

# An Information Paradigm Shift is Required to realise EHR Benefits

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## Abstract

The use of EHRs and the benefits from them is a significant one for healthcare and health informatics. Data form the basis for any EHR and its potential to realize these benefits . This paper considers the place of information and knowledge management in an EHR system. Are we experiencing a revolution in healthcare? Findings from an investigation of alternative approaches, followed by an evaluation of the importance of the adoption of a standard information model relative to benefit realization, is presented. We conclude that an EHR in any environment is not just about, sharing, or information exchange. A paradigm shift in thinking, based on the requirement for standardized concept representation, is required. This is an essential pre-requisite for a new vision of healthcare supported by digital technologies.

## Keywords:

Electronic Health Record, Knowledge Management, Terminology, Medical Informatics, Education, Technical Standards

## Introduction

Healthcare in its current form is not sustainable[1]. Information technology is increasingly used as a means to improve information availability and flow to support healthcare delivery and outcome improvement. Despite this these systems often deliver minimal benefits rather than an integrated raft of positive outcomes for the investment. Consideration of maximizing benefits is rarely undertaken.

Healthcare is dependent upon information systems from disparate vendors who have their own information structure which they value as intellectual property. It is to the advantage of vendors to retain their existing structure as this makes their systems unique and encourages take up of associated products from the same vendor. The impact of this is information representation which is inconsistent between products and systems. There is a need for the introduction of a disruptive technology.

Healthcare is a team activity requiring multiple use of the same data by different members of the team at different times for a variety of purposes. They need to make use of numerous alternative technologies even though many information system implementations focus on singular activities, or worse singular data representation minimizing multiple data use opportunities.

Traditional knowledge acquisition methods, such as clinical trials, are limited in scope, costly to run, and take time to deliver viable results. Information stored in health records could be used to reduce time and costs associated with knowledge

discovery but this is not on the agenda for most healthcare system implementations. Traditional reporting and statistical analysis for public health, finance, and other purposes are equally expensive and dedicated to singular purposes, rather than finding their place in the data continuum.

Decision making and project management in health informatics is often limited by a lack of understanding of what individuals in the system do not know. Most healthcare administrators neither know what they need to know, nor the skills they need to support their decision making and projects. There is a resistance to start fresh with systems due to existing investment, yet when major new investments are made the long term vision is often lacking.

Transition strategies to move towards realizing a long term vision are not in place. Such transition requires the use of existing systems in a manner that enables a progressive move towards a defined vision. Lack of understanding of such a journey is a consistent problem, as demonstrated by a focus on projects of implementation, rather than of progressive development of data, systems and people.

## Methods

This research represents findings based upon a range of information gathering methodologies. These include literature review, participation in and interviews with key experienced eHealth standards developers and implementers, and an analysis of:

- The outcomes of eHealth initiatives and implementations
- The capabilities of current systems and approaches
- The outcomes declared
- Skill development initiatives
- The characteristics of data, information and knowledge and the relationship between the information to be shared, stored and retrieved and how that relates to the technical infrastructure, and
- Inhibitors/enablers such as funding arrangements, organisational structures.

This paper focuses on an evaluation of our findings. It's important to differentiate between EHRs and EHR Systems. EHRs are essentially a data repository that needs to be an integral part of an entire healthcare system. Early information systems in healthcare were all about reporting and finance. Today these requirements, though still present vie with the need to represent data for healthcare requiring different data representations. This variety of data representation in information collection systems and the requirements for standardized but different representations for different

healthcare reporting and other purposes present a unique data dilemma.

These differences stem from two primary causes:

1. the requirement for data use in patient care to accurately and reliably represent facts,
2. reporting systems requiring classified data that aggregate concepts.

Classified data indicates where necessary that a case fits in the 'other category' or special rules apply for how to collect the data, for example when coding clinical data into the International Classification of Diseases (ICD) –any version codes. . Each approach to data is relevant to purpose but every purpose requires different data presentations whilst data also needs to be managed across the continuum of use. Though the principal of data re-use is often discussed, the need for consistent approaches to achieve the conversion of data from disparate systems and information models is a challenge. This challenge is made more difficult as the original data meaning may vary based on context. These differences lack clarity in the absence of a comparable information model in a system using meaning based data representation.

The variations in original systems and the requirement needs for standardized reporting, mean that conversion approaches such as data maps are being increasingly used. Such maps are only consistent when built and applied to a single known purpose[2] and must be kept up to date. Lack of appreciation of the implications of using maps results in data which appear comparable but which may not actually be so.

### **Importance of a Standard Information Model**

Health software vendors have traditionally controlled the structure and representation of information in healthcare systems and consider these data structures proprietary. This has resulted in data representation and systems which do not share common meaning and require effort to share data with others and to manage data over time. This approach discourages healthcare system purchasers to change their systems to reduce disruption and cost, but this approach exponentially increases costs due to increasing maintenance costs with potential negative impacts on safety, and the ability to cost effectively, accurately and comprehensively represent EHR data across the healthcare continuum.

Investigation of implementations of electronic health record systems to date has shown that it is common for these proprietary systems to be chosen and implemented with a vision aimed at solving simple problems, such as transitioning from paper based to electronic record systems or to support improved information access with little consideration of the greater list of functional requirements[3] [4] [5]. Nguyen et al [3] identified serious 'concerns regarding the accuracy and completeness of records'. These authors also identified a need for further work into information system quality for EHR implementation evaluative research. The results of this extensive literature has demonstrated that current EHR limitations have resulted (or will result) in the need to change systems and undergo costly re-invention of the data and associated data exchange protocols for current systems to be extended to address new functional needs as these arise.

The research gap identified also demonstrates a lack of understanding of the new paradigm of health data. Around the world healthcare initiatives focus on information exchange. Though there is no doubt such exchange is necessary, a more critical requirement is to be able to accurately subject data to

computer processing without loss of meaning. There is a strong relationship between data accuracy and the technical schema used for data exchange. This is poorly understood and rarely seriously considered in system implementation, yet functional requirements determine the degree and type of interoperability and hence technical schema/system architecture required.

Electronic Health Record systems are being widely adopted with the intention of delivering some or all of the following benefits:

- Longitudinal patient records – records able to be retained, queried and retrieved over time to support patient care and knowledge acquisition.
- Retrieval and presentation of the right information to the right care provider or to the patient/carer to support clinical care and improve health outcomes
- Use of clinical decision support to improve the application of clinical knowledge and health outcomes
- Facilitate information exchange
- Enable patient / carer access to information
- Support reporting and data re-use
- Enable knowledge acquisition from systems
- Support research and epidemiology/public health

The implementation of electronic health record systems tends not to differentiate between the record and the systems used for data collection and exchange to support such records. Existing systems and paper based records often convert data without considering the actual clinical knowledge relationships between the data and systems prior to the need for conversion.

In some cases much has been able to be achieved despite this lack of vision and understanding of system capacity and requirements through the individual efforts of clinical informaticians with the knowledge to creatively implement system approaches to data and knowledge[6]. Where understanding and skills to implement change are combined, significantly more is achieved. Of the implementations around the world which have delivered significant benefit few have done so without leveraging such expertise and leadership.

### **Significance of system interoperability**

Many standards are designed for information exchange for a purpose. HL7 internationally is moving towards a single terminology representation shared across all of its products, and many countries are standardizing national data dictionaries. The move to the use of well managed terminologies such as SNOMED CT, LOINC or the use of a machine readable terminology source such as the Unified Medical Language System (UMLS), support this need. However these innovations are not required to be applied to health records perse. We have found through experience that a general re-usable terminology cannot serve all aspirations for clinical information systems that need to make use of data contained in EHRs. In addition it is necessary to consider data structures and the meaning of data (context) relative to the technical system architectures in use. Only then are distributed systems enabled to exchange information in a meaningful and accurate manner. This requires system architectures that make use of a common standard reference model.

The development and use of sustainable clinical information (concept) models, used in conjunction with these terminolo-

gies, that use standard data types and defer to a standard information model, is less well understood and rarely implemented, Brazil[7] and Norway are two notable exceptions. National adoption is the best possible solution to maximizing the value of EHR adoption for all parties, including software developers/vendors.

Semantic requirements between distributed systems as used by the health industry were investigated seeking to determine whether healthcare is actually different from other industries with similar issues, and if so why so, if not why not.

Health data is certainly more complex than other industries such as accounting, but it is not just the complexity or the constant changing nature of the knowledge development about health and healthcare. It's also that frequent variations and knowledge evolution needs to be accommodated by EHRs in a timely manner.

Accountancy has used a consistent information model for many hundreds of years. The terminology used is largely numeric and therefore consistent and comparable. The general ledger approach is consistent around the world and understood by all systems, with local modifications within known rules and knowledge of concepts such as income, profit and loss, cost of goods sold. Healthcare does not have such a standard structure for information and this, along with the complexity of health data is a significant hindrance to progress.

Adoption of a standard information model provides context. It supports simpler and cheaper information exchanges between multiple systems using the same information model[8] It also supports the development and maintenance of rule based clinical decision support, which can be applied universally in such systems, automation of reporting and many other healthcare functions requiring extensive accurate data and knowledge use. This includes accurate data aggregation from multiple individual EHRs (big data) and linkages with other types of data for research, public health, and epidemiological use.

### **Why is this not well understood?**

The literature regarding research aimed to achieve semantic interoperability for distributed systems has by and large been undertaken by software architecture developers and other technical experts, who as a rule do not appear to have fully appreciated or understood health data characteristics, its variability, evolution, uses, or the need for accuracy.

A review of the courses offered for health professionals revealed that it does not have a workforce with an understanding of data and systems, or today's methods of data collection, or health record data storage structures. Projects associated with health data collection rarely include an education or skill development strategy for the data, information, knowledge continuum nor its link with available information and communication technologies. Often existing expertise is not sought, and implementation plans are developed from scratch. In addition a review of ICT courses offered by Australian Universities revealed that semantic interoperability is rarely mentioned, nor is data science a topic that is routinely included in such courses.

The lack of a skilled workforce and poor use of expertise is another contributing factor to the cost of new initiatives and change. The health workforce is large and highly skilled already. The inclusion of additional knowledge in already stressed courses is problematic unless this can be integrated in current curricula. A significant limitation is that those who

teach in university programs are often not cognizant of the impact of or need for knowledge of health informatics in their professions[9].

Health Informatics as a profession has worked to define its body of knowledge and to encourage quality education[10] However the existing workforce needs practical and often just in time learning opportunities. Only a small number are likely to return to university based education to develop the skills they need. Australian universities offering Health Informatics courses struggle to attract and sustain a significant number of students. Alternative approaches to skill development are needed.

Another reality is that educational organizations have few health informatics skills. The research based university model delivers highly skilled individuals with highly specialized knowledge, but few with skills in teaching the broader emerging societal and industry requirements of health informatics. Maintenance of skills across this broad area of needed knowledge is difficult and not valued. Universities are hampered by the lack of demand, employers do not understand the skills they need in their organizations, and the workforce do not see rewards for having knowledge of health informatics. This cycle of demand must be broken if investment in education of practical value is to be delivered.

### **Discussion**

If the electronic health record is to be sustainable, a technology agnostic solution is needed. A solution which is not system dependent but rather it needs to be data dependent. Only then is the delivery of health record systems that are vendor, time and technology independent, possible. If this is achieved patients, providers, vendors, organizations and governments can move to new technologies, and continue to use and gain value from the data in existing systems. It will be possible to develop any number of niche application systems that all link to EHRs with increasing sophistication.

A nationally shared standard information model which is clinically valid, maintained and represents an ontology based concept representation system, is a key requirement to achieving this sustainability. CEN/ISO 13606, a European norm also approved as an international ISO standard[11], identifies a common high level model and archetype (content) models for such information. It defines a rigorous and stable information architecture, designed to achieve semantic interoperability in the electronic health record communication[12]. Implementations of this approach include the OpenEHR clinical knowledge resources which represent a maximal model of the concepts stored in healthcare records[13]. This information model can be referenced by content models using standard terminologies such as SNOMED CT or ICNP to represent clinical concepts modeled.

The relationship between the information model, concept representation and the technical infrastructure or systems architecture needs to be better understood. Collectively these components deliver digital systems that suit all healthcare environments. Achieving this vision requires the implementation and use of internationally accepted formal and informal (eg well governed opensource) standards. Adoption requires a deliberate initiative aimed at taking advantage of new technologies. This transitioning to a fully digital world is no different than transitioning from the stone or industrial or information ages; It's about empowering a paradigm shift to the use of a disruptive technology. For such a shift in thinking to be

achieved there is a need for relevant professional development of the health workforce. What is the knowledge and skill gap? Unless we understand and leverage the paradigm shift we will be implementing solutions which are not sustainable, which require change and are expensive to constantly fiddle with. The health and ICT workforce need to appreciate that:

- change regarding data use is with us (from a technology perspective, who knows what is next).
- there is need to adopt strategic thinking, to better plan, take advantage of opportunities and minimise risk.
- decision making methods need to change; implementation decision making needs to be in line with a vision for the electronic record, beyond that of simply implementing a system, or replacing paper based records. That vision seeks a more long term sustainable solution. Community and workforce expectations can be met (sustaining the workforce) via integrated just in time learning

Knowledge Gaps include:

- Understanding, using and governing data, including the technical infrastructure needed to maximise potential use and the continuum of data use).
- Ability to identify key data for which data governance strategies need to be adopted.
- Understanding the pathway from business case and functional specifications development of EHRs and related system, to system acquisition, implementation and use - this is a journey, purchasing software is not a destination.
- The knowledge and skills needed to best complement existing expertise and meet potential new role requirements.
- Knowledge and Skills required to design and implement systems that meet patient/customer, organisational, disciplinary, optimum work and information flow and national data requirements to suit multiple purposes.–

A complete understanding of what is required of data and systems to achieve the desired outcomes across our data and systems is needed. Such understanding enables a vision of the future and a truly progressive transition to that future.

## Conclusion

It was found that projects and systems around the world tend to focus on delivering local immediate needs at the expense of considering a bigger vision, future proof and sustainable EHRs with associated systems for which the local implementation is simply a beginning representing a significant component of a much bigger system. It's about small data supporting healthcare at the point of care, but also about big data supporting research and new knowledge acquisition and discovery.

Adopting a standard open information model for all of healthcare, using consistent concept representation where appropriate, an Information and knowledge governance strategy and implementation approach, the conversion of existing knowledge into a computational format consistent with the information model and concept representation system plus appropriate workforce skill development enables the realization of everything we are wanting. This includes the automation of reporting or statistical analysis. Technology can change but the information continues to develop yet it will be usable and calculable in a sustainable manner.

Every nation needs a transition strategy that makes the best possible use of existing EHR systems, concurrently with a future vision and a strategic pathway towards realizing that vision. This requires a paradigm shift in thinking by all decision makers.

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