

# CROSS-ENTERPRISE SHARING OF MEDICAL SUMMARIES (XDS-MS)

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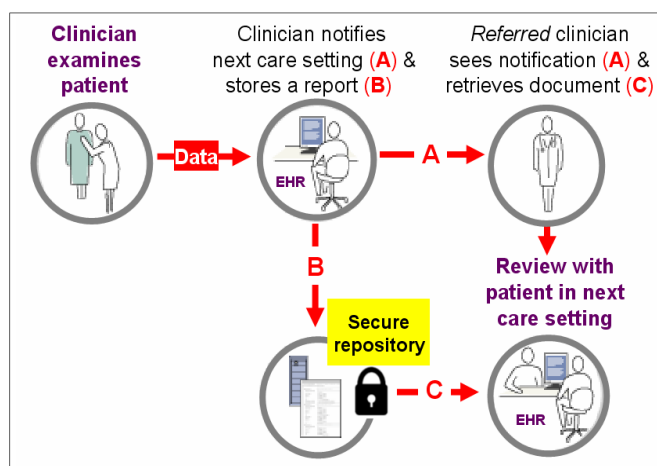
## Dealing with Jargon

- Technical terms are used if thought essential to understanding XDS-MS. The *first use* of such terms are shown in *bold italic* with concise definitions placed in adjacent margins as below.
- ***IHE profile*** — a well-defined and tested solution to a specific information exchange and use requirement within healthcare.
- ***Patient path*** — wherever the patient goes; a patient-centred information system serves all parts of the patient path: different clinical departments, primary care locations and in the future, home, work, mobile locations.
- ***Structured data documents*** — implies a standardised document mark-up (see ebXML in text) and meaning (semantics) for a given clinical document function (e.g. a discharge summary). 'Structure' is also standardised for the purpose of information exchange to be both human-readable and computer-readable — see CDAR2, later. Structured documents can constitute messages between systems and thus supply timely data for clinical decision support applications.

## APPLYING XDS-MS TO CLINICAL INFORMATION SHARING

**Overview** This IHE-UK user guide focuses on a simple solution to a common problem: transferring summary information between different healthcare settings. The guide introduces an ***IHE profile*** called Cross-Enterprise Sharing of Medical Summaries or XDS-MS. The XDS-MS profile is being adopted in many countries throughout the world as a standards-based approach to sharing clinically-relevant information between electronic health record (EHR) systems. The profile is based on a comprehensive but simple approach to secure sharing of many kinds of clinical documents and data that might be generated along the ***'patient path'***.

The strength of XDS-MS lies in the way it can be applied in many different types of real-world clinical workflows with relative ease and high cost-effectiveness. A typical application scenario is shown in the diagram above. The technical details behind the data flows are standardised, so if the profile is being applied by two different care



A typical application of the XDS-MS profile in secure sharing of EHR-based data across care settings (see later).

organisations, data will flow between them consistently. A key advantage is the simple way original data can remain within trusted systems (run by people to whom the patient has given explicit consent to how their data can be subsequently stored and used). As explained later, with XDS-based profiles there is no need to centralise patient data in a single large database. Instead, legitimate sharing of data is achieved by links back to the original data. The XDS Profile stores healthcare documents in an

**ebXML registry/repository** to facilitate their sharing (see below). ebXML (Electronic Business using eXtensible Markup Language) is a family of XML-based standards sponsored by OASIS and UN/CEFACT that aim to provide open, XML-based infrastructure for the global use of electronic information in an interoperable, secure, and consistent manner by all partners. **ebXML extensions** can specify complex **clinical workflows** between multiple enterprises that may use different systems.

## A DIVERSITY OF STRUCTURED DATA CAN BE SHARED USING XDS

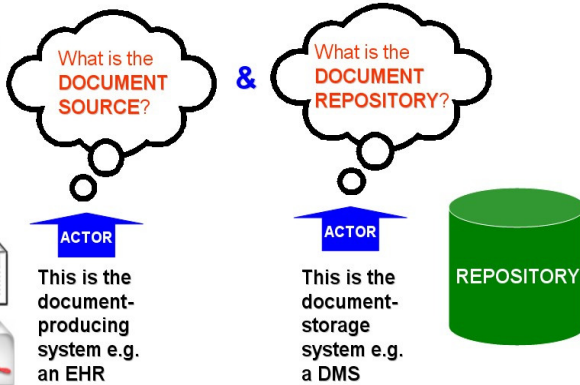
Before we revisit the specific topic of sharing medical summaries (and their clinical applications) we need to say a little bit more about XDS *per se*. The initials XDS stand for ***X*** (cross-enterprise) ***D***ocument ***S***haring. 'Documents' can include ***structured data***

***documents*** that encapsulate data generated in different clinical settings along the patient path. Documents can contain information of diverse types — in addition to CDA (generated and read consistently by a variety of EHR's) there may also be

Word documents, Excel files, TIFFs, mpeg's, PDF's etc. An integration strategy might seek to standardise on document type, but the critical point is that documents in a number of agreed formats can be shared using XDS.

# XDS BASICS—DOCUMENTS, SOURCES & REPOSITORIES

Always think...



The basic arrangement underpinning XDS workflows — documents, document source and document repository ‘actors’.

As described, information along the ‘patient path’ can come in a variety of document types, including those shown in the adjacent figure. When a document is to be *shared*, one should first specify the *document source*. Most likely the source could be an EHR, cardiology or lab data system. One also should specify where the document is to be stored—i.e. the *document repository* — this might be a ‘legacy’ database or a hospital document management system (DMS). Once defined, the document source and repository become *actors* in the XDS profile. Basic, standardised definitions like

these allow quite complex *transactions* to be specified in real-world terms. While the *Document Source* actor may be *any* system that is documenting clinical activity, the *content* can be *anything* one needs to share for clinical benefit (e.g. a PDF of a care plan, a jpeg of an ECG trace, a flat file of specialised application data). The *Document Repository* actor (as a database or DMS) may have useful, familiar archival functions built-in and so these do not need to be recreated. If they do not exist, DMS can be created from standard inexpensive components and/or be repurposed from legacy systems.

## Jargon

- **Actors** — in functional terms, IHE actors are applications that produce, manage or act on information. Each actor supports a given set of standard transactions. A given information system may support one or more actors.
- **Transactions** — Transactions are exchanges of information between actors using messages based on established standards (such as HL7, DICOM and W3C). Each transaction is defined with reference to a specific standard and in the context of additional detailed information, including use cases.
- **Metadata query** — Put simply, XDS specifies predefined elements describing documents, submission sets and folders. These elements assist ‘document discovery’ in subsequent (metadata) queries—see below.

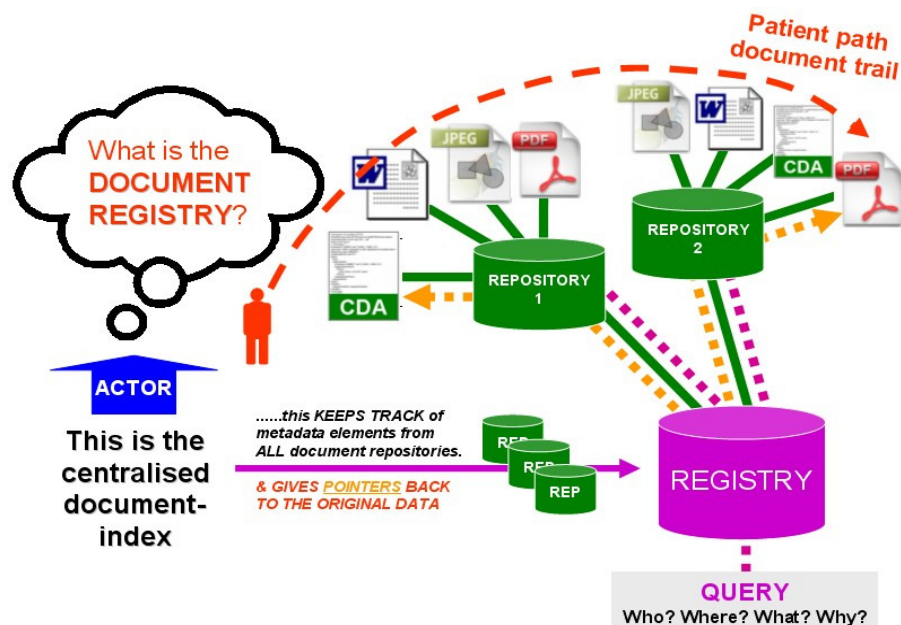
“...a metadata query into the registry can retrieve all relevant patient history documents from the timeline”

## THE DOCUMENT REGISTRY(INDEX)

Another key ‘actor’ involved in an understanding how XDS works is the *Document Registry* (see diagram below). The red dotted line in the figure shows that as the patient moves between care settings a ‘document trail’ will be generated. These documents (containing data of various types) may be stored in several Document Repositories, each associated with a care setting ‘on the path’ (see figure). The XDS Document Registry uses software that keeps track

(chronologically) of document submissions to the various repositories. The registry records some basic data *about the document* — (*metadata*). The repository metadata also includes an electronic link (pointer) to the stored document. The registry does not store any documents, but a *metadata query* into the registry can retrieve all relevant patient history documents (for example) from the timeline. A technical advantage of stor-

ing data ‘distributed’ in this way is that there is no need to have a large centralised data store (i.e. inherently more ‘scalable’ to local variations in demand). There are also profound advantages when dealing with large data sets such as images. Moreover, distributed storage may better respect patient’s wishes to store their data with trusted local ‘custodians’. Naturally, stringent role-based access and data privacy controls apply throughout the XDS system.



# WHAT QUERIES ARE POSSIBLE TO CREATE SUMMARIES?

	Who	What	Where	When
<i>Searches with respect to the document</i>	<b>Re: Unique Patient Identifiers</b> Name?* Address?* Gender?* Date of Birth?* <b>Author:</b> Institution? Person? Role? Specialty? Legal Authenticator?	<b>Re: Service Event**</b> Confidentiality* Document Type? Class? Format? Language?* Title?* URI?*	<b>Re: Health-care Facility Practice? Setting ?</b>	<b>Service start Service end Creation?</b>
<i>...about a folder</i>	<b>Owner</b>	<b>Code(s) Description*</b>		<b>Update</b>
<i>...about a submission set</i>	<b>Patient Identifier</b> <b>Author</b> Institution? Person? Role? Specialty ?	<b>Content</b>	<b>Source</b>	<b>Submitted</b>

The table at left summarises the simple but powerful queries that can be made into the XDS registry as part of document sharing. **Note that they are used in combination to 'gather' and display structured information from different sources to create the medical summary output that is required.** This structured query method is highly flexible and can be used to retrieve specific sets of documents or to re-present data for decision support. It thus provides a pragmatic method for serving clinical information needs e.g. "...I want a summary that will tell me patient A's data for B, C, D in facility E for period F..." Parts of the document 'tree' can be readily displayed by an application on the users screen in any desired format.

\*Metadata items in **red** are searchable in XDS, other items in **black** are stored metadata.

\*\*A service event i.e. "what was done" - examples might be a radiology report or discharge summary

# WHAT IS GOING ON IN THE BACKGROUND?

The mechanism that creates clinical summaries is part of a robust set of transactions defined by ebXML. Other global standards such as those published by ISO HL7 are also key to making things work. The figure below further describes the kinds of transactions that go on in the background when a user of an IHE XDS system

'pushes the button'. It is important to see that this mechanism is not 'proprietary' and so can be widely adopted by a wide range of suppliers as well as health service IT departments. The costs of implementing such systems are inherently lower because of the standards-based design and the fact that globally

many sites are developing solutions which are applicable elsewhere. Standard transactions mean systems that solve the clinical information sharing problem can be realised more cost-efficiently. While the technical details are hidden from the user, appreciating the flexibility of the messaging transactions may be useful

for end-users to better understand the ways in which information can be shared for clinical benefit. After all of the transactions take place, a medical summary (like that shown on the right of the figure below), which well-articulates 'status' can be readily produced.

### KEY - BACKGROUND IHE TRANSACTIONS

### IHE ACTORS

[ITI number] ~ A SPECIFIED IHE IT INFRASTRUCTURE FRAMEWORK REFERENCE

**SMTP**

Simple Mail Transfer Protocol

**DOCUMENT SOURCE**

**NOTIFICATION SENDER**

**PATIENT IDENTITY SOURCE**

PATIENT IDENTITY FEED [ITI-8] ↓

**DOCUMENT REGISTRY**

PROVIDE & REGISTER DOCUMENT SET [ITI-15] →

↑ REGISTER DOCUMENT SET [ITI-14]

**DOCUMENT REPOSITORY**

RETRIEVE DOCUMENT [ITI-17] ←

**DOCUMENT CONSUMER**

QUERY REGISTRY [ITI-16] ←

**NOTIFICATION RECEIVER**

RECEIVE NOTIFICATION [ITI-26] →

SEND NOTIFICATION [ITI-25] →

**SMTP**

RECEIVE ACKNOWLEDGEMENT [ITI-28] ←

SEND ACKNOWLEDGEMENT [ITI-27] ←

Patient: Ellen Ross  
 17 Elm Rd.  
 Blue Bell, PA 19380  
 HP: (717) 555-1212  
 Birthdate: January 27, 1960  
 Consultant: Bernard Wiseman, Sr.  
 MRN: 12345  
 Sex: Female  
 Created On: March 29, 2005

**Good Health Clinic Care Record Summary**

Reason for Visit/Chief Complaint  
 Ankle Sprain

Reason for Referral  
 Follow-up care for Ankle Sprain

Advance Directive  
 • Living Will  
 • Power of Att  
 • Healthcare Pr  
 • Organ Donor

History of Present  
 Patient slips

Family History  
 Father, alcoh

Social History  
 • 3/26/2005 Community Hospital, ED Visit for Ankle Sprain  
 • 4/26/2002 City Hospital, Gull Bladder Surgery  
 • 5/12/2002 Community Hospital, Labor and Delivery  
 • 10/26/2001 Community Hospital, ED Visit for Ankle Cholecystitis

Conditions  
 Review of System  
 • Cholecystitis  
 • Pregnancy, 5  
 • Ankle Sprain

Physical Examination  
 Left foot and ankle are swollen profusely.

Allergies and Adr  
 • Patient in all

Medications  
 • Indomethacin, 50mg bid with food, 12/19/2003 - present  
 • Acetaminophen with codeine, #3 1-2 tablets for pain as needed, 03/26/2005

Immunization  
 • DTP - 1962  
 • MMR - 1961  
 • MMR - 1961

Procedures  
 • Laparoscopic Cholecystectomy, 9/26/2002  
 • Cesarean Section, 10/22/2002

Prior Encounters  
 • 3/26/2005 Community Hospital, ED Visit for Ankle Sprain  
 • 4/26/2002 City Hospital, Gull Bladder Surgery  
 • 5/12/2002 Community Hospital, Labor and Delivery  
 • 10/26/2001 Community Hospital, ED Visit for Ankle Cholecystitis

Vital Signs  
 Date Height Weight Temperature BP Pulse Respiration O2  
 3/28/2005 5'9" 215 lbs. 98.7 F 120/80 68 16 99%

Related Reports  
 X-Ray Study - Left Ankle, No Fracture, 3/26/2005

Plan of Care  
 Acetaminophen with codeine prn for pain.  
 Stop off the foot. Keep foot elevated, and use supplied air splint and crutches.  
 Follow-up with orthopedist in next 5 days.

Date	Height	Weight	Temperature	BP	Pulse	Respiration	O2
3/28/2005	5'9"	215 lbs.	98.7 F	120/80	68	16	99%

## XDS SHARING PRINCIPLES APPLIED TO MULTI-CENTRE CLINICAL RESEARCH

### Jargon

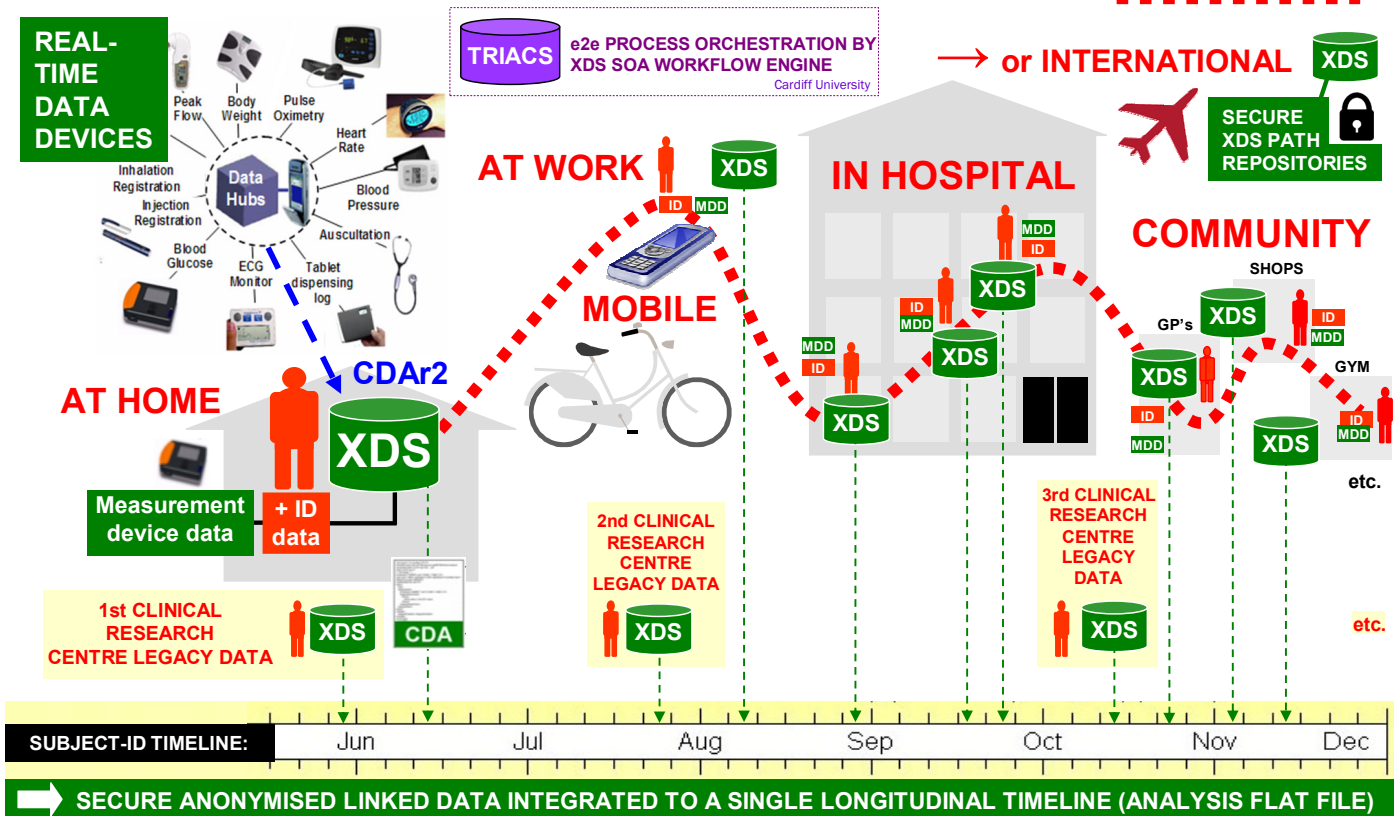
- **Longitudinal studies** — generally, repeated observations of the same data types over long periods of time; useful for discovering risk factors, markers or developmental trends highly related to specific outcomes e.g. across a life span.
- **Prospective (or retrospective) studies** — put simply, longitudinal research looking forward in time (or back in time), recording data events as they occur (or did occur) and relating these observations to specific outcomes.
- **Anonymised linkage** — a common mechanism of breaking the link between recorded data along the patient path and the identity of the subject. *AL* can be implemented as a secure information service to perform irreversible anonymisation or pseudonymisation according to the rules of ethical information governance applicable to the study.

The flexibility of XDS in helping to solve problems of medical data sharing—in a globally-standard manner—can also be applied to clinical research data. This function is required when a *subject's* 'timeline' data needs to be collated from primary, secondary and tertiary systems (in order to compile a complete dataset for **longitudinal studies**). A likely scenario is where secure anonymised id-linked data exists in a large number of 'silos' that normally do not interoperate—and actually may be distributed across many centres throughout the country. A research study requiring the standardised aggregation of many millions of records (e.g. into analysis-ready flat files comprising input and outcome variables to compute risk relationships more reliably) can exploit the global standardisation inherent in XDS. By combining XDS-MS, CDAR2 and an SOA workflow engine capa-

ble of federating many research database repositories, large research data collections can be created according to the specification of the study. Multi-centre **prospective or retrospective studies** generally require an integration (harmonisation) standard in data preparation phases. In this case an XDS-compliant data collation workflow engine can invoke multiple standards-driven information services as needed (e.g. for pseudonymisation, ethical compliance, datatype selection, quality assurance, information governance, controlled terminologies, statistical transformations etc.). Providing an **anonymised linkage** mechanism to a multi-centre federated patient ID exists, each 'silo' only needs to map its outputs to XDS/CDAR2 once (to merge legacy data with real-time data at patient level (figure). The simplicity of the XDS data shar-

ing model permits scaling and direct integration to electronic data capture systems 'along the *subject path*'. Such flexibility is important to invoke flow of key risk data from data repositories . A scenario for the standards-driven collation of multi-centre data and 'patient path' source data (e.g. from medical devices and instruments irrespective of location) is shown in the figure below. The capacity of structured CDAR2 or other specialised (standardised) document type to collate risk data orchestrated by a workflow engine has high enabling potential for longitudinal outcomes-based research. It is able to support pre-defined cohort studies producing patient-level summaries for standalone analysis. This novel application illustrates the problem-solving potential of XDS-based methods in large-scale retrospective and prospective studies.

### XDS-mediated multi-source ethical data linking anywhere on the subject's path



Concept version drawn 071228 © 2007 for CU DRU - Clinical Research Collaboration (CRC) Network Lead hosting WORD Individualised Risk Analysis Project