Eletronic Helth Record for Birth Registration as a step for UNHS Pipeline Research

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Abstract

The aim of this study is to develop an archetype of an Eletronic Health Record for birth registration, using openEHR specifications, as a step of a Universal Newborn Hearing Screening (UNHS) pipeline research. For the modeling process a 3 step process was applied: investigate the data fields that need to be filed during a birth registration; search in the Clinical Knowledgment Manager (CKM) for archetypes that contain those data fields; editing those archetypes, in the Archetype Designer platform, to develop a new one that gathers all the information needed. The process of modulation from existent EHR in the openEHR was possible since the standardization of clinical concepts allowed the re-utilization of a lot of already existent archetypes. Therefore, this process was speed up in comparison to the creation of a new archetype from scratch. During this process some hurdles were faced due to the translation of the concepts when creating or editing archetypes and also due to the lack of national wide accepted terminologies. As this process is eased by the robustness of existent archetypes, the creation of a default birth registration EHR validated by a special commission, would probably be advantageous since the interoperability and semantics standardization would allow effective transmission of information between all the health care agents. Having the archetype been created, then it would be possible to incorporate it into a UNHS pipeline, whose final goal would be the creation of a Business Intelligence interface for the visualization of indicators that allow to evaluate the UNHS at a national level. Although in this study only the 1st stage of this pipeline was carried out, with the development of the archetype, in a future work the goal is to finish this pipeline.

1 Introduction

Hearing loss is estimated to affect 1 to 3 in every 1000 healthy newborns and 20 to 40 in every 1000 risk newborns. Nowadays many risk factors for newborn hearing loss are known, such as cytomegalovirus infection and bacterial meningitis. However, if the risk factors were used as a sole criterion to carry out neonatal hearing screening, it would only be possible to identify 50% of cases of deafness [1]. On the other hand, there is clinical evidence that early intervention positively influences the prognosis of the child's linguistic, cognitive and social development. Therefore, in 1992 the Universal Newborn Hearing Screening (UNHS) was created, which aims to test all the children at birth or, at most, up to 30 days after birth and, in case of confirmed hearing loss, the baby should start early and appropriate intervention, up to 6 months of age [2].

An Electronic Health Record (EHR) is an electronic collection of medical information about a person that is stored on a machine, usually a computer, and it includes clinical documentation, test and imaging results, computerised provider order entries, and decision support information [3]. The quality of the EHR can enhance health care quality [4] and facilitate the research for academic purposes, by contributing to a more evidence based medical practice [5]. Furthermore, there is a consensus about the need of a system that is designed to allow maintainability and interoperability of this records[6–8]. To achieve this, the advantages of standardized clinical concepts and reference models come as a need [6]. This is precisely the goal that the OpenEHR foundation [9] proposed to reach, because, with the openEHR approach, patient data can be structured, stored, managed, and exchanged in a safe and reliable way between different healthcare providers and other interest groups [10].

The UNHS provides an excellent opportunity to demonstrate the potential for quality of care improvement with EHR implementation, because within the context of UNHS, there is a series of information that must be recorded, namely data related to pregnancy, birth and the newborn, the identification of risk factors for deafness and the results of the Apgar score [11, 12]. Therefore, the aim of this study is to develop an archetype of an EHR for birth registration, using openEHR specifications, as a step of a UNHS pipeline research.

This article includes six sections. After the Introduction the 2nd section, Background and Related Work, presents some studies similarly to this one. On Tools and Methods, the 3rd section, the tools and methods used in this study are mentioned and described. On section 4, the modulation of the birth registration archetype is explained as well as its integration on the UNHS Pipeline Research. The discussion is on the 5th section, followed by the conclusion and future work on the last section.

2 Background and Related Work

Antje et al. [13] developed an openEHR based approach to achieve interoperability in Clinical Decision-support Systems (CDSS), by designing and implementing an exemplary system for automated systemic inflammatory response syndrome (SIRS) detection in pediatric intensive care. The designed concept was successfully transferred into a clinically evaluated openEHR based CDSS, by reusing internationally agreed-upon archetypes, incorporating LOINC terminology and creating AQL queries, which allowed retrieving dynamic facts in a standardized and unambiguous form. The technical capabilities of the system were evaluated by testing the prototype on 16 randomly selected patients with 129 days of stay, and comparing the results with the assessment of clinical experts. This lead to a sensitivity of 1.00, a specificity of 0.94 and a Cohen's kappa of 0.92.

Jasmin et al. [14] developed a prototype of a neonatology electronic patient record (EPR) using openEHR archetypes. The EPR was necessary to support the complex communication tasks in the Department of Neonatology at Heidelberg University Hospital. To create the EPR, the data to be documented was analysed and then merged into clinically meaningful concepts. Then, those concepts were mapped to existing archetypes, which were later edited in the Archetype Editor and the ADL Workbench. In addition,to deal with situations where the existing archetypes did not present the necessary concepts, new ones were developed. The last step was creating templates, using the Template Designer, by combining items from different archetypes. The data analysis revealed a total of 1818 items, which were arranged into 70 clinical concepts that were then mapped to 132 openEHR archetypes. 58 of these archetypes were reused and 67 were newly developed. To combine and constrain archetypes for local settings, 16 templates were developed and used, not only within the hospital, but also for trans-institutional data exchange.

Joao et al. [15] created OpenEHR templates for a pregnant woman hospitalization admission in the Obstetrics department at Hospital de Sao João, Porto, to be used by an experimental version of the OpenObsCare health information system, that is currently being used in this department. That was achieved through the modulation of existing EHRs defined in the OpenObsCare platform. Firstly, the data fields that already existed in the OpenObscare were selected. Then, it was made a search both in Clinical Knowledge Manager (CKM) and National E-Health Transition Authority (NEHTA), for archetypes that contain the data fields previously selected. Whenever a data field did not appear on an existing archetype, a new one was created both in CKM and in NEHTA. In this study, 1 archetype (openEHR-EHRCLUSTER.exam-vagina.v1) and 6 templates (Admission Note; Ultrasounds; Current Pregnancy; Obstetric history; Family history; Personal history) were developed in the Ocean Archetype Editor and the Ocean Template Designer, respectively.

3 Tools and Methods

3.1 OpenEHR

OpenEHR is an open standard [16] maintained by the openEHR Foundation, which aims to convert health data from a physical form into an electronic form and ensures universal interoperability among electronic data in all forms [17].

It also facilitates the interoperation of EHR systems, because a complete EHR dataset can be fully represented using shareable archetypes.

The openEHR approach has 4 major pillars: the Reference Model (RM), the Archetype Model (AM), the terminology and the Foundation Types (FT). The RM is a stable and formal information model that focuses on the logical structures of an EHR and defines the basic structures and attributes needed to express EHR data instances, including data types, data structures, and components of an EHR [18].

The AM consists of archetypes and templates. Archetypes are the formal and semantic artifacts that facilitate collecting, storing, retrieving, representing, communicating and analyzing clinical data, which can be modeled by clinical professionals and health informatics experts by constraining RM. Archetypes play an important role in the openEHR approach, which not only supports representing the semantics but also facilitates maintainability [19], scalability and interoperability [20], and input from the clinical practitioners [21]. There are many types of archetypes, one of them being the evaluation, that represents opinions and assessments on the patient, such as diagnosis, risk assessment, goals and recommendations. Regarding to the openEHR templates, these assemble and constraint archetypes for context-specific purpose, which is closest to users and typically used to generate application programming interfaces(APIs), XML schema definitions (XSDs), user interface forms and storage schemes. Since openEHR is a terminology-neutral approach, then, it allows referring to external terminologies in archetypes, such as SNOMED CT [18].

At last, the FT are generic low level types assumed by and used throughout the openEHR components and specifications. The FT includes all the data types that can be used in the archetypes and templates [22]. Examples of data types are text (free text), coded text (coded textual representation of terms, such as strings, numbers, symbols or others), quantity (measurable physical quantities such as mass and length), duration (duration of an event or (in)activity, as days, hours, minutes, and seconds), boolean (true or false), datetime and count (countable quantities, for example, number of cigarettes smoked in a day). In this study the openEHR standard was followed, which included the use of the RM, the AM, a terminology and also the FT to build the final archetype [23].

3.2 SNOMED-CT

SNOMED CT is a multilingual clinical healthcare terminology, with scientifically validated clinical content released monthly, which enables consistent representation of clinical content in EHRs. It provides a standardized way to represent clinical phrases captured by the clinician and enables automatic interpretation of these. Furthermore, the SNOMED CT enables support systems to check the record and provide real-time advice. To achieve all of this, the SNOMED CT logical model defines the way in which each type of SNOMED CT component and derivative is related and represented. The core component types in SNOMED CT are concepts, descriptions and relationships. The logical model specifies how this components can be managed in an implementation setting to meet a variety of primary and secondary uses [24].

3.3 Clinical Knowledgment Manager

The main work of the openEHR International community is performed by 4 'programs' which respectively focus on specifications, clinical modelling, software, and education. At the clinical modelling level, there is the Clinical Modelling Program, which is performed by clinical professionals and health informatics experts working in the Clinical Knowledge Manager (CKM) environment [17]. The CKM is a system for collaborative development, management and publishing of a wide range of clinical knowledge resources, such as archetypes, templates and termsets [25]. In this article, archetypes that already existed in the CKM were used to build the final archetype.

3.4 Archetype Designer

As part of an effort to expand the global openEHR community, Better and openEHR International have launched Archetype Designer, a free web-based clinical modelling environment for openEHR archetype development. It allows visual authoring of archetypes and templates, including full archetype parsing, validation, flattening, and serialisation. With the Archetype Designer, users have access to multiple repositories from which they can input and obtain templates and archetype models with multiple export options [26]. In this study, the Archetype Designer framework was used to search, modify and use archetypes to build a final archetype about birth registration.

4 Results

4.1 Modulation of the birth registration archetype

In order to develop an EHR archetype for birth registration (Figure 1), it was necessary to find out what information do doctors or nurses fill in when a baby is born. For that, the Personal Child Health Record (PCHR), also known as the red book, was used, because this is the document used in most countries to register those information [27]. Knowing the information that the archetype must present, it was then possible to search for archetypes, that exist in the Archetype Designer repositories, and that would be useful for the construction of the archetype related to birth registration. These archetypes were selected from the ckm-mirror repository, which is a mirror of the CKM, containing all the templates and archetypes that exist in it. After this research was carried out, the selected archetypes were:

- openEHR-EHR-OBSERVATION.height.v2, which records the length of the body from crown of head to sole of foot of an individual and it can be used

at any event or in the birth (point in time), allowing to register the first weight, measured soon after birth. [28];
- openEHR-EHR-OBSERVATION.head_circumference.v1, which records the measurement of the longest distance around the head and can it be used at any event or in birth [29];
- openEHR-EHR-EVALUATION.pregnancy_summary.v0, used to support the recording of an overview of an identified pregnancy and outcome, including the antenatal period, labor, birth and the immediate postnatal period [30].

Among these archetypes, the one with the greatest number of fields similar to those in the red book was the pregnancy summary archetype. Thus, this was used as the basis for the construction of the final archetype, having been made all the changes, additions and removals in this archetype. Among the information present in this archetype, those that were not in the red book were eliminated. Thus, the clusters 'EDB Based on Cycle', 'EDB Based on Ultrasound', 'Agreed EDB', 'Model of Care' were eliminated, as well as the fields related to the conception and contraceptive methods and to the duration of the 3 labor stages. The fields related to the Apgar scores were also eliminated, not because they are not present in the red book, but due to the fact that in the UNHS pipeline, which will be explained in the next section, there is an archetype developed that is exclusively related to the Apgar Score. The remaining fields had to be changed, as most were free text and in the details section, the creators of the archetype suggested changing those fields to coded text according to a certain terminology. In addition, the fields that were already in coded text also had to be changed, as they were coded with different internal terminologies and the objective was to standardize all the coded text fields using a single terminology. In this case, the terminology chosen was the SNOMED-CT [24].

In order to group the different fields into categories, 3 clusters were created, 1 for pregnancy, another for birth and another for the newborn. The 3 clusters can occur 0 or more times, thus giving the opportunity to be filled or not. The fields present in the clusters can occur 0 or 1 time, because if they are filled in, that will only happen once, at birth. In the pregnancy cluster there are 5 fields. The 1st is related to the duration of the pregnancy, presenting a data type of duration and weeks as the units. The 2nd is a boolean that must be filled in as true if the prenatal surveillance scheme was completed. The 3rd field has the count type and is used to record the number of appointments that the mother went, during her pregnancy. The last 2 fields are coded text, being the first related to the risk of pregnancy and coded using the SNOMED-CT terminology and the 2nd, which was added to the archetype, was related to the mother's blood group.

In the 2nd cluster, childbirth, there are 9 fields, all related to the baby delivery. The first 4 fields are coded text, 3 of them (place of birth category, mode of birth and induction method) coded with the SNOMED-CT terminology and the 4th, concerning the onset of labor, presents the original coding of the archetype, as there is no coding in the SNOMED-CT terminology related to this topic. The 5th field is related to the total duration of labor, with days, hours and minutes as the available units. The next field is a boolean for epidural usage. Then there are 2 count fields that record the number of livebirths and the number of dead fetuses at birth, respectively. Finally, there is a free text field, to enter birth concerning observations.

The 3rd and last cluster, newborn, has 12 fields, the 1st being of the date-time type and it allows the registration of the date/time of birth. There are also 3 fields of the quantity type and they allow the recording of weight, height and head circumference. As this archetype did not contain fields for filling in height and head circumference, 2 extra fields were created for this purpose. The fact that 2 fields were added, instead of directly adding the archetypes OBSERVATION.height.v2. and OBSERVATION.head_circumference.v1 to the archetype EVALUATION.pregnancy_summary.v0, was because height and head circumference are normally measured and recorded after the baby is weighed. Therefore, it is more practical for these fields to be consecutive with the remaining fields related to the newborn. In this cluster there are also 5 fields of the coded text type, 4 of which have the original coding of the archetype (sex, breastfeeding, baby outcome and skin-to-skin contact and breastfeeding). The 5th field was the baby's blood group and it was added to the archetype. Finally, there is a boolean field concerning the need to resuscitate the baby, another of the count type that indicates, in case of twin birth, what was a the sequential order in which the baby was born, and a free text field with observations about the newborn. Regarding the RM and the archetype protocol, these were not changed.

At last, in the archetype developed, it was specified that its number of occurrences can only be one, since this archetype can only be filled once, after the birth. Besides, the archetype was developed in English and then translated to Portuguese and Spanish, so that users are able to fill it in any of those 3 languages.

4.2 Archetype integration on the UNHS Pipeline Research

Although this study only focuses in the development of an archetype for birth registration, the goal is to, at a later stage, include this archetype as a step in a UNHS pipeline research. For this, it will be firstly necessary to join the developed archetype to a main template that contains archetypes with all the other information filled in the scope of the UNHS, namely the identification of risk factors for deafness and the Apgar scores. After that, all the openEHR modeling is done and therefore, the 1st step of the UNHS pipeline research, which is represented in Figure 2, is completed.

The next step is to extract different fields from the template, that were filled with real data from patients, and save them in a JSON file, that can later be stored in a NoSQL database. In addition to this data, data from a private dataset that is stored in a relational database will also be used. This

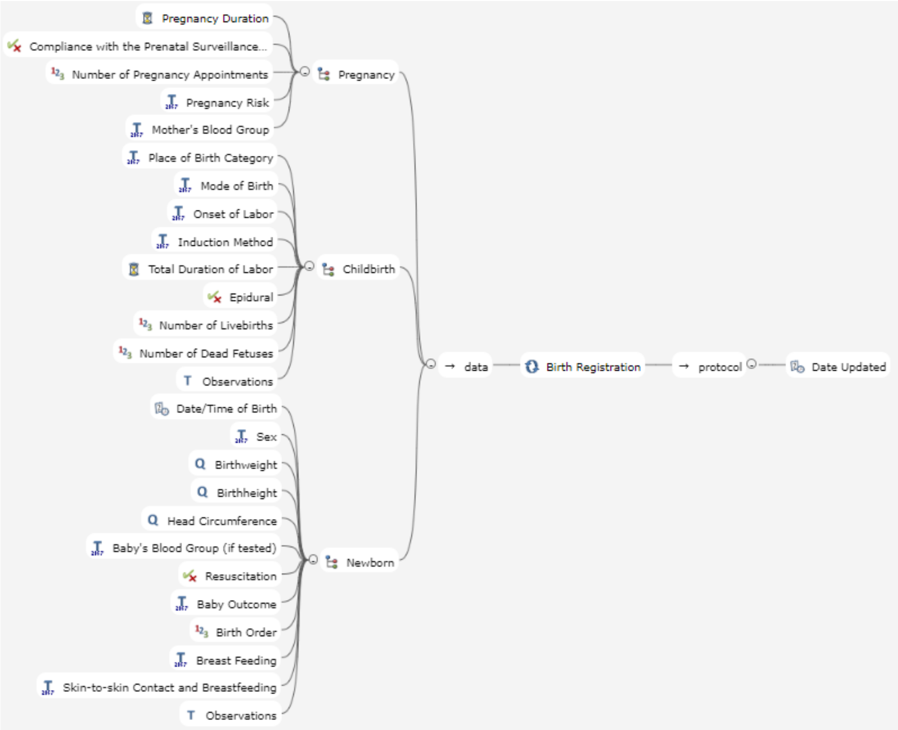

Fig. 1 Mindmap view of the birth registration archetype.

dataset contains several attributes, each corresponding to one of the different fields present in the final UNHS template.

With the data stored in the NoSQL database and in the relational database, it is possible to go to step 5, which is the Data Warehouse (DW) modeling. This includes the creation of fact and dimension tables and the choice of an appropriate architecture. In this step it is also included the mapping between the data from the databases and the correspondent path of the field in the final template.

In the next steps, the Extract-Transform-Load (ETL) process will be executed, whose objective is to extract and adjust the data, so that separate sources can be used together and finally deliver the data in a presentation-ready format [31]. This process is described between steps 6 and 8 in Figure 2. Starting with the 6th step, the data from the NoSQL database and from the relational database is extracted. Once the extraction is completed, it is necessary to proceed to the data transformation, cleaning and conformation, which includes, for example, the treatment of null values. Once the data is all prepared, then it is possible to populate the DW, by loading the data from the databases.

Finally, from the data present in the DW it is possible to extract information and develop UNHS indicators, that can be used in a Business Intelligence interface to evaluate the UNHS at a national level.

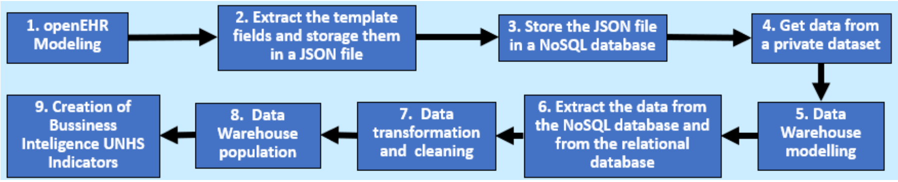

Fig. 2 UNHS pipeline research.

5 Discussion

The process of creating an archetype for birth registration was possible mostly using archetypes already defined in OpenEHR and CKM. This is an advantage compared to the process of creating new ones from scratch, since those already available to be shared were validated by a group of specialists and so its robustness is inevitable [15]. In this study, 1 archetype was developed, being mainly derived from a pre-existent evaluation archetype (EVALUATION.pregnancy_summary.v0). This was necessary since there was not an already available archetype or template to represent all the data that needs to be registered after a birth. To modify that archetype, it was use as reference the information present in the baby's red book, because it contains the information filled during a birth registration. Furthermore, all the recommendations of the OpenEHR Information Model document were followed and it to edit the archetype it was used the Archetype Designer Editor, a tool to support archetype authoring [7, 25]. The archetype developed can be used for health professionals to fill the data whenever a baby is born, however it still lacks the analysis of obstetrics and pediatrics specialists for being submitted to validation in openEHR CKM repository [15].

Although the use of OpenEHR specifications in the development of archetypes and templates presents numerous advantages, it also has some drawbacks, such as the translation of the concepts when creating or editing archetypes. Other common problem noticed was the use difference of terminologies in the same archetype, which indicates the need for a national or international level standardization in terminologies [32, 33]. Furthermore, in the pregnancy summary archetype, many of the fields were in free text and, therefore, it was necessary to code them, which made the process of developing the archetype much more laborious and time consuming.

As the modulation of an existent EHR was possible and bearing in mind the advantages of using openEHR to achieve national interoperability, it is possible to see the enormous advantages of creating a national level commission to create a birth registration archetype, such as a common language spoken by all Health Informatic Systems and a consensus on what is essential for an birth registration EHR [32].

On the other hand, the archetype created gathered a lot of important information recorded after the baby is born and that is important for the rest of his life, because, the way the labor proceeded and the first measures are important indicators about the patient's health and the existence (or not) of pathologies. In this way, these information should be present in all Health Care Units (HCU), so that, whatever the HCU to which the patient goes to, a more informed service can be provided, and therefore more effective. So, the use of this archetype as a EHR is a starting point that could be able to bring effectiveness to the exchange of information between HCU, facilitating the decision making of the professionals involved, reducing costs and improving the perceived quality by the patient [34].

Finally, the incorporation of the archetype developed in a more comprehensive pipeline related to UNHS, would allow extending the benefits of the archetype to the development of a template that could be used at a national level and, in turn, facilitate the creation of UNHS indicators, because all HCUs would collect the same data filled in from the same template.

6 Conclusion and Future Work

In the current article the modulation of a birth registration archetype according to the OpenEHR specifications was performed. The process was easier than the classic one, by which medical specialists transmit the requirements of the system and then these data models are created from scratch, because in this case, it was possible to reuse existent validated archetypes. Both OpenEHR and CKM contain good solid archetypes reviewed by a community of medical specialists in an iterative process, that aims to achieve an EHR standardization that allows interoperability between different systems.

In this study, it was only need to edit 1 archetype, which was completed with fields based on the information that has to be present in the baby's red book. For the archetype development it was also used the multilingual clinical healthcare terminology SINOMED-CT, in an effort to build a nationwide standard archetype, that allows the transition to an interoperable and semantics standardized EHR. However there are still more steps ahead and the process of application and maintainability of this type of EHR must be ascertained.

As a future work, it is suggested the incorporation of the developed archetype into a UNHS template, which could be used in all HCUs at a national level and, in this way, facilitate the collection of data for the development of a Business Intelligence interface with UNHS evaluation indicators.

Conflict of interest

The author declares that there are no conflicts of interests associated with this work.

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