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Implementing structured data in Electronic Health Records

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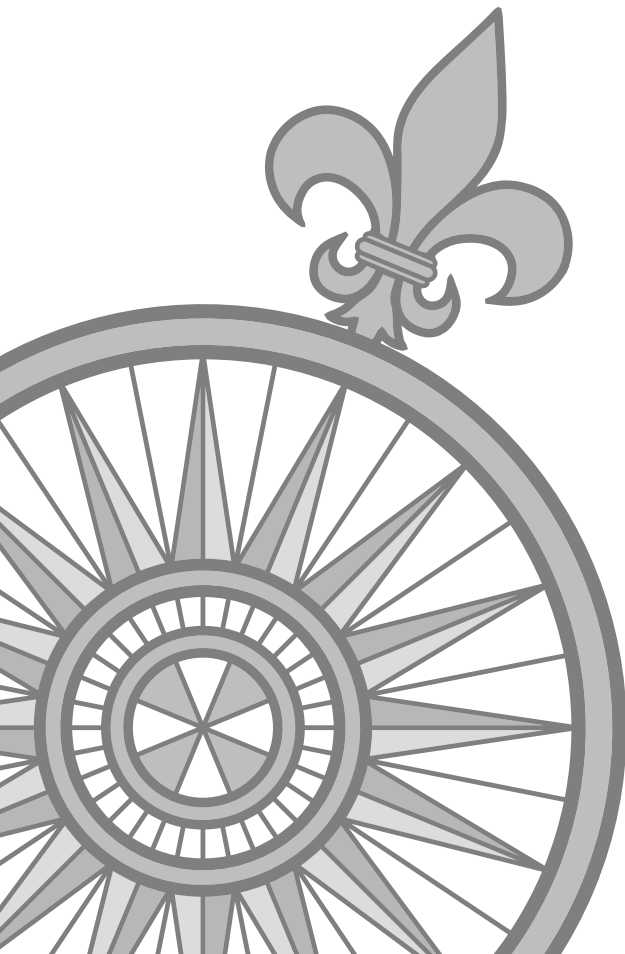
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Chapter 1

General introduction



But do you know that, although I have kept the diary for months past, it never once struck me how I was going to find any particular part of it in case I wanted to look it up?

Bram Stoker
Dracula, 1897

A brief history of healthcare data recording

To appreciate where the practice of recording healthcare data stands today, and to identify the origin of some of the current problems in this process, one has to know some history of healthcare data recording. One of the early examples of recording medical data dates back to 1600 BCE. An Egyptian papyrus describes a number of surgical cases that can be interpreted as an early textbook on surgery [1]. A more patient oriented view on data recording can be found at the school of medicine on the Greek island of Kos of around 400 BCE. This school was based on the learnings of Hippocrates, who was at that time alive or in living memory [2]. Hippocratic medicine is founded on an evidence base which required careful observation and documentation [3]. Physicians had to record complete and detailed medical histories including patient characteristics, symptoms, and diagnoses [3]. For many centuries any recording of medical data was purely meant for educational purposes or, later on, the progression of science [4, 5]. The well-known bills of mortality were produced initially to monitor the number of burials in London starting as early as 1528 and on an annual basis from 1603 [6]. These bills were preceded by similar records in other cities, such as Barcelona [7] and a number of Italian cities [8] in the 15th and 16th century. From 1629 the cause of death was added to the London lists, providing us with an early, albeit incomplete, collection of health statistics. More detailed medical data recording, and recording on an organisational level, started at the end of the 18th century. We illustrate the progress of data recording using the New York Hospital as an example. This organisation is an interesting example because its archives from 1793 onwards have survived [9], including the meeting minutes of the board of governors [10]. Starting in 1793 the New York Hospital's apothecary created admission and discharge books containing tables describing identifying, financial, and very basic medical information of each patient [9] in part to meet state legislature [10]. These overviews did not include any detailed individual medical data and were purely administrative.

During the first quarter of the 19th century more systematic recording of medical cases started in central volumes preserved in libraries of hospitals. Only those cases were recorded that would be of interest as teaching material for medical students. The board of governors of the New York Hospital commissioned the apothecary to record case reports into a central register [9]. The report consisted of "the history of the disease, the causes producing it, the remedies employed and the results of the case" [9]. These reports were retrospective, free-form narratives with no specific format based on the notes the physician had made in his or her own private notebook [10]. As the entries were chronological, these records can be called time-oriented.

Then in 1830 the New York Hospital decided that records should be kept on all patients in the hospital [10]. This only changed the inclusion criteria, the method of recording remained similar as before with retrospective, free-form narrative in time-oriented records. As there was no determined format for these records, the entries could be either very short or highly detailed. In the 1860s the records became more elaborate and started including positive as well as negative findings and more importantly: the cognitive process of the physician [10]. These records were still meant to advance science and education and were still ordered by discharge date and categorised by the final diagnosis. In the 1880s records started to become increasingly important as legal documents and the content and quality of the records became an area of interest to hospital administrators [4]. Still these records were not used in patient care. For that purpose, physicians used their own personal notes.

In 1898 a number of important changes in the recording of patient data were introduced [4, 10]. First, the records were ordered by the admission date instead of discharge date. Second,

more and more forms were used to enable data recording in a structured format. These records mainly consisted of observations without the cognitive process of the physicians. It was, however, the first time that records created at the bedside became the official hospital record rather than an abstract from the personal notes of the physician. This change partially originated from the problem that copying the physicians' notes to the central volumes created a large burden on the organisation [9]. Unfortunately, records from surgical, medical, and outpatient departments were kept in separate files making it difficult to gain a complete overview of a patient.

A radical change in recording practices came about in 1907. Dr. Henry Plummer of the Mayo Clinic suggested giving each patient a clinic number and recording all information about this patient in one file [11]. This meant that patient records went from time-oriented (chronological entries in one large file) to patient oriented (all entries on one patient combined in one file). This made retrieving all data about one patient considerably easier. In 1916 this technique was improved upon by introducing a form of standardised input by using specified formats for basic clinical data [4].

The next important step in recording patient data started in the 1960s when dr. Lawrence Weed of the Cleveland Metropolitan General Hospital introduced his Problem Oriented Medical Record (POMR) [12,13]. This heralded the change from patient oriented records (all information about one patient in one file, but still chronologically recorded) to problem oriented records (all information per patient ordered per problem). In a number of rules [12] Weed states that each problem of the patient should be discussed separately, that a numbered list with all past and present problems of the patient should be made, and graphs and tables containing "moving parameters" should be kept. Based on the numbered list all orders, plans, progress notes, and numerical data should be recorded and linked to one of the problems on the list [13]. This means that it is explicitly recorded why an order is placed, showing at the same time the cognitive process of the physician. This was a big step towards structuring medical records such that it would be easier to record and retrieve patient information.

This same era culminated in the initiation of the now ubiquitous Electronic Health Record (EHR), a computerized version of the classic paper-based records. The same Lawrence Weed started in 1967 with developing the Problem Oriented Medical Information System (Promis) while working at the University of Vermont Medical Center [14]. Where other research groups were working on entering dictated or written words of physicians into computers, Weed et al. decided that the healthcare professionals should be interfaced to the computer directly [13,15]. To achieve this, they needed to develop techniques and tools to facilitate this direct interface. This signalled the start of recording the medical data in digital records by the healthcare professionals themselves. It was also this decision that put the responsibility of correct digital recording of patient data with the physicians and other healthcare providers. However, as they were mandated to work with digital systems that have their limitations in usability, there is a tension between what is expected from physicians and what they can actually achieve. Especially, in the limited time they have available.

Roles of the EHR

Since those first versions of the EHR, technology has come a long way. The advancement of computers and digital possibilities means that modern EHRs offer a plethora of functionalities next to the basic recording of patient data. More and more tasks in the daily work of healthcare providers are performed in or with the EHR. Primarily, data are collected to pro-

vide care to individual patients. The patient file serves as a record of all information that has been collected, including considerations and decisions of the treating physicians. Additionally, the EHR can use the collected data to aid the physician in recurring tasks such as writing a discharge or referral letter. It can also advise the physician through decision support systems or alerts, when patient data and scientific evidence on certain treatments, such as types of medication, show discrepancies or even potentially harmful consequences for the patient.

Recording the data of all patients in an EHR also enables aggregating these data to serve other essential purposes. For example, routinely collected data can be used for information needs at a managerial level, to do scientific research on groups of patients or to calculate quality indicators more easily and reliably. The latter of these benefits echoes the main goal of the 1964 paper by Weed: auditing physicians or medical institutions on a routinely basis [12].

The goals of modern day EHRs can be summarised in a number of roles [16, 17], it:

- represents the patient's health history,
- provides a method for clinical communication and care planning among the individual healthcare practitioners serving the patient,
- serves as the legal document describing the healthcare services provided,
- is a source of data for clinical, health services, and outcomes research,
- serves as a major resource for healthcare practitioner education, and
- assists in providing care by providing relevant evidence-based knowledge (through decision support and alerts).

Structured data

To enable all these roles of the EHR, a number of requirements have to be met. Primarily the data need to be structured and standardised [18], meaning that all data elements and their values are unambiguous and are consistently stored in the exact same location. This step of making sure that the recorded data are structured and can be reused is a current focus of innovation in the field of EHRs.

First, we need to define what to capture and where to store it. This structure of the data is usually based on information models. These models define the structure of the stored data elements, that is how their values will be stored in the underlying database. For example, a model could define that each measurement has a name, a date on which it was measured, a unit, and a value. The result of this process is structured data: each item of recorded data has its own specific place and form in the database. When data are properly structured, it is easy to find an item because it is known where it is stored. This helps with reusing the data because queries can be made that retrieve specific data correctly each time.

The way these data are presented to the user is another form of structure. For example, we could define that for each patient a date of birth and a diagnosis have to be recorded. We can stipulate that each problem has to be shown in a central problem list (conf. Weed [12]), and the date of birth in a specific field should always be displayed at the top of the screen, together with the derived age, instead of only having it in a letter from the referring general practitioner. This is advantageous to end-users, since they can easily find the data they are looking for. With the introduction of the Problem Oriented Record and the proliferation of EHRs, the structure of data has been a constant point of attention for the people designing, implementing, and using EHRs.

Specifying where the data have to be stored and shown, however, is not the only important aspect to efficient and effective data storage and use. Next to deciding where we record the data, we need to agree on how to record the data. Recording standardised data requires the use of terminology systems such as SNOMED CT that provide a predefined list of all possible (medical) concepts and their describing terms that could be recorded in the EHR. Each concept is also coded with an alphanumeric code that enables communication within and between healthcare organisations. Using a terminology system ensures that data that are stored and exchanged between systems are unambiguous. This can be done on two levels: visible by the end-users and behind the scenes. In the former situation, the end-user will have to choose the best option from a list with suggestions based on the underlying terminology system. For example, suppose the physician wants to record type II diabetes as a diagnosis and types 'diabetes' in the diagnosis field of the EHR. The EHR then suggests different types of diabetes (e.g. type I, type II, or gestational diabetes) and the physician chooses the correct option. This is recorded in the EHR with the corresponding code (e.g. using SNOMED CT). In the second scenario the physician just records information in the EHR, and in the background the system, or a clinical coder, appends the correct code to the recorded information. Hereafter, we will refer to structured and standardised data simply as structured data.

Balance effort and benefit

Recording data is inextricably linked with the clinical process. Any change in recording practice therefore also has a large influence on the clinical process. Recording structured data requires a specific recording practice. It is no longer possible to record all data about a patient in free text in a seemingly random place of the patient record, a process that could easily follow the workflow of the physician precisely. To record structured data, however, check boxes and specific fields are used to structure the data. Additionally (code) lists with medical concepts are used to standardise the values within the fields. For many healthcare providers this feels like more work during the clinical process and thus it creates a documentation burden. This documentation burden indicates that healthcare providers feel that too much time is spent recording patient data [19], time that they want to spend by talking to and caring for the patient [20].

The challenge is to strike the right balance between benefits and burden [21]. The design of the implemented EHR is a key element in maintaining this balance. If the design is too demanding and restricting, the scale tips to high documentation burden. If the design is too free and accommodating, the data are not reusable anymore, strongly decreasing possible benefits. To find equilibrium, it is necessary to know how healthcare providers experience structured data recording, and to find what can be done to increase the adoption of structured data recording.

Current affairs

Most advancements in the field of EHR development up to this moment have been on which data to record, for what reason, and how to structure this in the patient record. Using an EHR can bring a number of benefits [22, 23]. Because of these benefits, many western hospitals have at least some form of electronic recording implemented at the moment [24, 25]. In many hospitals, paper-based files and electronic forms of data recording are used together. Only in

a handful of hospitals, the paper-based files have already been discarded completely. Therefore, the current phase in the ongoing change process concerning the recording of patient data is transitioning to completely digital systems and abandoning the last paper remnants. In some cases, this means finally making the step from paper-based to electronic recording by implementing the first EHR. In other situations, where an EHR was already implemented, it means transitioning from a partial or patchwork EHR to a completely integrated EHR.

Coping with change

The process of implementing an EHR is lengthy. From the conclusion that a new EHR is necessary or wanted, it takes five or more years before the users finally work with the new system in daily practice [26–28]. During this period the requirements need to be formalised, the most appropriate vendor has to be selected, the optimal design of the system needs to be prepared, the staff have to be trained, and the system needs to be installed within the organisation. After the implementation it takes time to get accustomed to the new situation.

The initial decision to put the physician behind the screen of the computer (started in the 1960s by Weed et al. [15]) means that an EHR implementation is not just a technical process. The implementation of integrated EHRs changes work processes and the recording practice of healthcare providers [29–32]. The way personnel interact with patient files, with each other, and above all, with the patient, changes. These personal and social aspects mean that the implementation of an EHR can be considered a sociotechnical process [33,34]. Therefore, it is as important to observe the human interactions and perceptions, as it is to observe the system itself in order to optimize the EHR implementation success [35].

Evidence-based implementations

As each organisation is different, all implementations will be different. However, this does not mean that there are no general best practices that could be formulated that apply to most implementations. It is essential that research tries to identify the effects of certain choices on the outcomes of the implementation. This should result in a description of factors that lead to success or failure in EHR implementations. Based on this kind of research the ultimate goal would be to create guidelines that could help to perform an evidence-based EHR implementation.

This requires studies that are performed around the implementation of EHRs in healthcare organisations. Unfortunately, doing systematic scientific research is not a standard aspect of most implementation projects. Time limitations, or the fear of negative outcomes, results in a lack of scientific studies being performed during EHR implementations. Additionally, several reasons, such as possible conflicts with EHR vendors, might result in a publication bias when the results of the implementation are less than optimal [36,37]. It is important to study implementations and publish the results regardless of the (positive or negative) findings. Currently, there is only a small evidence base and not much systematic research on implementations [38,39].

Organisational context

When implementing or designing an EHR there are a number of important organisational aspects that should be considered. For example, the baseline recording practice of an or-

organisation before implementing a new system, or the maturity of the EHR (i.e. how advanced the EHR is) when implementing structured data recording. In terms of baseline recording practice, organisations can come either from paper-based records or from a previous, legacy, EHR. The changes when transitioning from paper-based recording to digital recording might be different from those when updating an old EHR to a new generation EHR. The implementation in paper-based organisations needs a larger change and starts with a focus on digital recording in general. The implementation in legacy EHR organisations may need to focus on the many small and interacting changes between the two systems. When an organisation wants to increase the adoption of structured data recording, the maturity of their EHR might be something to take into consideration. Very mature, advanced systems could in theory be better at supporting structured data entry, than low-maturity or even paper-based records. It is important to analyse the effects of this organisational context. Therefore, in this thesis we will investigate the perceived effects of implementing an EHR in two academic hospitals to see which factors might influence these perceptions. Additionally, we investigate determinants for structured data recording in seven out of eight Dutch academic hospitals, which have different levels of EHR maturity.

Aims and outline

In this thesis, we describe five studies that are designed to support our two aims. We will describe both our aims and how the chapters of this thesis contribute to them.

Aim 1: To determine the effects of implementing a structured and standardised EHR on healthcare providers' perceptions of EHR use and performance, and to assess whether these effects differ for centres starting with a paper-based or legacy EHR at baseline.

In Chapter 2, we explore what the personnel of an academic centre expect of an EHR implementation process. We use concept mapping to find the most important aspects of an EHR implementation to consider before and during the implementation process. Then in Chapter 3, we evaluate an actual EHR implementation to identify effects this implementation had on the perceptions of the healthcare providers on EHR use, data use, and data reuse. By administering a questionnaire to all personnel before and after the implementation, we can detect differences in perception. Because we included two centres that came from two different baseline settings, we were able to identify differences between formerly paper-based and legacy EHR centres. In Chapter 4 we focus on one aspect of EHR use: documentation time. With a time-and-motion study, we evaluate what percentage of time physicians spent on data recording during outpatient consultations and whether this is different before and after the implementation of a new system.

Aim 2: To determine factors that influence healthcare professionals' intention to record structured data.

In Chapter 5, we create a theoretical model to explain the determinants of structured data recording. We use Partial Least Squares Structural Equation Modelling (PLS-SEM) to validate the model. In Chapter 6 we assess which of the items from the model from Chapter 5 are most important to increase the adoption of structured data recording. We distinguish between centres with different EHR maturity levels to see whether this influences the factors of importance. In Chapter 7 we provide a general discussion of the results from Chapter 2, 3, 4, 5, and 6.