Challenges of Electronic Medical Record Extracts for a Personal Health Record

Kathleen CHARTERS^a

^aCreative Computing Solutions, inc., Rockville, MD U.S.A.

Abstract. The goal of providing electronic medical record (EMR) extracts is to facilitate patient participation in their healthcare and enhance patient-provider collaboration. There are many challenges in selecting a subset of the information available in an electronic medical record (EMR) for export to a Web-based personal health record (PHR). Critical success factors include perspectives in decision-making about what information to extract and assumptions about how extracted information will be used. Existing hard copy release of electronic medical record information provides a starting point. Guiding principles for the extract selection process include extracting information with meaning for the patient, user-friendly presentation of that information, and identifying how the patient will learn more about the information presented. Since a patient may choose to share their extract, a context is necessary in order for a healthcare team member to make sense of the extracted information. Part of the extract selection process is identifying patient education, clinical adoption, and evaluation strategies. Models and frameworks to guide evaluation are essential for success.

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1. Introduction

Definitions of electronic health record (EHR), electronic medical record (EMR), and personal health record (PHR) are in flux, "and it is difficult to point to a single universally accepted agreement for definitions for any of these terms." [1 p25] Comparisons of PHR definitions across American Health Information Management Association (AHIMA), American Medical Informatics Association (AMIA), Markle Foundation, and Healthcare Information and Management Systems Society (HIMSS) reveal these organizations agree a PHR is universally accessible, is *a lifelong tool for managing relevant health information*, allows secure access to information, is secured to protect the privacy and confidentiality of the health information, is not a legal record, and *empowers healthcare consumers to manage their health*. [emphasis added] [1 Table 3A-1] HIMSS recognizes that an interoperable electronic personal health record (ePHR) is an appropriate direction for development.

HIMSS proposes a minimum data set for ePHRs: personal identifier, clinical summary, results/reports, histories, contact and registration information, current and historical insurance information. The clinical summary includes active prescribed medications, historical prescribed medications with the reason for discontinuation, current non-prescribed (over-the-counter) medications, allergy information, diagnoses/problem list, and immunization status. Histories include immunization history, past medical history, surgical history, family history, and social history.

"HIMSS envisions ePHRs that are universally accessible and *layperson* comprehensible, and that may be used as a lifelong tool for managing relevant health information...The ideal ePHR would receive data from all constituents that participate in the individual's healthcare" [emphasis added] [1 p47] HIMSS supports ePHR

models that import data from other applications, such as an EMR. The tethered or connected ePHR model allows patients to view their information from other applications. Since "The ePHR is owned, managed, and shared by the individual or his or her legal proxy(s)" data that passes from the EMR into the PHR is managed, shared, and controlled by the PHR user. [1 p48, 2 p15] Provider concerns about a PHR tethered/connected to an EHR/EMR include *sharing of inappropriate information* with patients and *patient understanding/literacy* of the data. [emphasis added] [1 p50]

The National Alliance for Health Information Technology (NAHIT) defines EMR as "an electronic record of health-related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff within one healthcare organization...A main objective of an EMR is to improve the ability of a clinician to document observations and findings and to provide more informed treatment of persons in his or her care" [2 p16] According to HIMSS, EMRs generally include clinical documentation, results review and management, patient lists, provider order entry, best practice alerts, and clinical messaging. [1 p26]

2. Candidates for Extracts

If the goal is to share information from the EMR by making a copy of it and providing that information in the PHR as a snapshot in time, then a determination must be made as to what data should be extracted for this purpose. The intersection between data contained in an EMR and the proposed minimum data set for the PHR is one way to identify the candidates for extracts. An option for identifying extract candidates is to take each data file in an EMR and determine its relevance to meeting the PHR goals of *a lifelong tool for managing relevant health information* and *empowers healthcare consumers to manage their health*.

Another option is to look to an EMR summary document that would provide a snapshot in time of pertinent data. "The Continuity of Care Record (CCR) is a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's healthcare, covering one or more healthcare encounters. It provides a means for one healthcare practitioner, system, or setting to aggregate all of the pertinent data about a patient and forward it to another practitioner, system, or setting to support the continuity of care. The primary use case for the CCR is to provide a snapshot in time containing the pertinent clinical, demographic, and administrative data for a specific patient." [3 Abstract] "The CCR data set includes a summary of the patients health status (for example, problems, medications, allergies) and basic information about insurance, advance directives, care documentation, and the patients care plan." [3 Section 1.1.1, see also 4]

2.1. Material and Methods

A vision document is used to collect, analyze, and define high-level needs and features for stakeholders and users of a PHR. The following list was created and each item reviewed to determine what data elements, if any, should be extracted from the EMR for the PHR:

- Admissions/discharges
- Allergies
- Appointments
- Chemistry/hematology
- Copay

- Cytology
- ECG
- Electron microscopy
- Immunizations
- Medications
- Microbiology
- Pathology (Surgical Pathology)
- Personal information
- Problem list
- Progress notes
- Radiology
- Vital signs
- Wellness reminders

A multidisciplinary team determined the original requirements. The vision document was revisited after a pilot was built and users gained experience in receiving extracts. A new multidisciplinary team reviewed the pilot screen shots and considered the usefulness of each data element. Many questions were raised and addressed.

One question raised was whether implementing the Continuity of Care Record (CCR) core data set in the EMR and then extracting that information following the format set by the American National Standards Institute C32 HITSP Summary Documents Using HL7 Continuity of Care Document Component would achieve the PHR goals. "The Summary Documents Using HL7 Continuity of Care Document (CCD) Component describes the document content summarizing a consumer's medical status for the purpose of information exchange. The content may include administrative (e.g., registration, demographics, insurance, etc.) and clinical (problem list, medication list, allergies, test results, etc.) information. This Component defines content in order to promote interoperability between participating systems such as Personal Health Record Systems (PHRs), Electronic Health Record Systems (EHRs), Practice Management Applications and others." [5] The multidisciplinary workgroups candidate data was mapped to the CCR to see the extent of overlap.

2.2. Results

There are overarching considerations for releasing copies of EMR data. The first consideration is to develop a process for positively identifying the owner of the PHR. The prerequisites for receiving extracts include: The PHR user account must indicate the user is a patient of the organization hosting the EMR. (This allows reconciliation with the EMR Master Patient Index.) The user must view an orientation video and read and sign a release of information form specific to the PHR. To be in-person authenticated the PHR user must appear in person at a treatment facility with a government issued photo ID. Then the release of information clerk administratively indicates the patient is eligible to receive extracts, which triggers PHR synchronization with the EMR Master Patient Index and sets a flag on the cover sheet of the EMR. The second consideration is to give providers flexible control over the release of admissions/discharges, chemistry/hematology, cytology, ECG, electron microscopy, microbiology, pathology, problem list, progress notes, and radiology. There is a sevenday hold after these results are finalized in the EMR. This allows providers time to

contact patients before the results are sent to the PHR. Providers have the option of placing an additional hold of up to 30 days on results (hold for review). There is also an option for providers to put the result in a referral status without an expiration date. The way information is displayed to providers and to PHR users is the third consideration. To let providers know which patients have been in-person authenticated and are eligible to see extracts, a flag is set on the EMR cover page for that patient. Since users can also self-enter information, whenever there is a corresponding self-entered data element, the user has the option to see a blended view of self-entered data along with EMR extracted data.

2.3. Discussion

Evaluation must be part of the vision. During the four phases of the development cycle a formative model is used for evaluation (see Figure 1). [6] Once features are in production, a modified RE-AIM framework is used to guide evaluation (see figure 2). [7]



Figure 1 Evaluation model.



Figure 2. RE-AIM framework

2.4. Conclusion

To meet the goal of providing EMR extracts that facilitate patient participation in their healthcare and enhance patient-provider collaboration, an evaluation model for the formative stage of development and framework for evaluating the effect of the release is critical. Which extracts and what data elements to send to the PHR should be determined by the extent to which they meet the goal.

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Email address for correspondence kcharters@mac.com