A CONCEPTUAL DATA MODEL FOR A PRIMARY HEALTHCARE PATIENT-CENTRIC ELECTRONIC MEDICAL RECORD SYSTEM

Paula Kotzé[1,2], Rosemary Foster[1,2]

[1]Council for Scientific and Industrial Research Meraka Institute and [2]School of ICT, Nelson Mandela Metropolitan University
PO Box 395, Pretoria, 0001, South Africa
paula.kotze@meraka.org.za, foster.ehealth@gmail.com

ABSTRACT

The development and use of national guidelines for the exchange of patient-centric healthcare data from electronic medical record systems are essential for the consistent and efficient use and analysis of those data. These guidelines must be based on a core national data model. This paper proposes a basic conceptual data model for primary healthcare patient-centric electronic medical record systems, derived for the South African district health system context, which would provide a suitable set of information to ensure continuity and longitudinality of patient-centric healthcare information. The data model was compiled based on the characteristics of the district – based primary healthcare model, data collected from best practices internationally regarding continuity of care, typical healthcare protocols, a study of public healthcare district hospital information systems and both public and private primary healthcare information systems.

KEY WORDS

Primary healthcare, e-health, patient-centric health information systems, public health informatics.

1. Introduction

According to the declaration of Alma-Ata [1], primary healthcare (PHC) is "essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination … It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process".

The World Health Organization defines e-health as "the use, in the health sector, of digital data — transmitted, stored and retrieved electronically — in support of health care, both at the local site and at a distance" [2:2].

This paper presents a basic data model for patient-centric (or person-centric) primary healthcare electronic medical record (e-health) systems derived for the South African district health system context.

The district health system in South Africa is the vehicle for providing quality PHC to everyone in a defined geographical area. It is a system of healthcare in which individuals, communities and all the healthcare providers of the area participate together in improving their own health. A health district is a clearly delineated area within one of the nine provinces of South Africa in which PHC is delivered to all the people in that area and in which one health authority is responsible for PHC, including community-based services, clinics and district hospitals [3].

2. Background

2.1 Patient-Centric Healthcare

The central attributes of good quality PHC are [4]:

- First point of contact (accessibility).
- Continuity and longitudinality (person-focused preventive and curative care over time).
- Patient-oriented comprehensiveness and coordination (including navigation towards secondary and tertiary care).

The PHC team deals with early signs and symptoms and combines cure, care and prevention, with an emphasis on effective and efficient diagnostic and therapeutic interventions. The team deals with continuous care for all unselected health problems in all patient groups, irrespective of social class, religion, financial position, etc. The PHC team also acts as the hub in the navigation of the patient through the healthcare system, e.g. when the patient is referred to another level of care.

Patient-centric healthcare aims at putting people at the centre of healthcare, so as to make the delivery of services more effective, efficient and equitable [5].

Table 1 summarises the key differences between conventional healthcare and patient-centric healthcare.

Table 1
Conventional healthcare vs. patient-centric primary
healthcare (adapted from [5])

Conventional ambulatory care in clinics or outpatient departments	Patient-centric primary healthcare
Focus on illness and cure	Focus on health needs
Relationship limited to the moment of consultation	Enduring personal relationship
Episodic curative care	Comprehensive, continuous and person-centred care
Responsibility limited to effective and safe advice to the patient at the moment of consultation	Responsibility for the health of all in the community along the life cycle; responsibility for tackling determinants of ill-health
Users are consumers of the care they purchase	People are partners in managing their own health and that of their community

2.2 Data Uses

Data from patient-centric health information systems can serve multiple users and a wide array of purposes [6], for example:

- Individual level data about the patient's profile, healthcare needs and treatment serves as the basis for clinical decision-making and individual clinical care.
- Health facility level data, both from aggregated facility level patient records and from administrative sources, such as drug procurement records, enable healthcare facility managers to determine resource needs, guide purchasing decisions for drugs, equipment and supplies, and develop community outreach.
- Aggregated population level patient data are essential for public health decision-making and generate information not only about those who use the services but also, crucially, about those who do not use them.
- Aggregated data from patient records can be used in public health surveillance with a primary focus on defining problems and providing a timely basis for action. This is especially important when responses need to be urgent, as for epidemic diseases.
- Aggregated data from patient records can provide critical information about health status and burden of disease at all levels – facility and community, district, provincial and national.

2.3 Electronic Medical Records vs. Electronic Health Records

The proposed data model in this paper specifically refers to electronic medical records (EMRs). The difference between EMRs and shared electronic health records

(EHRs) is based on the following health record dimensions [7]:

- The completeness of the information:
  - A partial health record that holds a portion of the relevant health information about a person over their lifetime.
  - A complete health record that holds all relevant health information about a person over their lifetime.
- The possible custodian of the health information.

An electronic medical record (EMR) is an electronic record of episodes of medical care within a single institution e.g. a clinic or a single hospital. It is a partial health record under the custodianship of a healthcare provider / facility that holds a portion of the relevant health information about a person over his/her lifetime [7]. This is often described as a provider-centric or health organisation-centric partial health record of a person [7].

An electronic health record (EHR) is a longitudinal complete health record, under the custodianship of a healthcare provider(s), of patient health information across multiple care settings that holds all relevant health information about a person over the person's lifetime. This is often described as a person-centric health record, which can be used by many approved healthcare providers or healthcare organisations [7; 8]. It includes "(1) longitudinal collection of electronic health information for and about persons, where health information is defined as information pertaining to the health of an individual or healthcare provided to an individual; (2) immediate electronic access to person- and population-level information by authorised, and only authorised, users; (3) provision of knowledge and decision-support that enhance the quality, safety, and efficiency of patient care; and (4) support of efficient processes for healthcare delivery" [9: 1].

This paper focuses primarily on the design of EMRs for PHC, but with the concept of continuity of care and moving towards a shared national EHR system in mind.

2.4 The Need for a Conceptual Data Model

The development and use of national guidelines for the exchange of person-centric health data from EMR systems are essential for the consistent and efficient use and analysis of those data. These guidelines must be based on a core national data model [10].

An example of the use of a core data model is the OpenMRS data model that is based on a concept dictionary which includes diagnoses, tests, procedures and medications [11]. The model was developed by the Regenstrief Institute at University of Indiana as part of the open source project OpenMRS, and aims to cover all potential use cases for an EMR system.

However before generic data models such as this can be localised for implementation in different countries and settings, a conceptual data model that addresses local use cases and requirements must be defined.

The paper proposes a basic conceptual data model for EMRs derived for the South African district health system context that would provide a suitable set of information to ensure continuity and longitudinality when a shared EHR is established.

3. Conceptual Data Model for Primary Healthcare

The proposed conceptual data model was compiled from:

- A study of the characteristics of the district – based PHC model.
- Data collected from best practices internationally regarding data to support continuity of care.
- Typical healthcare protocols and the South African National Indicator Data Set (NIDS).
- A study of public healthcare district hospital information systems.
- A study of both public and private PHC information systems primarily aimed at clinics and community health centres (CHCs).

The data from these studies were integrated into the proposed data model, as discussed in the sections below.

3.1 Characteristics of District-based PHC

The South African district health model has been designed with patient-centred PHC in mind. Quality PHC through the district health system model is envisaged to have at least the following characteristics [3]:

- The service responds to health needs: A clear understanding of the major health problems in a district is required.
- The service views the person as a whole; not in bits and pieces: Services should be person-centric and offered as a 'one stop shop' with a full range of services offered in the district.
- The service is concerned with people's health and well-being; not just disease: Services offered should include the promotion of good health, prevention of disease and trauma, cure of illness, rehabilitation and palliation (when required).
- The service also includes district hospital care over and above care provided in clinics and community health centres (CHCs): District hospital services must be regarded as part of the provision of comprehensive primary health care, because they form the first level of support and referral for primary care. They would provide the level of healthcare which a general practitioner can reasonably be expected to provide.
- The service has clear systems of referral: This referral system must both ensure that sick people are treated by appropriately trained personnel, and that frontline healthcare providers have support and back-up for decision making. The referring healthcare provider needs to be informed of the outcome of the referral and the follow-up care of the patient after 'discharge'.

The conceptual data model presented in this paper is aimed primarily at facility-based EMRs for PHC, and specifically aimed at community clinics and CHCs, which may refer patients to district hospitals.

3.2 Scope of Primary Healthcare Addressed

The scope of primary healthcare, for the purposes of this paper, is seen as the provision of patient-centric preventive, promotive, curative and rehabilitative outpatient care services [12] that include [13]:

- Maternal, women and child healthcare including:
  - Immunisation
  - Maternity services for uncomplicated pregnancies
  - Antenatal care
  - Postnatal care
  - Uncomplicated deliveries.
- Out-patient care for chronic non-communicable diseases, such as diabetes and hypertension.
- Out-patient care for communicable diseases, including HIV/AIDS and TB.
- Out-patient care for violence and injuries.
- Out-patient care for common health problems including:
  - Reproductive health e.g. sexually transmitted diseases
  - Oral health
  - Vision and hearing
  - Mental health and disability.
- Community outreach services e.g. through community health workers.
- Acute care, including pre-hospital care, ambulatory care.

The service points for these services are located in facilities of varying sizes, ranging from mobile clinics and small satellite clinics open only one day a week, to large community health centres (CHCs) that are open 24 hours a day, seven days a week [14]. A community health worker may also be seen as a mobile service point.

As stated above, district hospitals also form part of the PHC system in that they support PHC and are the facilities to which patients are referred from clinics and CHCs. Ideally clinics provide the first point of care for the patient and may refer patients to a CHC or to the district hospital if no CHC exists in the area. CHCs may refer patients to a district hospital when care that is more specialized is required. Down-referrals may also occur, e.g. when a patient with HIV/AIDS is receiving anti-retroviral treatment at a CHC and is stable, he/she may continue to receive treatment and be monitored at a clinic.

Although most of the care at a PHC clinic or CHC is outpatient care, there is some short-stay inpatient care, e.g. when a woman who has a pregnancy without

complications is admitted to a clinic/CHC for the delivery of her baby.

3.3 Continuity of Care

The data model proposed in this paper has been drafted with continuity of care in mind. Continuity of care is an important causal factor of effectiveness, whether supporting healthy childhood development, chronic disease management, maternal health, etc. Continuity of care depends on ensuring continuity of information as a person gets older, moves from one area to another, or when different healthcare providers interact with an individual patient [5]. Access to comprehensive, accumulated, coordinated medical records and discharge summaries improve the selection of the course of treatment and coordination of care, including the tracking of patients, e.g. for adherence to treatment [12].

Continuity of care requires person-specific and event driven capturing of information as care events occur [15]. The term 'person-specific' means that all data in the EMR must be connected to a person/patient. All information in a patient's file/record is tied to a care event that has either occurred in the past, is occurring now or is planned to occur in the future. This is in support of the district health model to support effective delivery of health services to individuals.

The key to recording these events is to accurately, consistently, and unambiguously identify who the patient is, who the provider is, what type of event occurred, where the event occurred, when the event occurred, and the detailed data about the event.

To do this uniformly across all possible sources and care settings requires the use of shared registries for patients, healthcare providers and healthcare facilities [15].

Continuity of care also requires 'clinically-relevant' information [15]. This means, for example, that information regarding all clinical observations, test results, medications prescribed and dispensed, treatment and procedures must be recorded and shared amongst all the healthcare providers seen by the patient.

3.4 Survey of Existing Health Information Systems

In order to determine the typical functions performed by current healthcare information systems used in PHC, a study of existing systems deployed across South Africa was conducted. The study included 27 public health district hospital information systems, 28 clinic and CHC information systems deployed both in public and private healthcare, one national health laboratory system and six health surveillance systems.

3.4.1 Data Collection

Data was collected by means of surveys and site visits during a two-phased approach, as well as discussions with key stakeholders. In the first phase interviews (based on standardised questionnaire) were used to gather information on hospital information systems deployed in the public sector in South Africa. The majority of these institutions also perform a primary healthcare function. Four different groups of stakeholders were interviewed for each system, including chief information officers, system administrators, end-users and system vendors/developers. The surveys were followed up with visits to sites where the systems are deployed to observe the use of the systems in an operational environment. The data collected during this process were captured and categorised using spreadsheets, and analysed to determine the typical and generic functionality supported by these systems.

An initial data model was drafted based on this analysis, which was further refined following discussions with key primary healthcare stakeholders (including policy makers, healthcare managers, clinicians, international funding agencies and e-health practitioners). The resulting data model was used to draft a survey used to assess the functionality of 28 primary healthcare clinic (including out-patient) and CHC information systems, deployed across various sectors in South Africa. The survey included systems deployed at healthcare facilities in the public, private and mining sectors. Over and above the standard range of primary healthcare functions, the majority of these facilities also dispensed medicines, albeit a restricted range in some cases. These surveys were completed by a technical expert with in-depth knowledge of the system. The survey was followed up with a demonstration by the vendor/developer of the system and visit to a site where the system was actively being used.

The data collected through the entire process were then consolidated and analysed to determine the generic data model.

3.4.2 Findings

The study revealed the following typical groupings of functions for PHC information systems:

- Identification, authentication, authorisation and patient and healthcare provider registration.
- Identification and registration of facility and service points.
- Patient record management, including the management of duplicate records and temporary records, management of paper folders, and uploading of information received from external systems.
- Appointments and scheduling.
- Recording information on a clinic/CHC visit, including information on which patient was seen by which provider at which service point within a particular facility.
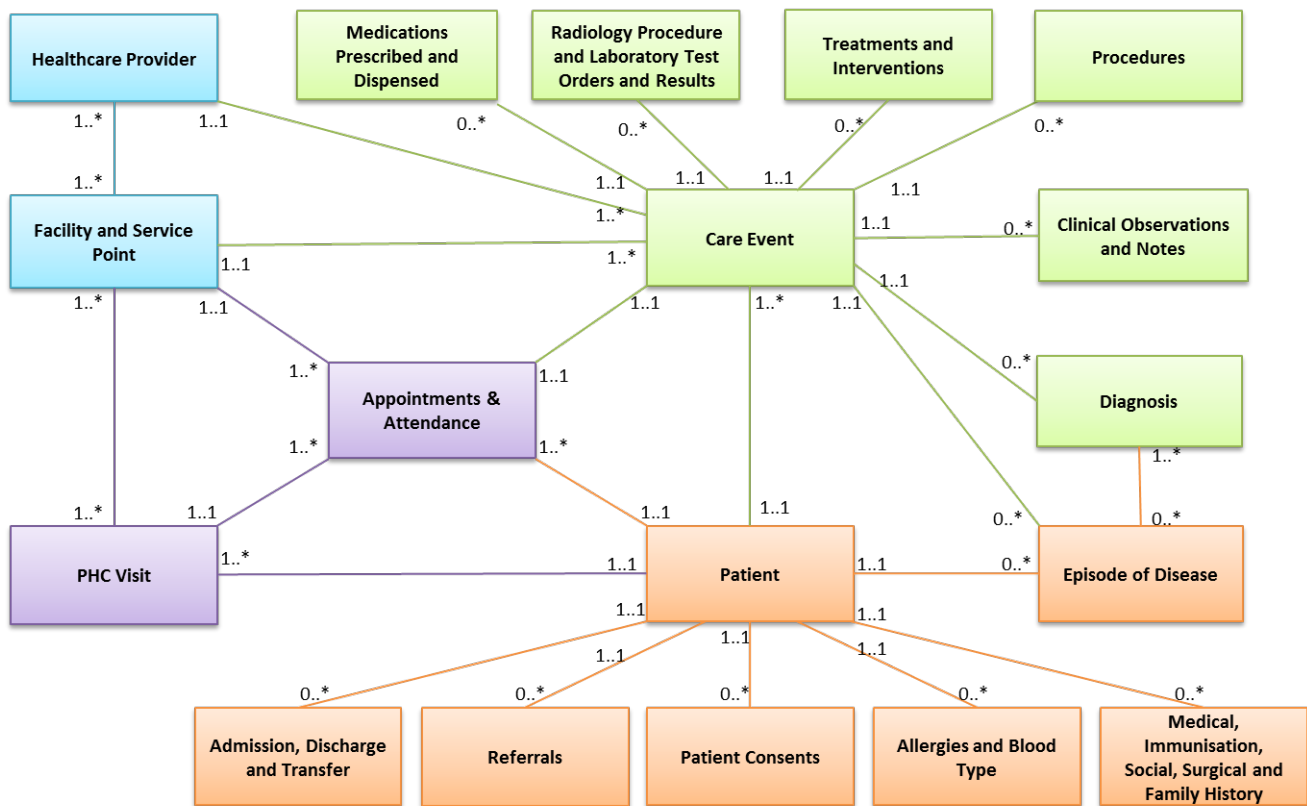
Figure 1. Entities in the core data model for primary healthcare

- Care event, including observations and diagnoses, interventions, procedures and treatments, recording of patient consents, allergies, blood type, referrals, medication prescribed and dispensed, ordering and recording the results of laboratory tests and radiology procedures, etc.
- Admission, discharge and transfer.
- Routine data, reports and communication, including data for notifiable diseases, data for the NIDS, and ad hoc reporting.

3.5 The Conceptual Data Model

Combining the information gathered from all the various resources, the proposed conceptual model was composed. Figure 1 illustrates the relationship between the various entities in the proposed conceptual data model for PHC.

As stated above, a care event forms the core of a PHC EMR system. A *care event* takes place when, at a given time, a patient is seen by a *healthcare provider* e.g. a doctor, nurse, community health worker or therapist, at a *facility service point*.

The *care event* may include one or more of the following services or procedures, depending on the service point:

- A physical examination to allow the provider to make *clinical observations and notes* about the patient.
- A consultation e.g. when the provider asks the patient about their *medical, immunisation, surgical, social* or *family history, any known allergies* and *blood type (*if known*)*.
- Medical or surgical *treatment or intervention* e.g. debridement and suturing of a wound, physiotherapy.
- A *procedure* e.g. implanting a contraceptive device subcutaneously, immunisation, etc.
- *Prescribing and dispensing of medicine*.
- Taking blood or sputum samples for *laboratory testing*.
- Sending the patient for a *radiology procedure*.
- *Referring* a patient to another healthcare provider or facility.
- Any of these activities or procedures may require *patient consents*.
- An outreach activity e.g. checking up on a pregnant woman at her home.

During a care event, the healthcare provider may *diagnose* the patient with a specific condition. An *episode of disease* is linked to a *diagnosis*, especially in the case of a chronic disease. A patient may experience many care events between the start and end of an episode. For example, an episode of bronchitis may end after two care

events, an episode of TB may end after six months of successful treatment, while an episode of HIV/AIDS has no end date.

A PHC *visit* by a patient to a *facility* may include more than one *care event*, e.g. a patient may come to a clinic for on-going treatment for HIV/AIDS, but may also be pregnant and require antenatal care. *Appointments* are scheduled for each *care event* and involve linking a *patient* to a *healthcare provider* at a particular *facility service point*.

Although most of the care at a PHC clinic or CHC is out-patient care, there can be some short-stay in-patient care, e.g. when a woman who has a pregnancy without complications is admitted to a clinic/CHC for the delivery of her baby. In such a case the patient will be *admitted*, *discharged*, and when continued care is needed and such care cannot be provided by the PHC facility, the patient will be *transferred* to another facility.

3.6 Way Forward

To implement and use the data model, the next step will be to define the exact data elements that would be required as attributes to each of the entities in the data model. These data elements would as a minimum be dictated by the information to be stored in the envisaged national/provincial shared electronic health records.

4. Conclusion

The development and use of national guidelines for the exchange of patient-centric healthcare data from electronic medical record systems are essential for the consistent and efficient use and analysis of those data. However, before any generic data models such as OpenMRS, can used or localised for implementation in different countries and settings, a core conceptual data model that addresses local use cases and requirements must be defined.

This paper proposed a basic conceptual data model for primary healthcare patient-centric electronic medical record systems, derived for the South African district health system context. The data model should provide a suitable set of information to ensure continuity and longitudinality of patient-centric healthcare information and can be used as basis for the design of EMRs for PHC, but also as the basis for continuity of care within a shared national EHR system. The data model, and pre-defined data elements associated with the data model entities, can also be used in a procurement exercise to determine whether a particular system will meet the minimum criteria as far as data requirements is concerned.

References

[1] The International Conference on Primary Health Care, Declartion of Alma-Ata (Alma-Ata, USSR, 1978).

[2] WHO, eHealth for health-care Delivery (eHCD): Strategy 2004 - 2007 (pp. 44) (Geneva: World Health Organisation, 2004).

[3] D. Harrison, *A Pocket Guide to District Health Care in South Africa* (Durban: Health Systems Trust, 1997).

[4] B. Starfield, Is primary care essential? *The Lancet, 344*, 1994, 1129-1133.

[5] WHO, *The World Health Report 2008: Primary Health Care Now More Than Ever* (Geneva: WHO, 2008).

[6] WHO, Monitoring the Building Blocks of Health Systems: A Handbook of Indicators and their Measurement Strategies (Geneva, 2010).

[7] Canada Health Infoway, EMR, EHR, and PHR – Why all the confusion?, 2011, Retrieved 15 January 2013, from http://infowayconnects.infoway-inforoute.ca/blog/electronic-health-records/374-emr-ehr-and-phr-%E2%80%93-why-all-the-confusion/

[8] HIQA, Developing National eHealth Interoperability Standards for Ireland: A Consultation Document (Dublin: Health Information and Quality Authority, 2011).

[9] IOM, Key Capabilities of an Electronic Health Record System (Washington: Committee on Data Standards for Patient Safety, Board on Health Care Services, Intitute of Medicine, 2003).

[10] M. Spohr, C. Bailey, & P. Boucher, Data exchange standards for electronic medical records *Roundtable Consultation on Standards and Challenges in Health Information Systems*, Geneva: World Health Organization. 2007.

[11] M. Downey, & R. Korytkowski, Data Model, 2012, Retrieved 1 April 2014, from https://wiki.openmrs.org/display/docs/Data+Model

[12] J. Gill, The structure of primary care: framing a big picture. *Family Medicine, 36*(65-68), 2004.

[13] IUSS Norms and Standards Working Group, IUSS Health Facility Guides: Outpatient Department (Vol. Discussion Draft 1) (Pretoria, 2013).

[14] IUSS Norms and Standards Working Group, IUSS Health Facility Guides: Primary Health Care Facilities (Vol. Discussion Draft 1) (Pretoria, 2013).

[15] Canada Health Infoway, EHRS Blueprint: and Interoprable EHR Framework Version 2, 2006).