# OHIE Terminology Services

# Implementation Guide

# **Introduction**

**Background**

One of the primary objectives of a Health Information Exchange (HIE) is the consistent integration, aggregation and communication of diverse healthcare information. While the immediate goals of this integration can be varied: public health reporting, utilization review/analysis, clinical decision support, etc., the need for comparable, consistent data is paramount. Unfortunately, even highly developed countries face difficulties in achieving this integration. The underlying challenge is that healthcare providers, labs, clinics, pharmacies and hospitals often lack a shared understanding of commonly used health and medical concepts and a lack of a common language in which to document their findings.

The purpose of the Terminology Services component in the OpenHIE Architecture is to provide a central resource for the definitional assets of the HIE, i.e., terminologies, ontologies, dictionaries, code sets, value, sets, that can be used by other HIE components to achieve normalization of clinical data and consistent aggregation and reporting.

It is important to understand that the objective of Terminology Services is NOT to dictate the way data is captured by point-of-care and other clinical systems. As will be described later, these systems will often use proprietary or local dictionaries (often called *Interface Terminologies*) to document care in a manner appropriate to their care settings. Once this data participates in an HIE, however, it is imperative that this locally-encoded data be associated with (or *mapped to*) industry standard *Reference Terminologies* to enable regional and national-level analysis.

[does the example below go here or later?]

One out-patient clinic may refer to a certain lab test as a “White Count”. A hospital, on the other hand, has a test called a “WBC”. For a computer to report and analyze these tests accurately, they should be encoded in an industry standard Reference Terminology such as LOINC. The Terminology Services component can perform this function on behalf of the HIE and report that both tests are examples of LOINC 6690-2 “Leukocytes [#/volume] in Blood by Automated count”.

Terminology Services provides a central “source of truth” for Reference Terminologies and the mappings between Interface Terminologies and Reference Terminologies to support the overall objectives of the HIE. The Terminology Services component provides facilities for the management, maintenance and curation of the terminological assets, often by country Ministry of Health employees, and electronic interfaces by which these assets can be used by other OpenHIE components such as the Interoperability Layer and Shared Health Record.

**Objectives**

The objective of this Guide is to assist health system stakeholders – planners, designers and implementors – to better understand the role of Terminology Services within an HIE and assist in the subsequent planning and implementation of a Terminology Services capability. The Guide tries to address both policy development and technical implementation considerations.

The Guide’s goals are to:

* Explain the problem of lack of data and information consistency within and between information systems.
* Offer a blueprint for how a Terminology Services capability which can solve this lack of consistency can be implemented within the Open HIE.
* Explore lessons learned from other OHIE implementations in countries like Rwanda, Tanzania and the Philippines.

**List of countries with projects and brief descriptions with links to relevant resources?**

This Guide is dynamic--a work in progress. No single step-by-step approach to facilitating data exchange will apply to every country. Instead, each nation will likely hinge its program on multiple factors—focusing on rapidly developing solutions to the most pressing health management concerns. The Guide provides procedures by which health systems can analyze their knowledge, skill, expertise, experience and infrastructure and then choose from among multiple available options to bring about data standardization within their health information exchange. It also documents how health systems can customize and adapt the most successful and appropriate strategies and tactics to address pressing healthcare needs and priorities.

Ideally, health system professionals and ministers of health will turn to each other as colleagues and indispensable sources of information and knowledge on Terminology Services strategies, tactics, best practices, and guidelines.

**Terminology Services and Terminology Management**

**Definition and Benefits**

Terminology Services helps to bridge the gaps between isolated clusters of patient data found within varied systems, applications and networks. Through the process of analysis, implementation and data mapping, Terminology Services help countries make use of a variety of different types of terminologies found within electronic health records (EHRs), data warehouses, and clinical systems. Terminology Services also support the mapping of local and proprietary dictionaries and code systems to standards.

Through the use of Terminology Services, a health system can achieve *semantic interoperability* of its data. Semantic interoperability (or interoperability by meaning), enables accurate, consistent reporting and aggregation of clinical data, enabling effective exchange of information among the provider community leading to more informed patient care decisions.

The benefits of Terminology Services to OpenHIE stakeholders include:

* Accurate and consistent data aggregation to improve patient care quality and safety.
* Comparable patient data within and between patient populations.
* Consistent analysis of use of healthcare resources, leading to more intelligent decisions about resource allocation.
* Effective evaluation of the impact of treatment plans on health outcomes.
* Reproducible quality, safety and efficiency measurements of patient care.
* Identification and re-engineering of patient care processes.
* Satisfaction of national standards for healthcare delivery.
* Consistent progress toward evidence-based medicine and the use of clinical decision support.

In a national healthcare system, Terminology Services provides a central management point for key data structures that ensure that incoming data is normalized to nationally-defined standards, stored (persisted) using these standards, and analyzed by other HIE components in a consistent and reproducible manner. Similar to other “registries” such as the Facility and Provider registries, Terminology Services is the “registration entity” for clinical data standards used throughout the HIE. By localizing access to, and management of, common data, registries simply the creation, evolution, and distribution of this data to all components of the HIE.

In describing Terminology Services is helpful to first define a few key terms or concepts. These terms are commonly used within the international eHealth community and facilitate discussions with other HIE components.

**Terminology** – For the purposes of this document, a Terminology, also known as a code system, vocabulary or ontology, is a set of names, codes, and descriptions relating to a specific body of knowledge. A Terminology can be as simple as the set of HL7 gender codes or as complex as a SNOMED CT. A Terminology can be “local”, developed by a single organization, or even a single individual, for a specific purpose, or “standard”, meaning it has been developed by a national or international standards body.

**Interface Terminology** - An Interface Terminology is a Terminology, or simply a set of words, terms or phrases, used by a clinical application to describe a domain of knowledge. These are the terms or phrases which users see in the application. Interface terminologies may include unique codes and descriptions, or just be terms. Interface terminologies are used to present “surface” lexical forms to an end-user application such as an EHR, and may be the form exported in data exchange messages. An Interface Terminology could be an internationally –recognized terminology such as the OCL, or be entirely locally-defined and used. The important factor is that an Interface Terminology is “user-facing”.

**Reference Terminology** - A Reference Terminology is a formal terminology, usually created and maintained by a sanctioned Standards Development Organization (SDO), which can be used as the basis for Semantic Interoperability of information drawn from different data source systems. Each element in a Reference Terminologyusually includes a unique identifier (called its Code) and a textual description (called its Name). Reference Terminologies usually include extensive attributes on their concepts/codes and relationships between its concepts/codes which support aggregation and inference. Examples of Reference Terminologies include ICD-10, LOINC and SNOMED CT. Reference Terminologies are usually not user-facing (they are not used as Interface Terminologies) but are used in back-end systems such as Clinical Data Repositories to support semantic interoperability.

**Mapping** – A Mapping is a correspondence between two Terminologies. Mappings are used to “translate” from one Terminology to another, such as from an Interface Terminology to a Reference Terminology. Because of the significant differences between terminologies (including differences in their developers, their focus, and their “world-view”) mappings are very seldom equivalences and are often use-case dependent. They are at best, “computationally useful correspondences” that enable healthcare computer systems to consistently compile, aggregate, and report clinical information in useful ways.

Building a national Terminology Services program for health information exchange is a five step process:

1. Conduct an environmental assessment.
2. Perform a data inventory.
3. Establish an overall Terminology Services plan.
4. Create a plan for coding, data standardization, mapping and data modeling.
5. Integrate terminology services
6. Establish governance and maintenance structures.

The remainder of this guide outlines this process.

**Step One: Environmental Assessment**

An environmental assessment is a holistic overview of the existing health system’s policies and procedures. In support of a terminology Services plan, the assessment focuses on the creation, management and use of clinical data, including terminologies, clinical vocabularies and other health data standards.

Key to success of any HIE effort is the ability to integrate, or bring together, existing and future healthcare data sources. Planning for this integration requires an understanding of the HIE’s current “data environment”. In in other words, the attributes of the existing edge (feeder) systems – lab systems, EMRs, mobile platforms, etc. – whose data are to be integrated into the HIE. We have developed a simple 2 x 2 matrix that can assist in understanding the state of this infrastructure. This state, in turn, helps determine a number of the subsequent operational and policy decisions that are required to implement Terminology Services.

The two dimensions of the matrix (see below) are:

1. Data Element Control – Does the HIE governing body [right phrase?] have control, either directly or via policy, of the data elements/encoding that are transmitted by the edge systems? In a mature, existing environment, data elements are likely to have been developed overtime and are not based on any existing national or international standard. Policy mandates, for example, “all systems shall transmit in LOINC”, which can be effective in an emerging infrastructure, may not be viable in a mature infrastructure. Where data element control is not possible, additional data mapping work is likely required to ensure that data held in the repository is comparable.
2. Message Format Control – A companion to data element control is message format control. Do existing edge system transmit data in industry standard formats, such as HL7 V3, or must a variety of message formats be supported?

[picture]

In the upper right quadrant, edge systems transmit messages in standard formats, using standard data formats. Note that this does NOT mean that the edge systems use Reference Terminologies “natively, as their Interface Terminologies; only that outgoing messages include both the verbatim (interface) forms and the normalized reference forms. It is always recommended that the original (verbatim) form be included (not replaced) for clinical accuracy. HIEs in this quadrant do not require message transformation and normalization although message validation is still required.

In the lower left quadrant, edge systems transmit messages in non-standard formats with non-standard data elements. This quadrant requires that a central message handling system must perform message transformation to a standard form, e.g. HL7 V3, and must use maps to normalize data elements to standard (reference) forms. HIEs must develop these transformation and mapping engines as part of HIE installation and ongoing maintenance. It is important to remember that no terminology map is ever static – both the source and target terminologies will necessarily change in response to a changing healthcare environment, requiring ongoing vigilance and maintenance of the mappings.

Where the HIT infrastructure is new or recently evolving, the governing body has significant opportunities to define new data sources. The body can develop, or more cost-effectively acquire, standardized interface terminologies to meet the needs of edge applications. Often these interface terminology come with mappings to appropriate reference standards. The governing body can then maintain these terminologies centrally, in the Terminology Services component, distributing them on a regular basis to edge systems.

If necessary, the health system can also develop or acquire the requisite mappings between the edge system interface terminologies and the desired (set of) reference terminologies to meet normalization requirements of the SHR. Again, these mappings should be persisted and maintained within the central Terminology Services component and distributed to the edge systems on a regular basis. The organization’s position in the 2 x 2 control matrix will direct which of these options is most cost-effective.

Once the basic data environment is understood, more details assessments can be made. The list below suggests common areas that are included in an Environmental Assessment. For example, the health ministry of Rwanda worked with outside consultants to evaluate available resources, as well as the health system’s capacity in handle codes and standards. Among the questions posed in Rwanda with applicability to other nations:

* **Resources**: What are the country’s human, financial and technology resources for tackling this project?
* **Maturity:** What is the country’s level of maturity and experience in dealing with information systems, classification, coding and standards?
* **Track record**: Are there entities in the country that have already achieved gains in applying codes and standards? Are adequate tools in place?
* **Standardization:** Which terminologies are currently in use? What results have the terminologies achieved?
* **Governance:** How strong is the movement toward standardization? Is the HIE governing body in a position to require compliance with codes and standards?

[is this the right list? Is Rwanda reference needed?]

Other criteria should also be addressed. These include:

* **Technology:** Is the required technology available? How easily and at what cost can the health system implement this technology? How can the health system remove or minimize barriers to implementation?
* **Policy:** How relevant is existing thinking, policy and legislation? How could current policies facilitate or disrupt the program? How easily and fast could the government develop or modify policies or pass legislation?
* **Use cases**: Will the program have an adequate number of high-quality use cases? (state what good use cases need to have)
* **Barriers:** Does the program face barriers or roadblocks to innovation, such as culture, education, politics, technology, human resources and financing? How can these barriers or roadblocks be minimized or removed?
* **Enforcement**: How will the healthcare system/ government enforce code sets and ensure compliance? How will it pursue enforcement via fines and penalties if healthcare professionals lack the resources/capacity to implement the program?
* **Feasibility:** Is this program feasible, workable and practical? Consider the case of Rwanda. The country mandated the use of SNOMED only to discover that SNOMED was unable to function there. [why? What is this about?] When Partners in Health decided to offer maternal and child healthcare service to Rwandan patients, it learned that existing policies /would limit success. [what policies?] The program initially generated intense friction among providers, researchers and a government pushing for standardization.

**Step Two: Conduct a Data Inventory**

A data inventory is the next logical step after an Environmental Assessment. The Data Inventory identifies and catalogs the specific data sources and coding systems in use within the HIE’s community. Sometimes the data inventory becomes just part of the environmental assessment, but in other cases, a specific data inventory task is required due to the level of detail required.

Typical steps of a data inventory include:

* Identification of each of the existing edge systems or data sources. The primary use-case of the system should be documented: a maternal health questionnaire, an eHealth (mobile) monitoring system, an outpatient EMR. Edge system identification can often be linked to the development of the initial facility catalog for the Facility Registry, but note that a given facility may use multiple electronic systems and thus represent multiple data sources.
* For each of the data sources, documentation of the types of data collected and what, if any, coding system is being used. A regional clinical laboratory might report test results in LOINC, for example, but a mobile data collection application may use a local, internal dictionary for chief complaints.

Other considerations of the data inventory can be:

* **Stability:** How stable are the local dictionaries in use? Do they have a formal governance structure or are they undergoing constant modification?
* **Provider understanding**: Are healthcare providers able to understand how to properly use the existing name/codes? Is additional training required to ensure clinical accuracy??
* **Use Cases**: Have the existing use-cases been document? Are the desired clinical use-cases covered? Would intense focus on a specific condition like diabetes or obesity improve the population’s overall health status?

The Data Inventory represents the “current state” of your clinical data infrastructure. It is likely that one result of the inventory is identification of data “gaps”: clinical areas that are desired to be present in the HIE (part of the targeted use-cases), but are currently not supported. These “future state” efforts can then be cleared called out in the HIE and Terminology Services implementation plan.

**Step Three: Establish a Terminology Services Plan**

The results of the previous two steps (Environmental Assessment and Data Inventory) inform the development of a detailed Terminology Services plan. The Terminology Services plan lays out a “roadmap” for the development, implementation, maintenance and governance of a national Terminology Services capability. The plan should cover both the “what” (the standards to be used in each of the clinical use-cases/domains and the messaging protocols to be supported) as well as the “how” (the hardware, systems software and software applications).

Overall, the plan should document the full terminology service roll-out, including requirements, implementation steps, participants and pathways for addressing problems and crises. Typical areas to address within the plan are:

[these need a good review]

* **Requirements:** What are the underlying health needs and priorities of the health system and Ministry of Health? What are the goals and objectives of the plan? What are its anticipated quantitative and qualitative results? How will implementation of the plan improve care quality, safety, efficiency, cost, access and outcomes? What use=cases are most critical now and which ones can be deferred until later?
* **Resources**: What kinds of resources—human, financial and technological—are required to develop and implement the plan through the life cycle? How can these resources be mobilized? Who will participate in plan development and implementation? Who, for example, will assume responsibility for needs assessment, implementation, communication, training, tracking and evaluation?
* **Implementation**: Through which processes or steps will the plan be created and implemented? Who will do what when and how and at what cost?
* **Barriers**: How will potential barriers and roadblocks be minimized or removed? How will crises be handled?
* **Timeframe**: Over what timeframe will the plan be developed and implemented? What are the key targets and milestones?
* **Evaluation:** How will plan development and implementation be monitored and evaluated?

Create a plan where Terminology Services supports the overall goals of the HIE. Typical “stakeholders” that should be addressed include:

**Healthcare professionals**: Be prepared to advise physicians, nurses and other clinicians on the use of the selected terminologies. It is not necessary that every provider “speak the same language”. Interface Terminologies should be used to simplify data entry and user comfort with the data collection systems. The objective of the Interoperability and Terminology Services layers is to ensure that these Interface Terminologies come together seamlessly to form a standardized medical record.

**Administrators:** Address the needs of administrators within the Ministry or other governing body. These professionals may not understand the intricacies of the delivery system, but are very focused on utilization and/or quality metrics of the overall HIE. How will value be delivered to these stakeholders?

**Systems Analysts:** Analysts are the “technologists” of the HIE. The Terminology Services component must be able to validate health data sent from edge systems to the shared health record and meet analyst’s need for consistent, reproducible reports and aggregations. The objective is for all users to have a common, shared understanding of health information.

In developing a plan, look first at the requirements of the edge systems and then review how you plan to act upon these requirements. By identifying requirements, you can begin to isolate goals, objectives and targets. The ideal scenario is to make the selected terminology standards and classifications (including local interface terminologies) easily available to the edge systems from a single, accessible resource.

As required, national and international standards committees can often be of assistance to recommend technology and governance policies and oversee program roll-outs, maintenance, enforcement and compliance.

[how much of this detail do we feel is appropriate?]

Keep in mind that comprehensive, well-intended plans sometimes fail to generate anticipated results. In Rwanda, for example, the ministry of health developed a plan that identified stakeholders, developers, and a logistics management system.

A ministerial order dictated that any developer or group that wanted to develop/share information electronically had to rely on the same standards. This applied to the providers who delivered and recorded care, as well as to healthcare financing and insurance transactions.

Despite strong leadership from the ministry of health, Rwanda’s standards directive failed to generate positive health outcomes. The country’s limited resources made it difficult for the ministry to sustain the program. Because few professionals understood how to choose and use available code sets and no one used ICD-10, physicians had to write in codes by hand. That, in turn, created a demand for education and training.

The original centralized plan has now evolved into a more decentralized one. The Ministry of Health makes decisions about standardization while an external healthcare consultant chooses the specific mappings and codes. After developing a requirements document and reviewing paper forms featuring some 100 terms, Rwanda generated code sets and loaded a complete set of ICD 10 and LOINC to implement every code.

Sierra Leone, however, took a different approach. Instead of working with the universe of potential codes and insisting on standardization, it focused on a subset of codes-- -20 of the most common conditions and symptoms. But doing so required that the Health Ministry train providers in the use of terms like “edema” in lieu of “swelling” and find better ways to track a pregnant woman with a condition like malaria. Getting these results wasn’t easy. A training program with exercises called on healthcare providers to practice by writing in sample codes.

The Philippines, on the other hand, has already begun to create a dictionary and relies on the U.S.-based disease classification system. With a highly educated workforce, the country can code electronic health records overnight. Entire teams of professionals now review the latest version of ICD-10 to develop a list of required terms. The majority of countries in South East Asia, including Indonesia, are in a similar position.

[the sections below expand on (some of) the plan dimensions. What level of detail is necessary? What sections should be added?]

**Requirements: Use Cases**

The most effective way to understand and document the actual system requirements is through detailed use-case descriptions. [expand on example use cases, how are use-cases developed]

The most important questions for a nation’s health system to pose are these: What data should be captured so that the use-case can be met? When and where should the data be captured?

**Resources: People and Technology**

In identifying healthcare professionals with the right mix of talent and skill, rely on a terminology expert who can navigate between the real world of healthcare delivery and code use. This person should understand how disciplines like maternal and child health function in the real world, as well as how to make terminologies available to providers and build vocabularies internally.

Making the right decisions about technology calls for internal expertise to build clinical environments, translate codes into content and make content available for provider use. . While it’s easy for a health system to import expertise from other countries, it’s important to develop talent, skill, knowledge and experience on a local level using local professionals. Potential staff can be drawn form individuals having a variety of backgrounds such as health systems coders, researchers, informaticists, and even medical and laboratory technicians.

[what are the key Roles that are required:]

Terminology Services Administrator – a technical resource that maintains the Terminology Services component. Responsible for loading new terminology files and exporting artifacts to other components. The Terminology Administrator role can often be part of the responsibilities of an overall HIR Administrator.

Chief Terminologist –is responsible for the selection, validation and curation of terminology content in the Terminology Service. The Chief Terminologist should have a good understanding of all of the Interface and Reference Terminologies used in the HIE and have sufficient clinical informatics background to service as the champion for Terminology Services among all HIE stakeholders.

Subject Matter Experts – provide domain-specific expertise to the Terminology Services team. These SMEs may be part-time participants in Terminology Services but can play important roles in the evaluation of prospective Interface and Reference Terminologies, data modeling decisions, and development of mappings.

Before rushing to recruit and hire workers, be sure to review project and program goals, objectives, tasks, and roles. The key question: What kinds of knowledge, experience, competency and interpersonal skills are needed to fulfill each critical role within the project?

As a second step, pose these questions: Is the health system able to fill these roles with professionals in the immediate environment, assuming these professionals could participate in extensive online and offline education and training? Or would the health system benefit more from importing professionals to coach, mentor and work with locals to develop knowledge, skill and expertise over time?

In summary,

* Focus on a specific use case.
* Examine goals and tasks.
* Review professional roles.
* Evaluate local vs imported talent.

**Evaluation**

The best way to monitor plan deployment is through quarterly or annual reviews or preferably, on a real-time basis. Among the questions to address: Which codes are being used the most? How do healthcare professionals respond to and use codes? How are codes validated? How are alternative codes deployed?

One model for code analysis and review is AMPATH, which is located in Kenya and works in partnership with Indiana University. Working groups on informatics and forms meet often to discuss and debate the addition of new fields and questions and to ensure that providers understand the meaning varied codes must capture. Doing so is important in building accurate billing codes.

**BOX : Questions to Pose in Ongoing Code Evaluation**

Variations of working groups like Ampath in Kenya can help address multiple issues related to code performance:

* **Code appropriateness**: What are the most appropriate codes and storage systems?
* **Code access**: How can the healthcare system best access these codes--electronically or via paper based forms?
* **Domain development**: How should the healthcare system create new domains such as HIV management?
* **Process:** What is the preferred process for code selection, implementation and evaluation?
* **Asset inventory**: How can the healthcare system perform an asset inventory that identifies data definitions and dictionaries? Healthcare systems should know:
  + Which tools providers use most often
  + Which questions providers ask most frequently
  + Which codes providers access and use
* (END OF BOX???)

Among the takeaways for step four are these:

* Map at the highest level of granularity.
* Use reference terminology structures that support data roll-ups such as the total number of patients with a specific condition like asthma.
* Identify use cases and the types of reports you hope to create.
* Develop a strategy for matching use cases with data and reference standards.

**Step Four: Develop a Plan to Address Data Capture/Modeling, Coding/Standardization, and Mapping**

Once a general Terminology Services plan has been developed, attention moves to the specifics of capturing, coding and mapping the specific data elements targeted by the HIE. The sections below discuss the considerations and procedures for working through these activities.

**Data Capture/Modeling**

Considerations of data capture and modeling begin with the target use-cases defined for the HIE. Available data sources and data formats are initially drawn from the data Inventory. Do these data sources provide the information necessary to satisfy the primary use-cases?

Feel free to develop a sample first use case, making sure you have adequate resources to address the nature, scope and function of the case. For example, if you see an opportunity to develop a use case around maternal and child health, focus on types of clinical visits.

Validate draft use-cases with representative providers to ensure that the desired data can actually be collected in forms amenable to computer processing. This analysis may identify areas where new forms or data capture applications are necessary.

While paper forms are often a starting point for data capture (and terminology standardization) these forms often present challenges when converting (via scanning or data entry) to electronic forms. A box labeled “Pregnant” can be interpreted in many ways: now pregnant, ever pregnant, how long pregnant, etc. Data capture policies and processes should be put in place to ensure that ambiguities such as these are eliminated as much as possible and the data collected be as quantitative as possible to facilitate accurate analysis.

The transition from paper to electronic forms involves the transformation of fields found on these forms into electronic variables and then mapping these variables to standards. Among the steps:

* Identify the fields within pre-existing paper forms.
* Determine the meaning of these fields to providers: How do providers interpret and use these fields?
* Consider whether an existing Interface Terminology could provide improved data capture.
* Identify whether the fields have associated representation (codes) in Reference terminologies such as SNOMED CT, LOINC or ICD-10.
* If representative terms do not exist, can new terms be added, perhaps by working with the standards organization.

Some countries, including Rwanda, have generated country specific codes by reaching out to standards bodies that to guide code creation. Others have worked to translate codes like LOINC into their own language.

**Coding/Standardization**

Consistent and accurate analysis of clinical information from multiple sources requires that the information be quantitative and easily comparable. Comparability is most easily achieved by defining a set of standard Reference Terminologies to which input data is coded.

There are many such Reference Terminologies in use around the world: ICPC, ICD-9, ICD-10, LOINC, SNOMED CT, drug terminologies, etc., many of which may have overlapping use-cases and clinical domains. I is not necessary to select a single standard for all domains/use-cases. LOINC may the right standard for lab results, but SNOMED CT may be preferable for Diseases and Complaints. One key consideration is granularity: LOINC, for example, has specific codes based on substance measured, type of result and even type of machine performing the results. Reference terminology selection should be based at least in part on the required granularity desired, and the availability of input data to meet this granularity.

It is also not necessary to work with the totality of a reference standard. SNOMED CT has over 300,000 codes, but a specific use-case may only need a few hundred for full coverage. The Terminology Service has capabilities to define “subsets” or value-sets of larger terminologies to simplify use and deployment. Take advantage of these capabilities in your deployment models. Begin the process of developing a plan with a review of use-cases and workflows, asking: What are the codes needed to model these use cases and workflows?

Selection of the “right” standard(s) in a given HIE environment is often a mix of technical, political and economic considerations. The best approach for health systems is to choose standards based on familiarity and experience. If you lack expertise in standards selection, consider standards already in widespread use by other countries. Countries should look to international bodies, experienced consultants and nations who have developed similar systems to assist in their information gathering around standards.

Finally, whatever decision is made, it must be a “long-term” one. The value of an HIE is in its shared data repository and frequent changes to the underlying Reference Terminologies can result in expensive data conversions and loss of historical compatibility.

**Mapping**

The Data Inventory defined the source data elements of the HIE. These are likely encoded in Interface Terminologies. As was discussed earlier, some countries may be able to mandate the Interface and reference Terminologies used in the edge and HIE systems. In other cases, HIE policy can select the Reference Terminologies that will be used in the Shared Health Record, but existing Interface Terminologies must be supported. How are the input data elements from an Interface terminology converted into standard forms from the Reference terminology? This is the responsibility of the Mapping function in Terminology Services.

Many commercially available Interface Terminologies include mappings to Reference Terminology standards. And these mappings are maintained by the commercial organization as interface terms, and standard terms, change over time. Use of these Interface Terminologies greatly reducing the burden on the HIE. Most all HIEs, however, have some “locally-developed” Interface Terminologies (or adhoc dictionaries) that must be mapped to the HIE’s selected standards.

Mapping involves the creation of correspondences between the interface terms and code/concepts in the Reference Terminologies. We say “correspondences” because in many cases there is no exact equivalence between codes in different terminologies. A “best match” condition must be determined, often based on the end objective or use-case of the data. Is the objective of the mapping to facilitate population analysis or public health reporting, or it is to create a standardized bill? These two use-cases could result in different mapping sets.

What health systems need most is a retrospective batch approach to standardizing data combined with a more forward looking, visionary approach of how they hope to exchange and use data. The emerging question is this: How does this health system develop a plan for mapping locally coded information to standard data representations?

While some mapping can be automated, all maps require clinical or subject-matter-expert (SME) mediation. Sometimes, as described above, maps are available from a commercial or SDO source. At other times, the HIE organization must develop these maps for their unique source data fields. Such map development can be contracted to organizations specializing in data interoperability, or done internally by the organizations terminologists using available mapping tools.

Whichever development methodology is adopted, it is important to remember that no clinical map can be static. New laboratory tests are created, new diseases identified, new procedures are invented. All these factors introduce change into both source data elements and reference standards. The organization’s Terminology Services plan must include components for the governance and ongoing maintenance of the clinical maps required for their use-cases.

**Step Five: Integrate Terminology Services**

Terminology Services plays a vital role by validating and standardizing the data flowing through the HIE. This underlying interoperability-enabling function coordinates every important element of patient care: location, provider, patient, and care delivered.

There are two primary aspects of Terminology Services:

1. Terminology Server: A hardware/software component that resides in the OpenHIE infrastructure and acts as a repository for the organization’s terminology assets (Interface Terminologies, Reference Terminology, and Mappings), and
2. Terminology Service APIs: Programming interfaces that enable other OpenHIE components such as the Interoperability Layer and Shared Health Record to efficiently access interoperability functions. The OpenHIE Terminology Server uses the HL7 Common Terminology Services 2 (CTS 2) standard interface for accessing terminology Services.

Standing up an OpenHIE Terminology Server is a straightforward process. Detailed technical information is available on the OpenHIE web site, but the basic steps are:

1. Acquire the required hardware and systems software.
2. Install the Terminology Server software.
3. Load the desired Interface and Reference Terminologies. These can be acquired from the OpenHIE site, from commercial content distributors, or directly from associated Standards development organizations.
4. Develop or acquire required data maps and load then into the Terminology Server.
5. Using the Terminology Server’s API, connect other HIE components to achieve validation, lookup and conversion operations.

While most of the Terminology Server’s activity will be with other HIE components, the Server also provides a set of management applications. These applications assist in server operations (start/stop, load, export), and provide graphical interfaces for the organization’s terminologists to browse, study, and even develop, terminologies and mappings. Rwanda, for example, maps every concept or item within its data dictionary to standard terminologies. In its role as manager of the terminology service, the Rwandan Ministry of Health manually synchronizes and updates dictionaries for more than 400 clinics. Ministry of Health healthcare professionals routinely visit clinics to complete dictionary updates.

[how specific do we want to get re OpenMRS dictionaries?]

**Early involvement of clinics**. Countries that want to rely on Open MRS should involve the terminology service and clinics early on. A professional from the ministry of health should manage the Open MRS dictionary, making sure that information coming into the HIE is validated. For example, if a form features 20 routine observations, how does each observation—birth weight, for example--get validated?

**Standards for communicating terminology codes**. Know which standards to use to communicate with the terminology service. This typically involves CTS and sharing value sets within an HIE profile and other components of the HIE. The best advice: Use Open MRS and related software to develop a shared record and then address the problem of dictionary management. Develop guidelines on how to communicate, as well as a process that validates and synchronizes terminology sets.

Unfortunately, many health systems fail to look at the big picture, including the impact of terminology codes on patient care. They rush to employ system architecture, which is important but only postpones the task of reaching consensus on terms.

**Step 6: Create a structure for maintenance and governance**

This step involves developing a plan to maintain and update input sources, maps and coding systems. Consider these questions:

* **Structure:** What’s the best structure for maintenance-- centralized or federated model?
* **Legislation:** Should a national standards framework become part of the legislative framework for health insurance?
* **Reporting**: Should providers report on quality indicators to the ministry of health? If so, which indicators should they report and how often?
* **Policy**: How should elements like structure and reporting show up in national healthcare policy? .

The best approach is to not make acceptance and use of national coding standards an option. Health systems will never achieve interoperability by accident or luck. Interoperability will come to pass only when health systems adopt national or international standards. In most cases, this calls for a national mandate with enough legislative backbone to allow for provider compliance and enforcement.

The key is knowing how to choose standards and then operationalize these standards within a Terminology Services component that’s capable of performing these functions:

* Centralize access to, and management of, all standard terminologies used in the HIE
* Produce tools and services that create new mappings
* Validate incoming transactions, ensuring the receipt of standard mappings for local nonstandard codes
* Translate message content to add codification to Reference Terminologies enabled accurate, reproducible data analysis, decision support and reporting

Also important is using the terminology server to report on several critical issues:

* **Code popularity**: Which codes are most popular?
* **Error generation**: Which codes tend to generate errors?
* **Relationships:** Which codes are related to each other?
* **Use**: Which codes do providers use in conjunction?

Before a health system can operationalize a Terminology Tervice, it needs to fully understand its chosen coding system and map local codes to standard codes. Just as important is deciding which functions the health system will perform.

Not all health systems are interested in performing all functions. For example, in its work with Rwanda, the Regenstrief Institute evaluates c all incoming transactions. When the system generates exceptions due to error, they show up within an exception cue. This allows the health system to replace codes and evaluate how codes function.

**Looking Forward**

No matter what a country’s economic, social and health status, it can learn from how other nations have generated guidelines and terminology sets. With these the insights in this guide, you’ll be better positioned to make timely, accurate decisions about policy, planning, technology adoption and implementation of terminology services. What you can accomplish in one arena of healthcare is full of implications and insights for other diseases and conditions The future of healthcare—and the health and well-being of the patients we serve—is as broad an our imaginations.

**Resources**

Regenstrief Institute

<http://www.regenstrief.org>

OpenHIE

<http://ohie.org/>

OpenHIE Sandbox

https://wiki.ohie.org/display/resources/OpenHIE+Sandbox

Global Healthcare Delivery Online

http://www.ghdonline.org/

Regional Data Normalization Editorial Framework

http://www.grrhio.org/providers/services.aspx

Implementation Guide: Health Facilities Registries (Link ???)

Jembi Projects: Rwanda Health Enterprise Archiecture

<http://www.jembi.org/project/rwanda-health-enterprise-architecture-rhea/>

# Project Summary for CTS 2 incorporation of SVS

<http://www.hl7.org/special/committees/projman/searchableprojectindex.cfm?action=edit&ProjectNumber=946>

CTS2 Implementations

<http://informatics.mayo.edu/cts2/index.php/Implementations>

Derek Ritz Presejnts Collaboration Health Plan at RHEA

<http://www.youtube.com/watch?v=bIX2DKJ_K80>

Health IT: the African Approach

<http://www.himssasiapac.org/12/docs/speakerspresentations/standardsninteroperability/SI10_HealthITTheAfricanApproach.pdf>