Shared Electronic Health Record

Privacy Impact Assessment

Tū Ora Compass Health

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1.   Introduction

1.1.   Background

In 2009, the government released its Better, Sooner and More Convenient (BSMC)[1] initiative for primary and secondary healthcare. This approach prioritised providing a continuous health service across care settings based on collaboration and shared information.

The Shared Electronic Health Record (SEHR), also known as the Shared Care Record (SCR) allows approved alternative care settings to view a summary of the patient information stored in general practice. Health professionals that have access to an up-to-date summary of patient information at the time a patient presents, can deliver health care in a more accurate, efficient and thorough manner.

1.2.   Report Terms of Reference

This report serves to:

- Identify the potential effects an electronic summary shared electronic health record has upon individual privacy.
- Ensure the SEHR continues to comply with the twelve Health Information Privacy Code (HIPC) principles.
- Identify the mechanisms used to mitigate any undesirable impacts identified.
- Illustrate to the public that care and diligence has been taken in the implementation of the SEHR.

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[1] https://www.health.govt.nz/publication/better-sooner-more-convenient-health-care-community

2.   Overview

2.1.   Terminology

Shared Electronic Health Record refers to a read only online summary of a patient's clinical information. The SEHR sources information from a complete health record stored by the patients' enrolled general practice. This summary can be accessed by approved alternative care settings within the Wairarapa, MidCentral, Hutt Valley, Whanganui and Capital and Coast districts. This information is used to augment any further detailed information stored in their own systems and a physical assessment of the patient.

The SEHR is available in the following care settings:
- Afterhours Medical Centres
- General Practices
- Community Pharmacies
- Paramedics
- Emergency Department
- Other Hospital Departments
- Wairarapa School Clinics

The information available is a summary of the following:
- Medications
- Medical conditions
- Allergies
- Radiology results
- Immunisations
- Recalls
- Laboratory results
- Discharge summaries and other significant clinical documents (e.g. Advanced Care Plans)

The Shared Electronic Health Record is only a summary of the information stored in general practice so is not a full Electronic Health Record (EHR).

The SEHR can only be accessed by authorised health professionals in approved clinical settings; it is not designed to be used as a personal health record. Patients may be able to access a similar summary through their Patient Portal.

2.1.1. Future enhancements

Consultation notes

The original project did not include sharing of consultation notes. This was an intentional decision to minimise potential impacts on patient privacy. The public sentiment at the time the SEHR was originally rolled out, meant that decisions were more conservative from a HIPC perspective. As

sharing of information has become more accepted and the public now has an expectation of shared information, sharing of patient notes has started to be discussed. Sharing patient notes will only be considered with appropriate sign-offs by the nominated regions' clinical governance boards.

For any region who make consultation notes available via the SEHR, this will be clearly detailed on www.scr.org.nz.

2.2. Information Flow

There are two main flows of information within the SEHR.

- General Practice to SEHR.
- SEHR to alternative care settings.

2.2.1. General Practice to SEHR

General Practices are the gate keepers of information for the SEHR. The SEHR extracts a subset of the information practitioners input into their Practice Management System (PMS).

Patients can request specific health information be excluded from their SEHR, however, there are risks associated with excluding some of the information on the SEHR and these should be fully discussed between the health practitioner and patient.

2.2.2. SEHR to alternative Care Setting

When a patient presents to a care setting where the SEHR is available, such as the Emergency Department, the treating health professional will need to determine the patient's National Health Index (NHI). In most care settings, this step would be routinely done to appropriately associate health care information with the individual. Locating the patient's NHI can usually be done by using the patient's name and date of birth.

Once the NHI is located the health professional will then be able to log in to the SEHR and view pertinent information, if it exists. Practitioners are advised to inform patients that they have accessed their SEHR.

Initially, when the SEHR was launched, practitioners were required to gain verbal consent before accessing patient information. As the SEHR has developed, and due to public expectation that health records were already being shared between health facilities, the regional governance groups agreed that informing the patient of access to the SEHR after the fact, would fulfil any obligations set in place by the HIPC.

Being able to access the SEHR before meeting with the patient allows the practitioner to be better prepared during the consultation, providing a BSMC level of care and therefore being able to use their time with the patient more productively. This is particularly important where practitioners do not have access to computers during patient consults.

2.2.3. Access Query and Audit

Quarterly random sample audits are conducted by the designated Primary Health Organisation (PHO), to match access to health information via the SEHR to patient presentations at alternative care facilities. Auditors do not have access to clinical information and are assessing patterns of access only. Where further investigation of irregular access is required, such investigation will be carried out by nominated health professionals. All clinical staff, even those conducting an audit, can be subject to the same audit process. This fulfils both a monitoring and deterrent function.

Where Patient Portals are provided by the same vendor as the SEHR, patients with Patient Portals can review who has accessed their SEHR. The PHO will facilitate an audit process where patients have queries or concerns regarding access to their SEHR.

3.   Privacy Impact and Analysis

3.1.   Privacy Principles Considerations

Health information privacy is informed by the Health Information Privacy Code 1994[2] (HIPC). The impact of the SEHR on these twelve rules is detailed below.

3.1.1. Rule 1: Purpose of Collection

HIPC requires that information be collected only for a lawful purpose that is related to the function or activity of the health agency.

The SEHR has not changed any of the existing purposes of collecting the information. The SEHR does not impact on the purpose for which information is collected from a patient. GPs have a medico-legal obligation to make accurate notes on a patient and prior to the SEHR would share relevant information with other health professionals treating the same patient, to provide continuity of care.

3.1.2. Rule 2: Collection from Source

Health information needs to be collected as directly from the source of the information as possible. In most cases, this is directly from the individual or as a direct result of the individual consenting to clinical tests.

The SEHR does not change the source of the collected information. The patient still presents to their health professional, who collects the information in their PMS. A provider viewing the SEHR is viewing a summary of the information sourced directly from the patient and recorded by their GP.

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[2] https://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/HIPC-1994-2008-revised-edition.pdf

3.1.3. Rule 3: Collection from Individual

Those collecting the information need to ensure that the individual is aware of the information flows and the purpose of those flows. Its intention is to provide autonomy to the individual in the control of their health information. Rule 3[3] requires patients be made aware of what is happening to their health information.

Health services that provide detail to the SEHR will have patient education information in a prominent and accessible place. Patients will be made aware:

- That a summary of their information is available in approved settings outside of their general practice (HIPC, rule 3-1-c[3]). Patients will be made aware of the types of information shared and the care settings in which that information is available.
- That while the primary storage of their information remains within the general practice, a summary is stored by a third party (HIPC, rule 3-1-d-ii[3]).
- That they aren't required to supply information to the SEHR. That they can request specific information be excluded from or to be opted out of, the SHER altogether (HIPC, rule 3-1-e[3]). The consequence of excluding some or all information is that the patient may not experience a BSMC level of care.
- Of their right to access information held about them and their right to correct that information (HIPC, rule 3-1-g[3]). See 3.1.6 Access.

3.1.4. Rule 4: Manner of collection

Health information needs to be collected in a fair manner. The collection of information for the SEHR does not differ from the collection of information during normal clinical practice within general practice.

3.1.5. Rule 5: Storage and security

A summary of clinical information is accessible over the Internet. This carries with it some inherent risks from malicious attacks. All reasonable safeguards have been put in place to ensure the safety of this information from external agents. Organisations are required to ensure that their network, processes and procedures meet a minimum-security standard (based on Health Information Standards Organisation's (HISO) recommendations[4]).

Organisations with staff accessing the SEHR system are required to ensure that the employment agreements that they have with their staff have clauses that treat the breach of security to patient systems as serious misconduct.

Audits are conducted by the PHO quarterly to ensure all access is appropriate and matched to an episode of care. See 2.2.3 Access Query and Audit

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[3] https://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/HIPC-1994-2008-revised-edition.pdf
[4] https://www.health.govt.nz/publication/hiso-100292015-health-information-security-framework

3.1.6. Rule 6: Access

If patients have a Patient Portal they can access a summary of their health information. In most cases this is the same as what is recorded in the SEHR. This could differ due to what their general practice has shared with their patients during the setup of their Patient Portal or chooses to withhold certain information from the SHER.

Patients without a Patient Portal or those who would like a more complete view of their health information held on the SEHR, can request the information held about them from their practice or from the SEHR vendor directly.

Patients can free phone the PHO on 0800 727 664 to ascertain if a SEHR exists for them.

3.1.7. Rule 7: Correction of Information

The SEHR is a summary of a GP's record. Correction of information is not possible through the SEHR (or Patient Portal) directly. The process is the same as correction of a GP's notes. Patients need to contact their GP to correct any information.

Any disputes over the accuracy of the information will be recorded as a note attached to the item.

3.1.8. Rule 8: Accuracy

Providers document health records in an accurate and precise manner to ensure they meet their duty of care. The accuracy of the source information is unchanged with the implementation of the SEHR.

Simply providing a summary of health information to medical staff can have some limitations, (see 3.2.5. Data Quality Issues in Patient Management System Usage). Practitioners are made aware that the SEHR is a summary and is designed to be used as supplementary information in conjunction with other records and examination of the patient.

3.1.9. Rule 9: Retention

There are potentially three situations in which the retention of information within the SEHR must be considered. They are if the patient:
- Dies. Data is removed.
- Chooses to opt off the SEHR. Data is removed.
- Moves general practice. Information from their prior practice is removed.

3.1.10. Rule 10: Use of Health Information

The Purpose of the SEHR is to provide health professionals access to summary information about their patient.

Use of patient SEHRs by anyone other than health professionals, for any purpose other than providing direct clinical care to a patient, is explicitly forbidden.

Matching data should only be done with the patients NHI. Data contained within the SEHR should not be matched for any purpose, other than with another health agency providing direct clinical care to a patient for the purposes of providing a combined clinical record.

3.1.11. Rule 11: Disclosure

The SEHR has only changed the mechanism by which the information is shared, not whether it is shared. However, the 'gate keeping' mechanism for the disclosure has changed.

Where previously a GP could selectively provide only relevant or necessary information, now treating health professionals will have the ability to view all information contained within the patient's SEHR, whether it is pertinent to the referral or not.

As well as random quarterly audits, health professionals are required to maintain moral, ethical and professional standards ensuring patient doctor confidentiality. This should help mitigate some of the risk around perceived misuse of access.

3.1.12. Rule 12: Unique Identifiers

SEHR uses the NHI as the primary identifier of individuals. This allows for unique identification of the patient.

The NHI is the unique identifier that is assigned to each person that receives healthcare in New Zealand. The use and creation of NHI numbers is restricted by the HIPC. The SEHR's use of the NHI falls within those restrictions.

3.2. Specific considerations

3.2.1. Minors and privacy

Parents and guardians of children under the age of 16 can choose to opt their children out of the SEHR. Patients over the age of 16 have the right to choose if they have a SEHR and cannot be opted out by a parent or guardian without their permission. This is in accordance with the Guardianship Act 1968, allowing people over 16 years of age to consent to health care treatment.

While not explicit in legislation, common law does allow for minors under the age of 16 to consent to, or refuse, medical treatment if they are 'Gillick competent'. That is if the minor is mature enough to make and understand their decision. This follows into their right to opt-out or back into the SEHR without the consent, or knowledge, of their parent or guardian.

3.2.2. Opt-off Mechanisms

Given the low opt-out rates in other countries and the potential benefits of the SEHR, the opt-out approach was chosen to provide maximum coverage of the SEHR amongst the population.

Patient records are uploaded to the SEHR if they are enrolled at a participating practice and have not previously indicated that they do not want to have a SEHR. This methodology is referred to as an "opt-out" approach.

Patients can opt-out at any time in three ways:
- Via a form posted to a freepost PO Box (PO Box 27380, Marion Square, Wellington 6141)
- Via a toll free 0800 number (0800 727 664)
- Through their general practice.

3.2.3. Specialist and sensitive services
Specialist services dealing specifically in sensitive information, such as sexual health clinics, are excluded from submitting information to the SEHR.

3.2.4. Data Quality for Opted-off Information
Not sharing certain patient information could lead to another health professional making an incorrect decision, having assumed that they have access to all the relevant information.

SEHR is only a summary of clinical information and health professionals are educated to the fact that it may contain omissions.

3.2.5. Data Quality Issues in Practice Management System Usage
Throughout the region several different PMS' are in use. The SEHR must retrieve data from all of them. The differences in PMS' and the flexible nature of the systems provides an opportunity for information to be misinterpreted when automatically uploaded. However, this information is designed to be used only in conjunction with existing patient records and a practical examination of the patient, so any inaccuracies should be identifiable.

3.2.6. Access by people of patients choosing
As of 2018, a Shared Care Plan (SCP) tool to give selected non-medical people and practitioners outside approved care facilities access to a patient's SEHR is being trialled (within the Indici PMS). The SCP allows for a 'care team' to be created and collaborate on a patient's health requirements, as well as viewing their SEHR summary.

This is an opt-in system run through the same secure web portal as the SEHR, which should mitigate any initial privacy concerns, as patients are actively choosing to have a SCP.

A patient can, of course, choose to show anyone they wish any medical records they have access to, either through their Patient Portal or with any physical records they might have.

3.2.7. Ensuring Authorised Access
Only health professionals working within one of the approved care settings are granted access via unique logins to the system.

The PHO responsible for audits may be required to have access for the purposes of auditing access by practitioners. Any non-clinical staff with access to the SEHR, as part of the Audit Team, are restricted to viewing only non-clinical information sufficient to enable them to undertake administrative tasks related to the SEHR.

3.2.8. Human Rights, Stigmatisation

Many medical conditions carry stigma, including mental health or sexual dysfunction-related conditions. Making a patient's summary medical information available to a wider range of health professionals through the SEHR could potentially increase the chance they will be stigmatised.

The ability to filter what information is included in the SEHR should mitigate this. As patients can work with their practitioner to filter what information can be seen.

3.2.9. Community Pharmacists Use of SEHR

Pharmacists are an important safety mechanism in the process of prescribing medications. Their access to the SEHR allows them to more accurately access the appropriateness of the prescription.

Pharmacists need to make a clear distinction between a patient presenting for a professional service, rather than as a retail shopper.

3.2.10. General Practice Opt-In

The SEHR requires that each practice activate a regular upload of patient summary data. Without this, the SEHR cannot provide up to date information. The records of patients enrolled in practices that have not opted into the SEHR will be unavailable.

If a general practice chooses to discontinue their involvement, then the data already on the SEHR is removed.

Care settings not contributing to the SEHR need to advertise the fact that they are not going to load any data against the SEHR and the consequences of that decision.

3.2.11. Ownership and Intellectual Property

The ownership of patient data is still retained by the health professional and the patient, in joint ownership.

SEHR vendors own the intellectual property for the systems and structure that are used to store the information. However, the data that is contained within these systems is still owned by the patient. There is a clear distinction between the data contained within a system and the technical data structures that are used to store and serve that data.

3.2.12. Patients with Impaired Decision-making Capability

If a patient has impaired decision-making abilities, then their power of attorney or next of kin should be responsible for the decision to opt the patient out of the SEHR.

Likewise, if practicable the next of kin of power of attorney should be informed of access to the SEHR in the process of providing treatment.

4.   Governance

Each region has a governance group that has oversight of any changes to the SEHR. This group is responsible for endorsing any proposed change in the operation of the SEHR.

These groups consist of representatives from health consumers, general practice, primary health organisations and district health boards. It has a mix of clinicians, health managers, information technologists and privacy officers.

5.   Glossary of Abbreviations

Abbreviation	Description
BSMC	Better, Sooner and More Convenient
HER	Electronic Health Record
HIPC	Health Information Privacy Code
HISO	Health Information Standards Organisation
IMA	Information Management Alliance (Previously known as the Information Management Service Level Alliance (IMSLA)
NHI	National Health Index
PHO	Primary Health Organisation
PMS	Practice Management System
SCP	Shared Care Plan
SCR	Shared Care Record
SEHR	Shared Electronic Health Record