

Patient Registration and Identity Management Services for Health Information Exchanges

Two-Sentence Overview

IntraHealth's new Open Client Registry (OpenCR) represents a foundational global good supporting identity management needs in developing countries using leading technologies, including the powerful ElasticSearch engine and the reference standards-based HAPI FHIR server. Building on its successful real-world pilot, IntraHealth and partners Regenstrief, Ona, and IntelliSOFT seek to expand OpenCR into a robust, high-value global good and field test it with select ministries of health through a consortium that includes unparalleled international design and deployment expertise in client registry and identity management as well as leadership within the OpenHIE architecture and client registry communities.

Executive Summary

IntraHealth recently completed development of an open source, standards-based prototypical client registry, [OpenCR](#), which was built to safely and uniquely identify patients who have demographic information stored in multiple health information systems. Leveraging IntelliSOFT's relationships with ministries, Ona's understanding of the evolving security landscape, and Regenstrief's expertise developing client registries in high- and low-resource settings, the consortium proposes to rapidly expand the functionalities of OpenCR to meet the global community's unmet needs for a standards-based, advanced, yet accessible open source client registry to support longitudinal management of patient data across the health sector.

The initial use case driving development for OpenCR was developed to match and link records together under a single unique ID. With funding from Digital Square, the consortium team plans to complete the expansion of the OpenCR prototype into a broadly applicable global good across a wide variety of low-resource settings and use cases to enable countries to track patient records across health information systems.

Consortium Team

IntraHealth International is a global health NGO with a 40-year history in developing successful data tools and digital health applications for health workers and managers. We develop solutions that are open source, data-driven, sustainable, and collaborative. As a pioneer in the field of health workforce informatics, we're committed to using technology, information, and analytical approaches to support the people at the center of our health systems. IntraHealth will lead the overall solution development process. IntraHealth's consortium includes partners Ona, IntelliSOFT, and Regenstrief.

- Regenstrief is the creator of OpenMRS, an open source electronic medical record system and leaders in the OpenHIE Client Registry community. Regenstrief will support Work Package One with high-level solution design and will bring forth feedback from the OpenHIE community.
- Ona is a social enterprise based in the United States and Kenya that was founded in 2013 to build data infrastructure to drive change. Ona will contribute to Work Package One and deliver Work Package Three.
- IntelliSOFT Consulting Ltd. is a Kenyan-based company that has been implementing health information systems in East Africa since 2009. IntelliSOFT will use its national client registry and unique patient identifier experience in Tanzania and Kenya to undertake Work Package Two.

Project Description

Background and Problem Statement: IntraHealth developed OpenCR, a prototypical open source client registry, with USAID funding through MEASURE Evaluation. OpenCR was designed to uniquely identify individuals who have records in multiple information systems to help countries track patients through the continuum of care. Development was informed by stakeholders in Uganda, including the Ministry of Health (MOH) and the Central Public Health Laboratory (CPHL), as well as technical teams at CDC and USAID. OpenCR was built to support epidemic control by facilitating the deduplication of patients' lab test

results for tracking outcomes over time and identifying those lost to follow up. To meet both the needs of Uganda's specific use case and ensure global applicability the initial release of OpenCR supports:

- 45 algorithm variations using the popular ElasticSearch engine and plugins. This includes support for deterministic or probabilistic matching.
- Record linkage and Registration as a Service through the generation of unique IDs with a non-destructive, auditable history of submissions.
- A modern UI to view, break, revert breaks, and audit matching decisions.
- Updated OpenMRS MPI Client Module to support OpenCR.
- Open standards, including the FHIR-based Mobile Patient Demographics Query (PDQm ITI-78) and Mobile Patient Identifier Cross-reference Query (PIXm ITI-83).

The consortium proposes to complete development of OpenCR as a broadly applicable global good that fulfills the existing need within the OpenHIE architecture to track patient records across health information systems.

Objectives:

Work Package One: Modifications to design and functionality of OpenCR.

To meet the needs of additional use cases, grow capabilities within the OpenHIE Community, facilitate uptake, and provide a platform that grows with the needs of the users, we propose the following:

- Support **additional IHE profile actors and transactions** beyond existing support for PIXm and PDQm, including PMIR - Patient Identity Manager, Mobile Patient Identity Feed (ITI-93) and Subscribe to Patient Updates (ITI-94).
- Include **easy, configurable entity matching UI** and decision rule management.
- Support **merging and golden record management** for reviewing, accepting, and rejecting changes.
- Support **bulk matching** options to include the ability to bulk import and export patients.
- Support **attribute management**, including the ability to start from a default patient resource and then modify it to add common extensions.
- Provide a robust, flexible, easy-to-manage **authentication and authorization system** based on open source platforms, for enhanced security auditing.

A comparison of OpenCR to the OpenHIE Architecture Specification 3.0 reveals that OpenCR fully meets three of the four required workflows and five of the 10 functional requirements and recommendations. The proposed activities described above will finalize compliance with all workflow and functional requirements of the OHIE Specification.

Work Package Two: Validate Modifications with Ministries of Health

IntelliSOFT will focus on field testing OpenCR with one to two select ministries of health, including gathering requirements and validating use cases with governments grappling with the issue of identity management to ensure that the product is both accessible and functional in low resource settings. Potential countries for collaboration include Liberia, Uganda, Rwanda, and Malawi and specific activities include:

- Facilitating **community engagement and country-level field testing** of OpenCR with select ministries of health to validate use cases, functionality, and usefulness.
- **Testing the OpenMRS MPI Client Module.**
- **Exploring the use of OpenCR in cross-border contexts**, such as shared governance of a system between two sovereign governments and how to manage patient identities when data sets differ between countries.
- **Validating the Instant OpenHIE demo** and testing platform for OpenCR with potential users.

Work Package Three: OpenCR supporting a Shared Health Record (SHR).

Ona will facilitate laying the footprint for supporting a shared health record with OpenCR. OpenCR's technology stack supports the core workflows of storing FHIR documents with minimal additional investment. The REST APIs exist as a core feature.

- Add routes, access controls, and reporting to OpenHIM for storing and querying documents in the HAPI FHIR server
- Add client matching and validation for incoming FHIR documents, utilizing OpenCR search services.
- Develop test data at scale to ensure SHR performance.

- Update the OpenHIE community architecture documentation to reflect these transactions
- Scope required steps to integrate point of service applications, like OpenSRP, with the SHR.

Work Package Four: DevOps, Packaging, and Documentation

We will document proposed enhancements to OpenCR, building upon the [substantial documentation](#) we developed for OpenCR's first release, including:

- Documenting work developed under Work Packages One and Two.
- Enhancements to the OpenCR User Guide and Developer Guide.
- DevOps and packaging for the Instant OpenHIE platform.
- Create packaging, testing, and continuous integration and continuous delivery (CI/CD) processes.

Deliverables & Schedule

Work Package	Deliverables	Months
1	<ul style="list-style-type: none"> • Additional IHE profile actors and transactions • Easy, configurable entity matching • Merging and golden record management 	1-3
	<ul style="list-style-type: none"> • Attribute management • Authentication and authorization system 	4-6
	<ul style="list-style-type: none"> • Further iteration based on validation 	7-9
2	<ul style="list-style-type: none"> • Community engagement and country-level field testing • Testing the OpenMRS MPI Client Module 	1-3
	<ul style="list-style-type: none"> • Community engagement and country-level field testing • Exploring the use of OpenCR in cross-border contexts • Validating the Instant OpenHIE demo 	6-9
3	<ul style="list-style-type: none"> • Phase one: Prototypical Shared Health Record service API • Phase one: Product integration 	3-6
	<ul style="list-style-type: none"> • Phase two: Prototypical Shared Health Record service API • Phase two: Product integration 	7-9
4	<ul style="list-style-type: none"> • Documenting work developed under Work Packages One and Two. • Enhancements to the OpenCR User Guide and Developer Guide. • DevOps and packaging for the Instant OpenHIE platform. • Packaging, testing, and continuous integration and delivery (CI/CD) 	3-6, 7-9

Dependencies: Work Package One is the core development of expansions and modifications to the design and functionality of OpenCR. Work Packages Two, Three, and Four build upon the iterations in Work Package One and enable consultation with stakeholders to ensure that the features are based on the needs of potential implementers. There are no interdependencies between the packages other than dependence on the core deliverables in Work Package One.

Risk Mitigation: Software development in international development poses inherent functionality mismatch risks between what is built and what is wanted. We will mitigate this through a close collaboration with the OpenHIE Client Registry community and select ministries of health as part of Work Package Two. We expect to develop OpenCR through a transparent development process that includes a range of stakeholders in our requirements definition, roadmap design, software development, and testing processes.