



Electronic Health Record Sharing System and Your Personal Data Privacy [10 Privacy Protection Tips]



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The Electronic Health Record Sharing System Ordinance¹ came into operation on 2 December 2015. It provides a legal basis for the collection, sharing, use and safe keeping of patients' health data under the Electronic Health Record Sharing System ("System"). The System is an information infrastructure platform for healthcare providers (including doctors and other healthcare professionals) in both the public and private sectors to, with the consent of a patient, access and share the patient's health record in the System for healthcare-related purposes.

The System will commence operation in the first quarter of 2016. You may visit the website of the System (www.ehealth.gov.hk) for more details.

10 Privacy Protection Tips

1. Limited scope of sharable data

- Healthcare providers can only access to the data within the pre-defined scope of Electronic Health Record ("eHR") sharable data³ (not all your personal data provided during treatment). Hence, before joining the System, you should ascertain the scope of sharable data from healthcare providers.

3. Cautious consideration before giving consent

- "Consent" referred to in the System means **express** consent of a patient. Hence, if you have any questions about the collection, processing and protection of personal data in the System, you should clarify them with eHR Registration Centres⁶ or healthcare providers before giving joining consent⁷ or sharing consent.
- After you have given your consent, healthcare providers may access your eHR on the "**need-to-know**"⁸ principle. Hence, you must cautiously consider and decide before giving your sharing consent⁹.

2. Clear understanding before joining

- Before joining the System⁴, you should carefully read the Personal Information Collection Statement, Privacy Policy Statement and Participant Information Notice provided by the Commissioner for the Electronic Health Record to understand what personal data is kept in the System, how the data is used, the parties to whom the data may be transferred, etc.
- Before giving the sharing consent⁵, you should carefully read the privacy policy of a healthcare provider to understand how your personal data will be processed in the System, as the privacy policies vary between healthcare providers.

4. Right to revoke consent at any time

- Participation in the System is **voluntary**. You may withdraw from the System and revoke your sharing consent given to any healthcare providers¹⁰ by making an application to the Commissioner for the Electronic Health Record at any time.
- As it takes time to process your revocation or withdrawal request, if you need to receive treatment during this processing period, you should inform the healthcare provider of your application for revocation or withdrawal. The healthcare provider should respect your decision.

5. Maintaining consent record

- After you have given your sharing consent, the System will send you a notification by a means chosen by you (e.g. SMS). You may record the details of the sharing consent given to healthcare providers (including names of healthcare providers, dates of giving the sharing consent and validity of sharing consent) for future reference.



The Relationship between the Personal Data (Privacy) Ordinance and the System

Patients' health records in the System amount to personal data, which is protected under the Personal Data (Privacy) Ordinance². Healthcare providers and the Commissioner for the Electronic Health Record should act in accordance with the requirements under the Electronic Health Record Sharing System Ordinance as well as the Personal Data (Privacy) Ordinance (including the Six Data Protection Principles) when handling patients' health records in the System.

The functions and powers of the Privacy Commissioner for Personal Data, Hong Kong under the Personal Data (Privacy) Ordinance in relation to personal data in the System include:

- handling complaints of suspected breaches of the Personal Data (Privacy) Ordinance and initiating investigation if necessary;
- carrying out an inspection of the System in respect of its handling of personal data;
- providing guidance on personal data privacy in relation to the System to citizens and healthcare providers; and
- handling any data breach notification in relation to the System.

6. Right to access data

- For access to your personal data in the System, you may exercise your data access right¹¹ under the Personal Data (Privacy) Ordinance. You can make a data access request to the Commissioner for the Electronic Health Record by completing a Data Access Request Form issued by him.
- You may also make a data access request to an individual healthcare provider for accessing your personal data in its local system. As a data system operated by an individual healthcare provider is independent of the System, a healthcare provider is not entitled to provide you with the health records uploaded to the System by other healthcare providers, when you make a data access request to that healthcare provider.

7. Safekeeping of data

- You must safeguard the copies of eHR (in paper form or otherwise) obtained in a data access request to avoid leakage of personal data.

8. Right to correct data

- If you find your personal data accessed via the above channel to be inaccurate, you may request for data correction by writing to the Commissioner for the Electronic Health Record.
- However, as the eHR in the System is provided and uploaded by healthcare providers, you may make enquiries with the healthcare provider concerned first.

9. Paying attention to access notification

- All access activities will be logged in the System. At the time of registration, you may indicate the means (e.g. SMS) by which the System sends notification to you whenever your eHR is accessed.
- If you suspect that your eHR is accessed by an unauthorised party (e.g. a healthcare provider without your sharing consent), you should notify the Commissioner for the Electronic Health Record¹² immediately, or make enquiries with the healthcare provider concerned.

10. Giving consent on behalf of minors or persons incapable of managing their own affairs

- The System respects a participant's right to self-determination. Hence, decision of joining the System or giving sharing consent must be given by the participant himself, unless the participant is a minor (aged below 16) or a person incapable of managing his own affairs.
- For the above person, his parents, guardians, person appointed by court, his family member or a person residing with them, or a prescribed healthcare provider will act as a substitute decision maker¹³, who should make decisions in the best interest of the above person.

Complaints

- If you wish to lodge a complaint in relation to the System, you may write to the Commissioner for the Electronic Health Record. If, upon preliminary investigation, it is found that there may be contravention of the Personal Data (Privacy) Ordinance, the Commissioner for the Electronic Health Record may, with your consent, refer the case to the Office of the Privacy Commissioner for Personal Data [the "PCPD"], and the PCPD will follow up on the complaint in accordance with its Complaint Handling Policy.
- If you believe that your complaint may involve personal data in the System and a contravention of the Personal Data (Privacy) Ordinance, you may also consider lodging a complaint with the PCPD in writing directly and provide the relevant evidence for its follow-up action.



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- Chapter 625 of the Laws of Hong Kong
- Chapter 486 of the Laws of Hong Kong
- Scope of eHR sharable data includes (i) personal identification and demographic data; (ii) clinical note summary; (iii) referral between providers; (iv) adverse reactions and allergies; (v) birth and immunisation records; (vi) other investigation results; (vii) laboratory and radiology results; (viii) diagnosis, procedures and medication; and (ix) summary of episodes and encounters with healthcare providers. [The concerned authority may from time to time review or update the eHR sharable scope. Latest eHR sharable scope and details will be announced at the website of the System (www.ehealth.gov.hk)]. Data that fall outside the eHR sharable scope, such as billing and insurance plan information, will not be uploaded, stored and shared through the System.
- Joining consent = You agree to let the System store your personal identification and health data from participating healthcare providers who have obtained your consent. You agree the Hospital Authority and the Department of Health to view and upload your health record.
- Sharing consent = You agree to let a particular healthcare provider view and upload your health record.
- eHR Registration Centres are located at around 20 Patient Registration Centres under the Hospital Authority, around 20 clinics under the Department of Health, some private hospitals, university health services, etc. [Details of registration locations will be promulgated at the System website.]
- See Note 4
- Access to any health data of the patient is restricted to its healthcare professional who may perform healthcare for the patient; and the access is restricted to the health data that may be relevant for performing healthcare for the patient.
- Two options of Sharing Consent: (i) Indefinite Sharing Consent (valid without time limit, until revocation by patient, or registration withdrawn or cancelled) and (ii) One-year Sharing Consent (valid for one year from the date of consent provision, until revocation by patient, or registration withdrawn or cancelled).
- Except the Hospital Authority and the Department of Health
- Please refer to the leaflet of "Exercising Your Data Access Rights under the Personal Data (Privacy) Ordinance" published by the PCPD.
- Upon preliminary investigation, if it is found that the case involves contravention of the Personal Data (Privacy) Ordinance, the Commissioner for the Electronic Health Record may refer the case to the PCPD for follow-up after seeking your consent.
- Please refer to section 3 of the Electronic Health Record Sharing System Ordinance.



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