Case Study:
Open Health Information Exchange (OpenHIE)

OpenHIE: Communities Building Open Standards for Health Information Systems

Principle(s) Addressed
Use Open Data, Open Standards, Open Source &
Open Innovation; Be Collaborative

Key Terms

application programming interface (API): In computer programming, a set of subroutine definitions, protocols and tools for building application software [https://en.wikipedia.org/wiki/Application_programming_interface].

architecture: A collection of hardware and software components and their interfaces that establish the framework for the development of a computer system [https://en.wikibooks.org/wiki/Introduction_to_Software_Engineering/Architecture/Design].

health information system (HIS): Any system that captures, stores, manages or transmits information related to the health of individuals or the activities of organizations that work within the health sector [http://phinnetwork.org/resources/health-information-systems-his/].

interoperability: Applied to information technology, refers to the ability to exchange information meaningfully among separately developed systems, where the separate systems are able to understand the format, meaning and quality of the information being exchanged [https://en.wikipedia.org/wiki/Interoperability].

reference implementation: An implementation of a specification that serves as the standard, definitive form from which all other implementations are measured [https://en.wikipedia.org/wiki/Reference_implementation].

registry: A record of information in an HIS, typically of patients [https://www.ncbi.nlm.nih.gov/books/NBK164514/], health care workers and health facilities [https://ohie.org/facility-registry/].

Objectives

- Create an **open community** of organizations and individuals who are passionate about improving health and health care data sharing. The OpenHIE community is owned by countries and serves as a resource for capacity building, and it receives operational support from the Regenstrief Institute.

- Build and support an open architecture [https://wiki.ohie.org/display/documents/OpenHIE+Architecture] that countries can use either in pieces or as a whole to help their systems talk to one another.

- Work within an open process that invites anyone to participate and is transparent about its work.

- Encourage countries and organizations to use open standards [http://digprinciples.staging.wpengine.com/principle/use-open-standards-open-data-open-source-and-open-innovation/] when it makes sense, so that others can build on the work that has already been done.

specification: A description of a software system to be developed; the specification lays out functional and nonfunctional requirements and may include a set of use cases that describes user interactions, which the software must provide [https://en.wikipedia.org/wiki/Software_requirements_specification].

standard: A protocol or other common format of a document, file or data transfer that is accepted and used by one or more software developers while working on one or more computer programs [https://en.wikipedia.org/wiki/Software_standard].

terminology service: A list of standard words and terms with consistent meaning and shared understanding that are essential for human communication, comparison and integration of data, interoperation among HIS, and sharing and portability of electronic medical records [http://www.omg.org/ontology/sem_info_day09/term_svcs4healthcare_interop_Russ_Hamm.pdf].
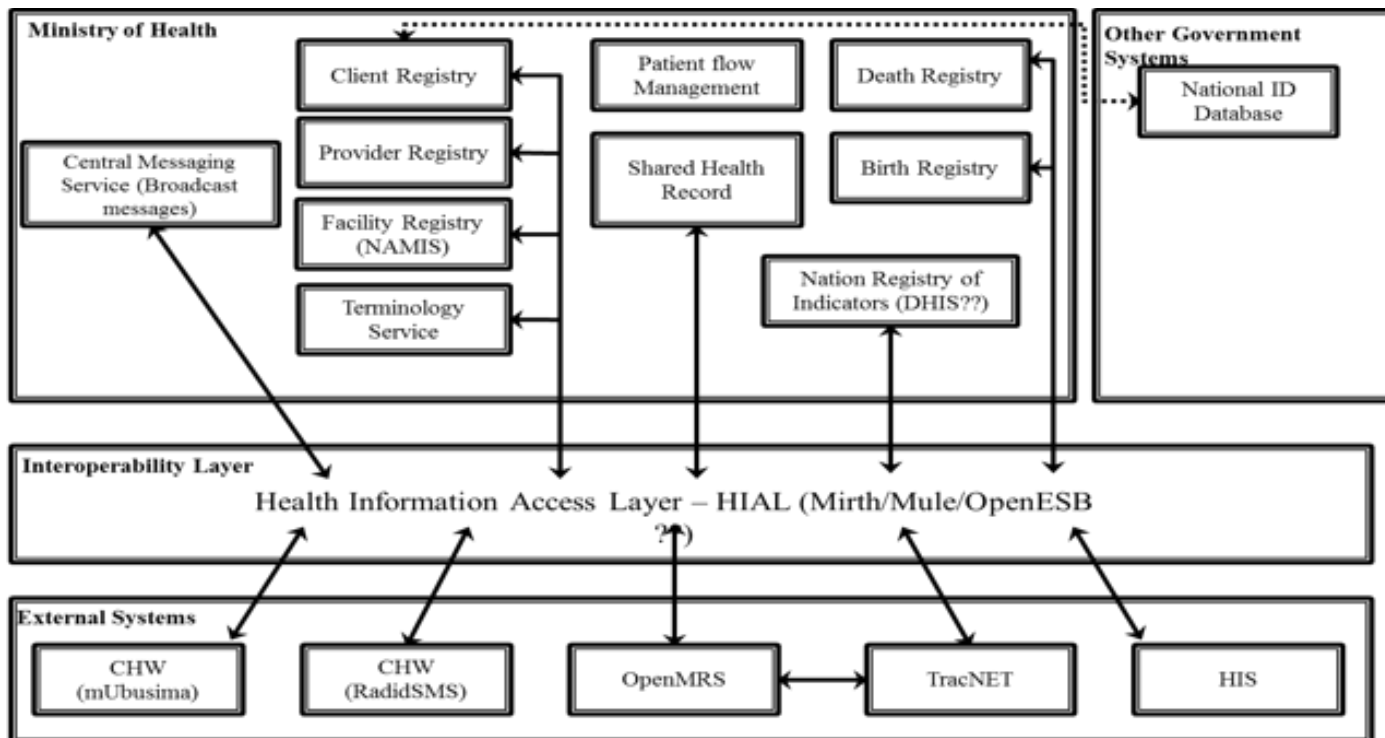
Overview

Open Health Information Exchange (OpenHIE) [https://ohie.org] is a community of practice that builds interoperable data standards so that HIS can talk to one another, enabling individuals across the health system to access the information that they need. Our mission is to improve the health of the underserved through collaborative development and by supporting open, country-driven, large-scale health information sharing architectures.

In a single country there might be multiple HIS to track patient and health worker information, and still other systems for managing health records, medical supplies and health facilities. OpenHIE's goal is to increase HIS interoperability, so decision makers — including clinicians, ministries of health and program leaders — can access the data they need to support improved health outcomes. With the input of a large number of stakeholder organizations, the OpenHIE community of practice collectively developed a reusable, open HIS framework that can be adopted and adapted by many countries.

Rwanda's HIS system design

Background

Within any given country, HIS typically operate independently of one another. The result is disaggregated information stored in different locations and formats, making it impossible for data to be harmonized and for health care personnel to share knowledge, collaborate in care and have a complete record of an individual's health history. Those who manage and oversee health systems have little ability to use data for monitoring and evaluation purposes. (See tip.) And low- and middle-income countries seldom have the capacity to build interoperable HIS independently.

Rwanda provides an example for how collaborating on open data standards for HIS can positively impact health outcomes. The Rwandan Ministry of Health was committed to improving maternal health, but it needed to coordinate information and care across providers and facilities. The Ministry of Health accomplished this by establishing an information architecture: the Rwanda Health Information Exchange (RHIE) [https://wiki.ohie.org/pages/viewpage. action?pageId=10486056]. Once the RHIE went live in 2012, several countries sought to replicate the model.
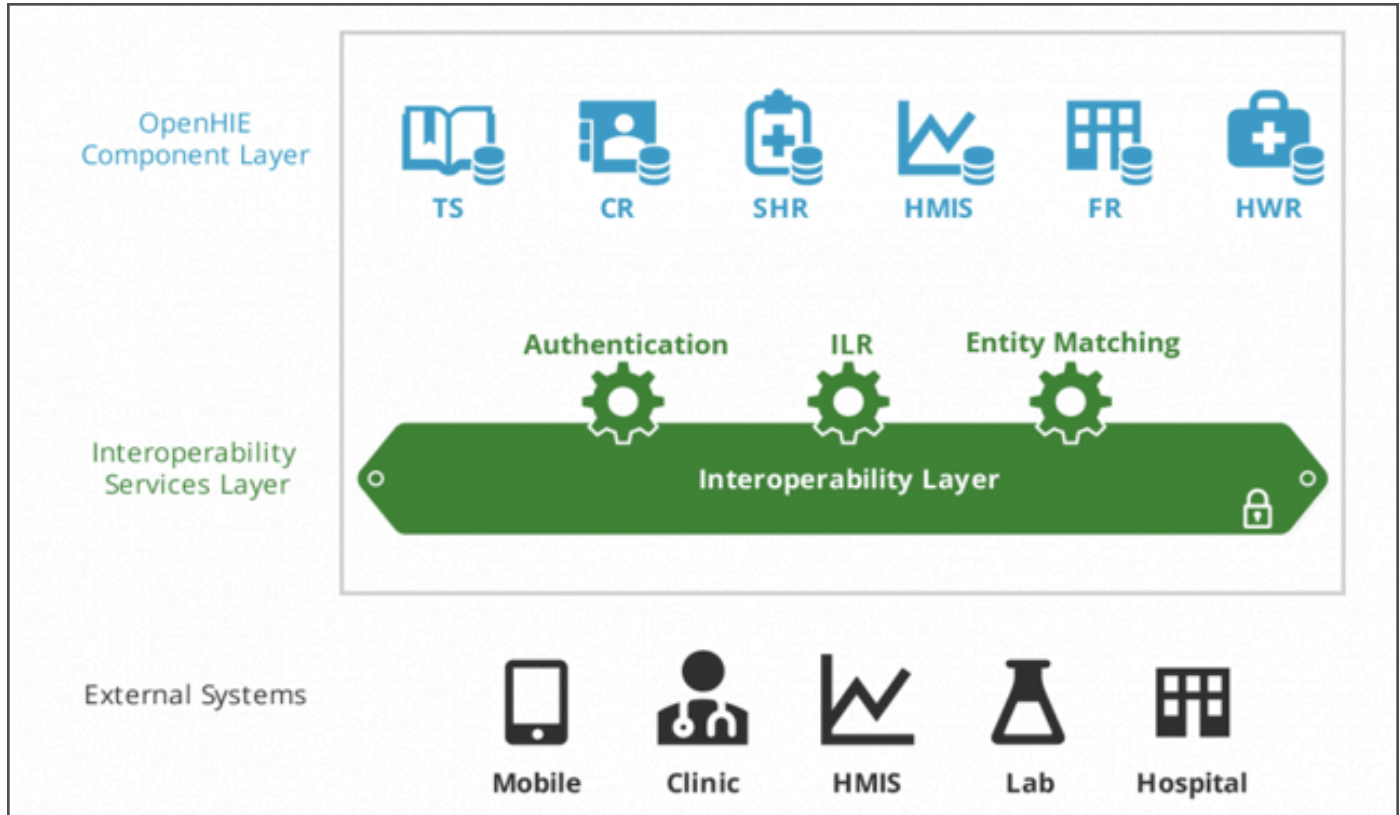
The whole picture of OpenHIE (TS = terminology service; CR = client registry; SHR = shared health record; HMIS = health management information system; FR = facility registry; HWR = health worker registry)

With the RHIE as an initial example of what could be achieved, the nascent OpenHIE community set out to advance an interoperable architecture for HIS that multiple countries could use to meet their needs. To achieve this, we created and managed mechanisms for communication that allowed a diverse community of stakeholders to contribute peer-supported processes, broad experience and reusable technologies. The result of this collaboration was a framework for countries to use to address their own health information architecture. This reusable framework uses a service-oriented approach, takes advantage of internationally endorsed health information standards, enables flexible implementation by country partners and supports interchangeability of components.

OpenHIE now serves as a community of practice, each member working on challenging aspects of developing open standards for health systems. The community has cultivated a culture of sharing

and openness through virtual mechanisms such as a wiki [https://wiki.ohie.org], regular calls and video sessions, and documentation of knowledge in notes and recordings that can be shared widely. The Regenstrief Institute provides operational support for the OpenHIE community through these and other mechanisms, cultivates leadership within the community and gives strategic input.

Project Lifecycle Application

- **Analyze & Plan.** To build buy-in and promote open innovation, we began by establishing a community of practice composed of health system stakeholders. We first worked to engage and energize ministries of health, hospitals, nongovernmental organizations and other stakeholders and convince them that open data standards could transform health care in low-resource countries. These stakeholders became part of the community of practice that informed the OpenHIE architecture, interoperability patterns and workflows. OpenHIE and the community collaborated to develop a shared mission, vision and guiding principles for the community of practice, with ownership firmly established across the countries and implementing organizations that were part of the community. We developed a leadership model and mapped out responsibilities for engaging stakeholders, coordinating the community, creating work plans, and planning and leading meetings.

- **Design & Develop.** OpenHIE set up and managed knowledge-sharing channels, such as the wiki, regular calls and video conferences, and documentation to support the growing community of practice. The OpenHIE community collaborated to develop a metadata clearinghouse to standardize medical terms across systems, which countries could use to populate their own registries; strengthened compliance of pre-existing client registry technologies with OpenHIE architecture; and collected and shared use cases that could serve as the foundation for the health worker registry. The community also discussed and agreed on reference components used to demonstrate the OpenHIE workflows. OpenHIE has participated in the Integrating the Healthcare

RESOURCES

Community Wiki, OpenHIE. https://wiki.ohie.org

IHE Connectathon, Integrating the Healthcare Enterprise. http://www.iheusa.org/ihe-connectathon-overview

OpenHIE. https://ohie.org

OpenHIE Architecture, OpenHIE. https://wiki.ohie.org/display/documents/OpenHIE+Architecture

OpenHIE Leadership Model, OpenHIE. https://wiki.ohie.org/display/documents/OpenHIE+Leadership+Model

Values and Digital Principles, OpenHIE. https://ohie.org/2017/03/openhie-values-and-digital-principles/

What OpenHIE Means — and Could Mean — for Health Sectors around the World, IntraHealth International. https://www.intrahealth.org/vital/what-openhie-means%E2%80%94and-could-mean%E2%80%94-health-sectors-around-world

Enterprise (IHE) Connectathon for the last three years, where reference technologies and workflows were formally tested for compliance with international standards [http://digitalprinciples. org/design-with-the-user/].

- **Deploy & Implement.** OpenHIE supported pilot programs to deploy the architectural model in Rwanda, Tanzania and South Africa and test the model of collaborative, open sharing. Leaders within the community spoke with ministry officials, funders and implementers about how open standards could transform health care in low- and middle-income countries, and they published profiles and white papers to spread the word about OpenHIE. The wiki has evolved into a "go-to tool" for implementers, allowing countries to share technical resources, put ideas into action, and discuss challenges and opportunities.

The OpenHIE community has now championed open standards in many countries. In some cases, community members have even been lead developers of new standards, such as aggregate data exchange (ADX) and care services discovery (CSD). Community members have also developed demonstration technologies that are made available via liberal open source licenses.

OpenHIE promotes the deployment of an ecosystem of options for open standards, not the enforcement of a particular ideology for implementation. The OpenHIE model includes reference technologies that serve as examples of desired technological standards, but the open-standards design means countries can choose to use other technologies while still adhering to the overall framework. For example, Tanzania used OpenHIE as a conceptual model for its national e-health data sharing strategy and is exploring implementing a commercial software component for its interoperability layer; the use of open standards made this possible. In Kenya, significant progress had already been made in creating a national facility registry. Once Kenya joined the OpenHIE community, this country-level work was not abandoned. Rather, the community supported Kenya to make technical adjustments to align the registry with the OpenHIE architecture.

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- **Cross-cutting: Monitor & Evaluate.** As countries are writing their e-health strategies, we are seeing OpenHIE concepts and architecture included. OpenHIE applies the principles of openness and collaboration to gather data on implementation and to iterate based on user experience. The community does not assert a specific monitoring and evaluation framework in countries where OpenHIE is deployed. Instead, the free information exchange that the community cultivates has given insight into how open data standards are practically implemented at significant scale in low-resource countries. Many of the country experiences within the community have both validated these standards as viable within resource-constrained environments and encouraged fundamental revisions. The OpenHIE architecture review board examines these lessons and uses them to improve [http://digitalprinciples.org/reuse-and-improve/] on the OpenHIE architectural model — knowing that a viable, reusable model is iterative in nature. Therefore, the community of practice is a fundamentally important information resource to better understand what's needed.

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Lessons Learned and Recommendations

- Collaboration is worth the effort [http://digitalprinciples.org/be-collaborative/]. OpenHIE facilitates an expansive international community of practice composed of country governments, nongovernmental organizations, technical providers and other stakeholders who are driven to implement HIS. A significant amount of upfront work was required to build momentum around this concept, to get stakeholder agreement on the ideas of community collective ownership and leadership, and to create country awareness of the role of OpenHIE in their work. Despite these challenges, this collaborative approach, combined with using open standards, open source and open data, has promoted a sharing of expertise and innovation that has translated into success.

- Community promotes sustainability [http://digitalprinciples.org/build-for-sustainability/]. The community of practice facilitated by OpenHIE has become a public good. As lessons learned and technical expertise are shared in an open manner, organizations can use these resources at little to no additional cost to their initiatives, and they come to view participation in the community as a net value to their implementation work. In this way, much of the cost of maintaining the community of practice is shared across organizations through voluntary participation, where all parties derive direct benefit.

- Establish a formal governance model. OpenHIE began as a loosely networked community effort, with the goal of building consensus iteratively rather than beginning with a set of formal governance structures. As the community matured and reached consensus, it became apparent that a lack of governance would make it difficult to implement community behaviors at scale. To address this, OpenHIE developed formal governance structures such as a leadership group [https://wiki.ohie.org/display/documents/OpenHIE+Leadership+Model] to facilitate decision making, as well as an architectural review board that is empowered by the leadership group to make decisions about standards and specifications. Developing formal governance structures that complement the existing ecosystem [http://digitalprinciples.org/understand-the-existing-ecosystem/] of technological, legal and regulatory policies is crucial to the successful development and use of open standards for HIS.