

## Executive Summary

Every day, over 2,000 patients in Hong Kong are waiting for an organ transplant to extend their lives. However, the organ donation rate in Hong Kong is currently amongst the lowest in the world at 6.3 donors per million people, seven times lower than that of Spain in 2016. Some Hong Kong patients even die whilst waiting for an organ transplant.

Hong Kong has long maintained a policy of ‘voluntary organ donation’. Under this mechanism, everyone can register themselves on the Centralised Organ Donation Register to show their willingness to donate their organs after their death. Currently, family members of potential donors legally hold the power to make the final decision; their consent must be given for the donation of the deceased’s organs.

In June 2017, the government released a paper titled ‘Background Information on Organ Donation and Transplant’. Views have been invited on the feasibility of three main suggestions, namely, a lowering of the age requirement for live organ donation, a paired donation scheme, and an opt-out scheme.

As the future masters of our society, young people, apart from making their own decisions on organ donation, might also be required to make decisions regarding their dead relatives. According to a report conducted by the Statistic and Census Department, young and middle-aged persons were more willing to donate their organs after death than persons in other age groups. This shows that it is important to know young people’s views and attitudes on organ donation, for these can provide insights into promoting organ donation amongst the general public.

In conducting this research, data were collected for analysis through a survey of 527 young people aged 18-34, three focus groups with 20 young people, and interviews with six experts or academics, from December 2017 to January 2018. It is hoped that this research will shed light on young people’s views on organ donation and will result in useful recommendations for promoting organ donation in Hong

Kong.

## Main Discussion

- 1. Young people in Hong Kong are apparently willing to be organ donors. Yet, given their high willingness, the number of registrants on the organ donor registry is surprisingly low. Therefore, strategies for promoting organ donation should be focused most on the younger generation.**

The organ donation rate in Hong Kong is currently amongst the lowest in the world, at 6.3 donors per million people. In the research, it was found that, of the respondents (527 young people aged 18-34), 85.8% agreed that organ donation could be life-saving. However, their high willingness to donate was accompanied by a low registration rate; 48.8% of respondents reported that they had not signed up as an organ donor although they were willing to be an organ donor.

Therefore, the government should first be focused on promoting registration for those willing to be organ donors in order to boost the general organ donation rate in Hong Kong in the long run. Additionally, as young people's willingness to donate their organs is relatively high, they should be the main target of organ donation promotion.

- 2. For young people, the main barriers to registering to be an organ donor were reported to be 'lack of clarity about registration procedures' and 'lack of time'. Therefore, the government should have multiple promotional strategies to increase registration amongst young people.**

According to the survey, for the respondents that were willing to be an organ donor but had not yet registered, the main barriers were 'lack of clarity about registration procedures' (26.5%) and

'lack of time' (21.0%). Experts and scholars also indicated in the interviews that the general public only have limited knowledge of organ donation due to the government's ineffective promotion; their methods still adhere to old-fashioned practices, such as exhibiting booths in the streets, and are ineffective in engaging with the general public to increase organ donor registration.

The first priority should be to increase the registration rate of the general public, and young people especially. To address the barriers faced by young people, the relevant authorities should increase the promotion of registration procedures and make registration more convenient.

**3. Early identification and referral of potential organ donors can provide more patients the opportunity of donating their organs.**

Early identification of persons with a devastating brain injury and referral to intensive care units can provide more patients the opportunity of donating their organs. However, patients with brain trauma always miss the proper opportunity to donate their organs. Such patients are normally admitted to a General Medical Ward, the busiest ward in a hospital with each nurse assigned to take care of 15 patients. As the limited resources must be left for the most urgent patients, the situation of potential organ donors cannot constantly be monitored by the medical workers. Without intensive care that aims to incorporate the option of organ donation into a patient's end-of-life care plan, the organs of a patient might not be adaptable for organ transplant due to organ damage or failure.

The experts also indicated that there were insufficiently few Organ Transplant Coordinators in Hong Kong. Currently, coordination with family members can only be focused on the large-scale hospitals. In fact, potential organ donors can be found in all hospitals, not just large-scale ones.

Based on this, it is important for the government to intervene in the healthcare system by making available more medical resources and

manpower. Further, the pool of potential donation-after-brain-death donors may increase substantially when more resources are put into the healthcare system.

**4. Consent must be given by family members to donate a deceased person's organs. Therefore, registration and family communication are important elements for final donation.**

Between 2012 and 2016, there were 546 medically certified brain-dead persons in Hong Kong. In 45% of these cases, consent was given by the family members to donate the deceased's organs. There were 18 registered organ donors out of all 546 brain-dead persons, only two of whose organs failed to proceed to donation due to the objection of family members. In other words, most family members of the registered organ donors were willing to donate their organs.

Family communication is also an important factor contributing to organ donation. In this research, respondents were asked to indicate the likelihood of donating family members' organs in the case of their death in different situations. Respondents were willing to donate a family member's organs if the family member had a donor card or was on the organ donation register (67.7%). If the family member had not expressed their wish to donate, only 24.9% were willing to donate a family members' organs.

The general consent rate of organ donation by family members was not low. Furthermore, most of the family members were willing to donate the deceased's organs if they had registered as an organ donor. Therefore, the government should take measures to increase the willingness people to allow organ donation as well as encourage communication on the issue of organ donation amongst family members.

**5. Work in the education sector should continue to address the obstacles posed by traditional culture.**

As a Chinese society, Hong Kong is deeply affected by traditional Chinese culture. People in Hong Kong rarely talk about issues relating to death, as doing so is taboo in Chinese society. According to this survey, amongst the respondents willing to be an organ donor after death, 62.3% of them had not expressed their wishes regarding donation to their family members. Furthermore, 66.7% and 59.9% of respondents did not know their father's and their mother's stance on organ donation respectively.

Family members' ignorance of each other's wishes regarding organ donation decreases the chances of after-death organ donation. Therefore, work in the field of education should continue to address the obstacle of traditional culture so that discussion of death and organ donation will no longer be taboo in the future.

- 6. Of the three suggestions proposed by the government, the paired donation scheme was most supported by the general public; both lowering the age requirement for live donation and the opt-out scheme were more controversial than the paired donation scheme.**

The current Human Organ Transplant Ordinance is ambiguous and does not clearly allow the suggested paired donation scheme. The scheme was supported by the interviewed experts and scholars, who felt it would be life-saving for patients and reduce the waiting time for an organ transplant. The government should review the ordinance immediately to provide legal backing for such a scheme. The experts generally disagreed with lowering the age requirement for live donation, as those younger than the current age limit may be incapable of making such a decision. Additionally, they felt that now is not a suitable time for an opt-out scheme, as this may change the nature of organ donation, which should be voluntary rather than compulsory.

In this survey, the acceptability of the paired donation scheme was also the highest of the three government suggestions; 53.3% of the respondents agreed that a paired donation scheme should be

implemented in Hong Kong to increase the supply of organs, whilst only 9.7% disagreed. For the other schemes, 36.2% of the respondents agreed to lower the age requirement for live donation, whilst 28.6% disagreed and 28.6% were torn between the two choices. The opinion regarding the opt-out scheme was more divided, with the proportion of respondents agreeing and disagreeing roughly equal, 33.4% and 33.0% respectively.

The government should take the easiest to implement of the three schemes as its first priority. To save the lives of dozens of patients, reviewing the ordinance to provide legal backing for a paired donation scheme should be at the top of the government's agenda. As both lowering the age requirement for live donation and an opt-out scheme were more controversial, the government should implement these only when they have had fully consulted with and been given the consent of the society it governs.

## Recommendations

This study proposes the following recommendations:

- 1. Increase registration rates through the application of multiple measures**

Since a territory-wide identity card replacement exercise will start in the final quarter of this year, this study recommends that the Department of Health should collaborate with the Department of Immigration. Citizens applying for the new card will be asked if they want to be an organ donor. In addition, the relevant authority should also collaborate with other departments so that when citizens file application forms when using public services they will also be asked whether they want to be an organ donor. This should make the process more efficient and could significantly boost the number of registered donors.

The government should also put more effort into promotion and

education, for example by holding more life-and-death courses in the community, in order to prevent misunderstanding of organ donation.

## **2. Increase the donor pool by identification of more potential donors**

This study also recommends that public hospitals in Hong Kong make reference to the end-of-life care practice in Spain, where after-death donation is optimised and possible donors who are brain-dead can be admitted to an intensive care unit; one to two beds in intensive care units in all Hong Kong public hospitals should be reserved for potential organ donors.

In the future planning of new hospitals, an additional one or two beds and health workers should also be provided in intensive care units for potential organ donors.

The government should also expand the number of Organ Transplant Coordinators from the current total of just nine for all Hong Kong hospitals to two in each hospital cluster.

In order to investigate the possibility of using other sources of organ donation to increase the donor pool, the government should lend more support to clinical research on organ transplants, such as the use of organs from donors with expanded criteria, non-standard risk, and circulatory death in Spain.

## **3. Prevention and education**

The government should educate the general public about the ways in which healthy lifestyle choices, such as exercising more and smoking and drinking less, can lower the possibility of suffering from organ failure. If someone, unfortunately, suffers from a chronic disease, seeking medical advice and treatment early on may also prevent organ failure.

#### **4. Subsidies for live donors**

This research also recommends that subsidies should be available for live donors, who normally stop work and have to stay in hospital for six to eight weeks. A government subsidy from the Community Care Fund, equivalent to at least two months of paid leave at the same rate as minimum wage, should be given to live donors.