

Distributed Custody for Electronic Health Records Preservation: A Proposal

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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 becomes evident, 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. In this model, archivists, healthcare facilities and vendors should see each other as strategic partners and accept the new responsibilities that come with the model. This paper envisages a debate on possible collaboration between archivists and healthcare facilities on the possibility of distributed custody for EHRs.

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

I. INTRODUCTION

This article based on the original paper titled “Electronic Health Records and the Archival Question: Shared Responsibility as a Panacea” [1] of the HEALTHINFO 2025 : The Tenth International Conference on Informatics and Assistive Technologies for Health-Care, Medical Support and Wellbeing. The original 5-paged conference paper briefly problematizes the preservation of EHRs and proposes the shared responsibility model as an alternative to the physical custodianship of these records. Whilst the extended manuscript is premised on the same argument, it

presents new and extensive literature and new sections that help magnify the problem of EHRs preservation. This article also addresses pertinent issues such as the responsibilities of key stakeholders such as healthcare facilities, vendors and archivists, governance and legal considerations as well as financial implications of the proposed model. This ensures that the model speaks to the realities and possibly the most considerations for all the strategic stakeholders in the model. Electronic Health Records (EHRs) are fast becoming ubiquitous across the health sector worldwide. Actually, countries across the globe are preoccupied with the implementation of EHRs, Electronic Medical Records (EMRs) and Electronic Personal Health Records (EPHRs) or similar technologies [2], possibly owing to the use of such EHRs systems being touted as possessing great potential of transforming healthcare [3]. This has been accelerated by the development of Information Technology which, through health informatics, has made it easier to build applications that enhance the experiences of service providers and patients. EHRs, EMRs, EPHRs, and Hospital Information Systems enable the capture and registration of patient health data, including texts, symbols, charts, graphics, data as well as other information [4] about a patient. They have been touted as a game changer in the health sector due to the benefits that they promise. However, scholars still recommend more empirical studies on the benefits of EHRs on clinical outcomes [5]. From the perspective of health records archiving, this development calls for proactive thinking in terms of the preservation of such records. In fact, “a lifetime EHR is a presumed goal and will require data retention—active and archived— for perhaps 125 years” [2]. This is so because an EHR is actually the health data of a patient throughout their entire life [6], literary from cradle to grave. Thus, “data and information long-term preservation is a crucial issue in the healthcare and clinical research domains” [7]. 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 [8]. Thus, digital healthcare archival remains one area in which limited work has been done, resulting in electronic hospital and medical records being listed as “endangered” on the Digital Preservation Coalition’s (DPC) Bit List of

endangered unarchived data [9]. In 2025, DPC hosted an open meeting whose aim was to address some of the challenges affecting healthcare data and its archiving [10]. Topping the agenda items was the definition and scope of healthcare archives challenges, as well as an exploration of potential solutions to the challenge [10]. Some of the imminent threats to EHRs and EMRs, include potential loss of context, loss of integrity or authenticity, unconducive storage conditions, staff turnover, generation of data in large volumes, variety of data, poor records management practices, weak transfer and integrity mechanisms, poor migration and normalization strategies, application of paper recordkeeping practices to digital content, encryption as well as uncertainty surrounding Intellectual Property Rights [9]. Indeed, data preservation challenges are a threat and potential barrier to the adoption of e-health, and to future healthcare systems [2] if left unaddressed.

An EHR is “medical information compiled in a data-gathering format for retention and transfer 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” [11]. It is “a digital repository of a patient’s medical information that documents their entire healthcare journey in real time. Everything from diagnoses, medical history, medications and immunizations, to X-rays, laboratory results and clinical notes, is updated automatically so that doctors and providers have the most recent information when they access a patient’s EHR” [12]. Thus, an EHR is real-time patient oriented digital health information of a patient that is generated and maintained by a healthcare facility [13]. EHRs 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 [14]. The question of EHRs ownership is another 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 [14]. 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 [15]. 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. [16] 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 in light of the “active” EHR [17]. 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...” [8]. 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. Without addressing the archival question in EHRs, healthcare facilities and archival institutions will find themselves in situations where they can re-use the large amounts of health data that they have interest in for various reasons. Thus, “long term preservation of electronic health information is a key issue for life-long electronic health records; however, it is poorly implemented in healthcare institutions and little attention is given to problems like obsolescence of formats and EHR applications or changing regulations, which jeopardize reusability of information after decades of preservation” [17].

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” [8].

This paper intends to discuss the archival challenges that are presented by EHRs and propose the shared responsibility, also known as the distributed custody model as a possible solution to the identified archival challenges. The paper is argumentative and theoretical in nature and recommends archivists, healthcare facilities and vendors to engage in close collaboration in the proposed distributed custody model.

The paper is organized as follows. In Section I, and introduction to the study is given. Section II is a discussion on the impetus behind the preservation of health records. In Section III, the challenges of preserving EHRs are presented, followed by the presentation of the shared responsibility model which is being proposed as a viable alternative to physical custody model for EHRs in Section IV. In Section V, governance issues relating to the proposed distributed custody approach to the preservation of EHRs are discussed. In Section VI, the legal framework that supports the proposed model is presented, followed by a statement on financial implications for the model in Section VII. Finally, Section VIII concludes the study and proposes future research work in this area.

II. WHY SHOULD HEALTH RECORDS BE ARCHIVED?

EHRs, which are part of a hospital’s health information system, gradually and eventually become passive information units after a reasonable amount of time being inactive [18]. 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” [19]. Medical archives support quality healthcare and evidence-based decision making, advance medical research and protect healthcare facilities from legal liabilities [19]. Thus, it is important for health and medical records to remain accessible as it pertains to diagnosis and treatment, for follow-ups on medical cases, for supporting clinical, epidemiological research and for strengthening the quality-of-care assessment and development [16].

Because EHRs, just like their paper counterparts, also contain administrative information, it therefore follows that such information should be stored for legal reasons [16]. This supports the creation and preservation of a legal health record. A legal health record (LHR) is “the documentation of the healthcare services provided to an individual in any aspect of healthcare delivery by a healthcare provider organization. The LHR is individually identifiable data, in any medium, collected and directly used in and/or documenting healthcare or health status. The term includes records of care in any health-related setting used by healthcare professionals while providing patient care services, for reviewing patient data, or documenting observations, actions, or instructions.” [20]. It, thus, limits itself to a patient’s health record that is designated as official, and is created and managed by a healthcare institution in a manner which satisfies the legal requirements of a legal health record. That way, it excludes all the other documents or records such as Electronic Personal Health Records that are managed by patients.

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” [16]. 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] [21]. 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” [14].

The study was guided by the following objectives.

1. To discuss 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 long-term preservation of EHRs is attributed to several challenges, including technical and non-technical ones. The section below presents some of the pressing challenges that characterise the preservation of EHRs throughout their life cycle.

A. Complexity of EHRs Systems

The complexity of EHRs architecture is the culprit, presenting a domino effect on 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 for paper records. The complexity of EHRs “resides in a multitude of interdependent elements which must be organized” [15]. 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” [22]. Indeed “the EHR must meet the diverse needs of multiple, and often operationally distinct, clinical services for documentation, patient management, billing, and regulatory compliance, among other functions” [22].

An EHR, according to the International Organisation for Standardisation (ISO), typically consists of, but not limited to the following:

1. Patient health information: This is the main component of an EHR system comprised of key patient information such as medical histories, diagnostic records and medication details.
2. Order entry systems: These enable medications and tests to be ordered electronically, thereby simplifying workflow processes.
3. Decision support systems: These systems support healthcare staff through evidence-based recommendations, thereby improving the provision of crucial health information during patient care.
4. Security protocols: Addressing one of the important aspects of healthcare, that is, patient dignity, privacy and confidentiality, this system regulates access to a patient’s health information. It ensures that access to patients’ health information is provided to legally authorized individuals across the hospital. This also greatly minimizes litigation risks and boosts compliance with privacy and confidentiality laws.
5. Communication tools: These enable health practitioners and various hospital sections such as laboratories and pharmacies to coordinate their activities in a unified approach to patient treatment [12].

This results in an EMRs being a collection of a variety of heterogeneous sources of data about patients and related health and medical activities performed on or associated with patients [4]. Therefore, the challenge presented by the EHR is that it is divided based on various components and by data source, compared to its paper counterpart, which is archived by patient, containing all the data about the data

[15]. In some cases, EHRs are sometimes designed in such a way that they are customized to specific healthcare facilities.

Alberty et al., lamenting this challenge write: “while the digital infrastructure for a health care organization often has some recognizable architectural components—EHRs, admission-discharge-transfer systems, picture archiving and communications systems, and others—an industry has yet to fully form around common architecture concepts, let alone define how such blocks may fit together. This lack of cohesion often makes the digital infrastructure of health systems differ in crucial ways from others. Often, even neighboring departments within a single health system have incompatibly different digital infrastructures” [23]. 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.

Furthermore, the health record itself is a complicated phenomenon in the sense that it comprises different components resulting from different specialists. For example, a health record comprises of a patient’s dental, ophthalmological reports, radiology information, pharmacy records, laboratory results, and images, as well as financial transactions of a patient. All these carry different retention and disposal schedules depending on their values to medical research as well as legislative requirements, whilst they collectively represent a health record. In an EHR environment, the challenge arises as to which component of the record should be disposed of either by transfer to the archives or by destruction. For example, does the EHR system allow a dental image to be removed from the system independently by transfer to the archive? How does that impact the composition and completeness of the EHR? This further creates complications for the preservation of the EHR system.

B. Unpredictable Life Cycle of Health Records

Whilst many public healthcare facilities and systems are still grappling with the implementation of institutional and cross-institutional EHRs, limited attention is being given to the implication of such digitization of health data and its storage over extended periods of time as per relevant regulations or life-long EHRs [17]. 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 [6]. 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 [6].

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 should only selected components of the EHR 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 [16]. 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...)” [16].

However, they immediately lamented: “Will the record be still accessible? Will it be complete?” [16]. 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 [6]. 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.

C. Technical Challenges of Digital Preservation

For decades, actually, from the time electronic records were born, archivists and technologists have been grappling with long-term preservation challenges. The greatest challenge with the long-term preservation of electronic materials such as EHRs is that access to electronic objects is only possible through the use of computer software [16]. To date, the search for a permanent solution to the challenge of long-term preservation of electronic records continues and remains elusive.

The question is, can archival institutions cope with the EHRs complexities from the perspective of physical custodianship and guarantee 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 [6].

Therefore, “an EHR is a complex unit of information that requires different treatment in the long term, not as a single

unit of information.” [6]. 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 [24]. At that time, the Swedish National Archives had approved paper and microfilm as the most stable and permanent storage mediums for archival preservation [11]. 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 [24].

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. Some of the most recent projects that have been conducted specifically focusing on the archiving of health information under the auspices of the European Union include the one titled “Archiving and Preservation for Research Environments”, which ran from 2019 through to 2022, scooping the EU award for developing several solutions for archiving and preserving scientific data in an accessible format [25]. The project works by combining several ICT technologies and business models in cloud environments, facilitating end-to-end archival and preservation services [25]. Another latest preservation method, although not specifically for the preservation of digital health information and data is Piql. Through its Piql 3- Piql-GO (Ultra-secure data storage- and long-term preservation of digital and analogue data), which ran between 2018 and 2021 [26].

The Piql system operates on a technology that converts “photosensitive film into digital, migration-free storage medium from which data can be guaranteed retrieved in the future, but never hacked, manipulated, or deleted” [26]. This shows the perennial challenge of preserving electronic data in general, and health data in particular. Interesting to note is that the full capacity of all the preservation technologies is yet to be fully tested over time, and the market will continue to be flooded with new technologies that promise to provide stable and permanent solutions to this challenge. In terms of relatively old projects, the Open Archival Information System (OAIS) has been recognized as one of the persistent old archival protocols that even newer preservation tools have used.

Thus, “originally developed as part of a broader effort to develop formal standards for the long-term storage of digital data generated from space missions, the Open Archival Information System (OAIS) has since formed the foundation of numerous architectures, standards, and

protocols, influencing system design, metadata requirements, certification, and other issues central to digital preservation” [27]. The OAIS architecture has been used in various digital preservation projects irrespective of the sector across the economy. The OAIS basically serves as a framework upon which to build preservation standards and infrastructure and may be used in electronic and traditional paper environments, with some arguing that it is not specifically preservation architecture for the preservation of digital content, but rather a set of conditions for the long-term preservation of content, irrespective of format. Figure 1 below summarises the OAIS architecture.

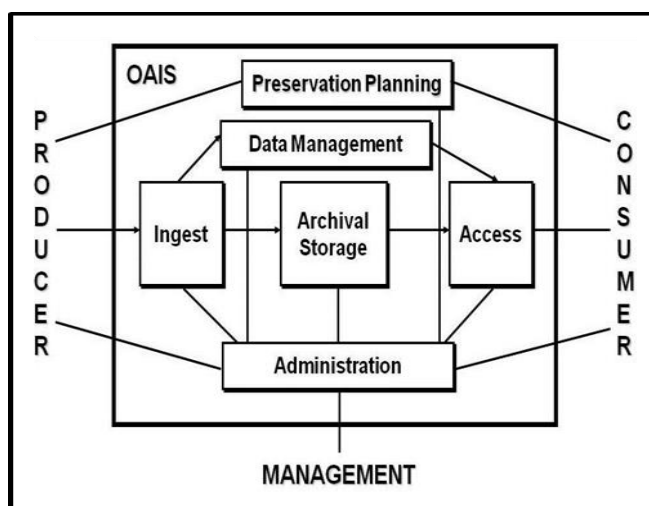


Fig. 1. The OAIS architecture
Source: Digital Preservation Coalition.

OAIS is a product of a Consultative Committee for Space Data Systems in collaboration with various digital preservation experts from other disciplines with the aim of informing the creation of digital preservation repositories [28]. The model, as explained by the Digital Preservation Coalition, has 6 components that comprise the framework, viz:

- i. Ingestion stage: as the first stage, this process serves as the interface between the source of the data, information or object, known as the producers. Basically, data to be ingested includes validation, by ensuring that the data is incorrupt, complete and suitable for archival storage. It also entails the extraction of descriptive metadata in order to support retrieval and discoverability of the data/record in the archival storage.
- ii. Archival storage: this could be considered as the main component of the model that is responsible for the desired long-term preservation and maintenance of the information that has been pushed into OAIS. Depending on the preferred mode of storage, the information can be maintained online, nearline or offline, ensuring that the content

remains accessible over time. To achieve this, various procedures such as refreshment or format migration have to be performed on a regular basis. Although not providing direct access to users, the storage function should be able to provide retrieval functionality for the data that is stored in the OAIS to support user requests.

- iii. Data management: this functionality is responsible for supporting the internal operations of the OAIS by serving as a database of descriptive the metadata and related descriptive tools that are necessary for the discovery of the information.
- iv. Preservation planning: this aspect ensures that the entire OAIS environment is compliant with preservation requirements. It works by monitoring the external environment to detect and respond to any threats to the preservation environment.
- v. Access: this component serves as a link between the OAIS system and the end user, commonly known as the community. Through this functionality, users can query the system for responses and presenting the retrieved information in a manner that is understandable to the user.
- vi. Administration: this final strand operates as a coordinating tool for all the afore-mentioned components of the model. It is responsible for overseeing the overall operation of the entire architecture, for example, by updating archival policies [27].

Although OAIS has been widely used as the basic architecture in digital preservation projects, there are other platforms such as Access to Memory (ATOM), Archivematica and Preservica that archivists have developed as digital preservation platforms. However, the last two, just like Piql, are commercial platforms that are accessible through subscriptions, pushing them beyond the reach of many archival institutions that are already financially struggling. Archivists have also explored alternative preservation methods such as system preservation, migration, refreshing and encapsulation but the ability of these techniques to cope with the challenges of digital preservation has been dwindling over the years. The birth of cloud computing services has been hailed for storage purposes, but the question of maintaining EHRs as complete, accessible and usable remains unanswered.

D. Fast Accumulation of EHRs, Coupled with Evolving Changing Standards for EHRs

Health, healthcare and wellness support generate enormous volumes of data [2]. The generation of such huge amounts of data by healthcare facilities across the globe in the form of EHRs is made possible by the current technological era [29]. Research showed that the health sector was set to become the most data intensive industry in

the world between 2018 and 2025. Figure 2 below shows data for this prediction.

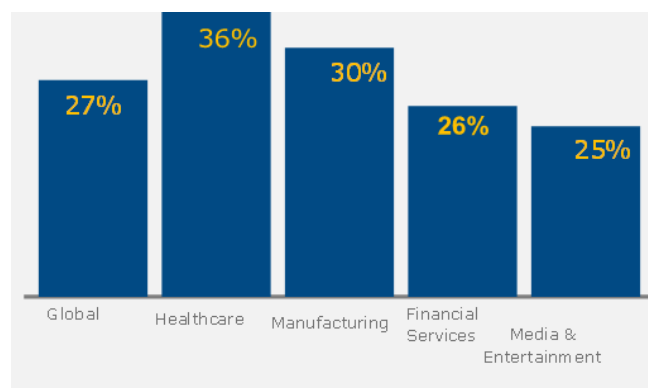


Fig. 2. Projected data growth by industry, 2018-2025
Source: IDC white paper [30]

Thus, the volume of health and clinical data worldwide is growing at an exponential rate [29]. Certainly, EHRs have a share in the projected health data growth depicted in Figure 1 above. But what does this mean from the perspective of archiving EHRs? Just like their traditional counterparts, EHRs storage and preservation for keeping the records available and accessible do not come for free. 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 14641:2018 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 and covert them to new formats for the sake of long term-preservation. Questions of records completeness amid a multiplicity of EHRs components and EHRs vendors arise. Furthermore, the standards themselves change over time, implying that access to documents whose standards vary poses an additional challenge to the preservation of EHRs [16]. As Kiefer laments “as standards like HL7 and DICOM evolve over time, no one can really ensure that electronic medical documents will still be reusable after decades of preservation when formats, standards and applications become obsolete” [17].

Formats such as XML have been touted as the more stable for archival purposes as they are independent of format, thereby potentially addressing the challenge of ever-changing standards and formats of electronic content. Whilst XML appears to have relatively withstood the test of

time in terms of being receptive to changing standards following its invention in the last 1990s, the standard is not a bullet magic to the challenge of preserving electronic records. Thus, “not only software and hardware changes might be out of control, but mainly, it might appear dangerous to be confident in the future for the human management of various databases depending on various bodies” [16].

Archival institutions are not expected to have the capacity of acquiring and preserving EHRs systems that healthcare facilities use across the spectrum and archive them, even with the presence of standards such as XLM that is amenable to changing content standards.

E. Limited Archivists Training in Digital Preservation

Whilst archivists generally take digital preservation courses as part of their studies at college or university, most of them may lack the technical aspects of undertaking digital preservation projects. Preservation, arguably, is a highly technical exercise that goes beyond just knowing the requirements for preservation. As a practice, digital preservation is not the preserve of information technology experts, but several players [31], including archivists. In fact, digital preservation directly speaks to the duty of archivists and archival institutions to maintain records accessible for as long as they possess archival values such as research and historical values. Therefore, ordinarily, archivists are expected to be champions of digital preservation. However, they have instead, been found wanting in terms of digital preservation competencies.

A study by Ahmed that was conducted on the state of digital preservation staffing and skills availability in memory institutions, archives included, revealed stunning results where a whopping 59.9% of the studied institutions reported staffing shortages [32]. A further staggering 60.1% of the staff were found were suffering from a digital preservation skills gap [24]. Although these challenges were more pronounced in Africa and Asia, the developed regions were not spared as they continued to suffer from the same challenges.

In light of the prevailing skills and staffing gaps regarding digital preservation, coupled with the rest of the complexities associated with EHRs, it the distributed custody model can be explored as a possible a workable model of tackling the challenge. The skills shortcomings of staff at memory institutions as attributable to the highly technical side of digital preservation. For example, the Digital Preservation Framework that was developed by the Digital Preservation Coalition has an Information Technology strand which requires IT competencies that most memory workers may not immediately possess. The strand requires that for any one to be competent in digital preservation, they need to be able to:

- i. Develop algorithms and generate related programmes;
- ii. Understand and work with different electronic information systems and formats.
- iii. Design, document and use workflows that are necessary in the management of digital information.
- iv. Map out the requirements for a new system or services for the selection and procurement of a new solution.
- v. Understand the requirements for a storage infrastructure that is robust enough for ensuring the preservation of content at a bitstream level.
- vi. Understand and contribute to the implementation of appropriate security measures and processes [8].

These skills are not easily acquired by archivists, prompting them to heavily rely on IT staff for digital preservation projects. Given these challenges for memory institutions, archival institutions included, the proposed shared responsibility model may benefit from the already available IT pool at healthcare institutions who have been responsible for the implementation and maintenance of the EHRs and already enjoy relatively stable relationships with the vendors for technical support.

F. Constrained Budgets for Archival Institutions to Sustain Long-Term Preservation of EHRs Systems

Archival institutions across the world suffer from chronic underfunding, despite their pivotal role in the preservation of irreplaceable national documentary heritage. In the context of EHRs, to imagine such underfunded institutions ingesting and preserving diverse EHRs records from public healthcare facilities across an economy falls short of being practical. Given that EHRs are meant to be preserved in a live state where they are not just accessible, but are complete and preserve their meaning, an archival institution will need to either develop a format and standard-independent platform such as XML based architecture that will ingest such systems, retaining their functionalities, something that is practically costly for the already underfunded archival institutions.

G. Limited Archival Collaboration between EHRs, Vendors, Hospital IT and Archivists

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” [8]. 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 are 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 EHRs. 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. Figure 3 summarises the challenges associated with the preservation of EHRs from an archival perspective.

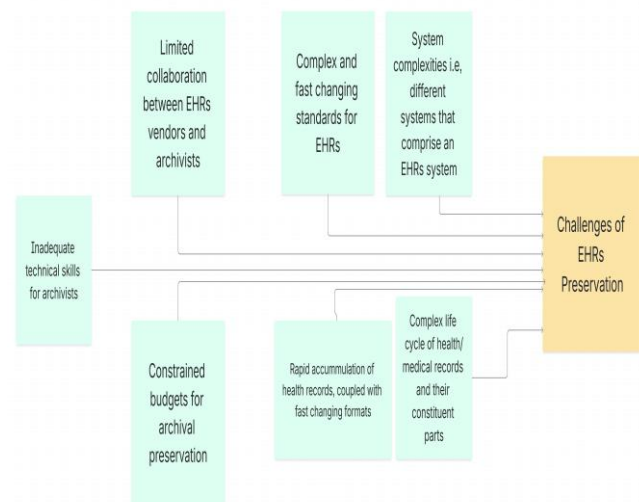


Fig. 3. Challenges of preserving EHRs.

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

A couple of archival scholars including Cunningham, Ngoepe, Hedstrom, Cook among other, have written about the concept of distributed custody in archives, almost agreeing that archivists must rethink their archival models for digital archives. As noted by Bastian [34], 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.

The National Archives of Australia [35] defined distributed custody as “as an arrangement whereby records are managed by another party in facilities not under the control of the Archives beyond the period where they would normally be transferred to the Archives or at the request of a personal donor. It covers situations where records are retained by an agency, as well as those where the records are transferred from the Archives' custody to a custodial organisation. The custodial organisation may be the creating or controlling agency, or other organisations such as a community or private organisation.” This implies that the creating agency is left to retain physical custody of the records, including archival ones, with archivists coming in to advise on best archival practices. To Ham, cited in Bastian [36], 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, and a few archival institutions have implemented the model with clear and practical policies. The National Archives of Australia and the National Archives of Canada are some of the institutions that have led by example by providing and promulgating policies for the distributed custody approach to archiving, although the records provided for are not necessarily EHRs. In South Africa, Ngoepe [36] lamented the dilemma facing digital records where on one hand, such records are due for transfer to the National Archives and Records Services of South Africa (NARSSA) when on the other hand, the institution is ill-equipped to deal with electronic records.

In light of the challenges presented by 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. Actually, it can be argued that most archival institutions are failing to take custody of EHRs, thereby silently promoting distributed custody. Thus, the earlier archival institutions admit and regularize distributed custody as a more pragmatic approach to the management of EHRs, the better.

A. Archivists' Responsibility in the Distributed Custody Model

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. National archival institutions are responsible for all classes of records that are generated by public sector institutions, despite most of them operating on limited budgets, leaving them with limited to no capacity to adequately deal with the challenges of long-term preservation of EHRs. 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. Specifically, archival institutions should be responsible for the following:

- i. Prescribing the types or categories of records in EHRs that should be preserved to meet the archival requirements.
- ii. Prescribing archival standards for long-term preservation of EHRs in a manner which guarantees their accessibility over time. It should be the responsibility of archival institutions and archivists to keep track of latest developments in terms of preservation standards and prescribe them for healthcare facilities.
- iii. Stipulating access conditions for archival records, ensuring that access is granted as per the provisions of the archival laws governing health records. Health and medical records are particularly susceptible to data breaches on top of being sensitive. It is imperative for archival institutions to communicate clear access and restriction conditions that are guided by archival laws for health records, irrespective of

the fact that they will be resident in the systems of healthcare organisations.

B. Responsibility of EHRs Vendors and Healthcare Facilities

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. In the distributed custody model, healthcare facilities, working in collaboration with vendors, will be responsible for the following:

- i. Implementing long-term preservation of EHRs beyond their semi-active stage, ensuring their accessibility. This should include the implementation of digital preservation standards as recommended by the national archives as well as implementing sustainable digital preservation strategies.
- ii. Ensuring the protection of EHRs from potential disasters, including cyberattacks. This includes the creation of backup systems for EHRs.
- iii. Implementing appraisal and disposal schedules for EHRs in liaison with the national archives. This will ensure that healthcare facilities do not keep materials that do not have archival value, or records beyond their required period of retention. Health records are particularly known for their rapid accumulation, and the absence of clear and up-to-date retention schedules will see healthcare facilities incurring unjustified expenses of preserving records that are of no archival value.
- iv. Liaising with national archival institutions on all archival matters, including the provision or restriction of access to archival EHRs. This is particularly important as researchers and other users will be accessing such records at healthcare facilities.

C. Implications of the Distributed Custody Model in the Preservation of EHRs

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 inactive 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, or rather extended responsibilities to archivists, healthcare facilities and the vendors, requiring a high degree of commitment and consensus from the three stakeholders. Healthcare facilities are already enjoying some cordial and sustained relations with vendors in the form of technical and other support mechanisms, further making it easy for collaboration to take place. For archival purposes, archival institutions may consider acquiring selected samples of unique cases that may be needed for research and other purposes that can be scanned or microfilmed for posterity rather than trying to acquire EHRs in their entirety as archives.

V. GOVERNANCE ISSUES

Since this is a proposal for the adoption of the distributed model for the preservation of EHRs, it is imperative to clarify the governance of the model. Governance considerations include a clear structure in terms of decision making, ensuring accountability and putting in place practical implementation techniques for the long-term preservation of EHRs. First, regarding how decisions are made, the model proposes national archival institutions as the key decision makers regarding an array of archival consideration, including the determination of retention and disposal schedules for EHRs, the types of health records to be archived, and methods of destruction. Such decisions should be communicated to healthcare facilities for implementation, with the supervision of national archival institutions. Thus, there must be a clear line of communication between national archival institutions that shall retain the role of overseeing all archival decisions and ensuring compliance by healthcare facilities. Healthcare facilities shall be required to consult national archival

institutions prior to destroying any health records. National Archival institutions should be able to conduct regular checks on the inventory of EHRs at healthcare facilities to account for all the records that are at healthcare facilities. There should be a committee comprised of representatives from the national archives and healthcare facilities that should oversee governance issues for the distributed custody model. Second is accountability. Healthcare facilities should be accountable to the national archives regarding archival actions taken on EHRs in their custody, including preservation.

Perhaps the greatest question is the fate of EHRs in the event of the healthcare facility discontinuing. Whilst this question is not easy to answer, it is prudent for all EHRs to be handed over to the national archives for continued preservation.

VI. LEGAL FRAMEWORK

Currently, most archival laws are crafted based on the physical custody model where archival institutions take full custody of all records that have been accorded with the archival status. Such laws, therefore, cannot function as a distributed custody model where the care of archival records is shared between archival institutions and the creating organisations, in this case, archival EHRs that may be resident in the systems of healthcare facilities. Archivists should review their archival laws and provide for the distributed custody model. Such new laws should clearly state the archival responsibilities of healthcare facilities for EHRs, including consequences for non-compliance. Having clear legal provisions for distributed custody will ensure that there are clear boundaries regarding responsibilities, making accountability easy to enforce and monitor.

VII. FINANCIAL IMPLICATIONS

Traditionally, the preservation of records of national significance has been, and remains primarily a prerogative of national archival institutions. Adopting the distributed custody model for the preservation of EHRs therefore implies the new financial responsibility for healthcare facilities. The models means that healthcare facilities have the responsibility of ensuring long-term preservation and accessibility of EHRs beyond their semi-active stage as archives. Healthcare facilities will be mandated to embed long-term preservation standards in their EHRs systems that should prolong the availability and long-term accessibility of EHRs. Additional financial burden will arise from the need for additional storage space for archival EHRs. For example, cloud space is one of the major expenses that directly arise for healthcare facilities in this model. This will require archival institutions to be proactive in the development of retention and disposal schedules that will ensure that healthcare facilities are not burdened with the responsibility of preserving everything, as is usually the case with traditional paper health records whose disposal is

usually by transfer to the archives, with limited to no destruction at all.

VIII. 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 and strengthen 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 in the context of EHRs. The model should be considered as a collaboration between the three stakeholders, rather than a loss of control of archives by archivists.

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