*MEDINFO 2019: Health and Wellbeing e-Networks for All*
*L. Ohno-Machado and B. Séroussi (Eds.)*

*doi:10.3233/SHTI190300*

# Towards an Open-Source Oncology Electronic Medical Records System for Low-Resource Settings: Development of Chemotherapy Management in OpenMRS

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**Abstract**

*Cancer is a major public health challenge in low and middle income countries (LMICs). In this paper, we describe work in progress to develop functionality within an open-source electronic medical records system to support safe and standardized cancer care in low-resource settings. We engaged cancer care providers from LMICs to elicit and prioritize requirement, and following a rapid application development approach we developed chemotherapy prescription and documentation functionality within OpenMRS.*

***Keywords:***

Developing Country; Electronic Health Records; Neoplasms

## Introduction

Cancer is a major cause of mortality and morbidity worldwide. As of 2018, there are an estimated 14 million cancer cases and 9.6 million cancer deaths worldwide, according to the WHO [1]. Cancer causes more deaths than HIV/AIDS, Malaria, and Tuberculosis combined.

The cancer burden is heaviest in low and middle income countries (LMICs) where it is fast replacing infectious diseases as a leading public health challenge. Sixty percent of cancer cases and over 70% of cancer deaths are occurring in LMICs. Yet cancer has not been receiving the needed attention and priority, e.g., in the form of funding. Cancer receives only 2% of the funding that is put towards other diseases in LMICs [2].

Leveraging health information technologies such as electronic medical record (EMR) systems in oncology in LMICs can contribute to the improvement of cancer care outcomes through improved care coordination, standardization of treatment, facilitation of guideline adherence and computerized clinical decision support (CDS) [3]. Cancer is a complex family of diseases and cancer care is also complex. There are hundreds of cancer types, each with different risk factors, prevention strategies, presentation, staging, investigations and treatment approaches, including chemotherapy, radiotherapy, and surgery [4]. In addition, health care systems in LMICs are varied, often with limited availability of cancer care specialists and services such as radiotherapy and pathology [2; 5]. Medical errors, e.g., in chemotherapy administration, are common in such complex care environments [6] and the lack of standardization of care affects outcomes. Lack of good quality data for research and planning is also a major challenge for cancer care in LMICs [3; 7] that EMRs could help address.

Unfortunately, adoption of EMRs in oncology in LMICs remains low. For example, the majority of EMRs in Africa are implemented within HIV/AIDS care programs, and only 27% in non-HIV related programs [8]. There have been few reports on EMR implementations in cancer, e.g., in Rwanda [7], but these implementation projects are still in their infancy.

The complexity of oncology is a factor in this low EMR adoption because oncology is thought to require complex and expensive software systems [9] which are not affordable in LMICs, especially considering the lack of prioritization and funding in LMICs.

Open source software systems offer a potential solution to the prohibitive cost, in addition to fostering collaboration and enhancing the use of interoperability standards [10; 11]. Open source systems are arguably more secure since the source code is reviewed by many independent members of the open source community. OpenMRS (https://openmrs.org/) is one such open source EMR platform that is widely used in LMICs particularly in the management of HIV/AIDS, tuberculosis, malaria, and maternal and child health [12]. It is a robust, modular and scalable web-based platform built in Java. It uses MySQL databases and has an extensive data dictionary called CIEL (Columbia International eHealth Laboratory) which maps to ontologies such as ICD-10, SNOMED CT, RxNORM, and LOINC. OpenMRS also uses interoperability standards such as HL7 and FHIR. It is freely available for download and has a large community of active developers and implementers in over 40 countries.

In this paper, we describe work in progress to leverage the OpenMRS platform to develop a fully functional oncology EMR that meets the needs and requirements of cancer care in LMICs [13]. The initial work focused on developing a chemotherapy management module to facilitating efficient, standardized, and safe chemotherapy ordering, documentation, and tracking by doctors and nurses.

## Methods

### Stakeholder Engagement and Requirements Elicitation

Stakeholders were purposively identified to include general doctors, oncologists, nurses, and others working in cancer care, especially those in LMICs or those familiar with this context. Organizations represented included Partners in Health (PIH), Uganda Cancer Institute, Dana-Farber Cancer Center and UNC Project Malawi. We also involved software engineers from the OpenMRS community (mostly from PIH), the OpenMRS leadership team, and IBM Health Corps. These regularly engaged in a variety of meetings and communication interactions: via email, video conferences, OpenMRS Talk (http://talk.openmrs.org), OpenMRS design forums, and face-to-face meetings in Boston, MA, to elicit and prioritize requirements, discuss design considerations and review sketches and prototypes. The technical members of the team also visited and engaged with those on the ground at the PIH's cancer treatment facility in Mirebalais, Haiti to review the current workflows, paper forms, and treatment protocols, and to interact with target end-users.

### Development Process

We followed the rapid application development approach. The software engineers and OpenMRS implementers were co-located in Boston, MA over approximately one month. We reviewed the existing code (freely available in GitHub), the OpenMRS data model and concept dictionary to determine what needed to be modified and what could be reused. Then we developed mock-ups and prototypes for the user interfaces implementing the chemotherapy protocols. These were iteratively reviewed by target end users and changes made immediately. Several modules that are already available in the OpenMRS platform were used e.g., the metadata module for adding new concepts, and the OpenMRS API, a REST web service used to implement the technical workflows.

## Results

### Requirements

Several requirements for comprehensive oncology support were elicited, including oncology-specific documentation (e.g., tumor description), exporting data to cancer registries, computerized clinical decision support in terms of diagnosis, reminders, etc.

Chemotherapy management was prioritized of all the requirements because it is a high-risk part of the oncology workflow – complex drug combinations, tightly controlled doses, severe toxicity and need for several safety checks [14]. Currently, chemotherapy ordering at the represented cancer centers is paper-based and relies on verbal instructions between care team members.

For the chemotherapy management module, requirements, include the following: (i) provide an oncology-specific patient overview with patient identification, cancer diagnosis, cancer journey summary (e.g., On CHOP cycle 3 of 6); (ii) show list of appropriate chemotherapy regimens and pre and post medication for the cancer diagnosis, (iii) automatically calculate body surface area (BSA) from height and weight, and (iv) calculate doses and generate a prescription when the doctor chooses a regimen (v) allow the prescriber to modify the dose by a given percentage but provide a reason for the modification (vi) track cumulative doses of certain drugs (e.g., Anthracyclines) and notify the prescriber when ceiling doses are reached.

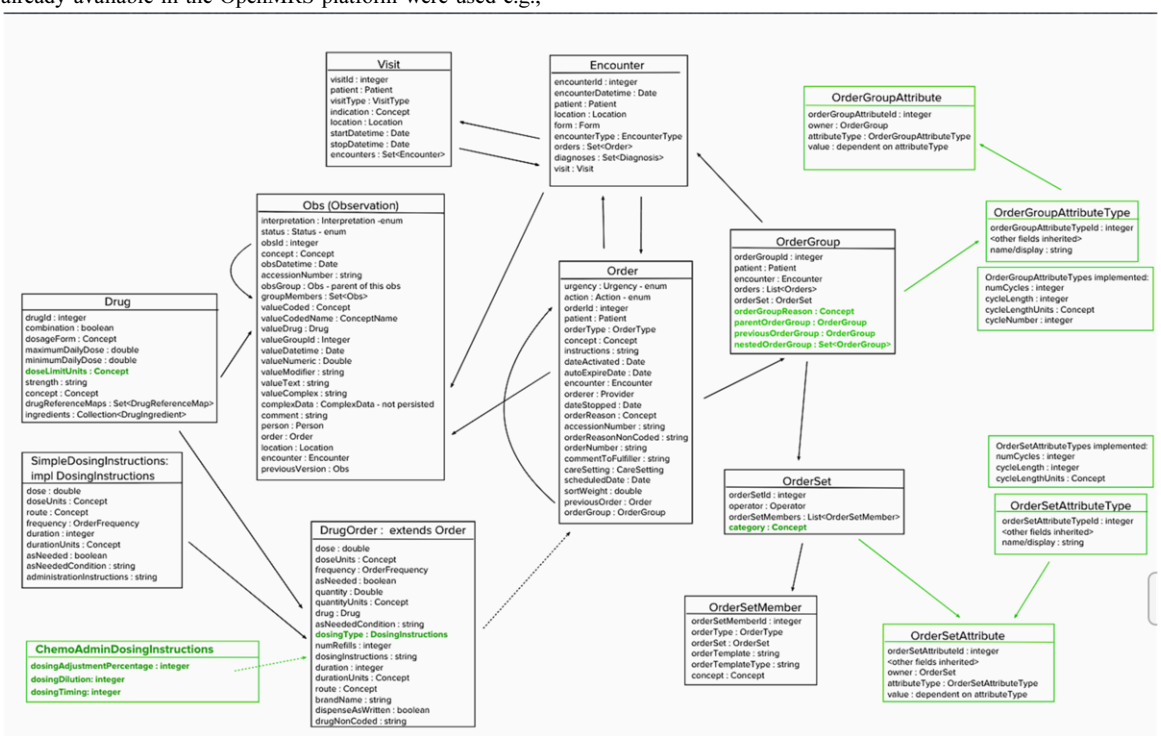


*Figure 1 – Data model with chemotherapy related concepts added (in green).*

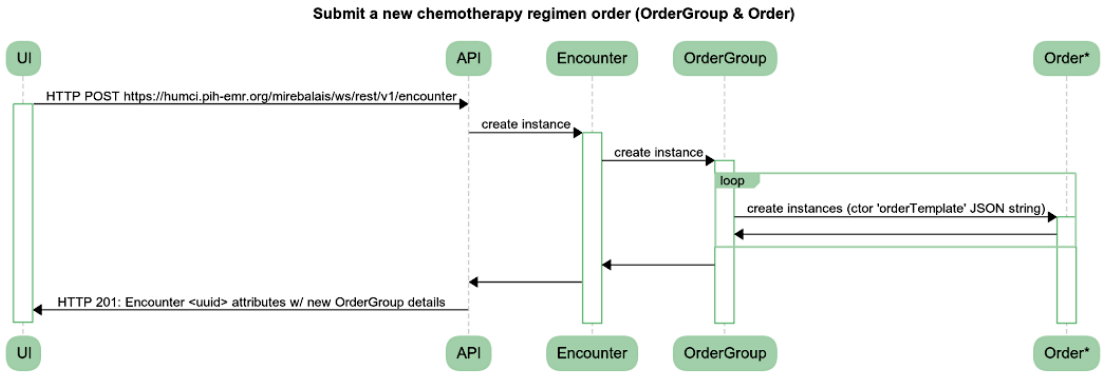


*Figure 2 – OpenMRS API Invocation to create a chemotherapy order*

**Changes in OpenMRS**

The oncology module required introduction of new concepts that are currently not available in the OpenMRS data model and concept dictionary. **Figure 1** shows the data model with chemotherapy-related concepts that were added during this project colored in green. These concepts are related to drug combinations and the cyclic nature of chemotherapy, as well as the requirement to track number of cycles in regimens, cycle numbers (e.g., 3 of 6), length of cycles, administration group (e.g., chemotherapy, pre medication, post medication), and maximum lifetime dose.

The *OrderGroup* (attribute of *Order*) and *Drug* objects that already exist in OpenMRS were modified to enable capture of information about chemotherapy regimen, such as *cycleNumber*, *cycleLength*, *cycleLengthUnits*, and *DoseLimitUnits*. *ChemoAdminDosingInstructions* was also added to The *DrugOrder* object (extension of *Order* object) to capture special instructions that are not captured by *SimpleDosingInstructions*. Classification into pre-medication, chemotherapy, and post-medication leverages the *OrderType* concept field in *Order*.

We also used the CIEL dictionary currently in PIH's version of OpenMRS, which contains oncology concepts, constrained to the workflow and context, e.g., mappings to ICD-O, the oncology subset of ICD. While each facility can add concepts to CIEL, a team of terminology experts at Open Concept Lab (https://openconceptlab.org/) coordinates and distributes CIEL, and encourages all local additions to be added centrally to ensure consistence.

After addition of the concepts, we hardcoded templates for twelve chemotherapy protocols currently used at Mirebalais for management of lymphomas, breast cancer and other solid tumors. The templates were made as metadata files in the YAML syntax, describing each chemotherapy regimen's medications and cycle details. YAML is data serialization language similar to XML but with a minimal syntax that focuses on data interchange rather than document mark-up. We chose to make the regimen templates in this format to facilitate ease of future addition of new chemotherapy treatments to the initial set, and to ease update of the delivered chemotherapy regimens by trained doctors, clinicians, and non-software programmers.

To allow changes to the chemotherapy regimen templates, or add new ones easily by different cancer centers, we developed the Yet Another Automated Regimen (YAAR) management tool, which can process the YAML files and manage the OpenMRS REST API back-end messaging. The tool was implemented in Python and is meant to be extended as requirements evolve. As a future goal, the tool should be extended to support additional treatment types (new schemas) beyond the chemotherapy regimens targeted in this project.

**User Interface Design**

We used the React UI framework (Material UI) to develop the front end. This first displays the oncology-specific patient summary as per the requirements above, with an option select "Prescribe chemotherapy". The prescriber is then taken to a screen that shows chemotherapy regimens and pre and post medication, their schedule, doses and information such as dose modifications or cumulative dose. With a few clicks the prescriber selects the appropriate regimen, schedule and doses, adds notes if necessary and submits the order.

**Figure 2** shows a sample OpenMRS API invocation to create a new *OrderGroup* and *Orders* during chemotherapy ordering, and **Figure 3** shows some of the screens for the chemotherapy prescription interface. We also made a nurses' interface that allows the nurse to document the treatment after it has been administered as well as details such as patient reaction to medication or toxicity, track cycle numbers, etc.

All the code, documentation, workflow analysis and mock-ups, as well as links to other project resources are available in GitHub (https://github.com/openmrs/openmrs-module-oncology).

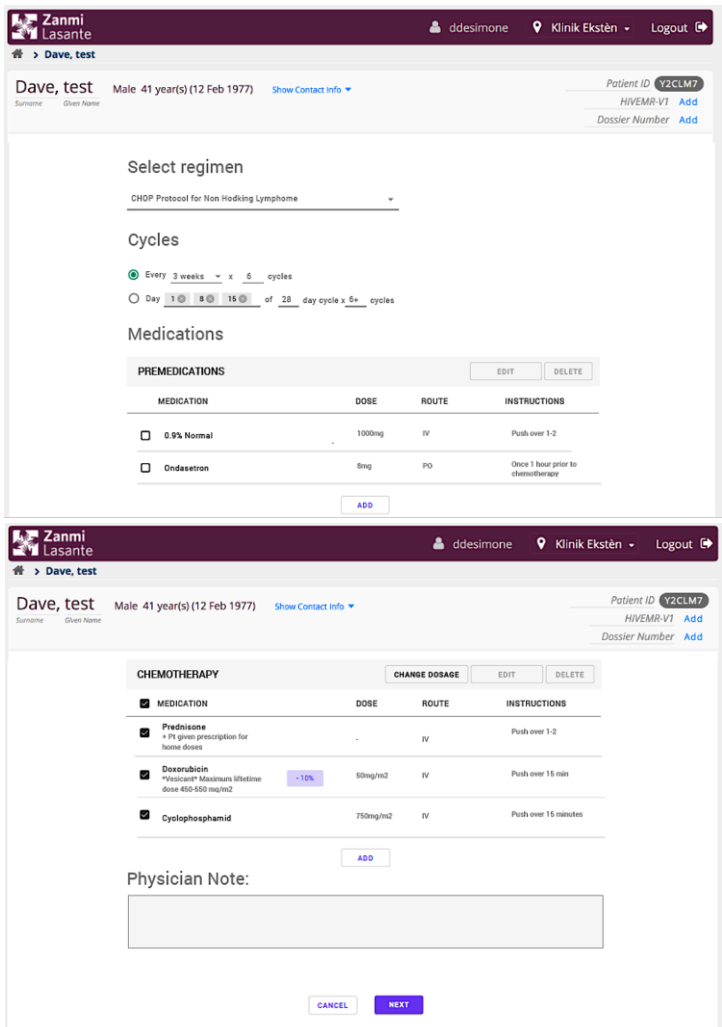


*Figure 3 – Examples of user interface screens for chemotherapy prescription workflow*

## Discussion

In this paper, we describe collaborative efforts towards developing a fully functional oncology EMR for low resource settings based on the open source EMR OpenMRS. We began by focusing on chemotherapy management, and currently we have a functional prototype based on the workflow and clinical services at the PIH Mirebalais cancer center. We implemented twelve chemotherapy regimens and documentation requirements, but the product is scalable using the chemotherapy template authoring (YAAR) tool which allows new regimens to be added so that the system can be used in different contexts or at other cancer care centers. The prototype has been evaluated as part of the development process by oncologists and other cancer care providers from Uganda, Rwanda, Malawi, Haiti, and the US but the module is yet to be implemented at point of care. The twelve chemotherapy protocol templates that were configured were based on the care process at Mirebalais cancer center and that is where initial implementation is planned, but with minimal changes the module can be used elsewhere. Evaluations and further development for implementation in Uganda, Rwanda and Malawi are ongoing, and feedback from these clinical applications will inform future iterations of development.

This project also provides a basis for development of clinical decision support such as automatic body surface area calculation, automatic dose calculation, safety checks and alerts for dose (including lifetime cumulative doses) and schedules basing on protocols integrated in the system, as well as better clinical data capture and (re)use for forecasting and planning.

Future features will include the addition of pharmacist workflows to complete the chemotherapy administration workflow, as well as other forms for complete oncology documentation e.g., diagnosis, staging and treatment, follow up and interfacing with cancer registries.

Some challenges faced during the project included difficulty in gaining consensus on data model changes to support cancer specific concepts, and a complex code base that was hard for new developers to learn. Current challenges include dedicated software development teams and project management to advance the work quickly.

## Conclusions

This project demonstrates the potential for collaborative development of affordable open source systems for addressing the cancer epidemic in LMICs. The system will facilitate a safe and standardized prescription of chemotherapy as well as proper documentation and monitoring. This is important because chemotherapy is very toxic, and cancer care is complex and prone to medical errors, which can be detrimental for the patient.

In this project, we also developed tools which can be used by other cancer care providers to implement their own protocols. Using the rapid application development approach allowed us to accomplish this project in a relatively short time. Constant interaction with the end users at all stages of the project was crucial for a proper understanding of the requirements and the oncology domain in general. Co-location of the technical team was advantageous since some members of the team were new to OpenMRS.

## Acknowledgements

This work was financed by IBM Foundation in form of man-hours of user experience/interface (UX/UI) designers, business analysts and software developers as well as funding for design workshops and meetings. We appreciate the contributions of the following:

IBM team: Alexis Casaceli, Rebecca Dahlman, Mario De Armas, Ian Lewis, Elma Maksumic, Pravesh Patel, Oleksandr Sabov, Joel C. Mangan.

Partners In Health contributors: Ellen Ball, Ruth DeMuse, David DeSimone, Dayo Fadelu, Mark Goodrich, Lauren Greenberg, Michael Seaton.

OpenMRS Community: Darius Jazayeri, Andrew Kanter, Burke Mamlin.

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