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Implementation of an HIV Case Based Surveillance Using Standards-Based Health Information Exchange in Rwanda

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Abstract. As Rwanda approaches the UNAIDS *Fast Track* goals which recommend that 95% of HIV-infected individuals know their status, of whom 95% should receive treatment and 95% of those on treatment achieve viral suppression, the country currently relies on an inefficient paper, and disjointed electronic, systems for case-based surveillance (CBS). Rwanda has established an ecosystem of interoperable systems based on open standards to support HIV CBS. Data were successfully exchanged between an EMR, a client registry, laboratory information system and DHIS-2 Tracker, and subsequently, a complete analytic dataset was ingested into MS-Power Business Intelligence (MS-PowerBI) for analytics and visualization of the CBS data. Existing challenges included inadequate workforce capacity to support mapping of data elements to HL7 FHIR resources. Interoperability optimization to support CBS is work in progress and rigorous evaluations on the effect on health information exchange on monitoring patient outcomes are needed.

Keywords. Case-based Surveillance, Health Information Exchange, HL7 FHIR

1. Introduction

Rwanda is among very few countries in sub-Saharan Africa that are close to attaining the Joint United Nations Programme on HIV and AIDS (UNAIDS) *Fast Track* goals which recommends that 95% of people with HIV know their status, 95% of those with known HIV-positive status are receiving anti-retroviral therapy (ART), and 95% of those receiving ART are virally suppressed [1]. The Rwanda Population-based HIV Impact Assessment (RPHIA) conducted in 2019 showed that there were 216,000 HIV infected

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persons among whom 83.8% knew their status, with 97.5% of them receiving ART and 90.1% virally suppressed [2]. Although the national HIV prevalence among adults aged 15-64 years has stabilized at 3.0% between 2015 and 2019[3, 4], there were notable variations in sub-populations; for example, higher HIV prevalence was observed among female sex workers (35.5%) and men who have sex with men (10%) in 2020 [3, 4].

With Rwanda achieving high coverage in HIV treatment, comes the challenge of monitoring individual level outcomes. The World Health Organization (WHO) recommends the collection and use of patient-centered data across the HIV testing, care and treatment cascade leveraging a case based surveillance (CBS) system [5]. A sentinel event is a pre-defined key event for which data are collected, analyzed, and reported to a public health agency for action. The sentinel events tracked in Rwanda CBS are *HIV diagnosis, recent infection status of HIV infection, ART regimens, immunological status based on CD4 and viral load, opportunistic infection, and outcome (alive and on ART, stopped treatment, lost to follow-up, transferred out and death).* The complete case report form includes health facility information, patient demographics, HIV acquisition risk factors, HIV testing and recent infection information, partner notification, ART regimens, and clinical status.

Rwanda currently uses inefficient and potentially error-prone paper-based and disjointed electronic systems for active CBS which has two components: 1) active case finding based on index, family and social network testing for non-passive case finding (ACBS); and 2) routine case-based surveillance (RCBS) to track the HIV continuum of care at the individual level. Advanced technology solutions are needed to generate timely and high-quality data from disparate sources to track analyze sentinel.

As part of the Rwanda Health Information Exchange System (RHIES), we established an ecosystem of interoperable systems at 4 health facilities in Kigali City to support the RCBS guided by WHO's consolidated guidelines on person-centered strategic information [5]. The RHIES includes an Electronic Medical Record (EMR), Laboratory Information System (LIS), DHIS-2 Tracker, a Client Registry (CR), Facility Registry (FR) and Shared Health Record (SHR). The main objective was to show that a health information exchange ecosystem that is based on open standards can support the generation of the complete dataset needed for routine HIV CBS to monitor individual patient level outcomes in Government owned health facilities in a low-resourced setting.

2. Methods

Rwanda has implemented an OpenMRS EMR (ver. 2.3) instance which supports HIV care. The United States President's Emergency Plan for AIDS Relief supports OpenMRS implementations at 192 health facilities serving approximately 128,000 ART patients as of September 2022. The LIS is known as Viral Load Sample Management System (VLSM), and it is primarily used for viral load lab orders and results management.

RHIES is adapted from the Open Health Information Exchange (OpenHIE) architecture which is a shared infrastructure that acts as a universal translator to make data sharing between systems possible [6].

2.1. The RHIES architecture

The RHIES architecture has 3 layers, namely:

- The centralized resources or component layer that is made up of registries (client, facility, provider, terminology), and a shared health record
- The national health service bus or interoperability layer (IL) is a middleware which performs the orchestration of transactions between systems. The IL performs core functions such as authentication, routing, logging and audit
- The point of care applications layer consisting of various instances of an EMR, LIS, DHIS-2, and other systems

2.2. Health Information Exchange Mediators for RCBS

Mediators are microservices that allow the processing of data so that they can be communicated from one interface to another [6]. The mediators are made up of transaction channels. Two channels were used for the EMR-LIS integration:

- VLSM order: channel used to submit a lab order to VLSM system
- VLSM find order: channel used to retrieve lab results submitted from VLSM

Three channels used were for the EMR-DHIS-2 integration:

- DHIS-2 enrollment: channel used to create RCBS enrollment record in DHIS2
- DHIS-2 forms: creates DHIS-2 events corresponding to RCBS forms in EMR
- DHIS-2 events: adds data to created events in DHIS-2 from forms from EMR

2.3. The Role of Registries in Record Matching and Linkage in RHIES

The CR is implemented as a registry of all patients and their demographic data. A Unique Person Identifier (UPID) generator (which is part of RHIES) assigns each patient a UPID using demographic data prior to registration in the EMR and is linked to various identifiers (e.g., Passport no, National ID, HIV TRACNET_ID). The data representation in Rwanda's CR follows the HL7 FHIR Person Resource. A local instance of the CR maintained at each health facility was routinely synchronized with the national Master Patient Index (MPI). The CR employs a basic search function using a deterministic matching algorithm. The EMR consults the CR during the patient registration, enrollment in the RCBS and clinic visits for identity management.

The Facility Registry is a comprehensive repository of uniquely coded health facilities. Rwanda's national facility registry is built on the DHIS-2 hierarchical structure. A Formation Sanitaire (FOSA) code is the unique identifier used to identify each facility and is part of the metadata that support the routing of data between systems in the RHIES.

2.4. Recording Sentinel Events for RCBS

Once a UPID is assigned and patient enrolled on treatment, the electronic RCBS enrollment form (pre-populated with the demographic data) was generated. The viral load request from the EMR uses the *"VLSM order"* channel and the test results are called from the LIS into the EMR using the *"VLSM find order"* channel.

"DHIS-2 *Enrollment"* and *"DHIS-2 Events"* channels are used to trigger an enrollment on DHIS-2 and add events from the EMR to DHIS-2 Tracker, respectively.

2.5. RCBS Analytic Dataset and Data Visualization

The RCBS data stored in DHIS-2 were reviewed for completeness and duplicates by generating a summary report and comparing to the summaries from the EMR. A custom Microsoft Power Business Intelligence (PowerBI) Connector Software Development Kit was leveraged to transform data from DHIS-2 to PowerBI for analysis and visualization.

3. Results

3.1. Data exchange experience

Various components of the RHIES needed for RCBS data were implemented, tested and functional. Four scenarios were encountered during patient registration: (1) patient had an ID and the facility had Internet connectivity; (2) patient did not have an ID but the facility had Internet connectivity; (3) patient had an ID but the facility had no Internet connectivity; (4) patient had no ID and the facility had no Internet connectivity. In scenario (1) a search was conducted on the CR/MPI and new ID assigned if patient is not found. In scenario (2), a search was conducted on the CR/MPI using patient's demographics. In scenario (3) and (4), a temporary ID was issued, if not found on CR, until Internet connectivity was restored, and a search conducted on MPI.

During EMR-lab data exchange, an internal server error code 500 was encountered at one facility due to a bug on the OpenMRS instance data sync storing null IDs. This was resolved by modifying the OpenMRS primary care module to avoid null IDs.

3.2. Complete dataset for RCBS

The data exchanged between various systems in the RHIES ecosystem provided a complete dataset for RCBS. The UPID generated by the CR, demographic and clinical data captured on the EMR during clinic visits and the viral load from the LIS.

A comparison of the sentinel events data captured on the EMR RCBS module and those transmitted to DHIS-2 over the RHIES showed a 100% match after the errors displayed on the OpenHIM Admin Console were resolved.

3.3. RCBS analysis of longitudinal data

Data from DHIS-2 was successfully ingested into PowerBI for analysis and visualization. Sample dashboard and analysis will be presented in future evaluations.

4. Discussion

We demonstrated that a health information exchange ecosystem based on open-source technologies and open standards can support the generation of a complete dataset needed for routine HIV CBS in Government owned health facilities in Rwanda. a low-resourced setting. A comparison of data between the source systems (EMR, LIS, CR) and the DHIS-2 showed a 100% match, indicative of the accuracy of the data exchanged.

Unique identification of patients remains a key challenge in many sub-Saharan African countries, as they do not have strong citizens registration systems [7, 8]. We demonstrated that unique identifiers managed in a CR that is linked to multiple identifiers can support record matching and linkage in a complex data exchange ecosystem. The UPIDs were successfully used for various patient registration scenarios in the EMR (e.g. lack of ID or Internet outage).

HIE has been shown to be beneficial in health programs. Shade *et al* and Herwehe *et al* observed improved quality of care and care coordination, and a reduction in missed opportunities to intervene with individuals not in HIV care after deployment of an HIE [9, 10]. The work described in this paper, once scaled up nationally, and interoperability optimization completed, could potentially save time currently spent generating RCBS data from paper-based and disjointed electronic systems.

We encountered some challenges as we implemented the systems to support RCBS. For the EMR-DHIS-2 data exchange, the UPID generated by an algorithm implemented on the DHIS2 system was not compatible with the EMR due to expected null data attributes. We modified the DHIS-2 instance to accept the TRACNET_ID (HIV clinic ID) as an alternate identifier. Other challenges encountered included inadequate workforce capacity to conduct mapping of data elements to HL7 FHIR resources. This is being addressed through ongoing training of the software developers.

5. Conclusion

We demonstrated a successful standards-based health information exchange use to support HIV case-based surveillance in a low resource. Rigorous evaluation is needed to assess its effect on HIV treatment outcome monitoring and CBS processes once the RHIES is fully implemented, and interoperability optimization completed.

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