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Panel on Health Services

Background brief prepared by the Legislative Council Secretariat for the meeting on 12 February 2007

Storing organ donation details through electronic means

Purpose

This paper gives an account of the past discussions by the Panel on Health Services (the Panel) on the issue of storing a person's organ donation details through electronic means so that upon his/her death, the relevant information can be instantly obtained by authorised personnel to save patients suffering from terminal stage organ failure.

Background

2. In Hong Kong, a person who wishes to donate his/her organ(s) after death for transplant purposes may record the wish by either signing and carrying an organ donation card, or making the wish known to his/her family members. The person is not required to inform or register with the Department of Health (DH) on his/her signing of the card. The Government therefore has no information on the number of people that have signed organ donation cards.
3. 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.
4. According to Hospital Authority's statistics in 2006, organ donation cards were found in only 2% to 7% of potential donors interviewed by 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 donation card or were told of the decision. 41% of respondents agreed to donate if their relatives had not expressed such a wish.

5. In the light of the above, there have been calls from some quarters in the community to identify an alternative and convenient means for prospective organ donors to indicate their wish.

6. In addition to storing a person's organ donation details in the organ donation card distributed by DH, the Hong Kong Medical Association (HKMA) has developed a computer database for recording the wish of potential organ donors. Access to this database is, however, limited to a small number of hospitals and there is little publicity about the database.

Past discussions

7. At the meeting of the Panel held on 13 February 2006, the Administration sought members' views on storing a person's organ donation details electronically through the Smart ID Card or a backend computer system to supplement the current organ donation card system. A number of issues which required careful consideration before implementation included -

- (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 or the backend computer system 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 was allowed under the principles of personal data privacy protection;
- (c) detailed arrangements for allowing the prospective donor to change organ donation information on his/her Smart ID Card or stored in the backend computer system, such as withdrawal of consent and a change of the organs covered by the consent;
- (d) the administrative costs involved; and
- (e) the effects of such incorporation on promoting organ donation among the community.

The Administration stressed that, given current societal values, even if the proposal of storing a person's organ donation details electronically was 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.

8. The main views/concerns of members and the Administration's responses are outlined in the ensuing paragraphs.

9. Dr Hon KWOK Ka-ki and Hon LI Fung-ying asked whether there was sufficient spare capacity in the Smart ID Card to store all organ donation details.

10. The Administration replied that further studies needed to be conducted to confirm if the existing spare capacity of the Smart ID Card was sufficient to store all organ donation details and the associated maintenance and access control scheme. There was also a need to explore ways to enable the donor to amend the Smart ID Card anytime he/she wished to do so and to allow authorised persons to access the organ donation details in case the donor was unconscious or dead.

11. Hon LI Fung-ying and Hon Vincent FANG were of the view that the replacement cost of the Smart ID Card, arising from the cardholder wishing to incorporate or make changes to his/her organ donation details in the ID card, should be borne by the Administration. The Administration responded that it should not be difficult for it to bear the replacement cost.

12. Dr Hon YEUNG Sum pointed out that the proposal of incorporating a person's organ donation details in the Smart ID Card was at variance with the view generally held by Members of the Legislative Council that personal data stored in the ID card should be kept to a minimum for privacy purpose.

13. Hon Bernard CHAN and Hon Mrs Selina CHOW considered the proposal of incorporating a person's organ donation details in a backend computer system was more preferable than in the Smart ID Card, as the former arrangement did not require any legislation and was more straightforward. According to the Administration, there should not be a need theoretically for legislation to enable the storing and retrieval of a person's organ donation details through a computer system for the reason that the storage of such was done voluntarily by prospective donors on the understanding that their organ donation details would be retrieved by authorised persons upon their death. On the other hand, should the proposal to incorporate organ donation details in the Smart ID Card be adopted, legislative amendments to the Registration of Persons Ordinance (Cap. 177) and the Registration of Persons Regulation (Cap. 177A) would be required to enable the Director of Immigration (as the Commissioner of Registration) to include the data in the ID card. Notwithstanding, Dr Hon KWOK Ka-ki was of the view that the Administration should continue to pursue the option of incorporating a person's organ donation details in the Smart ID Card.

14. Having considered members' views, the Administration undertook to pursue the setting up of a backend computer system for storing a person's organ donation details as the first option as a start. Should such a proposal gain wide public support and acceptance, action would next be taken to take forward the incorporation of a person's organ donation details in the Smart ID Card in consultation with the Commerce, Industry and Technology Bureau.

Latest development

15. The Chief Executive announced in his 2006-2007 Policy Address the Administration's plan to work with HKMA to improve on the latter's computer database for recording the wish of potential organ donors, so that more potential donors would be

attracted to record their wishes and the number of cadaveric organs available for transplant could be increased. It is estimated that the development of this improved database would be completed by end of 2007.

Relevant papers

16. Members are invited to access the LegCo's website (<http://www.legco.gov.hk>) for details of the relevant paper and minutes of the meeting.

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