

Legislative Council Panel on Health Services

Centralised Organ Donation Register

Purpose

This paper informs Members of the progress of the development of a centralised organ donation register (CODR) to facilitate organ donation and the associated promotion efforts.

Background

2. We informed Members at the meeting of this Panel on 13 February 2006 that, in order to facilitate organ donation, the Administration would pursue setting up a back-end computer system to store organ donation details of prospective organ donors provided by them voluntarily. The policy initiative to develop an organ donation computer database in consultation with relevant organizations has subsequently been included in the 2006-07 Policy Agenda. The purpose of developing such a system is to make it more convenient for prospective donors to voluntarily register their wish to donate organs after their death, and for such wish to be more reliably kept and retrieved by authorised persons such as Transplant Co-ordinators of the Hospital Authority (HA) to facilitate arrangement of possible organ donation.

3. Since 1994, the Hong Kong Medical Association (HKMA) has set up a register for voluntary registration of information and details of organ donors in Hong Kong. Prospective organ donors are invited to sign and return HKMA's organ donation forms, which are then scanned and stored in a computer database. Remote access to the database is provided for major transplant centres under the Hospital Authority (HA), so that Transplant Co-ordinators of HA can access the registration records and arrange for possible organ donation accordingly. So far, HKMA has successfully captured the details of more than 40,000 prospective donors in the register.

Centralised Organ Donation Register

4. Building upon the successful experience of HKMA and in collaboration with HKMA, the Government plans to set up a CODR for prospective organ donors to voluntarily register their organ donation details. It will be a computerised register accessible over network by authorised persons, specifically Transplant Co-ordinators of HA. The register will be set up and maintained by the Department of Health (DH).

5. Phase I of the CODR project will consist of setting up a computer database located in DH and providing secured network links for Transplant Co-ordinators to access the database through terminals in HA hospitals. Phase II of the project will include providing more channels for registration as organ donors, including electronic means such as online internet interface etc. Possible options and technical feasibility are currently being examined. The system will incorporate features to ensure protection of data confidentiality and security, including access only by persons authorised by DH. Appropriate means of authentication and verification of information supplied is also being explored.

Operation of the Centralised Register

6. Upon setting up of the CODR, a person who wish to donate his organs after death may register with DH through all means available under the system (initially by mail or fax and subsequently by electronic means). Their particulars will be stored in the computer database maintained by DH. The current organ donation forms and organ donation cards will also be merged to tie in with the setting up of the central register and to facilitate registration as far as possible. After registration, a person may request to amend or withdraw their registration through application to DH.

7. When a Transplant Coordinator is alerted that a patient might be in a stage of brain stem death, he would check the registry whether the patient has registered as an organ donor, and in parallel he would also ask the family members concerned whether they are aware of the patient's intention to donate organs. If either the person has registered or has otherwise expressed a wish (e.g. by carrying a signed organ donation card) to donate his organs after death, the coordinators would in accordance with current practice seek the consent of the next of kin of the deceased to donate the deceased's organs for transplant. Experience indicates that if there had been an express wish by the deceased, the next of kin would usually respect his wish.

8. It should be noted that the proposed CODR does not replace other means for organ donation. As at present, a person who wishes to donate his

organ(s) after death may still 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. The drawback of these alternatives, however, is that the organ donation card would need to be carried at all times. The transplant coordinators have no knowledge of such intention and cannot readily know if a person who died in a hospital has expressed a wish to donate his organs. In the absence of a signed organ donation card and if the patient has not informed his family of his wish to donate (an) organ(s), family members tend to be hesitant about donating the patient's organs.

9. Through the setting up of the CODR as a more convenient alternative, we hope that more people would register as organ donors, and by making their charitable wish more reliably kept and more readily retrievable to Transplant Coordinators in hospitals, we also hope to increase the rate of successful organ donation.

Funding and Timetable of the CODR

10. It is estimated that the project as a whole will cost about \$6.814 million. Funding for development of the project is being sought through the Office of the Government Chief Information Officer. Subject to funding availability, Phase I of the project is targeted for completion by the third quarter of this year. Depending on the options and features to be incorporated, Phase II of the project will commence as soon as Phase I is completed, and is tentatively planned for completion by end of this year.

Associated Promotional Efforts on Organ Donation

11. Providing the CODR as a convenient means for the public to register as organ donors is only part of our efforts on organ donation. In general, we need to aim at promoting broader public awareness of the importance of organ donation, and nurture a social culture which embraces the notion of voluntary organ donation. We therefore plan to step up the promotional efforts for organ donation in parallel with setting up the CODR.

12. DH, in collaboration with HA and HKMA, has launched a territory-wide organ donation promotional campaign entitled "Light up lives, support organ donation" at a conjoint press conference in December 2006 for the year 2006-07. Activities of the campaign included the display of posters at all MTR and KCR stations in December 2006 and January 2007 respectively, as well as distribution of promotional windscreen stickers to drivers at tunnel toll booths during off-peak

hours on 18 and 19 December 2006. Patient groups, professional organisations and non-Government organisations will be partners in these promotional activities.

13. Appeals were also made to various Government departments, non-governmental organizations and private companies to solicit their support in making organ donation cards/forms readily available to their employees and clients. They were also encouraged to motivate partner organizations and other companies that they have working relationship with to do likewise. As of 14 January 2007, there were 67 supporting organizations to the campaign, a list of which would be uploaded onto the organ donation website.

14. In the coming months of 2007, DH will organize a series of roving exhibitions to spread the message across the community and coordinate a “Train-the-trainer” programme for young people and secondary school students. It is hoped that upon the completion of training, participants can help promote the organ donation message among their peers and family members.

15. Further publicity and promotion will be developed in collaboration with HA and HKMA in anticipation of the launch of the CODR in the third quarter of this year, with the aim of further promoting organ donation including registration of organ donors. A new form for registration of intention to donate organ after death will be publicised for use. We will also explore for instance providing facilities for clients of various public services to register as organ donors (e.g. during application of driving license, vehicle license registration, passports, etc.) and distributing organ donation forms through public service counters and bills.

Conclusion

16. Through the setting up of the CODR and launching active campaigns to promote organ donation, our aim is to increase both the number of willing organ donors as well as the rate of successful organ donation, so as to relieve the distress of the long queues of patients waiting for organ transplant.

17. Members are invited to take note of the content of this paper.