Bills Committee on Electronic Health Record Sharing System Bill

The Administration's Response to the issue arising from the discussion at the meeting on 26 February 2015

This paper sets out the Administration's response to the issue arising from the discussion of the Bills Committee on the Electronic Health Record Sharing System (eHRSS) Bill on 26 February 2015 i.e. the implications of removing Clause 16 from the bill.

Arrangement of sharing consent for the Hospital Authority (HA) and the Department of Health (DH)

- 2. The underlying concept of the design of the eHRSS has incorporated two tiers of consent. First, all patients (including HA and DH patients) are free to decide whether to give "joining consent" to join the eHRSS. Second, for those patients, i.e. healthcare recipients, who have joined, they could choose to selectively give "sharing consent" for individual private healthcare providers (HCPs) to access their electronic health record (eHR).
- 3. As for the two largest public HCPs (i.e. HA and DH), Clause 16 of the bill provides that when a healthcare recipient or his/her substitute decision maker on his/her behalf gives a joining consent to participate in the eHRSS, he/she will be taken to have given a sharing consent to HA and DH as well. Such sharing consent will be in effect as long as the joining consent is in effect.
- 4. We have previously explained to the Bills Committee the background and justifications for the consent arrangement for HA / DH and the due process of formulation of the proposal. To recap, the eHRSS is a Government-funded sharing platform of which the fundamental objective is to foster the two-way sharing of eHR **between public and private** HCPs for the benefit of patients. HA and DH are the largest

HCPs in Hong Kong possessing vast amount of health data. These data would be the essential building blocks of patients' life-long eHR, conducive to the continuity of care of the patients. Without these data, the content of patients' eHR may become much more flimsy, and the value and benefits of joining the eHRSS would be substantially undermined. The experience of our pilot Public Private Interface-Electronic Patient Record also reflects the popularity of access to HA's data.

5. There has been due deliberation and consultation on the sharing consent arrangement for public and private HCPs with the Steering Committee on eHR Sharing and its working groups. Their membership comprises various stakeholders including patient groups, healthcare related professional bodies and experts in particular sectors or representatives of relevant organizations. The proposed consent arrangement was also put forth in Chapter 4 of the public consultation document on "The Legal, Privacy and Security Framework for Electronic Health Record Sharing" in 2011-12. The above consent arrangement for HA and DH was subsequently incorporated as a core feature of the entire consent arrangement of the eHR sharing, which is reflected in the Stage 1 system now developed and the related operational workflows. eHRSS Bill provides the necessary legislative backing for the consent arrangement.

Implications of removing Clause 16 of the bill

6. Clause 16 of the bill, together with other clauses, were drafted as an integrated whole to give effect to the presently developed eHRSS, which has incorporated the consent arrangement as a core component. While there is no specific textual cross-referencing to Clause 16 in other clauses of the bill, the removal of the clause would render the amended bill unable to support the implementation of the arrangement. In turn, the legislative backing for the operation of the eHRSS as presently developed would be seriously undermined. Even if the amended bill is passed, the currently designed eHRSS could not commence operation.

- 7. As mentioned in our written response following the 6th meeting of the Bills Committee on 29 July 2014, the Administration has looked into the technical feasibility of modifying the presently developed eHRSS. We made a preliminary assessment on how to accommodate special requests for "opting out" from the sharing consent arrangement for HA and DH by healthcare recipients or their substitute decision makers. We came to the view that the technical alteration, though not insurmountable, would require substantial modification such as the redesign of workflows, change of system design and logics as well as the programmes and applications involved. We estimated that it would take no less than 12 months to complete these work. We envisage that it would take even more time to carry out system alteration if Clause 16 is to be deleted and the entire developed consent arrangement for HA and DH is to be cancelled.
- 8. If Clause 16 is removed, there will be significant consequential delay of the commencement of eHRSS operation. Such consequence would also deprive the majority of patients who have been visiting both public and private HCPs and are agreeable or have no objection to HA/DH accessing their eHR. The cancellation of the arrangement would be also against our policy perspective regarding the realization of the fundamental objective of the eHRSS as explained above.
- 9. For those patients who only consult private HCPs or for special reasons not intend to let HA/DH access their record, they should choose not to join Stage 1 eHRSS. We anticipate that by Stage 2 after the study on enhancement of patient choice is completed and new device developed, they could reconsider participating.

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