

# Research Brief

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## Organ donation in Hong Kong

July 2016

*Hong Kong's organ donation rate is currently among the lowest in the world, at 5.8 donors per million people in 2015. This has invited intense discussion about whether Hong Kong should switch from an opt-in to an opt-out system in order to increase the number of potential donors. At present, Hong Kong adopts an opt-in system based on voluntary decisions of people to donate and the family consent to the donation after death.*

*The opt-out system does not necessarily guarantee a remarkable increase in the organ donation rate, in particular when virtually all opt-out countries with higher donation rates adopt a "soft" system which still requires family consent to organ donation.*

*Nevertheless, there are other success factors that can be identified from the experience of Spain and Australia. Both countries experienced a marked increase in their organ donation rate after the implementation of reform measures in 1989 and 2009 respectively. These measures include (a) establishing a dedicated authority charged with the overarching responsibility for organ donation and transplantation activities; (b) providing funding support to donation and transplant hospitals; and (c) setting up a dedicated team within each hospital for early identification of potential donors. Australia has also implemented theme-based organ donation promotion measures which target at young people and promote family discussions about donation wishes to ensure that every potential donor's decision is upheld.*

*The subject of organ donation falls within the policy area of the Panel on Health Services.*



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### 1. Background

1.1 In Hong Kong, as in many parts of the world, there are many people with organ failure in desperate need of organ transplant. Organs used for transplant come from two sources: living and cadaveric donations. While living donation is an option for some patients with organ failure, cadaveric organs are the main source of organs in transplant.

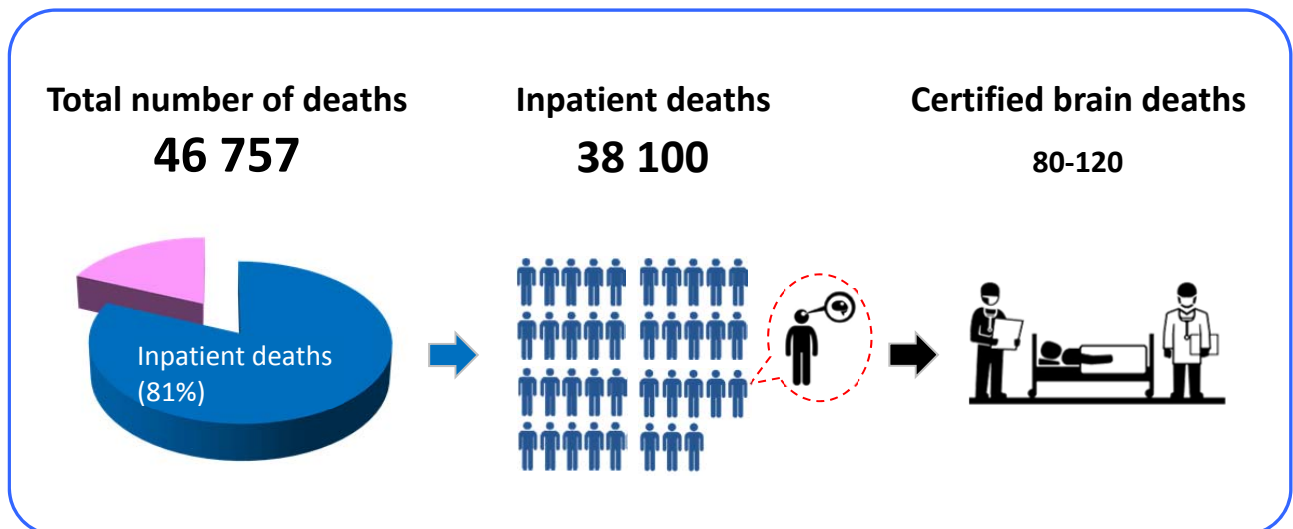
1.2 The decision whether to use an organ for transplant is based on strict medical criteria. Hence, even if people are willing to be organ donors, it may turn out that their organs may not be suitable for transplant. The most common circumstance for cadaveric donations is donation after brain death (**Figure 1**).<sup>1</sup> Brain-dead donors can donate both organs and tissue because even though their brain stem is dead, their heart continues to beat and their organs remain viable for transplant. In 2015, about 80-120 deaths or 0.2%-0.3% of deaths were certified brain deaths. The other circumstance for cadaveric donations is donation after

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<sup>1</sup> According to the World Health Organization (2009), brain death means irreversible cessation of cerebral and brain stem function characterized by absence of electrical activity in the brain, blood flow to the brain, and brain function as determined by clinical assessment of responses. A brain-dead person is dead, although his or her cardiopulmonary functioning may be artificially maintained for some time.

cardio-circulatory death, which is donation after the donor's heart stops beating. Since circulation has ceased, the deceased can mostly donate tissue only, such as corneas and skin.

**Figure 1 – Number of brain-dead persons in Hong Kong, 2015**



Data sources: Census and Statistics Department, and Hospital Authority.

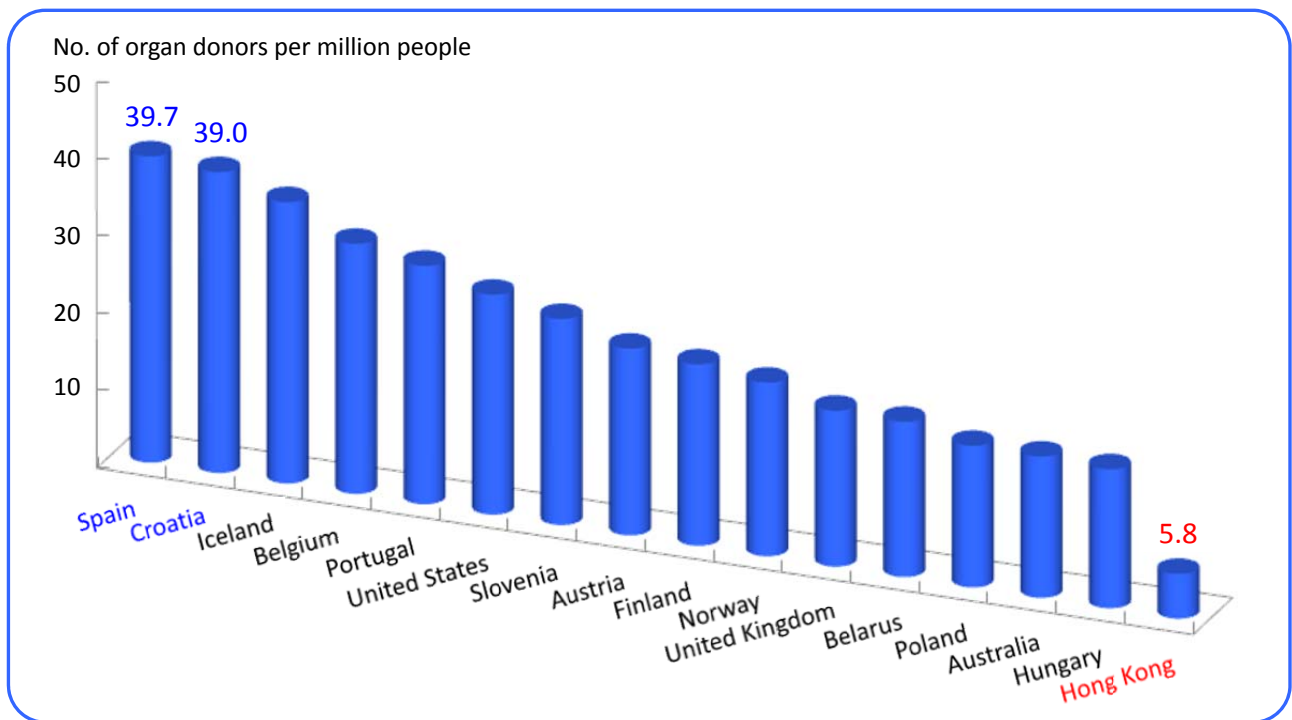
## 2. Organ donation in Hong Kong

2.1 Organ transplant is a well-proven health intervention which improves and saves lives of patients suffering from end-stage organ failure. The success rates of organ transplant are very high in Hong Kong. According to the Queen Mary Hospital, a total of 1 207 liver transplants had been performed by end-2015.<sup>2</sup> The 1-year, 3-year and 5-year survival rates were 93.0%, 88.1% and 85.7% respectively.

2.2 Notwithstanding the medical advancement, the availability of donor organs remains the biggest challenge to organ transplant in Hong Kong. This is particularly the case in view of its organ donation rate as measured by the number of donors per million people ("pmp"). According to the International Registry in Organ Donation and Transplantation, only 5.8 in every million people in Hong Kong donated in 2015. This figure is among the lowest in the world, representing only a seventh of that of high-donation places like Spain (39.7 donors pmp) and Croatia (39.0 donors pmp) (**Figure 2**).

<sup>2</sup> See Liver Transplant Centre (2015).

**Figure 2 – Organ donation rates in selected places, 2015**



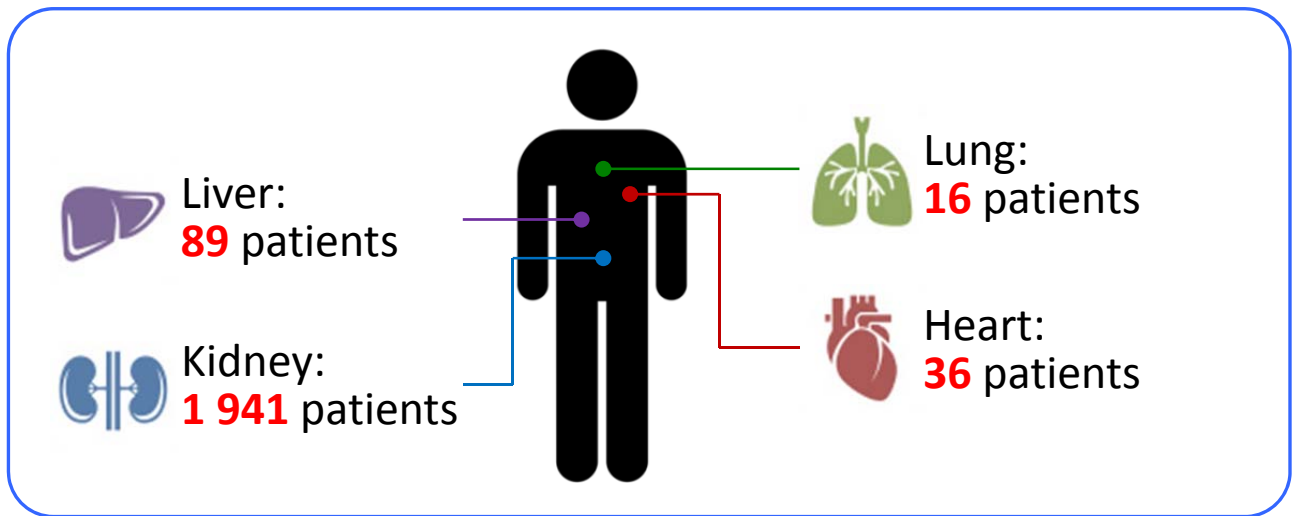
Data source: International Registry in Organ Donation and Transplantation.

2.3 Amid the low organ donation rate, the rising pool of people with end-stage organ failure adds to the number of patients on the organ transplant waiting list in Hong Kong. In 2015, kidneys were the most needed organ with 1 941 patients on the waiting list (**Figure 3**). The ratio of the number of patients waiting for renal transplant to the number of donations was 24 to one, and the average waiting time was 51 months (**Figure 4**).<sup>3</sup> Yet, both figures might not reflect the true demand for kidney transplant. Some patients might have received a pre-emptive transplant from a living donor before entering end-stage renal failure, so they will not appear on the waiting list. There are also patients who do not meet the criteria for a transplant although they would benefit from one. Indeed, there are currently more than 7 000 patients with end-stage renal failure in Hong Kong,<sup>4</sup> and only some 2 000 of them have been accepted onto the waiting list for a kidney transplant.

<sup>3</sup> According to the Hong Kong Ideas Centre (2015), the longest waiting time was up to 32 years.

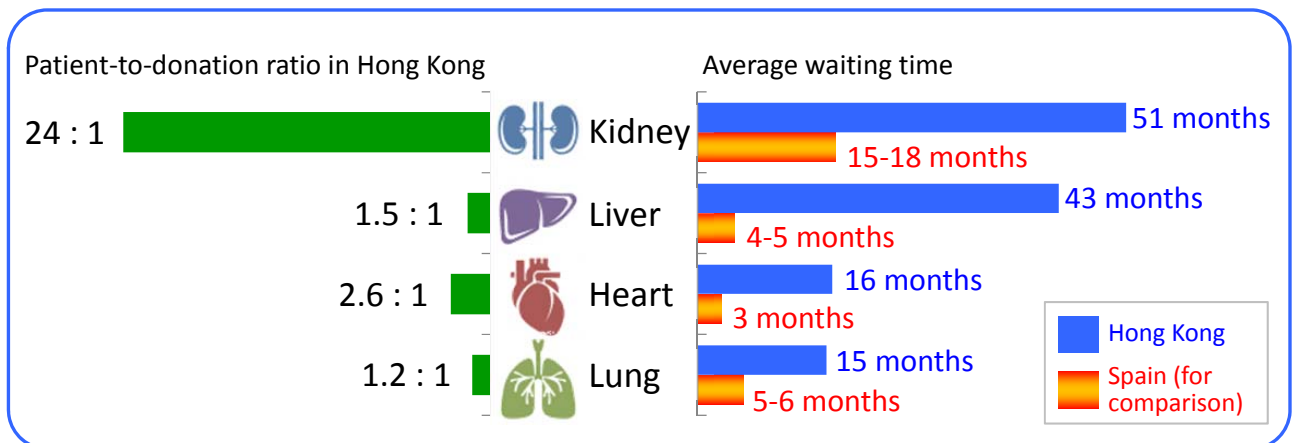
<sup>4</sup> See Smart Patient (2015).

**Figure 3 – Number of patients on organ transplant waiting list, 2015**



Data source: Hospital Authority.

**Figure 4 – Patient-to-donation ratio\* and average waiting time for organ transplant, 2015**

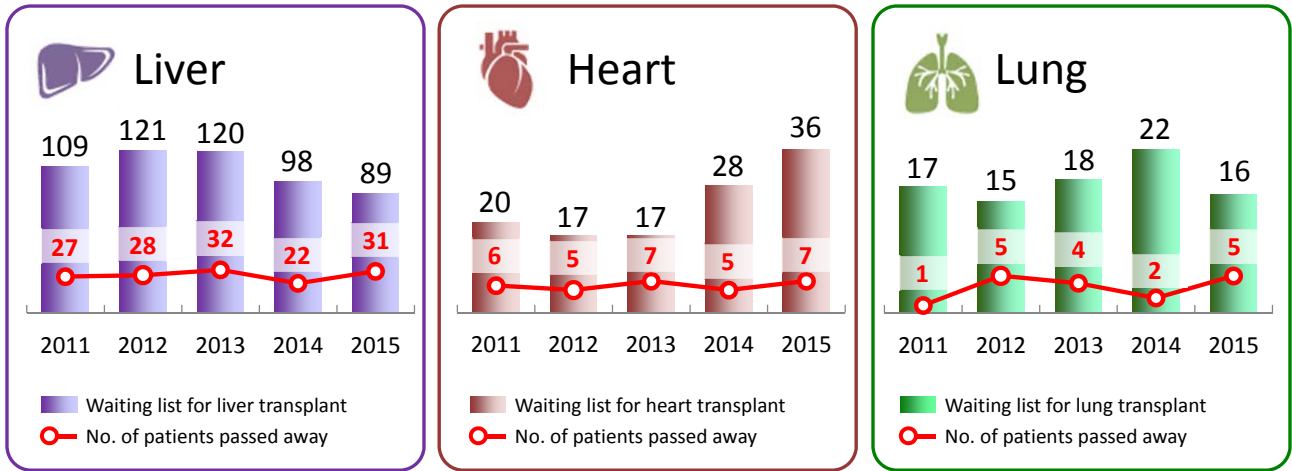


Note: (\*) Patient-to-donation ratio is the ratio of number of patients waiting for an organ transplant to the number of donations.

Data source: Hospital Authority.

2.4 As a result of the shortage of donor organs, many patients cannot live a normal life due to organ failure. Some patients with heart, lung or liver failure even died while waiting for organ transplant (**Figure 5**).

**Figure 5 – Number of patients passed away while waiting for organ transplant, 2011-2015**



Data source: Hospital Authority.

2.5 In recent years, the shortage of organs for transplant has triggered intense discussions about the ways to boost the organ donation rate. There have been proposals for Hong Kong to change to an opt-out system for the purpose of increasing the number of potential donors. Under the system, everyone would be considered an organ donor unless they sign up to specifically opt out. Currently, Hong Kong adopts an opt-in organ donation system which requires an individual to explicitly express his or her wish to donate organ through carrying a signed organ donation card or registering online with the Centralised Organ Donation Register. Yet, the decision to donate after death ultimately rests with the family members of the deceased donor and the donation will not proceed if they object.

### 3. Opt-out organ donation system

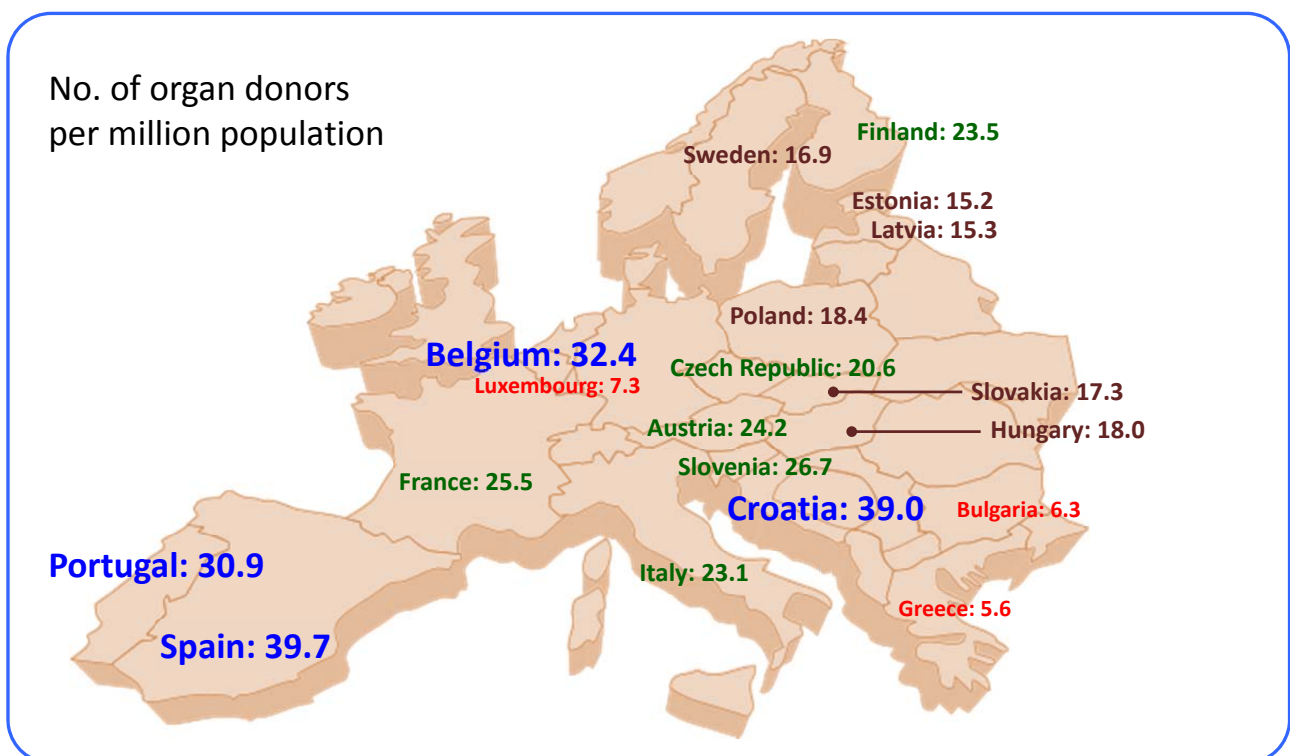
3.1 Presumed consent or opt-out system is common in Europe as evidenced by the adoption of such system in most European Union countries. In Asia, Singapore has taken the lead in introducing the opt-out system with the implementation of the Human Organ Transplant Act as early as in 1987. At present, all Singaporean citizens and permanent residents aged 21 years or above, and are not mentally disordered, are included in the opt-out system.

3.2 Actual practices for opt-out system differ across countries. Some countries such as Spain and Croatia implement a soft opt-out system. Under the system, even though the deceased has not signed the opt-out form, his or her family

members are still consulted and their consent to organ donation is still required. In contrast, countries like Austria and Singapore administer a hard opt-out system, under which organs can be transplanted from anyone who has not registered his or her opposition to donation and it is not necessary to consult his or her family members. There are currently very few opt-out countries following the "hard" system, and virtually all opt-out countries with higher organ donation rates allow families to have a final say on organ donation after death. With the predominance of the "soft" system and the implicit requirement for family consent to organ donation, the switching from an opt-in to an opt-out system might not necessarily lead to a higher donation rate.

3.3 Apart from the difference in the requirement for family consent, the organ donation rates also vary among the places adopting the opt-out system. As shown in **Figure 6**, there is a wide disparity in organ donation rates achieved by those European countries adopting opt-out system, ranging from a high of 39.7 donors pmp in Spain to a low of 5.6 donors pmp in Greece. In Asia, the organ donation rate remains at a low of 6.5 donors pmp in Singapore.

**Figure 6 – Organ donation rates in European opt-out countries, 2015**



Data source: International Registry in Organ Donation and Transplantation.

3.4 Against the above, there seems to be no conclusive evidence suggesting that adoption of opt-out system will directly result in higher donation rates. Indeed, donation practitioners in those opt-out countries with high donation rates attribute the good results to factors other than presumed consent legislation.<sup>5</sup> As the opt-out system might not be a decisive factor to high donation rates, there are other success factors that can be identified from experience of countries with high donation rates. These include a dedicated authority for coordinating organ donation and transplantation, funding support to donation and transplant hospitals, hospital-based transplant coordinators, and theme-based organ donation promotion strategy. The ensuing paragraphs focus on the study of Spain and Australia which both experienced a marked increase in their respective organ donation rate after the implementation of the policy measures in one or more of the above areas.<sup>6</sup>

#### **4. Dedicated authority for organ donation and transplantation**

4.1 Some countries have achieved higher organ donation rates after the establishment of an authority specifically in charge of formulating strategies and allocating resources to facilitate coordinated organ donation and transplantation activities.<sup>7</sup> While these authorities might have different scope and form, they all have an explicit mandate to increase the organ donation rate.

4.2 Spain established the National Transplant Organization ("ONT") in 1989 to coordinate organ donation and transplantation activities in the country. These activities include managing the donor and recipient lists and providing training programmes for medical professionals in all aspects of the organ donation process. As a national agency under the Ministry of Health, Social Services and Equality, ONT promotes altruistic donations with the sole goal that each Spanish citizen who needs a transplant will have the best chance to obtain it.<sup>8</sup> In the 26 years since the creation of ONT, Spain's organ donation rate had increased significantly from 14.0 donors pmp in 1989 to 39.7 donors pmp in 2015.

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<sup>5</sup> In Spain, the opt-out system was introduced in 1979 with the enactment of the Transplantation Law. According to Dr Matesanz, director of the National Transplant Organization, the opt-out system had no impact whatsoever on Spain's organ donation rates for the 10 years that followed enactment of the Transplantation Law. Only with the establishment of the National Transplant Organization in 1989 as the national coordinating body to improve the identification of potential donors did the organ donation rate in Spain begin to rise. See the Scottish Parliament (2015).

<sup>6</sup> Spain's organ donation programme is so successful that the so-called Spanish model has been adopted, with slight variations, by many countries in Europe and Latin America.

<sup>7</sup> See British Heart Foundation (2014).

<sup>8</sup> See Global Observatory on Donation & Transplantation (2016).

4.3 Similarly, Australia established the Organ and Tissue Authority ("OTA") in 2009 to implement a nationally consistent and coordinated approach to organ donation and transplantation. Being an independent statutory agency, OTA aims to increase the number of people from all parts of Australian society who consent to organ donation. As such, OTA has established the DonateLife network across Australia, which consists of DonateLife Agencies<sup>9</sup> and hospital-based medical and nursing donation specialists to work specifically on organ and tissue donation in 78 hospitals. Reflecting the efforts of OTA, Australia's organ donation rate increased by 51% during 2008-2015 from 12.1 donors pmp to 18.3 donors pmp.

4.4 Hong Kong has not established any dedicated authority for coordinating organ donation and transplantation activities either as a stand-alone entity as in Australia or located within the Ministry as in Spain. Currently, policy matters related to human organ donation and transplantation fall within the general purview of the Food and Health Bureau, which is also entrusted with formulating policies and allocating resources for the running of many other areas of Hong Kong's health services.

## **5. Funding support to donation and transplant hospitals**

5.1 Many top-performing donation countries provide direct compensation to donation and transplant hospitals for the additional costs associated with each organ donation and transplant event, e.g. investment in transplant infrastructure (e.g. intensive care beds and operating theatres) and extra staffing required.

5.2 In Spain, organ donation and transplant is considered a medical activity, which is to be properly funded like any other medical activities.<sup>10</sup> As such, donation and transplant hospitals are reimbursed for their activities, including both human and material resources. The corresponding regional health authorities will allocate a specific budget to cover the resources needed for the effective development of the activities at every donation and transplant hospital. In Australia, OTA provides funding for DonateLife Agencies and hospital-based medical and nursing donation specialists across the DonateLife Network in each state and territory.<sup>11</sup>

5.3 In contrast to Spain and Australia, Hong Kong has not set aside a specific budget to fund the organ donation and transplantation activities in the territory. The related expenditure is absorbed in the overall expenditure of the Department of Health and the Hospital Authority.

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<sup>9</sup> DonateLife agencies have been established in each state and territory to coordinate organ donation and provide support for donor families as well as education for hospital staff and the community.

<sup>10</sup> See Jox et al (2016).

<sup>11</sup> In 2015-2016, OTA received government appropriations totalling A\$52.8 million (HK\$310 million).



## 6. Hospital-based transplant coordinators

6.1 Early identification of potential organ donors<sup>12</sup> in patients with imminent brain death facilitates donor screening and maintenance. This in turn helps provide better transplant result since brain-dead patients need to remain in mechanical support in order to keep their organs in good conditions for transplantation. There have been cases where medical professionals are unable to report every potential donor prior to their brain death due to the heavy workload at hospitals.

6.2 In this regard, Spain has put much effort on the early identification of potential donors. ONT ensures medical professionals working in intensive care units ("ICUs") and emergency wards receive continuous training in all aspects of organ donation process from the outset of their clinical practice. The training includes particularly the early identification and timely referral of possible organ donors. In addition, ONT also encourages hospitals to incorporate organ donation as a regular activity in the daily routine of ICUs and emergency wards.

6.3 More importantly, ONT has significantly increased the number of transplant coordinators and ensured that every hospital in Spain has its own coordinator. In Spain, transplant coordinators are mostly intensive care specialists who are supported in their role by nurses. They typically spend 10%-50% of their time on organ donation activities, depending on the size of hospitals and its potentials for organ donation. These activities include visiting emergency wards and ICUs on a daily basis, checking the status of patients and identifying potential donors. Transplant coordinators also approach the potential donors' family members for consent to organ donation.<sup>13</sup>

6.4 In Australia, DonateLife hospital-based medical and nursing donation specialists are responsible for organ donation processes in their hospitals. Medical donation specialists are mostly intensive care specialists who undertake the donation role part-time, and are responsible for ensuring optimal donation processes within the hospital, including identification and referral of potential donors. Nurse donation specialists perform a similar role of identifying potential donors within hospitals. In consultation with the medical and nursing donation specialists, the donation specialist coordinator will discuss organ donation with, and/or request consent for donation from, potential donor families.

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<sup>12</sup> A possible donor is defined as a person with severe brain damage and possible evolution to brain death in a short period of time. See National Transplant Organization (2011).

<sup>13</sup> See Fabre (2010) and Lai (2013).

6.5 In Hong Kong, there is no dedicated team specifically established within hospitals to facilitate early identification of potential donors. Potential donors can be identified by medical professionals within ICU or in General Wards. In general wards, if the patient meets the referral criteria, doctors/nurses will activate the clinical referral triggers<sup>14</sup> to optimize early recognition and referral of potential donors. Patients will then be further assessed for suitability and diagnosis of brain death if criteria meet.

6.6 In case of the presence of a brain-dead patient, the Organ Donation Coordinator would approach family members of the patient and explain to them the details of organ donation in the hope that they will give consent to donate organs of the deceased. Organ Donation Coordinators in Hong Kong are all nurses, and there are nine Coordinators covering seven clusters of 41 public hospitals scattered across Hong Kong. There have been concerns over the heavy workload of the nine Organ Donation Coordinators and the lack of formal coordination of their work.<sup>15</sup>

## 7. Promotion of organ donation

7.1 A key to cadaveric organ donation is the willingness of individuals to donate their organs after death and acceptance of their family members to the donation decision. This necessitates the promotional efforts on enhancing public understanding and awareness of organ donation, encouraging registration as an organ donor, and facilitating the discussion of one's donation decision with his or her family members and close friends.

7.2 In Australia, OTA has launched a national campaign – the national DonateLife Community Awareness and Education Program – since 2009 to promote the message of "Discover, Decide and Discuss".<sup>16</sup> Under the programme, every Australian is encouraged to: **discover** the facts and benefits about organ donation; **decide** about becoming an organ donor; and **discuss** donation decisions with family members and close friends. Funding support is provided under the Community Awareness Grants Program<sup>17</sup> for the launch of projects or activities that contribute to the delivery of the DonateLife Community Awareness and Education Program.

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<sup>14</sup> Clinical trigger is a tool used for the early identification and referral of potential donors in Accident & Emergency Department, ICU and general ward. The trigger is activated when a patient fulfils the criteria such as reaching Glasgow coma scale of 3 and intubated on ventilator.

<sup>15</sup> See Lee (2015) and Hong Kong Ideas Centre (2015).

<sup>16</sup> In contrast to Australia, Spain does not put much effort in public campaigns. ONT has little budget for advertising, public relations or marketing and it relies primarily on systematic organization of the healthcare system to support organ donation. See Eurotransplant (2010) and The Conversation (2015).

<sup>17</sup> The Community Awareness Grants Program was launched in 2009. According to the 8<sup>th</sup> round of the Program, 22 organizations received a total funding of about A\$462,000 (HK\$2.7 million) from the Australian government in 2014.

7.3 On discovering the facts and benefits about organ donation, OTA has targeted its public education programme at young people who tend to think that organ donation is irrelevant to them. It produces comprehensive education resources specifically for teenagers, which cover a wide range of areas from basic understanding of organ donation to explanation of brain death and discussion of organ donation barriers. School teachers are encouraged to use these education resources to introduce the subject of organ donation to students.

7.4 With an opt-in system, OTA also focuses on promoting family discussion about donation wishes to ensure that every potential donor's decision is upheld. It is well recognized in Australia that if family members know one another's wishes, they are more likely to consent to a donation request. During 2010-2012, OTA introduced a two-phase national campaign to encourage Australians to promote family discussion.<sup>18</sup>

7.5 In Hong Kong, the Department of Health, in collaboration with the Hospital Authority and relevant non-governmental organizations, has implemented organ donation promotional measures on various fronts. These included (a) public education through exhibitions, talks and seminars; (b) publicity campaigns using various media channels; and (c) institution-based networking by inviting Government departments, non-governmental organizations and private companies to work together to promote organ donation. Most recently, the Government set up the Committee on Promotion of Organ Donation in April 2016 to further promote organ donation.

7.6 Over the years, the Government has focused much of its promotional efforts on enhancing public awareness/understanding of organ donation and encouraging people to register as an organ donor. The educational materials provided are for the general public, without addressing the unique concerns of potential donors of different age groups.

7.7 There is also a lack of concrete measures to promote family discussion of donation wishes, although the Government has iterated its importance on a number of occasions. In Hong Kong, the most significant obstacle to increasing the number of cadaveric organs for transplant is obtaining family consent. According to a focus group study conducted by the Department of Health in April 2015, the majority of the respondents agreed to allow their family members to donate organs after death if the deceased had expressed their desire beforehand. Those respondents who

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<sup>18</sup> Phase one of the national campaign, "DonateLife. Discuss it today", encouraged Australians to discuss their organ donation wishes with family members. Phase two of the national campaign, "DonateLife. Know their wishes, OK?", prompted Australians to make sure that they know the donation wishes of their family members. To follow up on the national campaigns, OTA has produced the "Family Discussion Kit" to educate people about the everyday situations that can be used as an ideal start to a conversation with the family about the organ donation.

were unwilling to donate organs themselves tended to respect their family members' wish to donate organs. However, if their family members never expressed their willingness to donate organs, the respondents tended to make decisions according to their own willingness.

## **8. Observations**

8.1 The following observations are made based on the findings above:

- (a) the availability of donor organs remains the biggest challenge to organ transplant in Hong Kong. In 2015, only 5.8 in every million people in Hong Kong donated his or her organ(s). This organ donation rate is among the lowest in the world, representing only a seventh of that of high-donation places like Spain (39.7 donors pmp) and Croatia (39.0 donors pmp);
- (b) amid the low donation rate, there have been proposals for Hong Kong to change to an opt-out system where every person at time of death is considered for organ donation unless he or she has specifically registered to not donate. Currently, Hong Kong adopts an opt-in system which requires an individual to express his or her consent to become a potential donor. At the time of death, the consent from the family members is still required for the removal of organs from the deceased donor;
- (c) however, there is no conclusive evidence suggesting that the adoption of opt-out system will directly result in higher donation rates, in particular when virtually all opt-out countries with higher organ donation rates adopt a "soft" system still requiring family consent to organ donation;
- (d) as the opt-out system might not be a decisive factor to higher donate rates, there are other success factors that can be identified from the experience of Spain and Australia. These two countries experience a marked increase in their donation rate after the implementation of reform measures in one or more of the following areas: (i) a dedicated authority for coordinating organ donation and transplantation, (ii) funding support to donation and transplant hospitals, (iii) appointment of hospital-based transplant coordinators who are mostly intensive care specialists trained to identify potential organ donors and approach donors' families for consent to organ donation, and (iv) theme-based organ donation promotion;

- (e) in contrast to Spain and Australia, Hong Kong does not have a dedicated authority for coordinating organ donation, nor does it have a specific budget set aside for funding such activities. There is also no dedicated team within hospitals to facilitate early identification of potential donors. As to the job of seeking family consent to organ donation, it is undertaken by nine Organ Donation Coordinators who cover seven clusters of 41 public hospitals scattered across Hong Kong; and
- (f) a key to cadaveric organ donation is the willingness of individuals to donate their organs after death and acceptance of their family members to the donation decision. In this connection, Australia has targeted its public education programmes at young people as well as promoting family discussions about donation wishes to ensure that every potential donor's decision is upheld. While in Hong Kong, the focus of promotion campaigns is on enhancing public awareness of organ donation and encouraging people to register as an organ donor, there is also a lack of measures to promote family discussions of donation wish, although the Government has iterated its importance on a number of occasions.

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