OHIE Client Registry

Planning and Implementation Guide



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Introduction

Client Registry Background

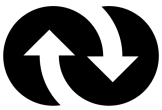
The identity of an individual who receives health services is crucial to enabling healthcare record sharing across institutions and systems. Yet, sharing healthcare records can be a challenge in a complex environment where there are multiple systems across multiple healthcare institutions and each institution and / or system has a different way to identify their clients. Even in environments where citizens are assigned national identification cards, there is still a need to ensure the unique identity of an individual amongst the myriad of fragmented information systems which collectively represent a person's electronic health record. The Client Registry is designed to assist in uniquely identifying individuals who receive healthcare services by:

- Maintaining a central registry of all patients and their demographics and assigning a unique identifier to each patient.
- Linking patient registration entries that result due to changes in patient demographics (patient moved to another location), data entry errors during patient registration, or missing demographic information.
- Enabling healthcare workers to identify facilities where a patient has received care.

> **Example:** An example of a client registry implemented with the OpenEMPI software can be found at http://demo.ohie.org/.

Purpose and Structure of the Guide

The purpose of this document, Client Registry Planning and Implementation Guide, is to provide guidance for a team or individual responsible for the end-to-end implementation of a Client Registry. The guide is intended to help teams think through the nuances and specific decisions required to implement a Client Registry. It is informed by past experiences and practices, promoted by OHIE and documented from ongoing implementations. (e.g., Rwanda) Because it is based upon implementation experiences the guide is a living document that will be updated based upon the experience and feedback of implementers. It is intended as a framework that can be adapted to a specific context. It is not intended to detail every aspect of running an information technology project.

Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
					
Analyze the Current Environment	**Establish Leadership and Ownership**	**Document Specifications and Requirements**	**Implement Specifications**	**Create Support Plan**	**Post-Production Evaluation**

This guide is broken into the following steps:

Step 1: Analyze the Current Environment
Step 2: Establish Leadership and Ownership
Step 3: Document Specifications and Requirements
Step 4: Implement Specifications
Step 5: Create Support Plan
Step 6: Post-Production Evaluation

Community Engagement

OpenHIE is designed to bring together community processes, broad reaching experience, and a series of re-usable technologies to give countries a framework in which they can start to address their own health information needs. Prior to planning and implementing a Client Registry, we recommend engaging with the OHIE Client Registry Community. The community is composed of technical and implementation stakeholders with experience developing and deploying client registries. The Client Registry Community is happy to discuss the particular details related to your local context and connect you to other relevant resources. Here are some ways to get started:

1. Join the Client Registry Group and introduce yourself. The community is open to

anyone who wants to participate. You can find regularly scheduled meetings, meeting minutes and other documentation on the wiki.

Link: https://wiki.ohie.org/display/SUB/Client+Registry+Community

2. Set up an introductory call with Regenstrief Institute, the community's lead organization. We are here to discuss your specific context, answer questions, and walk with you through the implementation process.

3. Review an existing OHIE reference implementation of the Client Registry.

Step 1: Analyze the Environment

The planning and implementation process begins by analyzing the current environment. This step is intended to answer the questions:

- *How can we benefit from a Client Registry? / Why are we interested in implementing a Client Registry? What problems are we trying to solve with a client registry?*
- *Who are the interested parties? Is the national health ministry interested?*
- *Are there different/varying motivations among interested parties?*
- *Are there advocacy groups that can help?*
- *How will you know if you have succeeded?*
- *What are the challenges or barriers to successful implementation?*

Activities to answer these questions are described below, and the answers will lay the groundwork for the client registry implementation.

Job aid: Job Aid – Analyze the Current Environment

1.1 Identify Stakeholders and Systems

Interest in a client registry may span a diverse network of stakeholders with various types of information systems. Stakeholders will help drive the project and set the stage for the use cases and value that the HIE can deliver. Identify potential stakeholders by listing the organizations and systems that currently create or use client (patient) data.

Organizational stakeholders may include:

- Organizations that create patient data
- Any existing Client Registries
- Patients or Clients
- Healthcare professionals
- Organization or group managing a national healthcare id
- Organizations driving the project
- Insurance providers
- The Ministry of Health

Once potential stakeholders are identified, it is helpful to understand high-level stakeholder motivations and challenges. Understanding these motivations will help teams engage and recruit the individuals that will represent the organizational stakeholders. For a client registry, motivations might include the desire to share data across systems in order to provide a more holistic view of the patient's health.

1.2 Understanding Existing Patient Identifiers

There are two types of patient identifiers. The first one is the unique code or set of codes used to identify a patient in a given system and the second one is the set of demographic attributes used to describe someone uniquely.

Understanding the existing unique set of codes for uniquely identifying the patient in existing point-of-care systems and any national healthcare identification systems will provide insight that will help Client Registry implementers appropriately design and configure the Client Registry. Each country's context will be different. Some countries may have a national health ID or a national ID that can be used to identify patients. If there is a national identifier, determine if all individuals are identified. For example, one will need to understand if are infants identified at birth. In addition, each point-of-care system that will interact with the registry most likely generates a unique ID for the patients in that system. For the systems identified in Step 1, be sure to understand the different IDs that are currently used to identify a patient.

Within each context, a set of demographic information is used to specify a patient's identity. Each implementing country or region may have different types of demographic attributes that help identify their patients. In many cases, it will include:

- Name - Name may include a first name, middle, name, and last name (surname), and / or familiarized data (mother/father).
- Gender – Male or Female
- Birth date- Day, month and / or year the patient was born.
- Geographic Data – Various levels of data that used to locate a client's residence. In some countries, this may include a street address, village or city, a state or region and a country.
- Phone number – phone number may be used in some countries.
- Ethnicity

In each context, the types of data will likely be different based upon cultural naming practices and structures for specifying a person's geographic location or address. Countries often find value in documenting the demographic fields that are used to identify individuals in your context. This will be covered in Step 3.3 Document Data Specifications.

> **Resource:** Developing and Using Individual Identifiers for the Provision of Health Services including HIV**.** Amongst other topics, this resource provides insight into different implementations of National IDs and the issues that need to be addressed.

1.3 Identify Applicable Standards

While researching the demographic fields used to identify patients in your context, list any sources of applicable data standards used in your context. The source of these standardized data lists can either be from international sources or defined by appropriate national bodies. Each standardized list should include a code that components of the health information system can use to refer to the element as well as a textual representation of that element in one or more languages.

> Example: Philippines National Health Data Dictionary
> Example: ISO (International Standards Organization)/IEC 5218 for Gender
> Example: ISO/TS 22220:2011 Identification of Subjects of Healthcare
> Example: ISO 21091:2013: Health informatics -- Directory services for healthcare providers, subjects of care and other entities.

1.4 Identify System Constraints

Identifying the high-level system constraints will help implementers understand the factors that need to be addressed in order to design a system that fits the unique context. Identify known constraints such as:

- Data Capacity - What is the country's population? How many of those people will the client registry need to support? How many patients are already stored in point-of-care applications?
- Data Quality - How complete and accurate is the patient demographic data captured in the existing point-of-care and/or national identifier systems? Which existing records are paper and which are electronic?
- Network Capacity and Reliability - Are there constraints on the network reliability or capacity? Are secure network connections between organizations already established?
- Power Constraints- Are there any constraints on electricity or power? If so, what are they?
- Data Privacy Laws and Regulations– Are there any local or regional data privacy laws that apply to the client's demographic data?
- Other healthcare software laws or regulations – Are there applicable guidelines for managing healthcare records or for validating healthcare software?

Based upon the country's unique context, there may be additional constraints that need to be documented.

Step 2: Establish Leadership and Ownership

2.1 Establish Leadership

Stakeholder leadership is essential for supporting the successful implementation of a client registry. Effective leaders should be identified and join together to form a stakeholder leadership group (SLG) for the development and implementation of a Client Registry. The group should have shared ownership of the registry and be committed to the outcomes. Once established, the SLG should be the authority under which the Client Registry operates and includes responsibilities such as:

- Defining project scope (See 2.3 Define Project Scope)
- Vetting and prioritizing key use cases and user stories for the Client Registry (See 3.1 Document User Stories)
- Ensure agreement on the data specifications used in the Client Registry (See 3.3 Document Data Specifications)

SLGs should be involved throughout the implementation of a client registry, not just at the beginning. As new business cases arise, the group should strategically plan scale up and implementation in-line with national and international standards. The composition of the SLG should be dynamic with new members joining the group in support of new business cases.

2.2 Establish Owners and SMEs

It is recommended that the following types of roles be filled for the client registry. In some cases, it may be impossible to find a single individual with the knowledge described. In these cases, it is recommended that this knowledge be developed through training or other means. In the case of the subject matter experts (SMEs), the knowledge may be spread across several individuals. As the project progresses, the level of different SME participation may vary because of their diverse knowledge and expertise.

Role	Description Examples
Client Registry Content Owner	• Has knowledge of the contents of the data. • Knows applicable data privacy, security and data management regulations and practices. • Has knowledge of the data sources and consumers. • Has knowledge of applicable data standards. • Has knowledge of justifications for data access or data transfer (includes individual or interfacing system access). • Approves data sources, data access and data transfer. • Ensures access is removed when no longer needed. • Ensures privacy requirements are met. • Ensures there is a contingency plan in place for operating should the system be unavailable due to a disaster or unplanned outage.

Client Registry Software Owners (Transactions and Content Management software)	• Have knowledge and understanding of good practices for developing, implementing, managing and retiring systems. • Have knowledge of software quality practices and any applicable regulations for managing electronic records. • Have knowledge of applicable data privacy, security and management regulations and practices. • Works with the Content Owner to design and implement appropriate software privacy controls.
Infrastructure Owner	• Has knowledge of system quality practices and any applicable regulations for managing electronic records. • Has knowledge of applicable data privacy, security and management regulations and practices. • Has knowledge of good practices for applicable network and hardware operation and management. • Works with the Content Owner to design and implement appropriate hardware and network privacy controls. • Work with Client Registry Software Owners and Content Owners to establish appropriate system back-up and recovery plans.
Subject Matter Experts (SMEs)	• Have an understanding of the current environment including existing data sources and formats and business processes. • Have expert knowledge of point-of-care systems that need to interact with the registry. • Engage in applicable communities of practice such as the OHIE Client Registry Community, https://wiki.ohie.org/display/SUB/Client+Registry+Community • Have knowledge of the processes and systems for supplying data to or receiving data from the Client Registry. • Have knowledge of the candidate software and other technologies involved. • Provide requirements, develop and support processes, create and review proposed solutions and may assist in the support of the solutions where appropriate. • Provide technical expertise in client matching algorithm configuration.

2.3 Define Project Scope

We strongly recommend an iterative registry implementation process. When using an iterative process, implementation teams should designate an initial scope for a project. While the vision may be to have all patients in the country or region listed in the client registry, this may not be practical or necessary for the first implementation of the registry.

One of the main objectives for a SLG (see 2.1 Establish Leadership) is to determine the scope of use cases and user stories that will be supported by the Client Registry. An important step in this process is defining the patients that will be kept in the registry. This

decision should be based upon the user stories that need to be supported. For example, you may need to determine which point-of service providers or national ID systems will interact with the client registry in the initial implementation. Or, you may determine that only the women of childbearing age will be included. Each country will need to set the scope based upon the HIE strategy, goals and priorities for the project.

Step 3: Document Specifications and Requirements

A client registry should be responsive to users' needs and the local context. User stories and data specifications are two ways to describe: "*What will the client registry achieve and How should it operate?*" A primary objective of this guide is to promote and facilitate a country driven and user requirements based process. The ideal solution will be responsive to users' needs and their context. To complete the activities in Step 3, an in-country meeting of stakeholders is highly recommended and can expedite the process.

3.1 Document User Stories

User Stories are a mechanism to gather user requirements and/or core requirements describing the desired registry functionality. They are a short and simple description of a how a particular user needs to interact with the system. They tell who, what and why the person is interacting with the system.

Example User Story – Other Clinic Visits
A pregnant woman enters the clinic for her first appointment. The healthcare worker collects the patient's name and demographic information. The worker wants to see if the woman has had visits at other clinics so the worker enters in the demographic information and asks for data from other institutions. The system will determine if the patient has visited other point-of-care facilities and return the references to those visits.

Example User Story – Insurance Verification
A man walks into a clinic he has not visited before. The health worker needs to verify the man's insurance. The health worker asks for his name and geographic information. The man provides the information. The health worker enters in his information and asks for insurance verification. The system will use the information entered to check with insurance providers and verifies that the man has insurance.

> **Resource:** INVEST in Good Stories, and SMART Tasks
> **Resource:** Examples of Rwanda User Stories for RHIE - This is an example of user stories that were written for Rwanda. In this example, the user stories are for the broader Health Care Information Exchange and not just the Client Registry.

3.2 Determine Authoritative Source Strategy

The authoritative source is the system that contains the official record for the client's demographic information. When implementing the client registry, there are two different approaches to implementing authoritative sources for the demographic data. Based upon your country's requirements and needs, one approach or the other may best meet your needs. One of the following approaches will need to be selected.

Approach 1 - Point-of-Care Authority Approach

In this approach, the point-of-care systems are the authoritative source and they create and manage registry updates for their records. This means that there would be one registry entry for each point-of-care facility that the patient has visited. These entries would be linked based upon a patient matching algorithm. The benefits of this approach are that the demographic data from the point-of-care facilities is "mirrored" in the registry and point-of-care systems do not update or change registry data created by other systems.

This approach is well suited for contexts without a national health identifier or contexts where point-of-care systems want to manage the integrity of their information.

This approach is characterized by the following:

- The point-of-care systems that provide data to the registry maintain their individual unique patient identifiers.
- The registry uses a matching algorithm to analyze the demographic data and link records from the different point-of-care systems that belong to the same patient.
- The registry mirrors the demographic data stored in the point-of-care systems.
- When a point-of-care system queries the registry for a patient's demographic record, that system's instance of the patient's demographic record can be provided or all demographic entries from different point-of-care systems can be provided.

Approach 2 - Registry Authority Approach

This approach assumes a controlled and curated approach to the client registry where the client registry is the authoritative source for the client's demographic data. In this approach, there would be one registry entry for the demographics of a single patient. When demographic data is updated or changed in a point-of-care system, the registry entry is updated or changed.

This approach is well suited for contexts where it is important to have a single set of demographic data that is managed through the registry. It may also be suited for contexts where there is a national identifier for each potential patient.

This approach is characterized by the following:

- The registry is the authority for the demographic data for a patient.

- There may be individuals responsible for maintaining the demographic data in the registry or the point-of-care systems may update the registry demographic record each time there are changes in a patient's demographic data.

3.3 Document Data Specifications

Using data standards and systems identified in the analysis phase of this project, the data specifications for the registry will need to be documented. A data specification document is a technical tool describing the master client list data elements or the information to be managed in the client registry. This is a similar concept to a data dictionary where the contents and format of data elements in the system are documented. It is recommended that a stakeholder meeting be used along with the tools below to expedite the process of documenting a data specification.

> **Job Aid:** Job Aid - Data Specification Guide
> **Tanzania Example:** TZ Data Specification See section 2.3 where geographic zones for a building's location are outlined. This type of information may also be used to designate an individual's residence. The document also contains examples of how postal codes, phone numbers and email addresses are defined.
> **Rwanda Example:** RW Registry Specifications

3.4 Document Data Privacy Impact and Requirements

Because the data in the registry contains patient demographic data that is used to identify a person, it is important to understand any national and/or local data privacy laws that apply to this data. The role of the SLG (see Step 2: Establish Leadership and Ownership) and content owner is to understand privacy laws and ensure policies, procedures and processes are in place to protect patient privacy.

Based upon applicable privacy and electronic records regulations for your context, an implementation team may need to address privacy and the appropriate management of electronic healthcare records through measures such as:

- Guidelines for granting access to the client registry (Who approves access? Who can access the registry and when is access allowed?) The guidelines may need to consider:
    1. Physical access to servers and data
    2. Database access via DBA(Database Administrator) or technical resource and perhaps a client registry application
    3. Exchange access (What systems can provide data to or receive data from the registry?)
- Documented annual or regular privacy training for those with access to the registry data
- Process for annually reviewing data access
- Privacy and security incident management processes. How are potential breaches of security or privacy to be handled?

Resource: Guidelines on Protecting the Confidentiality and Security of HIV Information - While aimed at HIV patient data, this resource can be used to help understand privacy, confidentiality and security concerns for patient information.

3.5 Document Workflows

The following are the Client Registry workflows that are currently defined by the OpenHIE Client Registry Community. These workflows include the detailed standards based message protocols that are used to interact with point-of-care systems.

OHIE Client Registry Workflows:

- Register Patient Workflow
  https://wiki.ohie.org/display/documents/Register+patient+workflow
- Get Patient Workflow
  https://wiki.ohie.org/display/documents/Get+patient+workflow
- Query Patients Workflow
  https://wiki.ohie.org/display/documents/Query+patients+workflow
- Update Patient Workflow
  https://wiki.ohie.org/display/documents/Update+patient+workflow

These workflows and perhaps additional workflows may be required to support your country's user stories. Document and prioritize the required workflows that are required with each point-of-care system.

Rwanda Example: Connecting OpenMRS to the Client Registry

Step 4: Implement Specifications

4.1 Determine Resources and Project Plan

The resource plan and project plans need to address the following types of activities:

- Selecting, procuring, installing and configuring software and hardware.
- Point-of-Care systems, insurance systems and / or national registry systems that will interact with the Client Registry may need to be enhanced to communicate with the Client Registry through the Interoperability Layer of the architecture.
- Configuration and testing with interfacing point-of-care systems, insurance systems and / or national registry systems that are within the scope of the project.
- Documentation of the technical solution and information required to support the solution.
- Testing to prove that the system operates as desired.
- Development of policies and procedures required to support the systems and business processes.

Along with the typical technical expertise required to develop and implement a technology solution, the registry requires technical knowledge of healthcare transactions standards such as IHE PIX/PDQ.

4.2 Select Software

Based upon the requirements documented in step 3, your team will need to evaluate and select software solutions. In addition to defining an architecture and making recommendations on standards to use, OpenHIE is certifying client registry tools that comply with the OpenHIE architecture and data exchange standards.

To operate a Client Registry within the OpenHIE architecture, the following architecture components are necessary:

- Client Registry Tool
- The Interoperability Layer: Receives all communications from point-of-care applications within a health geography, and orchestrates the exchange of data.

While these are two of the components that are needed to support the Client Registry, it is likely that the user stories within a context require additional OpenHIE architecture components.

4.3 Determine Hardware Needs

The software needs, the high-level system constraints (see Identify System Constraints) and the architecture will drive hardware needs.

4.4 Patient Matching Algorithm

One of the unique features of a client registry is its patient matching algorithm used to identify if the client already exists in the registry. There is a spectrum of matching options from simple matching, exactly matching key fields, to complex matching, configuring an algorithm that establishes weights for particular data values.

Using too simplistic of an algorithm may result in a higher percentage of duplicate records Therefore; it is recommended that the SLG and the Content Owner work through a process to determine the appropriate matching scheme. This process involves:

1. Performing initial data analysis to identify candidate fields for matching and blocking
2. Validate candidate fields
3. Identify blocking schemes
4. Configure / parameterize matching algorithm (deterministic or probabilistic)

To evaluate the patient-matching algorithm, it may be necessary to use production data. If so, the use of this data needs to be controlled and managed under the privacy guidelines created for the project. (See 3.4 Document Data Privacy Impact and Requirements).

4.5 Software Validation and Testing

There are many components required to validate and test software that is used to manage healthcare records. Some ministries of health like the United States FDA have specific guidance documents that need to be followed to ensure that healthcare software has been appropriately validated and tested and that electronic records requirements are being met. The purpose of this section is not to detail good software validation practices, but to *highlight* specific testing considerations for the Client Registry.

Workflow Testing (Integration Testing)

You will need to test to ensure that the client registry appropriately integrates with the Interoperability Layer and each of the point-of-care systems or other systems that will provide or receive data. One approach for this testing could be to test various iterations of each workflow that will be used between the Client Registry and the point-of-care system. This testing would then be repeated for each system that is in scope.

Performance and Load Testing

There are two aspects of performance testing that will need to be addressed. First is transaction through-put. This can be tested by estimating the number of transactions that will be expected during peak business times and ensuring that the network and hardware can support this volume of transactions.

Example: Rwanda Client Registry Implementation

The second aspect of testing that needs to be considered is ensuring that the registry is configured to support the number of patient records required to be stored in the Client Registry at its peak usage for the given scope. The Client Registry's hardware, databases and matching algorithm will need to be tested to ensure that they are appropriately configured and tuned to handle this number of records.

Step 5: Create Support Plan

It should be expected that requirements and requests for the registry data feeds will evolve over time. For this reason support strategies should be developed and should remain in place to triage requests for data, system enhancements, integrations, operations support or general troubleshooting among users. Common types of ongoing support are described below.

5.1 Operations Support

Operations support is intended to maintain the logistics and infrastructure required for the Client Registry. The content owner, infrastructure owner and software owners (see 2.2 Establish Owners and SMEs) will need to support the system. This support includes: monitoring error logs, maintaining a server, ensuring security protocols, carry out backups, and software and hardware updates as needed.

5.2 Developer Support

Developer support is important to facilitate any future adaptations of the client registry. For instance it may be desirable to create a specialized data curation function, additional workflows, or other application that would work in coordination with the registry in a service oriented fashion. Developer support will also include the identification, documentation and resolution of any enhancement requests or software bugs.

5.3 Integration Support

Ongoing support will be required to triage integration, issues, and new requests to provide data to the registry and/or consume data from the registry. Technical assistance may be required to resolve data exchange issues and to add and test new data exchanges with HIE components or external systems.

5.4 Data Support

Ongoing support will also require assistance for issues related to data collection, curation, analysis and utilization. While the Client Registry is designed to fulfill user requirements there will be ongoing requirements to provide training, troubleshooting and respond to data access requests by users. In addition, there needs to be support for ensuring and maintaining data quality and addressing data issues.

5.5 Help Desk Support

Help desk support may not be required initially, but as more users and organizations start using the client registry it may become important to identify, document, triage and direct response to types of requests from the varied types of users.

5.6 Capacity development and Training

To appropriately provide the supports mentioned above, there will need to be training to build the capacity of support personnel to enable them to perform basic administration of the client registry, data and quality improvements outlined in the support plan.

Step 6 Post-Production Evaluation

Post production, it is important to capture lessons learned. One helpful exercise is to have the team make two lists. In the first list, the team should document the aspects of the project that worked well. This will provide insight into processes that can contribute to the success of additional project iterations. In the second list, the team should note the items that could be done differently next time. This exercise is important as the implementation process is meant to be iterative.

Once the system is running and stabilized, the iterative development process can begin again with an expanded scope. New interfaces, user stories or workflows may need to be added.

Job Aid – Analyze the Current Environment

Identify Stakeholders and Systems (Step 1)

Stakeholders are people, groups and organizations that have an interest, or stake in the Client Registry or the Client Registry project. Make a list of potential stakeholders, their organizations and motivations. It is best to include detailed names or roles where you know them. Once they are identified, there will need to be a process for appropriately engaging them in the project. Once you have identified the potential stakeholders, think about their motivations and note any systems that may interact with the Client Registry.

Organizational stakeholders may include:

- Organizations that create patient data
- Any existing Client Registries
- Patients
- Healthcare professionals
- Organization or group managing a national healthcare id
- Organizations driving the project
- Insurance providers
- The Ministry of Health

Motivations and challenges (or barriers) may include these types of topics:

- Quality of care
- Data privacy
- An existing system
- Lack of an existing system
- Cost
- Political Environment
- Data quality and control

Example Stakeholder Chart

Be as specific as possible.

Stakeholder Name and/ or Role	Organization	Motivations	Challenges	Systems
		1. 2.	1. 2.	
		1. 2.	1. 2.	

Job Aid - Data Specification Guide

The goal of this job aid is to provide guidance on documenting a data specification for a Client Registry. This specification is a similar approach to a data dictionary where the contents and format of data elements in the system are documented, but the data specification is initially done prescriptively. Critical to the process of creating a data specification is input from a representative group of stakeholders who will use the registry.

Data Specification

It is helpful to organize and define the types of data that will be stored in the Client Registry data specification. While other types of metadata, information about the data, may be added at the discretion of the group of stakeholders, recommended metadata types include:

Variable Name: The short name and/or the database code used to describe the data element.

Definition: A simple description the data element, along with any relevant context.

Data Type: Predefined data types are helpful to understand the formatting associated with a data element. Some common data types that have been used in other registries include: Text, Numeric, Yes/No, Select One, Select Many, Hierarchy, Date, Email, & Phone.

Hierarchy or List Metadata: Hierarchical, single and multiple select data elements will have additional categorical or leaf metadata which should also be documented in the data specification.

Data Rules: A description of constraints or conditions that should be applied to a data element to improve accuracy and clarity. A single select variable, numerical, text field, or a specific algorithm for an identifier.

Data Source: a description of the individual, group and system where this information is generated. Often a client registry will collect data from other systems and it is helpful to understand the source of each data element.

Standards: Documenting any standards or common code sets used as metadata. Documenting these will help with interoperability with other systems.

Example: As new stakeholders review the data specification a helpful tool to interpreting the documentation is to provide examples of values that each data element