

A BRAVE NEW SYSTEM? AN ANALYSIS OF THE POTENTIAL IMPLEMENTATION OF AN OPT-OUT ORGAN DONATION SYSTEM IN MALAYSIA

Sofiya Imran*

An Overview of the Organ Crisis in Malaysia

Much like most controversial healthcare matters, the subject of organ donation and transplantation is besieged with a myriad of questions that are medical, legal, ethical and moral in nature. In certain jurisdictions, like Malaysia, where religion and culture are inextricably intertwined with state policies and legislation, an assessment of organ donation and transplantation would not be complete without a proper consideration of the crucial role played by religious and cultural norms and practices. However, before this article delves into the intricacies of these issues, it is worth noting at the outset the worldwide shortage of organs. It goes without saying that this is a tremendous problem of global proportions and, as such, countries all over the world are desperately trying to combat this crisis via the implementation of their respective organ donation systems. So far, only a handful of countries – Spain¹ and Croatia² included – have been successful in their quest to increase the number of available organs. Unfortunately, Malaysia has yet to join these ranks³ and it would seem that, as a nation, we have much to do before that becomes a reality.

This then prompts us to ask the question: why does such a shortage exist, and that too on such a massive scale? On the face of it, it seems quite clear-cut that people would not hesitate to donate their organs, particularly after death. After all, one certainly does not need one's organs if one is no longer living, so why not donate them 'for the greater good'? However, this assumption overlooks the many dilemmas that often muddy the waters surrounding the decisions (or, indeed, refusals) to donate one's organs.

When it comes to cadaveric organ donation, there are two organ donation models i.e. the opt-in system and the opt-out system. The former system prioritises the *explicit* consent of the potential donor above all else. To frame it differently, a person's organs can only be removed posthumously if he/she has made it very clear (when they were alive) that said removal is in accordance with their wishes. This is the system adopted by Malaysia and, until very recently,

* Lecturer, Faculty of Law and Government, HELP University.

¹ Adam Arshad, Benjamin Anderson and Adnan Sharif, 'Comparison of Organ Donation and Transplantation Rates between Opt-Out and Opt-In Systems' (2019) 95 *Kidney International* 1453, 1458.

² Makmor Tumin, Khaled Tafra and NurulHuda Mohd Satar, 'Family Response To Presume Consent System On Organ Donation From A Review Of Literature' (2015) 9(3) *International E-Journal of Science, Medicine & Education* 20, 25.

³ Yuen Meikeng, 'Worrying Lack of Transplants' *The Star Online* (Kuala Lumpur, 26 July 2018) <<https://www.thestar.com.my/news/nation/2018/07/26/worrying-lack-of-transplants-experts-more-kidney-failure-patients-turning-to-dialysis-instead>> accessed 5 August 2019.

England,⁴ which will be shifting to the opt-out system from next year onwards.⁵ A strong driving force behind this new opt-out system, also known as Max and Keira's Law, is the need to increase actual donation rates in England to bridge the gap between the supply of organs and the demand for organs. Government ministers contend that this legislative change could potentially save up to 700 lives a year,⁶ which is by no means an insignificant number. It remains to be seen if the new Organ Donation (Deemed Consent) Act 2019 will actually deliver on this promise.

A quick Google search tells us all we need to know about the sorry state of organ donation and transplantation rates in Malaysia, with the country's organ dearth emblazoned on various newspaper headlines.⁷ Datuk Dr Ghazali Ahmad, who doubles as both a prominent nephrologist and the President of the Malaysian Society of Transplantation, laments at our "miserably low" organ donation rate, which was a mere 2 per million population (pmp, for short) for live donor kidney donation and between 0.4-0.6 pmp for deceased organ donation during the 2015-2017 period.⁸ These figures are rendered even more dismal upon realising that 1) the total population of Malaysia is well over 30 million⁹ and 2) there are more than 40,000 Malaysians on dialysis, a list which welcomes more than 7,000 new patients a year.¹⁰ In short, the supply of organs in Malaysia is in no conceivable way close to meeting the sheer demand for organs in the country, notably kidneys. This then begs the question: is our current opt-in system not fit for purpose?

The Opt-Out Organ Donation System: A Potential Panacea?

Before tackling that question, it is pertinent to briefly examine the opt-out system, which presumes that a person has consented to have their organs removed after their death in the absence of an explicit refusal. Both Spain and our neighbour on the other side of the Causeway are examples of countries practising the opt-out system. The Spanish model in particular is often lauded as an ideal for others to emulate, with its high donation rates from deceased

⁴ Editorial, 'Opt-out Organ Donation 'in place by 2020' for England' *BBC News* (London, 5 August 2018) <<https://www.bbc.com/news/health-45056780>> accessed 5 August 2019.

⁵ Wales was the first UK nation to introduce this "revolutionary" system at the end of 2015. See 'Organ Donation Law 'Revolution' Starts in Wales' *BBC News* (London, 1 December 2015) <<https://www.bbc.com/news/uk-wales-34964382>> accessed 5 August 2019.

⁶ Fergus Walsh, 'Organ Donor Law Change Named after Max and Keira' *BBC News* (London 26 February 2019) <<https://www.bbc.com/news/health-47359682>> accessed 5 August 2019.

⁷ Rizalman Hammim, '25,000 Still Waiting for Kidney Transplant in Malaysia' *New Straits Times* (Kuala Lumpur, 8 October 2018) <<https://www.nst.com.my/news/nation/2018/10/419094/25000-still-waiting-kidney-transplant-malaysia>> accessed 5 August 2019; Datuk Dr Ghazali Ahmad, 'Poor Rate in Organ donation' *The Star Online* (Kuala Lumpur, 4 August 2018) <<https://www.thestar.com.my/opinion/letters/2018/08/04/poor-rate-in-organ-donation>> accessed 5 August 2019.

⁸ Ibid.

⁹ 'Demographic Statistics Second Quarter 2019, Malaysia' (*Department of Statistics Malaysia* 15 August 2019) <https://www.dosm.gov.my/v1/index.php?r=column/cthemedByCat&cat=430&bul_id=VTJdStOakJd2EwcEVVTm4yRDZSQTO9&menu_id=L0pheU43NWJwRWVVSZklWdzQ4TlhUUT09> accessed 20 August 2019.

¹⁰ Meera Murugesan, 'A New Benchmark for Kidney Care' *New Straits Times* (Kuala Lumpur, 28 March 2019) <<https://www.nst.com.my/lifestyle/heal/2019/03/473745/new-benchmark-kidney-care>> accessed 5 August 2019.

patients.¹¹ In 2018, Spain achieved a historical high by beating its own record and reaffirming its position as the “world leader” in organ donation and transplantation with a staggering donation rate of 48 pmp and 114 transplants pmp.¹² However, it is interesting to note that Singapore does not share Spain’s success,¹³ in spite of the fact that the opt-out system operates in both countries. According to statistics released by the Ministry of Health, Singapore’s deceased organ donation rate in 2017 was 6.6 pmp, representing only a marginal increase from 5 pmp a decade previously.¹⁴ Whilst these figures are considerably better than ours, Singapore’s progress is still a far cry from Spain’s. Thus, yet another question emerges: would transitioning to an opt-out system actually ‘cure’ the severe shortage of organs in our country?

The questionable effectiveness of the opt-out system aside, we ought to ask ourselves whether Malaysia could, or indeed should, follow in England’s footsteps in taking that drastic leap towards an opt-out system. Unlike our Western counterparts who are predominantly secular, religion and culture remain significant in Asian countries and communities; Malaysia is no different. Therefore, any scrutiny of a potential or hypothetical move towards the implementation of an opt-out system must be done in light of the multicultural and multireligious elements that are woven into and ingrained in our nation’s tapestry.

Scope of the Article

This article will first briefly look at the different types of organ donation made available through medical advancement and technological innovation. It will also explore, in some detail, the laws surrounding organ donation and transplantation in Malaysia, the UK, Spain and Singapore. Furthermore, the overall Malaysian attitude towards organ donation and transplantation will be examined in an attempt to determine why Malaysians are just not keen on becoming organ donors. Given the predominantly Muslim population in Malaysia, an analysis of the Islamic view on organ donation and transplantation will be included, along with a brief consideration of Buddhist, Hindu and Christian beliefs on the subject. Finally, this article will conclude with an examination of whether the Malaysian organ donation system is in need of reform and, if so, whether an opt-out system is the reform we need.

Types of Organ Donation

i. Living Organ Donation

Non-vital organs (e.g. kidneys as well as lung and liver lobes) can be taken from living donors,¹⁵ a practice which has the capacity to increase the pool of potential organ donors and maximise the number of healthy organs available for transplantation. Because this procedure

¹¹ Ibid (n 1) 1455.

¹² ‘Spain, The World Leader in Donations and Transplants’ (*España Global*, 15 January 2019) <<https://espanaglobal.gob.es/en/current-news/society/spain-world-leader-donations-and-transplants>> accessed 5 August 2019.

¹³ Jacqueline J L Chin and Theodora H X Kwok, ‘After Presumed Consent: A Review of Organ Donation in Singapore’ (2014) XI No 3 *Indian Journal of Medical Ethics* 139.

¹⁴ Jalelah Abu Bakar, ‘Are You Sure He is Dead?’: Doctors Struggle With Families’ Lack of Understanding of HOTA’ *Channel News Asia* (Singapore, 5 May 2019) <<https://www.channelnewsasia.com/news/singapore/human-organ-transplant-act-doctors-families-understanding-11459284#targetText=Singapore%20had%20a%20deceased%20organ,donors%20pmp%20a%20decade%20ago.>> accessed 5 August 2019.

¹⁵ Emily Jackson, *Medical Law: Text, Cases and Materials* (4th edn, OUP 2016) 629.

involves the donor undergoing a major operation strictly for the medical benefit of another individual, it is often perceived to be an act driven by altruism and selflessness. On the flip side, the practice of living organ donation is deemed controversial to some. Findings from a number of studies illustrate that living organ donation does pose real, albeit small, health risks to the donor, including psychological symptoms. For example, a study by Walter et al found that 10% of living liver donors encountered difficulty coping with the psychological impact of their donation.¹⁶ However, there is strong evidence illustrating that living organ donation contributes to increased self-esteem and feelings of wellbeing¹⁷ amongst donors, suggesting that this form of donation does not solely benefit the recipients.

ii. Deceased or Cadaveric Organ Donation

From a theoretical, medical science point of view, any organ can be removed from a person almost immediately after death. Unlike living organ donation, cadaveric organ donation makes all organs – including vital ones like the heart and lungs – available. Traditionally, one of two systems are in place to procure cadaveric material: opt-in and opt-out. The difficulty lies in ensuring that the organs of the deceased individual are actually utilised for the purposes of donation and transplantation. To achieve this end, the philosopher John Harris is of the opinion that it should be lawful to retrieve organs from the dead even without authorisation from either the deceased or the deceased's family,¹⁸ thus creating a system of “organ conscription”¹⁹ rather than organ donation. Of course, such a system would never enjoy public or governmental support, which is why Harris later revised his position and posited an opt-out organ donation system as the second-best option.²⁰ Nevertheless, as we shall see, the implementation of an opt-out system in itself does not automatically increase organ donation rates. Unlike with living organ donation where the donor explicitly gives permission to have his or her organs used, surviving relatives of the deceased individual can be instrumental in authorising or impeding the retrieval and subsequent utilisation of organs, even in cases where the deceased had previously consented to having his/her organs removed upon death. Here we see that the individual's consent can be overridden by familial wishes, which accordingly has the detrimental effect of further reducing the number of organs actually donated.

Organ Donation Legislation

i. Malaysia: The Human Tissues Act 1974

The sole legislation to regulate organ donation and transplantation in Malaysia is the Human Tissues Act (HTA, for short) 1974. In force for almost half a century, the HTA has never been added to or amended, and is possibly one of the shortest pieces of legislation we have with only five sections to its name. The brevity of the Act makes sense as it only governs cadaveric donation and is completely silent on living organ donation – which means that the practice of living organ donation in Malaysia is unregulated by statute and is solely protected by the common law. The HTA imposes two conditions which need to be fulfilled before the removal of organs from the deceased is lawful: 1) there must be an express request of the

¹⁶ M Walter et al, ‘Quality Of Life of Living Donors before and after Living Donor Liver Transplantation’ (2003) 35 *Transplantation Proceedings* 2961.

¹⁷ Roberta G. Simmons, Susan D. Klein and Richard L. Simmons, *Gift of Life: the Social and Psychological Impact of Organ Transplantation* (Wiley: New York 1977).

¹⁸ John Harris, ‘The Survival Lottery’ (1975) 50 *Philosophy* 81.

¹⁹ Margaret Brazier and Emma Cave, *Medicine, Patients and the Law* (5th edn, Penguin Books Ltd 2011) 513.

²⁰ John Harris, ‘Law and Regulation of Retained Organs: The Ethical Issues’ (2002) 22 *Legal Studies* 22.

donor either in writing or orally in the presence of two witnesses²¹ and 2) there must be no objection to the removal of organs from either the deceased *or* the surviving spouse or surviving next of kin.²²

A quick perusal of section 2 of the HTA reveals that the Malaysian organ donation system is an opt-in one; in other words, individuals have to, while they are still alive, record their intentions to donate. Nevertheless, the consent of the individual in question is not the only important element doctors take into consideration. The language of section 2(2) is crucial: it makes clear that the wishes of surviving relatives can, in fact, legally supersede the instructions of the deceased over his or her own body and organs. Hence, in practice, should there be an unresolvable conflict between the wishes of the deceased potential donor and that of his or her family members, organ donation will be abandoned entirely because approval of the next of kin is required by law. The overall veto power vested in relatives of the deceased by virtue of the HTA indicates that one's next of kin become the final arbiters on whether organs are retrieved for donation or otherwise. It could be argued that it is only appropriate that the law accords proper respect and consideration to the deceased's family, particularly at such a tragic time, but to what end and at what cost? At this juncture, we need to ask ourselves whether the law as it currently stands is right in allowing the wishes of the family to triumph over an autonomous decision made by the deceased.

Whilst the HTA makes no mention of living organ donation, the publication of the National Organ, Tissue and Cell Transplantation Policy in June 2007 attempts to clarify Malaysia's position regarding this type of donation. Article 6.1 maintains the country's preference for cadaveric donors but provides that "where appropriate, organs and tissues from living donors may be used"²³ and professes a commitment towards protecting the rights and welfare of living donors.²⁴ However, this policy document is merely that: a policy. There is no doubt that it serves as a helpful guide for the relevant stakeholders, but there is no legal force ascribed to it. Furthermore, the policy does not stipulate those who are subject to it and whether any form of non-compliance with the policy will be met with consequences or sanctions. Thus, whilst the policy does indeed soundly emphasise Malaysia's responsibility towards promoting organ donation and transplantation of the highest ethical and professional standards, it seems to do little else.

The introduction of this article set out Malaysia's cadaveric organ donation rate (0.4-0.6 pmp), a rate which regrettably classifies us as having one of the lowest deceased organ donation rates *in the world*.²⁵ To add insult to injury, as of 30 June last year, Malaysia has a total of 21, 230 people on the organ waitlist, the vast majority of whom are waiting for kidneys, amounting to 21, 212 people.²⁶ In light of these dismal numbers, there have been

²¹ Section 2(1) of the Human Tissues Act 1974.

²² Section 2(2) of the Human Tissues Act 1974, emphasis added.

²³ Article 6.1, National Organ, Tissue and Cell Transplantation Policy, Ministry of Health, Malaysia (June 2007). See also Article 6.

²⁴ Article 2.5, National Organ, Tissue and Cell Transplantation Policy, Ministry of Health, Malaysia (June 2007).

²⁵ Makmor Tumin, Abdillah Noh, Raja Noriza Raja Ariffin, Nurulhuda Mohd Satar, Yong Sook Lu, Lim Soo Kun and Ng Kok Peng, 'Low Organ Donation Rate in Malaysia: A Survey' Volume 17(1) Journal of Health and Translational Medicine 14.

²⁶ Editorial, 'Health Ministry: 'Opt Out' System Not an Option', *The Star Online* (Kuala Lumpur, 26 July 2018) <<https://www.thestar.com.my/news/nation/2018/07/26/health-ministry-opt-out-system-not-an-option>> accessed 5 August 2019.

calls for the country to transition to an opt-out system instead. However, said calls have been met with a resounding ‘no’ from the Health Ministry, on the grounds that the Malaysian public is “just not ready”²⁷ for such a system. Given the lack or absence of public readiness, what more can be done to rectify our current organ deficiency? The proposed Organ and Tissue Transplantation Bill might just be the answer to our prayers. Apart from acting as a replacement for the Human Tissue Act 1974, the new Act proposes, *inter alia*, to ban organ trading involving Malaysian organ-seekers and to put live organ donation on a legal, regulatory footing, and therefore possesses a broader ambit than its predecessor. Furthermore, under the planned new law, anyone involved in the procurement of organs and tissues from a donor (living or dead) without prior consent or authorisation risk facing a hefty fine of up to RM500,000 or a prison sentence for a period not exceeding 15 years, or both.²⁸ Explicit authorisation is still required under this new Bill and, as such, the opt-in system remains unaffected, just bolstered by strong deterrent elements. The Bill was drafted six years ago in 2013²⁹ and has resided in the Attorney-General’s chambers for further deliberation since 2015.³⁰ Since there appears to have been no update on the matter and the Bill has yet to become formal law, any discussion on its merits remains purely academic.

ii. The United Kingdom

The United Kingdom’s legal position on organ donation is quite unique in nature because there is currently no uniform position which applies across the country. As we all know, the UK is comprised of four separate nations, namely England, Wales, Scotland and Northern Ireland. The Human Tissue Act 2004 is the primary legislation regulating donation and transplantation, and applies to England, Wales and Northern Ireland, whereas organ donation in Scotland is governed by the Human Tissue (Scotland) Act 2006. The principle of explicit consent for cadaver donation underpins the 2004 Act³¹ and could occur in one of the following scenarios:

- (i) The deceased himself gave appropriate consent to donate or he refused consent;
- (ii) Consent is given by the deceased’s nominated representative; or
- (iii) Neither of the above apply and consent is given by a close family member or friend who stood in a “qualifying relationship” with the deceased prior to his death.³²

Here we see the difference between this Act and the Malaysian 1974 Act – close family members only get involved *in the absence of* the deceased’s explicit consent under the 2004 Act. Should the deceased’s wishes be available, they cannot legally be overridden by that of his next of kin. Nevertheless, the dictates of the law are not always translated into practice. The NHS Blood and Transplant website is frank about the reality in the UK:

²⁷ Ibid.

²⁸ Sarban Singh, ‘Move to Curb Trade in Human Organs’ *The Star Online* (Kuala Lumpur, 18 September 2013) <<https://www.thestar.com.my/News/Nation/2013/09/18/Move-to-curb-trade-in-human-organs/>> accessed 5 August 2019.

²⁹ Ibid (n 28).

³⁰ Yuen Meikeng, ‘A Price Tag for Human Organs’ *The Star Online* (Kuala Lumpur, 4 October 2015) <<https://www.thestar.com.my/news/nation/2015/10/04/a-price-tag-for-human-organs>> accessed 5 August 2019.

³¹ The Human Tissue (Scotland) Act 2006 also operates on an opt-in basis.

³² Section 3(6) Human Tissue Act 2004.

Although registering a decision to donate...is a legally valid decision to donate your organs, in practice if your family strongly feel that they cannot support donation...donation doesn't go ahead.³³

Thus, whilst the law does not permit the existence of a family veto, medical practice does exactly that. This is presumably the case because healthcare professionals are extremely hesitant to act in a manner which could damage or undermine the relationship of trust and confidence which ought to exist between them and their patients' loved ones. The reluctance of the medical professionals could also be attributed to the fact that, unfortunately, conversations concerning cadaveric organ retrieval only occur at what is an obviously bleak and upsetting time for the family. As such, those professionals involved in organ retrieval would be particularly sensitive to the family's grief and loss of a loved one. However, it is submitted that the medical profession has taken this "compassionate sentiment"³⁴ too far, to the point where it has not only usurped the right the deceased has over what happens to his own body but also denied the gift of life proffered by him.

At the time of writing, only Wales has introduced and implemented the opt-out system (also known as a system of 'deemed consent'). It did so via the enforcement of the Human Transplantation (Wales) Act 2013 which came into effect in 2015, thereby amending the Human Tissue Act 2004. Although the Act is only a few years old, it appears to have made a demonstrable improvement in the procurement rates for both living and deceased donation. Data released by the NHS in July 2017 signal that Wales is experiencing more registered donors, fewer family refusals and a higher rate of living donations.³⁵ Does the 2013 Act, through the adoption of deemed consent, alter the weight previously allocated to family refusals? Just like the Human Tissue Act 2004, the 2013 Act makes it lawful to remove organs from registered donors, even in the face of family objections. When such objections take place, specialists are under the duty to discuss the matter with the family, encourage them to accept the deceased's decision and emphasise that the family does not have a legal right to override his recorded decision or wishes.³⁶ In spite of that, family objections will *still* often result in the organs not being removed. This is in accordance with the Specialist Nurses-Organ Donation (SN-OD) national guidelines which deny the existence of a legal family veto but goes on to declare that, it is "not unlawful not to proceed"³⁷ with organ retrieval when it is met with familial objection. In short, despite the paradigm legislative shift, actual practices under the opt-out system in Wales do not differ from the rest of the UK which is still governed by an opt-in system. This suggests that something more than a mere switch from opt-in to opt-out is needed. A study on the short-term impact of the opt-out system in Wales by Noyes et al

³³ 'Families Saying No to Donation Results in Missed Transplant Opportunities for Patients' (*NHS Blood and Transplant*, 15 January 2016) <<https://www.organdonation.nhs.uk/get-involved/news/families-saying-no-to-donation-results-in-missed-transplant-opportunities-for-uk-patients/#targetText=If%20you%20have%20registered%20a,in%20discussions%20about%20organ%20donation.>> accessed 8 August 2019.

³⁴ *Ibid* (n 19) 518.

³⁵ Andreas Albertsen, 'Deemed Consent: Assessing the New Opt-Out Approach to Organ Procurement in Wales' (2018) 44 *Journal of Medical Ethics* 314, 314.

³⁶ 'How is Consent for Organ Donation Established?' (*NHS Blood and Transplant*) <<https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/faq/consent/>> accessed 8 August 2019.

³⁷ Section A, 4.3, Policy POL164/5 – Consent/Authorisation for Organ and/or Tissue Donation (2017) <https://nhsbtb.blob.core.windows.net/umbraco-assets-corp/4531/consent_authorisation_for_organ_and_or_tissue_donation_poll164.pdf> accessed 8 August 2019.

concluded that moving to the opt-out system is but “the first step of a longer journey”,³⁸ and that a country’s efforts should not stagnate there.

Unconvincing progress aside, Wales can be seen as a sort of trailblazer, as both England and Scotland are soon to follow in its footsteps. Come spring next year, England will move to an opt-out system following the enforcement of the Organ Donation (Deemed Consent) Act 2019 which received Royal Assent on 15 March. Upon receiving Royal Assent on 18 June 2019, The Human Tissue (Authorisation) (Scotland) Act 2019 will introduce a similar system in Scotland, though it is envisioned that there will be at least another 12 months before this new system is introduced. This is to ensure that the people of Scotland are fully informed about the change and what their choices are.³⁹ Through these brand-new Acts of Parliament, adults in England and Scotland will be considered potential organ donors unless they choose to opt out or fall under one of the groups excluded by the law. As previously mentioned, it is projected that the legislative jump from opt-in to opt-out will be a “vital step” in saving many more lives, in the words of former Prime Minister Theresa May.⁴⁰ We shall wait with bated breath to see if she is right.

iii. Spain: Spanish Law 30/1979, 27 October, on Organ Extraction and Transplant

Spain, with their opt-out system, stands head and shoulders above the rest of the world in the arena of organ donation and transplantation, and they have done so for quite some time now. Published data reports that 2,183 people in Spain became organ donors upon their deaths in 2017, which amounts to 46.9 pmp.⁴¹ Hence, it seems rather fitting that Spain’s National Transplant Organisation (*Organización Nacional de Trasplantes* or ONT, for short) confidently labels their country as “*imbatible*”.⁴² With figures like that, it is no wonder that Spain is so revered internationally in this regard, with certain countries moving to the opt-out system in an attempt to recreate ‘the Spanish model’. However, one must not be hasty in assuming that the success of the Spanish approach wholly hinges upon its deemed or presumed consent system. The reality is that the Spanish model is so much more than its chosen legal framework.

To begin with, opt-out legislation has been in place in Spain from as early as 1979 but a positive growth in transplant rates was only noticeable a decade later, once the ONT was

³⁸ Jane Noyes, Leah McLaughlin, Karen Morgan, Philip Walton, Rebecca Curtis, Susanna Madden, Abigail Roberts and Michael Stephens, ‘Short-term Impact of Introducing a Soft Opt-Out Organ Donation System in Wales: Before and After Study’ (2019) 9 *BMJ Open* 1, 4.

³⁹ ‘Organ and Tissue Donation Law in Scotland’ (*NHS Blood and Transplant*) <<https://www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-scotland/>> accessed 8 August 2019.

⁴⁰ Gemma Mitchell, ‘Opt-out Organ Donation Bill Passed into English law’ (*Nursing Times* 15 March 2019) <<https://www.nursingtimes.net/news/policies-and-guidance/opt-out-organ-donation-bill-passed-into-english-law-15-03-2019/>> accessed 9 August 2019.

⁴¹ “Nota de prensa: España, líder mundial en donación y trasplantes, vuelve a alcanzar un nuevo récord con 46,9 donantes p.m.p y 5.261 trasplantes”, Ministerio de Sanidad, Servicios Sociales e Igualdad (2017).

⁴² ‘Unbeatable’ in Spanish. See generally Chris Baraniuk, ‘Spain Leads the World in Organ Donation – What’s Stopping Other Countries Catching Up?’ *The Independent* (London, 29 July 2018) <https://www.independent.co.uk/news/long_reads/spain-leads-world-organ-donation-organ-transplant-health-science-a8417606.html> accessed 9 August 2019.

created.⁴³ The ONT is “a national network of specifically trained, part-time, dedicated and strongly motivated hospital physicians in direct charge of the whole process of donation”,⁴⁴ and its formation has served to increase cadaveric donation rates in Spain in an effective and sustained manner. Quigley et al sum up the key principles of the Spanish model and view the transplant coordination network and the profile of the transplant co-ordinator as pivotal.⁴⁵ A salient characteristic of the Spanish model is this network of transplant coordinators who are located at hospital, regional and national levels. There is at least one team of transplant coordinators in every hospital with an intensive-care unit (ICU, for short)⁴⁶ whose responsibilities are intrinsic to the Spanish success. Transplant coordinators are tasked with identifying and evaluating donors, supporting the maintenance of potential donors in the ICU and interviewing donor families. In spite of the opt-out system in Spain, families are still consulted and the next of kin can, in practice, veto donation.⁴⁷ However, the availability of a family veto has not reduced donation rates in the country. The low family refusal rate is very much linked to the indispensable role played by transplant coordinators.

Because these coordinators are primarily ICU doctors, they are uniquely placed to cultivate a bond of trust with the patients’ families, a bond which proves to be highly valuable when requesting for organ donation. When faced with an ICU patient with the potential to become an organ donor, transplant coordinators are meticulous and considerate in taking the time to gently introduce the possibility of organ donation to family members. The effort expended in this respect goes a long way in increasing the likelihood of relatives actively consenting or not objecting to donation in the event of death. To illustrate, Spain has one of the lowest rates of family refusal of organ donation in the world with only 13% of next of kin refusing donation.⁴⁸ Therefore, it is evident that the Spanish success story is the result of the country’s strong commitment to ensuring the creation, availability and maintenance of the necessary infrastructure and resources,⁴⁹ and not its opt-out framework as some might suggest. Whilst the Spanish model should continue to be viewed by other countries as the gold standard for organ donation, those looking to replicate its accomplishments would do well to remember that legislative reform is but the tip of the iceberg. For any serious and substantial progress to be made, there must exist, on multiple levels, a carefully considered and well-coordinated organisational scheme designed specifically to manage organ donation and transplantation in the country.

iv. Singapore: The Human Organ Transplantation Act (HOTA)

Given the close geographical, historical, political, social and cultural relationship Malaysia shares with Singapore, it is only sensible for this article to analyse the organ donation policies of our neighbour in the south. Singapore is the only Asian country to enable a system of

⁴³ Muireann Quigley, Margaret Brazier, Ruth Chadwick, Monica Navarro Michel and David Paredes, ‘The Organ Crisis and the Spanish Model: Theoretical Versus Pragmatic Considerations (2008) 34 No 4, *Journal of Medical Ethics* 223, 223.

⁴⁴ *Ibid.*

⁴⁵ *Ibid* (n 43).

⁴⁶ R Matesanz, B Miranda and C Felipe, ‘Organ Procurement and Renal Transplants in Spain: The Impact of Transplant Coordination (1994) 9 Issue 5 *Nephrology Dialysis Transplantation* 475.

⁴⁷ Amanda M. Rosenblum, Lucy D. Horvat, Laura A. Siminoff, Vensha Prakash, Janice Beitel and Amit X Garg, ‘The Authority of Next-of-Kin in Explicit and Presumed Consent Systems For Deceased Organ Donation: An Analysis of 54 Nations’ (2012) 27, *Nephrology Dialysis Transplantation* 2533, 2542.

⁴⁸ *Ibid* (n 42).

⁴⁹ *Ibid* (n 43) 224.

presumed consent (opt-out), so in that regard it is highly unusual and an interesting dynamic to examine. The Human Organ Transplantation Act (HOTA, for short) came into force in 1987. It focused only on cadaveric kidney donation and applied to all Singaporeans, initially exempting Muslims and individuals over the age of 60 from the opt-out system.⁵⁰ HOTA was amended in January 2004 to legally permit living organ donation as well as the retrieval of other organs.⁵¹ A further amendment was made in 2008 to bring Muslim donors into the fold.⁵² The most recent amendment came in March 2009 to 1) remove the upper age limit for potential deceased donors, 2) provide permission for paired kidney exchange, 3) increase penalties for organ trading and 4) provide for donor compensation.⁵³

Although both Spain and Singapore's organ donation systems operate on an opt-out basis, it would seem that that is where the similarities between the two end. Unlike Spain, Singapore does not allow families to veto organ donation,⁵⁴ which makes it a 'hard' opt-out system.⁵⁵ Armed with section 5 of HOTA, hospitals are legally authorised to retrieve any organ from the body of a citizen or permanent resident over 21 years old who has died there *and* who, during his lifetime, has not formally opted out of donating all or specific organs via the HOTA opt-out form. If the wishes of the family do not trump the presumed consent of the deceased, a position that is solidified by the law, surely it would follow that Singapore enjoys quite a high rate of deceased donors? Alas, that is not to be. Despite the absence of a family veto and low percentage of opt-outs,⁵⁶ the number of cadaveric donors actualised per year remains consistently low. Again, we see the reluctance of the medical profession to interrupt a family's grief and 'demand' that their (very recently) dearly departed's organs be removed to give a stranger a chance at life. Legally, doctors do have the right to bypass the family and their loss, but it is an act that could potentially be perceived as 'inhumane' or 'insensitive', which might do more harm than good in the long run. This is particularly the case as potential donors in Singapore are not required to expressly consent to the removal of their organs for donation. Therefore, one is unable to argue that by acquiescing to the family veto, the medical profession is disrespecting the explicit, autonomous wishes of the deceased – which was the argument posited against opt-in systems overriding the unambiguous wishes of the deceased.

To sum up, although an opt-out system premised on presumed or deemed consent to organ donation has been in place in Singapore for over three decades now, it has not yet realised the goal of increasing organ donors. The Singaporean reality reinforces the point that opt-out laws and frameworks, in and of themselves, are not the silver bullet⁵⁷ they are often made out to be.

⁵⁰ Ibid (n 13) 139.

⁵¹ Ibid.

⁵² Valerie Chew, 'Human Organ Transplant Act (HOTA)' (*National Library Board Singapore*) <http://eresources.nlb.gov.sg/infopedia/articles/SIP_1401_2009-01-08.html> accessed 11 August 2019.

⁵³ Ibid.

⁵⁴ Ibid (n 47) 2542.

⁵⁵ The Spanish model would therefore be described as a 'soft' opt-out system.

⁵⁶ Jean Liu, 'Commentary: Timely to Review Out Opt-out Organ Donation Policy' *Channel News Asia* (Singapore, 18 October 2017) <<https://www.channelnewsasia.com/news/singapore/commentary-timely-to-review-our-opt-out-organ-donation-policy-9317580>> accessed 11 August 2019.

⁵⁷ Christopher WY Liu, Vui Kian Ho and Jean CJ Liu, 'Is the Human Organ Transplant Act (HOTA) to Blame? Addressing Our Organ Shortage from a Public Policy Perspective' (2017) 46 No10 *Annals of the Academy of Medicine, Singapore* 392, 392.

Organ Donation and Transplantation: The Malaysian Attitude

Bearing in mind the heterogeneity of Malaysian culture, it might be a form of over-generalisation to assume that there exists just 'one' Malaysian attitude towards organ donation and transplantation. However, given the truly paltry donation numbers in the country, it might actually be the case that Malaysians, on the whole, are united in our lack of readiness or willingness to become committed actual donors.⁵⁸ A more microscopic view of this public non-commitment towards an act which could be deemed a public service reveals that the overall Malaysian attitude regarding organ donation and transplantation transcends simple apathy. Cultural traditions, religious beliefs as well as misconceptions stemming from a lack of quality information from key stakeholders all play a part in contributing towards the lack of willingness to donate our organs, which consequently affects the nation's donation rates in a negative way. In short, there is an undeniable domino effect at work here.

Robson *et al*'s article looks at a variety of reasons impacting organ transplants in Malaysia and highlight a few social misconceptions unique to the Malaysian society which first need to be considered.⁵⁹ This includes the fear that the body of the deceased donor will be "mutilated and treated badly" in the course of the organ retrieval procedure, or that the organ retrieval team will remove organs other than those specified for donation by the deceased.⁶⁰ Those who subscribe to either of these beliefs are sorely mistaken because 1) organ removal surgery is a routine operation whereby the bodies of the deceased are treated in a dignified manner and 2) if the donor only consented to have certain organs removed for donation, doctors cannot disregard his specific instructions. Another misconception concerns the fear that doctors would be more swayed by the utilitarian good that comes from one's status as an organ donor and, in order to maximise the potential of those organs, they would not try to save that individual's life.⁶¹ This fear is again misplaced because the doctors who treat the patient *are not* the doctors on the transplant team. Robson et al make clear that the organ procurement team are only notified once all lifesaving efforts have failed and after death has been determined. As stated earlier, there is a further hurdle to overcome before the deceased's organs are removed in Malaysia i.e. consent from the next-of-kin. This functions as an additional barrier precluding transplant doctors from removing whatever they want, whenever they want, however they want.

It does not take much for the misconceptions elucidated above to take root and grow amongst the public, consequently causing Malaysians to have little to no trust in the organ donation process. The lack of information surrounding organ donation coupled with the fact that organ donation is generally not something most people think about (especially when there is no medical urgency involved) need to be actively addressed if Malaysia wants to see real, positive change in our organ donation and transplantation rates. How we can do this as a nation will be discussed later in the article.

Organ Donation and Transplantation: Cultural and Religious Views

⁵⁸ Farah Salwani Muda, interview with Dr. Ghazali Ahmad, Consultant and Head of the Department of Nephrology at Kuala Lumpur General Hospital, Malaysia (Kuala Lumpur, 12 February 2008)

⁵⁹ N Robson, N Dublin and AH Razack, "Organ Transplants: Ethical, Social and Religious Issues in a Multicultural Society" (2008) 22(3) *Asia Pacific Journal of Public Health* 271.

⁶⁰ *Ibid.*

⁶¹ *Ibid* (n 59).

It is impossible to conjure up a true image of the Malaysian society without due regard for the diverse range of races, cultures and religions it encompasses. The way in which the vast majority of Malaysians lead their lives is very often shaped by our respective cultural practices and religious beliefs. In the Malaysian context, the reach of religion cannot be overstated as it permeates through every aspect of our lives, including healthcare and medical matters, with the acceptability of certain medical practices being dependent on religious doctrine. Organ donation and transplantation are no different. Since Malaysia is home to a number of different religions, the main religions' perspectives on the permissibility of organ donation will be briefly considered below.

i. Islam

Malaysia is a Muslim-majority country with Muslims accounting for approximately 61.3% of the population.⁶² Given the substantial majority of Muslims, it is vital to examine whether or not the largest religious group in the country is religiously authorised to donate their organs. However, this is not at all straightforward. Robson et al rightly state that there is “a striking variability in attitudes towards transplantation throughout the Muslim world”.⁶³ For example, Saudi Arabia⁶⁴ and Iran⁶⁵ have given organ donation and transplantation the green light, whereas the practice is non-existent in Afghanistan and Turkmenistan.⁶⁶ Even Islamic scholars are not unanimous in their opinions. Because neither the Quran nor the hadiths explicitly address contemporary medical issues like organ donation and transplantation, Sharia law permits scholars to deliberate on such issues before coming up with *fatwas*,⁶⁷ which are later adopted by Muslims.

It is imperative to remember that scholars, though well-versed in Islamic scripture and jurisprudence, are ultimately individuals. As such, resulting *fatwas* will almost certainly be influenced, to some degree, by any scholar's subjective interpretation. The majority of scholars encourage organ donation and transplantation on the basis that it 1) prioritises the saving of human lives (as per the Quran)⁶⁸ and 2) is in accordance with Prophet Muhammad's *Sunnah* which implores Muslims to “make use of medical treatment, for Allah has not made a disease without appointing a remedy for it, with the exception of one disease, namely old age”.⁶⁹ This is the line embraced by a number of countries including Saudi Arabia, Kuwait, Singapore, the United Kingdom and Egypt.⁷⁰ However, Mufti Muhammad Shafi (the late grand Mufti of Pakistan) issued a fatwa in the 1960s *against* organ donation, which was

⁶² ‘Malaysia Demographics Profile 2018’ (*IndexMundi.com*) <https://www.indexmundi.com/malaysia/demographics_profile.html> accessed 12 August 2019.

⁶³ *Ibid* (n 59).

⁶⁴ S Aswad, ‘Cadaveric Transplantation in Saudi Arabia: A 5-year Experience’ (1992) 24(5) *Transplant Proceedings* 1837.

⁶⁵ B Larijani, F Zahedi and E Taheri, ‘Ethical and Legal Aspects of Organ Transplantation in Iran’ (2004) 36(5) *Transplant Proceedings* 1241.

⁶⁶ AJ Ghods, ‘Current Status of Organ Transplant in Islamic Countries’ (2015) 13 *Supplement 1 Experimental and Clinical Transplantation* 13.

⁶⁷ Islamic legal pronouncements, issued by a *mufti* (expert in religious law), pertaining to a specific issue where *fiqh* (Islamic jurisprudence) is unclear.

⁶⁸ “...and if anyone saved a life it would be as if he saved the life of the whole people...” Surah I-Maidah [5:32].

⁶⁹ Al-Tirmidzi, Muhammad ibn ‘Isa ibn Sawrah ibn Musa ibn Dahhak. (1975). *Sunan al-Tirmidzi*, Volume 4. Egypt: Mustafa al-Babi al-Halabi, 383.

⁷⁰ ‘Organ Transplantation from the Islamic Perspective’ (*Ministry of Health Malaysia*, 2011) 24-26 <<http://www.moh.gov.my/moh/resources/auto%20download%20images/589d7ab14fcd6.pdf>> accessed 12 August 2019.

endorsed by a number of Indo-Pakistani religious scholars.⁷¹ In short, there is no such thing as an Islamic consensus on the issue of organ donation and transplantation.

Where do Malaysian Muslims stand on this ‘to donate or not to donate’ debate? In June 1970, the National Fatwa Council decided that cadaveric donations are permissible in Islam under certain considerations and that living donation is allowed as long as donors are not inflicted with harm such as death or disability.⁷² If the faith – as far as Malaysian Muslims are concerned – endorses organ donation and transplantation, why are Muslims the least likely to donate their organs after death?⁷³ A more recent study attempts to rationalise this peculiar state of affairs by investigating the actual views of Malaysian Muslims and found that more than half of the participants believed organ donation to not only be permitted in Islam but is also a “communal responsibility”.⁷⁴ Nevertheless, the mere belief that organ donation is a communal responsibility is not equivalent to actually donating one’s organs when the time comes. Tumin et al suggest that, in order for pro-donation beliefs to translate into organs actually donated, the state has to go the extra mile and address the Muslim population’s concerns about organ donation through effective policy tools.⁷⁵

ii. Buddhism

Like Islam, there are no scriptural rules in Buddhism for or against organ donation. However, Buddhists place a lot of emphasis on alleviating suffering and could view organ donation as an act of charity.⁷⁶ In Buddhism, the decision to donate (or otherwise) is left up to the individual concerned, and his/her wishes should not be overshadowed by the desire to save the life of another.⁷⁷ Like most other religions, there are different schools of Buddhism. Followers of Tibetan Buddhism in particular take the view that one’s consciousness remains in the body for some time after death. So, for as long as consciousness resides in the body, the body cannot be disturbed. This belief clearly has implications for organ donation as it is vital that donated organs are retrieved very soon after death, at a time where consciousness (probably) would have yet to exit the human bodily vessel.

Despite the inconclusive religious mandate, the practice of organ donation by Buddhists is worthy of commendation. Findings from a Malaysian study examining the deceased donation rates among Malaysians revealed that the willingness to donate among Buddhists

⁷¹ Mohammed Ghaly, ‘Religio-ethical Discussions on Organ Donation Among Muslims in Europe: An Example of Transnational Islamic Bioethics’ (2012) 15 *Medicine, Health Care and Philosophy* 207, 213.

⁷² *Ibid* (n 70) 16-17.

⁷³ Rajah Rasiah, Rishya Manikam, Sankara K Chandarsekaran, Gowindamal Thangiah, Saravanan Puspharajan and Dasan Swaminathan, ‘The Influence of Socioeconomic and Demographic Variables on Willingness to Donate Cadaveric Organs in Malaysia’ (2014) 93 No 12 *Medicine* 1, 3.

⁷⁴ Makmor Tumin, Abdullah Noh, NurulHuda Mohd Satar, Khaled Tafran, Nawi Abdullah, Wan Ahmad Hafiz Wan Md Adnan and Mohamad Yusoff Sanusi, ‘Muslims’ Views on the Permissibility of Organ Donation: The Case of Malaysia’, (2016) 10(1) *International E-Journal of Science, Medicine and Education* 41, 41 and 44.

⁷⁵ *Ibid* 45.

⁷⁶ ‘Buddhism and Organ Donation’ *BBC.co.uk* (London, 27 November 2009) <<https://www.bbc.co.uk/religion/religions/buddhism/buddhistethics/organdonation.shtml#targetText=There%20are%20no%20rules%20in,much%20on%20an%20individual's%20decision.>> accessed 12 August 2019.

⁷⁷ *Ibid*.

was significantly higher than Muslims, and even Hindus.⁷⁸ These results echoed that of a previous study which recorded Buddhists being the most likely religious group willing to donate their organs after death.⁷⁹

iii. Hinduism

In its efforts to promote organ donation awareness and increase organ donation rates among black, Asian and minority ethnic (BAME, for short) groups in the UK, the NHS produced and disseminated leaflets containing comprehensive information regarding various religions' perspectives on organ donation, Hinduism included.⁸⁰ Although, naturally, the sacred texts do not specifically mention organ donation, the endorsement of the *concept* of organ donation can be found in a verse from the Manusmriti: "of all things that it is possible to donate, to donate your own body is infinitely more worthwhile". This coupled with the distinct Hindu ethos that "the physical integrity of the body post-death is not crucial" and the strong belief in reincarnation⁸¹ might make organ donation far more palatable to Hindus.

The overall support for organ donation seems to be mirrored by the results obtained by Loch *et al* in 2010, where 63.8% of the study's Hindu participants indicated their willingness to donate their organs upon their deaths.⁸² However, only 45.8% - fewer than half - of the Hindu respondents in Rasiah *et al*'s study four years later were willing to donate their organs after death.⁸³ Perhaps more education and awareness efforts are required to drive up the numbers of Hindu organ donors.

iv. Christianity

Organ donation, according to mainstream Christian beliefs, has been defined as "a worthwhile act of charity", with most Christian faiths either openly supporting or tacitly approving the practice.⁸⁴ The former Pope, Pope Benedict XVI, described organ donation as "a profound act of love" and has been a registered organ donor since the 1970s. Even though his decision to donate may eventually be rendered merely theoretical (as the Vatican dictates that Popes are to be buried intact), his enthusiastic endorsement of organ donation as a "genuine expression of charity"⁸⁵ could serve as the religious motivation required by Catholics to become organ donors themselves. Moreover, the Church of England has even declared organ donation a "Christian duty" that is in accordance with giving oneself and one's possessions freely.⁸⁶

⁷⁸ R Rasiah, R Manikam, S K Chandrasekaran, N Naghvi, S Mubarik, R Mustafa and S Pushparajan, 'Deceased Donor Organs: What Can be Done to Increase Donation Rates Using Evidence from Malaysia?' (2016) 16 *American Journal of Transplantation* 1540, 1545.

⁷⁹ *Ibid* (n 73).

⁸⁰ NHS Blood and Transplant, 'Organ Donation and Religious Beliefs: A Guide to Organ Donation and Hindu Beliefs' (2012).

⁸¹ Mike Oliver, Aimun Ahmed and Alexander Woywodt, 'Donating in Good Faith or Getting into Trouble? Religion and Organ Donation Revisited' (2012) 2(5) *World Journal of Transplantation* 69, 71.

⁸² A Loch, I N Hilmi, Y Pillay and D S K Choon, 'Differences in Attitude Towards Cadaveric Organ Donation in a Multiracial Malaysian Society' (2010) 17(3) *Hong Kong Journal of Emergency Medicine* 236, 240.

⁸³ *Ibid* (n 73).

⁸⁴ *Ibid* (n 81) 70.

⁸⁵ Nick Squires, 'The Pope is an Organ Donor but His Body Parts Cannot be Donated' *The Telegraph* (London, 4 February 2011) <<https://www.telegraph.co.uk/news/worldnews/the-pope/8303510/The-Pope-is-an-organ-donor-but-his-body-parts-cannot-be-donated.html>> accessed 13 August 2019.

⁸⁶ Editorial, 'Organ Donation a 'Christian Duty' *BBC News* (London, 8 October 2007) <<http://news.bbc.co.uk/2/hi/health/7034487.stm>> accessed 13 August 2019.

Not many studies have focused on the view of Malaysian Christians on the topic of organ donation. However, a study conducted by Nur Idayu Badrolhisam and Zulkarnain Zakaria found that only 56.7% of their Christian respondents believed that their faith permitted organ donation.⁸⁷ Given the resounding sanction of the practice by the Church, it is a little concerning to note that a little over half of Malaysian Christians are aware of the ‘official’ religious view. Again, one draws the conclusion that a greater degree of awareness and education is needed from all sectors, and that such education and awareness also need to come from religious or faith leaders.

Reform in Malaysia: High time for Malaysia to opt-out?

There is no doubt that Malaysia is in dire need of concrete change in the organ donation and transplantation department for the simple reason that the status quo – where the demand for organs far exceeds the available supply – is neither practical nor sustainable. To exacerbate the situation even further, the already severely limited supply of organs appears to be experiencing a decline. The National Transplant reported that the number of new transplant patients decreased from 113 in 2007 to 82 in 2016,⁸⁸ the lowest it has ever been in Malaysia. One could not agree more with the Report’s pronouncement of the 41% decrease in the number of new transplants performed in 2016 as “disturbing”.⁸⁹ Nevertheless, a segment of Malaysian society refuses to be hindered by the country’s lack of organs and transplants; instead, they become ‘transplant tourists’ and seek out the organs they need from countries like China, India, Pakistan and Afghanistan.⁹⁰ The National Registry Report briefly makes reference to the transplant tourism phenomenon, stating there were 16 reported cases which took place in China in 2016.⁹¹ The issues and ethical considerations raised by transplant tourism are many and beyond the purview of this article. It is, however, worth mentioning that transplant tourism is by no means cheap. As such, Malaysians who engage in tourism of this nature more often than not come from the wealthier and more privileged sections of our society. This creates an unjust situation whereby one’s procurement of a much-needed organ is dependent, not on one’s medical need, but on one’s financial ability.

Although some may argue that the aforementioned 16 cases constitute a negligible amount, these cases were the only reported ones, so it remains a distinct possibility that the actual number is greater. Malaysia would do well to nip the occurrence of transplant tourism in the bud, and an obvious way to curtail it would be to increase the domestic supply of organs by changing our current organ donation and transplantation system. The question is: how do we do this? Do we completely overhaul the current system by moving to an opt-out system, which is the approach chosen by England and Scotland? Or can real, positive change be effected by updating and reforming the present opt-in machinery?

⁸⁷ Nur Idayu Badrolhisam and Zulkarnain Zakaria, ‘Knowledge, Religious Beliefs and Perception towards Organ Donation from Death-Row Prisoners from the Perspective of Patients and Non-Patients in Malaysia: A Preliminary Study’ (2012) 2 No 24 *International Journal of Humanities and Social Science* 197, 202.

⁸⁸ H S Wong and B L Goh (eds) *24th Report of the Malaysian Dialysis and & Transplant Registry 2016* (Kuala Lumpur, 2018) 183.

⁸⁹ *Ibid.*

⁹⁰ Frederike Ambagtsheer, Damián Zaitch, René van Swaaningen, Wilma Duijst, Willij Zuidema and Willem Weimar, ‘Cross-Border Quest: The Reality and Legality of Transplant Tourism’ [2012] *Journal of Transplantation* 1, 3.

⁹¹ *Ibid* (n 88).

It has been argued by some that the phrase ‘presumed consent’ is a misnomer as consent is meant to be an active process whereby the patient expressly permits a medical procedure or treatment to be carried out on their person.⁹² In the absence of informed consent, a doctor may only act on the basis that his actions are being carried out in his patient’s best interests, which is *not* equivalent to a ‘presumption’ of consent.⁹³ Many people believe that an opt-out system does not give the patient’s personal autonomy due respect. Instead, the prioritisation of the collective good that results from presumed consent to organ donation is questionable, and any move to enact an opt-out system in Malaysia may be met with considerable objection and hostility.

It is true that an opt-out system removes the ‘burden’ of registering a decision to donate from willing potential donors. However, this burden is repackaged and is now shouldered by those *un*-willing to donate their organs. In order to ensure that their decisions not to donate are legally respected, these individuals need to take that extra step and formally register their decisions. Failure to do so would mean that their organs are retrieved for donation and transplantation, irrespective of whether this might violate their personal (unexpressed) wishes. Thus, the public need to be made fully aware that, to avoid being categorised as donors by default, they need to register an explicit refusal under the opt-out system. This would entail the government rolling out nationwide awareness campaigns, particularly targeting the rural population to ensure that they are equally aware of and educated about their rights under the new system. Campaigns of this degree are naturally financially demanding and might not be viable in the long run. However, the absence of such campaigns would create a situation where large pockets of the Malaysian population are not sufficiently well-informed or educated and are therefore unable to make fully informed decisions. An opt-out system cannot thrive under these circumstances.

We have seen instances where the opt-out system *is* thriving, like in Spain, prompting opt-out advocates to use it as a benchmark. However, caution must be exercised here because, as illustrated earlier, the Spanish opt-out law was not the catalyst for the country’s impressive organ donation and transplantation rates; it was the establishment of the ONT, and the transplant coordination network associated with it. If Malaysia truly intends on reaching the same heights as Spain, legislative reform will simply not be sufficient. There is still every risk that, in introducing an opt-out mechanism, Malaysia will go the way of Singapore and not Spain.

It is Muda’s belief that Malaysia can still generate a greater number of potential organ donors via the opt-in system, but the system has to be maximised accordingly,⁹⁴ a view reiterated by Dr Ghazali Ahmad.⁹⁵ This article adopts a similar stance and takes the view that Malaysia’s efforts to improve our donation rates have not nearly been robust enough. Whilst the principle of opt-in or explicit consent ought to be maintained (for now), it is argued that the Human Tissues Act 1974 is in need of serious reform. As previously raised, the current opt-in system as practiced in Malaysia often ignores the wishes of the deceased, as all too often

⁹² Organ Donation Taskforce, *The Potential Impact of an Opt-Out System for Organ Donation in the UK – An Independent Report from the Organ Donation Taskforce* (2008) Article 5.2, 11.

⁹³ *Ibid.*

⁹⁴ Farah Salwani Muda, ‘A Socio-Legal Study on Organ Shortage in Malaysia’ (PhD Thesis, University of Southampton, 2012) 143.

⁹⁵ *Ibid.* 145.

doctors bow to familial pressure. In other words, even at present, the donor's autonomy is denied the respect and recognition it deserves.

Autonomy is a – if not *the* – key principle underpinning medical ethics. It dictates that medical decisions, no matter their nature, made by competent adults ought to be respected and adhered to. Whilst these decisions can be reached with the input of family members or close friends, it is the individual undergoing the medical procedure or treatment who has the final say. His or her word is ultimately what the medical profession relies on, above all else. It would seem that the medical profession in Malaysia, in general, accords patient autonomy the highest respect. Crucially, however, this profound respect for autonomy is absent when healthcare professionals confronted with organ donation decisions kowtow to the next-of-kin, completely side-lining the express wishes of the deceased donor.

Thus, should one's next-of-kin ever have a say when it comes to organ donation? We cannot exactly shy away from the fact that Malaysians are very family-oriented and, as such, family members (particularly immediate or close ones) often feature heavily in medical decisions. Furthermore, completely dismissing or eliminating familial consent would not only be “ghoulish” and demonstrate a lack of respect to the grieving family but also reduce the already finite number of donors,⁹⁶ which is something Malaysia most definitely must avoid at all cost. One comes to the inevitable conclusion that a delicate balance must be struck between individual autonomy/consent and the family veto.

The valid and authoritative status of familial refusal to organ donation in Malaysia, even in the presence of explicit permission from the deceased, needs to be removed from its present pedestal. One of the most effective ways to preclude families from flexing their organ-refusal muscles and exercising any authority over the wishes of the deceased is by legally amending the Human Tissues Act 1974 and removing section 2(2)(b) which deals specifically with the family veto. If the HTA 1974 is going to be replaced by the Organ and Tissue Transplantation Bill, this new Act should also make clear that families do not get to override the direct consent of the deceased. If family members will not give way on their own accord to the explicit wishes of their recently deceased loved one, the law must compel them to do just that. Nevertheless, family members will still be able to decide on behalf of the deceased in the event he or she passes away *without* leaving any explicit instructions on the subject of organ donation. This should suffice as a sort of compromise between personal autonomy and familial views, without totally sacrificing one for the other.

Of course, the aforementioned legislative change is not enough to give us the donor numbers we need. A key reason why our current system is ineffective is because it fails to identify potential donors quickly. Muda suggests that Malaysia is in need of an “effective, computerised and user-friendly registration system”⁹⁷ which is also made public. People need to be fully aware that such a system is in place, of how it functions and that it is actually being utilised for the good of society. Even without introducing opt-out laws, we can still take a page out of Spain's book in setting up a national database which links all the local hospitals (with organ retrieval resources and infrastructure in place) with the National Transplant Registry.⁹⁸ In this way, healthcare professionals will be able to identify, in a timely fashion,

⁹⁶ Thomas May, Mark P Aulizio and Michael A DeVita, ‘Patients, Families and Organ Donation: Who Should Decide?’ (2000) 23 No 2 The Milbank Quarterly 323, 328.

⁹⁷ Ibid (n 94) 240.

⁹⁸ Ibid (n 94) 294.

patients who are registered organ donors and the specific hospitals they have been admitted to.

The effectiveness of a national donor registration system and database will only be hampered if those on the ground are not fully equipped to handle the rise in donors. The Malaysian equivalent of Spain's ONT – the National Transplant Resource Centre (NTRC) – would benefit tremendously from emulating the ONT's role in coordinating organ donation and transplantation matters. To begin with, the public need to be made aware of the very existence of the NTRC so that they know that there is a specific body in place to handle organ donation and transplantation in the country. In order to promote real public trust and confidence in the NTRC, appointed staff must be highly trained, not only medically speaking but also with regard to the different situations which could arise between donors and their families. By discarding section 2(2)(b) of the HTA 1974, NTRC staff need to ensure that organ donation must take place where the deceased has provided clear, unequivocal consent. However, in making sure that donation is carried out, staff need to be trained to approach the matter and the bereaved families with the utmost sensitivity, so as not to present the impression that their views are carelessly overruled and their grief ignored.

The current lack of facilities and medical staff specialising in the area of organ donation and transplantation also contribute to the organ shortage in Malaysia and must be addressed. This will be costly to rectify but it will be money well spent. As Muda rightfully points out, there must be real improvements made to the structure and working conditions of the transplant coordinator network in Malaysia and recommends that at least one transplant coordinator is appointed to every state hospital in the country.⁹⁹ This would not only relieve the larger hospitals of the burden of catering for all transplantation cases but also means that transplant patients will not need to travel considerable distances to bigger hospitals for the procedure.

It is crucial to remember that the availability of state-of-the-art donation and transplantation facilities, resources and infrastructure must be buttressed by concentrated education and awareness campaigns. Efforts to educate the public on the moral and social good of organ donation ought to begin in schools. The sooner Malaysians are exposed to organ donation being the norm, the greater the likelihood of an increased pool of donors. Organ donation should no longer be a 'taboo' topic – young and old alike need to be exposed to the consequences of the organ dearth and the role we all play in minimising it. Organ donation campaigns need to be rolled out across the country, particularly in rural areas as the population there historically do not enjoy the same opportunities as their urban counterparts. Above all, these campaigns need to be informative and also tackle certain challenges that might prevent Malaysians from becoming actual organ donors. For instance, organ donation campaigns need to stress the significance of an open dialogue between potential donors and their families as well as the need for next of kin to respect decisions to donate. It is not enough for potential donors to record a formal donation decision; they also need to inform family members of their wish to be a donor and discuss said decision with their respective families. Although the family veto will be erased under the suggested removal of section 2(2)(b) of the 1974 Act, it is important that families are kept in the loop regardless, even if their views will not amount to a veto. Educational and awareness campaigns should also include a religious and cultural facet by calling upon local religious leaders and clerics to clarify various faiths' viewpoints surrounding organ donation and transplantation. The influence of local faith leaders cannot be

⁹⁹ Ibid (n 94) 254.

underestimated, so it is vital that these individuals are visible, approachable and well-informed.¹⁰⁰ It is of tremendous importance that religious clarification is done accurately and effectively in the more rural areas to clear up any confusion that might still linger among those communities. Because Malaysian Muslims are the least likely to register as donors and the most likely to refuse donation on behalf of their relatives, the contents of the 1970 national fatwa that permits living and cadaveric organ donation ought to be heavily publicised. This is so that Muslims are fully aware that organ donation does not constitute a transgression of their faith.

Finally, all of the reforms and changes mentioned above will not be possible without continuous, high-level government support. It must be emphasised that the current organ shortage in Malaysia is a national problem. As such there must be strong political commitment on the national level to reversing this deficiency before the nation can see any real change. When the public see politicians and members of government visibly and vigorously championing the cause, organ donation is transformed from a private medical matter to a national social issue. Only then will the people, as a collective, take action.

To sum up, opt-out legislation is by far from being the panacea to the organ shortage it is conveniently portrayed to be. The success of the Spanish model is the product of the infrastructure implemented by the country in its efforts to boost donation numbers, and not simply because they introduced opt-out laws. Therefore, preservation of the current opt-in system, with the addition of a number of key changes and improvements, could be the solution Malaysia needs. The road ahead is indeed a long and challenging one, but it is not one the nation should shy away from. There is far too much at stake.

¹⁰⁰ Ibid (n 94) 283.