IHE Work Item Proposal (Short)

# Proposed Work Item: Patient-Centric Data-Element Location Service

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Domain: IT Infrastructure

# The Problem

Records are currently shared for more than 200 Millions patients, on a daily basis, world-wide leveraging the use of:

* the peer-to-peer query and retrieve between edge systems (IHE XCA Profiles)
* queries to a shared document registry (IHE XDS Profile) followed by retrieve from repositories

IHE has extended the access (query and retrieve) from mobile devices to the above records with the more recent IHE MHD Profile (XDS/XCA on FHIR).

This has demonstrated that the sharing of documents across community/regional/national health information exchange platforms is one of the fundamental mode of exchange of health records. However, such health information exchange platforms that support document sharing, are often extended by offering cross-document data aggregation. This has been addressed in part with the “On-demand Document” option in XDS/XCA Profile and with the QED Profile that supports the access to specific data elements (e.g. list of medications, list of allergies). The QED Profiles was based on HL7 V3, and may likely be superseded by HL7 FHIR (Restful access to specific resources). Such FHIR resources are being standardized by HL7 are maturing with the soon to be released DSTU 3, with input from the US Argonaut group.

This proposal is intended to introduce fine grained access to health data to coexist and complement coarse grained (document as a coherent set of fined grained data elements) access.

# Key Use Case

Following an encounter of a patient with a family physician, a transfer of care document is shared. The patient is advised by the family physician to make an appointment for a surgery. The patient, then picks up his prescribed medication at the local pharmacy that results in sharing a dispensation document. The patient makes an appointment with the local hospital for a scheduled surgery. Being back at home, the patient uses his smart phone to:

* Access the recent prescription and recently dispensed medications to review the posology and take his medication with the right dose. For this, the prescription and dispensation information need to be extracted from these documents.

However the patients’ condition worsens resulting in an emergency hospitalized. When admitted, the emergency physician

* needs to urgently stabilize the patients’ condition and seeks to obtain his current medication list (the medications prescribed and dispensed need to be extracted from at least two documents)
* needs to complete the patient admission and schedule the intended surgery. For this, he needs to retrieve the transfer of care document.

To prepare the surgery:

* the anesthesiologist needs to obtain the medication history and the list of known allergies (the allergies need to be extracted for the past 10 years from all shared documents for the patient)

# Standards & Systems

Several alternative approaches should be analyzed:

Just like documents’ metadata are recorded in a document registry, data elements (or Resources in the cases of HL7 FHIR) could be recorded in a sort of resources registry or a records location service.

The duality between document-level access and resources (data element) level access should also be considered to consider a document registry (a resource in the MHD sense) to be exploded as a composition of resources that make up the document content. This would allow a restful access to a document content (e.g. drilling into a CDA document). This may be considered an extension to MHD, setting relationships, between the document, its composition and individual resources.

This use case need to be articulated with related use cases:

* The non-patient centric search for services and and-points offered by APIs

There are some efforts in Argonaut to create a directory that can be used for this. At the minimal end, it is a replacement for a UDDI. The present proposal is not to duplicate this on-going effort for which IHE could get more visibility, so that the international community might become interested.

* One can't expose patient information until one has a trust-framework. It is only when there is a basis of trust that one should expose any patient specific information.

# Discussion

IHE ITI, possibly with collaboration with PCC, is the best venue to address this use case.

It is indeed strategic to introduce such a service, not only as a new profile to be deployed stand-alone, but also as a companion profile to MHD (XDS/XCA on FHIR) and to XDS/XCA.