## Legislative Council Panel on Health Services Meeting on 13 February 2006 at 8:30 am

# Incorporation of organ donation details in Hong Kong's Smart Identity Card

#### **PURPOSE**

This paper seeks Members' views on the proposal of incorporating a person's organ donation details in the Hong Kong Smart Identity Card.

#### **BACKGROUND**

- 2. Each day in Hong Kong, there are quite a number of patients suffering from terminal stage organ failure who urgently need organ or tissue transplantation to regain a normal and healthy life. The number of organ / tissue donations in Hospital Authority (HA)'s hospitals from 2000 to 2005, and the number of patients waiting for transplant as at end of 2005 is in the **Annex**.
- 3. End stage organ failure is one of the common end results of most of the common chronic illnesses in Hong Kong. With the advancement of medical technology, organ transplant becomes the only means of treatment for these patients. Cadeveric organs are the preferred source of organs in organ transplant. However, due to cultural and religious belief and lack of general knowledge of organ donation, not many people are willing to donate their organs after death. The supply of cadeveric organs is in general insufficient. The second source of organs is from living persons. The source of organs for most of the organ transplant between living persons in Hong Kong was from donation by family members and close relatives. However, living donors do experience risks arising from the transplant operation.
- 4. According to the experience of transplant coordinators in HA, unwillingness to decide on behalf of the deceased because the deceased had not expressed wish to donate and lack of family consensus on organ donation accounted for 15% and 26% of the reasons for family's refusals to donate organs in 2004.

#### **ORGAN DONATION CARD**

5. In Hong Kong, a person who wishes to donate his organ(s) after death could sign an organ donation card, or consent in writing or orally under the presence of two or more witnesses that his organ(s) be used for

transplant after his death. Countries adopting similar approach as Hong Kong include Germany, the Netherlands, and Australia. In respect of organ donation cards, in the last two years (2004 to 2005), the Department of Health (DH) has distributed over 430,000 organ donation cards through its clinics, hospitals under the Hospital Authority, other government departments and public amenities as well as non-governmental organizations. However, under the present arrangement, a person is not required to inform or register with DH on their signing of the card. The Government therefore has no idea on the number of people that have signed organ donation cards.

- 6. The drawback is that although public attitude on organ donation has changed significantly in recent years, there is a discrepancy between public support on organ donation and people actually getting a card, signing and carrying it.
- 7. According to HA's statistics, organ donation cards were found in only 2 to 7% of potential donors interviewed by the transplant coordinators. According to surveys on the general population by academics, 85% of respondents were willing to donate a family member's organ if they knew that he/she had consented to donate (either through a signed organ donation card, or were told of the decision). Fewer people (41.1%), however, agreed to donate if their relatives had not expressed such as wish.

#### **PROPOSAL**

8. In the light of the above, there has been a suggestion that, with the introduction of the Smart ID Card, we should explore the possibility of allowing a person to incorporate his organ donation details into the ID Card so that upon his/her death, the relevant information can instantly be obtained through the card electronically.

#### **OUR INITIAL VIEWS TO THE PROPOSAL**

9. We believe the proposal of using Smart ID Card to carry or access organ donation information merits further consideration. Conceptually, we believe that the Smart ID Card could be used as an alternative and convenient means for prospective organ donors to indicate their wish through electronic channels. This will supplement (not replace) the current organ donation card system. However, we wish to stress that, given current societal values, even if the proposal is adopted, the existing practice of seeking the consent of the next-of-kin of the deceased for organ donation should be continued and the decision of the next-of-kin should be respected.

- 10. Legally, under the present framework, data that can be collected from a registrant of an ID card and the use of the data collected are governed by the Registration of Persons Ordinance (Cap 177) and the Registration of Persons Regulation (Cap 177A). Under existing provisions, information about a person's willingness to become an organ donor is not a prescribed particular that is required to be furnished for the purpose of the registration and issue of an ID card. Should the proposal to incorporate organ donation details in the Smart ID Card is adopted, legislative amendment to the above laws will be required to enable the Director of Immigration (as the Commissioner of Registration) to include the data in the ID card.
- 11. Technically, it is not possible, at the moment, to confirm if spare capacity would be sufficient to store all the organ donation details, without the exact amount of data to be stored, the type and level of access control that would be required. We will conduct further studies in this respect. We will also need to further explore how we could provide for the donor to amend the record in the Smart ID Card anytime he/she wishes to do so, and to allow authorized persons to access the organ donation details in case the donor is unconscious or dead.
- 12. A number of other issues which require careful consideration include -
- (a) a determination of who, amongst public officers, should be given the authority and responsibility to incorporate organ donation data into the Smart ID Card and verify the accuracy of such data and legitimacy of the process;
- (b) a determination of who should be allowed to access the information and the circumstances under which access is allowed under the principles of personal data privacy protection, whether witness is required etc.;
- (c) detailed arrangements for allowing the prospective donor to change organ donation information on his/her Smart ID card (such as withdrawal of consent, a change of the organs covered by the consent, etc);
- (d) the administrative costs involved; and
- (e) the effects of such incorporation on promoting organ donation among the community.

### **WAY FORWARD**

13. Members' views are sought on the above proposal. If we decide to take matters forward, we will work with CITB to continue to explore a feasible business model.

Health, Welfare and Food Bureau Office of the Government Chief Information Officer

## **Annex**

## Total Number of Organ / Tissue Donation in Hospitals under H.A.

(from 01.01.2000 to 31.12.2005)

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Year	2000	2001	2002	2003	2004	2005	Waiting
Organ/tissue							
Kidney							
Cadaveric	41	49	73	41	44	50	1316
Living	19	14	9	7	6	8	
Liver							
Cadaveric	18	23	30	18	20	24	141
Living	36	37	45	36	55	38	
Domino					11	1	
Combined							
transplant:	0	0	0	1	0	1	0
kidney & liver							
Heart	6	10	11	5	7	8	20
Lung	0	1	3	0	0	2	6
Heart-lung	0	0	1	0	0	0	1
Cornea (pieces)	166	239	295	198	230	214	400
Sclera (pieces)	12	20	22	17	32	16	Uncertain
Skin*	45	37	22	5	30	13	Uncertain
Bone*	6	6	5	0	4	3	Uncertain

- \* the nos. of donor with tissue collected
- As at 31.12.2005, the nos. of patients on waiting lists of kidney and liver transplantation were 1316 and 141 respectively.