



# National Integrated Services Framework

29-30 October 2013  
Dublin

Part I

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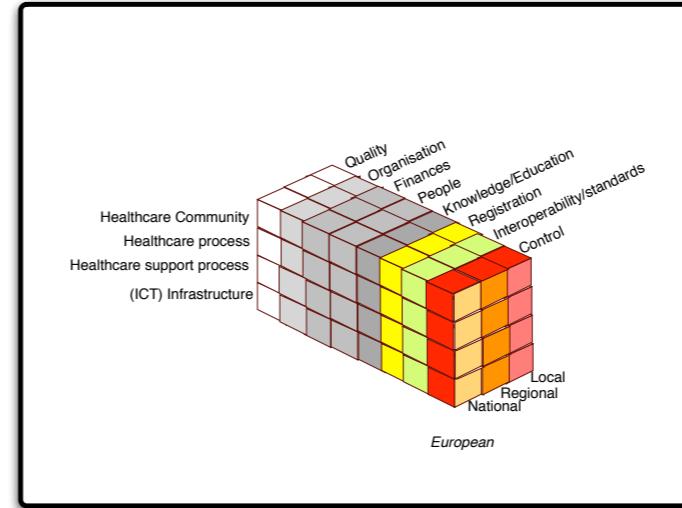
# Workshop I

## 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

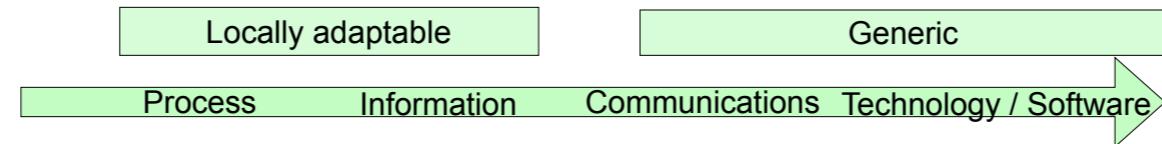
- Business and Strategy
- Clinical, Safety and Research
- Technical
- Allied Agencies
- others



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:

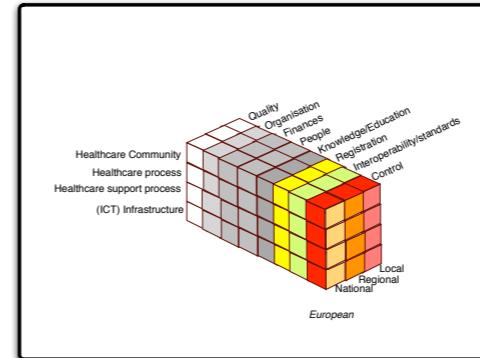
- Healthcare driven IT-development

## 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.

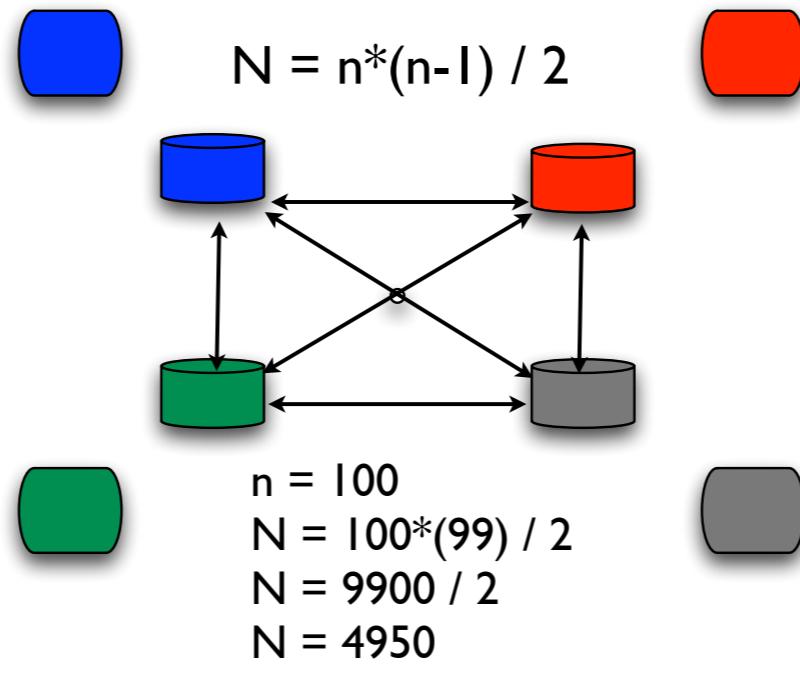
It is our task to reduce complexity  
and support the healthcare domain and IT-vendors

- **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

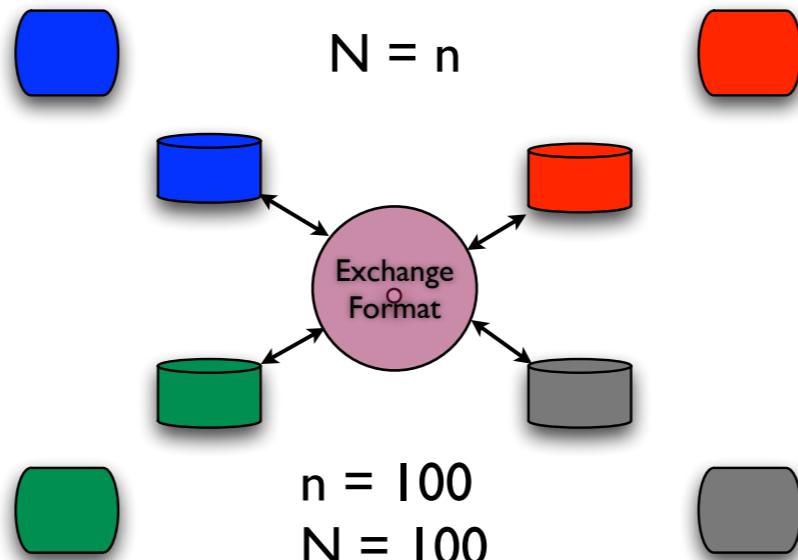


4 Systems are depicted.

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**.

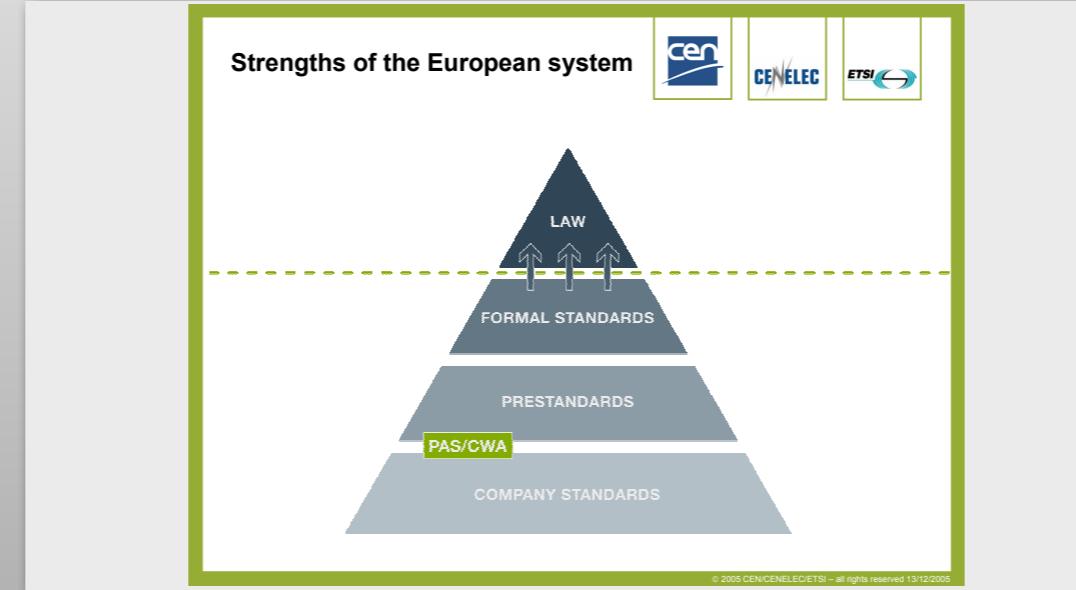
- 27 European countries**
- Many cultures, many languages**
- One united European Community**
- Free movement of goods, people, money and services**
- One big competitive European economic space**

# 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:

# 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



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Other important European developments.

One is the new Directive

**On Patients' Rights in Cross-border healthcare**

# 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.

# European developments



Brussels, 6.12.2012  
COM(2012) 736 final

COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN  
PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL  
COMMITTEE AND THE COMMITTEE OF THE REGIONS

eHealth Action Plan 2012-2020 - Innovative healthcare for the 21st century

**The European Commission's eHealth Action Plan 2012-2020 provides a roadmap:**

- to empower patients and healthcare workers,
- to link up devices and technologies, and
- to invest in research towards the personalised medicine of the future.



Brussels, 6.12.2012  
COM(2012) 736 final

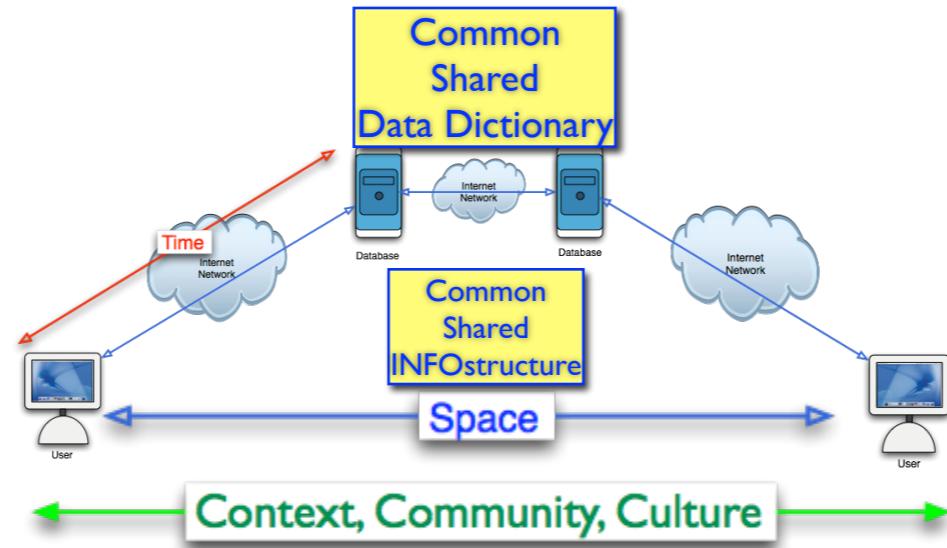
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COMMITTEE AND THE COMMITTEE OF THE REGIONS

eHealth Action Plan 2012-2020 - Innovative healthcare for the 21st century

# 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.

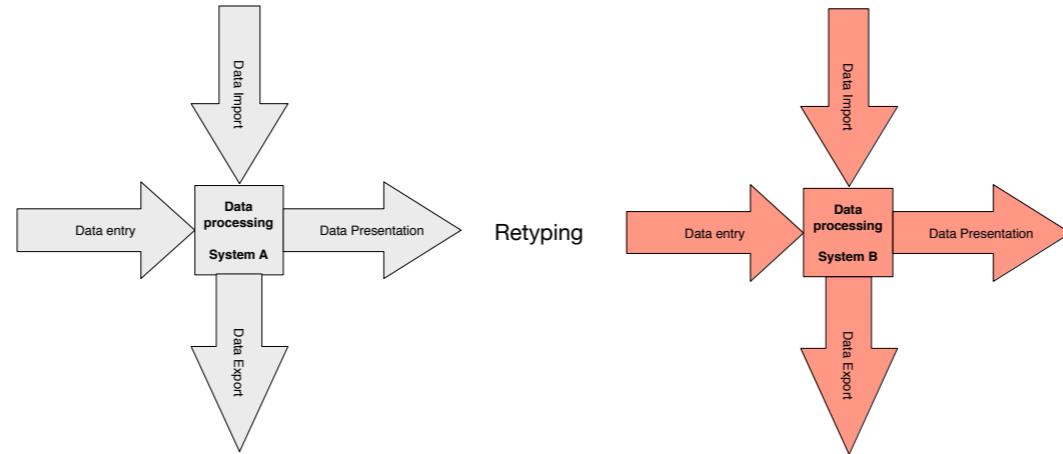
Stable open International standards are indispensable.

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:

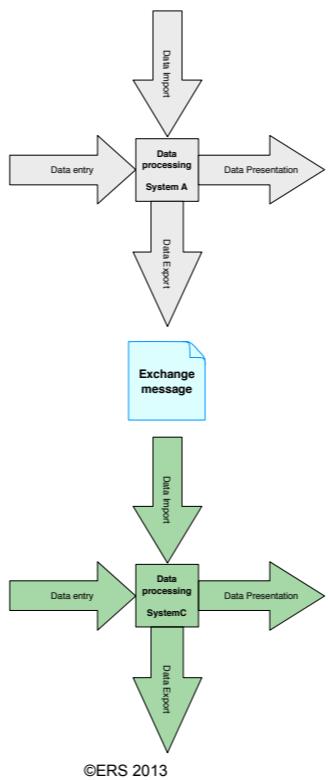
- RETYPING

# What Standards for IT-System Data Exchange

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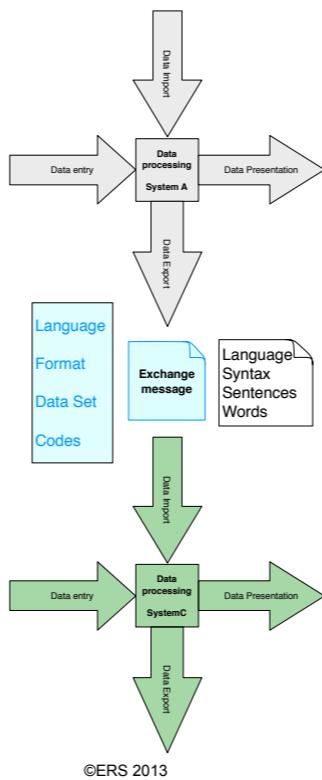
What is needed is:  
electronic Data Exchange between IT systems  
using Exchange Messages.

# 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.

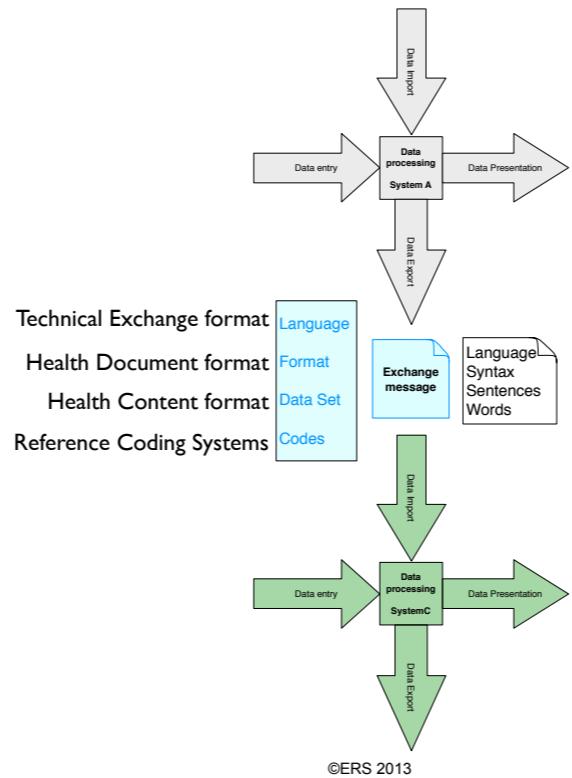
(Local coding systems must/can be mapped on the Reference Coding System (TERMINOLOGY)

# What Standards for IT-System Data Exchange

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The standards that are needed are for:

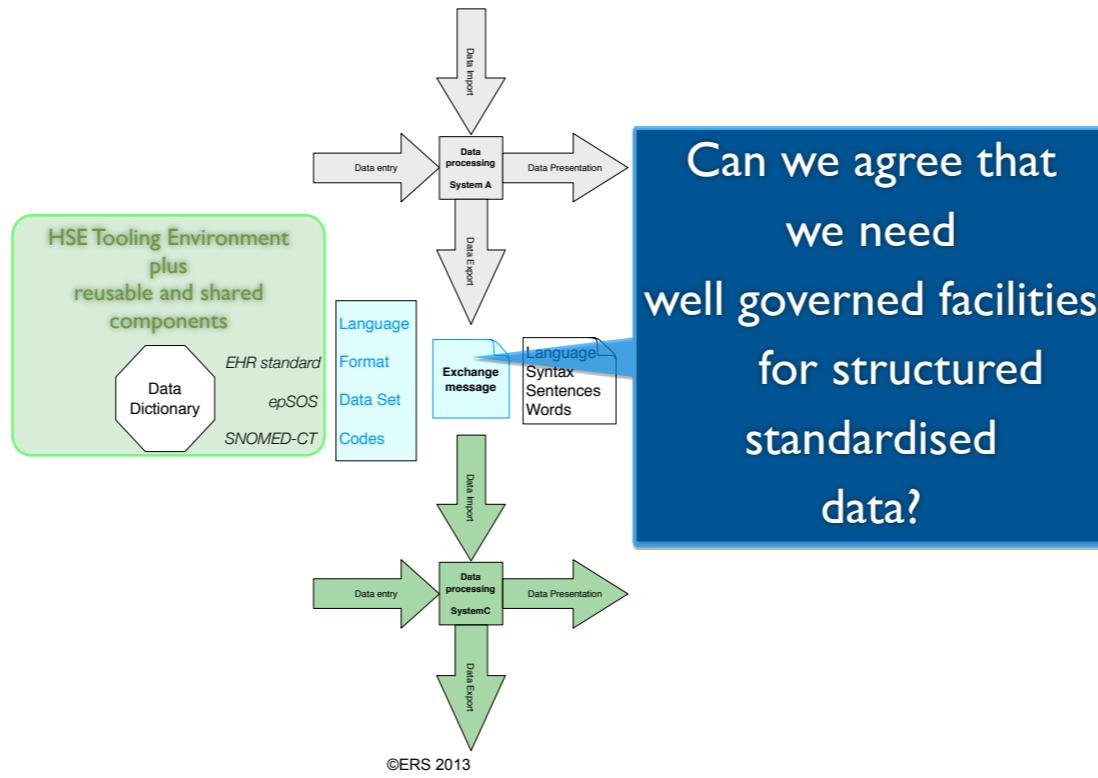
- Technical Exchange Format (e.g. XML)
- Health Document format
- Health Content format to express the data needs of the communicating partners
- Reference Coding System and its codes where local code list can be mapped to.

# What Standards for IT-System Data Exchange

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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, storedm 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.

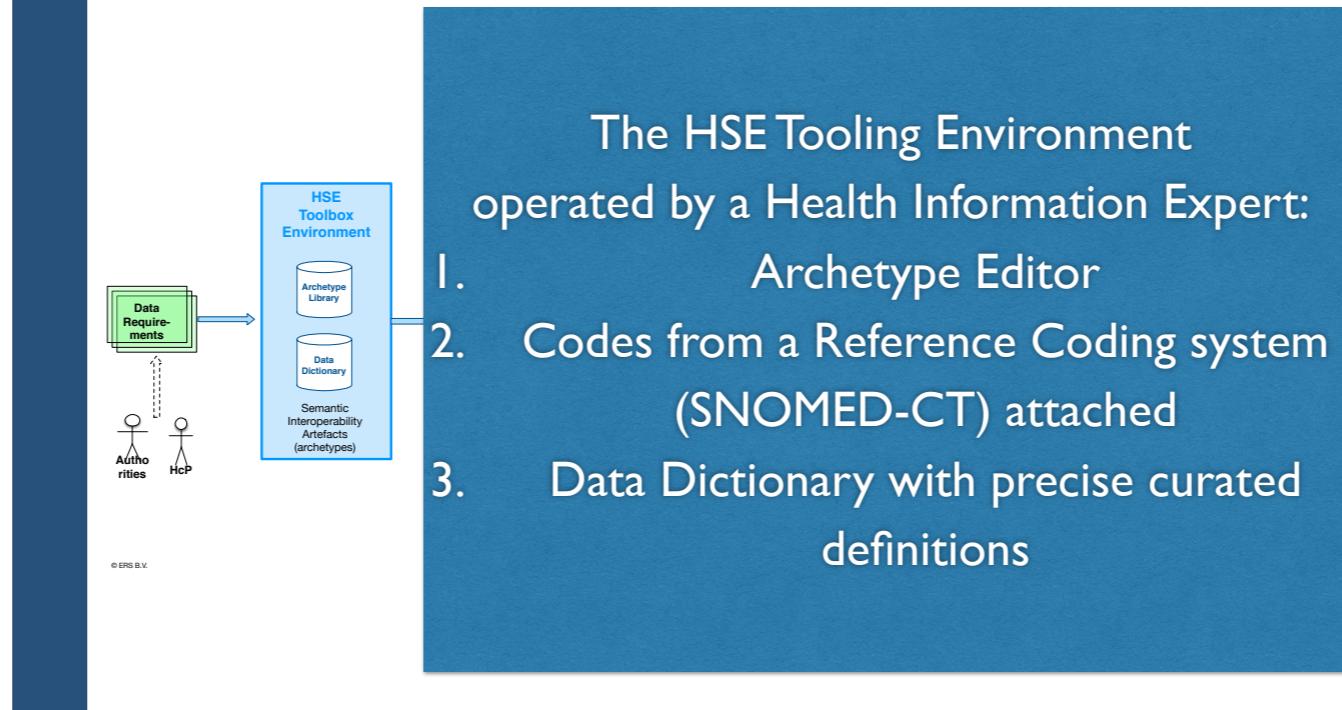


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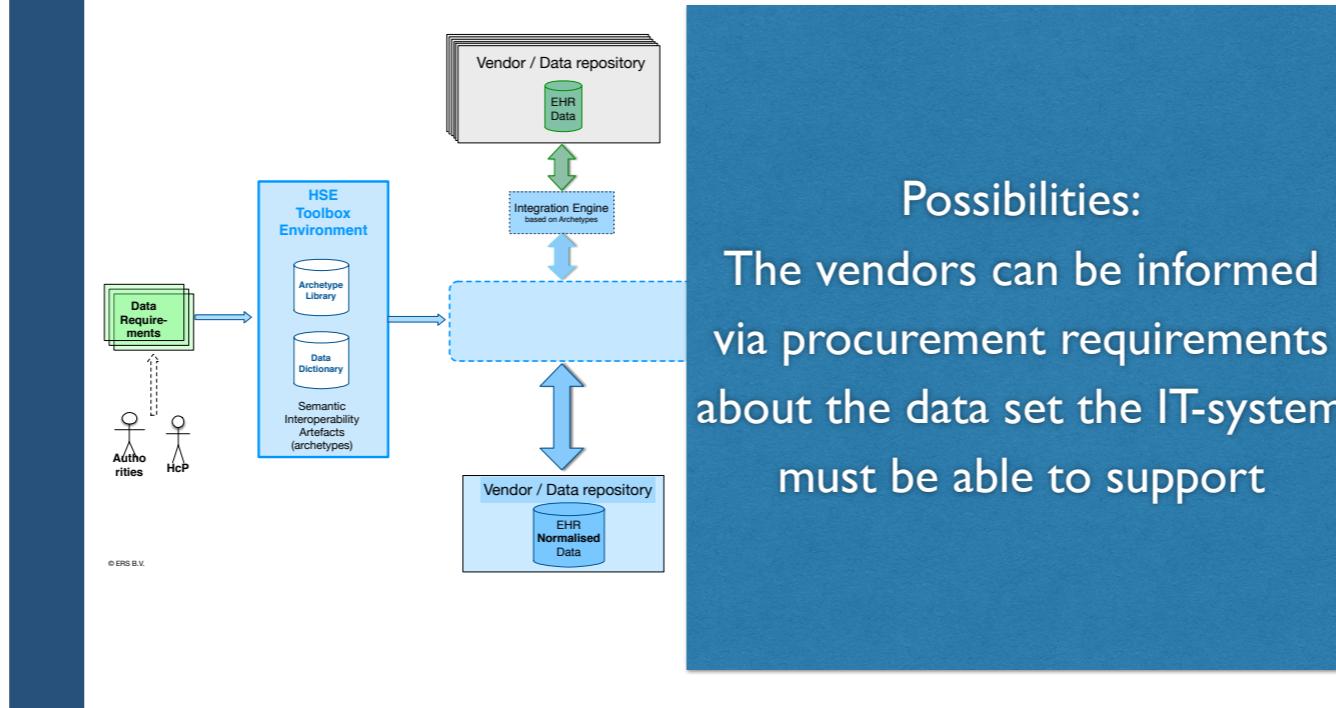
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Who will benefit from the HSE INFOStructure?  
And how is the high level Information Architecture?

Authorities and Healthcare providers define their information needs in any form or shape.  
These areare the Subject Area Models also know as Archetypes or Data Sets



Via the help of a **Health Informatician** the data sets are transformed into a Library of Archetypes.  
In a Community portal these archetypes will be **governed**, hosted, discussed, improved, maintained and published.  
Also the Data Dictionary will be filled with the accepted **curated** data sets.



### Possibilities:

The vendors can be informed via procurement requirements about the data set the IT-system must be able to support

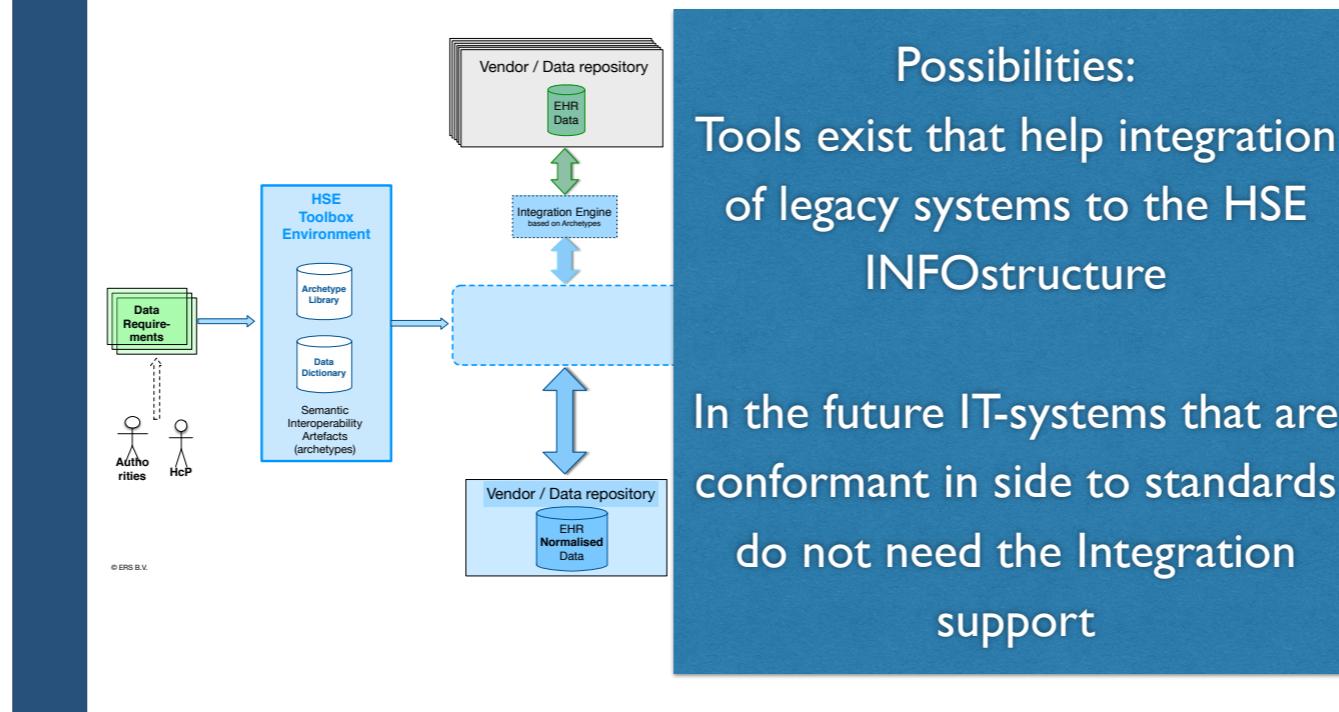
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This arrangement will create many benefits for many.

IT-vendors will know what data their system needs to handle as part of procurement.

IT-Vendors can create interfaces such that the structured and standardised data from the data sets can be exchanged.

Healthcare providers can start to collaborate and report.

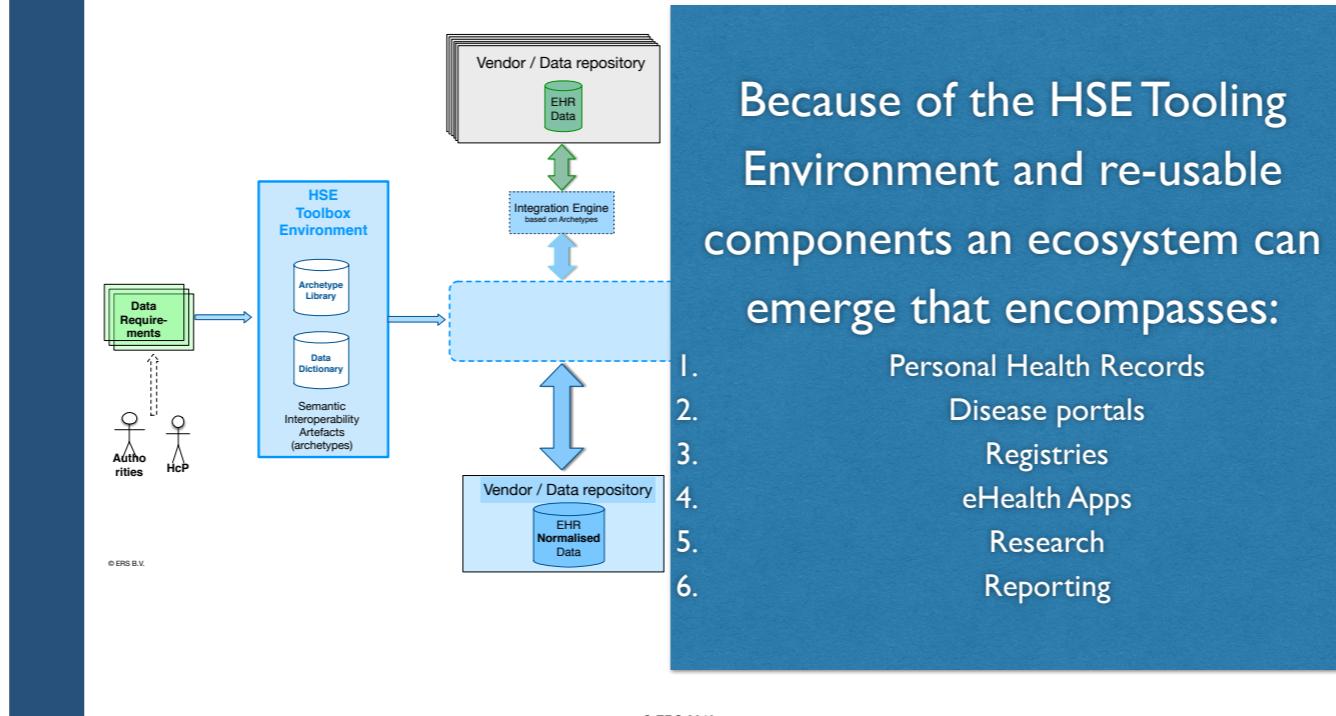


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Observe that proprietary systems will need an ADAPTOR that translate the proprietary data into the standardised and structured format.

As part of an evolutionary process vendors can migrate to systems that can deal with the standardised and structured data without the need for translation.

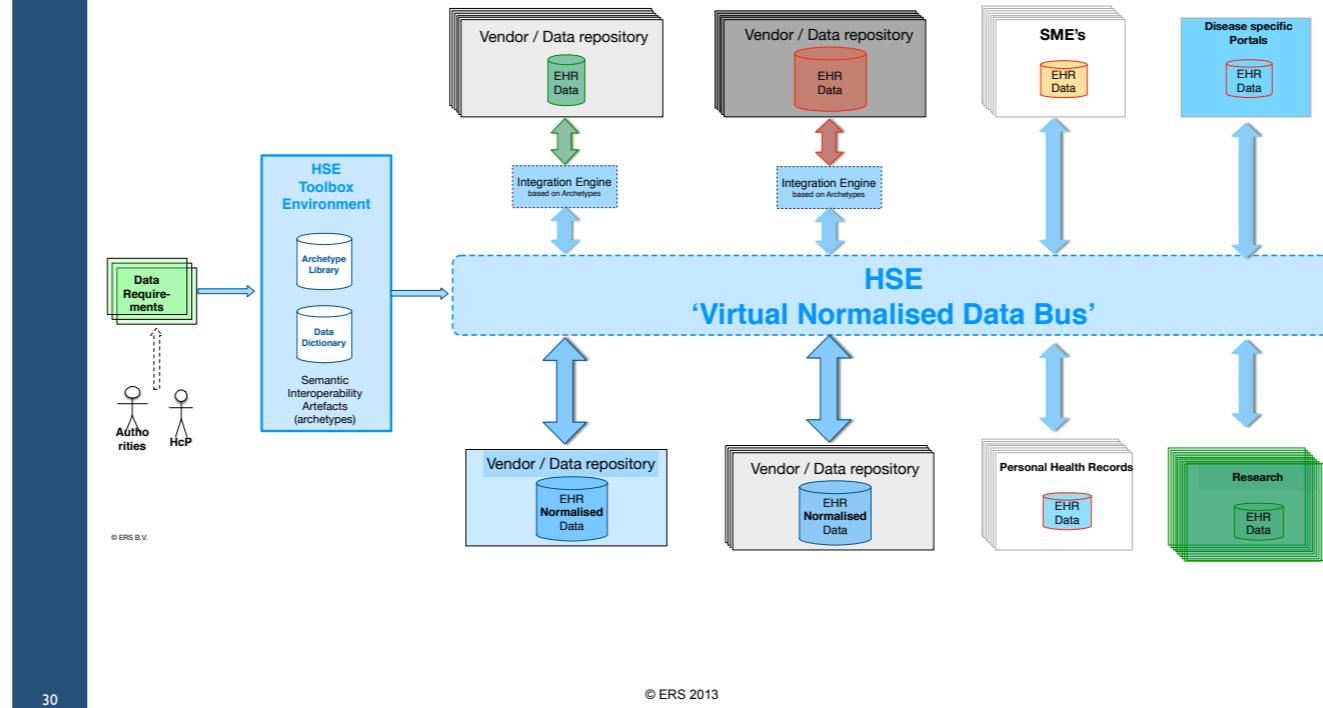


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Since data is standardised and structured more will be enabled and become possible.

An ECOSYSTEM can arise because small companies can start to provide new innovative services, or clinical research can be integrated into existing systems, or Healthcare providers can start to submit structured and standardised data to authorities.

As can be seen in this slide.



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The end result is depicted.  
A 'Virtual Data Bus for structured data

- 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 Element	Comment	Formal Name	Type & Lateness	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.	

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For the demo later this year we will use the European epSOS project as use case.

It can be imagined that a Diabetes Use case could be piloted in real life after this project.

**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.”

epSOS is a European project about Cros Border Patient Summaries and Medication prescriptions.

## 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.

A description of the content of the epSOS data set that will be used in the DEMO in this project.

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

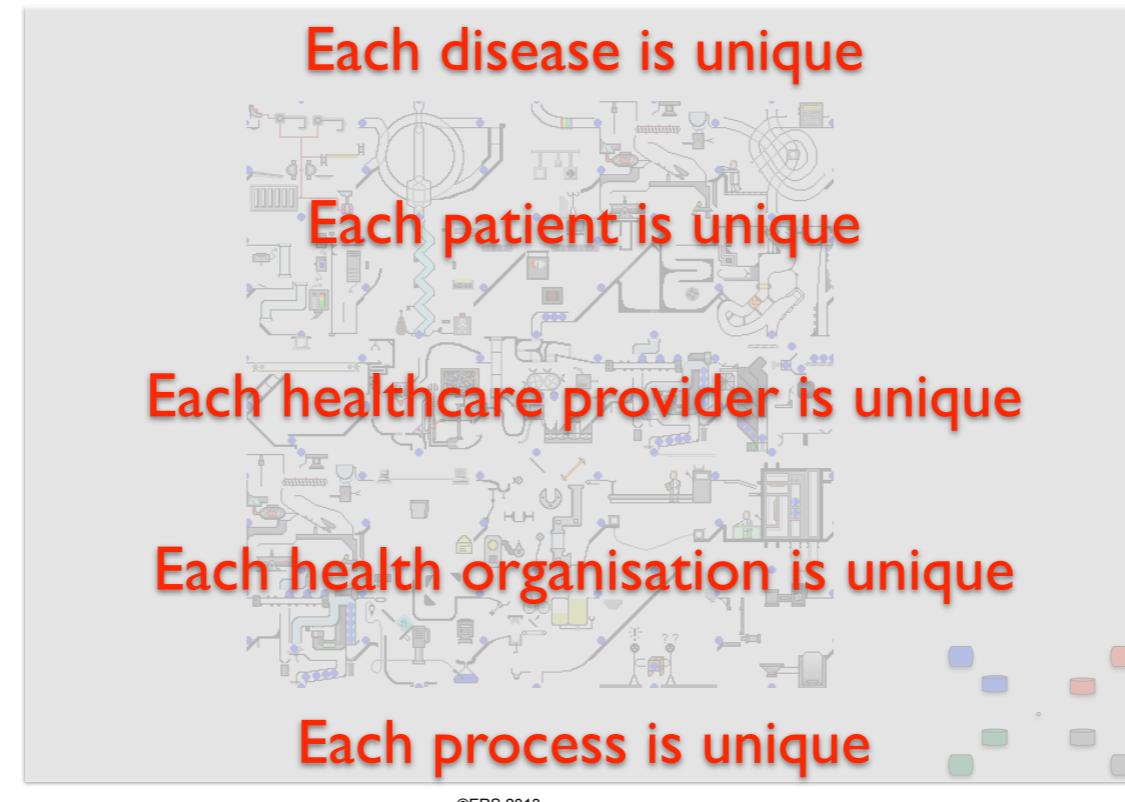
**USA:** Clinical Information Modeling Initiative  
**(CIMI):**

Intermountain, Kaiser Permanente, Mayo, Stanford, NIH,  
VHA  
HL7, CEN/tc251, 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



What will be facilitated by the HSE Tooling and Components library (Data Dictionary)



# 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 ...

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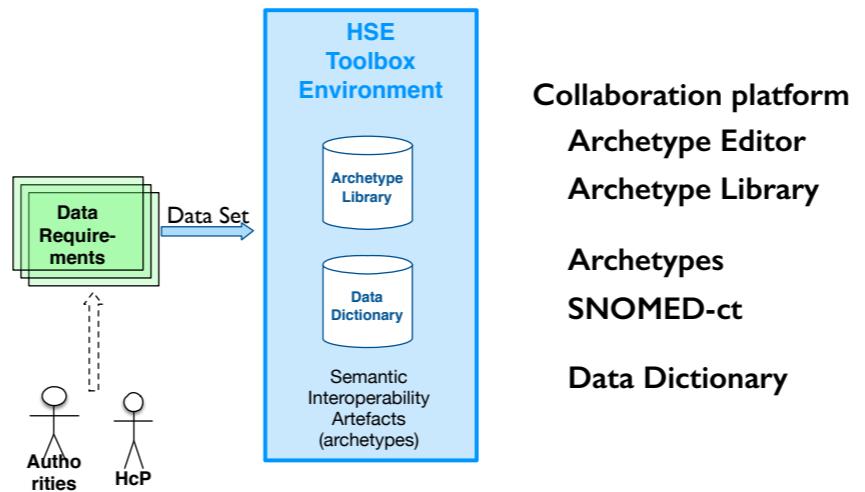
This slide shows a fictive Use Case

And what the various stakeholders can do supported by the HSE INFOstructure.

## 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

This slide describes the process going from requirements to deployment



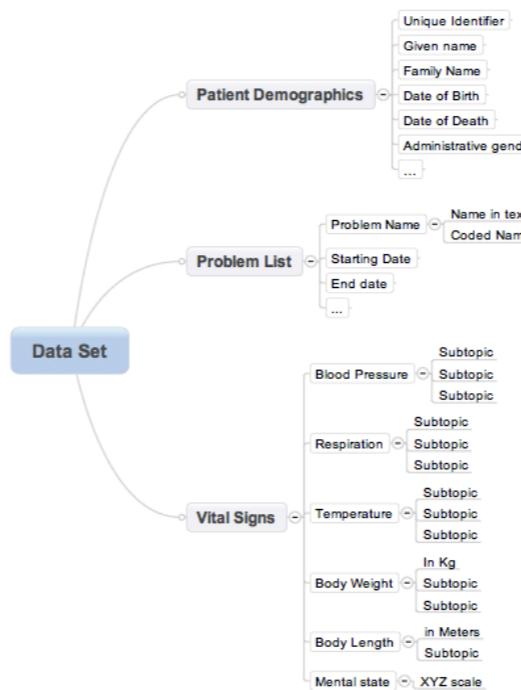
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The Tools and Components that will be used in the HSE Tooling environment

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



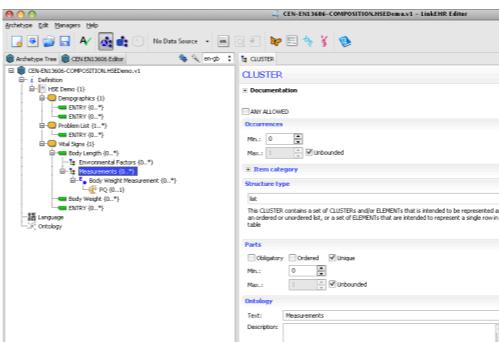
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During the development process for instance Mind Maps can be used to describe the data set

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.



```
CEN-EN13476-COMPOSITION-HSEDev.v1.ad
1 archetype {id,version:1.4}
2   CEN-EN13476-COMPOSITION-HSEDev.v1
3
4   version:1.4
5   [+2000]
6
7   language
8     original_language = <ISO_639-1:en-gb>
9
10 description
11   original_description =
12     <P>B999 9.V.</P>
13     <P>Version: 1.4</P>
14     <P>Language: <iso-639-1:en-gb> English (United Kingdom)</P>
15     <P>Last update: 2013-01-01</P>
16
17 lifecycle_state = "Draft"
18
19 detailset =
20   <P><code>CEN-EN13476-COMPOSITION-HSEDev.v1</code></P>
21   <P>language = <ISO_639-1:en-gb></P>
22
23
24 definition
25   COMPOSITION{occurrence: matches (1..1) matches ( -- HSE Dev)
26     cardinality: matches (0..1) occurrence: matches (0..*) unorderd: matches ( -- HSE Dev)
27     SECTION{occurrence: matches (1..1) matches ( -- Demographics
28       matches: matches (0..1) cardinality: matches (0..*) unorderd: unique: matches ( -- Demographics
29         matches: matches (0..1) cardinality: matches (0..*) unorderd: unique: matches (*)
30         item: matches (0..1) cardinality: matches (0..*) unorderd: unique: matches (*)
31       )
32       ENTRY{occurrence: matches (0..*) matches ( -- ENTRY
33         matches: matches (0..1) cardinality: matches (0..*) unorderd: unique: matches (*)
34       )
35     )
36     SECTION{occurrence: matches (0..1) matches ( -- Clinical
37       matches: matches (0..1) cardinality: matches (0..*) unorderd: unique: matches (*)
38       matches: matches (0..1) cardinality: matches (0..*) unorderd: unique: matches (*)
39       matches: matches (0..1) cardinality: matches (0..*) unorderd: unique: matches (*)
40       matches: matches (0..1) cardinality: matches (0..*) unorderd: unique: matches (*)
41     )
42   )
43 }
```

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The Health Informatician will produce the archetypes.  
Clinicians can inspect this but Mind Maps and text generated will enable them to validate the archetypes in detail.

Observe that other output of the Archetype Editor Tool is XML that IT-specialist can work with.

## One language, one meaning

More than one way to express the same meaning

The figure consists of three parts. At the top, there are two boxes labeled "Information entity". The first box contains the text "No Previous History:" followed by a text input field containing "Diabetes". The second box contains the text "Past History:" followed by three radio buttons labeled "Yes", "No", and "Unknown", with "No" being selected. Below these is another box labeled "Information entity" with the text "Past History:" followed by a text input field containing "Not diabetic". At the bottom, there are three separate windows labeled 1, 2, and 3, each titled "History". Window 1 has sections for "Symptoms / Problems" (with a dropdown menu and a "Chest Pain" button), "Family History Heart Failure" (with radio buttons for Yes, No, Unknown, and one checked), "Diabetes" (with radio buttons for Yes, No, Unknown, and one checked), "Organ Failure Diagnosis" (with dropdown menus for "Organ" set to "Heart" and "Status" set to "Suspected"), and "Caused by Physical Exercise" (with radio buttons for Yes, No, Unknown, and one checked). Window 2 has sections for "Symptoms / Site" (with a dropdown menu and buttons for "Pain" and "Chest"), "Family History" (with a dropdown menu and a "Heart Failure" button), "Other diseases" (with a dropdown menu and a "no diabetes" button), and "Diagnosis" (with a dropdown menu and a "Suspected heart failure caused by physical exercise" button). Window 3 has sections for "Others" (with a dropdown menu and a "FH of heart failure" button), "Diagnosis" (with a dropdown menu and a "Heart Failure" button), "Status" (with a dropdown menu and a "Suspected" button), and "Cause" (with a dropdown menu and a "Physical Exercise" button).

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This slide explains why a Data Dictionary is essential.

On top:

three ways to collect information about the History of Diabetes.  
All three ways look different but mean the same thing.

Below idem dito.

Many ways go to Rome in healthcare.

A Data Dictionary allows us to deal with this diversity.

The Data Dictionary contains 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?**