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Goodbye Electronic Health Record?

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Abstract. The Electronic Health Record has failed to meet its intended purpose. We propose a new approach focusing on the use of data for health and health care. The first step is to create a repository of all patient data with data storage independent of data use. All use functionality is external to data storage. We propose the development of a common data model in which data elements have a rich set of attributes including actionable knowledge. Finally, functionality is provided through a series of application program interfaces (API). New APIs will address directly new methods for using data to increase the effectiveness of data application to improve management of the health and care of a patient. Together these components will open a pathway to finally accomplish the goals of a better future health system.

Keywords. EHR, patient data repository, common data model, APIs

1. Introduction

What we now refer to as the Electronic Health Record (EHR) was doomed from the beginning. First, computer engineers, mostly from the aviation industry, designed the first systems with little input from the clinical community. Second, the systems were designed exclusively for inpatient systems because only large hospitals could afford the large, mainframe computers required. Third, systems focused on service functions, not on managing patient data. These systems were known as Hospital Information Systems (HIS). Laboratory Systems were developed separately as part of a service package. Fourth, early financial systems were developed independently with their own databases. Fifth, patient management systems largely duplicated the paper chart. The development of these early systems is well-documented in *A History of Medical Informatics* [1, 2, 3].

The dependence on computers continued to increase, particularly in financial processing, patient accounting, patient billing, and claims processing. An increasing number of hospitals installed HIS on large mainframe computers. With the advent of the minicomputer, the cost of computers decreased significantly. Patient management systems with a variety of names started appearing, developed as homegrown systems. Most of these early systems were simply copies of the patient record, a fact that has changed little in today's commercial systems. Among the first patient management systems that survived several decades include COSTAR developed by Octo Barnett and

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associates at Massachusetts General Hospital; The Medical Record (TMR), developed by Ed Hammond and associates at Duke University; the Regenstrief System (RMS), developed by Clem McDonald and associates at the Regenstrief Institute; and HELP, developed at LDS Hospital by Homer Warner and associates [1].

In 1991, in an attempt to create new concepts and new requirements, the Institute of Medicine, now the National Academies, [4] published a set of objectives for what they named the computer-based patient record, an essential technology for health care. To support these objectives, the Computer-based Patient Record Institute was created in 1992. In 1997, the National Academy published a revised edition of the original book [5]. In spite of the significant increase in technology in terms of computational power and storage capacity, the objectives defined in the 1991edition were still unmet. The editors decided to simply republish the book as originally written but to add two new chapters to discuss what changes had occurred in the field of informatics and medicine. One chapter presented the U.S. view and the other the European view.

It would be interesting to do a second revision of this book today. There is little, if any, progress made in meeting the original objectives. Yet, the volume and types of data have increased exponentially. New topics would include motivations for data sharing requiring data liquidity, interoperability requirements, new knowledge, use of artificial intelligence, increased use of clinical decision support, and many other changes. Specifically, this paper addresses a new approach to realizing how to better use technology for patient management. Due to space constraints, topics are presented at a high level, and details are omitted. The first step is the recognition that today's concept of the EHR is wrong. In fact, even the name itself is a misnomer.

2. Lessons learned from early experiences – Revisiting TMR

At Duke University, we began the development of a computer-based patient record in the late 1960s with access to a minicomputer. The first approaches were fragmented and focused on specific functionality. We used assembly language programming and developed our own database structure. A scarcity of resources, including funding, and limited computer speed and storage forced innovation in our design. In time, repetition of functions migrated the assembly language programs into a more formal structure of a programming language we called Generalized Programming Language for Community Health (GEMISCH) [6]. At the 2000 AMIA Annual meeting, Dr. Hammond presented the ACMI Distinguished Lecture on the history of TMR titled "How the Past Teaches the Future". [7]. This presentation documented many of the lessons we learned in a variety of settings and our successes. The key to our success was the ability to fit the application to the requirements of the site while using the same programs. Unfortunately, today's systems are not able to do that. Current commercial systems provide a lot of functionality that are largely "one size fits all". In TMR, a metadata dictionary provided the focused functionality and language tailored for clinical specialties to individual users.

Much of the design of TMR was serendipity, but we learned. Each of TMR's functional development had a clinical partner and an informatics partner. Each taught the other, and they worked as a team. Data were stored in a data structure that represented data according to its meaning as contrasted by how it was collected or its intended use. Modular structure simplified documentation and the use of data. Data independent programming through data definition dictionaries permitted the same programs to function differently in a variety of clinical settings. A combination of problem-oriented

and time-oriented formats enhanced the use of data for patient care, query protocols, and research.

Because of the slower computer speed, we needed to know instantly if a datum had ever been collected; our database design accomplished that. We needed to be able to retrieve a datum independent of the time it was collected. For example, a patient's height was not collected at the same frequency as weight, so to calculate body mass index we needed to pull both values for calculation. Through the data dictionary, we were able to tie knowledge to a data element. For example, an attribute of a problem or diagnosis included a link to potential causal problems. Likewise, another link listed possible problems that could result from this condition. Similar links were tied to data elements to collect, recommended medications, decision support algorithms, and other knowledge.

We learned there are major differences between inpatient and outpatient settings, but there are critical flows of data between the two settings. The time value of the two settings was different. The workflow is different, but the two settings must be tightly coupled. A key finding using TMR that applies to the future is the adoption of a data model with input, storage, and functional use that are all independent. We practiced "the user is always right, but they have to prove it." Another lesson was understanding the complete requirement and automating every step. Look at all potential problems and eliminate them. Today's systems focus on one problem rather than understanding the big picture.

The perfect health system requires an understanding of all requirements and all stakeholders. In today's world, this requires coupling all types of data from all potential sources and the universal use of that data by all stakeholders for all purposes. This requirement means a universal understanding of the data.

We now describe our recommendations for the replacement of the EHR. Our next step is to build a prototype of this approach to understand the full set of requirements.

3. Data Storage Independent of Use Functionalities

At the present time, data about patients is likely contained across multiple files stored in many different locations. We propose that all data related to a patient be managed as a single entity. That data includes all types of data including genomic, social and economic, behavioral, clinical, and environmental. The data includes data for research as well as clinical. Physically the data may be stored on multiple devices or in a cloud; it is managed however as a single unit. The data may be stored in different file types – relational, flat file, SQL, non-SQL, or other. However, it should be indexed in such a way that any data can be located immediately.

Our premise is that data structure should represent data according to its meaning in contrast to how the data will be used. This freedom from use permits reconstructing data in many different ways. Data could be presented in problem-oriented formats or time-oriented formats. Data from different sources could be combined for new purposes. Data could be displayed in many different formats for different purposes.

The interaction with this patient data repository should be through Representational State Transfer (REST). In simplest terms, the interaction with the patient data repository would be: create, read, update and delete (CRUD). An expanded interface would provide the ability to define a logic-based retrieval of data similar to Bulk FHIR. Bulk FHIR permits dealing with multiple patient records at the same time.

It is important to note that other data is critical for the administrative functioning of a health unit. That data would include usable material such as ventilators, needles, blood, medicines, and many more. These non-patient-specific data should also be managed by a single system with an obvious connection between the two systems. A lot of detail is left out of this discussion, but the key point is the independent storage of data and the independent management of the database.

4. Common Data Elements

The need for data liquidity has never been greater. The energy, time, and money spent in mapping from one system to another are senseless. Every mapping results in a loss of information. We need to share data for patient care and for research. We have a mobile population that we need to track over time.

Of equal importance, we need to develop a rich set of attributes including embedded knowledge with each data element. That knowledge includes ontology linkages, decision support links, quality assurance links, risk factors, phenotypes, and management data. That knowledge is critical to maximizing the ability of technology to deliver what is needed for technology to deliver what is needed to support health and health care. For a common data model, the attributes of a data element are representative and do not include attributes for the specific categories of data such as diagnoses, physical findings, laboratory and other tests, and medication. Research by clinical experts will be required to define additional attributes to incorporate actionable knowledge into the data element. We suggest that FHIR adds functionality to manage the data elements along with the actionable knowledge.

The ultimate goal of the common data model is that it includes all data elements used in health and health care. Such a process must be open, but the data elements and their attributes must be defined by knowledgeable experts. Creating these data elements with attributes is not a consensus process although it is an open one. We propose inviting the clinical societies to provide the expertise to create the data elements in their field of expertise. A clinical society, such as the American College of Cardiology, may create subgroups of experts to focus on a specific area such as echocardiology. The societies would become the single steward of a set of data elements and be responsible for the care and maintenance of the data elements. We are working on a detailed plan for this process. We also recognize that there are other groups who also need to be identified to provide stewardship to certain groups of data elements.

5. Functional Application Program Interfaces

HL7 International[®] data transport standard Fast Healthcare Interoperability Resources[®] (FHIR[®]) is coming into general use globally. Building on this standard, we propose that all use functionality be provided through application program interfaces. There are many advantages to using this approach. SMART on FHIR[®] provides an interoperability standard for creating APIs. APIs open the marketplace for competition or choice in functional APIs which should drive the cost of computer systems down. Updates may be economically made to keep up with new technology and with the change in knowledge. Specialization in data use and data presentation can be economically accommodated.

Functional APIs will provide the functionality required for routine workflow now provided by commercial EHR systems. The administrative functions of admission and discharge, ordering of tests, scheduling, prescribing, reporting, notes, and many other activities could be pulled from existing EHR systems.

The most significant advantage of using APIs is that we can focus on new ways to use data. For example, APIs can generate a functional and productive problem list. That problem list can then be used to drive activities and clinician behaviour. APIs can aid documentation. APIs can link different types of data in innovative ways. APIs can use phenotypes to drive effective use of knowledge along with patient data to reduce uncertainty and aid decision-making. We submit that APIs are key to changing from passive data storage to innovative partnerships in patient care.

6. Conclusions

It is clear we need a replacement for the current EHR if we are to realize the goals set forth by the National Academies in 1991. Although this report presents a U.S. perspective, the content is globally applicable. That replacement serves as more than documentation of care. It is more than a transaction log based on departmental systems. Even today, there is little agreement about what is an electronic patient record, what is its form, what should it contain, and who owns it. Technology has provided the potential to make visions become reality. New systems should be able to converse with providers – before, during, and after a patient encounter – with answers at the fingertip. Communication among all persons involved in care – including the patient – will be increased. The multi-media, ubiquitous, population-wide, decision-making, common and understandable language with data that can be queried will enhance our understanding of what needs to be done to whom, by whom, and when. Interoperability at an international level will permit the appropriate access to data for care, the creation of worldwide clinical trials, a better understanding of the quality of care as a function of geography, and access to all available knowledge about improving health and health care.

Clearly, to accomplish these goals and objectives we will need a lot of work from a lot of people. Now is the time.

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