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ehealth

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An Introduction to the Legal, Privacy and
Security Framework for Electronic Health Record Sharing

eHealth Record Continuity of Care for You



Food and Health Bureau
Hong Kong Special Administrative Region Government



Message from Dr York Y N CHOW, GBS, JP Secretary for Food and Health

Dear Citizens,

In 2008, the Government embarked on a reform of our healthcare system to ensure its sustainable development and respond to the increasing healthcare needs of the community. The proposal to develop a territory-wide patient-oriented eHealth Record (eHR) Sharing System was first put forward as one of the service reform proposals and received broad support from the community.

The eHR Sharing System will provide an essential infrastructure for access and sharing of participating patients' health data by authorised healthcare providers in both the public and private healthcare sectors. Through timely sharing, different healthcare providers can provide collaborative patient-centred care more efficiently and in a seamless manner, and to realise the concept of "records follow patients".

The benefits of the system are obvious and participation is entirely voluntary. We would also ensure the privacy and data security of patients in the development of the eHR Sharing System. To this end, we endeavour not only to deploy the appropriate technologies to safeguard system security, but also to formulate specific legislation to provide robust legal protection for the privacy and confidentiality of patient information. Specifically, participating healthcare providers have to be properly authorised and need to follow certain requirements to be set out in the legislation, code of practice or guidelines, in line with the "patient-under-care" and "need-to-know" principles.

We need your participation and your views to realise the potential and benefits of the eHR Sharing System. We are launching this consultation to seek your views on the proposed legal, privacy and security framework for the eHR Sharing System. I encourage you to go through our proposals and share your views and suggestions with us.



Dr York Y N CHOW
Secretary for Food and Health
December 2011



The eHR Programme

What is eHR sharing?

An eHR is a record in electronic format containing health-related data of an individual. In Hong Kong, the eHR Sharing System (the System) is a Government-owned electronic platform for healthcare providers to upload and access individual's health-related data.

What are the benefits of eHR sharing?



For Clinicians

- ✓ Improved availability and transparency of information shared between the public and private sectors
- ✓ Efficient clinical practice
- ✓ Efficiency gains by avoiding the need to store, collate and transfer paper records



For Patients

- ✓ Reduced medication errors
- ✓ More efficient and effective use of diagnostic tests
- ✓ Timely treatment
- ✓ Improved accuracy of diagnosis and disease management



For Healthcare System

- ✓ More efficient and better quality healthcare
- ✓ Better disease surveillance
- ✓ Support public health policy making



The eHR Programme

**We are already enjoying the benefits of eHR sharing!
By end September 2011 -**

- ✓ Over **170 000** patients enrolled in the Public-Private Interface – Electronic Patient Record (PPI-ePR) Sharing Pilot Project with their medical records kept by the Hospital Authority (HA) accessible by participating private healthcare providers and other registered institutions.
- ✓ About **13 700** patients benefited from the Radiological Image Sharing Pilot Project, with their radiological images sent by participating private healthcare providers to HA via electronic means.
- ✓ Around **30 000** patients and more than **170** private doctors / healthcare providers benefited from the two-way sharing of clinical information in various public-private healthcare partnership schemes.

When will the System be available?

The Government has taken a leading role in developing the System and the target is to set up the eHR sharing platform by 2013-14 under the first stage eHR Programme for connection with all public and private hospitals.

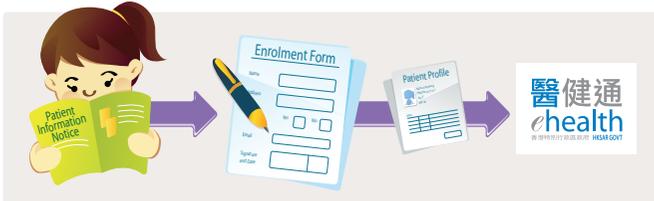


The Legal, Privacy and Security Framework

How can patient participate in eHR sharing?

Participation in eHR sharing is entirely *voluntary* and based on the patient's *express and informed consent*. With its huge benefits, we believe there is a compelling reason for both patients and healthcare providers to participate in eHR sharing.

Participation in eHR sharing should be based on the patient's **Express and Informed Consent** and on a **Voluntary Basis**

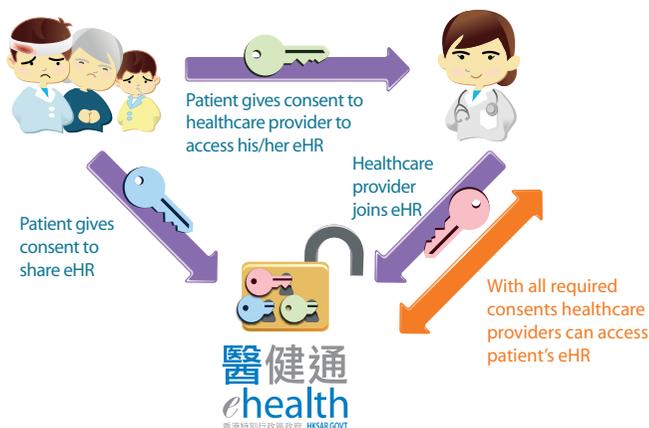


To facilitate the patient's informed decision, a *patient information notice* setting out the scope, rights of patients, privacy safeguards, etc. will be handed out to patients upon their enrolment.

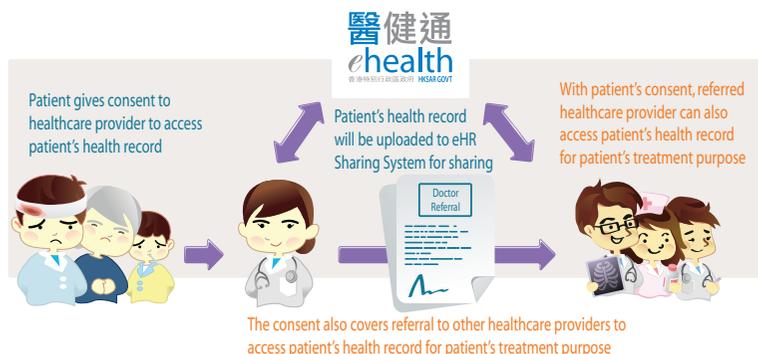
How can healthcare provider access patient's eHR?

- Healthcare provider voluntarily participates in eHR sharing and signs and complies with the terms and conditions of the agreement with the eHR Sharing System operating body (eHR-OB).
- The patient grants consent to this eHR participating healthcare provider to access/upload data to his/her eHR through the eHR sharing platform.
- Emergency access to the eHR of a patient without his/her prior consent in line with the Personal Data (Privacy) Ordinance will be allowed. As a safeguard, the System would log and report any misuse.

The Legal, Privacy and Security Framework



Patient can grant consent to individual healthcare providers at his/her own choice. Such consent covers consent for the referred healthcare providers to access his/her eHR for the patient's treatment purpose.



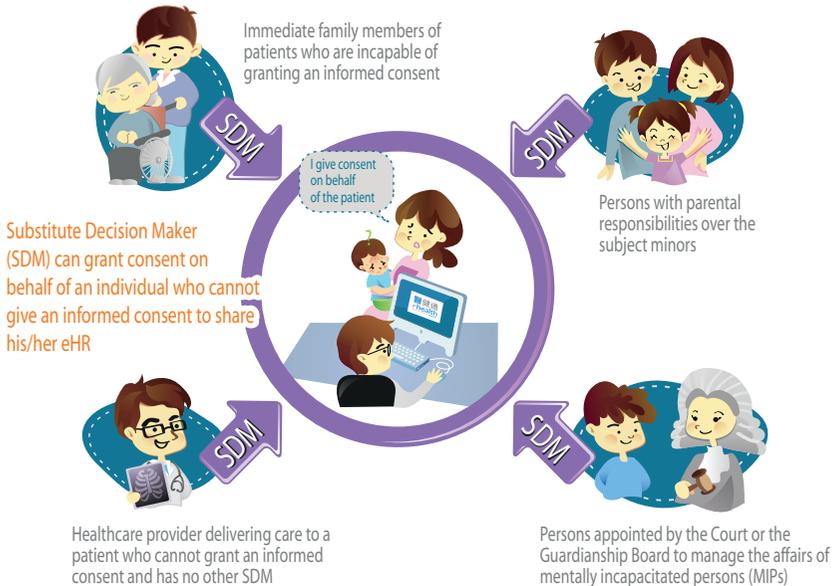
Healthcare providers may access the health data of only patients for whom they are delivering care and with their consent ("*patient-under-care*" principle), and only those health data that are necessary for the delivery of care for the patients ("*need-to-know*" basis).



The Legal, Privacy and Security Framework

Any special arrangement for an individual unable to grant an informed consent to share his/her eHR?

Substitute decision makers (SDMs) may give consent on behalf of an individual who is unable to make an informed decision to share his/her eHR. These include minors under the age of 16, mentally incapacitated persons (MIPs) and patients who cannot make an informed decision.



How about patient's record in HA and the Department of Health (DH)?

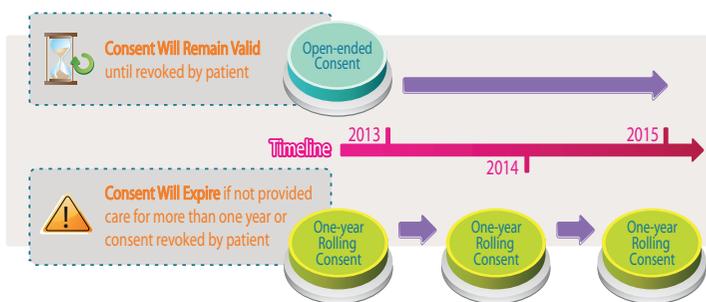
Patient's consent to eHR-OB covers consent to HA and DH for accessing and uploading data to the patient's eHR.



The Legal, Privacy and Security Framework

How long will patient's consent last?

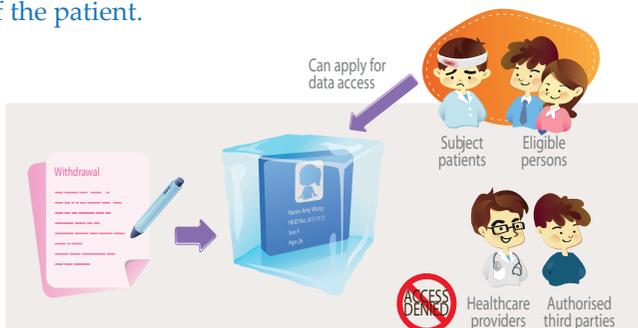
Patient may choose to give an **open-ended consent** until revocation or a time-limited **one-year rolling consent** to a healthcare provider for access to their eHR.



How to handle patients' eHR upon withdrawal/death of patient?

Participant may withdraw from eHR sharing at any time. Deceased patient's consent will expire after his/her death. Upon withdrawal or death of patient -

- eHR data of withdrawn patient would be frozen for three years; while the eHR data of deceased patient would be frozen for 10 years;
- frozen eHR data cannot be shared, and can only be accessed by eligible persons; and
- all frozen eHR data, and the corresponding archive and backup data would be completely de-identified after the expiry of the frozen periods to protect the privacy of the patient.

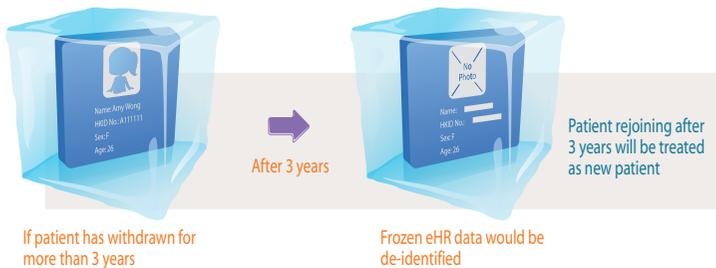
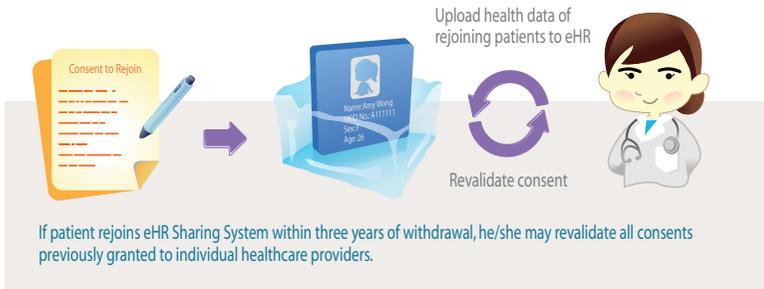




The Legal, Privacy and Security Framework

How to handle the eHR of withdrawn participant if he/she re-joins eHR sharing?

- Frozen eHR of withdrawn patient will be reactivated if he/she rejoins eHR sharing within three years of withdrawal. After revalidating the patient's previous consents, healthcare providers will be requested to upload data of the rejoining patient to the System.
- Frozen eHR of withdrawn patients cannot be reactivated if the subject patient rejoins after three years of withdrawal. The patient will be treated as a new participant since his/her frozen eHR would have been de-identified.





The Legal, Privacy and Security Framework

What will be shared?

Only data necessary and beneficial for the continuity of healthcare will be shared over the System. In the first phase of eHR development, the scope of sharable data will cover -

- (a) personal identification and demographic data;
- (b) episodes/encounters with providers (summary);
- (c) referral between providers;
- (d) adverse reactions/allergies;
- (e) diagnosis, procedures and medication;
- (f) immunisation records;
- (g) laboratory and radiology results; and
- (h) other investigation results.

What uses of eHR data will be allowed?

Primary use: for care of patient.

Secondary use:

- (i) *anonymised eHR data* for justified research proposals; and
- (ii) the Secretary for Food and Health may approve use of *patient-identifiable data* for public health research or disease surveillance purpose.



The Legal, Privacy and Security Framework

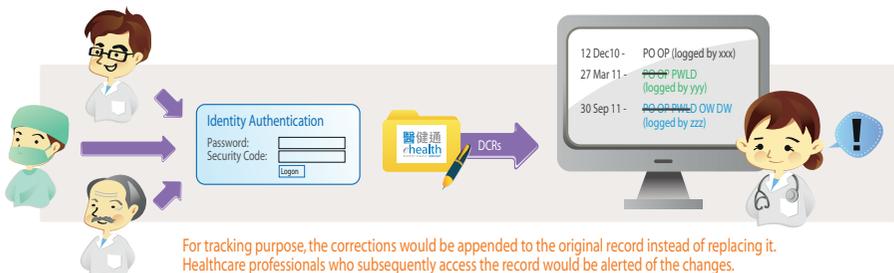
Can patient access his/her own eHR?

Only subject patient, person with parental responsibilities over minor, and guardian of MIP appointed by Court can make *Data Access Requests* for patient's eHR.

Can patient request amendment to his/her eHR data?

Only subject patient, person with parental responsibilities over minor, and guardian of MIP appointed by Court can make *Data Correction Requests (DCRs)*. DCRs will be handled by healthcare provider contributing the data. When amending/correcting the data -

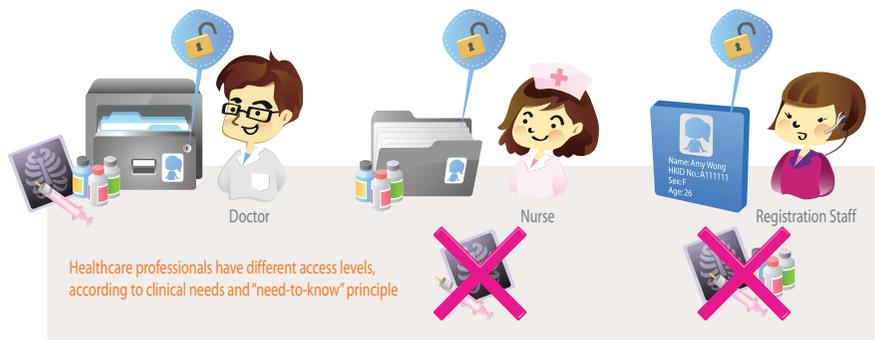
- Original data will not be overwritten. The corrections would be appended to the original record instead of replacing it (track and trace).
- As certain security safeguards in the System rely on the Person Master Index (PMI) data (name, sex, identity document number, mobile phone number, etc.) of the patient, healthcare providers would require patient's consent to edit the PMI data on patient's behalf.



The Legal, Privacy and Security Framework

What are the safeguards to protect privacy and security in the System?

- **Role-based access control:** differentiated access control will be built-in to regulate authorised healthcare professionals' access to the System. The System will register, authenticate and implement role-based access control on healthcare professionals participating in eHR sharing with a central healthcare professional database.



- **Restricted downloading of eHR data:** strictly limited to the PMI data and allergy information necessary for clinical record management and decision support. Other eHR data can only be viewed from the System.
- **Data validation and encryption:** imported data and important patient demographic data will be validated to avoid inputting errors. The System will also encrypt eHR data in the databases, files, archives and during transmission as appropriate to guard against unauthorised access.
- **Access notification to patients:** patient will be notified via a Short Message Service or other means to report suspected unauthorised access of eHR data.



We Need Your Views

We need your views

To take the proposal forward, we welcome the views from all of you on the proposed Framework.

Please send us your views on our proposals on or before 11 February 2012 via the contact below. Unless otherwise specified, all responses will be treated as public information and may be published in future.

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