Developing a National-Level Concept Dictionary for EHR Implementations in Kenya

Aggrey Keny[a], Steven Wanyee[b], Daniel Kwaro[c], Edwin Mulwa[d], Martin C. Were[a,e]

[a] *Academic Model Proving Access to Healthcare(AMPATH), Eldoret, Kenya*
[b] *International Training and Education Centre (ITECH)-Kenya, Nairobi, Kenya*
[c] *The Kenya Medical Research Institute / Centers for Disease Control (KEMRI-CDC), Nairobi, Kenya*
[d] *KEMRI-UCSF Family AIDS Care and Education Services (FACES), Kisumu, Kenya*
[e] *Indiana University School of Medicine and Regenstrief Institute, Inc., Indianapolis, IN, US*

Abstract

The increasing adoption of Electronic Health Records (EHR) by developing countries comes with the need to develop common terminology standards to assure semantic interoperability. In Kenya, where the Ministry of Health has rolled out an EHR at 646 sites, several challenges have emerged including variable dictionaries across implementations, inability to easily share data across systems, lack of expertise in dictionary management, lack of central coordination and custody of a terminology service, inadequately defined policies and processes, insufficient infrastructure, among others.

A Concept Working Group was constituted to address these challenges. The country settled on a common Kenya data dictionary, initially derived as a subset of the Columbia International eHealth Laboratory (CIEL) / Millennium Villages Project (MVP) dictionary. The initial dictionary scope largely focuses on clinical needs. Processes and policies around dictionary management are being guided by the framework developed by Bakhshi-Raiez et al. Technical and infrastructure-based approaches are also underway to streamline workflow for dictionary management and distribution across implementations. Kenya's approach on comprehensive common dictionary can serve as a model for other countries in similar settings.

Keywords:

Terminology; Electronic Health Records; Concept dictionary; Developing Countries.

Introduction

Developing countries are increasingly adopting information technology applications through the implementation of electronic health records (EHRs) for clinical and managerial activities [1]. This has enabled geographic expansion of access to healthcare, improved data management and reporting, and communication between healthcare providers and their clients [2].

At the heart of each EHR is a concept dictionary, which forms the basis for database organization and semantic interoperability [3]. Concept dictionaries allow the creation of accurate and consistent patient records that can be shared within and across organizations [4]. The use of common terms and concepts in patient records has been shown to enhance the quality of healthcare delivery as numerous decision support systems rely on these terminologies [5].

By their very nature, concept dictionaries are living entities, evolving over time to meet needs within the care organization. Ensuring that dictionaries evolve gracefully usually requires

resources and relevant expertise. For a single institution, there are well-defined approaches to assure graceful dictionary management can be achieved [6]. The task however becomes exponentially more complicated when terminologies across multiple institutions have to be semantically interoperable. Dixon et al. succinctly put the problem in context describing the translation of local terminology into available standards as being a complex, costly and resource intensive process [7].

The Unified Medical Language System (UMLS) has allowed the integration of different terminologies without restricting content, structure, or semantics of the original terminologies. This has enabled the creation of mappings among equivalent entities used in different contexts and purposes. This allows semantic interoperability between different terminolgy systems while each evolves to serve its primary purpose [8].

As developing countries start to implement EHRs at scale, they are rapidly running into the issue of assuring semantic interoperability between individual implementations. Unfortunately, clearly defined approaches do not exist to inform how to develop dictionaries to serve multiple implementations within limited resource settings. In most instances, data sharing and system interoperability is only achieved through piecemeal concept mappings. The mappings are often either done between a few local implementations or between a single local implementation's dictionary to multiple standard terminologies [9]. This process is resource intensive and there is often no guarantee that the mappings are accurate [10].

Developing countries with limited resources and few skilled personnel need guidance on approaches that will alleviate the complexity, cost and resource-intensive nature of supporting semantically interoperable dictionaries. In this paper, we describe an approach, taken by Kenya, to come up with a national level concept dictionary to serve multiple EHR implementations across the country. We touch on process, infrastructure, capacity, and foundational issues in creating a national-level concept dictionary that can serve cross cutting needs of clinical care, research, monitoring and evaluation, and reporting. Based on our experience, we outline key principles and approaches that can be used by countries in similar resource-limited settings to comprehensively develop and evolve semantically interoperable dictionaries.

Methods

Setting

Kenya is one of the leading countries in health information technology in Sub-Saharan Africa. Recognizing the important need to manage and use patient data better at the various levels

of care, Kenya's Ministry of Health (MOH) Division of Health Information System developed a Health Information Policy and Strategic plan (2009-2014) [11], and Standards and Guidelines for EHR for the country [12]. After the standardization process was completed, the MOH selected two systems for initial national roll out, namely IQ-Care and KenyaEMR, an adaptation of the open source OpenMRS EHR (http://kenyaemr.org). The MOH also decided that the initial disease foci to be served by these EHR would be HIV, Tuberculosis, and Maternal and Child Health (MCH), with an option to expand to other domains moving forward. Two implementation partners, I-TECH (http://www.go2itech.org/) and Futures Group (http://www.futuresgroup.com/) were selected to implement the selected EHR, and by September 2014, 646 implementations of both systems had been realized at MOH facilities throughout the country.

The national roll out of the two systems occurred in a field that was already increasingly dotted with other EHR implementations. As an example, the Academic Model Providing Access to Healthcare (AMPATH) [13], Kenya Medical Research Institute (KEMRI), and Family AIDS Care and Education Service (FACES), which all offer care services within MOH facilities, already had EHRs with their own local dictionaries.

Challenges

Several challenges related to dictionary management and semantic interoperability quickly became evident in the milieu of multiple EHR implementations. Key challenges included:

- *Inability to share data across EHR:* This example emerged when MOH sites were reorganized to different implementing partners. As an example, it was difficult to easily share data between the Ampath Medical Records System (AMRS) and KenyaEMR systems, despite both being based on the OpenMRS platform due to the different dictionaries in use.
- *Lack of expertise in dictionary management*: With 600 standalone implementations, it was evident that local sites lacked the skill-set to manage dictionaries or new proposed concepts at the local level.
- *Lack of coordination and ownership:* Even when it became clear that a harmonized approach to semantic interoperability was needed across implementations in the country, there were no clear leaders or owners of the problem.
- *Conflict between care, research and reporting needs:* While the MOH aimed to collect data at one reporting level, clinical priorities dictated a higher level of granularity of concepts, while research needs often dictated a broader range of data to be collected beyond what would normally be needed for care or reporting.
- *Lack of policies or processes:* Comprehensive dictionary management requires laid down policies on how to request new concepts, how to make changes to existing dictionaries, and how to prioritize new concept requests for action. In the country, there were big gaps in the relevant policies to guide coordinated management of concept dictionaries.
- *Technical Infrastructure:* The fact that most previously implemented EHRs worked as standalone systems and were not connected to a central server made it difficult to know what the concept needs were at the local level, and also served as a barrier to automatically transmitting concept requests for action centrally.

- *Lack of automated mapping systems:* Even when requests for new concepts could percolate through, their management tended to be largely manual, with deficient mechanisms to automatically map concepts against standardized terminologies.

Approach

Kenya constituted a Concept Dictionary Working group. This working group was made up of 32 individuals with varied but relevant backgrounds, namely: (a) *Healthcare providers* – physicians, clinical officers and nurses; (b) *Data Managers* – Health Records and Health Information Officers, and Monitoring & Evaluation Specialists; (c) *Health Informaticians* - dictionary managers, health system developers and programmers; and (d) *Health Administrators* – MOH County Health Management teams, National EHR implementation coordinators, and program managers.

The Concept Working Group held an in-person meeting between October 29-31, 2014 in Kisumu, Kenya, to define and implement approaches for comprehensive and coordinated national concept dictionary management. This meeting brought together implementing partners and institutions that participate in various healthcare activities as custodians, care providers, information technology solution providers and researchers. Participants were drawn from MOH, I-TECH, AMPATH, KEMRI, FACES, Médecins Sans Frontières (MSF), Elizabeth Glazer Pediatric Aids Foundation (EGPAF), OpenSource Health Management Information System (OpenHMIS) and LakeHUb Kisumu.

The work of the Concept Working Group is largely consultative, but highly informed by well-established lessons, guidance and frameworks around dictionary management.

Results

We describe outcome of the work by Kenya Concept Dictionary initiative, along each of the dimensions outlined in the challenges above.

Common Data Dictionary Considerations

Other than a couple of large institutions in the country, most facilities did not have the skill-set or capacity to create and maintain their own dictionaries. Further, allowing multiple independent dictionaries was already causing interoperability problems. The team recommended that a common national-level concept dictionary be created.

Multiple approaches existed on how to create this common dictionary. Options included:

1. Developing a new dictionary from scratch without influence from existing dictionaries;
2. Taking all existing dictionaries and combining their terms to create a new common dictionary;
3. Using an existing dictionary as the foundation, mapping other dictionaries to it, and evolving it moving forward.

Eventually, the third approach was chosen. This approach is similar to what the Indiana Network for Patient Care (INPC) used when it was coming up with its common dictionary for the Health Information Exchange in the state of Indiana, USA [14]. INPC based its dictionary on the one used by the Regenstrief Medical Record System [15].

It was decided that the Kenya Common Concept Dictionary would be based on the dictionary maintained by Columbia International eHealth Laboratory and the Millennium Villages Project (CIEL/MVP dictionary). The CIEL/MVP dictionary is

already mapped to standard terminology such as SNOMED CT, LOINC, ICD-10, RxNORM and CVX. It also has provisions for Interface Terminology, allowing for easy use within clinical contexts [15]. Given the extensive nature of the CIEL/MVP dictionary, Kenya would only start with those concepts immediately relevant to its needs – these are identified based on clinical needs, relevant MOH forms within the EHR (e.g. MOH 257 – HIV patient care card), previously defined minimum datasets [17], common clinical observations, tests, drugs, procedural observations among others (Figure 1). From this initial subset, some concepts may appear redundant but these will eventually be mapped when future concepts are added as needed. It was also recognized that the CIEL/MVP would not have some terms that would be specific to Kenya, and as such, the Kenyan dictionary would eventually include a small set of its own local terms, but only when these terms were not relevant for incorporation to the larger CIEL/MVP dictionary, and could not be mapped to any other existing vocabulary standard.
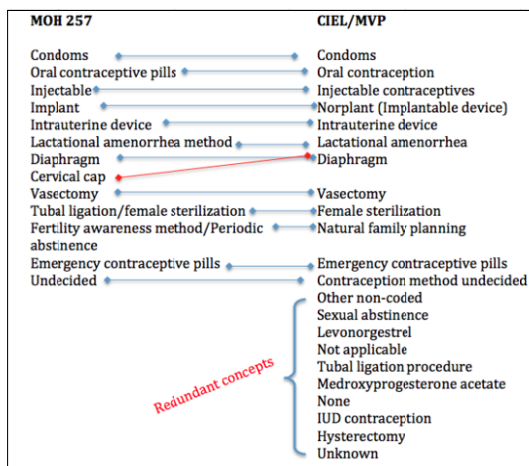

Figure 1: Sample manual mapping of local terms to CIEL/MVP dictionary

Handling conflict between care, research and reporting

A major topic of continued discussion is the scope and granularity level of the Kenya Common Concept Dictionary. There is always tension as to how dictionaries can meet the diverse needs of the various stakeholders, including clinicians, MOH and researchers, among others. Fortunately, Kenya is not the first country faced with this problem. Guidance in this space exist from Chute et al. [18], Cimino's Desiderata [6], and the ISO specifications on terminologies [19]. General recommendations point against creating a single monolithic terminology that attempts to meet all user needs. Instead, terminologies developed should be scoped to serve specific usage categories well [20]. For the case of Kenya, key categories include clinical documentation, administrative, reporting, and research.

Given that EHR being implemented in Kenya are primarily meant to meet clinical needs, a large scope of the Kenya Common Concept Dictionary aims to meet clinical needs. Luckily, key MOH clinical cards (e.g. MOH 257) and registers, which are being replaced by the EHR, already serve the dual purpose of clinical documentation and reporting. We will pay special attention to ensure that we not only have a robust reference terminology, but that it meets interface terminology needs, including appropriate synonyms and multi-lingual functionality. The issues of pre- and post-coordination

will continue to be actively considered as the dictionary evolves to meet various needs.

The team recognizes, however, that over time different dictionaries might have to be developed to best serve the various scopes. As an example, a reporting focused dictionary might have concepts that are derivations of multiple concepts in the clinical-targeted dictionary using pre-defined logic. Where appropriate, these dictionaries would also have simple mappings between one other.

Policies and Processes

A core task for the Concept Working Group is to come up with the policies and processes around all aspects of the Kenya Common Concept Dictionary. This organizational aspect of dictionary maintenance is guided by the framework developed by Bakhshi-Raiez et al. [21]. The framework outlines a primary component called 'Execution' which details the various policy and procedural aspects of maintaining a dictionary. Within this framework, criteria and guidelines are provided for submitting new concept proposals, validating them and verifying changes, documentation and version management. In addition to the above, the concept modeling in Kenya is guided by well-established standards for concept creation, curation and evolution [6, 18, 22, 23].

The other components, which support 'Execution', include 'Process Management', 'Change Specifications' and 'Editing Tools'. Under process management, the Concept Working Group has created a team to coordinate its activities, with the custodian institutions being ITECH-Kenya (a leading national EHR implementation) and AMPATH (a large clinical care setting serving a catchment of 3 million people) [24, 25]. Work in progress includes constituting an appropriate maintenance team with procedures to assure responsiveness to requests and creating policies relevant to the dictionary management procedures.

Resources and Human Capacity

Concept dictionary management is resource intensive. The financial support for the Concept Working Group has been provided by the Centers for Disease Control (Grant # U91HA06801). However, extensive resources are still needed to support the executional aspects of this work. Core disciplines that would form the dictionary maintenance team would include user/domain experts, terminology experts, health informaticians, software engineers, coordinators and client support personnel. This formal team has not yet been constituted, and the approach taken so far involves having personnel coming from multiple implementation partners to fulfill these roles. MOH's support and/or custodianship of this initiative would help to assure continued success.

To improve the human capacity to manage dictionaries within the country, special short-courses around Forms, Concepts and Dictionary Management have been conducted by programs such as the Fogarty-funded Regional East African Center for Health Informatics (*REACH-Informatics*) [26]. Emerging programs like the Masters and PhD programs in Health Informatics at Moi University will also have a dedicated coursework that touch on dictionary management - Clinical Decision Support, Ontologies and Workflow (HIC 824). In addition to formal training, the Concept Working Group is leveraging larger informatics networks, especially the OpenMRS community, the OpenHIE Terminology Services [27], the CIEL group, among others to help with various aspects of dictionary maintenance. Implementation partners within the country are also sharing experiences around dictionary management amongst themselves and with the Concept Working Group.

Technical & Infrastructure Consideration

Several technical and infrastructure issues remain relevant to the Kenya Common Concept Dictionary. The dictionary currently does not have a permanent home, with ITECH serving as its custodian. The eventual plan is for the dictionary to be hosted in the National Data Center which is being set up by the Ministry of Health. Software applications still need to be developed to streamline the workflow around concept request, management, mapping and distribution. Mapping, as an example, has remained largely a manual process, with searching done on the Open Concept Lab / Maternal Concept Lab site [28]. In the roadmap for the national concept dictionary is incorporation of semi-automated mapping tools, similar to those employed in other settings and systems [29, 30].

A key technical lesson the country is quickly learning is that EHR implementations that rely on a concept dictionary should not exist without connectivity to a central server. Connectivity is not only essential for health information exchange, but also provides a mechanism for automatically submitting new concept proposals from implementations. Existing approaches to distributing the most current dictionary usually involve emailing of a snapshot, or deployment via SFTP file transfer. Similar to the OpenHIE model, the goal is to eventually be able to deploy the dictionary via API calls from various EHRs.

Discussion

In this paper, we describe efforts by a developing country to implement comprehensive mechanisms for managing concept dictionaries in support of EHR implementations across its MOH facilities. Kenya is not unique in this need. Almost all other developing countries will have similar challenges as they start implementing EHRs at scale. Ideally, countries should anticipate these challenges and needs, and they should put plans for dictionary management in place before glaring challenges emerge. In fact, this issue should be a key focus of initial implementation planning, with countries well advised to appreciate the amount of work and resources required to get it done well. Constituting the right technical working groups, and having appropriate consultations with groups with relevant experience is very important.

Key considerations as outlined in this paper revolve around identifying initial corpus of concepts and assuring that the scope is appropriate for the country's primary needs. Policies and procedures are needed to enable graceful evolution of the dictionary and high quality responsiveness to implementers. Keys to success are the availability of financial resources to support the infrastructure and the right team, recognizing that diverse competencies will be needed. Ideally, the MOH needs to embrace its responsibility as the custodian of this dictionary, and provide the requisite support. This is not to say that the maintenance team has to sit within the MOH, as this responsibility could also be appropriately outsourced to a group that is highly skilled in this area. Capacity building efforts should however be integral to the country's strategy for dictionary management as the responsibilities can require a highly specialized skillset.

Fortunately for developing countries, there is a wealth of resources and research around the optimal approaches for dictionary management for health information exchange semantic interoperability. An appreciation of the core principles, guidelines and frameworks would serve the technical team well [6, 18-20, 22]. Key lessons can also be learned from approaches taken by various Health Information Exchange efforts in the Western world [14]. In addition to consulting developing country partners, countries should also leverage extensive communities around eHealth systems that are working specifically on vocabularies and ontologies. Further, countries are encouraged to share experiences and lessons. Appropriate forums should be constituted to allow these lessons to be shared for multiple levels of stakeholders.

This field is very complex. In fact, there are multiple debates on the optimal approaches to managing dictionaries [31]. The approaches taken by Kenya and presented above might not necessarily be the most optimal in this evolving field. Our team recognizes its limitations, and is willing to adjust direction as needed. The country is also committed to being adaptive and versatile, to assure that it can take advantage of emerging and new approaches to dictionary management. As an example, the OpenHIE Terminology Service is working on a '*Subscription Service*' that would significantly reduce the burden to developing countries in managing concept dictionaries. Kenya's team is already working with this team, and hopes to use this service as needed in managing the Kenya Common Concept Dictionary.

The eventual hope is for countries like Kenya to truly realize truly comprehensive Health Information Exchange systems. The beginning of an Enterprise Health Architecture is starting to be realized in the country, and a comprehensive terminology service would be central to this architecture. In fact, systems like mHealth that are now often implemented in isolation will soon be expected to embrace the same concept dictionary terms that are being used in MOH supported EHR. Obviously, a lot of work remains to help realize the vision of the Kenya Common Concept Dictionary, but the country should be commended for having taken the bold first step in comprehensively addressing the issues around semantic interoperability.

Some of the limitations of this process include the voluntary nature of contributions and participation by individuals and organizations. Required technical and infrastructural supports are not assured. It is hoped that the government can invest more resources and organizations can dedicate more personnel and time in this process.

Conclusion

A Concept Working Group made of multiple stakeholders is leading the evolution of a national level common concept dictionary for Kenya, with close guidance to use well tested approaches for concept dictionary management. The approach by Kenya can be used as a model for other countries hoping to implement terminology based services to support multiple implementations.

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Address for correspondence

All correspondence to be addressed to:
Dr Aggrey Keny
AMPATH Centre
P. O. Box 4606
Eldoret, 30100
Kenya. Email: agris57@yahoo.com