

Electronic Health Records and the Archival Question: Shared Responsibility as a Panacea

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Abstract— Literature on the benefits of Electronic Health Records (EHR) across the health sector abounds. However, as all the hype about EHRs revolutionizing healthcare, there is not a commensurate discourse on the archival question in the era of EHRs. As EHRs are being hailed and hyped, an archival dilemma of such systems is looming. The archival question is about the long-term availability of EHRs as archives versus the traditional custodial roles of archival institutions. Through an argumentative approach, the paper argues that due to their complexities, EHRs need not be transferred to archival institutions but rather require a distributed custody strategy where archival institutions allow healthcare facilities and vendors to retain and preserve EHRs to ensure that their EHR systems guarantee long term preservation of records generated by such systems (as archivally deemed fit), and that healthcare facilities implement and maintain archivally compliant EHRs archives. In the process, the distributed custody will ensure that archival institutions promote the availability of the record for now and the future by collaborating with healthcare facilities as an archival protector whilst the custody of the EHR remains with the healthcare provider. For this approach to work, archival laws need to be reviewed in order to reflect and cope with the new realities and address current challenges presented by EHRs. It is suggested that archivists, health IT experts and vendors start viewing EHRs not merely as systems from which archival health records will be extracted at a later stage, but as health records in their own right, that need to be treated as archives, as they are resident in the systems.

Keywords—archiving; electronic health records; long term preservation; shared responsibility.

I. INTRODUCTION

EHRs are fast becoming ubiquitous across the health sector worldwide. Ironically, there seems to be a dearth of commensurate discourse on the archival question around EHRs. The situation of limited attention being given to the archiving of clinical data persists to-date in the EHRs [1]. An EHR is “medical information compiled in a data-gathering format for retention and transferal of protected information via a secured, encrypted communication line. The information can be readily stored onto an acceptable storage medium, such as a compact disk” [2]. They have been hailed for revolutionizing the health sector by overcoming the shortcomings of their predecessors—paper records, including illegibility of handwriting, limited shareability, as well as space challenges. With the advent of

Artificial Intelligence (AI), Machine Learning (ML), big data analytics and many other forms of computing, the value of EHRs has only increased. The advent of Electronic Personal Health Records (EPHR) where patients have control over their own health records has accelerated the interest of researchers in EHRs. For example, some scholars are beginning to advocate for EHRs preservation models that will see the control of EHRs being moved away from healthcare facilities to their owners [3]. The question of EHRs ownership is another one that is a highly contested issue, but not a topic for discussion in this paper. However, some scholars are already acknowledging that EHRs are currently residing with healthcare providers, not with archival institutions, further demonstrating the need for a genuine debate about EHRs preservation and the custody question [3]. This indirect acknowledgement by certain scholars shows that healthcare facilities with EHRs vendors, have become the default archivists of EHRs.

The phenomenon of EHRs has been, and continues to be, a subject of research in health informatics for several years now [4]. However, as all this is happening, archivists are conspicuously absent from the stage regarding how EHRs should be archived for long term availability as archives. Such absence of archivists and archivally sound techniques and policies has not only created an archival chasm but has seen the question of long-term availability of EHRs—which is usually discussed with the ownership of such records, as a matter between healthcare facilities and EHRs vendors. What France et al. [5] identified as the challenge for the long-term preservation of EHRs still stands today and continues to make the dream of EHRs archiving elusive to archivists and all the other stakeholders. It can be observed that EHRs and most information systems for hospitals and all the other healthcare facilities, private and public, are built considering the “active” EHR [5]. This implies that the archival function for EHRs comes as an afterthought, if ever it arises, too late a stage for archival institutions to ingest the EHRs for posterity, owing to large volumes, multiple vendors, ever-changing technical standards etc., coupled with the freedom of healthcare facilities to select, implement and discontinue EHRs at their own discretion. This further results in a state where health records generated and held by EHRs are not subjected to archival processes, such as

appraisal and preservation, with the consequence of failure to identify and preserve archivally valuable health records. Owing to the dearth of clearly pronounced archival policy and a review of archival laws as they relate to the archival question for EHRs, archival institutions, especially national ones that are legally mandated to acquire and preserve such records, find themselves in a position where they are not able to execute their mandate, or sub consciously abrogating their archival role and duty to healthcare providers and EHRs vendors. Writing in the context of the USA when EHRs were still a relatively new and buzzy phenomenon, Corn warned that “several ongoing health care and information storage developments suggest that a fresh look should be taken at the policies that govern the preservation of medical records...” [1]. One can say that the archival question in terms of the legal mandate or responsibility versus practical considerations for EHRs preservation is part of Corn’s statement.

The current state of literature shows preoccupation with privacy and security of health data in EHRs, but little has been said about the real archival question, that is, are archival institutions abrogating their legal responsibilities of acquiring and preserving health records to healthcare facilities and vendors without explicitly mentioning this? Corn, referring to the question about the preservation of clinical data as a rarely asked question, further stated “*how to archive clinical data so as to preserve most efficiently the information and access to the information will require collegial resolution of complex technical and social problems, analogous to the efforts of many major libraries to develop archiving policies. Reevaluation of U.S. medical record retention policies would require consideration of a number of issues that are not often discussed*” [1].

This paper is structured as follows. In Section I, an introduction to the study is given. In Section II, a case for the preservation of EHRs is presented. In Section III, the archival challenges of preserving EHRs are given. In Section IV, the shared responsibility approach to EHRs is proposed. Finally, the study is concluded in Section V.

II. WHY SHOULD HEALTH RECORDS BE ARCHIVED?

The importance of medical archives cannot be overemphasized. According to the Mansoura University Specialized Medical Hospital, a medical archive is a “fundamental pillar in any health institution, as it is the memory that preserves the history of patients and their health conditions, as it is responsible for preserving the services provided to patients, whether in paper or electronic form, for reference when needed” [6]. Medical archives support quality healthcare and evidence-based decision making, advance medical research and protect healthcare facilities from legal liabilities [6]. From a global perspective, “national laws state that medical record should be preserved for patient’s health care and for legal purposes, for a certain number of years, after his departure or after the patient’s death. This duration varies by country” [5].

Although medical records are primarily created for the care of patients, medical archives are used for a number of reasons, including medical practitioners understanding previous case history in the event of the case resurfacing, historians studying the history of medicine, fiction authors wishing to understand a contemporary setting or character for their stories as well as genealogists researching their relatives [and other persons of their interest] [7]. Despite the acknowledgement of the secondary use of health records, progress towards their preservation for such meaningful use remains a serious hurdle. In the following words, Klementi and colleagues, lament: “although the need for health data reuse is widely recognised, actual progress in that area has been moderate. The reasons for this are the vendor-specific proprietary database schemes used by EHRs systems, semantic heterogeneity and the sensitive nature of clinical data that sets legal and ethical restrictions on sharing” [3].

The study was guided by the following objectives.

1. To unpack the archival challenges that are presented by EHRs.
2. To propose the distributed custody approach for the preservation of EHRs.

III. ARCHIVAL CHALLENGES PRESENTED BY EHRs

The complexity of EHRs architecture is the culprit, presenting a domino effect on the other aspects, such as the ability of archival institutions to cope with technical and custodial challenges of such systems. EHRs are not just a replacement of paper records. The complexity of EHRs “resides in a multitude of interdependent elements which must be organized” [4]. Franca, Lima and Soares, summarising the complexities of EHRs, wrote: “*One health application that is considered very complex not only to develop but also to operate and maintain is the Electronic Health Record (EHR), which refers to software systems that store health information about patients in a digital format. EHRs are used by different health professional teams, including physicians, nurses, radiologists, pharmacists, laboratory technicians and radiographers. Even patients can add information into the EHR, provided this is validated by physicians*” [8].

Thus, EHRs are complex integrated systems from various operational units and functions of health. This makes it difficult for national archival institutions to play their traditional roles of acquiring, managing and archiving EHRs. This complexity further implies that EHRs are fluid and ever active, which further complicates the archival work of identifying what constitutes archivally worth records in such systems. A hospital archive consists of both active health and passive health records [9]. Active health records, on one hand, include those whose data are being updated on a continuous basis of a patient receiving care at a healthcare facility, whilst passive health records, on the other hand, are health records that have not been updated over a reasonably long period of time [9].

In today's EHRs environment, determining passive health records is increasingly becoming difficult due to the treatment of EHRs — they are ever active data used in big data analytics, training AI algorithms and in ML. Further compounding the situation is how to archive EHRs themselves, that is, should the entire EHR system be archived, or only selected components of the EHR should be archived? Some of the early scholars, such as France and colleagues suggested that certain records be extracted from EHRs systems and earmarked for archiving [5]. They wrote “data will have to be extracted from the administrative database (admission, dates of admission and discharge, clinical services, notes of the physician, nurses, drug orders, laboratory computers, X rays, surgery and anaesthesia protocols, final report, medical record summary...)” [5].

However, they immediately lamented: “Will the record be still accessible? Will it be complete ?” [5]. For example, in their study in the long term preservation abilities of EHRs among healthcare facilities in Barcelona, Bote, Termens, and Gelabert discovered that while most analogue health records easily became passive within a period of 3 – 5 years, the case was likely to be different from EHRs systems as information workflows and treatment in EHRs are completely different from an analogue environment and both active and passive EHRs were lying in the same electronic systems that however, were not running on the same software [9]. So, how do archival institutions exercise their archival role in such complex environments? This is a critical question for archivists as their response to it will determine how to perform the appraisal function for EHRs.

The question is, can archival institutions cope with these EHRs complexities from the perspective of physical custodianship and guaranteeing long term availability and accessibility of the EHRs? For example, if the entire EHR is to be archived, the question is who should do this and how? Should healthcare facilities migrate their EHRs system once they become due for archiving? Should the archival institution ingest the EHR system or migrate it to a new system for long term preservation? Bote, Termens, and Gelabert advise that an archival shift is necessary in such an environment [9]. Therefore “an EHR is a complex unit of information that requires different treatment in the long term, not as a single unit of information.” [9].

When the headache of long-term preservation of EHRs storage started, some attempts were made, for example, The Swedish Institute for Health Services Development, working with Sahlgrenska University Hospital created the project called DEJAVU, whose aim was to come up with a general format for the long-term preservation of electronic patient records [10]. At that time, the Swedish National Archives had approved paper and microfilm as the most stable and permanent storage mediums for archival preservation [10]. The project proposed the development of a standardised electronic patient record based on the Standard Generalized Markup Language, ISO 8879:1986/A1 :1988, allowing records to be extracted from

their original EHRs systems and converted into a Standard Generalised Markup Language (SGML) format for long-term accessibility [10]. However, the sustainability of such a practice, as well as the ability of the new and stable SGML EHR to remain interactive and comprehensive over time under the care of an archival institution remains a concern, given that records would have to be extracted from their original systems into the SGML. To date, a plethora of EHRs standards have been developed, including standards from Health Level Seven (HL7), International Organisation for Standardisation (ISO)/ Technical Committee (TC) 215 Secretariat on Health informatics. Some of the relevant standards by ISO include ISO 14641:2028 Electronic Document management- Design and operation of an information system for the preservation of electronic documents- Specifications, the European Committee for Standardisation (CEN) 254 and many others. However, the afore-mentioned standards are best applied to the EHRs systems that create, store and preserve such records, rather than applying them to third parties, such as archival institutions that will have to extract such records from their original EHRs, convert them to new formats for the sake of long term preservation. Questions of records completeness in the midst of a multiplicity of EHRs components and EHRs vendors arise.

Limited collaboration between health records and IT personnel at healthcare facilities and the national archival institutions also have a domino effect on the ability of archival institutions to preserve EHRs. As Corn put it “another important complicating issue for the archiving of electronic information is the fragmentation of responsibility and diversity of technical systems for varying data types within a single enterprise: laboratory, pathology, imaging, sensor information, and other forms of data are often maintained by the unit performing the service, while the EHR proper is the responsibility of the organization's IT department.” [1]. As the above mentioned situation continues to obtain across the EHR environment, it is obvious that the bulk, if not all the health records—active or inactive (archival), generated by EHRs is under the control of IT staff at healthcare facilities and vendors, thereby making them “default archivists”, yet there is limited dialogue between archivists and such technical personnel who are in real control of health records. Even in cases where there is a medical record librarian or archivist at a healthcare facility, they tend to bear influence on traditional paper records only.

Thus, the fragmentation is not only witnessed in the components of the EHR system, but between and among the personnel and institutions handling EHRs across the spectrum, including archivists and Archives, IT personnel in healthcare facilities and vendors. This has resulted in disjointed and limited efforts towards addressing the archival question as far as EHRs are concerned. This has manifested itself in the form of policies that are focused on the regulation of operational issues of EHRs, with a loud

silence about the archival question, especially in terms of whose responsibility it is to preserve the archival health record beyond its operational value for immediate care of a patient. Fig 1 summarises the challenges associated with the preservation of EHRs from an archival perspective.

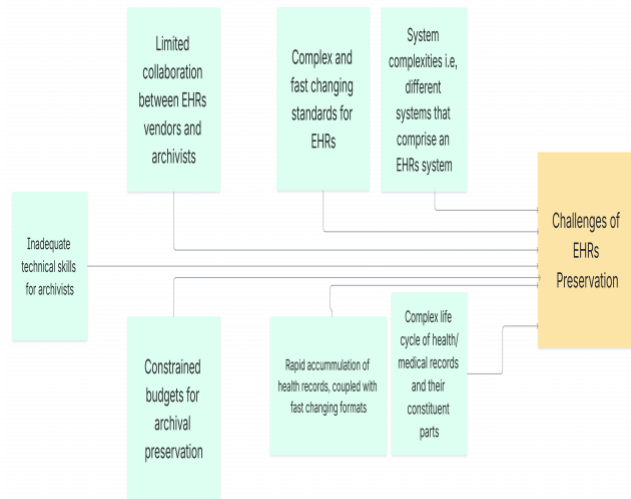


Fig. 1 Challenges of preserving EHRs.

IV. SHARED RESPONSIBILITY AS A MEANS OF ADDRESSING THE ARCHIVAL QUESTION FOR EHRs

As noted by Bastian [11], the idea of shared responsibility in archival science, also known as post-custodialism, was first coined by Ham, who encouraged archivists to rethink their physical custodial role over archives and allow a situation where archivists and archives let of the physical custody of records whilst retaining their legal control. This implies that the creating agency is left to maintain physical custody of the records, including archival ones, with archivists coming in to advise on best archival practices. To Ham, cited in Bastian [11], the insistence of archivists on the physical control of records, especially in the era of electronic records, is seen as a deterrent to the effective management of records.

Despite the shared responsibility having a relatively long history in archival science, it is yet to gain scholarly and practical traction in archival science as a handful of scholars have researched it. In light of EHRs, Ham's post-custodial approach is being proposed as the most plausible one to the preservation of EHRs. Whilst early scholars recommended a transfer of EHRs to standard archival storage medium, such as microfilm, DVD and CD-ROMS, clearly this system is no longer viable today. Despite such medium having become an obsolete technology, the very approach of extracting records from EHRs systems into a different platform implies migration from one platform or medium to the other, which in the case of EHRs, I argue, is not viable, due to the complications of the EHRs today and in the near and long future. The multiplicity of different systems for

different health operations during the lifetime care for a patient, supported by different vendors, operating on different platforms, technical incapacities of many archival institutions as well as incommensurate archival strategies for EHRs all work against the traditional custodial approach to the long-term preservation of EHRs. As a result, the post-custodial/shared responsibility model, which archivists have long touted but not yet supported by clear archival policies and laws due to the fear of entrusting the archival function to healthcare facilities and vendors, is proposed.

In this model, archival institutions and archivists stick to their legal supervisory mandate and loosen up on the custodial component. This means that archival institutions focus on the development of policies and advocate for the updating of archival laws that promote the shared responsibility model. Specifically, archivists may stop insisting on taking custody of EHRs as this demands them to have as many software applications as the number of EHRs variations that exist on the market, which is neither practical nor economic for poorly funded archival institutions. This will see archivists being responsible for setting policies and standards that EHRs vendors and healthcare facilities should ensure as they share the custody of EHRs, including retention and disposal schedules as well as access policies for EHRs.

Likewise, healthcare facilities and vendors where necessary, will be expected to take full or shared custody of EHRs systems, embedding in them, the archival policies and standards for the records to meet the archival needs of the health record, including research uses. This means that EHRs will no longer follow the traditional custodial cycle of records where in-active records are handed over to the archives, but remain in the system of the healthcare facility, in conjunction with vendors where necessary, to preserve them as archives. This means allowing the healthcare facilities and vendors to protect and make available, legally acceptable EHRs for as long as required by the law under the custody of their creators, duties that traditionally lie squarely with archivists and archival institutions. In this model, archivists, IT specialists and EHRs vendors work together and come up with the best framework that factors in the technical, operational and legal realities of all the stakeholders, at the same time protecting and propagating EHRs that meet legal and archival requirements for health records. Through this model, the policy, technical and communication fragmentation that currently characterizes the EHRs can be reduced, and a more coordinated long-term EHRs can be imagined.

The proposed distributed custody model, however, will not come without challenges. Whilst from a custodial perspective, this approach seems to be a panacea, it creates a new demand from archivists and archival institutions—that of educating and ensuring compliance with archival policies and standards for EHRs vendors and healthcare facilities. The success of the model depends on the cooperation of the vendors and healthcare facilities. The archival endeavor has

been the prerogative of archivists, with creators and vendors only interested in the technology that supports the daily operations of healthcare facilities, with little to no regard for the records when they have fulfilled their primary administrative needs. Thus, giving them the archival role of preserving their in-active EHRs may not enjoy positive reception. On the part of the healthcare facilities and vendors, the distributed custody model may come with additional expenses, for example, maintaining archival EHRs accessible as archivists would diligently do. Archival preservation is an expensive and cumbersome endeavor that vendors and healthcare facilities may not keep pace with. Thus, the model presents new responsibilities to archivists, healthcare facilities and the vendors, requiring a high degree of commitment and consensus from the three stakeholders.

V. CONCLUSION AND FUTURE WORK

Although archivists have been reluctant to adopt and promote the shared responsibility approach to address the archival question in the case of electronic records, owing to them being “collecting professionals” with the keeping of records in the archives as a way of vouching for their authenticity, EHRs coupled with their complexities, undoubtedly present themselves as a good candidate for this approach. The proposed shared responsibility approach that this paper advocates for is going to be challenging as it needs very strong coordination efforts among archivists, healthcare IT experts and vendors, as well as a great deal of a mindset shift from the afore-mentioned stakeholders, allowing each of them to adapt to their new professional roles in this model, including incurring expenses.

It is recommended that archivists, EHRs vendors and healthcare organisations engage in feasibility discussions on the distributed custody approach for EHRs. Archivists should develop policy and compliance mechanisms to ensure the success of the model, whilst vendors and healthcare providers should be willing to bear the archival responsibility of ensuring the long-term availability of EHRs in their custody, at the same time fulfilling the information needs of society and researchers. Empirical studies are required to understand the feasibility of the

distributed custody approach from policy, legal, technical and financial considerations for the model to work.

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