

Electronic Health Record Sharing System

Participant Information Notice



Background – What is Electronic Health Record?

Electronic Health Record (eHR) contains a person's personal and health-related information. With the person's express and informed consent, healthcare providers (HCPs) in the public and private sectors may access the person's eHR for healthcare purposes through an electronic platform called the Electronic Health Record Sharing System (eHRSS). This aims to enable more timely treatment and diagnosis, and reduce duplicative diagnostic tests.

Any person, for whom healthcare has been performed, is performed or is likely to be performed (i.e. a healthcare recipient (HCR)) can apply to join eHRSS. If the HCR is a minor (under 16 years old) or lacks the required mental capacity to join eHRSS, a person known as a "substitute decision maker" (SDM) can assist the HCR to join eHRSS.

Part I – How can an HCR give Joining or Sharing Consent in eHRSS?

Giving of Joining Consent

- (a) An HCR or an SDM on behalf of an HCR can give joining consent to join eHRSS.
- (b) By giving joining consent, the HCR or his/her SDM agrees to let the Commissioner for the Electronic Health Record (eHRC) share the HCR's sharable data in eHRSS, for healthcare and referral purpose, with any prescribed HCP who has been given sharing consent by the HCR or his/her SDM. When the joining consent is given, the HCR or the SDM on behalf of the HCR is taken to have given sharing consent to the Department of Health (DH) and the Hospital Authority (HA).

Giving of Sharing Consent

- (a) eHRSS will not automatically allow HCPs (other than DH and HA) to access an HCR's health data kept in eHRSS. The HCR or his/her SDM may choose to separately give sharing consent to an HCP participating in eHRSS who is providing or is about to provide healthcare to the HCR.
- (b) DH, HA and HCPs who have been given sharing consent can provide the HCR's sharable data to and obtain it from eHRSS, and can share it with another prescribed HCP for healthcare referral purpose.

Duration of Sharing Consent

- (a) An HCR or an SDM on behalf of an HCR can choose to give sharing consent to a prescribed HCP for an indefinite term or for a one-year renewable period (other than

DH and HA for whom the sharing consent is taken to be valid as long as the HCR is participating in eHRSS).

- (b) The HCR or his/her SDM can revoke any sharing consent given to a prescribed HCP (other than the sharing consent for DH and HA) at any time.
- (c) All sharing consents will be terminated if the HCR or the SDM on behalf of the HCR withdraws from eHRSS or if the HCR's registration is cancelled by eHRC.

Ways of Giving Consent

- (a) An HCR may use his/her Hong Kong Identity Card (Smart ID) as a means to give joining and/or sharing consent.
- (b) An HCR can insert his/her Smart ID into a government-approved card reader and allow his/her card face data (including the HCR's name, date of birth and identity card number) to be obtained.
- (c) An HCR may choose to give consent by signing on a printed form.
- (d) An HCR may choose to use his/her Access Key (a unique number assigned to him/her upon his/her registration to eHRSS) as a means to give sharing consent.

Part II – What to know about eHRSS?

Protection of eHR

- (a) eHR in eHRSS is under the protection of the eHRSS Ordinance (Cap. 625) (eHRSSO) and other relevant laws in Hong Kong, including the Personal Data (Privacy) Ordinance (Cap. 486) (PD(P)O).
- (b) Under emergency situations when an HCR is incapable of giving sharing consent to an HCP (e.g. the HCR has been injured in an accident), the eHR of the HCR may be accessed by HCPs for the purpose of providing emergency treatment to the HCR.
- (c) All access and use of eHR (including emergency access) in eHRSS must be under proper authorisation and will be logged and subject to audit.
- (d) The HCR or his/her SDM will receive notifications through the communication means chosen by him/her when the eHR of the HCR in eHRSS has been accessed.

Sharable Data in eHRSS

Scope of sharable data is defined based on professional advice. Only data within sharable scope will be shared on eHRSS. The scope of sharable data will be reviewed and updated from time to time. The joining and sharing consent given will remain valid for any changes in sharable scope. The scope of sharable data include the following:

- a. Personal Identification and Demographic Data (including name, date of birth and identity document number, etc.)
- b. Allergies and Adverse Drug Reactions
- c. Diagnosis, Procedures and Medication
- d. Encounters / Appointments (e.g. summary of appointments / bookings)
- e. Clinical Note / Summary (e.g. Discharge Summary)

- f. Birth and Immunisation Records
- g. Laboratory and Radiology Reports
- h. Other Investigation Reports
- i. Healthcare Referrals

The latest scope and details will be published on the eHRSS website (<http://www.ehealth.gov.hk/>). At this stage, individual HCPs may only be able to share some but not all data within the sharable scope.

Use of eHR

Data in eHRSS may be used for healthcare, disease control and surveillance, or as permitted under any other law. Data in eHRSS may also be used for research and statistics after the relevant provisions in eHRSSO come into operation. Data in eHRSS may also be used for healthcare-related education and training.

Benefits and Limitations of eHR

eHR is an integrated summary of an HCR's health information contributed by different HCPs. It is not a complete record of an HCR's entire health history and it shall not be taken as a replacement of patient records kept by HCPs. An HCR should inform his/her HCPs all relevant health information when receiving healthcare service.

Part III – What are the matters relating to registration and de-registration?

Registration

An HCR may join eHRSS by giving joining consent and allow sharing of his/her eHR by giving sharing consent if he/she is able to understand the purpose and implications of joining eHRSS and eHR sharing.

Important Notes for SDM Handling Registration Matters on Behalf of an HCR

For an HCR under 16, or aged 16 or above and fulfills any of the following descriptions, an SDM may act on behalf of an HCR for eHRSS registration matters including giving of joining consent and sharing consent, renewal or revocation of a sharing consent, and request for withdrawal of participation in eHRSS.

1. Mentally incapacitated as defined by Mental Health Ordinance (Cap. 136) section 2(1);
2. Incapable of managing his or her own affairs;
3. Incapable of giving joining consent at the relevant time as defined in eHRSSO;
4. Incapable of giving sharing consent at the relevant time as defined in eHRSSO.

An SDM shall confirm that the person whom he/she is acting for and on behalf of meets the conditions for requiring an SDM as listed above.

An SDM may handle eHRSS registration matters for and on behalf of an HCR by submitting an application form in person at the Electronic Health Record Registration Office (eHR RO) or at one of the eHR Registration Centres or sending an application form to eHR RO by way of fax, postal mail or drop-in box.

When making the application on behalf of the HCR (e.g. when the consent is given by signing on the application form and sent to the eHR RO), the SDM should be accompanying the HCR and have regard to the best interests of the HCR.

The SDM shall be responsible for all matters regarding eHRSS registration acted for and on behalf of the HCR in the circumstances.

The SDM shall ensure that he/she is an eligible SDM in accordance with the requirements listed below.

Eligible SDM for HCR <u>under 16</u>	Eligible SDM for HCR <u>aged 16 or above</u> and is incapable of giving the person's own consent
<ul style="list-style-type: none"> (a) the person's parent; (b) the person's guardian¹; (c) a person appointed by court to manage the person's affairs; (d) if there is no one in (a)-(c), the person's family member or a person residing with him/her; (e) if there is no one in (a)-(d), a prescribed HCP who provides or is about to provide healthcare to him/her. 	<ul style="list-style-type: none"> (a) the person's guardian²; (b) the Director of Social Welfare or any other person as guardian under Mental Health Ordinance³; (c) a person appointed by court to manage the person's affairs; (d) if there is no one in (a)-(c), the person's family member; or a person residing with him/her; (e) if there is no one in (a)-(d), a prescribed HCP who provides or is about to provide healthcare to him/her.

¹ Appointed under Guardianship of Minors Ordinance (Cap. 13) or appointed by court

² Appointed under Mental Health Ordinance (Cap. 136)

³ Appointed under Mental Health Ordinance (Cap. 136) s44A(1)(i), 44B(2A) or 59T(1) or 44B(2B) or 59T(2)

Withdrawal of Registration

- (a) An HCR or an SDM on behalf of an HCR may at any time request for withdrawal of the HCR's registration.
- (b) eHRC will notify the HCR or his/her SDM when the withdrawal takes effect.

- (c) Once withdrawal is effective, the HCR's sharable data cannot be obtained from or provided to eHRSS by any prescribed HCP.

Suspension of Registration

- (a) eHRC may suspend an HCR's registration to eHRSS if eHRC reasonably suspects that the HCR's application for registration does not comply with eHRSSO or for other reasons as set out in eHRSSO.
- (b) eHRC will notify the HCR or his/her SDM when the suspension or lifting of the suspension takes effect.
- (c) Once suspension is effective, the HCR's sharable data may continue to be provided to eHRSS but cannot be viewed by any prescribed HCP.

Cancellation of HCR's Registration

- (a) eHRC may cancel an HCR's registration if the eHRC opines that the application for registration does not comply with eHRSSO or the HCR has died or other conditions set out in eHRSSO.
- (b) eHRC will notify the HCR or his/her SDM when the cancellation is effective and the reasons for the cancellation. If the HCR has died, cancellation takes effect on the day eHRC has confirmed the death information.
- (c) Once cancellation is effective, the HCR's sharable data cannot be obtained from or provided to eHRSS by any prescribed HCP.

Revocation of Sharing Consent

- (a) An HCR or an SDM on behalf of an HCR may at any time revoke a sharing consent given to any prescribed HCP (but not DH and HA).
- (b) eHRC will notify the HCR or his/her SDM when the revocation takes effect.
- (c) Once revocation is effective, the HCR's sharable data cannot be obtained from or provided to eHRSS by the prescribed HCP whose sharing consent given has been revoked.

Retention of eHR after Withdrawal or Cancellation

- (a) eHR will be retained for 3 years from the date of effective withdrawal or cancellation for the purposes of handling complaints, investigation or legal proceedings. If an HCR withdraws from eHRSS and re-joins within 3 years from the day the withdrawal becomes effective, eHRC will access the person's data kept in eHRSS to verify the person's identity for re-registration purpose.
- (b) During the retention period after withdrawal or cancellation of registration, sharable data of the HCR concerned cannot be obtained or viewed by any prescribed HCP.
- (c) eHR of any HCR who has deceased will be retained, in which the identifiable information will be erased 10 years after the death of the HCR.

Part IV – Any other matters an HCR or an SDM on Behalf of an HCR should be aware of?

How to Obtain a Copy of or Amend the Record in eHRSS

An HCR or an SDM on behalf of an HCR may obtain a copy of the HCR's personal information kept in eHRSS and submit correction request for such information according to PD(P)O.

How to Appeal against Decisions regarding the Registration

If a person disagrees with eHRC's decision in refusing to register him/her or to suspend or cancel the person's registration, the person may within 28 days from the date of receipt of the notice of the decision, appeal to the Administrative Appeals Board.

Limitation of eHRC's Responsibility

Please take note that:

- eHRC makes no representation or warranty regarding eHRSS on
 - its fitness for a particular purpose.
 - its freedom from computer virus or other use as a conduit to damage others' systems.
 - its availability and proper functioning at any time.
- eHRC is not responsible for the delivery of data over the Internet or handling of data by systems that are not owned or operated by eHRC.
- eHRC is not liable for
 - any unauthorised access or use of eHR but eHRC will take appropriate and reasonable steps to protect the security of the data in eHRSS.
 - any direct, indirect, special or consequential losses or damages arising from access to or use of eHRSS, use of any eHR in eHRSS, or providing or obtaining data or information to and from eHRSS.
 - for any liability that is excluded by eHRSSO.
- eHRC does not guarantee the accuracy, completeness or correctness of the data kept in eHRSS as the data are contributed by the HCRs or their SDMs, and by the prescribed HCPs.

Further enquiries

An HCR or an SDM may contact the following for more information:

- Electronic Health Record Registration Office
- Address: Unit 1193, 11/F, Kowloonbay International Trade & Exhibition Centre, 1 Trademart Drive, Kowloon Bay, Hong Kong.
- Telephone: 3467 6300
- Fax: 3467 6099
- Email: ehr@ehealth.gov.hk
- Website: <http://www.ehealth.gov.hk/>

Glossary

DH means the Department of Health.

Electronic Health Record (eHR) means health-related data and information, including the Healthcare Recipient Index Data, of healthcare recipients stored on the Electronic Health Record Sharing System.

The Commissioner for the Electronic Health Record (eHRC) means the public officer appointed under section 48 of the Electronic Health Record Sharing System Ordinance (Cap. 625) to operate and maintain the Electronic Health Record Sharing System.

eHR RO means the Electronic Health Record Registration Office.

Electronic Health Record Sharing System (eHRSS) means an information infrastructure established and maintained by the eHRC for keeping the eHRs of registered healthcare recipients, and sharing and using data and information contained in those eHRs.

Electronic Health Record Sharing System Ordinance (Cap. 625) (eHRSSO) means the Ordinance which provides for the establishment of eHRSS, the sharing and using of data and information stored in eHRSS, the protection of eHRSS, data and information; and to provide for incidental and related matters.

HA means the Hospital Authority.

Healthcare Provider (HCP) means a person that provides healthcare.

Healthcare Recipient (HCR) means an individual for whom healthcare has been performed, is performed, or is likely to be performed in Hong Kong.

Registered Healthcare Recipient (HCR) means an HCR who is registered under section 8(1) of eHRSSO.

Identifiable means identity of an HCR is ascertainable from the data and information.

Joining Consent given by an HCR or a Substitute Decision Maker on behalf of an HCR (if applicable) is for the eHRC to share data with prescribed HCPs who has obtained sharing consent from the HCR or the Substitute Decision Maker on behalf of the HCR or who provides healthcare services by referral.

PD(P)O means Personal Data (Privacy) Ordinance (Cap. 486).

Prescribed Healthcare Provider means DH, HA, or a registered HCP.

Sharing means the act of providing or obtaining any sharable data of a registered HCR through eHRSS.

Sharing Consent given by an HCR or a Substitute Decision Maker on behalf of an HCR (if applicable) is for the prescribed HCP to share the data of the HCR through eHRSS with other prescribed HCP(s) who also have obtained sharing consent from the HCR or his/her Substitute Decision Maker.

Substitute Decision Maker (SDM) means an eligible person giving consent on behalf of and in the name of the HCR under the requirements of eHRSSO.

Use, in relation to any data or information contained in an eHR, includes disclosure and transfer of the data or information.

The content of this booklet is subject to updates from time to time. The latest Participant Information Notice (PIN) of eHRSS is uploaded to the eHRSS website at www.ehealth.gov.hk. The latest version of the PIN published at the eHRSS website shall prevail wherever there is a discrepancy between the website version and the printed version.