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## Commentary: Timely to review our opt-out organ donation policy

Despite significant progress since the Human Organ Transplant Act was passed, the wait for an actual organ remains long. Yale-NUS College's Jean Liu explores the successes and challenges of an opt-out system.



Has the Human Organ Transplant Act (HOTA) come of age? (Photo: AFP/Mahmoud Zayyat)

SINGAPORE: Channel NewsAsia recently ran the story of Madam [Tan Sock Lian](#), a mother who offered four of her son's organs for donation when he died of a brain haemorrhage at 27.

The recipient of his heart – 30-year-old Tan Chwee Suan – lived for another 26 years following the transplant. When Mdm Tan saw how Chwee Suan cherished the new life she had been given, she told Channel NewsAsia that she had no regrets.

Despite stories like these, medical advances and one of the best healthcare systems globally, Singapore continues to face a severe organ shortage that prevents individuals with organ failure from receiving an organ transplant.

In 1987, the Human Organ Transplant Act (HOTA) was passed to address this scarcity. Through this legislation, and with its subsequent amendments, Singaporeans and permanent residents are automatically registered at age 21 to donate their kidneys, liver, heart and corneas upon death, unless they opt out with the Ministry of Health.

Thirty years since HOTA came into force, it is timely to review its successes and limitations.

### TWO KEY FEATURES OF HOTA

In analysing its outcomes, two features of HOTA are noteworthy.

First, HOTA institutionalises reciprocity. If an individual, who is registered as an organ donor, is in need of one, he or she is given higher priority to receive an organ, while those who have chosen to opt out of the scheme may find themselves at the bottom of a long waiting list.

While it is a practice in fairness, one can also think of this as an insurance policy, where registered donors can take heart in knowing that they have better odds of receiving an organ should they need one.

The second important feature of HOTA is that it presumes consent: The default position is that of a willing donor, and individuals who disagree with this position must actively opt out.

This increases the pool of donors by ensuring that individuals do not miss out simply because of administrative reasons, such as forgetting to complete a donor registration card.



A default position also guides decision making for those on the fence. If they choose to go with the default, this adds to the number of organ donors.

These features have made HOTA successful in expanding Singapore's pool of donors. As of this year, the number of registered donors extends to 97 per cent of the resident population, with an average of 196 transplants performed a year through HOTA – up from a meagre five kidney transplants yearly in the period preceding it.

#### STILL CONTROVERSIAL AFTER 30 YEARS

Despite significant progress, the wait for an actual organ transplant remains long in Singapore.

On average, patients with organ failure wait nine to 10 years for a kidney, or one to two years for a liver or heart. This trails behind countries such as Croatia and Spain, where the median waiting time for a kidney is between one to two years.

One reason for this discrepancy may be controversy over HOTA's presumed consent system. This assumes that all eligible donors who do not want to donate their organs know about HOTA and will opt out accordingly.



Inadequate awareness of organ donation policy and practice may account for the lower yield of transplantable organs.

However, these assumptions may not be true as seen from several highly-publicised cases, where family members have opposed the donation of their deceased relative's organs, claiming that the patient had not been aware of the law.

These families viewed the position of default consent as invalid and donation under HOTA amounting to a violation of their deceased relative's will.

In some cases, families have removed life support before an assessment of brain death can be conducted, therefore circumventing HOTA altogether.

Research suggests that although individuals may agree to donate their own organs, they are far more reluctant to donate a family member's organs. Without knowing for sure where a deceased relative would have stood on the issue, families usually choose to act conservatively.

This highlights potential problems with the execution of HOTA, resulting in missed opportunities for patients awaiting organ transplantation.

In response to these concerns, some commentators and parliamentarians called last year for HOTA to be removed, rooting instead, for a mandated consent policy that requires every Singaporean to declare in writing whether or not they would like to be an organ donor.

A mandated consent system would retain some benefits of an opt-out system since willing donors would register their intent, they said.

At the same time, they argued removing ambiguity about what a deceased patient wants could reduce family reluctance, potentially increasing the rate of conversion from donor registration to actual transplants.

#### THE FUTURE OF HOTA

Advancements in medical technology hold promise of a future with xenotransplantation and artificial organs. If these are developed, human organ donation will no longer be the primary solution for patients, and our current discussions would be irrelevant.

Until then, however, what does the future hold for HOTA?

It is clear that HOTA has not yet come of age. At the same time, it is unlikely that ridding it for a mandated consent scheme will be a silver bullet for the current organ shortage.

It is telling that at present, talks are in place for several mandated consent systems to be replaced with opt-out systems (such as in the state of Texas), whereas no domain is considering the reverse.

This highlights the very real possibility that when a default option is removed, the pool of registered organ donors could shrink.

Perhaps a middle ground can be sought, where HOTA's opt-out system is maintained, while requiring every resident to sign off during regular junctures that all Singaporeans go through, such as during one's passport renewal exercise every five years.

Alternatively, opt-out forms can be made easily available to increase both Singaporeans' knowledge of and ability to opt out if desired. These measures maximise the benefits of an opt-out scheme, while promoting confidence in an individual's registration on the donor list.

As we review HOTA's outcomes, it is also important to dig deeper into the idea of organ donation. The act of signing one's name to consent is not the end of its associated complexities.

One pertinent complication relates to our understanding of death. Most countries recognise two forms: Brain death and circulatory death.

While the heart stops in the latter, brain death is diagnosed when the heart is still pumping blood throughout the body. The diagnosis of brain death is a careful decision made after two highly trained specialists have ensured that all brain functions have ceased irreversibly.

This is the primary context under which organ transplants occur in Singapore, since vital organs quickly become unusable after the heart stops beating.

Although the medical world considers brain death to be final, many Asian cultures struggle with this definition. For them, as long as the heart is beating, organ removal under brain death may seem akin to euthanasia.

The complexities of policy, psychology and cultural beliefs make HOTA a policy that requires continual fine-tuning.

Moving forward, a more extensive package of solutions that targets not only the individual, but also families and society at large, can help to reduce the extent of Singapore's organ shortage.

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Source: CNA/sl