

**Views on the Electronic Health Record Sharing System Bill**

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**My qualifications to provide informed comment**

I am an applied statistician and research methodologist with more than 30 years experience of medical research (nearly 10 years as a member of the FHB Grant Review Board) and have been involved with the data protection legislation in Hong Kong for more than 20 years from the beginning, as a member and then chairman of the Law Reform Commission sub-committee on privacy. I have attended numerous presentations on the eHR system and was a member of the PCPD audit team that reviewed the HA system and found some significant privacy issues. I have chaired a human research ethics committee in HKU for five years and have recently prepared a draft policy on research data management for HKU.

**General feedback**

I fully support all the points made in the PCPD submission, so I will highlight just two of the points made by the PCPD and two additional points, all of which cause me considerable concern about the current legislative proposal.

**PCPD Points**

1. Compatibility with the PDPO. The principles enshrined in the PDPO are time-tested and should certainly not be weakened in any way for health records, especially since health records may include personal data that are sensitive in the two key domains, namely where the disclosure consequence is high (e.g. current disease status or history, such as sexually transmitted diseases) or the data contains unique, unchangeable identifiers (e.g. DNA).
2. Sharable scope and exclusion of data. I made this point repeatedly to the eHR team, including during the public consultation, but they chose to ignore it. It is completely unacceptable to insist on consent being on “all-or-nothing” basis. This means that any patient who wants their family physician to see most, but not all, of their past medical history, is unable to make this choice. For example, my family doctor is my brother-in-law and if there is one element of my past medical history in the eHR system (e.g. a visit to a DH clinic for sexually transmitted diseases many years ago) that I wish him not to see, I cannot let him access my eHR. As pointed out by the PCPD, this is clearly not a technical problem as the system is designed to have access restrictions for some items given the “relevant to the referral” restriction promised. However, the eHR system proposed will not allow the data subject ANY control other than “all-or-nothing”. This lack of choice can only be seen as a form of blackmail that clearly is inconsistent with the PDPO principle of fair collection (this is quite distinct from emergency situations where an override of access restrictions may be essential if the patient is unconscious or unable to give consent for some other reason). It is easy to see other possible problems, such as a pre-employment health check, where a patient will be unable to make the reasonable choice to allow the physician to see some, but not all of their eHR.

**Additional points**

3. Re-identification risk. As noted under point 1, medical data may include unique, unchangeable identifiers, such as DNA. The consequence of this is that anonymised data cannot be assumed to be privacy safe, as there is a non-trivial and increasing risk of re-identification. Another example would be that full details of hospital and clinic visits may also be a unique identifier. This means that releasing of anonymised health records for research cannot be assumed to be privacy safe and **MUST** be required to undertake careful review to minimise the reidentification risk to a safe level (or refuse release).
4. I am also greatly concerned that the process for review of research access of eHR records is largely undefined in the legislation and there are no guarantees that the membership of the review board will be competent to assess not only the medical research value but crucially the privacy risk that must be balanced against the research value for access to either anonymised or identified records.

**Conclusion**

The eHR system does has the potential to improve the delivery of health care in Hong Kong, but is essential that patient choice and minimising privacy risk are at the core of the legislation. As the proposal stands, neither issue has yet been adequately addressed. This proposal will lead to unfair choices for citizens and dangerous consequences may follow from eHR records being shared for research in an unsafe manner.