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# Towards Characteristics of Lifelong Health Records

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**Abstract.** Since the beginning of this century, the view has developed that high quality health care can be delivered only when all the pertinent data about the health of a patient is available to the clinician. This viewpoint brings forth the notion of a lifelong health record. Various types of health records have emerged to serve the needs of healthcare providers and more recently, patients or consumers. The purpose of this paper is to present a set of characteristics or best practices for lifelong health records which are seen independently from implementation constraints such as technology and operational context. The characteristics, comprised by four core characteristics and nine dimensions, are synthesized from the characteristics of various types of health records used by healthcare providers and consumers. Examples are provided of evaluation measures that give an indication of compliance to the broadly stated characteristics of lifelong health records.

**Keywords:** Lifelong Health Record, Personal Health Record, Electronic Health Record, Electronic Medical Record

## 1 Introduction

For as long as healthcare has existed, there has been health information stored in some kind of record. The earliest such records were kept in the paper files of the provider, whereas currently, a combination of paper and computer media for recording health information is used. For a variety of reasons, these individual health records have become fragmented into multiple information systems and dispersed across the planet. At the same time, the information inside the records has become more complex, and is required on a regular basis by an increasing number of commercial, educational, and governmental information systems [1]. Factors like these, have led the quest to create a single lifelong health record that is easily accessible, comprehensive and complete.

A health record or medical record is a chronological written account of examination and treatment of the patient that includes their medical history and complaints, the physical findings of the physician, the results of diagnostic tests and procedures, and medications and therapeutic procedures [2]. A degree of interaction is required between both the doctor and patient for this health record to be complete. For many years, the doctor/patient relationship has been asymmetric, with the doctor

traditionally seen as holding the balance of power and the patient as being dependent. There are many reasons for this and one of the most important is the asymmetry of knowledge; the doctor controlled almost all the information and often shared it sparingly.

Technology has developed along the same lines. The need for administrative and clinical e-health systems originated from healthcare providers. Electronic Medical Records (EMRs) and Electronic Health Records (EHRs) were created to address the needs of healthcare providers and to provide them with a tool that enables them to be more competent in their daily activities. Over the past years, a dramatic shift in the amount of information available to the patient has been witnessed. This shift has contributed to a noticeable increase in patient autonomy and choice in medical care. Information is more easily available due to major advances in technology. This led to the development of consumer-focused e-health systems.

The developments in healthcare provider versus consumer-directed e-health systems have resulted in two main types of electronic health records, based on the ownership of the record. These include healthcare provider-owned health records, for example, EMR/EHRs and consumer- or patient-owned health records, for example, Personal Health Records or PHRs. Hybrids between these two types are common. Operationally, each of the health record types can satisfy the need of being a truly lifelong health record to a greater or lesser extent [3].

The purpose of this paper is to present a set of characteristics or best practices for lifelong health records which are seen independently from the implementation constraints such as technology, operational context and similar. The characteristics, comprised by four core characteristics and nine dimensions, are synthesized from the characteristics of the various types of health records used by healthcare providers and consumers. Examples are provided of evaluation measures that give an indication of compliance to the broadly stated characteristics of lifelong health records.

## **2 The case for lifelong health records**

It is apparent when viewing the medical error statistics of only the United States of America (US), that the importance of lifelong health records cannot be underestimated. The total number of medical errors and deaths in the US is equivalent to six 747 aircraft crashes daily for a year. Specific statistics in this regard include [4]:

- 7,000 patients die annually because of careless handwriting;
- 7.5 million unnecessary medical and surgical procedures are performed annually;
- More than half of the U.S. population has received unnecessary medical treatment which equates to 50,000 people per day;
- 42% of people have been directly affected by a medical mistake, procedure or drug;
- 84% of the population personally know someone who has been a victim of a medical error;

- Preventable medication mistakes affect 1.5 million patients yearly;
- Nearly 14% of doctor visits were missing test results and other documentation resulting in 44% of patients being adversely affected;
- Over 59% of patients have received delayed care or duplicate services with doctor visits; and
- 160,000 lab misidentification errors occur each year.

These figures raise serious concerns. An accurate, complete lifelong health record could reduce these medical errors by providing the healthcare provider with the opportunity to correctly diagnose a condition by viewing the *complete* “picture”.

This leads to the question of what precisely constitutes a lifelong health record. It is important to conceptualize the core intentions of the various health record types to characterize the true essence of lifelong health records, as seen from a generic point of view.

### 3 The True Essence of Lifelong Health Records

Various authors have defined the characteristics of the different types of health records [5],[6],[7],[8],[9],[1]. This paper synthesizes these characteristics into four core characteristics and nine associated dimensions of generic *lifelong* health records. These broadly stated core characteristics and dimensions are taken to represent the characteristics of lifelong health records. These are summarized in Table 1 and discussed thereafter.

**Table 1.** Characteristics of Lifelong Health Records

<b>CHARACTERISTICS OF LIFELONG HEALTH RECORDS</b>	
<b>Core Characteristics</b>	<b>Dimension</b>
Interoperability	Standardization
Comprehensiveness	Integrity Accuracy Completeness Apomediation
Legal Value	Privacy Confidentiality Auditability
Availability	Accessibility

### 3.1 Interoperability

Interoperability refers to the interconnectedness of multiple healthcare organizations or systems using a model that enables the full interchange of healthcare information. An overwhelming majority of people, currently, receive their care from more than one caregiver or provider. A lack of integration means that choice leads to fragmentation of the health care experience of the patient. Fragmentation, in turn, results in errors, duplication, lack of coordination, and many other problems [10] as confirmed by the statistics provided in Section 2. Health information will remain in proprietary silos without both interoperability and health information exchange.

*Standardization* is the main dimension of Interoperability. Standardization, in the field of health informatics, strives to achieve compatibility and interoperability between independent information systems and devices, and to reduce the duplication of effort and redundancies. Healthcare Information Technology (HIT) standards are developed, adopted, or adapted by standards development organizations, government agencies, professional associations, and care providers [11]. The creation of a lifelong health record will be unattainable without standards which facilitate proper interoperability between the different types of health records.

### 3.2 Comprehensiveness

Comprehensiveness can be subdivided into four dimensions, namely *Integrity*, *Accuracy*, *Completeness* and *Apomediation*.

A lifelong health record must provide information to improve care quality. The healthcare provider must trust that the information provided in the health record is correct for this to be considered true. The general principle of *Integrity* implies that no unauthorized person is able to add, remove, or change any data in the health record.

*Accuracy* implies that the information captured in the lifelong health record, reflects exactly the original meaning of the paper copy or diagnosis made by the healthcare provider. This maps closely to the garbage in, garbage out (GIGO) concept. Valuable output is attained from the lifelong health record when the information that is captured is both accurate and correct.

*Completeness* implies that all the latest relevant information about the health of the patient is contained in the health record for it to be considered lifelong. There should be no significant delay between when the data is entered into the record and when it becomes available to the different healthcare providers [3].

There has been much discussion about what data or information belongs in a lifelong health record. Advances in data storage devices and their related capacity have made this a less pressing issue. A lifelong health record should contain any information relevant to the health of the patient. Examples of information to be captured include the following [12]:

- Personal identification, including name and birth date;
- People to contact in case of emergency;

- Names, addresses, and phone numbers of the physicians, dentists, and specialists of the patient;
- Health insurance information;
- Living wills, advance directives, or medical power of attorney;
- Organ donor authorization;
- A list and dates of significant illnesses and surgical procedures;
- Current medications and dosages;
- Immunizations and their dates;
- Allergies or sensitivities to drugs or materials, such as latex;
- Important events, dates, and hereditary conditions that occur in the history of the family;
- Results from recent physical examinations;
- Opinions and notes of clinical specialists;
- Important tests results; eye and dental records;
- Correspondence between an individual and his or her healthcare provider;
- Diet and exercise logs, in addition to a list of over-the-counter (OTC) medications.

*Apomediation* - The term apomediation was defined by Dr. Gunther Eysenbach, a Health Policy and eHealth professor at the University of Toronto. This newly coined term is best explained by Dr. Eysenbach who states that: "Apomediation is a new scholarly socio-technological term that characterizes the process of disintermediation (intermediaries are middlemen or gatekeepers, e.g. health professionals giving relevant information to a patient, and disintermediation means to bypass them), whereby the former intermediaries are functionally replaced by apomediarities, i.e. network/group/collaborative filtering processes. The difference between an intermediary and an apomediarary is that an intermediary stands in between the consumer and information/service, i.e. is absolutely necessary to get a specific information/service. In contrast, apomediation means that there are agents (people, tools) which stand by to guide a consumer to high quality information /services/experiences, without being a prerequisite to obtain that information/service in the first place" [13].

Apomediation is affected in the lifelong health record through current advances in technology. The contents of a lifelong health record can be enriched with collaborative filtering and recommender systems like bookmarking, blogs, wikis and communication tools. These networked/collaborative systems enable the creators of lifelong health records, to better capture information contained in scripts, the notes written by healthcare providers and general written information contained in the paper-based patient file. Certain terminology and abbreviations are meaningless to a non-medical person, but through having access to these blogs, wikis and other tools, it is possible to capture the record accurately and have a sense of understanding while doing so.

### 3.3 Legal Value

The addition of legal regulations and amendments to current regulations, with the intention of increasing security pertaining to HIT, is a norm in the modern day society [14]. This underscores the importance of the *Legal Value* core characteristic. The three main dimensions of this core characteristic are *Privacy*, *Confidentiality* and *Auditability*.

*Privacy* implies that the patient gives consent for other parties to access their personal health information. Patients can allow or deny sharing their information with other healthcare workers. Consent is either implied or explicitly given before the act of sharing. Implicit consent assumes the patient to have consented by default unless they specifically state otherwise. This is referred to as opt-out. Explicit consent or opt-in is the reverse, where the access to the information is prohibited unless the patient gives consent [9].

*Confidentiality* requires that proof is given that the information has not been made available or disclosed to unauthorized entities, whether persons or systems. This can be implemented in two ways. Either information is tagged with metadata about its confidentiality status or confidentiality is enforced through access rules. The use of access rules to enforce confidentiality relies on audit logs to verify that confidentiality has not been breached.

*Auditability* refers to the ability of the lifelong health record to be used for the following [9]:

- The monitoring of access to and possible misuse of the record, preferably in real-time;
- Review purposes to keep track of previous versions;
- Legal disputes to verify claims about what information was available and whether it was accessed.

One auditability technique is to use audit logs which document all the actions performed on the information and the users who perform those actions to enable the restoration of the past state of the data. The logging should include all events and not be restricted to the information handled. This leads to a huge amount of audit data that should be kept secure for future analyses. For best security, audit logs should be kept and stored separate from the lifelong health record.

### 3.4 Availability

A lifelong health record must be available when the healthcare provider needs it. It is necessary to make the system housing this lifelong record robust. Failure of the lifelong health record device is not an option, because human lives are at risk. A health record is deemed lifelong when it is continuously available. The main dimension of this characteristic is *Accessibility*.

*Accessibility* of the health record can be contentious. Ease of accessibility increases the risk that the record can be compromised. Alternately, a record that is too secure and cannot be accessed in case of emergency, nullifies the creation of a

lifelong health record. Any access control mechanism that protects the healthcare data needs to be relatively simple and fast. These mechanisms should protect the privacy of the patient by disclosing information only in those situations when it is needed. This latter requirement requires a highly complex mechanism and is hard to combine with the first requirement of a simple mechanism. A middle way needs to be found that addresses the problem of availability versus confidentiality.

This concludes the discussion on the core characteristics and dimensions of a lifelong health record. The next section provides examples of measures towards evaluating compliance with the characteristics. The strengths and weaknesses inherent to the various health record types can be identified by applying the evaluation measures, while taking cognizance of the implementation constraints of technology, social context and similar. For example, an EHR might be weak in the area of *apomediation* because when it was designed, the intent was not to allow for user collaboration and patient interaction. Alternately, the PHR developments by Microsoft and Google do not satisfy *integrity* and *legal value* when measured against these characteristics [3].

#### 4 Evaluation Measures

The evaluation measures listed in Table 2 can be used to determine whether a particular health record type satisfies the dimension that the measure represents. The list is not exhaustive and can be supplemented if required. Each evaluation measure must be used to quantify the extent of achievement of the relevant dimension.

**Table 2.** Evaluation Measures

<b>CHARACTERISTICS OF LIFELONG HEALTH RECORDS</b>		
<b>Core</b>		
<b>Characteristics</b>	<b>Dimension</b>	<b>Evaluation Measures</b>
Interoperability	Standardization	<ul style="list-style-type: none"> <li>▪ Does the record support (secure) two-way data exchange?</li> <li>▪ Does the record use common standards, like XML and PDF/H?</li> <li>▪ Does the record have the ability to store non-text data such as x-rays, scans and MRI's?</li> </ul>



Comprehensiveness	Integrity	<ul style="list-style-type: none"> <li>▪ Is this record in a state of entirety and free from corrupting influences or motives?</li> </ul>
	Accuracy	<ul style="list-style-type: none"> <li>▪ Is this record up-to-date?</li> <li>▪ Do the data values in the record correspond to the real world objects or events?</li> <li>▪ Does the data entry application provide for drop-down boxes and checklists to eliminate possible errors?</li> </ul>
	Completeness	<ul style="list-style-type: none"> <li>▪ Is this record complete, i.e. does it contain the entire health history and all health providers seen?</li> </ul>
	Apomediation	<ul style="list-style-type: none"> <li>▪ Does the online record provide education about condition, surgeries, medications, etc of the patient and the ability to interact with patients with similar illness to achieve a more complete and correct health record? (Health Information Portal)</li> <li>▪ Does the record bridge language and cultural divides by providing skills to increase the health literacy of the patient and therefore supporting the accuracy of the record?</li> </ul>
Legal Value	Privacy	<ul style="list-style-type: none"> <li>▪ Does the patient have the facility to grant and/or revoke access or consent to his online record?</li> </ul>
	Confidentiality	<ul style="list-style-type: none"> <li>▪ Can the online record be accessed by unauthorized parties?</li> <li>▪ Can changes to the record be limited to authorized parties?</li> </ul>
	Auditability	<ul style="list-style-type: none"> <li>▪ Does the online record contain access logs?</li> <li>▪ Does the health record support non-repudiation (one cannot deny making an entry)?</li> <li>▪ Does the record provide full auditing features, like tracking of all changes, additions, deletions, etc?</li> <li>▪ Can the record be restored to a past</li> </ul>

Availability	Accessibility	state? <ul style="list-style-type: none"> <li>▪ Are audit logs stored separately from the lifelong health record?</li> <li>▪ Can the online record be accessed from any place at any time by patient and health care providers?</li> <li>▪ Is the system housing the health record robust?</li> <li>▪ Can emergency access be enabled for health professionals?</li> <li>▪ Does the capturing frontend provide an offline mode to capture and synchronize later when online?</li> </ul>
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From Table 2 it is clear that the health record by itself (i.e. the *data*) is not the only contributor to the success or failure of satisfying a particular dimension. Kaelber et.al. [15] state that three primary components of a health record can be identified, viz. *data*, *infrastructure*, and *applications*. For example, the *accuracy* of the record can be improved if the *application* supports data entry through the use of drop-down boxes and checklists. Other obvious examples include provision for educational material and sensitivity to cultural divides, which must be supported through HIT applications. Again, the role of implementation constraints, in this case technology, comes to the fore in the “performance” of the lifelong health record.

## 5 Conclusion

The main output of this paper comprises a set of characteristics of lifelong health records, which are expanded to include associated dimensions and examples of relevant measures. The set is not necessarily complete, but represents a first attempt at providing such a guideline for lifelong health records. The conceptual nature of the characteristics precludes the consideration of technological, legal, social or economic aspects that relate to the implementation of lifelong health records. However, when evaluating compliance with the characteristics, operational realities tend to determine the extent of achievement of particular health record types. For example, the integrity value of the patient-owned PHR is debatable, given the right of patients who are not health professionals, to update their health records.

While this paper proposes a set of characteristics of lifelong health records, no single solution exists to satisfy all of the stated requirements. As proposed in Wainer [3], it seems that the most one can do is to prioritize and accept that not all the core characteristics and associated dimensions will be achieved. The solution will be geared to the socio-technical, economic and medico-legal requirements of the

operational context, while the goal will always be to improve healthcare costs, quality, and efficiency.

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