



National Integrated Services Framework

29-30 October 2013
Dublin

Part I

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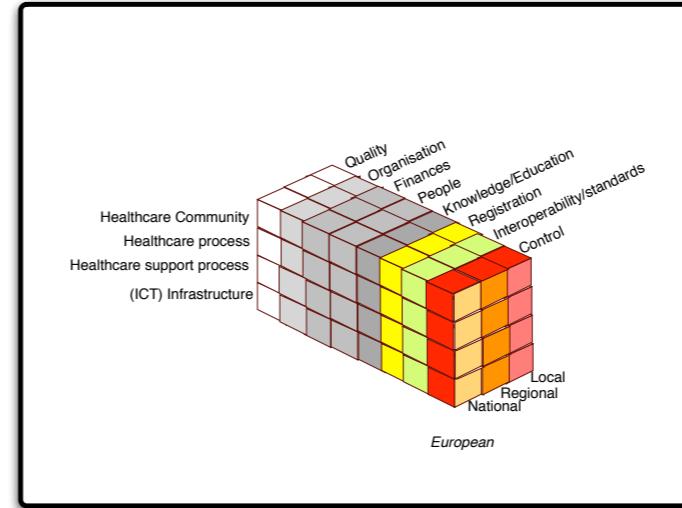
Workshop I

Information Architecture

The context of this project is:

- Requirements based
- facilitation
- the **exchange** of
- standardised, structured
- **health and care data**
- between IT-systems
- based on open International standards

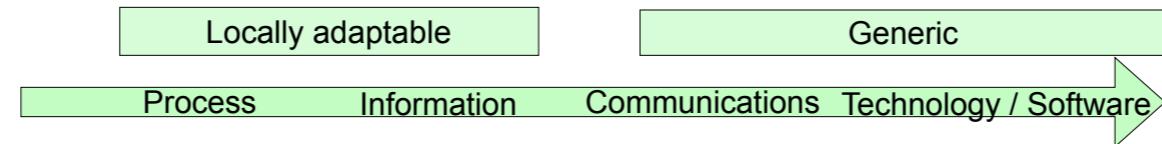
- Business and Strategy
- Clinical, Safety and Research
- Technical
- Allied Agencies
- others



Stakeholders have been collated in 4 Stakeholder Groups.

The picture shows that at many level many have to participate.
One axis is geographical: Local,

What is important?



Healthcare is in the lead



Healthcare is suffering



Uniform / rigid / 'one size fits all'

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- Until the present time IT in Healthcare is IT-technology driven

We need to migrate to:

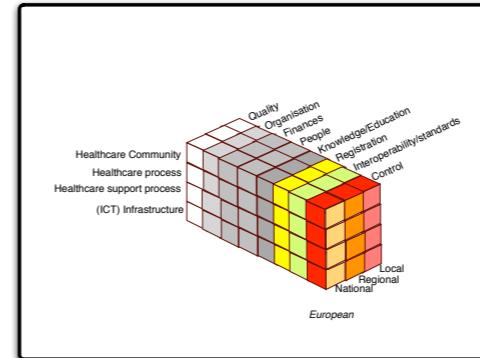
- Healthcare driven IT-development

Complexity

- IT is complex?
- Exchange of data between systems is complex?
- Healthcare is complex?
- Co-operation in healthcare is complex?

How must/can we reduce complexity for:

- healthcare providers?
- authorities?
- IT-industry?



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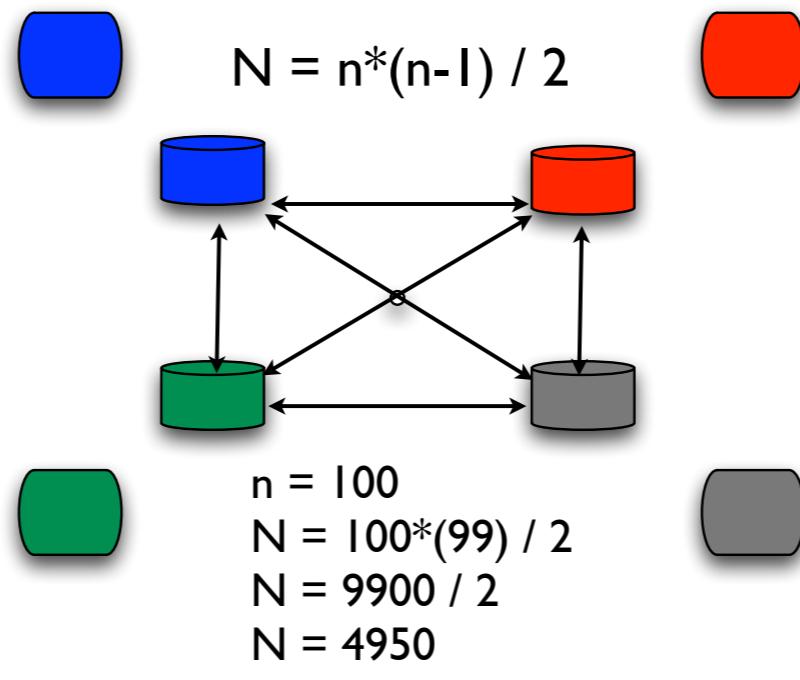
As described health IT is complex.

It is our task to reduce complexity
and support the healthcare domain and IT-vendors

- **Introduction: Setting the scene**
- **Why Standards**
- **What standards**
- **Exchange of data between systems**
- **Patient Summary: epSOS**
- **European Concurrent Use standards**

The Introduction is complete.
The problem is clear.

The rest of the presentation is about possible solutions:
- based on standards

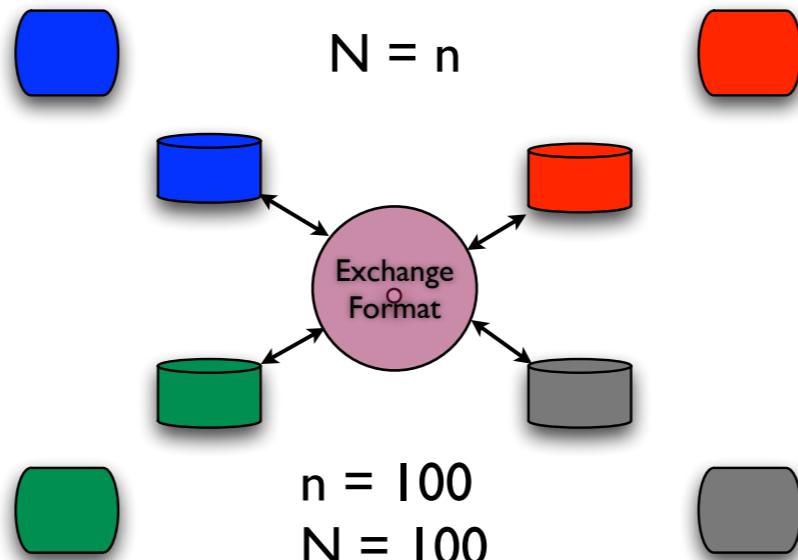
NO STANDARDS

4 Systems are depicted.

In the case of 100 systems that communicate there are nearly 5000 interfaces to be maintained.

This is NOT manageable.

EXCHANGE STANDARD



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4 Systems are depicted.

In the case of ONE single standard and 100 IT-system vendors
only 100 interfaces need to be deployed and maintained.

This is is **manageable**.

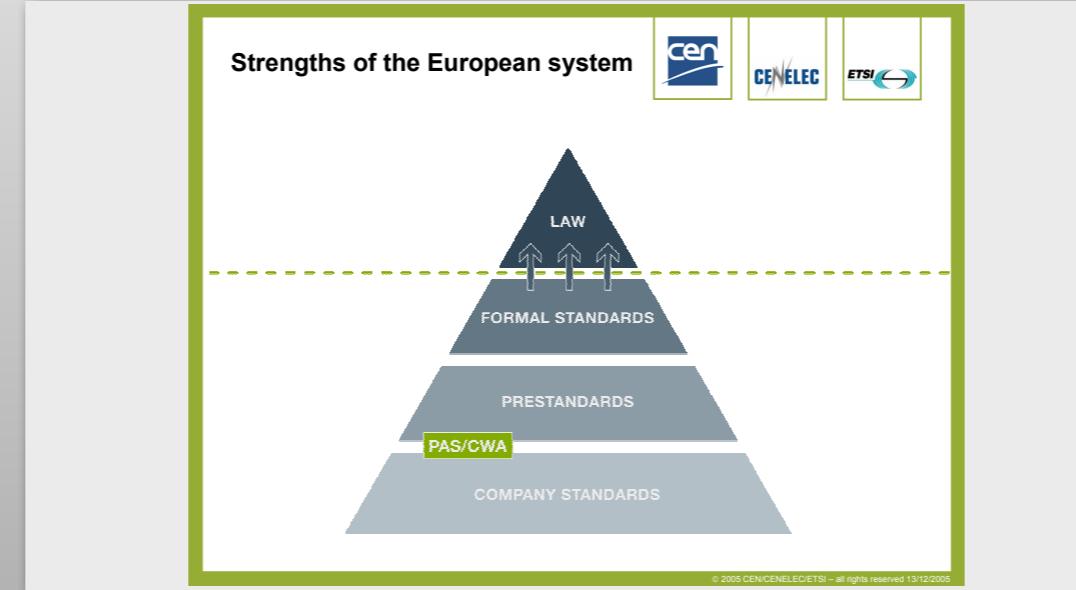
- **27 European countries**
- **Many cultures, many languages**
- **One united European Community**
- **Free movement of goods, people, money and services**
- **One big competitive European economic space**

European Standardisation

European standards play
a special role:

- Only National standards derived from European standards can be used in *legislation*
- National and European standards play a role in *procurement*

European Standardisation



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Only European standards play a formal role in legislation:
ENvironment, medical devices, Electrical appliances, etc, etc.

European developments



Directive on patients' rights in cross-border healthcare



The 3 aims of this Directive



1. Help patients to exercise their rights to reimbursement for healthcare received in another EU country

2. Provide assurance about safety and quality of cross-border healthcare

3. Establish formal cooperation between health systems



European developments



Directive on patients' rights in cross-border healthcare



3. Cooperation between health systems

- **Recognition of prescriptions**
A prescription issued in another EU country will be more effectively recognised
- **European Reference Networks**
They will bring together specialised centres across Europe helping health experts to disseminate information and expertise
- **Health Technology Assessment**
A permanent EU structure of cooperation to help decision-makers to make the right decisions on health investment and spending
- **eHealth**
A first step towards "interoperability" of ICT for health at EU level for safety and quality of care, continuity of care, and health research



European developments



Directive on patients' rights in cross-border healthcare



The legislative process

- **Adoption:** of the Commission proposal: 2 July 2008
- **First reading:** July 2008 - September 2010
- **Second reading:**
 - 19 January 2011: Vote in Parliament
 - 28 February 2011: Formal adoption of the Council
- **Publication in the Official Journal:** 4 April 2011
- **Entry into force:** 24 April 2011

European developments



Directive on patients' rights in cross-border healthcare



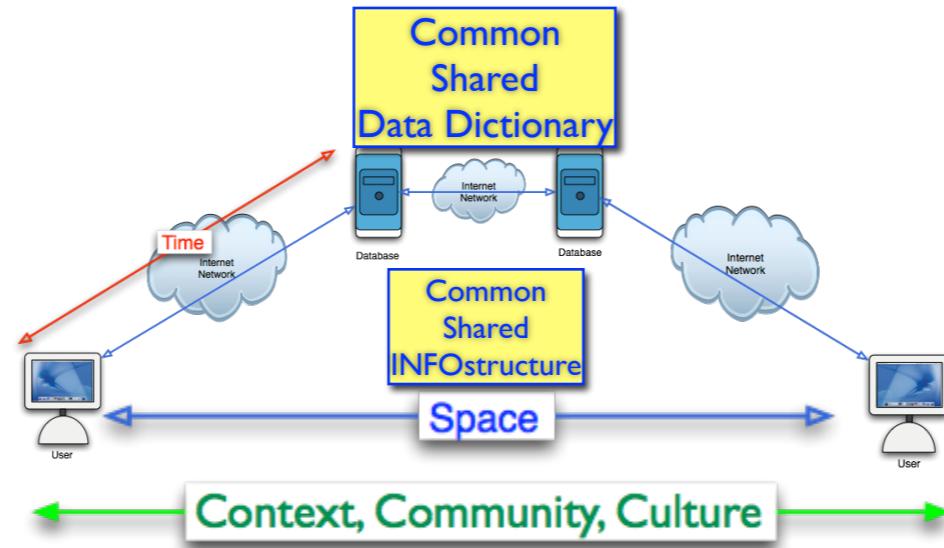
The transposition process

- **Transposition period:** 30 months (25 October 2013)
- **Bilateral discussions** with 27 Member States (MS):
 - COM questionnaire on the transposition of the measures provided for in the Directive (May – October 2011)
 - COM bilateral visits in all 27 MS (2011 – 2012) to discuss particular issues related to transposition
- **Committee on Cross-Border Healthcare**
 - Formal forum created by the Directive where all 27 MS will meet regularly to vote on implementing acts and discuss general issues linked with the transposition of the Directive.

WHAT Exchange of Data

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Exchange of Data in general.

Transport over time via a database.

Transport over space,

Result in problems because of a change of:

- Context
- Community and
- Culture

"A person, yet to be born, using an IT-system, yet to be developed, must be able to interpret all the data safely."

This possible, only, when TRUST over long periods of time can be created.

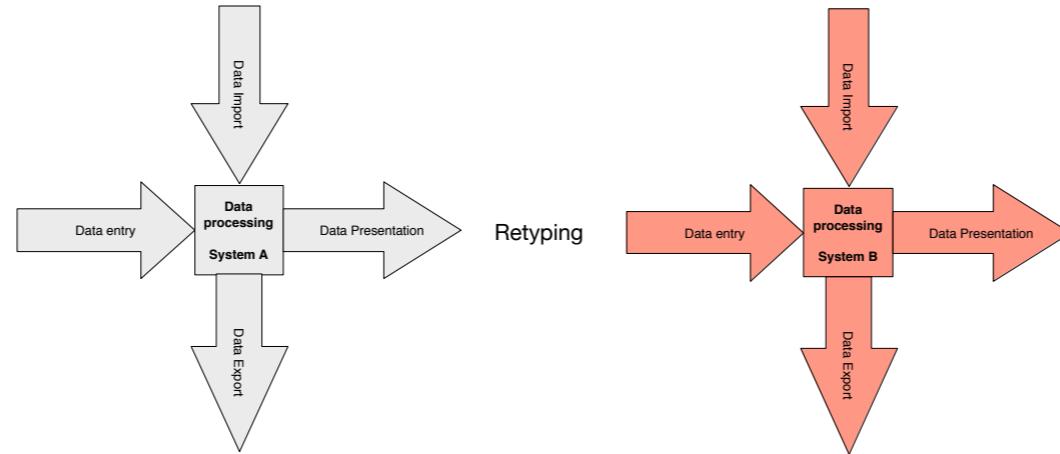
Stable open International standards are indispensable.

All long term agreements will be captured, governed and published in a shared common consolidating DATA DICTIONARY.

What Standards for IT-System Data Exchange

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Any user types new data and reads the stored documented healthcare delivery.

Data silo's are the result, because each vendor (and implementation) uses his own proprietary standards.

The present modus for exchange of data between SILO's:

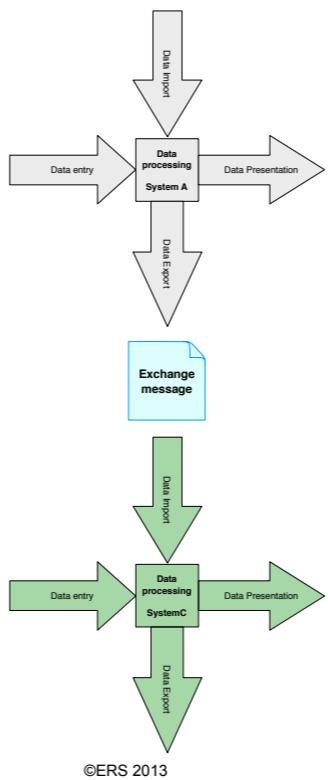
- RETYPING

What Standards for IT-System Data Exchange

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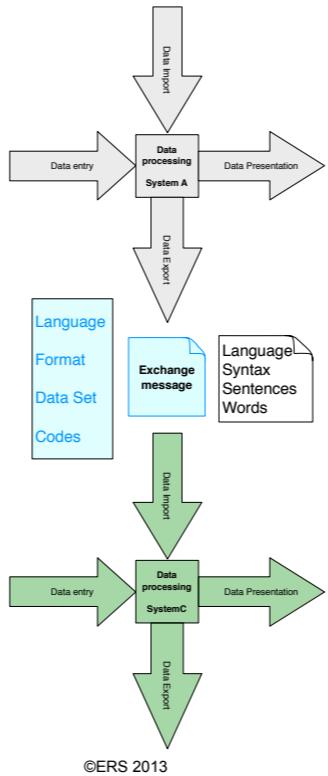
What is needed is:
electronic Data Exchange between IT systems
using Exchange Messages.

What Standards for IT-System Data Exchange

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When, we humans, communicate we use:

- Language with its specific
- Language rules : SYNTAX
- Words as defined in a DICTIONARY
- and produce phrases / SENTENCES / STATEMENTS

When IT- systems exchange electronically the same things must be in place:

- Language used
- Format used
- Data Set used and
- The Codes (from a coding system) that is used.

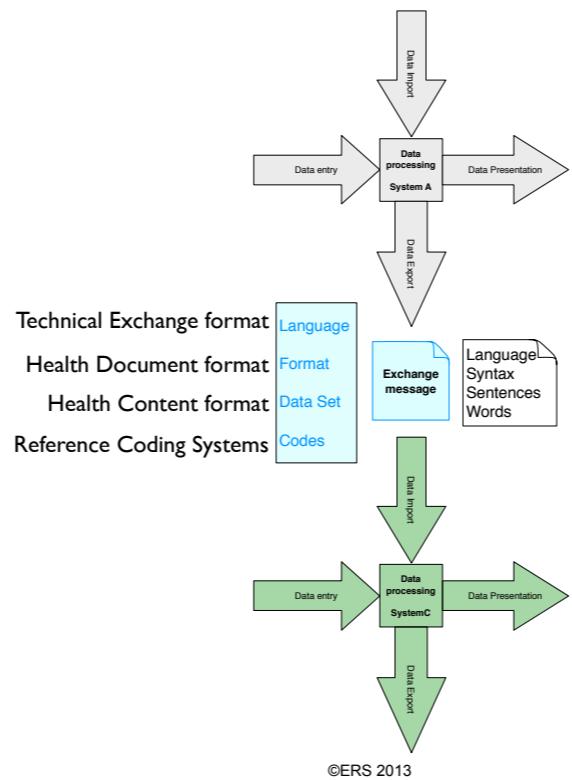
(Local coding systems must/can be mapped on the Reference Coding System (TERMINOLOGY)

What Standards for IT-System Data Exchange

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The standards that are needed are for:

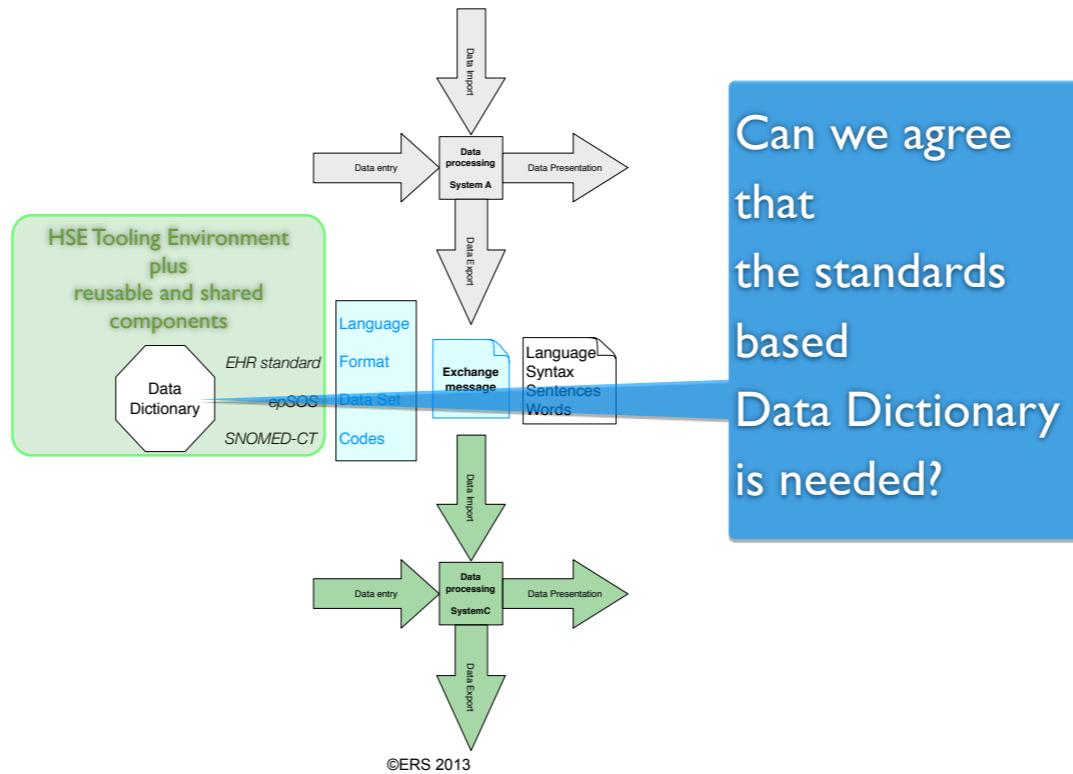
- Technical Exchange Format (e.g. XML)
- Health Document format
- Health Content format to express the data needs of the communicating partners
- Reference Coding System and its codes where local code list can be mapped to.

What Standards for IT-System Data Exchange

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Can we agree
that
the standards
based
Data Dictionary
is needed?

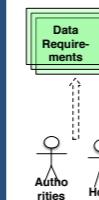
The present project will define:

- TOOLING ENVIRONMENT based on standards
- Possibility to produce Data Sets stakeholders providers need
- Standardised re-usable components

All components are consolidated in a standards based Data Dictionary.

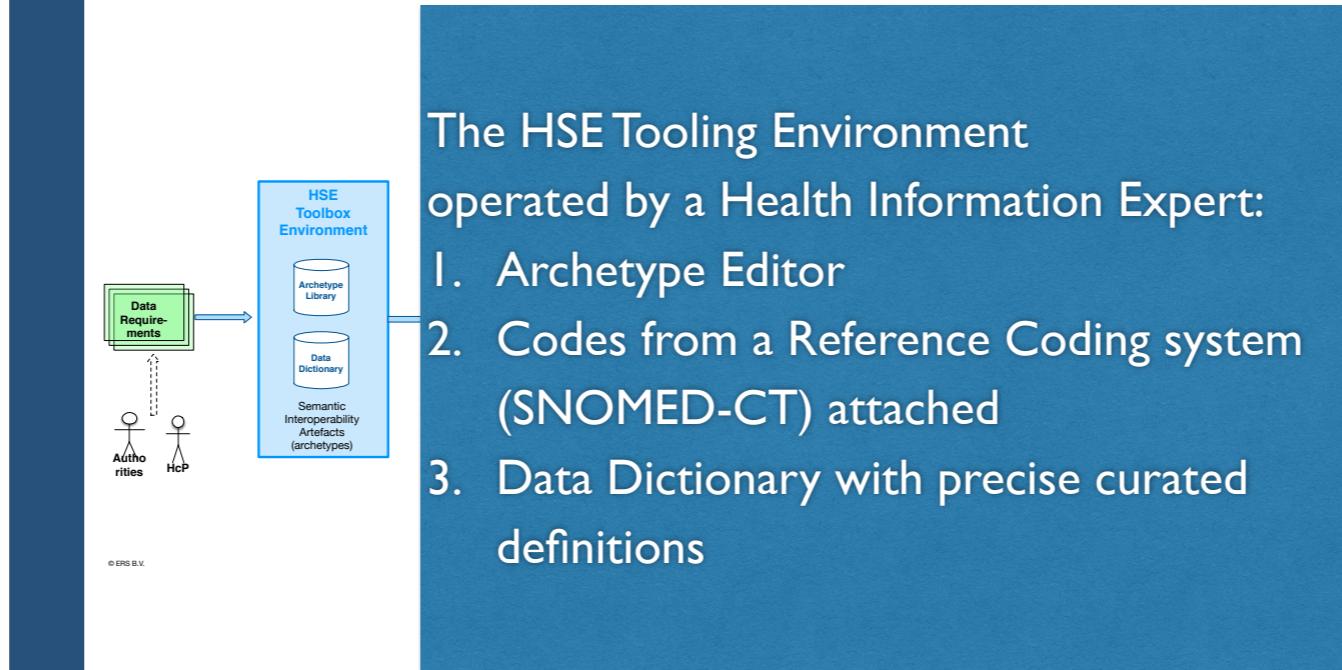
The DATA DICTIONARY and the TOOLING allow:

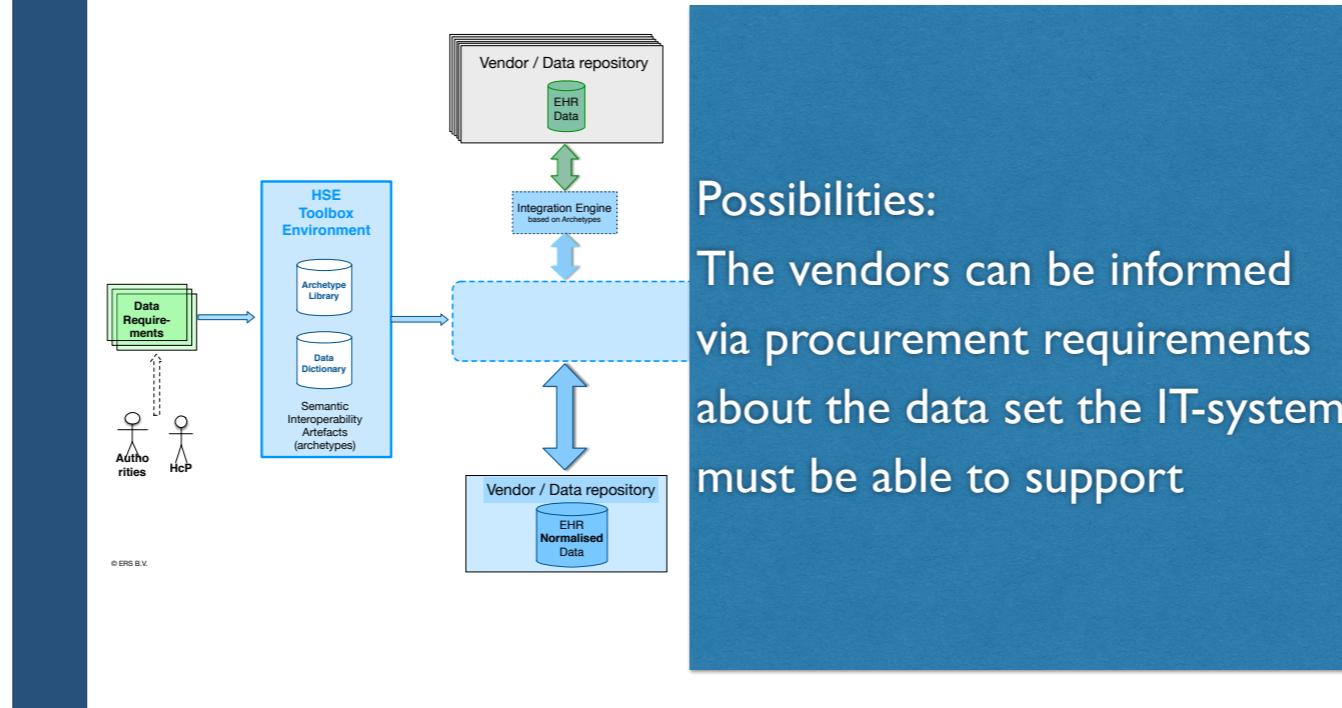
- Healthcare providers to express what they need/want to store, retrieve and exchange
- Authorities can express what needs to be reported
- Researchers can (like HCP's) define what needs to be entered, stored/retrieved and exchanged.
- The defined standards, Tooling and Re-usable components and common and shared data sets can be used in a PROCUREMENT process.
- IT-vendors can, using the Data sets and standards as defined during PROCUREMENT, comply with the wishes of their customers.

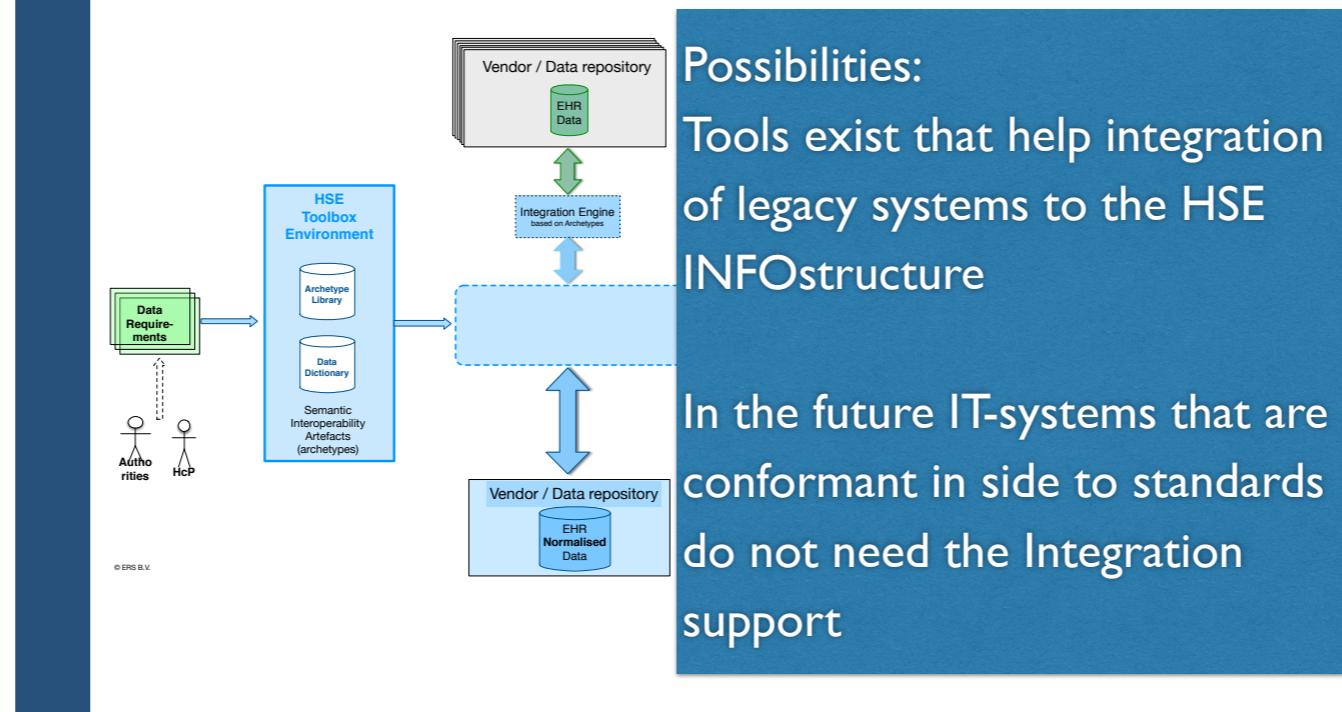


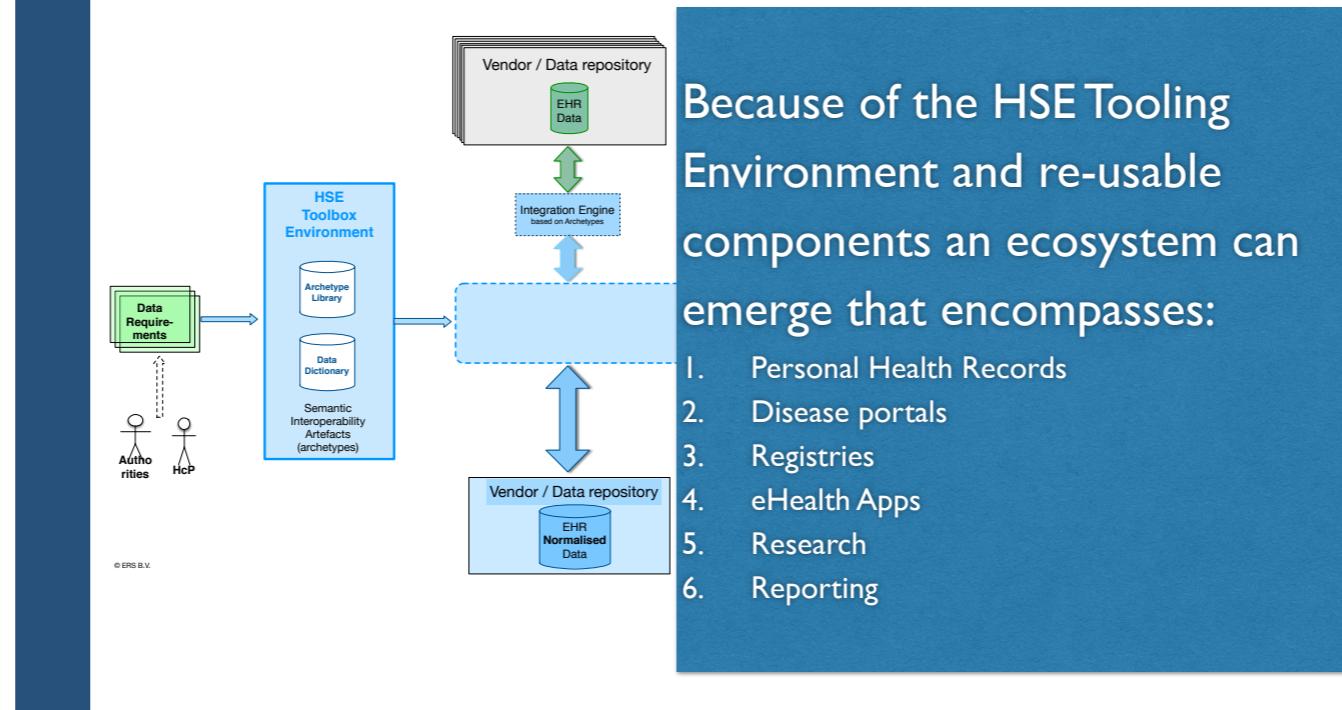
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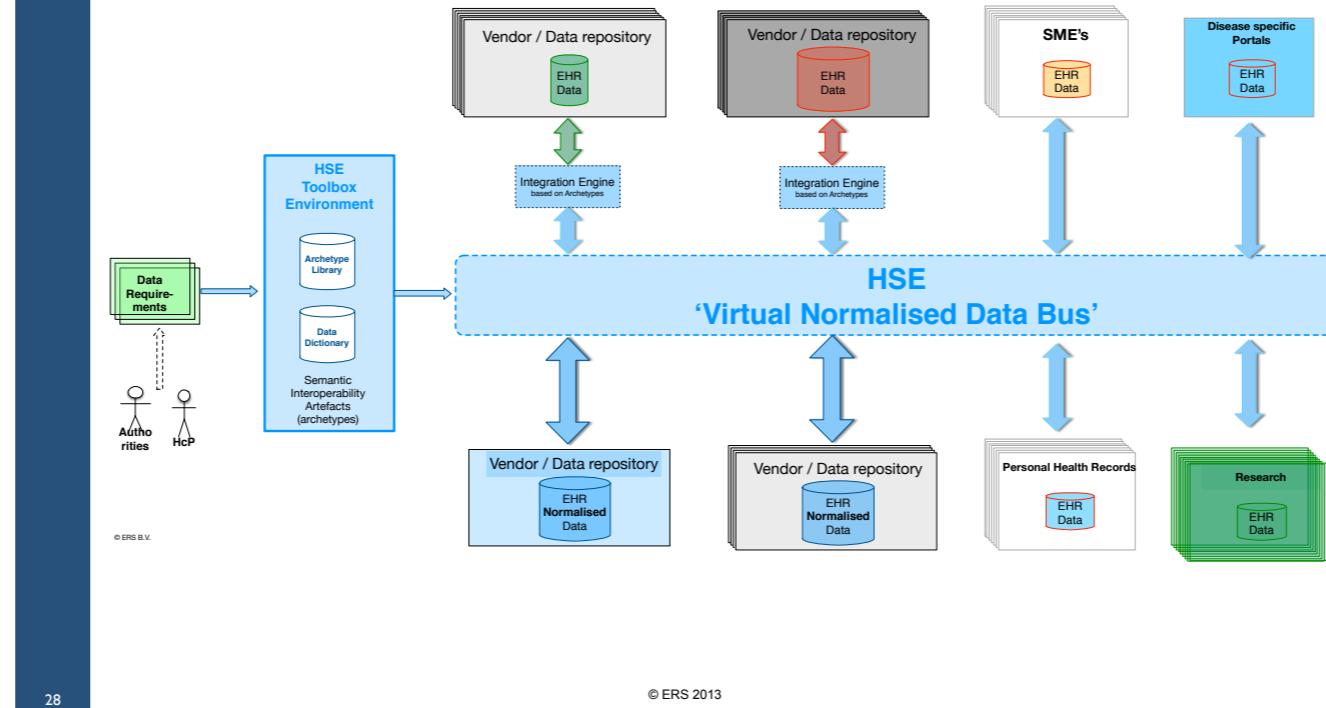
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- Health care stakeholders need to define their data requirements (data set)
- Each group will have its own requirements
- Each group must be able to construct its own data set and validate it
- Co-operating partners will have their own data sets as defined as part of the co-operation contract
- Each IT-vendor must be able to support every, and ever changing, data set inside and between the IT-systems

Can we agree upon these principles?

Data sets produced re-use common and shared standardised components

Each co-operating group will contractually specify the data set they need. The standardised components will be used.

- Use cases provide the context for the Data Sets as the Subject Area Model (SAM).
- In the present project we will construct a demo using the epSOS Data Set.
- In an other project, for example, the Diabetes Use Case and Data Set can be selected as SAM to be deployed in real life.

Irish Standards Based Diabetes Core dataset for Primary Care							
Data Set Content	Comment	Formal Name	Type & Literality	Description	Parameter	Definition	Field No
1	Demographic Data	Practice name	n/a	IMC Practice Code 27527 Format	6 Digit Practice Code	The GP practice name is received from the Health Atlas Directory.	
	Demographic Data	Practice identifier	n/a	IMC Practice Code 27527 Format	6 Digit Practice Code	The GP practice code is received from the Health Atlas Directory.	
	Demographic Data	Principal treating hospital identifier	n/a	IMC Practice Code 27527 Format	8 Characters	The Hospital Identifier code is received from the Health Atlas Directory.	
	Demographic Data	GP IMC code	n/a	IMC Practice Code 27527 Format	6 Digit Code	The GP IMC code is the personal identification number issued to each doctor by the Irish Medical Council permitted approval to practice medicine within the Irish Republic.	
	Demographic Data	GP GMS number	n/a	GMS Practice No. 27527 Format	6 Digit Code	General Practitioners (GPs) provide services to medical card holders in Ireland free of charge. Those GPs in the Primary Care Re-imbursement Service (formerly known as the 'General Medical Services') scheme enter into contracts with Health Service Executive (HSE) Areas to provide services. The PCRS / GMS number of the GP should be entered in this field.	

Goal: Cross border

- “to develop a practical eHealth framework and ICT infrastructure that will enable secure access to patient health information, particularly with respect to a basic patient summary and ePrescription, between European healthcare systems.”

PILOT OPERATION

Patient Summary

- access to important medical data from the patient's home country when receiving treatment abroad

ePrescription and eDispensation services

- access to an individual's ePrescription from the home country
ePrescribing: electronic prescribing of medicine using software to transmit the prescription data to the pharmacy
- dispensing: electronic retrieval of an ePrescription, the dispensing of the medicine to the patient and the submission of an electronic report

General Information

- Name, birth date, gender, identification, address, contacts, insurance

Medical Summary

- Alerts (allergies, vaccinations), current medical problems, medical implants, major surgical procedures during the last 6 months, treatment recommendations, list of current medications, life style, pregnancy, physical findings, blood group

Other information

- When and by whom generated, updated, etc.

EU: epSOS, Spain, Andalusia, Sweden, Slovakia, England

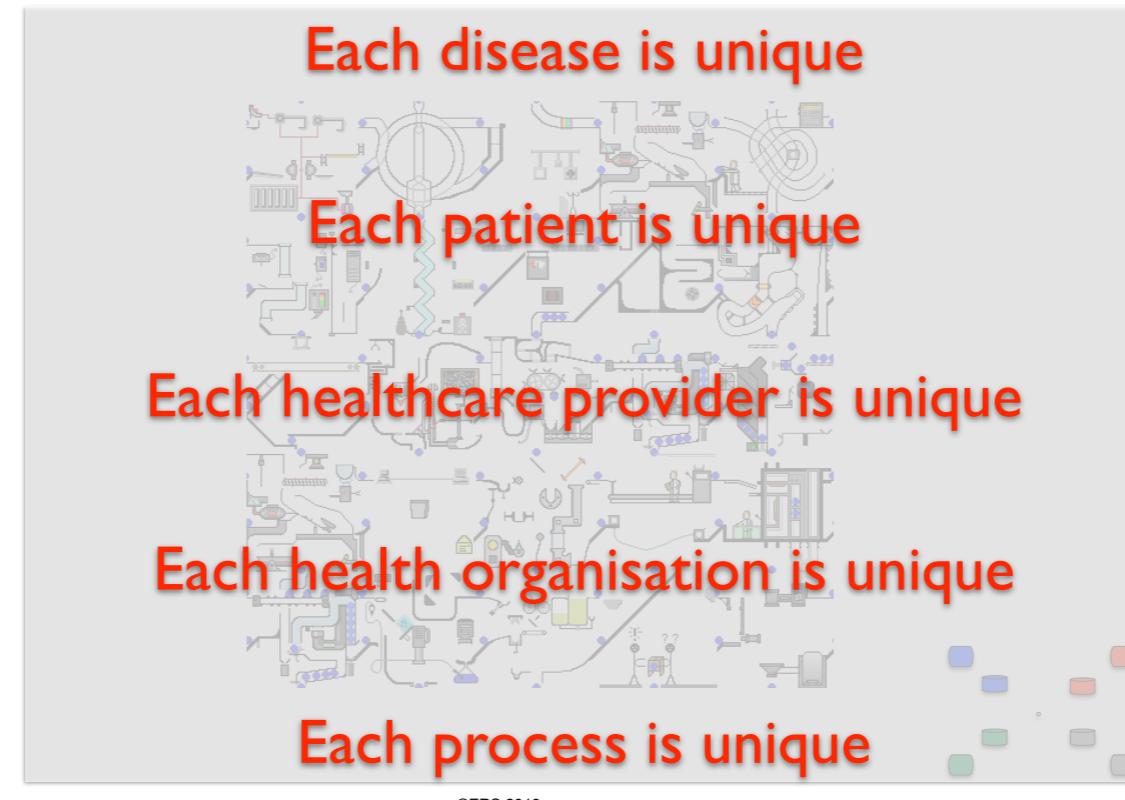
USA: Clinical Information Modeling Initiative
(CIMI):

Intermountain, Kaiser Permanente, Mayo, Stanford, NIH,
VHA
HL7, ISO/TC215, IHTSDO, CDISC
NHS England, Canada Infoway, Singapore, NETHA,
EN13606 Association,

Several European countries and regions use the CEN and ISO EHR Communication standard.

CIMI (Clinical Information Modelling Initiative) has important players from the USA and other countries as active members.
CIMI is in the process of defining the models and tools needed to define data sets. It is based on the EHR Communication CEN and ISO standards

- **EHR-Com** - EHR documentation and exchange
- **ContSys** - Health and Care processes
- **HISA** - EHR IT-System standardised services





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National Integrated Services Framework

28-29 October 2013

Part 2

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- Recapitulation
- HSE Tooling Environment
- Re-usable Components
- Why a Data Dictionary
- What are the benefits
- Summary

National Integrated Services Framework

- Exchange of health and care standards based structured data for primary and secondary (re-)use
- Health, Care and Management requirements based
- Health, Care and Management process driven
- HSE Tooling Environment plus re-usable common components
- Based on existing open International standards
- Usable in IT-systems procurement
- Evolutionary change process, gentle migration

Example Use Case Child Health Care

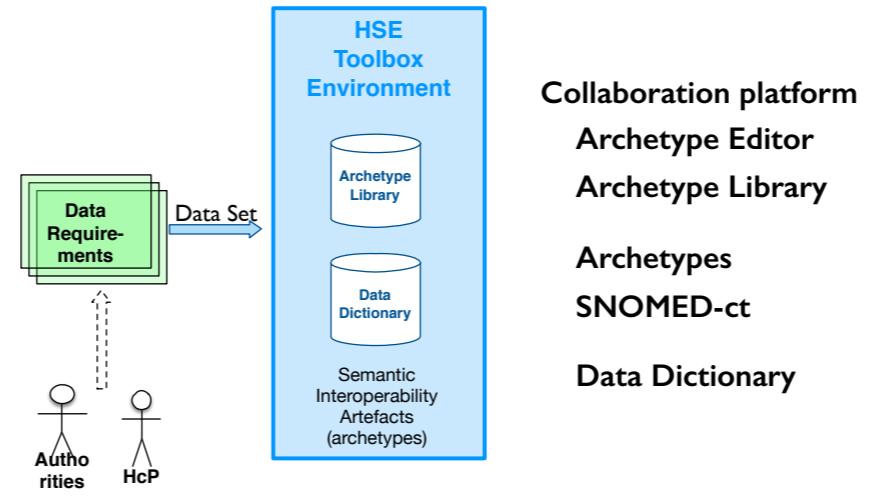
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Stakeholders	Activities
GP	Treats most common problems and needs to maintain an overview, Referral and discharge notes.
Pharmacists	Dispensing prescribed medicinal products and advice
Community Nurse	Monitoring the development new born, young children. Vaccination program
School	Monitoring the development of young children
Pediatrician	Clinical disease episodes, referral en discharge notes
Public Health	Monitoring: child developments, environment, infectious diseases, ...
Researcher	Own academic research or on behalf of third parties
Authorities	Monitoring the health care organisations and programs and projects
Patient / parents	Personal Health Record: collecting and reporting data obtained
Disease specific portal	E.g. Disease specific portal for Diabetes or Asthma , or ...

Intended process

- Definition of Data Sets by healthcare Stakeholder groups
- Production of Semantic Interoperability Components (Archetypes)
- Inserting codes for Reference Terminology
- Validation of health content
- Insertion and curation in the Data Dictionary
- Quality Assurance
- Publication and deployment

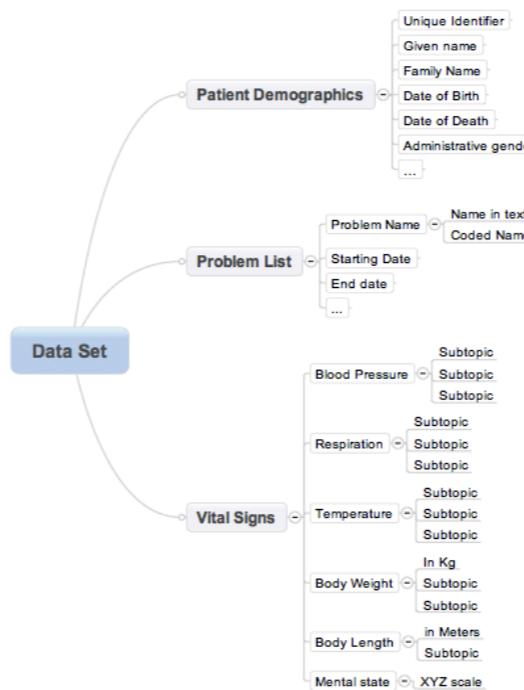


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Requirements can be captured in many formats:

- free text
- an excel
- or a Mind Map

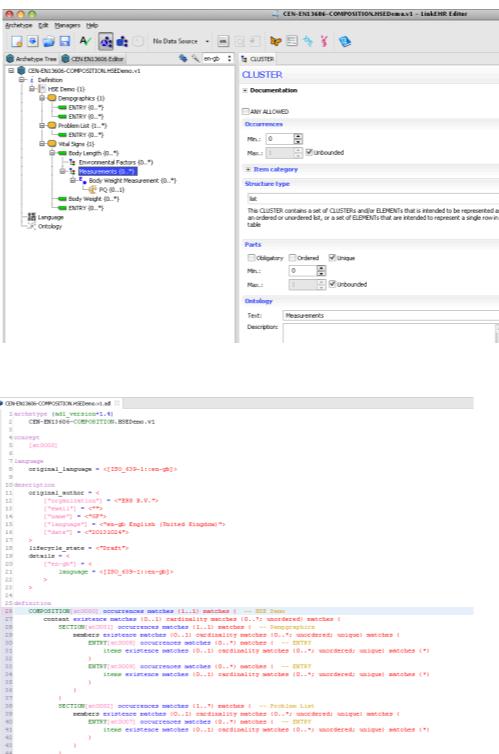
And transformed in to an Archetype using the Archetype Editor



The Archetype Editor uses pre-defined re-usable shared components from the HSE Archetype Library.

The pre-defined components have codes from SNOMED-CT attached to it.
Local codes can be mapped to the reference codes.

In this way any data set can be defined and data can be re-used.



One language, one meaning More than one way to express the same meaning

The diagram shows three levels of data representation:

- Information entity:** The top level consists of three separate boxes. The first box contains a text input field with the value "Diabetes". The second box contains a radio button group labeled "Past History" with options "Yes", "No", and "Unknown", where "No" is selected. The third box contains a text input field with the value "Not diabetic".
- User Interface Forms:** Below these are three numbered forms (1, 2, 3) representing the same data from different perspectives:
 - Form 1 (History):** Shows "Chest Pain" selected in a dropdown under "Symptoms / Problems". It also includes sections for "Family History Heart Failure" (Yes checked), "Diabetes" (No checked), "Organ Failure Diagnosis" (Heart selected), and "Caused by Physical Exercise" (No checked).
 - Form 2 (History):** Shows "Pain" selected in a dropdown under "Symptom | Site". It includes sections for "Family History" (Heart Failure selected), "Other diseases" (no diabetes selected), and "Diagnosis" (Heart Failure selected).
 - Form 3 (History):** Shows "Chest Pain" selected in a dropdown under "Symptoms / Problems". It includes sections for "Others" (FH of heart failure selected), "Diagnosis" (Heart Failure selected), "Status" (Suspected selected), and "Cause" (Physical Exercise selected).

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The national Data Dictionary contain standard data definitions and data elements for use in any Irish health or community services data collection.

They are the authoritative source of information about endorsed national data standards and provide the basis for consistent national collection, exchange and reporting.

Your expectations for data exchange and usage?

Your experience or perception of the major obstacles to achieving your data requirements?

What existing datasets, codes or standards if any you currently use?

Relevant current and emerging business activity?