Basic Requirements for a Shared Health Record in Rwanda

Introduction

Rwanda is currently embarking on a project to develop and implement an enterprise architecture reference implementation. This implementation will use a number of core national components in the technology stack that makes up the overall health information exchange. These components include national registries for clients, providers and facilities. The reference implementation also includes a Shared Health Record SHR), also referred to as an Electronic Health Record) as a core component. The first phase of the implementation will focus exclusively on maternal care. As such, the specific data will be exclusively maternal and newborn care. The general requirements for a longitudinal record however apply more generally to all domain areas. This document addresses only the general requirements; a companion document outlining the specific data to be included in the shared health record will follow.

Methodology

In a country without a real significant history or experience with individual patient records, explaining the concept of a shared health record was difficult. In addition there was no real pre-existing current state from which to build on incrementally, this was a paradigm shift in thinking for them.

Rwanda has experience in using the CRDM methodology in other domain areas. Although this was not specifically a domain area in the traditional sense- we wanted to use as many elements from that approach as possible.

The result of the general requirements as well as the specific data requirements were derived from the same process. Developing data requirements included the additional steps of mapping the field concepts between applications and against international standards.

Functional Requirements:

Information request:

The SHR must be able to retrieve an appropriate record in response to a request from valid location, with appropriate credentials.
The SHR must be able to respond to time based and cohort queries (such as all new entries for current patients in the POS application)
The SHR must be able to identify any new information since last update (for that user/system or patient).
The SHR must have security rules to validate data request (based on user/role and location)
The SHR must be able to enforce different security requirements on different data (for example HIV test results may require a higher level of security)
The SHR must be able to accommodate externally defined roles (these roles should match roles identified in the Provider Registry)
The SHR must provide an acknowledgment of an information request, including an error message if it is not successful. (This requirement may be addressed by an appropriate transaction management software/layer)
The SHR must maintain an audit log of all information requests (completed or not)
The SHR must identify when a subset of the available information is returned (due to insufficient security or other reasons)
The SHR must be able to retrieve information in specified aggregates or domain specific subsets (such as those associated with a pregnancy)
The SHR must be able to export either the full set of data for a particular patient, or a predefined subset based on user triggered predefined subsets (as above)

Information storage:

The SHR must verify the following are valid: patient, provider and location.
The SHR must validate the content is using the appropriate vocabulary.
The SHR must be able to perform a save in an asynchronous fashion. (via USB or a queue) This requirement may be addressed in the POC system or the messaging layer.
The SHR must retrieve both persistent person data and appropriate (based on security) encounter based data
The SHR must be able to identify “persistent” data and episodic data and store them appropriately (so they can be retrieved)
The SHR must contain trigger events for certain data that can serve to provide decision support or alerts for certain data. (See trigger rules below for examples)
Successful transaction must be acknowledged to originating system (This requirement may be addressed by an appropriate transaction management software/layer)
Unsuccessful transactions must be saved to a log with reasons for failure and the originating system notified

The SHR must have a method to correct/address any unsuccessful transactions.
The SHR must have a way to aggregate or collect several episodes inside of a series (commonly referred to as a "care composition") in this case all antenatal care, delivery and postpartum would be aggregated per pregnancy.

Interface/Communication

For the "pilot" phase there will be no end user interface to browse or display data- all data will be returned and viewed into the POC system
Data in the Shared Health Record must be available for reporting
Any update to data must be recorded and versioned- there must be a record of who changed it, the previous value, and a comment indicating reason for the change. There must also be a well defined process for making these changes (requiring specific authorization) the system needs to both enforce and support the workflow. (See change health data use case)

Business Rules

The shared health record will have the ability to define and implement business rules that are triggered by the entry of specific data. The rule set to be implemented needs to be expanded in functional documentation, but should work in the following general way:

1) *If a new pregnancy is registered and the woman has any of the following*:
   HIV pos, previous CS, previous still birth, diabetic?

.....Then the system will indicate this is a high risk pregnancy and will return to the POC system a message stating "the woman should seek ANC ASAP".

2) *If information is entered during an ANC visit that meets the following:*
   BP > ?, HIV positive

.....Then a message will be returned to the POC system to indicate a more advanced care may be required.

General

Reliable storage of the data must be guaranteed.
The system must be able to store all data types.
The system must be able to manage data saves or requests done in an asynchronous fashion (and process the messages appropriately according to the date/time stamp- not when they were received) For example a message containing an observation is delayed due to lack of connection, while that message is queued, the patient has another encounter, with new observations. The first message may arrive after the second message- but should be stored/ processed as though it is first. This is very important when changing information (such as an allergy).

Data Stored in the Shared Health Record

The specific data stored in the Shared Health record will be the subject of a companion document. In general the data will need to be organised according to the following:

Persistent person level data:

This data is of special significance, and needs to be identified as such. This data, once documented, rarely changes (unless it was documented in error). It has significance beyond the encounter in which it occurred.
The Shared Health record will need to have some way to identify these pieces of information. It is recognised that the solution will require substantial collaboration with the POC clinical systems and is also dependent on clinical workflow. More detail specifications will follow.
Examples: Allergies, specific conditions such as diabetes or sickle cell that will be with you for life, blood type etc.

Episode of care data:

This information will represent a very brief overview or subset of data from each encounter. This data needs to have relevance beyond the episode in which it occurred. Typically an entire hospital visit would be reduced to a single line summary which includes basic information about date, length of stay, facility and maybe diagnosis or major procedure (such as a surgery) and outcome (transfer, discharge home, death). It would not include every observation, result and procedure. If that level of detail is required- the entry provides enough information to request the data from source (hospital or health center).The specific subset of data will be outlined in a separate document.

Care Composite:

Episodes of care can be grouped together to form a meaningful unit. For example, all the data regarding a specific pregnancy would be grouped together so it may be retrieved as a unit. (this will likely require some type of indicator or “flag” that accompanies the data from the POC system).