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Integrating the Healthcare Enterprise

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For Public Comment

Cross Community Information Exchange
including Federation of XDS Affinity Domains

IHE ITI Technical Committee
Editor:
Karen Witting

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1 Introduction

As electronic medical records become more prevalent there is an increasing need to share medical data across organizations. The model developing within the United States suggests that medical data sharing will happen first at a local level, as part of Regional Health Information Organizations (RHIOs) and then between RHIO’s. The Integrating the Healthcare Enterprise (IHE) organization has defined an integration profile called Cross-enterprise Document Sharing (XDS) which defines document sharing within a RHIO or, using XDS terminology, within an XDS Affinity Domain. The XDS profile defines a coupling of facilities/enterprises for the purpose of patient-relevant document sharing. This document looks at the issues of how to achieve the sharing of patient-relevant healthcare information among multiple RHIO (or RHIO-like) environments. This can be seen as the problem of supporting a query which will 1) identify other RHIOs which have clinical data about the patient and 2) identify the patient identifier used by the other RHIOs for that patient and 3) request patient information from the RHIO.

1.1 Expected knowledge and references

It is assumed that the reader has a working knowledge of three key integration profiles defined within the IT Infrastructure Technical Framework which can be downloaded from:


The key integration profiles and section number in the above document are:

- XDS – Section 10
- PIX – Section 5
- PDQ – Section 8

Also useful background is a high level understanding of the Connecting for Health Common Framework. Connecting for Health is a public-private collaborative of more than 100 organizations working to realize the full potential of information technology in health and health care. See http://www.connectingforhealth.org/ for further information. The Connection for Health Common Framework can be retrieved from:

http://www.connectingforhealth.org/commonframework/overview.html

A good overview of Connecting for Health’s technical framework can be found in:

http://www.connectingforhealth.org/commonframework/docs/T1_TechIssues.pdf

2 Goals

This paper addresses the following goals:

- Show a vision for support of communication among XDS Affinity Domains.
- Show cooperation between IHE and Connecting for Health
The concepts presented in this paper are evolving rapidly as interest and technology adoption grows. The goal is to summarize current activities and set a statement of direction with full expectation that over time this direction will evolve as appropriate. This paper defines common technological building blocks which allow for a variety of strategies and policies to be used. The building blocks are described on a conceptual level only. Specific technology for the building blocks has not yet been chosen.

There are many aspects to sharing data among communities that this paper does not directly address. Things like patient consent, security, privacy, auditability and many more will all need to be considered by implementors. As the building blocks described herein are fleshed out and defined concretely we will ensure that a variety of policies related to these issues can be supported. Some things, like auditing, have already been defined by IHE (see IT Infrastructure Technical Framework Volume 1 referenced above). In those cases the relationship between the existing work and the new work will be explained.

2.1 Request for Feedback

The IHE IT Infrastructure Technical Committee requests feedback on the concepts described in this White Paper. In particular, we would like your thoughts on whether this paper captures the problem as you see it and what do you think of the solution. Comments can be submitted via the web discussion forum at http://forums.rsna.org.

2.2 Open Issues and Questions

- How does an organization declare itself as a community interested in sharing records? Is there a bootstrapping mechanism needed which lists communities? How will credentialing of organizations be handled? Is there some bootstrapping process needed to build trust?

3 Overview

This paper has evolved during several months of discussion and many versions of the paper. The discussion began with an analysis of use cases which is presented in A.1 Appendix - Use Cases. Not all use cases have been addressed. One use case was used to develop deeper understanding of the issues and this led to the discussion in A.2 Appendix - Strategies for solving the selected Use Case. Further discussion of the strategies and a review of current industry activities brings us to the current version of this whitepaper.

The document is organized as follows:

- Define community
- Generalize the many strategies of sharing patient health information into two common types: hierarchical and lateral. Define these concepts.
- Present an approach to cross community document sharing using existing IHE profiles.
- Propose future IHE ITI Integration Profiles in support of hierarchical and lateral Cross Community communication.
- Appendices
4 Community

For the purposes of this document we define the term “community” to mean a coupling of facilities/enterprises for the purpose of sharing patient-relevant medical information. A community must have an established mechanism for sharing medical information among the organizations belonging to the community. An example of a community is an XDS Affinity Domain which defines document sharing using the XDS profile. Another example is defined by Connecting for Health as a Sub-network Organization (SNO) which shares information using a Record Locator Server (RLS). The term Regional Health Information Infrastructure (RHIO) is essentially equivalent to a community, except that a community does not assume any regional context.

Communities can be composed into hierarchical collections of communities we will call meta-communities.

5 Hierarchical vs. Lateral

The many strategies of sharing patient health information can be generalized into two basic types: hierarchical and lateral. In a hierarchical approach some higher level authority is trusted to enable the sharing of data under a set of policies and procedures. Organizations and communities agree to participate by making a formal declaration and agreeing to follow the rules. We will call this a meta-community; although the only operational difference between a meta-community and a community would be that a meta-community would have a community within it with a different set of policies from the meta-community. A meta-community is any group of communities which has agreed to abide by a set of policies and procedures for the purposes of sharing medical records. In defining a meta-community each member would be a community of its own, although some may be so simple as to be a single enterprise or organization. In this sense a meta-community is a collection of communities where some of the communities may be just a single enterprise which can be expected to have well defined policies and data sharing mechanisms.

Lateral cross community communication is characterized chiefly by the lack of a hierarchically higher organizational entity to enable policy and technology decision making. Thus we use the term lateral when two entities are communicating without any prearranged or declared agreements about how the interaction will be managed. Lateral communication is very common today for healthcare enterprises sharing data. Commonly a manual process is followed where phone or FAX numbers are shared, patient consent is acquired and finally data is transferred. Once two enterprises have collected phone numbers and consent the next transfer may move quicker, but the initial work is manual and sometimes administratively challenging. Thus the policy and technology choices are defined in an ad-hoc manner between every two communicating peers. Given a small set of partners this interchange can be built up as needed. As the group of partners grows the connections grow exponentially and eventually cannot be handled in an ad-hoc manner. Support for lateral communication using manual processes for policy and technology choices is available today from IHE (see XDR and XDM profiles). Automating lateral communication among communities is potentially many years out. This
paper discusses the topic of automated support for lateral communication as a long term vision which will be supported by the short term plans.

We expect hierarchical and lateral models to coexist and overlap since they deal with different issues and solutions will be chosen based on the balance of the issues presented to the organization developing its communication model. The figure below shows a model of collecting three communities using a centralized index into a meta-community. That meta-community might then communicate laterally with other communities as shown on the right side of the figure.

5.1 Meta-community

When a set of clearly defined communities is willing to agree to common policies and mechanisms, composing communities into higher level communities using a hierarchical structure is the most effective mechanism for cross-community communication. A community may participate in more than one meta-community but it would need to handle the resulting privacy considerations. We make no attempt to address the privacy policy issues introduced when a community participates in multiple hierarchical communities.

It is clear that defining the policies under which a meta-community operates is a challenging process. We make no attempt to define those policies in this document, but do ensure that the design supports a broad range of policies. The design must support security and privacy policies defined by governmental agencies as well as a wide variety of organizational preferences.

A significant technical challenge in building a hierarchical grouping of communities is dealing with patient identifiers and patient record locations. Each community will have its own mechanism for handling patient identifiers and a mapping across communities is needed. The communities we are aware of are using some variation of a cross-referencing method for handling patient identifiers. Another alternative would be to assign a global (or global across the communities within the meta-community) identifier for each patient. This “meta-community identifier” is quite far from a national patient identifier, but may trigger a similar debate for
large meta-communities. Currently our analysis and experience has been that a patient (or consumer) identifier cross-referencing scheme is used.

There are several emerging mechanisms for support of the patient cross referencing. IHE has defined the Patient Identity Cross-Referencing profile (PIX) which includes nearly all the function needed. See 6 Creating a meta-community using existing IHE profiles for details about using the PIX profile to create a meta-community. Another technique uses Connecting for Health’s Record Locator Service to create a meta-community among XDS communities and other non-standard communities. The Entity Identification Service (EIS) being developed by the HL7 SOA SIG group is another potential mechanism. All these services require cooperation from all communities in the meta-community to feed and update the service. This is the main distinction between a meta-community and lateral cross community communication. A meta-community requires regular patient identification updates by all participating communities to enable the cross community communication.

Early work on this paper proposed a Patient-Data-Existence Locator which would tie communities together for the purposes of communication. This approach has evolved into the definition of a meta-community which uses the equivalent of a Patient-Data-Existence Locator within a hierarchical organizational structure. It is believed that patient demographic and record location information must be controlled by organizations which have a relationship with the patient. Accumulating this information at the community and meta-community level is acceptable but sharing it beyond that brings up significant concerns regarding privacy and security as well as organizational questions like what entity would maintain and run it, how would that entity be controlled and how would the data be kept up-to-date. The meta-community concept solves all these problems by operating under a set of policies and constraints agreed to by all participants.

### 5.2 Lateral

Lateral communication requires a process for identifying communities of interest and, for each one found, agreeing on a set of policies and a communication mechanism. Today’s medical environment does this manually with significant patient involvement. The patient might supply a FAX number or address for documents being sent.

Our vision for automation of lateral communication among communities (or meta-communities) includes sharing of attributes of a community, searching those attributes and using capabilities to agree on a communication mechanism. Please refer to 7.3 Cross Community Discovery for details.

### 5.3 Summary

The two mechanism under which cross community communication operates show the variety of policies and practices that must be supported by IHE profiles. The work to analyze and understand these techniques has been used in selecting the building blocks defined in section 7 Proposed Future IHE profiles.
6 Creating a meta-community using existing IHE profiles

6.1 Special restrictions required to create a meta-community using existing IHE profiles

The following limitations must be instituted to enable a meta-community using existing IHE transactions:

- All communities participating in the meta-community are XDS Affinity Domains and as such, each will have a single XDS Registry which contains entries for all documents (within that domain) to be shared.
- There must be at least one PIX server which receives patient feeds for every XDS Affinity Domain patient identification domain. This ensures that there is a PIX Server which can cross-reference patient identifiers among the participating XDS Affinity Domains.
- A one-to-one mapping between the XDS Affinity Domain patient identification domains (assigning authority) and XDS Registries must be defined. The XDS profile defines this relationship to be one patient identification domain per XDS Registry but there could be multiple XDS Registries assigned to one patient identification domain. To support a meta-community we must restrict this to a one-to-one relationship. This restriction enables the ability to map each unique patient identification domain to a unique XDS Registry URL. The Registry URL used for this mapping is the URL which supports the Registry Query transaction.
- The Cross Community Bridge (described below) is authorized to make XDS Query transactions into any XDS Affinity Domain within the meta-community.
- The Document Consumer actor is authorized to make XDS Retrieve transactions into any XDS Affinity Domain within the meta-community.

Note: An alternative to this assumption would be to expand the Cross Community Bridge to re-write all URL’s which reference repositories outside the community to be proxied through a service which handles cross-community authorization.

- Differences in coding systems in the metadata and documents must be handled. Document Consumers could handle coding mismatches, all XDS Affinity Domains could agree on a common coding system or the bridge could provide translations of coding systems before returning query results or documents.
6.2 Detailed Description

The following figure shows the transactions and behaviors of the actors involved. A new actor, Cross Community Bridge, is introduced here. Its purpose is only to encapsulate the missing functional elements into one entity. All transactions shown are existing IHE transactions without modification. For the purposes of the Registry Query transaction, the Cross Community Bridge pretends to be a Document Registry by federating all queries (acting as a Document Consumer) among registries in the meta-community. The Cross Community Bridge also acts as a PIX Consumer when it queries the common PIX Server. In future sections of this document we will expand the role of the Cross Community Bridge as a full IHE actor with support for new transactions.

Meta-Community using existing IHE Profiles

1. The Patient Identity Source for each XDS Affinity Domain in the meta-community must send a Patient Identify Feed for every patient whose records will be shared across the meta-community to the common PIX server. This will allow the common PIX Server to cross reference the patient identifiers among the XDS Affinity Domains. The publishing
of the patient id may be a consequence of a patient consent process reflecting the patient’s consent to “opt in” to participation within the meta-community. There are other approaches to handling of patient consent which would not use this mechanism.

2. A Document Consumer issues a standard XDS Query transaction to a new service, called herein the Cross Community Bridge. The Bridge supplies the extra work of cross referencing the patient identifiers, querying multiple XDS Registries and combining the query results. This service could be built as a single service provided for all participants in the meta-community or as a special service within a community. The diagram shows it as a special service within community A.

3. The Bridge issues a PIX Query using the identifier specified in the XDS Query. The PIX Server returns a list of matching patient identifiers and their patient identification domains.

4. The Bridge uses the list returned by the PIX Server and the mapping from patient identification domain to XDS Registry URL to replicate the originally received query to each registry. If the patient being queried does not have an identifier in a domain this indicates that there are no records for that patient in that domain and so no XDS Query will be issued to that registry.

5. The results of the queries are combined into one result and returned to the Document Consumer

6. The Document Consumer retrieves documents of interest from the XDS Document Repository in which they are located. Notice that the Document Consumer must be authorized to retrieve documents from other XDS Affinity Domains

This paper does not directly address privacy and security policies which are naturally essential to creation of a meta-community. We assume that those agreements have been put in place and acceptable to all parties. The transactions and behavior described here must be compatible with a reasonable set of policies in support of privacy and security

A similar meta-community can be created by replacing the PIX Server with an RLS. This will require simple adapters to translate from IHE PIX to RLS transactions.

7 Proposed Future IHE profiles

A prime purpose of this effort has been to define a direction for profile work in 2007. This section outlines a set of profiles that can be developed over the next few years. These profiles will support both meta-community creation and lateral communication.

1. Cross Community Location Service – this profile will define an actor which allows references to data across multiple communities to be saved and reused.

2. Cross Community Access – this profile defines actors and transactions which work together to form a bridge between a local community and a remote community in support of query and retrieval of patient data.
3. Cross Community Discovery – this profile defines mechanisms for automatically discovering communities of interest, based on community level attributes, and discovery services to automate the protocol and policy decisions required prior to exchanging data with a newly discovered community.

We believe that the first two, Cross Community Location Service and Cross Community Access, should be addressed together in the coming year. The third, Cross Community Discovery, is a long term objective and would be addressed in a future year.

7.1 Cross Community Location Service

The Cross Community Location Service profile defines an actor which is used to save locations of records. The records referenced are expected to be in many different communities. This service provides the ability to find records across community boundaries.

The actor providing this service is temporarily called RLS/PIX+. This naming scheme is chosen because the technology expected to be used to implement this actor will most likely be a Record Locator Service as defined by Connecting for Health or a PIX server with enhancements. As with all IHE profiles the focus of discussion will be on transactions and expected behavior of the actors. The technology used to implement an actor is beyond the scope of an IHE profile.

Since this paper is focused on conceptual building blocks we will not suggest a technology to be used for the transactions communicating with an RLS/PIX+, although we expect these to be based on technology used by RLS and PIX as they are defined today.

RLS/PIX+ provides a service to save, update, remove and query record locations. Record locations will be associated with patients by using demographic data. Thus, the addition of a record location will include patient demographic data sufficient to uniquely identify the patient whose records are being referenced as well as a reference to the data. The reference to data could take many forms and we make no attempt to define what that looks like at this time except to say that it, naturally, must be useable to find and retrieve the records referenced.

The RLS/PIX+ service must perform cross referencing of the patient demographics in order to respond to requests for data references for a particular patient.

The RLS/PIX+ service is useful as a centralized index of patient data within a meta-community. Each community could query the central RLS/PIX+ service to retrieve a list of references within the meta-community for the patient of interest.

The RLS/PIX+ service is also useful within a community; as a mapping of references within organizations associated with the community and, eventually, as a holder of previously discovered references within other communities.

The following diagram shows the RLS/PIX+ actor and transactions against it.
The RLS/PIX+ Feed is responsible for managing the accuracy of the data within the RLS/PIX+.

It must add new references, update existing references, remove invalid references and (possibly) merge patients to cause reference coalescence.

The RLS/PIX+ Consumer is the user of the data managed by the RLS/PIX+ service. It queries the service to find references for patients of interest.

### 7.2 Cross Community Access

The Cross Community Access profile defines several actors and associated transactions that support query and retrieval of patient data across communities. These actors and transactions are useful within a meta-community and in lateral interactions. The main purpose of the defined transactions is:

- To encapsulate within one actor all incoming and outgoing cross community communication. This keeps the management of cross community policies and practices in one place. Components within the community use this actor to carry out transactions with other communities. Other communities use this actor as the point of contact for all requests to the community. This actor is called the Cross Community Bridge.

- To define a query which will return data from multiple communities. This query will need to handle special problems like: significant time lags in query response, different data and coding formats, different privacy/security policies, etc. This query is called the Cross Community Query.

#### 7.2.1 Example use of Cross Community Access

The following picture illustrates an example of using the transactions and actors defined in this profile. This example shows a meta-community composed of XDS communities which is using the RLS/PIX+ actor defined previously to save record locations for the communities. The red dots reflect the priming activity which happens prior to a query. As documents are registered to an XDS Registry, records are added or updated in the RLS/PIX+ for the Meta-community which...
keeps track of which communities have records for a particular patient. This priming activity happens as records are added for a community and is used by the processing of a Cross Community query.

Use of the Cross Community Access profile in a Meta-community

1. The Cross Community Consumer issues a Cross Community Query which specifies the local patient identifier and any other arguments of the query.

2. The Cross Community Bridge processes the query request by first querying the RLS/PIX+ for the meta-community for patient record locations associated with the identified patient. This returns a list of XDS Registry locations.

3. The Cross Community Bridge issues an XDS Query to each of the identified registries. For external registries this request goes to the Cross Community Bridge of the external community which does any necessary additional security/privacy or other related work. The external Bridge then proxies the request to its internal registry and returns the result.

4. The Cross Community Bridge combines the query results and returns the result to the caller.
5. The Cross Community Consumer issues a normal XDS Retrieve which can be proxied through the Cross Community Bridge or sent directly depending on community configuration.

6. If the XDS Retrieve is proxied through the Bridge it is passed to the corresponding bridge, processed locally and returned.

7. The data retrieved from the external proxied community is returned to the initiator.

Use of an PIX/RLS+ is optional in this workflow. There are other ways to determine which communities to query, including a configured list of registries.

The following sections describe the new transactions and actors in more detail.

### 7.2.2 Cross Community Bridge

The Cross Community Bridge supports all inter-community communications. Although there may be situations where the overhead of using a bridge is not necessary and will be bypassed, we envision situations where passing all external traffic through one actor will be beneficial. This concept is similar to Connecting for Health’s Inter-SNO Bridge, which handles all external interactions, either into or out of the SNO. We believe this is a very good model for facilitating all cross community interaction and have, for the moment, labeled this actor the Cross Community Bridge. As with all things IHE, we expect the name may change as the profile is developed further.

The Access profile will describe only the transactions between Cross Community Bridges that enable the Cross Community Query. Further transactions supported by the Cross Community Bridge will be defined as part of the Cross Community Discovery profile.

For the Access profile the Cross Community Bridges must support two transactions:

These transactions could be equivalent to the existing XDS transactions although may have special security/privacy requirements and be extended to handle significant delays in response.

In the example above the Cross Community Bridge is shown as acting as an RLS/PIX+ Consumer for the purposes of determining which communities should be queried for records for a particular patient. Thus to build a meta-community as defined above there would have to be a coupling of a Cross Community Bridge actor and an RLS/PIX+ Consumer actor.

### 7.2.3 Cross Community Query

The Cross Community Query returns data about patient’s clinical data entries within multiple communities. This query is similar to an XDS query but must handle significant delays in
response time, simultaneous support of multiple policies, coding variation and any other restriction that comes to mind when collecting data from multiple unrelated or semi-related sources. The query is “federated” in that it is sent by the Cross Community Bridge to multiple other communities and the result is combined. But this is not equivalent to the ebXML use of a federated bit on queries which requires that the query be sent to all known registries without filtering. The Cross Community Query is sent to whatever entities the Cross Community Bridge is configured to send to. There are many ways to implement this approach, for example: the ebXML approach where the list is fixed, the approach detailed in the example earlier where an RLS/PIX+ entity is used to determine who to send the queries to, or any other implementation that works for the system. This profile will not dictate an approach for implementation; this is within the details of the Cross Community Bridge. The profile simply states that the query is expected to return results from multiple external communities and the receiver of the query must handle this.

One potential solution for querying across communities is to use the federated bit already available in the ebXML query. This is a simple solution but does not solve the problem of significant delay in processing of the query and handling non-XDS communities. At this time it is thought that there is no need for IHE to profile the use of the ebXML federated bit as it is straightforward and could be implemented by any vendor without interoperability problems. This may be reconsidered during detailed work on this profile.

The full transaction diagram for the Cross Community Access profile is:

![Cross Community Transaction Diagram](image)

The Cross Community Consumer issues a Cross Community Query and is aware that the query is going to return entries for more than the local community. Thus the entries returned may not conform to the local policies of the XDS Affinity Domain. The URL may refer to an external organization. This actor will also need to handle the potential for long delays in receiving a response. Profiling an asynchronous query or a protocol that allows the Cross Community Consumer to stop the transaction if it delays too long is needed.

The Cross Community Bridge must handle the resolution of patient identifiers within the query as well as combining the results of the query into one query result. It also may provide proxying of the URL so that the Consumer is not required to interact with a non-local Repository. The Bridge could also be required to translate the metadata so that it conforms to the local policies.
These questions must be resolved as part of the profile work, either to require, allow optional or leave out of scope of the profile.

A key area in need of further investigation is the need for handling significant delays in the query response. The existing XDS Query assumes a synchronous process with reasonable delay in results. Expanding the query beyond the local community increases the likelihood of delay in response. Connecting for Health has stated that all communication beyond the local community will be asynchronous. This seems unnecessarily restrictive as sometimes the communication will be quick and the overhead of an asynchronous transaction is unnecessary. A review of relevant standards is needed to determine the proper resolution of this matter.

Another requirement which must be addressed is the ability for the Cross Community Query to handle communication with non-XDS communities.

7.3 Cross Community Discovery

7.3.1 Overview

This section describes a workflow to support automated lateral communication of patient health information. Because lateral transactions do not have an overriding organizational mechanism (as in meta-communities) there is no common place to build up patient data existence locations. The transactions described in this section support using community attributes to identify communities holding patient records and building up a local index of those locations. The goal is that a community (or meta-community) is able to build an index of patient data locations for patients of interest to the community. There will be no national or global index of patient data locations, but for any patient there may be several communities which are identifying and saving an index of communities holding records for that patient.

The transactions in this section allow automatic buildup of patient record location references. Initially the identification and saving of references will likely be done through a manual process. As the number of communities desiring lateral communication grows the manual process will become unwieldy and there will be a gradual shift to automating some or all of the processing.

7.3.2 Example use of Cross Community Discovery

The following diagram presents a high level overview of the process of identifying communities holding records for a particular patient and updating the local RLS/PIX+ service with those references. The Cross Community Query uses references from the service to pull data from outside the community/meta-community.
1. Prior to the beginning of the workflow a community attribute search engine actor collects community attributes from every Cross Community Bridge. The ability to get metadata about the community for use in searching should be profiled to allow powerful search agents to exist within and independent of communities and meta-communities. In this chart the search engine is represented outside of any community.

2. A new actor is defined, Cross Community Searcher, which initiates this workflow. This actor would potentially be linked with other client type actors like Document Consumer, Cross Community Consumer or the like. The Cross Community Searcher initiates a Find transaction providing the patient demographics and a set of attributes to be used to look for communities which might hold information about the patient.

3. Acting on behalf of the Cross Community Searcher the Cross Community Bridge queries the Search Engine using the attributes specified in the initiating transaction. This returns a list of likely communities to be searched.

4. For each community, the Bridge queries the capabilities of the community to determine if communication is feasible. A community may not support the particular protocol required by the bridge, or it may have security or privacy restrictions that the bridge does not qualify for. If the bridge cannot communicate with a community for any of these or other reasons it continues with the other communities returned by the Search Engine.
5. In this example the community is an XDS Affinity Domain and as part of the capabilities the connection information for a local PDQ server is available. The Bridge queries this server, moderated by the Bridge on the other side, to get the correct patient identifier using demographics provided by the Cross Community Searcher application. If no patient is found the Bridge moves on to the next community assuming that there is no available data in this community. (Note: as the details of the profile are defined it may be determined that using a PIX transaction or new transaction to get the correct patient identifier would be preferable. This paper does not intend to imply which direction the detailed work will go, but only the general concepts.)

6. Assuming a patient is identified in the previous step the Bridge uses the patient identifier returned and the capabilities previously retrieved to query the XDS Registry, again moderated by the other Bridge, for document entries for the patient.

7. If entries are found the Bridge may optionally update its local RLS/PIX+ to record this information for use by the cross community query.

8. The Bridge returns information about what was found, or was not found, to the originator.

This workflow does not consider the case where Community B’s Bridge may want to update its local RLS/PIX+ to indicate that Community A has records regarding the patient. It also does not consider the case where a community is not XDS.

The following sections describe the new transactions in more detail.

7.3.3 Searching by attributes

Searching for communities of interest is based on attributes of the community rather than location of patient records. This solution is chosen because there is no authoritative mechanism for building a patient data locator like there is in a meta-community. Searching communities by attributes will not be as precise as using a patient data existence locator but will narrow the number of communities to a small enough number. The assumptions used to narrow this field are:

- Most people will have most of their medical information within a small set of communities, often only one.
- Given an appropriately chosen set of search criteria, most people would be able to provide enough information to narrow the list of communities likely to contain the data of interest to a small set.

The result of an attribute search will not be as precise as a patient data existence locator, but this method has many advantages over building a patient mapping service. And being precise is not critical, certainly at this point in time. If more precision is desired in the future, this first step will only enable the building of a more precise mapping mechanism. The advantage of
community indexing is it deals with only public information. Attributes of a community - like cities in which they have services, organizations participating, regional area, and medical specialty - are all public. This is information that can be passed around without concern for privacy or security. It also does not change as frequently as patient mapping. By requiring each community to make available a set of attributes about themselves, generalized search mechanisms, similar to Google, can be built by 3rd party vendors. This enables an industry around supporting good, reliable searching of community attributes. The most difficult part of this process is choosing a good set of attributes.

The result of an attribute search is a list of community identifiers, such as hostnames. A community identifier must imply access to a small set of services which are generally useful but not patient specific. This small set of services will enable automated lateral cross community communication.

There must be a formal naming system used to uniquely identify every community. Two likely mechanisms are the domain naming system and the OID naming system. At this time we do not declare a choice, only that a choice will be required.

The above diagram presents the proposed mechanism to enable search engines to be built. The fundamental building block is a service provided by all communities called “Get Attributes”. Given the hostname for a community there is a defined URL which must support the “Get Attributes” query. The query returns an XML structure which follows a defined schema. This mechanism allows any entity to pull the data needed to create a search engine. In the diagram there are two search engines defined, one living on the internet as an unaffiliated service available for all, and another provided by Community C as part of the services it hosts. Notice that Community C is not pulling attributes from Community A. There may be several reasons for this, one of which is that Community A uses a protocol not supported by Community C so therefore there is no point in indexing it. The diagram also shows Community B’s Cross Community Bridge using the unaffiliated search engine to find hostnames matching criteria...
specified as attributes. This gives the Cross Community Bridge a list of communities that is smaller than searching all communities.

**7.3.4 Capabilities Query**

After a list of community hostnames has been identified, there are still several problems involved in being able to communicate with any of the communities. What protocol(s) are supported by the community? What coding systems and document formats are supported? What authorization process is needed – in other words do I have a business relationship with this community or other entity which supports the secure transfer of patient health information? This kind of information will grow in complexity as more and more communities attempt to connect to others. For this reason we propose that there be a transaction defined as “Get Capabilities” which allows one community to find out the capabilities available in another it wishes to communicate with. This would be the second required transaction supported by a community.

This transaction would return an XML structure which would contain all the information needed to communicate with the community. For instance, for XDS it would identify the registry URLs, PIX/PDQ server URL, and perhaps an audit repository. It might have information about the policies of the XDS Affinity Domain like document format and coding systems supported. If the community were a Connecting for Health community it would identify the Inter-SNO Bridge (ISB) and potentially any other information that might be needed to communicate. Potentially there may be other types of community protocols that will emerge and the XML structure should be extensible enough to support other protocols when they are perceived to be pervasive enough.

The ‘Get Capabilities’ query identifies the communication mechanisms, like XDS and coding system and document structure. It also determines if the invoking community has the right set of credentials to talk to the responding community. The result of the transaction is that the Cross Community Bridge has all the information it needs to communicate with the external community, or has determined that communication is not possible.

Special services can be built within a community to support other forms of communication mechanisms. Like an XDS community might build a Connecting for Health adapter or vice versa.

Of course, there will be many cases where a community might be found in the search but for any number of reasons cannot be communicated with. The protocols might not match, there might not be the proper level of security for mutual trust. In this case the capabilities returned could include other mechanisms for transferring records, like the phone number of the records department, an email address or a FAX number.

The full transaction diagram for the Cross Community Discover profile is:
7.4 Summary

The long term vision for Cross Community Information Exchange includes profiled support which will enable hierarchical and lateral communication strategies. The new Cross Community Bridge actor facilitates all transactions into and out of the community. A Cross Community Query is defined which supports retrieving patient health records from external communities. The new RLS/PIX+ actor allows the collection of references to patient health records in multiple communities. And the discovery and automated configuration of inter-community lateral communications is defined so that automated lateral communication is possible without significant manual overhead.

A.1 Appendix - Use Cases

This section lists the use cases discussed in preparation for this paper. There is a long list of use cases that could be viewed as illustrating the problems to be solved by a Cross Community Information Exchange profile. This list is not necessarily complete and not all use cases are addressed by the technical objects defined in the paper.

Use Case: Multiple primary residences

This use case describes the situation where a patient maintains more than one principal residence. Generally the principal residences are not geographically close so the medical data generated while in each residence would be created by separate institutions.

A common example of this use case is what is described in the United States as the Snow Bird. This is a person who maintains two residences, one in the northern part of the USA for use during the hot summer months and one in the south for the colder winter. If a patient lives in...
Florida in the winter and in New York in the summer, this patient will likely have medical records in both places which need to be shared. If the patient is managing a long term medical condition, like diabetes, it will be important as she moves from New York to Florida and back that the background and related testing associated with management of the medical condition is readily accessible to the local physician.

A variation of this case involves a patient who lives on the border between two communities or works and lives at some distance. A patient who lives in Greenwich, Connecticut, which is on the border between the U.S. states of Connecticut and New York, may access health facilities both in New York and Connecticut. If that patient works in Manhattan, he would also access health organizations in New York City. All of these disparate areas, although closer geographically than New York and Florida would probably hold patient information in separate domains thereby requiring the same kind of cross domain sharing as the snowbird case described above.

**Use Case: Between two XDS Affinity Domains**

A doctor’s office is on the borderline of two XDS Affinity Domains and frequently deals with both. In this case the doctor may choose to be a member of both XDS Affinity Domains, submitting and retrieving documents from both - separately. This can be accomplished with existing profiles.

A patient lives on the border between different states or regions. This patient will likely access medical services in multiple regions.

A different example that fall in a similar use case is that of a Provider member of several XDS Affinity Domains that wish to locate the specific XDS Affinity Domain to which a Consumer has his PHR Service Provider located.

**Use Case: Patient Move**

A healthcare facility may need to do a one time transfer of information from one XDS Affinity Domain to another, perhaps because of a patient move. This might be a good application for the XDM (Cross-Enterprise Document Media Interchange) or XDR (Cross-Enterprise Document Reliable Interchange) profiles.

**Use Case: Vacationer**

Vacationer: A patient is traveling and goes to the hospital. The hospital needs to access records from the patient’s home region.

Once the treatment is complete the patient will want to have the records available to his home community. The transfer of the records to the home community might be a good application of XDM or XDR.

**Use Case: Mergers, aquisitions, divestitures.**

**Merger**

A large healthcare corporation, Bigco, acquires a small local hospital, Smallco. Before the records integration transition is complete, the medical records from Smallco reside locally at
Smallco. When a Smallco client is admitted to one of the other facilities of Bigco, their records appear to be stored locally at that other facility. But in fact, the records are being transferred as necessary from Smallco. There is also a transitional activity going on to transfer the Smallco records into the Bigco EHR. This does not happen instantaneously. In fact, it takes several weeks for the complete transition. During this period, a facility must track which patient records are kept in which EHR facility.

The transition can be managed by creation of one additional affinity domain that incorporates only Bigco and Smallco. The use the XDS affinity domain mechanisms to track locations of information during the transition to a single EHR. During this period there is a kind of federation between this internally motivated transitional affinity domain and the other affinity domains.

**Divestitures**

A healthcare facility splits into two new organizations: Newco1 and Newco2. At the start of the split, all records are being kept in a single EHR facility. For a period of time while organizational changes are taking place, the two organizations share that single EHR facility. But then, they set up their own internal EHR facilities. There is a gradual transition of medical records from the old EHR facility into the new separate facilities. During this transition, the three EHR facilities (Old EHR, Newco1, and Newco2) act as a federated system to track the current location of patient records.

A transitional affinity domain can be used to manage this transition. During this period, both Newco1 and Newco2 are members of it and of all the other affinity domains that Oldco had been a member in.

*This does raise the related issue of managing the transition when a healthcare facility decides to withdraw from an affinity domain.*

**Use Case: Transitory Alliances**

A medical facility and a research facility form a short term alliance for a research project. The two organizations would like to share information during this short period of time only. Rob Horn to add detail

**Use Case: Surveillance, CDC**

Multiple Local, State, Federal agencies are interested in the collection of largely overlapping information produced in the course of delivering care (e.g. laboratory or case information). Organizing this information in pseudonimized “digital objects” or documents shared between the many sources of clinical information through an XDS Affinity Domain that serves the various Public Health agencies Lori Fourquet to review.

**Use Case: Specialty treatment**

A large medical institution (located in Boston for example) frequently has patients from outside the region come for specialized treatment. The medical institution needs access to records
created prior to the specialized treatment and the home region needs access to records related to the specialized treatment.

Use Case: PHR Services

Personal Health Records systems will want to import data from and export data to a variety of EHRs where the consumer receives care. As those EHRs may belong to multiple XDS Affinity Domains, other than the XDS Affinity Domain to which the PHR Service Provider may belong.

Use Case: Remote Consulting.

One hospital would like to consult a specialist in a remote hospital. In order for this consultation to take place a number of patient records should be extracted and made available for one or more interaction between one or more clinicians across the two institutions. After some time (e.g. a couple weeks) this shared information is no longer needed and may be deprecated. XDS is in clinical use today between two Italian hospitals, one Spanish hospital, and a Dutch hospital. These hospitals may belong to different XDS Affinity Domains and access to this shared information may require a targeted federation.

A.2 Appendix - Strategies for solving the selected Use Case

In this section we will narrow the discussion to the use case involving multiple primary residences. In this use case, medical data is being collected in two or more geographically separate areas and sharing of that data is required in order to properly treat a patient’s on-going medical condition. The strategies outlined below are high level mechanisms for sharing patient data among communities.

A.2.1 Distributed

This is the typical data sharing mechanism currently used. Data is created within many communities and sharing of medical data is done using an ad-hoc method defined at the time that the sharing is needed. Typical methods for sharing are:

- The patient collects physical copies of appropriate documents and carries them to the receiving organization (known as the sneakernet method of sharing by some).
- U.S. mail or FAX.
- Collection of data on some electronic media (USB device or CD) which is then physically transported to the receiving organization – hoping that the format can be interpreted by the receiving organization.
- Creation of a special purpose sharing arrangement that connects them electronically through e-mail or the Internet using some locally defined protocol.

These methods, and probably more, all must be negotiated again and again and none are available without a significant level of cooperation from all parties involved.

A.2.2 Distributed, community indexed
In order to encourage the finding of information, an inter-community indexing service is designed and provided which collects metadata about each community (such as geographical region and/or a list of facilities within the community) and defines the mechanism for the sharing of medical information between communities. This allows, in our use case, the community in New York to search for the appropriate community in Florida and query and retrieve data from the Florida community. This strategy assumes that the retrieving organization has some understanding of the community from which it will be pulling data, or the retrieving organization has sufficient resources to query all communities in the index.

This strategy supports peer-to-peer communication in situations where there is no common cross referencing based on patient. It is believed that a national patient cross referencing service will not be acceptable for some nationalities, thus leading to this form of generalized, public search.

### A.2.3 Distributed, patient indexed

To encourage finding of information for a particular patient, an indexing service is provided which takes information about a patient (demographics most likely, another variation could use patient identifiers in some form) and return a list of communities which are expected to have information about that patient. The service or some other mechanism would also define the protocol to be used to query and retrieve data from a community once it has been located. The mechanism for identifying a patient is a common problem in all the strategies. It is assumed that demographics will be used to identify a patient unless the country uses a national patient id.

In the following diagram:

- **Patient-Data Existence Locator** – provides the locations which have some data for the patient. Interactions among Patient-Data Existence Locators is not addressed here.

- **Patient-Data Locator** – provides more detailed information about what data is available about the patient, i.e. queryable metadata and references to actual data. This entity, the XDS Registry, has a master patient id.

- **Data Repository** – contains the actual data about the patient.

- **Data Requester** – an entity which searches for, queries and retrieves medical data for a patient. The requestor may be a direct entity, or may act on behalf of other actors as a gateway to services outside the community.

In the diagram the thick black arrows show the requirement for a business relationship as well as a virtual transaction. The direct transactions may go through a gateway service or other mechanism for simplifying the transaction. But whether the actor acts directly or through a service the business relationship still must exist between the originator of the request which will receive the patient data and the provider of the request which controls the patient data.
This diagram shows the data requesters reaching across communities. The use of a gateway service would allow this cross-community communication to be encapsulated within a locally provided service which would handle the non-local communication. Every Patient-Data-Locator service would have to have a business relationship with the Patient-Data-Existence Locator in order to add and update entries for patients having data within the community.

This diagram implies that the data requester has a business relationship with every community containing records for the patient of interest. If the Patient-Data-Existence Locator identifies a community with which the data requester does not have a business relationship the data is not available to the requestor. This might trigger a business process to create a business relationship with the identified community.

The diagram assumes the patient has agreed to make records available outside the community. It is assumed that the data repository is controlling detailed access to records and would use some user authentication mechanism prior to providing records for the patient.

A.2.4 Collected metadata, distributed data

To promote timely searches for relevant information, all the metadata about the patient records is collected within one community. This community is referred to as the home or preferred community. A mechanism for identifying the preferred community for a particular patient is
needed, although the patient can generally provide this him/herself except in emergency situations.

By collecting metadata about a patient in a single place, a single query can identify all the documents that are available for that patient. This metadata is general, non-clinical (except in some situations and countries) information about the patient record (e.g. XDS Registry metadata). The patient data is still stored at the creating sites and retrieved from there if desired.

A standardized method for communicating queries and retrievals between communities is needed as well as a mechanism for getting the metadata to the home community; either by having other communities push it, or having the home community pull it. At issue is also how the metadata is kept up to date in case of modification.

Using the same system of components as presented for the last strategy we see that only one Patient-Data Locator has entries for a particular patient but the data still resides across communities.

The entry in the second Patient-Data Locator may be removed or retained but would not be expected to be used except by local community requestors.

In this case a business relationship is needed between the two registries to handle retrieving and updating the metadata for the document. The second (pale) entry may need to keep track of
where the data is stored and notify the other party in the case of an update. Alternatively, the copy of the entry might be refreshed at some interval, using typical caching algorithms.

This strategy assumes that the patient has agreed to have his data consolidated/collected.

One interesting consequence of the use of this strategy is when the collected and distributed are simultaneously used, perhaps for different patients. This might necessitate the specification in the Patient-Data-Existence Locator a flag indicating that for this patient the Patient-Data Locator expects to have a complete list of patient data available or only a subset.

### A.2.5 Collected data

To encourage quick access in the place of most frequent use, all data (not just metadata) is collected in one community, the home or preferred community. This is equivalent to the above, except that the data is moved or copied to one community.

This strategy introduces the issue of who the real owner of the data is, the creator or the home community storage system. If data is updated how is that managed?

Using the same system of components as presented for the last strategy we see that only one Patient-Data Locator has entries for a particular patient and all the data has been copied or moved to a local Data Repository.
The entry in the second Patient-Data Locator and the data in the Data Repository may be removed or retained but would not be expected to be used except by local community requestors.

**A.2.6 Multi-home collected**

Either of the collected strategies described above can be extended by using more than one home community and duplicating the data in both. This increases the questions regarding duplicate data, ownership, and processing of changes.

The following diagram presents a multi-home collected view. In this case the data requesters do not need to consult with any Patient-Data-Existence Locator since they know that all available data has been copied into the local community.
A.2.7 France home based

In the France model there are only a few XDS Affinity Domains (3 or 4) and all sources and requesters will be a participant in all the XDS Affinity Domains. This means that all Document Sources can submit documents to any Repository in the country and all Document Consumers can query and retrieve documents from any registry and repository. Every patient will be assigned a home repository and all sources of data will be required to submit all created documents to that repository. When data is being requested the data-existence locator will be used to identify which XDS Affinity Domain (there will only be one) contains the repository for the patient and the consumer will query the identified registry.

In the following diagram the green and red dots represent data from different patients. All data for patient “red” will be stored in the repository on the left and retrieved from there. All data for patient “green” will be stored in the repository on the right and retrieved from there.
Patient-Data-Existence Locator

Patient-Data-Locator
(e.g. XDS Registry)

Data Repository
(e.g. XDS Doc Repository)

Data Requesters
(e.g. XDS Doc Consumer)

Data Sources
(e.g. XDS Doc Source)