donate themselves [56]. Lack of educational programs on organ donation and transplantation has been shown to be one of the reasons for the shortage of organ donations [57]. The quality of the donation conversation and information provided within it, alongside the level of experience and professional training of staff, are the largest influences on rates of family consent to organ and tissue donation [58]. Hence, in order to improve donation rates within Australia, it is imperative that the reasons for non-consent and the beliefs of consenting families are included in the education of health professionals and medical students. Data from DonateLife supports that the training of health professionals in organ donation increases family consent rates. In 2020, 62% of families consented to organ donation when a trained doctor or nurse was involved in the process, compared to 24% of families consenting when a trained doctor or nurse was not involved [59]. Consent rates are further increased when staff are specifically trained as donation specialists through Donate Life with the consent rate for DonateLife Specialists being 55% compared to 33% for other trained staff and 28% for untrained staff. Despite this dramatic increase in consent, donation specialists currently exist in only 95 of Australia's 1350 hospitals, equating to approximately 7%, which indicates a drastic need for improvement. [59, 60].

There is also a special focus on training ED and ICU staff as they most frequently collaborate with hospice staff in the organ and tissue donation processes [58]. The training program for a donation specialist conducted by DonateLife involves a two-day Core Family Donation Conversation workshop, and completion of this program is a compulsory requirement of all ICU trainees [58]. The Best Practice Guidelines for Offering Organ and Tissue Donation by DonateLife also set out four critical practices that increase the likelihood of consent. The first is holding pre-donation and post-donation conversation meetings with the donation team, followed by separating the end-of-life and donation conversations. Thirdly, holding the donation conversation in an appropriate location and at an appropriate time and finally, being sensitive, compassionate and caring towards donors and donor families [58].

Additionally, including a focus in medical curricula on organ donation, transplantation and current discrepancies in the donation system would adaptly

educate medical students. This would enable them to intelligibly disseminate information on organ and tissue donation to their families, friends and counsel future patients. Thus, while the education of health professionals and medical students on this issue should be primarily driven by the ethics of organ and tissue donation, it may be beneficial to the consent and donation rates in Australia that the reasons which currently underpin the rates of non-consent are incorporated.

Beyond doctors, the organ donation process relies significantly on other allied health, including nurses and social workers [65, 66]. Nurses play a pivotal role in the organ donation process, and work collaboratively with surgical teams to facilitate the organ procurement procedure, intra-operatively. A 2019 study undertaken by the Australian College of Preoperative Nurses found that most nurses felt they lacked support resources and access to relevant education around the process of organ donation in Australia, and the role of nurses in the process [64]. In Australia, most hospitals do not have designated perioperative nursing teams for such an event, which adds pressure onto the nursing staff, and other professionals, who participate at short notice with no prior experience or significant preparation [66].

Hospital social workers are crucial in the liaison, counselling, and communication between family members of the potential donors [66]. In particular, they are important in obtaining informed consent and in working with families' experience of grief and loss in sudden, traumatic bereavement, and communicating that to other health care professionals [64]. It is pivotal for the success of organ donation, to ensure all medical staff are adequately trained and educated on their role in the process [65, 66].

Aboriginal and Torres Strait Islander Engagement with Organ/Tissue Donation

There exists a great disparity with access to both donating and receiving tissues/organs between the overall Australian population and the Aboriginal and Torres Strait Islander Peoples. Presently, Indigenous people represent only 2.4 percent of total organ donations in Australia [63]. Due to lack of trust and communication between families and medical staff, Indigenous families are far less likely to consent for a deceased donation than non-Indigenous families [63]. Aboriginal and Torres Strait Islander People undergoing transplantation have encountered issues such as cultural barriers, inefficient communication and mistrust of the medical system [64]. There also exists a decreased access to Organ transplants for Aboriginal and Torres Strait Islander peoples. For example, the AMA reports that Indigenous patients are 10 times less likely than non-Indigenous peoples to be added to the kidney donation wait list [62]. This is due to factors such as the greater burden of comorbidities amongst the Indigenous population, specialist perceptions of non-compliance and issues with HLA mismatching. Furthermore, for the Indigenous people who do undergo organ transplantation, clear differences exist in the post-transplant morbidity rates and long-time survival rates.

Organ Trafficking

One consequence of the gaps between organ donors and recipients on a wait list, has led to the promotion of unethical practices such as organ trafficking or transplant tourism. Organ trafficking is a broad concept that results in the economical exchange of human organs, leading to the exploitation of vulnerable groups of people [74]. This process may include removing organs from people in conjunction with sexual exploitation, human trafficking, or physical assault [73]. Organ trafficking is known to exist in countries such as India, the Philippines, China, Egypt and Pakistan, amongst others [74].



The existence of organ trafficking has led to the production of an established market known as Organ Tourism. This process involves individuals travelling to countries where organ trafficking is endemic, to purchase and undergo transplantation for the organ, illegally [74]. The WHO has marked organ tourism as an international threat to humanity, and has called for all countries to protect the poorest and vulnerable groups from this procedure [71].

The current Australian Organ Donation system is unable to provide citizens with the number of Organs they require, which may lead Australians to source their own organs, internationally [76]. Not only is this a violation of human rights and a major medical crime [74], but an immediate health risk to the donor and recipient. Recipients are known to have an increased risk of hypertension, organ failure, transplant rejection and infection to human immunodeficiency virus (HIV), hepatitis B and a variety of fungi [75].

Emerging Trends in Technology, Research and Ethics

Due to the systemic undersupply of organ donations across the globe, research has emerged in creating new and creative approaches to dealing with organ failure or loss. This includes the much anticipated stem cell applications, where different approaches allow for the creation of whole new organs that are genetically matched to the patient leading to no rejection [79,80]. Additionally, advancements in immunosuppressants and genetic engineering have allowed for the emergence of successful xenotransplants of organs from pigs to humans [78]. However, despite all this success in the field, Australian research trails behind other nations in this field. Thus, increased international collaboration in regards to research, and improved funding from all levels of the private and public sector should be encouraged.

Alongside this shift in technology, research and development, there have been shifts and growing debates about the present ethical frameworks and paradigms for organ donation. There has been shifts amongst the thoughts of bioethicists in moving away from thinking of organ donation as an act of heroism but as an act of moral duty. [69] Due to the power of organ donation in being able to extend and transform lives, this paradigm argues that it is a moral obligation for individuals to help the lives of others, once they themselves have passed away. Amongst some of the more controversial ethical concerns have been considerations to give priority to organ

donors for becoming recipients, and creating highly-controlled, government-regulated markets to increase the number of organs available for recipients. [70,71]



References

1. Organ and Tissue Authority. 2020 Australian Donation and Transplantation Activity Report [Internet]. Canberra: Organ and Tissue Authority; 2021 [cited 7 February 2022]. Available from: https://www.donatelife.gov.au/sites/default/files/2021-05/2020_australian_donation_and_transplantation_activity_report.pdf
2. DonateLife Network. About us [Internet]. DonateLife. 2022 [cited 7 February 2022]. Available from: <https://www.donatelife.gov.au/about-us>
3. Department of Health. Organ and tissue donation in Australia [Internet]. Canberra: Commonwealth of Australia. 2021 [cited 7 February 2022]. Available from: <https://www.health.gov.au/health-topics/organ-and-tissue-donation/organ-and-tissue-donation-in-australia#:~:text=The%20size%20of%20the%20problem,-Australia's%20donation%20rate&text=In%202020%2C%20there%20were%201%2C270,for%20a%20life%2Dsaving%20transplant>
4. Australia & New Zealand Organ Donation Registry. Patients Awaiting Transplant in Australia [Internet]. Organ Waiting List - ANZDATA. 2022 [cited 7 February 2022]. Available from: <https://www.anzdata.org.au/anzod/publications-2/organ-waiting-list/>
5. Kidney Health Australia. Kidney transplants | Kidney Health Australia [Internet]. Kidney Health Australia. 2022 [cited 7 February 2022]. Available from: <https://kidney.org.au/your-kidneys/treatment/kidney-transplants>
6. Transplant Australia. FAQ - Transplant Australia [Internet]. Transplant Australia. 2022 [cited 7 February 2022]. Available from: <https://transplant.org.au/faq/#:~:text=People%20waiting%20for%20a%20kidney,wait%20nine%20or%20more%20months>
7. Department of Health. Organ donation after circulatory death (DCD) - Organ and tissue donation [Internet]. Canberra: Commonwealth of Australia. 2022 [cited 7 February 2022]. Available from: <https://www.health.nsw.gov.au/organdonation/Pages/donation-following-circulatory-death.aspx>

8. National Health and Medical Research Council. Organ and Tissue Donation by Living Donors - Guidelines for Ethical Practice for Health Professionals [Internet]. Canberra: Commonwealth of Australia; 2007 [cited 7 February 2022]. Available from: <https://www.nhmrc.gov.au/file/5536/download?token=aPf1ZSz6>
9. DonateLife Network. Understanding living donation [Internet]. DonateLife. 2022 [cited 7 February 2022]. Available from: <https://www.donatelife.gov.au/all-about-donation/understanding-living-donation>
10. Kurleto P, Skorupska-Król A, Broniatowska E, Bramstedt K. Exploring the motives of Israeli Jews who were living kidney donors to strangers. *Clinical Transplantation*. 2020;34(10).
11. NSW Health. Kidney Donation - Living (including Directed and Non-Directed Donation) [Internet]. North Sydney; 2020 [cited 7 February 2022]. Available from: https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2015_041.pdf
12. Kidney Health Australia. Fact sheet: Non-directed Living Kidney Donation [Internet]. Kidney Health Australia. 2017 [cited 7 February 2022]. Available from: <https://kidney.org.au/uploads/resources/non-directed-living-kidney-donation-fact-sheet.pdf>
13. Etheredge HR. Assessing Global Organ Donation Policies: Opt-In vs Opt-Out. *Risk Manag Healthc Policy*. 2021 May 13;14:1985–98.
14. Arshad A, Anderson B, Sharif A. Comparison of organ donation and transplantation rates between opt-out and opt-in systems. *Kidney Int*. 2019 Jun 1;95(6):1453–60.
15. Willis BH, Quigley M. Opt-out organ donation: on evidence and public policy. *J R Soc Med*. 2013/10/24. 2014 Feb;107(2):56–60.
16. Wilkinson R. Organ donation: the debate. *Nurs Stand*. 2000;14(28):41–2.
17. Rithalia A, McDaid C, Suekarran S, Myers L, Sowden A. Impact of presumed consent for organ donation on donation rates: a systematic review. *BMJ*. 2009 Jan 15;338:a3162.
18. Abadie A, Gay S. The impact of presumed consent legislation on cadaveric organ donation: A cross-country study. *J Health Econ*. 2006;25(4):599–620.
19. Bilgel F. The impact of presumed consent laws and institutions on deceased organ donation. *Eur J Heal Econ*. 2012;13(1):29–38.
20. Coppens R, Friele RD, Gevers SKM, Blok GA, van der Zee J. The impact of donor policies in Europe: a steady increase, but not everywhere. *BMC Health Serv Res*. 2008 Nov 13;8:235.
21. Costa-Font J, Rudisill C, Salcher-Konrad M. 'Relative Consent' or 'Presumed Consent'? Organ donation attitudes and behaviour. *Eur J Heal Econ*. 2021;22(1):5–16.
22. Shepherd L, O'Carroll RE, Ferguson E. An international comparison of deceased and living organ donation/transplant rates in opt-in and opt-out systems: a panel study. *BMC Med*. 2014;12(1):131.

23. Thaysen JD, Albertsen A. Mandated Choice Policies: When Are They Preferable?: <https://doi.org/10.1177/1065912920936361>. 2020 Jul 10;74(3):744–55.
24. Shanmugarajah K, Villani V, Madariaga MLL, Shalhoub J, Michel SG. Current progress in public health models addressing the critical organ shortage. *Int J Surg*. 2014;12(12):1363–8
25. Kurzen J, Clavien C, Hurst S. General public's view on opt-in, opt-out, and mandated choice organ donation policies: a qualitative study involving Swiss French-speaking citizens favourably disposed towards organ donation. *Swiss Med Wkly* 2021 43. 2021 Nov 6;151(43):w30037.
26. Australian Government Department of Human Services. Australian organ donor register statistics [Internet]. Canberra: Australian Government Department of Human Services; 2019 [cited Feb 15]; Available from: <http://www.humanservices.gov.au/corporate/statisticalinformation-and-data/australian-organdonor-register-statistics/australian-organ-donor-registerhistorical-statistics>
27. Delriviere L, Boronovskis H. Adopting an opt-out registration system for organ and tissue donation in Western Australia [Internet]. Perth: Parliament of Western Australia; 2011 [cited 2019 Feb 15]; 32 p. Available from: [http://www.parliament.wa.gov.au/publications/tables/papers.nsf/displaypaper/3813336a792bbc8b9d40d54248257896000a9a44/\\$file/3336.pdf](http://www.parliament.wa.gov.au/publications/tables/papers.nsf/displaypaper/3813336a792bbc8b9d40d54248257896000a9a44/$file/3336.pdf)
28. Legislative Assembly of Queensland. Organ and tissue donation: report of the review of organ and tissue donation procedures select committee [Internet]. Brisbane: Queensland Parliament; 2008 [cited 2019 Feb 15]; 82 p. Available from: https://www.parliament.qld.gov.au/documents/committees/RODTPSC/2008/org_tiss_don/otd_report.pdf
29. Legislative Council Select Committee. Organ donation [Internet]. Hobart: Parliament of Tasmania; 2008 [cited 2019 Feb 15]. 67 p. Available from: <http://www.parliament.tas.gov.au/ctee/Council/Archived/REPORTS/Report080523sm.pdf>
30. Hennessy J. Identifying more organ donors to save more lives [Internet]. Melbourne: Premier of Victoria; 2018 [cited 2019 Feb 10]. 1 p. Available from: <https://www.premier.vic.gov.au/identifying-more-organ-donors-to-save-more-lives/>
31. Standing Committee on Uniform Legislation and Intergovernmental Agreement. Organ donation and transplantation: Report No. 25 [Internet]. Perth: Legislative Assembly, Perth, Western Australia; 2000 [cited 2022 Feb 20]. Available from: [https://parliament.wa.gov.au/Parliament/commit.nsf/\(Report+Lookup+by+Com+ID\)/CB5FAAA06CB2E6CC48257831003E951C/\\$file/rptno25.pdf](https://parliament.wa.gov.au/Parliament/commit.nsf/(Report+Lookup+by+Com+ID)/CB5FAAA06CB2E6CC48257831003E951C/$file/rptno25.pdf)
32. Matesanz R, Domínguez-Gil B, Matesanz R, Domínguez-Gil B. The Spanish Model of Organ Donation and Transplantation. *Organ Transplant Times Donor Short Challenges Solut*. 2016 Aug 6;59:303–12.
33. Koefoed-Nielsen P, Weinreich I, Bengtsson M, Lauronen J, Naper C, Gäbel M, et al. Scandiatransplant acceptable mismatch program (STAMP) a



- bridge to transplanting highly immunized patients. HLA. 2017 Jul 1;90(1):17–24.
34. Lewis A, Koukoura A, Tsianos G-I, Gargavanis AA, Nielsen AA, Vassiliadis E. Organ donation in the US and Europe: The supply vs demand imbalance. *Transplant Rev.* 2021;35(2):100585.
 35. DonateLife Network. Australian and New Zealand Paired Kidney Exchange (ANZKX) Program [Internet]. DonateLife. 2022 [cited 7 February 2022]. Available from: <https://www.donatelife.gov.au/for-healthcare-workers/ANZKX>
 36. Kidney Health Australia. An Introduction to Kidney Donation by Living Donors [Internet]. Kidney Health Australia. 2017 [cited 7 February 2022]. Available from: <https://kidney.org.au/uploads/resources/an-introduction-to-kidney-donation-by-living-donors-handbook-kidney-health-australia.pdf>
 37. Australia & New Zealand Living Kidney Donation Registry. Monthly Report on Living Kidney Donation in Australia - December 2021 [Internet]. Anzdata.org.au. 2021 [cited 20 March 2022]. Available from: https://www.anzdata.org.au/wp-content/uploads/2022/02/20220216_LKDMonthlyReport_2021December.pdf
 38. Hyde M, Masser B, Edwards A, Ferguson E. Australian Perspectives on Opt-In and Opt-Out Consent Systems for Deceased Organ Donation. *Progress in Transplantation.* 2021;31(4):357-367.
 39. Department of Health. Becoming an organ and tissue donor [Internet]. Canberra: Commonwealth of Australia. 2020 [cited 7 February 2022]. Available from: <https://www.health.gov.au/health-topics/organ-and-tissue-donation/becoming-an-organ-and-tissue-donor>
 40. DonateLife Network. Join the register [Internet]. DonateLife. 2022 [cited 7 February 2022]. Available from: <https://www.donatelife.gov.au/register-donor-today>
 41. Services Australia. AODR Intent Registrations 2021 [Internet]. Canberra: Commonwealth of Australia; 2022 [cited 7 February 2022]. Available from: <https://www.servicesaustralia.gov.au/sites/default/files/aodr-register-intent-registrations-dec-2021.xlsx>
 42. Services Australia. AODR Consent and 16-17 intent registration 2021 [Internet]. Canberra: Commonwealth of Australia; 2022 [cited 7 February 2022]. Available from: <https://www.servicesaustralia.gov.au/sites/default/files/aodr-register-consent-registrations-and-16-17-intent-registrations-dec-2021.xls>
 43. Overview: About Blood | National Blood Authority [Internet]. [cited 2022 Feb 21]. Available from: <https://www.blood.gov.au/about-blood>
 44. What we're doing about blood and blood products | Australian Government Department of Health [Internet]. [cited 2022 Feb 21]. Available from: <https://www.health.gov.au/health-topics/blood-and-blood-products/what-were-doing-about-blood-and-blood-products>
 45. Why donate blood | Lifeblood [Internet]. [cited 2022 Feb 21]. Available from: <https://www.lifeblood.com.au/blood/learn-about-blood/why-donate-blood>



46. What is plasma? | Lifeblood [Internet]. [cited 2022 Feb 21]. Available from: <https://www.lifeblood.com.au/blood/learn-about-blood/plasma>
47. What are platelets? | Lifeblood [Internet]. [cited 2022 Feb 21]. Available from: <https://www.lifeblood.com.au/blood/learn-about-blood/platelets>
48. Learn about blood | Lifeblood [Internet]. [cited 2022 Feb 21]. Available from: <https://www.lifeblood.com.au/blood/learn-about-blood>
49. Gahan L, Masser B, Mwangi C, Thorpe R, Davison T. Motivators, facilitators, and barriers to blood donation in Australia by people from ethnic minority groups: Perspectives of sub-Saharan African, East/South-East Asian, and Melanesian/Polynesian blood donors. *J Sociol*. 2021 Mar 19;58(1):95–112.
50. Bednall TC, Bove LL. Donating Blood: A Meta-Analytic Review of Self-Reported Motivators and Deterrents. *Transfus Med Rev*. 2011;25(4):317–34.
51. Donor Brochure – English - ABMDR [Internet]. [cited 2022 Feb 21]. Available from: <https://www.abmdr.org.au/downloads/donor-brochure-english/>
52. Donate your blood or bone marrow - Leukaemia Foundation [Internet]. [cited 2022 Feb 21]. Available from: <https://www.leukaemia.org.au/get-involved/other-ways-to-get-involved/donate-your-blood-or-bone-marrow/>
53. Common questions about stem cell donation – Ur the Cure [Internet]. [cited 2022 Feb 21]. Available from: <https://www.urthecure.com.au/common-questions>
54. Peripheral Blood Stem Cell (PBSC) Donation | Be The Match [Internet]. [cited 2022 Feb 21]. Available from: <https://bethematch.org/support-the-cause/donate-bone-marrow/donation-process/donating-pbsc/>
55. What's involved in stem cell and bone marrow donation – Ur the Cure [Internet]. [cited 2022 Feb 21]. Available from: <https://www.urthecure.com.au/whats-involved>
56. Neate, S., Marck, C., Skinner, M., Dwyer, B., Mcgain, F., Weiland, T., Hickey, B. and Jelinek, G., 2015. Understanding Australian Families' Organ Donation Decisions. *Anesthesia and Intensive Care*, [online] 43(1), pp.42-50. Available at: <<https://pubmed.ncbi.nlm.nih.gov/25579288/>> [Accessed 29 January 2022].
57. Radunz S, Benko T, Stern S, Saner FH, Paul A, Kaiser GM. Medical students' education on organ donation and its evaluation during six consecutive years: results of a voluntary, anonymous educational intervention study. *Eur J Med Res* [Internet]. 2015 [cited 2019 Feb 06];20(1):23. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4359403/doi:10.1186/s40001-015-0116-6>
58. 2021. *Best Practice Guideline for Offering Organ and Tissue Donation in Australia*. 2nd ed. [ebook] Australian Government Organ and Tissue Authority. Available at: https://www.donatelife.gov.au/sites/default/files/2021-05/final_best_practice_guideline_for_offering_organ_and_tissue_donation_apr2021.pdf [Accessed 1 February 2022].
59. Core Family Donation Conversation (FDC) Workshop. DonateLife [Internet]. [cited 2022 March 22]. Available from: <https://www.donatelife.gov.au/for->



- healthcare-workers/professional-training/core-family-donation-conversation-fdc-workshop
60. DonateLife. 2021. *2020 Australian Donation and Transplantation Activity Report*. [online] Available at: <https://www.donatelife.gov.au/outcomes/2020-australian-donation-and-transplantation> [Accessed 10 February 2022].
 61. Hospital care - Australian Institute of Health and Welfare [Internet]. Australian Institute of Health and Welfare. 2020 [cited 10 February 2022]. Available from: <https://www.aihw.gov.au/reports/australias-health/hospital-care>
 62. Johnson C, Toy L. Unacceptable kidney transplant rate for Indigenous Australians [Internet]. Australian Medical Association. 2017 [cited 8 July 2021]. Available from: <https://www.ama.com.au/articles/unacceptable-kidney-transplant-rate-indigenous-australians>
 63. Review of the Australian organ donation, retrieval and transplantation system [Internet]. Australian Government; 2018. Available from: <https://www.health.gov.au/sites/default/files/documents/2020/02/review-of-the-organ-donation-retrieval-and-transplantation-system-final-report-final-report.pdf>
 64. Walker CR, Abel S, Reynolds A, Palmer CS, Walker C, Tipene-Leech DC. Experiences, perspectives and values of Indigenous people regarding kidney transplantation: a systematic review and thematic synthesis of qualitative studies. *International Journal for Equity in Health*. 2019 December. 204 (2019); doi: 10.1186/s12939-019-1115-y
 65. Smith, Z., Woods, Cindy., Usher, K., & Lea, J. 2019. Australian perioperative nurses' attitudes, levels of knowledge, education and support needs related to organ donation and procurement sugar. A national survey. *The Journal of Perioperative Nursing*. 32 (2). Available from: <https://www.journal.acorn.org.au/cgi/viewcontent.cgi?article=1044&context=jpn>. Accessed [10/02/2022]
 66. Forbe-Smith, L., Haire, M., & Doneley, M. Social work practice in the donation of human tissue for transplantation: utilising social work values and competencies to achieve effective outcomes for transplant patients and donor families. *Soc Work Health Care*. 2002;35(1-2):377-89. doi: 10.1300/J010v35n01_03. PMID: 12365750. <https://pubmed.ncbi.nlm.nih.gov/12365750/> Accessed [10/02/2022]
 67. Cotrau P, Hodosan V, Vladu A, Daina C, Daina LG, Pantis C. Ethical, Socio-Cultural and Religious Issues in Organ Donation. *Maedica*. 2019; 14(1):12-14. Doi: 10.26574/maedica.2019.14.1.12
 68. Almassi B. Trust and the duty of organ donation. *Bioethics*. 2014;8(6):275-83. doi: 10.1111/bioe.12096. Epub 2014 Apr 15.
 69. May T, Aulisio M P, DeVita M A. Patients, families and organ donation: who should decide? *Milbank Quarterly*. 2000; 78(2): 323-36. doi: 10.1111/1468-0009.00172.
 70. Chandler J, Burkell JA, Shemie SD. Priority in organ allocation to previously registered donors: public perceptions of the fairness and effectiveness of

- priority systems. *Progress in Transplantation*. 2012; 22(4):413-22. doi: 10.7182/pit2012324
71. Alpinar- Sencan, Baumann H, Biller-Andorno N. Does Organ selling violate human dignity? *Monash Bioethical Review*. 2017; 34(3-4):189-205. doi: 10.1007/s40592-017-0070-x.
 72. World Health Organisation. Report: First Global Consultation on Regulatory Requirements for Human Cells and Tissues for Transplantation. *Health Product Policy and Standards*. 2004. Available from: <https://www.who.int/publications/i/item/9241593296> . Accessed [10/02/22]
 73. Gonzalez, J., Garijo, I., & Sanchez, A. Organ Trafficking and Migration: A Bibliometric Analysis of an Untold Story. *International journal of environmental research and public health*. 2020, 17(9), 3204. <https://doi.org/10.3390/ijerph17093204>
 74. Alnour, H., Sharma, A., Halawa, A., & Alalawi, F. Global Practices and Policies of Organ Transplantation and Organ Trafficking. *Experimental and Clinical Transplantation*. 2021. Available from: <http://www.ectrx.org/detail/epub/1/1/1/0/998/0>. Accessed [10/02/22]
 75. Scheper-Hughes, N. Keeping an eye on the global traffic in human organs. *The Lancet*. DOI :[https://doi.org/10.1016/S0140-6736\(03\)13305-3](https://doi.org/10.1016/S0140-6736(03)13305-3). 2003, 361: 9369 (1645-1648). Accessed [10/02/22]
 76. Kennedy, S., Shen, Y., Charlesworth, J.A, Mackie, J.D, Mahony, J.D, Kelly, J.J, & Pussell, B.A. Outcome of overseas commercial kidney transplantation: an Australian perspective. *Med J Aust*. 2005 Mar 7;182(5):224-7. PMID: 15748132.
 77. Liu Y, Yang R, He Z, Gao W. Generation of functional organs from stem cells. *Cell Regeneration*. 2013;2(1):2:1.
 78. Lu T, Yang B, Wang R, Qin C. Xenotransplantation: Current Status in Preclinical Research. *Frontiers in Immunology*. 2020;10.
 79. Liu Y, Yang R, He Z, Gao W. Generation of functional organs from stem cells. *Cell Regeneration*. 2013;2(1):2:1.
 80. World Health Organization. WHO guiding principles on human cell, tissue and organ transplantation [Internet]. Geneva: World Health Organization; 2010 [cited 2022 Feb 06]. 9 p. Available from: https://www.who.int/transplantation/Guiding_PrinciplesTransplantation_WHA63.22en.pdf?ua=1
 81. Wellesley H. A nudge in the right direction for organ donation- but is it enough?. *British Medical Journal*. October 2011; 343: d5726
 82. Etheredge HR. Assessing Global Organ Donation Policies: Opt-in vs Opt-out. *Risk Management and Healthcare Policy*. May 2021;14: 1985-1998.
 83. Katznelson G. Rethinking Organ Donation- when altruism isn't enough [internet]. Boston; Harvard Law; 2018. Available from: <https://blog.petrieflom.law.harvard.edu/2018/04/06/rethinking-organ-donation-when-altruism-isnt-enough/#:~:text=More%20recently%2C%20Illinois%20experienced%20success,have%20now%20agreed%20to%20donate.>



84. Prabhu PK. Is presumed consent an ethically acceptable way of obtaining organs for transplant? *Journal of the Intensive Care Society*. 2019 May 20(2);92-97. doi: [10.1177/1751143718777171](https://doi.org/10.1177/1751143718777171)
85. Bailey E. Should the State have rights to your organs? Dissecting Brazil's mandatory organ donation law. *University of Miami Law Review*. 1999 30(3);707-726.
86. Bosch X. Spain model; World leaders in Organ Donation. *JAMA* 1999; 282 17-18
87. Rafael M. Factors influencing the Spanish Model of Organ Donation. *Transplant International*. 2003; 16(10):736-41. doi: 10.1007/s00147-003-0623-1
88. Wilkinson T.M. Individual and Family Decisions about Organ Donation. *Journal of Applied Philosophy*. 2007; 24(1): 26-40
89. M Thomas, Aulisio MP, DeVita M. Patients, Families and Organ Donation: Who should decide?. *Milbank Quarterly*. 2000; 78(2): 323-336
90. McEwan PM. Valid Informed Consent; the key to increasing supply of organs for transplantation. *Critical Care and Resuscitation*. 2005; 7; 246-249



Appendix

Table 1: Summary of Models of Donation and Models of Consent

<u>Model of Consent and Donation</u>	<u>Definition</u>
Soft Opt-In	Individual decides to opt in to being a donor. If no decision is made, there is an assumption that the individual did not want to be a donor. Family consent is the final decision.
Soft Opt-out	Individual decides to opt out of being a donor. If no decision is made, there is an assumption that the individual did want to be a donor. Family consent is the final decision. Also known as 'soft presumed consent'
Hard Opt-in	Individual decides to opt in to being a donor. If no decision is made, there is an assumption that individual did not want to be a donor. The decision of the individual, not the family, is the final division.
Hard Opt-out	Individual decides to opt out of being a donor. If no decision is made, it is assumed that individual did want to be a donor. The decision of the individual, not the family, is the final decision. Also known as 'hard presumed consent'
Mandatory Choice	Individual is required to make a choice for organ donation preference when applying for government and legal documentation. This system can be used concurrently with any of the 4 above. Individuals may choose to refrain or defer choice.



Table 2: Summary of deterrents regarding individuals decisions to donate blood

<u>Deterrents</u>	<u>Definition</u>	<u>Example Items</u>

Lifestyle barriers, inconvenience	Donor has other commitments they believe make it too difficult to donate	<p>"Too busy; no time"</p> <p>"Work schedule conflict"</p> <p>"Donation location is inconvenient, appointment times are inconvenient"</p>
Misinformation, fear for own health	Believes their body size or total blood volume is too small for them to donate	<p>"Not having enough blood"</p> <p>"Afraid the nurse will take too much of my blood"</p>
Low involvement, lack of marketing communication	General disinterest in the activity, perceived lack of relevance to own needs/values, haven't engaged with any marketing	<p>"Never really thought of it, never been asked to give"</p> <p>"Don't know what the Red Cross does, not telephoned by the Red Cross"</p>
Lack of knowledge	Individuals are unaware about the need for blood donation or about their potential eligibility to donate	"Did not know it was important to donate"
Negative service experience	Dissatisfaction with service	Rude staff at the clinic, unpleasant clinic outlay
Fear	Fear of needles, pain, injury, own ill-health, contagion, blood, discovering illness	<p>"I don't like the sight of blood"</p> <p>"I'm not good with needles"</p> <p>"I don't want them to detect a disease"</p> <p>"Might be long-term consequences to my health"</p> <p>"Risk of getting AIDS from donating"</p>

Negative attitudes	Negative word of mouth, cynicism, outgroup prejudice	<p>"Friend had a bad experience"</p> <p>"Appeals for blood aren't really urgent"</p> <p>"Don't want [blood] to go to certain groups"</p>
Personal values/Religiosity	Moral obligation to avoid specific behaviours, or discouragement arising from religious affiliation or spiritual commitment	<p>"Against my religious beliefs"</p> <p>"I feel it is immoral to give blood"</p>



Table 3: Summary of motivators regarding individual decision to donate blood

<u>Motivators</u>	<u>Definition</u>	<u>Example Item</u>
Convenience of Collection Site	Ease of Access	Mobile blood drive at university, workplace Nearby located clinics
Personal Values/Religiosity	Feelings of moral obligation to perform specific behaviours such as blood donation – from personal moral norms, or from religious affiliation or spiritual commitment	"donating is a duty" "religious reasons"
Altruism, community collectivism	Motivation with the goal of increasing the welfare of others (whether individual, community or friends and family) without regard for social or material rewards	Humanitarianism
Reputation of Collection Agency	Extent to which collection agency is regarded as efficient and reliable in deployment of resources	"it is a good cause" "support for work of the Red Cross"

Perceived need for donation	Awareness that blood donation is necessary – either the ongoing need for blood, or especially in the aftermath of a catastrophic event	Helping the community, or national crisis “Because blood is needed”
Indirect reciprocity	Engaging in blood donation in response to, or in anticipation of, an act in kind by a third party, e.g friend or family having received blood in the past, motivation to donate after having personally received blood themselves, belief that if they help, they will in turn be helped if needed	Knowing someone who needed blood Can get blood when I need it Feelings of repayment for transfusion
Marketing communication	Advertising campaign and communications to recruit and retain blood donors	Organisation has blood drives Hearing appeal on TV, radio, paper Mailed or texted reminders to donate or return to donate
Social norms	Perceptions of how others typically behave in a given situation, perceived social pressure to perform a certain way	Friends who donate blood, encouraged by religious organisation, social group



Policy Details:

Name: Organ and Tissue Donation(2022)

Category: F – Public Health in Australia

History: Reviewed, Council 1, 2022

Bipandeep Banga, Aahana Dudani, Shun Hei Janis Hui, Melanie Weston, Megan Banks, Tess Dorrington, Patrick Rosengren, Mason Ginters (National Policy Mentor), Yufei Xu

(National Policy Mentor), Ashraf Docrat (National Policy Officer)

Reviewed, Council 1, 2019

Grace Newman (Co-lead Author), Jason Ong (Co-lead Author), Srishti Dhir, Anant Butala, Sophie He, Stephanie Lee, Daniel Zou (Policy Officer)

Reviewed Council 12, 2015

Adopted, Council 2, 2012

