# 立法會 Legislative Council

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#### **Panel on Health Services**

# Updated background brief prepared by the Legislative Council Secretariat for the meeting on 15 January 2018

#### **Organ donation**

#### **Purpose**

This paper provides background information on organ donation and summarizes the views and concerns of members of the Panel on Health Services ("the Panel") on issues relating to organ donation.

#### **Background**

#### Organ transplants in Hong Kong

- 2. End-stage organ failure was one of the common end results of many common chronic illnesses. According to the Hospital Authority ("HA"), there are more than 2 500 patients waiting for organs transplant as at end of December 2016. Organ transplant is regulated under the Human Organ Transplant Ordinance (Cap. 465) ("the Ordinance") which, inter alia, prohibits commercial dealings in human organs intended for transplanting; restricts the transplanting of human organs between living persons unless under specified circumstances; and restricts the transplanting of imported organs. The Human Organ Transplant Board ("the Board") is established under the Ordinance to perform the regulatory functions.
- 3. Organs used for transplant come from two sources: living and cadaveric donations. Cadaveric organs are the main source of organs for transplant. Only persons who are certified brain dead can be cadaveric donors. There are seven types of organs or tissues for which transplants are conducted in public hospitals, namely kidneys, liver, heart, lungs, corneas, bones and skin. Corneal transplant is conducted in some private hospitals or clinics. A breakdown, by

type of organ or tissue, of the number of patients waiting for organ or tissue transplant, the average waiting time for patients on the waiting list and the number of donations in public hospitals from 2014 to 2016 are in **Appendix I**.

#### Organ transplants between living persons

Under sections 5A and 5C of the Ordinance, a registered medical practitioner may carry out a restricted organ removal or a restricted organ transplant or both if he is satisfied that the recipient of the organ concerned is genetically related<sup>2</sup> to its donor, or is, at the time of the transplant, the spouse of the donor and their marriage has subsisted for not less than three years; or if the Board has given its approval in writing. For both cases, it is required under section 5D of the Ordinance that (a) the donor concerned must have reached the age of 18 years; (b) a registered medical practitioner has, in the absence of the recipient concerned, explained to the donor, and the donor has understood, the procedure and the risk involved of the proposed organ removal, and the donor's entitlement to withdraw consent to that removal at any time; (c) the donor has given his consent to the proposed organ removal without coercion or the offer of inducement and has not subsequently withdrawn his consent; (d) a registered medical practitioner has, in the absence of the donor, explained to the recipient, and the recipient has understood, the procedure and the risk involved of the proposed organ transplant, and the recipient's entitlement to withdraw consent to that transplant at any time; and (e) no payment prohibited by the Ordinance<sup>3</sup> has According to the International Registry been made, or is intended to be made.<sup>4</sup> in Organ Donation and Transplantation, Hong Kong's living organ donation rate as measured by the number of donors per million people was 7.4 in 2016.

Under section 5A(2) of the Ordinance, a person is regarded as genetically related only to (a) his natural parents and natural children; (b) his siblings of the whole or half blood; (c) the siblings of the whole or half blood of either of his natural parents; and (d) the natural children of any of the siblings mentioned in (b) and (c) above.

Under the Ordinance, "restricted organ removal" means the act of removing from a living person an organ for the purpose of transplanting it into another person. "Restricted organ transplant" means the act of transplanting into a person an organ removed from another person who was living at the time of the removal.

Under the Ordinance, "payment" means payment in money or money's worth but does not include any payment for defraying or reimbursing (a) the cost of removing, transporting or preserving the organ to be supplied; (b) the administrative cost incidental to the removal, transportation or preservation of the organ to be supplied; and (c) any expenses or loss of earnings incurred by a person and attributable to is supplying an organ from his body.

The registered medical practitioner who makes the explanation under item (b) or (d) shall not be the registered medical practitioner who is to carry out the restricted organ removal or the restricted organ transplant. The requirement in item (d) is waived under the circumstances specified in section 5E of the Ordinance.

5. For cases in which the patient who is eligible for an organ transplant and have a living related donor who is willing but unable to donate because of an incompatible blood type or tissue type, paired donation is an option to overcome this barrier. In paired donation, both medically approved incompatible donor-patient pairs donate organs to the other pair so that both patients receive compatible organs. In some places, the practice of paired donation has gone further to pooled donation, which involves more than two pairs of donors and recipients.

#### Cadaveric organ donations

- 6. 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. Persons who wish to donate their organs and/or tissues after death could voluntarily register, by means of the Internet, mail and fax, their wish in the Centralised Organ Donation Register ("CODR"), which was launched by the Department of Health ("DH") in November 2008 to make it more convenient for prospective donors to register their wish, and for such wish to be more reliably kept and retrieved by authorized persons, such as Organ Donation Coordinators (formerly known as Transplant Coordinators) of HA<sup>5</sup>, to facilitate arrangement of organ transplants. This apart, prospective donors who prefer not to register in CODR could express their wish by signing and carrying organ donation cards. For both cases, the family of the deceased has to sign a consent form to confirm the organ or tissue to be removed for transplant purpose. For deceased persons who had not indicated their wish by registering in CODR or signing the organ donation card, their organs or tissues can still be donated with the consent of their family members.
- 7. According to the International Registry in Organ Donation and Transplantation, there were 6.3 cadaveric organ donors per million people in Hong Kong in 2016. As at 31 December 2017, there were more than 278 600 registrations recorded in CODR. A breakdown, by type of organ, of the number of prospective donors registered in CODR from 2014 to 2016 is in **Appendix II**.

#### **Deliberations of the Panel**

8. The Panel held a number of meetings to discuss the introduction of CODR and the promotion of organ donation between 2007 and 2016. The

There are currently nine Organ Donation Coordinators who are responsible for, among others, liaise organ transplant matters at public hospitals, promoting organ donation among healthcare staff and providing support and co-ordination for external organ

donation promotional activities.

deliberations and concerns of members are summarized in the following paragraphs.

#### Organ donation registration

- 9. Members noted that while the family consent rate for solid organ donation was only about 50% in 2010, more than 90% of the bereaved families had agreed to the donation if the deceased had recorded his or her wish to donate organs after death. Question was raised as to why prospective donors were not required to indicate, at the time of registration in CODR, the persons to whom they had made their donation wish known. The Administration advised that to do so would not satisfy the requirement of the Privacy Impact Assessment which provided safeguards with respect to personal data collected for the purpose of establishing CODR.
- 10. On the question as to whether there was a target on the number of registrants for organ donation to meet the demand of patients in need of organ transplant, the Administration advised that it would be difficult to set such a target since it was not possible to predict when the organs of the registrants would become available and whether they were suitable for the patients in need of organ transplant.

#### Promotion on organ donation

- 11. Members expressed concern that despite the efforts made by the Administration over the years to promote organ donation, the number of people willing to donate their organs after death was still on the low side. They considered that the Administration should conduct study to find out the common characteristics of people willing to donate organs after death in order to shed light on how the promotion campaign should be run to greater effect.
- 12. Members further suggested that to promote organ donation, consideration should be given to making the new promotion campaign more family-centred, such as collaborating with non-government organizations ("NGOs") in making home visits to garner family's acceptance of organ donation; instilling in youths that organ donation was a charitable life-saving act through civic education in schools; disseminating organ donation message in hospitals or clinics; giving out inexpensive souvenirs to people registered to donate organs after death; encouraging television stations and making use of popular websites to spread the organ donation message in their programmes; rallying the support of social groups, such as university students, who had registered their wish to donate organs after death to promote organ donation amongst their peers; as well as publicizing the long waiting list for organ transplant and appeals for organ donation by family members of patients waiting for transplant. To help the families making the decision on organ donation, the Administration could

consider enabling the registrants on CODR to leave a personal message to their families about their wish to donate organs after death. A donor recognition scheme could be launched to honour the charitable act of organ donation. There were also suggestions that people should be requested to indicate their wish to donate organs after death when they applied for a driving licence or were issued with a Hong Kong Identity Card, and organ donors could be entitled to priority in the allocation of niches at public columbaria.

- 13. According to the Administration, the measures put in place to promote organ donation had to adhere to the World Health Organization's Guiding Principles on Human Cell, Tissue and Organ Transplantation. At present, the strategies for promoting organ donation focused on encouraging registration at CODR and expression of one's wish of organ donation to family members and To create a positive atmosphere for organ donation in the whole community, DH had taken various promotional measures, such as establishing an institution-based network to encourage registration at CODR in institutions; enhancing public understanding and acceptability of organ donation through public education and promotional activities on television, radio and the Internet, etc; encouraging public participation through electronic means, like setting up an Organ Donation Facebook Fan Page; and establishing the Garden of Life in Kowloon Park to recognize the charitable acts of organ donors and their families. The Committee of Promotion of Organ Donation had been set up in April 2016 to devise promotional strategies for the promotion of organ donation as well as coordinate the promotional activities of different sectors in the society.
- 14. Members noted with grave concern that the number of cases of organ donation was much lower than the number of patients waiting for organ and tissue transplantation. There was a suggestion that the Administration should conduct a public consultation exercise on adopting an opt-out approach for organ donation whereby every person at time of death would be considered for organ donation unless he or she had specifically registered to not to donate. Members were advised that the Administration would assess public understanding and acceptance of organ donation, including an opt-out system, through the Thematic Household Survey ("THS") to be conducted by the Census and Statistics Department ("C&SD").

#### Kidney donations

15. Members noted that kidneys were the most needed organ in Hong Kong with 1 941 patients on HA's waiting list as at the end of December 2015. Given the small number of kidneys donated for transplant, there was a question about the effort to be made by the Administration to address the pressing demand for kidney transplant. The Administration explained that patients could receive a kidney from a deceased or a living donor for kidney transplantation. Given that patients with renal disease could receive haemodialysis

treatment when waiting for kidney transplantation, there were relatively fewer living kidney donations when compared to other life-threatening diseases. The Administration would increase the resources allocation to HA for enhancing the haemodialysis service for patients with end-stage renal disease by providing additional hospital and home haemodialysis places.

#### **Recent developments**

- 16. In April 2017, a 17-year-old daughter was barred from donating a part of her liver to her mother. The incident has triggered wide community discussion about organ donation in Hong Kong. There have been proposals for Hong Kong to lower the eligible age of living donors and change to an opt-out system. A written question on organ donation was raised at the Council meeting on 10 May 2017. The question and the Administration's reply are in **Appendix III**.
- 17. The topic of organ donation was included in a round of THS conducted by C&SD from October 2016 to January 2017 covering persons aged 18 to 64. The THS Report No. 63 was published in December 2017. Its findings revealed, among others, that while 33.8% of the respondents supported the implementation of an opt-out system for organ donation in Hong Kong, 35.9% of the respondents did not support the implementation. The remaining 30.3% respondents were either neutral or did not specify their views towards the implementation.
- 18. The Administration will brief the Panel on its legislative proposal on paired/pooled organ donation and the findings of the THS on organ donation at the meeting on 15 January 2018.

#### **Relevant papers**

19. A list of the relevant papers on the Legislative Council website is in **Appendix IV**.

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The THS Report No. 63 can be accessed at C&SD's website (http://www.statistics.gov.hk/pub/B11302632017XXXXB0100.pdf).

# The number of patients waiting for organ/tissue transplant, the average waiting time of patients on the list and the number of organ/tissue donations from 2014 to 2016

| Year (as at 31 December) | Organ/Tissue   | No. of patients waiting for organ/tissue transplant | Average waiting time (months) <sup>2</sup> | No. of donations <sup>3</sup> |
|--------------------------|----------------|---|--|-------------------------------|
| 2014                     | Kidney         | 1 965   | 50   | 79                            |
|                          | Heart          | 28  | 5.4  | 9                             |
|                          | Lung           | 22  | 27.6                                       | 4                             |
|                          | Liver          | 98  | 39.9                                       | 63                            |
|                          | Cornea (piece) | 465   | 24   | 337                           |
|                          | Bone           | NA <sup>1</sup>                                     | NA   | 1                             |
|                          | Skin           | NA  | NA   | 9                             |
| 2015                     | Kidney         | 1 941   | 51   | 81                            |
|                          | Heart          | 36  | 16.1                                       | 14                            |
|                          | Lung           | 16  | 15.4                                       | 13                            |
|                          | Liver          | 89  | 43   | 59                            |
|                          | Cornea (piece) | 374   | 24   | 262                           |
|                          | Bone           | NA  | NA   | 4                             |
|                          | Skin           |   |  | 10                            |
| 2016                     | Kidney         | 2 047   | 52   | 78                            |
|                          | Heart          | 50  | 16   | 12                            |
|                          | Lung           | 19  | 12.9                                       | 9                             |
|                          | Liver          | 89  | 42.9                                       | 73                            |
|                          | Cornea (piece) | 298   | 15   | 276                           |
|                          | Bone           | NA  | NA   | 1                             |
|                          | Skin           |   |  | 10                            |

#### Note:

- 1. NA = Not Applicable. Patients waiting for skin and bone transplant are spontaneous and emergency in nature. As substitutes will be used if no suitable piece of skin or bone is identified for transplant, patients in need of skin and bone transplant are not included in the organ/tissue donation waiting list.
- 2. "Average waiting time" is the average of the waiting time for patients on the organ/tissue transplant waiting list as at end of that year.
- 3. The Hospital Authority has not kept statistics on the success or otherwise of the subsequent transplant cases.

Source: Administration's replies to Members' initial written questions during the examination of estimates of expenditure 2017-2018

# Number of registrations made in the Centralised Organ Donation Register from 2014 to 2016

| Year  | 2014   | 2015   | 2016   |
|---|--------|--------|--------|
| Number of persons registered:                   | 19 868 | 29 357 | 52 550 |
| Organs they wish to donate (number of persons): |        |        |        |
| All organs                                      | 17 874 | 26 658 | 47 798 |
| Kidney  | 1 732  | 2 400  | 4 168  |
| Heart   | 1 674  | 2 344  | 4 135  |
| Liver   | 1 690  | 2 365  | 4 137  |
| Lung  | 1 559  | 2 208  | 3 930  |
| Cornea  | 1 483  | 2 054  | 3 538  |
| Bone  | 696    | 1 012  | 1 724  |
| Skin  | 432    | 593    | 991    |

Note: A person can indicate his or her wish to donate more than one or all organs in the Centralised Organ Donation Register

Source: Administration's replies to Members' initial written questions during the examination of estimates of expenditure 2017-2018

# Press Releases 10 May 2017

LCQ5: Organ donation

Following is a question by the Hon Kenneth Lau and a written reply by the Secretary for Food and Health, Dr Ko Wing-man, in the Legislative Council today (May 10):

#### Question:

The Department of Health launched the Centralised Organ Donation Register (CODR) in November 2008 for members of the public to register their wishes to donate organs after death so that, upon their death, the relevant medical personnel can learn of such wishes from CODR. However, members of the public may continue to express such wishes by signing and carrying an organ donation card. On the other hand, the recent successive calls for organ donation from members of the public whose family members are in urgent need of organ transplants have aroused public concern about the current situation of organ donation in Hong Kong. In this connection, will the Government inform this Council:

- (1) whether it has estimated the current number of members of the public who have signed and carry an organ donation card; given that there are inadequacies by means of using organ donation cards to express the wish to donate organs (e.g. it is easy for members of the public to lose or forget to carry their organ donation cards), why the authorities have retained this arrangement after establishing CODR; whether they have urged members of the public who have signed an organ donation card to register with CODR so that medical personnel can learn of the wish of such persons upon their death;
- (2) of the respective numbers of registrations and deregistrations with CODR last year; whether the authorities have regularly reviewed CODR so as to remove the registrations of those who have passed away or permanently left Hong Kong; if so, of the details; if not, the reasons for that;
- (3) whether it knows (i) the respective numbers of patients who passed away last year while waiting for a liver, heart and lung transplant, and (ii) the number of the following cases in each of the past five years: it had been confirmed that the organ(s) of the deceased who had registered with CODR/carried an organ donation card was/were suitable for transplant, but the relevant transplant operations could not proceed due to objection from the deceased's family members;
- (4) given that the Hospital Authority (HA) increased the establishment of Organ Donation Coordinators from seven to nine in the 2015-2016 financial year, whether the Government knows (i) the main duties of such personnel, (ii) the effectiveness in promoting organ donation with the increased manpower, and (iii) whether HA will further increase the manpower to step up its efforts in promoting organ donation;

- (5) as the Government has indicated earlier that it is seeking public views on the establishment of an optout system for organ donation, of the progress of that work; whether it has explored other feasible measures to promote organ donation; and
- (6) whether, among the organs of the deceased, only organs of brain-dead persons are suitable for transplant; of (i) the number of brain-dead persons, (ii) the number of those, among them, whose family members were willing to donate their organs and (iii) the number of patients who received transplant of those organs, in each of the past five years?

#### Reply:

President,

To impress upon the general public the importance of organ donation and to gradually inculcate a culture that is receptive to and appreciative of organ donation, the Department of Health (DH) has been making promotional efforts on different fronts in collaboration with the Hospital Authority (HA) and community partners.

(1) The DH established the Centralised Organ Donation Register (CODR) in 2008 to provide members of the public with a convenient channel to register their wish to donate organs after death. The CODR also provides a reliable and effective means for Organ Donation Coordinators to ascertain, upon patients' death, their previously expressed wish to donate organs, so that they may approach the patients' families as soon as possible to seek their consent for donation of the deceased's organs to save patients in urgent need of organ transplant.

As an alternative, members of the public may sign an organ donation card. In fact, some people prefer carrying signed organ donation cards to registering with the CODR. However, the DH still encourages people who have signed an organ donation card to register with the CODR, so that Organ Donation Coordinators of the HA can identify their wish to donate organs more effectively and make arrangements as appropriate.

Since members of the public who have signed the organ donation cards do not need to report to the DH, we do not have the number of people who have signed the cards.

In support of the large-scale territory-wide organ donation promotion campaign co-ordinated by the Food and Health Bureau, the HA has been implementing the "Scan me to support organ donation!" campaign in all public hospitals and the community since June 2016 to disseminate three key messages, namely "Sign-up", "Register" and "Spread-out". The second message, "Register", seeks to encourage those who have signed the organ donation cards to register with the CODR.

(2) There were 52 550 new registrations and 859 deregistrations with the CODR in 2016. Under the existing system, Organ Donation Coordinators are

allowed to check the wishes of organ donation of deceased patients where necessary. Under the established mode of operation, the Government would not review regularly whether the registrants on the CODR have passed away or permanently left Hong Kong.

(3) The breakdown of the number of patients who passed away last year while waiting for a liver, heart or lung transplant is as follows:

| II()raan I | Number of patients who passed away in<br>2016 while waiting for a transplant |
|------------|--|
| Liver      | 20   |
| Heart      | 6  |
| Lung       | 1  |

The following table sets out the number of cases in each of the past five years where the organ(s) of the deceased who had registered with the CODR/carried an organ donation card was/were confirmed to be suitable for transplant, but the transplant operation (s) could not proceed due to objection from the family members of the deceased.

| Year | Signed an organ donation card/ registered online (no. of cases) | Donation failing to proceed due to objection from family members (no. of cases) |
|------|---|---|
| 2012 | 3   | 0   |
| 2013 | 4   | 1   |
| 2014 | 1   | 0   |
| 2015 | 3   | 0   |
| 2016 | 7   | 1   |

- (4) The duties of Organ Donation Coordinators of the HA include the following three main areas:
- 1. Approach families of brain stem dead patients who may be potential donors and explain to them the details of organ donation in the hope that they will give consent to donate organs of their family members;
- 2. promote organ donation among healthcare staff so as to raise their awareness of it; and
- 3. provide support and co-ordination for external organ donation promotional activities.

At present, the HA has nine Organ Donation Coordinators (the number of Organ Donation Coordinators increased from seven to nine in 2015-16). Regarding the work of approaching families of brain stem dead patients and promoting organ donation among healthcare staff mentioned in items (1) and (2) above, effective contacts have generally been made and promotional efforts have been strengthened.

As for item (3), given that the work of external promotion of organ donation virtually requires collaboration among various professional community partners (including the DH and other interested community and professional groups), Organ Donation Coordinators play a supportive and co-ordinating role. The HA will review the manpower of Organ Donation Coordinators as appropriate.

(5) The adoption of a legislative approach, such as drawing on overseas experience to introduce mechanisms like the opt-out system is very different from the existing organ donation regime. Regarding the establishment of a new mechanism, we should ensure that the relevant proposals are acceptable to the public, and a fair, transparent and widely acceptable mechanism will be developed, so that wishes of members of the public will be respected.

The Government is assessing the latest development regarding the public understanding and acceptance of organ donation, including the establishment of an opt-out system, via the Census and Statistics Department's Thematic Household Survey. A report on the subject is expected to be published in early 2018. We will assess the situation based on the survey findings and duly consult the public before making any substantial changes.

The Government will meet with medical professionals and patients' group in June to gauge their views on the several topics related to organ donation.

(6) Deceased organs for transplant purpose currently come from donations from persons who have been medically certified brain-dead. The breakdown is as follows:

| Year | Brain-dead<br>persons<br>(no. of<br>cases) | family members for donating deceased organs | Patients receiving organ transplant (no. of persons) |
|------|--|---|--|
| 2012 | 126  | 56  | 149  |
| 2013 | 91   | 50  | 123  |
| 2014 | 96   | 43  | 112  |
| 2015 | 110  | 43  | 129  |
| 2016 | 123  | 51  | 118  |

Ends/Wednesday, May 10, 2017 Issued at HKT 14:23

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## Appendix IV

## Relevant papers on organ donation

| Committee           | Date of meeting | Paper                             |
|---------------------|-----------------|-----------------------------------|
| Panel on Health     | 12.2.2007       | Agenda                            |
| Services            | (Item VI)       | Minutes                           |
|                     | 10.11.2008      | Agenda                            |
|                     | (Item III)      | Minutes Minutes                   |
|                     |                 |                                   |
|                     | 8.2.2010        | <u>Agenda</u>                     |
|                     | (Item IV)       | Minutes                           |
|                     | 14.3.2011       | Agenda                            |
|                     | (Item VI)       | Minutes                           |
|                     | , ,             |                                   |
|                     | 18.4.2016       | <u>Agenda</u>                     |
|                     | (Item VI)       | Minutes                           |
| Legislative Council | 14.7.2016 *     | Research Brief prepared by the    |
| Legislative Council | 14.7.2010       | Legislative Council Secretariat's |
|                     |                 | Research Office on "Organ         |
|                     |                 |                                   |
|                     |                 | donation in Hong Kong"            |

<sup>\*</sup> Publication date

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