Why a shared care record is an official medical record

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Abstract

The literature describes three categories of health records: the Official Medical Records held by healthcare providers, Personal Health Records owned by patients, and—a possible in between case—the Shared Care Record. New complications and challenges arise with electronic storage of this latter class of record; for instance, an electronic shared care record may have multiple authors, which presents challenges regarding the roles and responsibilities for record-keeping.

This article discusses the definitions and implementations of official medical records, personal health records and shared care records. We also consider the case of a New Zealand pilot of developing and implementing a shared care record in the National Shared Care Planning Programme. The nature and purpose of an official medical record remains the same whether in paper or electronic form.

We maintain that a shared care record is an official medical record; it is not a personal health record that is owned and controlled by patients, although it is able to be viewed and interacted with by patients. A shared care record needs to meet the same criteria for medico-legal and ethical duties in the delivery of shared care as pertain to any official medical record.

Background: record-keeping in New Zealand

The management of patient records involves complex and contentious issues such as how to protect patient confidentiality,1 who has ownership and access rights,2,3 as well as what are the roles and responsibilities involved in record-keeping.4

The New Zealand (NZ) Medical Council recommends that healthcare professionals should keep clear and accurate patient records reporting:

- Relevant clinical findings,
- Decisions made,
- Information given to patients, and
- Any drugs or other treatment prescribed.5

Standards regarding record-keeping are also published by local professional bodies such as the criteria of medical records by The Royal NZ College of General Practitioners (RNZCGP),6 as well as the guidance on documentation by the Nursing Council of NZ7 and by the Pharmacy Council of NZ.8

The Health Information Privacy Code 1994 (HIPC)9 provides rules on handling health information regarding the purpose of data collection, rights of access and limits on disclosure.10
NZ District Health Boards (DHBs) and the Ministry of Health, as public offices, are also governed by the Public Records Act 2005 that stipulates two core record-keeping requirements:

- DHBs must create and maintain full and accurate records which must be accessible over time, and
- DHBs must obtain the authority of the Chief Archivist in order to dispose of public records.\(^\text{11}\)

Accordingly, medical record-keeping under the current legal and ethical frameworks requires healthcare professionals to record what happened in patient care and to provide other healthcare providers the capacity, motivation and instruction to act if requested.

**The official medical record—increasingly stored electronically**

Health care information, including a patient’s medical record, is increasingly written, stored and accessed electronically; according to a 2009 international survey, 97% of NZ general practices used electronic medical records.\(^\text{12}\) These electronic records have been referred to by various terms in the literature, including computerised/electronic medical records, electronic patient records, and electronic health records (EHRs). They are provider-centric medical records in a doctor’s office or clinic;\(^\text{13}\) and their purpose is similar to that of a paper-based medical record—as “a legal document and a collaboration and reminder tool.”\(^\text{14}\)

Such official medical records, whether on paper or electronic, are held and controlled by a single healthcare professional or one institution as the legal records of what happened in the care delivered by that healthcare professional or organisation.\(^\text{14}\) It also serves the purposes of giving other healthcare providers a capacity, motivation and instruction to act when requested.

The nature and purpose of official medical records remain the same whether in the form of paper or electronic. As stated in Cole's Medical Practice in New Zealand, “the obligations around medical records exist regardless of the form in which they are kept.”\(^\text{10}\)

**What is a personal health record?**

As compared to the official medical record managed by healthcare providers, a personal health record is owned and personally supervised by the individual patient. Tang et al define a personal health record system as “a repository for patient data” with possible decision-support capabilities; personal health records “capture health data entered by individuals and provide information related to the care of those individuals.”\(^\text{15}\)

Patients can use personal health record to record details of screening, immunizations, and other health promotion or disease prevention information; and they have “the right to mask any information he/she does not want to be read”\(^\text{16}\) by others. Electronic personal health records may take any of a variety of forms, including thumb drives or smart cards held by the patient, but frequently are accessed as Web sites, in which case they may be termed ‘portals’.\(^\text{17–19}\) Personal health records can be standalone, can
link to the EHRs of one or more providers (termed ‘integrated’) or to just one provider (termed ‘tethered’).15

A 2007 US study found that most organizations that provided an electronic personal health record have supported patient-centred functions such as to facilitate communication between clinicians and patients and to enable data access by proxies for minors or those with other impairments (e.g. Alzheimers).20,21 Personal health record portals offer features such as to make appointments, view laboratory results, refill medications, and communicate with providers.18,22–24

The use of secure patient-doctor email messaging at Kaiser Permanente has been associated with improved effectiveness of care.17 A further potentially transformative capability of personal health records is to allow patients to offer amendments to linked provider records, e.g. to add information (such as Alternative Medicine treatments they may be pursuing), or to correct errors or incomplete information.25

**Shared care record—in-between an official medical record and a personal health record**

The NZ National Health Information Technology (IT) Plan proposes a single shared care record as a structured and comprehensive record developed by the patient, their family/carer and their health professional(s), and which defines mutually agreed problems, goals, actions, timeframes and accountabilities for all those involved.26

Implementing this IT Plan, NZ is conducting a pilot of the National Shared Care Planning Programme (NSCPP), which has been unfolding in progressively larger phases of deployment in the Auckland area from 2011 to 2013, to investigate approaches to implementing shared care planning as an enabler to support long-term condition management.27,28

The underlying principle of the shared care record is to connect all members of the care team including the patient. Central to its purpose is that a shared care record provides information access to multiple users, including those on a multi-disciplinary care team that, for instance, consists of healthcare professionals at primary and secondary services (from multiple organisations) as well as the patient themselves.

A shared care record is not to be confused with an opt-in (or opt-out) shared repository. Such a repository is often referred to as a ‘shared record’ meaning that it has been agreed to be shared. One example of this is Testsafe in the northern region, which brings together diagnostic results, reports and medicines information from DHB facilities and community laboratories, as well as medications dispensed by community pharmacists, and then gives healthcare providers access to this information for patients under their care.29

The shared care record concept applies to a patient’s medical record that is longitudinal, and is contributed to, validated and utilized by a multi-disciplinary group of healthcare professionals involved in the care of the individual. As a result, an electronic shared care record that supports shared access to common information can facilitate effective transfer of care,6 a patient-centric longitudinal (womb to tomb) electronic record,13 and continuing, efficient and quality integrated health care.30,31
It aims to facilitate active partnership for care delivery and record-keeping among multiple healthcare professionals, as well as with the patient themselves. However, the anticipated health benefits of a shared care record such as improvements in the quality and safety of care, access to care, and cost effectiveness are yet to be confirmed.32

There are a variety of shared care record approaches internationally. One example is the Danish model of a national health portal to shared records, which exports patient data from legacy EHR systems and stores the data in a repository database, then provides access to other authorised parties, including patients, through a secure web browser.33 The portal provides access to data such as biochemistry laboratory results, medication profiles and hospital discharge abstracts.13

The access control takes an approach that authorized healthcare professionals can look up any patient registered in the system with a prompt for a self-declaration of the access rule; the information retrieval will be logged in the system along with the declaration and this log can be monitored by the patient. The philosophy behind this approach is that “no patient should die because a system blocked access to vital data.”34

Another example of shared care record development is Australia’s “personally controlled electronic health record system (PCEHR)” as a centralized approach to a shared “health summary” record.35 The Australasian College of Health Informatics (ACHI) has pointed out that it has not been made clear whether the PCEHR is a standalone concept or part of a total EHR, and whether the desired outcome is a collection of personal health information for consumer reference like a health diary/log, a system to empower the patient to control access to their personal health information as contributed to and collected by healthcare providers, or a system to benefit healthcare providers in their day-to-day care of patients.36

Furthermore, medicolegal experts have warned Australian GPs to “be wary of assuming responsibility” for creating and maintaining such summaries because of 1) the information volume, 2) significant liability due to inaccuracies in the shared summary, and 3) shared liability for clinical mismanagement by another provider who used inaccurate information in this summary.37

**A shared care record is an official medical record—it is not a personal health record**

A patient’s health data can be stored in official medical records held by healthcare providers, personal health records owned by patients, and – as an in-between case – in shared care records. The distinction among these three categories involves issues such as funding models, governance, ownership and data stewardship.13

In the authors’ opinion, a shared care record is still an official record and needs to meet the criteria for ethical and medico-legal duties of medical records. It is a dynamic, real-time record and can be used to direct care (not historical or just storage); and it is not a personal health record that is owned and controlled by patients. The management of all three categories of patient records involves complex and contentious issues, especially the complications regarding a shared care record.
The implementation of shared care records presents several challenges including standards and interoperability (a shared care record may source data from multiple systems), clinical responsibility (with multiple data contributors, whose duty is it to validate and integrate the record?), and risks from a patient restricting health professional access to all or part of the information.

The UK Royal College of GPs (RCGP) has classified shared electronic patient record systems into four categories:

- A read-only shared record following an act of publication,
- A read-only system giving access to an external EHR system,
- Read and write access to a single logical record or separate records, and
- A shared record dependent on messaging.32

The American Health Information Management Association (AHIMA) pointed out the importance of authentication (assigning responsibility for user entries, including creating, modifying and viewing data) and attestation (applying electronic signature to show authorship and legal responsibility for a particular unit of information).38

While all healthcare professionals are responsible for all aspects of the shared record’s security, confidentiality, integrity and availability, a particular challenge is how security needs to extend to multi-authorship. As pointed out by the RCGP, in the shared care and shared record environment each healthcare professional has a responsibility to inform the practice of others involved in the care of the patient; subsequently, the governance rules need to be clear on who has responsibility for all content or parts thereof and for action based on that record content within and between organisations.32

A further dimension of complexity comes from patients’ contributions to a shared care record and patient communications through shared care IT portals. This presents a challenge to balance patient empowerment with the professional and legislative requirements of an official medical record. The RCGP’s 2010 guide to GPs regarding patient access to the EHR stated, “unsolicited additions may need to be treated with caution and should not be accepted as a proxy for medical assessment.”39

In 2012, the National Health IT Board held a series of public and community seminars concerning the issues of consumer and clinician input when personal health information is shared electronically.40 However, the degree of impact on clinical workflow, workload, financial models and clinical outcomes by the record validation and integration process remains unmeasured.

In addition, it remains a challenge how we design a health IT platform that will provide the capacity to interrogate and compare the large number of data points (including medical records and, in the foreseeable future, molecular data) for patients in the context of predictive, personalized, preventive and participatory (P4) medicine.41

Such data points will include official medical records, personal health records and shared care records. The value of personal health records in supporting self-management is evident particularly through supporting information access and facilitating communication with clinicians.
Although we believe it is important to distinguish shared care records from personal health records and to examine the three concepts (Shared Care Record, Personal Health Record, and Official Medical Record) separately, we also believe they will merge and augment each other in the future. In other words, a shared care record is the next generation official medical record that empowers the patients as well as the clinicians.

An urgent task, though, is to understand the implications of developing and implementing this shared care record concept. For instance, how do we foster confidence in healthcare professionals to use an iterative and real-time care planning/delivery process and to co-partner with the patient in this process?

A few challenges, with their sometimes complicated medicolegal implications, are the funding model, the shifting of workflow and the model of care, as well as the requirements for structural changes that will reward the benefits anticipated for shared care records. On the other hand, these challenges have not altered the nature and purpose of a shared care record, that is, to record what happened in a patient’s care and to provide other care team stakeholders the capacity, motivation and instruction to act. In terms of professional responsibility, a shared care record, irrespective of the patient’s participation in co-designing it, is still an official health record and must be managed as such.

Therefore, it must meet the criteria for medico-legal and ethical duties around record-keeping. And a patient will retain all the rights they have over the current paper record, including the right of access to information in their records, as this information belongs to the patient, whereas the record belongs to the provider. Both clinicians and consumers need to be aware that a shared care record is part of the official medical records, with all the ramifications thereof—clinicians cannot ignore the shared care record; and patients need to take the shared care record seriously as well, and to embrace both the opportunities and responsibilities of their more empowered role.

**Conclusion**

It is the opinion of the authors that shared care records are the next generation official medical records; they are not personal health records. The underlying principle of the shared care record is to connect all members of the care team including the patient. A shared care record is a means to improve the accuracy and completeness of health information and to enable informed planning and decisions that are based on more complete data.

As such the fundamental nature and purpose of a shared care record is to record information, care decisions and actions in a single place so as to enable the capacity, motivation and instruction to act across more than a single provider or discipline dimension. This complexity does not exclude it from ensuring the same quality of security, confidentiality and accuracy that is expected with our existing provider-based systems, it does however pose challenges. The ongoing attempts worldwide, including the NSCPP pilot, will help address these challenges by expanding our experience with shared care and enhancing the shared care record by-product.
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