

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

**The Administration's Further Response to the issues arising from the  
discussion at the meeting on 31 March 2015**

Further to our response to issues (a) and (b) arising from the discussion at the Bills Committee on the Electronic Health Record Sharing System (eHRSS) Bill on 31 March 2015 (vide LC Paper No. CB(2)1215/14-15(02)), this paper sets out the Administration's response to issues (c)(ii), (d) and (e).

**(c) Using identifiable electronic health record (eHR) for research and statistics**

The view of the Hong Kong Alliance for Rare Diseases

2. At the last meeting, a member enquired whether the Hong Kong Alliance for Rare Diseases (the Alliance) has expressed any view regarding the use of identifiable data in the eHRSS for research. We have accordingly checked the responses to our public consultation on "The Legal, Privacy and Security Framework for Electronic Health Record Sharing" conducted in late 2011 to early 2012, in which the proposal for using identifiable and non-identifiable eHR for research and statistical purposes was set out. The Alliance did not send us any submissions during that public consultation. Nevertheless, we note that it has recently put forward a position paper to the Government regarding the 2015 Policy Address and 2015-16 Budget. The paper included a recommendation to establish an "integrated and comprehensive rare diseases registry" to facilitate "research activities involving patients with rare diseases". The Alliance considered that the registry would "serve essentially as a repository of past rare disease cases, with regular updates, in order to inform and facilitate proper diagnosis and treatment". In this regard, we wish to indicate that the establishment of a disease registry would likely require the use of identifiable data.

#### **(d) De-identification of eHR**

3. At the last meeting, the Assistant Legal Advisor enquired about the comment expressed by one deputation attending the 3<sup>rd</sup> meeting on 26 May 2014 concerning data re-identification risk as his view was that anonymized data could not be assumed to be privacy safe.

4. We would not argue that under some circumstances, simply removing the personal identifiers such as name, Hong Kong Identity Card number, etc. may not be able to completely de-identify certain medical records. However, the definition in Clause 2(2) of the bill states that any data or information of a healthcare recipient (HCR) is “non-identifiable data if the identity of the HCR is unascertainable from the data or information”. To fulfill these requirements in the bill in relation to non-identifiable data will involve more than merely removing the personal identifiers of a particular record. In the process of the de-identification, careful review of the records will have to be conducted to remove any data that will pose the risk of re-identification as far as possible.

5. Examples of further safeguards that could be imposed on particular research projects include: using of range or category of data instead of the precise data as far as possible (such as age or age group instead of exact date of birth, district of residence instead of detailed residential address, year/quarter of admission and length of stay in days instead of admission and discharge dates) and restricting the use of certain types of data that may impose unpredictable potential privacy risk (such as clinical notes featuring a trait of individuals, if the total number of individuals possessing such trait in the population falls below an arbitrary threshold). It is worth noting that DNA, given by the deputation as the example of a unique and unchangeable personal identifier, is not included in the Stage 1 scope of sharable data of the eHRSS. We therefore would not be able to provide DNA data for research.

**(e) Legal liabilities of the Government and the healthcare providers (HCPs) in the use of data or information contained in eHRSS**

6. In our written response following the 3<sup>rd</sup> meeting of the Bills Committee on 26 May 2014 (vide LC Paper No. CB(2)1775/13-14(02)), we have explained that ensuring the “content accuracy” of data entered into local electronic medical record systems of HCPs for uploading to the eHRSS is the responsibility of HCPs. The HCPs and their healthcare professionals have to observe the requirements of Data Protection Principle 2 of the Privacy Ordinance, the Code of Professional Conduct promulgated by the Hong Kong Medical Council and the Code of Practices promulgated by various regulatory Professional Boards and Councils in Hong Kong. In the case of eHRSS, the data will be mainly medical data of the patients, which are largely professional assessment / opinion of healthcare professionals. They were contributed by the HCPs and their staff, not the Commissioner for the Electronic Health Record (eHRC). The eHRC, as the system administrator of the eHRSS, has no authority to vet nor the expertise and historical knowledge to check the content accuracy of such health data. That said, when the health data is to be shared via the eHRSS, the eHRC will take reasonably practicable steps to ensure the validity of input of data such as usage of standardized codes and correct matching of person master index data with the health data.

7. The respective circumstances under which the eHRC and the HCP would be exposed to legal liability in the use of data or information contained in eHRSS should be construed in accordance with the above, subject to the facts and circumstances of the individual case. Generally speaking, the burden is on the plaintiff to demonstrate, on balance of probabilities, that the eHRC or the HCP has committed a civil wrong, such as to establish any negligence on the part of the eHRC or the HCP.

8. As defined in Clause 2(1) of the bill, “healthcare”, in relation to an individual, means “an activity performed **in Hong Kong** by a healthcare professional for the individual” for improving the individual’s health etc. At the meeting of the Bills Committee on 31 March 2015, some members enquired about the issue of compliance with the future

eHRSS Ordinance when the data in the eHRSS is used in an activity performed outside Hong Kong. Following the subsequent discussion on 14 April regarding patient's interest, we intend to remove the phrase "in Hong Kong" from this definition of "healthcare". For further details, please refer to our written response following that meeting.

**Food and Health Bureau**  
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