

**Bills Committee on
Electronic Health Record Sharing System Bill**

**The Administration's Response to the follow-up issues arising from
the discussion at the meeting on 16 June 2014**

This paper sets out the Administration's response to the request for information raised by members at the meeting on 16 June 2014.

(a) Substitute Decision Makers (SDMs) of healthcare recipients (HCRs) – order of priority

2. As provided under clause 3 of the bill, certain persons are eligible in certain order of priority as an SDM of an HCR who is either (i) a minor (aged below 16)¹ or (ii) mentally incapacitated / incapable of managing his or her own affairs / incapable of giving a joining consent at the relevant time/ incapable of giving a sharing consent at the relevant time².

3. The above SDM arrangement is entirely and specifically designed for the giving/revocation of joining/sharing consents in relation to the Electronic Health Record Sharing System (eHRSS). It is

¹ The eligible SDM of such HCR is (a) a parent, (b) a guardian appointed under or acting by virtue of the Guardianship of Minors Ordinance (Cap. 13) or otherwise appointed by the court, or (c) a person appointed by the court to manage the affairs of the HCR, who accompanies the HCR at the relevant time. In the absence of (a) to (c), the eligible SDM is (d) an immediate family member who accompanies the HCR at the relevant time. In the absence of (a) to (d), the eligible SDM is the prescribed healthcare provider that provides, or is about to provide, healthcare to the HCR at the relevant time.

² The eligible SDM of such HCR is (a) a guardian appointed under the Mental Health Ordinance (Cap. 136) who accompanies the HCR at the relevant time; (b) the Director of Social Welfare or any other person under which guardianship of the HCR is placed; (c) the Director of Social Welfare in which guardianship of the HCR is vested; (d) the Director of Social Welfare or any other person performing functions of a guardian; or (e) a person appointed by the court to manage the affairs of the HCR who accompanies the HCR at the relevant time. In the absence of (a) to (e), the eligible SDM is (f) an immediate family member of the HCR who accompanies the healthcare recipient at the relevant time. In the absence of (a) to (f), the eligible SDM is the prescribed healthcare provider that provides, or is about to provide, healthcare to the HCR at the relevant time.

irrelevant to, and has no impact on, the existing decision-making arrangement for carrying out medical treatments for patients.

4. Generally speaking, medical treatment is to be provided on the basis of the patient's informed consent, though treatment of patients unable to give consent may proceed *without the patient's consent* under certain specified circumstances based on common law principles or other existing ordinance (e.g. Part IVC of the Mental Health Ordinance, Cap. 136). Even when medical treatment is allowed to proceed without patient's consent, it is not equivalent to the concerned medical professional "giving" consent on behalf of the patient.

5. We anticipate that for most cases when an eligible SDM makes a joining or sharing consent decision on behalf of a patient, the circumstances would not be an emergency situation. Under our SDM arrangement, a healthcare provider (HCP) serves as a last resort in giving a joining or sharing consent on behalf of the patient in the absence of other eligible persons. This is different in nature from the arrangement of proceeding with medical treatment without consent. Moreover, the power to decide to proceed with medical treatment is not applicable under general circumstances, but rather only under certain specified situations. We consider that our current SDM arrangement is suitable to cater for the needs of HCR incapable of granting consent when it comes to joining the eHRSS and giving specific sharing consent to a HCP. This proposed SDM arrangement received general support during the public consultation exercise conducted in 2011-12.

6. As regards whether the proposed SDM arrangement is consistent with the recommendations relating to medical decision-making for persons who were unable to make those decisions at the time of execution of the associated action put forth by the Law Reform Commission in its report on "Substitute Decision-Making and Advance Directives In Relation to Medical Treatment" (the Report), we note that the report is concerned with how decisions as to *medical treatment* can be made for patients who are unable to make those decisions themselves because they are comatose or in a vegetative condition. The report deals with the situation where decisions as to *medical treatment* are made on behalf of a patient by someone else, such as a doctor, when the patient is comatose or in a vegetative conditions (what is termed "substitute decision-making").

It also deals with the situation where the patient himself, while competent, gives instructions as to the medical treatment he wishes if he later becomes incompetent to make such a decision (referred to as an “advance directive”). As explained above, the proposed SDM arrangement in the eHRSS Bill is to deal with the giving/revocation of joining/sharing consents in relation to eHRSS i.e. concerning participation in the scheme and allowing particular HCP to access record. It is different in nature from the “substitute decision-making” mentioned in the Report which is about decision on medical treatment.

(b) Emergency access of the electronic health record (eHR) of an HCR in the eHRSS

7. For cases where emergency access of the eHR of an HCR in the eHRSS is necessary in tandem with the carrying out of emergency treatments on the HCR, the concerned HCP could access the eHR without consent by virtue of section 63C of the existing Personal Data (Privacy) Ordinance. Our SDM arrangement needs not even come into play in such context. This applies to all HCRs regardless of whether they are minors or mentally incapacitated. To safeguard these HCRs’ privacy, the concerned HCP would need to provide justifications for such access, which will also be logged and subject to audit.

(c) Requirement for SDM to “accompany” HCR

8. SDMs generally have to be “accompanying” the concerned HCRs “at the relevant time”. A Member enquired about the meaning of “accompany”, and asked whether a person eligible as an SDM could give consent on behalf of an HCR via a phone call to an HCP.

9. We are adopting the ordinary meaning of the word “accompanies” in clause 3(2) of the bill, which includes the element of physical presence. We will require the SDM to physically accompany the relevant HCR to facilitate proper authentication and record of the identity of the SDM. This is a safeguard of the privacy of the concerned HCR. The physical presence of an SDM is only required once per the giving of a consent. The physical presence of an SDM is not required for subsequent consultations with the HCP.

(d) Public-Private Interface – Electronic Patient Record Sharing Pilot Project (PPI-ePR)

10. To test the feasibility and acceptability of electronic health record sharing, the Hospital Authority (HA) has been implementing the PPI-ePR pilot project since April 2006. The pilot allows participating private healthcare professionals to view their patients' past medical records kept at HA, subject to the patients' consent.

11. The statistics of participation in the scheme reflects its growing acceptance among patients. In 2007, i.e. the first year after launch, around 10,000 patients were enrolled. However, by May 2014 (i.e. eight years after the initial implementation), over 360,000 patients and around 3,200 private healthcare professionals have been enrolled, with more than 930,000 access recorded through the system. In designing and developing the eHRSS, we have taken into account the experience gathered from this pilot and also the findings and recommendations of two studies conducted in 2008 and 2012-13.

PPI-ePR Survey in 2012-13

12. HA engaged the Jockey Club School of Public Health and Primary Care of the Chinese University of Hong Kong to conduct a survey on PPI-ePR in end 2012 to early 2013. The survey report was completed in February 2013.

13. The major aims of the survey are to identify and analyze the factors affecting programme participation, the awareness and acceptance of the scheme, perceived benefits of PPI-ePR and the reasons why some did not use it. The outcome of the survey revealed that 76% of the enrolled patients and 68% of doctors were satisfied with the programme. The findings and recommendations of the survey were subsequently taken into account in our design and development of the eHRSS and to accordingly put some emphasis on:

- Smooth transition with little migration efforts from PPI-ePR to eHRSS;
- User-friendly interface of future eHRSS;
- Simple enrolment procedure, training and technical IT support

- for doctors joining eHRSS;
- Simple enrolment procedures for patients joining eHRSS; and
- Large-scale publicity programmes to promote the benefits of eHRSS.

14. The executive summary of the survey is attached at **Annex A** for reference.

Qualitative Research Study in 2008

15. Prior to the survey, HA had also engaged a private market research company to conduct a qualitative research study in 2008 to obtain in-depth feedback from the participating healthcare professionals and patients. The outcome of the study reveals that:

- Most patients were quite satisfied with PPI-ePR for the benefits it brought about such as accurate diagnosis and saving in time, money, hassle and pain.
- Medical professionals found PPI-ePR useful and convenient in getting a clear patient history which would help them make more accurate diagnosis and prescription. Some commented that there were insufficient promotions about the scheme.
- PPI-ePR was considered by both patients and medical professionals as highly secured given its SMS alert and double authentication of log-in procedure (use of doctor's token and patient's password).
- Both patients and doctors considered the content of sharing sufficient and adequate. Patients generally did not have any reservation to disclose their entire patient record. Some doctors requested enriched content such as X-ray/CT scan/MRI images; all written lab test reports; out-patient, emergency and procedure records, etc.

16. The conclusion and recommendation of the study are extracted at **Annex B** for reference.

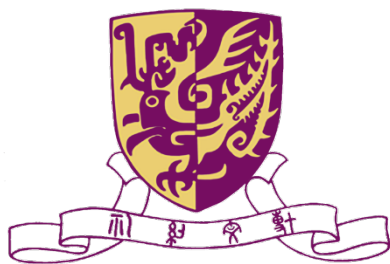
(e) “Safe deposit box” feature

17. We will make a further Powerpoint presentation on the issue at the upcoming meeting of the Bills Committee on 24 June 2014. The general concept of “safe deposit box”, the pros and cons of providing such type of function and relevant overseas experiences based on information available have been summarized in our written responses in relation to the meetings held on 13 May 2014, 19 May 2014 and 26 May 2014. As for views gathered during the public consultation on the “Legal, Privacy and Security Framework for Electronic Health Record Sharing” conducted from December 2011 to February 2012, they are set out in LC Paper No. CB(2)2279/11-12(05) considered by the Panel on Health Services on 11 June 2012. Paragraphs 10-18 of the paper are of particular relevance.

(f) Code of practice (CoP) to be issued by the Commissioner for the Electronic Health Record

18. As agreed at the last meeting of the Bills Committee on 16 June 2014, we will present further information on the nature and content of the CoP and address relevant issues at a meeting of the Bills Committee after the one on 24 June 2014.

**Food and Health Bureau
20 June 2014**



Survey Report
Executive Summary

**Provision of Survey Service of Public-Private Interface-
Electronic Patient Record Sharing Pilot Project (PPI-ePR)**

(Contract No.: 8110-004-815)

**Prepared for the
Hospital Authority**



JC School of Public Health and Primary Care,

The Chinese University of Hong Kong

February 2013

Executive Summary

1.1 Background: The Hospital Authority (HA) enlisted the School of Public Health and Primary Care, Faculty of Medicine, at the Chinese University of Hong Kong, to conduct surveys about the experiences of patients and private doctors have had with the PPI-ePR programme; to ascertain the reasons why some of them are not using the programme; to explore strategies to address the barriers of using the PPI-ePR; and to enhance public acceptance of the PPI-ePR.

1.2. Survey Objectives: This survey aims to: (a) study the factors hindering private doctors and patients using the PPI-ePR; (b) evaluate the awareness, acceptance and perceived benefits of the PPI-ePR by private doctors and patients; (c) assess the reasons why some patients and doctors are not using the system after having enrolled; and (d) consolidate areas for service improvement to facilitate public acceptance and usage of the PPI-ePR.

1.3 Methods for Patient Surveys: These were conducted from December 2012 to January 2013 by telephone interviews based on an enrolment list provided by the HA for patients and a Hong Kong-wide directory for non-enrolled respondents. A simple random sampling methodology was adopted and 1,701 valid surveys were conducted. The response rates were 91.9% and 73.4% for enrolled and non-enrolled patients, respectively.

1.4 Methods for Doctor Surveys: These were conducted in the same study period by postal questionnaires sent to 10,285 registered doctors after exclusion of non-private postal addresses. A total of 610 valid questionnaires were received consisting of responses from 409 enrolled doctors and 198 non-enrolled doctors (three with unknown status). The response rate was estimated at 14.4% (610 surveys/4,229 private doctors).

1.5 Factors hindering patients and doctors from joining PPI-ePR: The most important factors hindering programme participation by non-enrolled patients included unawareness, and not enough clarity about the project and its objectives. As well as that, the enrolment procedure was perceived to be complicated. Many doctors were concerned about the workload involved in migrating paper records to a computer and felt that they lacked the technical expertise to operate the systems.

1.6 The awareness and acceptance of PPI-ePR: The majority of the enrolled patients and doctors were aware of the PPI-ePR, but only around one fourth of non-enrolled patients were aware of the programme. Family doctors and HA seminars were influential to encourage participation among enrolled patients, and so was the media and their peers. Among both groups of doctors, peers in the healthcare sector and posters or leaflets from the HA were the most common means to learn about the PPI-ePR. Non-enrolled patients had high levels of acceptance for joining the programme upon recommendation from their family doctor.

1.7 The commonly perceived benefits of the programme among enrolled patients were a) the ability of the PPI-ePR to reduce repetition of health assessment and information provision; b) physician recommendation; c) accurate and comprehensive health information which can be retrieved by doctors; and d) medical record referencing. Among enrolled doctors, these were a) timely access to patients' medical records; b) the programme's ability to deliver higher quality of healthcare service; c) continuity of patient care; and d) improvement of patient safety.

1.8 Reasons why enrolled patients and doctors did not use the system after joining: Many patients did not use the PPI-ePR after enrolment mainly due to the fact that they didn't have a need to use it. Some doctors claimed there was no clinical indication, and a significant proportion reported forgetting the login password and patient factors.

1.9 Perceived strategies to increase the awareness of eHRSS: Those reporting satisfaction with the programme were mostly enrolled patients and enrolled doctors. Media, such as newspapers, television and magazines were regarded by enrolled patients as effective strategies to increase programme awareness, whilst doctors regarded medical newsletters as effective means.

1.10 Recommendation to enhance doctor enrolment: There is clearly a need to enhance promotional initiatives using strategies which are perceived as both attractive and effective by doctors and patients. The HA may consider to enlist enrolled doctors to clarify the simplicity of the enrolment procedure and share their experiences. In addition, the HA may formulate and implement a series of on-site clinic visits to facilitate participation by non-enrolled doctors. Also, a significant proportion of non-enrolled doctors were concerned about the migration of paper records to the computer system and also their lack of IT expertise as barriers to join the programme.

The PPI-ePR programme office may consider individualised recommendations for these doctors by providing technical expertise and educational seminars to address particular difficulties.

1.11 Recommendation to enhance patient enrolment: To enhance enrolment rates among non-enrolled patients, a series of advertisements could be planned for television, newspapers and magazines, which were perceived by patients as highly effective promotional means. As family members and friends were important sources of information about the PPI-ePR among non-enrolled patients, those who have already been enrolled could be encouraged to promote the PPI-ePR to their non-enrolled family members and friends. Also, since the surveys showed that most non-enrolled patients would join if recommended by their doctors, family physicians should be encouraged to promote the PPI-ePR programme in their private practice to patients who have not yet joined to further enhance patients' enrolment rate.

1.12 Recommendations for use of PPI-ePR after joining: Most enrolled patients did not use the PPI-ePR after enrolment because they didn't have a need for it, but some didn't use it due to non-participation by their family doctors and due to forgetting their login passwords. To enhance patients' use after enrolment, it is crucial for non-enrolled doctors to participate in the programme alongside their patients. Simpler and quicker strategies to facilitate memory retention of login passwords could be considered. For doctors who have enrolled yet did not access the medical records via the PPI-ePR after enrolment, the major reasons were forgetting their login passwords and non-participation of the attending patients. Measures to salvage forgotten passwords should be consolidated to help quick retrieval. Since a sizeable proportion of patients failed to provide login details to authorise access, support for retrieval of patient login details should be available in the doctors' private practice.

1.13 Recommendations to prepare for the future eHRSS initiative: The PPI-ePR programme office could leverage on the advantages of their computer system to further increase the programme's enrolment rates. Major barriers of enrolment reported by doctors, such as perceptions of complicated procedures and lack of technical expertise, will need practical support from the office. The impact of future measures to promote the programme's usage and the effectiveness of educational initiatives should be formally evaluated. The benefits of the PPI-ePR perceived by doctors and patients in this survey could be considered for inclusion as the main messages in the PPI-ePR's promotional initiatives.

Extract of Qualitative Research Study in 2008

Conclusion and Recommendation

PPI-ePR is well received by both patients and medical professionals. It is valuable as it is a platform that allows for better patient care with timely and accurate medical records, which in turn could save the pain and agony of patient and their lives.

Both patients and medical professionals are quite satisfied with the pilot esp. on speed, security and content, and expect it to see full launch of the program to all private hospitals and doctors in future. Bi-lateral information flow is also welcome and expected from private hospitals. They are receptive in using HA [Hospital Authority]'s CMS [Clinical Management System] as it is a sophisticated and comprehensive software.

Patients expect the program to be free-of-charge, but are willing to pay a small amount to cover the admin cost if really required. Medical professionals would transfer the fee to the patients if there is a fee to use the program in the future.

To fully achieve cooperation between public and private hospitals, the priorities lie on extensive user coverage and bilateral information flow. Below is a summary of the three key areas of improvement from the perspectives of both patients and medical professionals:

1. Publicity

- Extensive promotion to mass public
- Participation of more private doctors

2. Bilateral information flow

- Medical records at private hospital / clinics to be retrievable by HA

3. Enriched content

- (Must) All written lab test reports
- (Nice to have) “New” or “Updated” icon for new lab test results
- (Nice to have) Out-patient / emergency / procedure records
- (Nice to have) X-ray / CT scan / MRI images