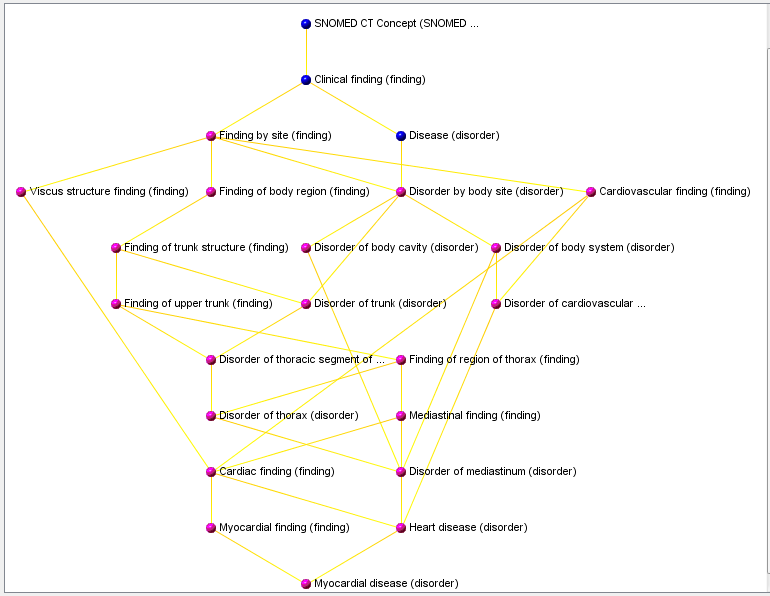
OHIE Terminology Services

Implementation Guide



Draft 3 - OpenHIE - 2014

Table of Contents

[Introduction 4](#_Toc385785648)

[Background 4](#_Toc385785649)

[Goal and Objectives 5](#_Toc385785650)

[Terminology Services and Terminology Management 6](#_Toc385785651)

[Definition and Benefits 6](#_Toc385785652)

[Step One: Environmental Assessment 9](#_Toc385785653)

[Step Two: Conduct a Data Inventory 12](#_Toc385785654)

[Step Three: Establish a Terminology Services Plan 13](#_Toc385785655)

[Requirements 13](#_Toc385785656)

[Resources 14](#_Toc385785657)

[Technology 15](#_Toc385785658)

[Implementation 15](#_Toc385785659)

[Governance 16](#_Toc385785660)

[Evaluation 18](#_Toc385785661)

[Step Four: Develop a Plan to Address Data Capture, Coding, and Mapping 19](#_Toc385785662)

[Data Capture 19](#_Toc385785663)

[Coding 20](#_Toc385785664)

[Mapping 21](#_Toc385785665)

[Step Five: Integrate Terminology Services 22](#_Toc385785666)

[Looking Forward 23](#_Toc385785667)

[Resources 23](#_Toc385785668)

# 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 Open HIE 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.

One ambulatory 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 coded in an industry standard 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”.

This Implementation Guide will describe the rationale behind Terminology Services, the functions of a Terminology Services component in support of an HIE, and how Terminology Services can be effectively created, implemented and managed. A major focus of the document is the five step process for building a national Terminology Services capability. At each step, key questions must be answered:

* Conduct an environmental assessment – Who is managing the clinical data? Is there an existing infrastructure or is a new one being created?
* Perform a data inventory – What data is currently present? In what forms? What additional data is anticipated in the future?
* Establish an overall Terminology Services plan – How will Terminology Services be deployed? How will it be managed? What governance structures must be created?
* Create a plan for coding, data standardization, mapping and data modeling – How will the various components of Terminology Services be developed?
* Integrate terminology services – How can Terminology Services be most effectively deployed in the HIE?

Throughout the document you will see that the development of a Terminology Services capability is not simply a technical problem, but one that requires balance and consensus among technical capabilities, economic realities and socio-political complexities.

## Goal and Objectives

The goal of this Guide is to assist health system stakeholders – planners, designers and implementers – 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 objectives are to:

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

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, ministers of health, health system professionals and information system specialists 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, data mapping, and implementation, Terminology Services help countries make use of a variety of different terminologies found within electronic health records (EHRs), data warehouses, and various other 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, safety and reporting.
* 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, evaluation 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 accessed 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 clinical 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 that developed by the Maternal Concept Lab, 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 local data source systems. Each element in a Reference Terminologyis a Concept (a unit of meaning) and usually includes a unique identifier (called its Code) and a text description (called its Name). Reference Terminologies typically 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 Decision Support Systems and Clinical Data Repositories to support semantic interoperability.

**Mapping** – A Mapping is a correspondence between the Concepts in two different 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.

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 described above, these systems will often use *Interface Terminologies* (proprietary or local dictionaries) to document care in a manner appropriate to their care settings. Once these data sets participate in an HIE, however, it is imperative that these locally-coded sets be associated with (or *mapped to*) standard *Reference Terminologies* to enable regional and national-level analysis.

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.

As outlined in the Introduction, 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

The remainder of this Guide describes this process.

# Step One: Environmental Assessment

A Terminology Services environmental assessment is an analysis of a health system’s “current state” with regard to clinical information: its data and messaging 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 source data 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:

Data Element Control – Does the HIE governing body have control, either directly or via policy, of the data elements/encoding that are transmitted by the edge systems? In a mature health information technology environment, data elements are likely to have been developed over time and are not based on any 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 feasible 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.

Message Format Control – A companion to data element control is message format control. Do existing source systems transmit data in industry standard formats, such as HL7 V3, or must a variety of message formats (or other data structures) be supported? What formats are currently in use, e.g., HL7 V2 or even proprietary?

*Data Element Control*

High

Low

Low High

*Message Format Control*

In the upper right quadrant, edge systems transmit messages with standardized data elements, using standard message 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 with non-standard data elements in non-standard message formats. 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 standards. 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 HIE. 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.

It must be recognized that this planning matrix is not a “road map” or a “maturity model”. There is no right or wrong quadrant. The position in the matrix simply informs the organization as to what types of actions need to be taken in subsequent implementation steps.

Once the basic data environment is understood, more detailed assessments can be made. The list below suggests common areas that are included in an Environmental Assessment.

**Resources**: What are the country’s human, financial and technology information resources for tackling this data standardization?

**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 ministry, or equivalent governing body, in a position to require compliance with codes and standards?

**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**: Does the program have an adequate number of high-quality use cases? Successful HIE deployments focus on specific, well-documented use cases. Use cases must clearly define the actors, activities, and ultimate measurement criteria.

**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?

Recognizing the lack of experienced internal resources, the Rwanda Ministry of Health worked with outside consultants to evaluate available resources, as well as the health system’s capacity to handle codes and standards. Rwanda originally considered mandating the use of SNOMED CT only to discover that the cost of SNOMED CT was prohibitive and did not satisfy their most important use case: maternal health. When Partners in Health decided to offer maternal and child healthcare service to Rwandan patients, it learned that existing policies /would limit success. The program initially generated intense friction among providers, researchers and a government pushing for standardization. [need clarification here].

# 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:

1. Identification of each of the existing data sources (a maternal health questionnaire, an eHealth (mobile) monitoring system, an outpatient EMR) and its primary use-case (capture of peri-natal data, vital signs, clinical encounter summary). Source data 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.
2. 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 and Maintenance:** How stable are the local dictionaries in use? Do they have a formal governance structure or are they undergoing constant, perhaps haphazard, modification? What are the current mechanisms, processes and tools for editing and updating the local dictionaries?
* **Availability**: In what forms is the clinical information available? Databases, Excel spreadsheets, text documents, hard-copy only?
* **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 documented and 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 the “why” (the goals of the HIE), the “what” (the standards and protocols to be used in each of the clinical use-cases/domains and the hardware, systems software and software applications to be installed), the “how” (the timeline and action plan for the actual implementation), and the “who” (the individuals who will use, manage, and govern the infrastructure).

The objective of the plan, like this document, is to inform HIE stakeholders. These are the individuals, and groups, upon whose support the success of the HIE is dependent. Typical stakeholders include:

**Healthcare professionals**: Be prepared to advise physicians, nurses, para-professionals and health delivery administrators 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 the data using the, possibly various, 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 implementers and maintainers of the HIE. The Terminology Services component must be able to validate health data sent from source 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.

Overall, the plan should document the full Terminology Service roll-out, including requirements, implementation steps, participants and pathways for addressing problems and crises. Most importantly, create a plan that supports the overall goals of the HIE. The Terminology Service is not an end in itself. It exists to facilitate the flow of consistent and comparable data across the HIE.

Specific areas to address within the plan are described below.

## Requirements

This is the “why” of the Terminology Services implementation. Understanding these requirements begins with the previously cited overall use-cases of the HIE. What are the underlying health needs and priorities of the health system or Ministry of Health? What are its goals and objectives? What are the anticipated quantitative and qualitative results? How will implementation of these use-cases improve care quality, safety, efficiency, cost, access and outcomes? What use-cases are most critical now and which ones can be deferred until later? How will the proposed use-cases be addressed?

The HIE use-cases, which should be outlined in the Terminology Services plan, drive the specific requirements for the Terminology Services component.

Consider the following (simplified) HIE use-cases:

* Report the malnutrition rates of children in each village in a district before and for each month thereafter following implementation of a new supplemental vitamin program.
* Track and flowchart the blood glucose levels of a target population that is nomadic and receives care from multiple care settings.

Both use-case describe a highly distributed data collection effort. What data should be captured so that the use-cases can be met? In the first case, the data may be qualitative based on provider interpretation: what is “malnutrition”? In the second, the data is quantitative, reflecting specific laboratory results. When and where should this data be captured? Will the data be captured on a paper form or electronically? What coding, if any, can be supported by the data collection process? These are the questions that should be answered in the requirements section.

## Resources

Resources are the answer to the “who” of Terminology Services. What types of individuals are required to develop and implement the plan through the life cycle? How can these individuals be mobilized? Who will participate in implementation and evolution? Who, for example, will assume responsibility for needs assessment, implementation, communication, training, tracking and evaluation?

Identifying healthcare professionals with the right mix of talent and skill relies on a terminology expert who can navigate between the real world of healthcare delivery and terminology use. This person should understand how disciplines like maternal and child health function in the real world, as well as how data standards are built, deployed and used in the clinical setting.

Making the right decisions about a Terminology Services implementation calls for experience in building clinical environments, translating healthcare reality into concepts and coded content, and making this content available for provider use. While it may be easiest initially 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 resources can be drawn from individuals having a variety of backgrounds such as health systems coders, researchers, physician or nurse informaticists, and even medical and laboratory technicians.

Based on experience in many Terminology Services deployments, three key implementation roles can be identified:

**Terminology Services Administrator** – The resource who maintains and runs the Terminology Services component. The Terminology Services Administrator is responsible for acquiring the necessary terminology data files, loading them into the Terminology Services component and exporting terminology artifacts like mappings to other HIE components. They maintain the Terminology Services software and associated management tools. Depending on the size of the overall HIE installation, this administrator can be a dedicated individual or the shared responsibility of an overall HIE Administrator.

**Chief Terminologist** – The 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** – Subject Matter Exports (SMEs) provide domain-specific expertise to the Terminology Services team. SMEs may be part-time participants in Terminology Services but play important roles in the evaluation of prospective Interface and Reference Terminologies, data modeling decisions, and especially in the development of data 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?

Finally ask 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 local staff to develop the required knowledge, skill and expertise over time?

## Technology

Technology is the “what” of Terminology Services. The Terminology Services component consists of:

* Terminology Services server software and management tools
* Server/Operating System software, e.g. Windows Server or Linux
* Database software, e.g. MySQL, Oracle or SQL Server
* Associated hardware

The Terminology Services server resides in the HIE infrastructure and acts as the repository for the organization’s terminology assets (Interface Terminologies, Reference Terminology, and Mappings). As will be described later in Step Five, this server provides administrative/management tools to enable configuration and maintenance of the capability and expose programming interfaces that are used by other HIE components such as the Interoperability Layer to access base terminology and mapping data.

## Implementation

The implementation section of the Terminology Services Plan describes “how” the overall capability will be created and deployed in the HIE. What implementation processes or steps will be followed? Will the capability be deployed primarily centrally or in a distributed fashion? Who will do what when and how and at what cost?

No matter what the deployment methodology, the ultimate goal is to make the selected Interface Terminologies, Reference Terminologies and data Maps easily available to the edge systems from a single, accessible resource.

Standing up an OpenHIE Terminology Server is a straightforward process. The subcomponents above must be acquired, integrated and tested in order for Terminology Services to be operational in your environment. 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.

Further details on these last two points can be found in the descriptions of Steps Four and Five.

A critical part of the implementation plan should be the identification of barriers: how will potential barriers and roadblocks be minimized or removed? Obviously not all circumstances can be foreseen, but discussions with similar HIE installations can often identify potential common concerns:

**Connectivity**: Are network connections across the HIE reliable? Of sufficient bandwidth? A centralized Terminology Services implementation relies on high availability of connectivity. Problems in network infrastructure can often be overcome by using a more decentralized, e.g. ETL-based, approach.

**Hardware availability and support**: What backup facilities and processes are available? Can off-site or cloud-based services be used? Should redundant systems be employed to ensure required uptime?

The plan should describe the overall timeframe for the implementation and identify key (interim) targets and milestones. This enables ongoing tracking of implementation progress and remediation of problems before they become severe.

## Governance

A step frequently missing from Terminology Services plans is ongoing governance. Medicine is constantly changing, and with it, the local and standard terminologies in which medical data is coded. Changes can be due to economics, politics or advancing clinical knowledge, but whatever the reason, Terminology Services lives in a dynamic, evolving world.

Terminology Services governance involves developing a plan to evaluate, maintain and update input sources, maps and coding systems. Consider these questions:

**Structure**: What’s the best structure for maintenance—a centralized (national) model or a decentralized/ federated model based on states or provinces?

**Policy**: Should a national standards framework become part of the legislative framework for health insurance? Can such a mandated framework be policed?

**Reporting**: Should providers report on quality indicators? If so, which indicators should they report and how often? Are the necessary data elements for this reporting available in a standardized form in the HIE?

The most direct approach is to not make acceptance and use of national coding standards an option. Health systems do not achieve interoperability by accident or luck. Interoperability will only be achieved when health systems adopt national or international standards. In most cases, this calls for a national mandate with enough legislative support to allow for provider compliance and enforcement.

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, 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.

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. The governance structure should then:

* Centralize access to, and management of, all standard terminologies used in the HIE, for both Interface and Reference Terminologies.
* Create or acquire tools and services for the development and maintenance of data mappings
* Validate incoming transactions, ensuring the receipt of standard mappings for local nonstandard codes
* Translate message content to Reference Terminologies that enable accurate, reproducible data analysis, decision support and reporting

It is not necessary that all health systems to perform all governance functions. For example, in its work with Rwanda, the Regenstrief Institute evaluates all incoming data transactions. When exceptions are noted, e.g., unknown or erroneous input codes, the transaction show up on an exception queue. This allows the health system to replace codes and evaluate how codes function.

## Evaluation

The final aspect of the implementation plan should address the sort- and long-term evaluation process of the Terminology Services capability.

The best way to monitor component deployment is through quarterly or annual reviews or preferably, on a real-time basis. Among the questions to address in the evaluation are:

* Code Use: Which codes are being used the most? How do healthcare professionals respond to and use codes?
* Code validation: How are codes validated? How are alternative codes deployed?
* Errors: Which codes tend to generate errors? Is this due to choice of a coding system that does not meet the needs of the use-case, or lack of adequate training of the providers on the code system
* Redundancy: What codes are always used with others? “Over-coding” can be just as problematic as “under-coding”.

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.

In summary, when developing the Terminology Services plan:

* Focus on one, or more, specific use cases.
* Examine goals and tasks.
* Review professional roles.
* Evaluate local vs. imported talent.
* Acquire the requisite software and hardware
* Execute and monitor a well-defined implementation plan
* Evaluate your results

# Step Four: Develop a Plan to Address Data Capture, Coding, and Mapping

Once an overall 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

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, to develop a use case around maternal and child health, focus would typically be 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 are:

* Identify the fields within pre-existing paper forms. For example, if a form features 20 routine observations, what does each observation, e.g., birth weight, mean?
* Determine the meaning of these fields to providers: How do providers interpret and use these fields? Do all providers interpret the fields in the same way?
* How is the provider’s interpretation captured, in free text or codified?
* Could an existing Interface Terminology provide improved data capture?
* Do the required fields have appropriate 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.

When looking for a coding system (Interface or Reference Terminology) research code sets used in similar countries or HIEs, and those being developed by standards committees such as the International Healthcare Terminology Standards Development Organization (IHTSDO), WHO or HL7.

## Coding

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. It 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?

Sierra Leone, took such a domain-specific 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.

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 an HIE 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. 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.

Every implementation, and Reference Terminology selection strategy, is unique. Some countries like Rwanda have generated country-specific codes by reaching out to standards bodies to guide code creation. Others have used standard code systems but worked to translate systems like LOINC, primarily available in English, into their own language to facilitate local adoption.

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 data compatibility.

The Philippines has already begun to create a dictionary and relies on the ICD-10 disease classification system. With a highly educated workforce, the country felt the choice of ICD would facilitate electronic health records coding. 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 taking a similar approach.

## Mapping

The Data Inventory defined the source data elements of the HIE. These are likely encoded in local or 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.

Integration of Terminology Services was introduced in the Implementation subsection of **Step Three, The Terminology Services Plan**. As described there, the key integration aspect of Terminology Services is the computer programming interface, or API. This interface enables other OpenHIE components such as the Interoperability Layer and Shared Health Record to efficiently access Terminology Services data and functions.

Typical functions of the Service include:

* Code System Query: Is SNOMED CT available? (Catalog of Interface and Reference Terminologies)
* Concept/Code Validation: Is Code ‘123456789’ in SNOMED CT?
* Code Translation: What is the LOINC Code for Clinic A’s ‘CBC’?
* Value Set (Subset) Query: Is the Maternal Health Value Set available?
* Value Set Resolution: Return the contents of Maternal Health Value Set.

These functions are exposed through a documented technical interface. Many Terminology Service APIs are available but the OpenHIE Terminology Server uses the HL7 Common Terminology Services 2 (CTS 2) standard interface for accessing terminology Services.

Each HIE component has its own requirements from Terminology Services. The Interoperability Layer relies on the Terminology Service to map locally-coded items from incoming HL7 messages to their standard (Reference) codes. The Shared Health Record uses Value Sets from the Terminology Service to produce standard reports and Reference Terminology hierarchies to produce reproducible aggregations. Refer to the documentation on the individual OpenHIE components for more information on these interactions.

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 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.

# 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>