



National Integrated Services Framework

29-30 October 2013
Dublin

Part 1

Workshop 1

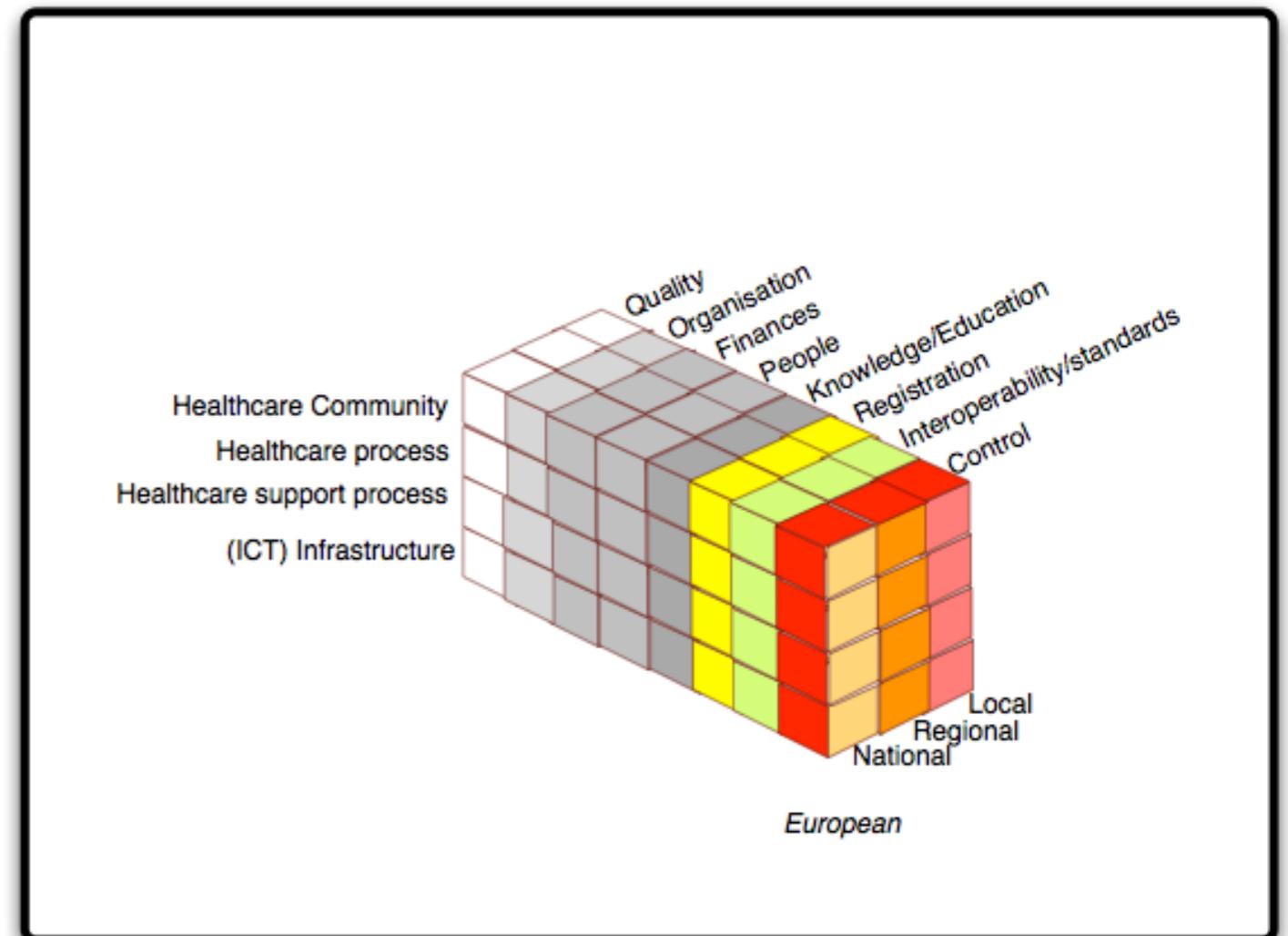
Information Architecture

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

Information Architecture Stakeholders

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

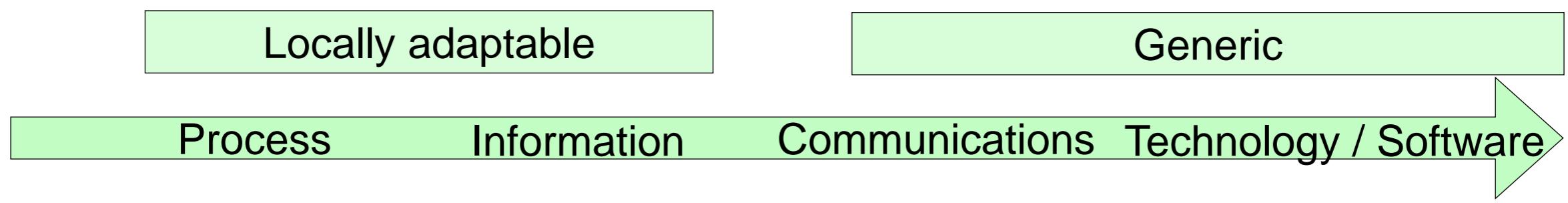


Introduction

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What is important?



Healthcare is in the lead

P

I

C

T

Healthcare is suffering

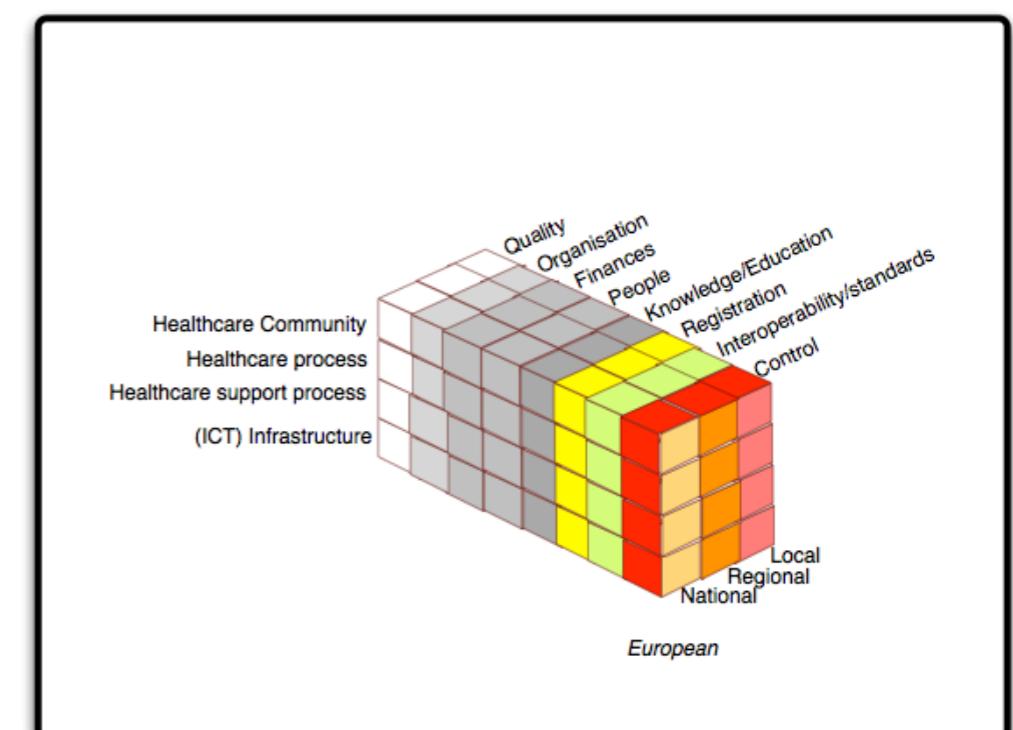


Complexity

- **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?**



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

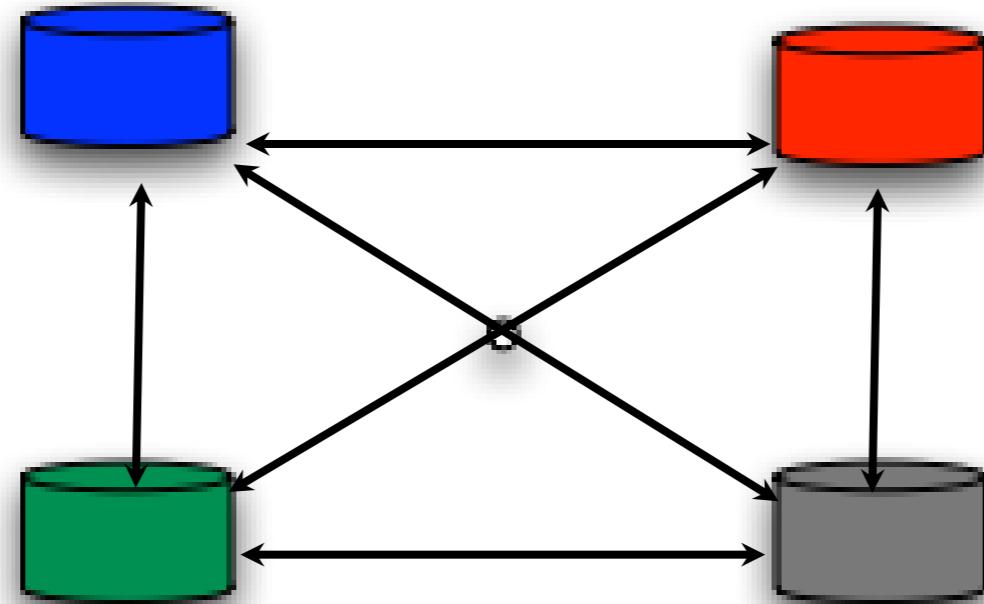
Why Standards

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NO STANDARDS

$$N = n*(n-1) / 2$$



$$n = 100$$

$$N = 100*(99) / 2$$

$$N = 9900 / 2$$

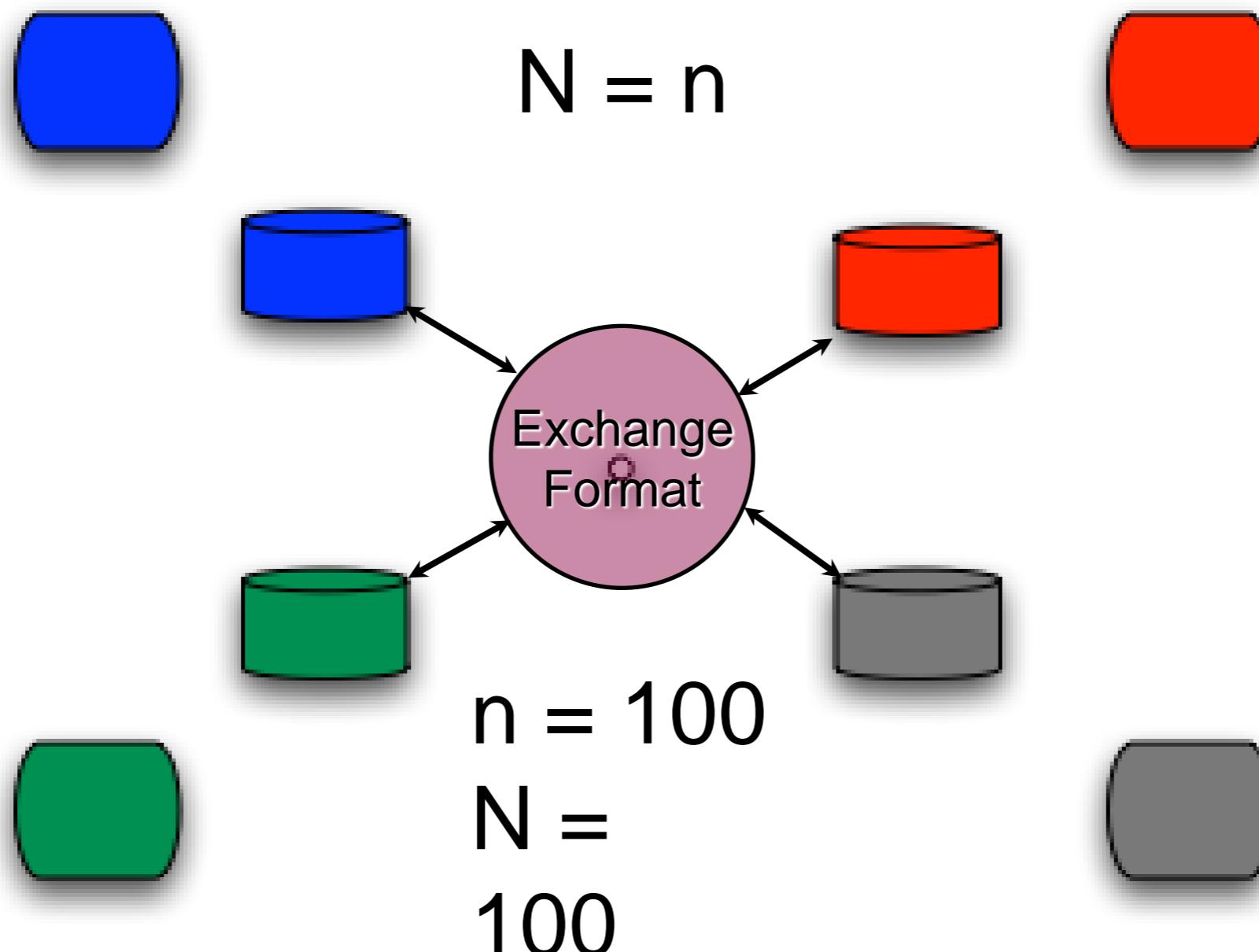
$$N = 4950$$

Why Standards

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EXCHANGE STANDARD



Why European Standards

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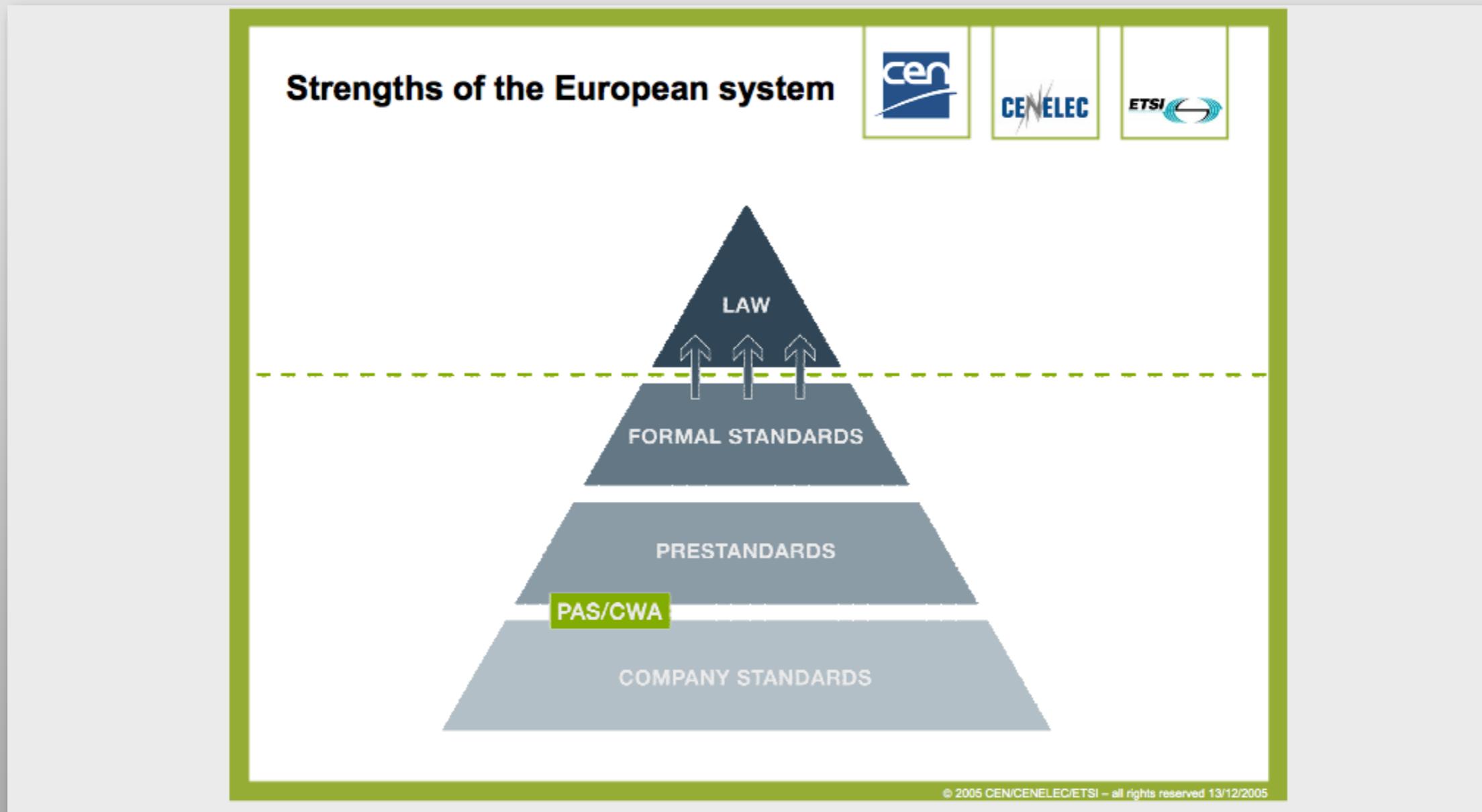
- **27 European countries**
- **Many cultures, many languages**
- **One united European Community**
- **Free movement of goods, people, money and services**
- **One big competitive European economic space**

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



European developments



Directive on patients' rights in cross-border healthcare



Directorate-General for
Health & Consumers

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



Directorate-General for
Health & Consumers

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



Directorate-General for
Health & Consumers

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.**



EUROPEAN
COMMISSION

Brussels, 6.12.2012
COM(2012) 736 final

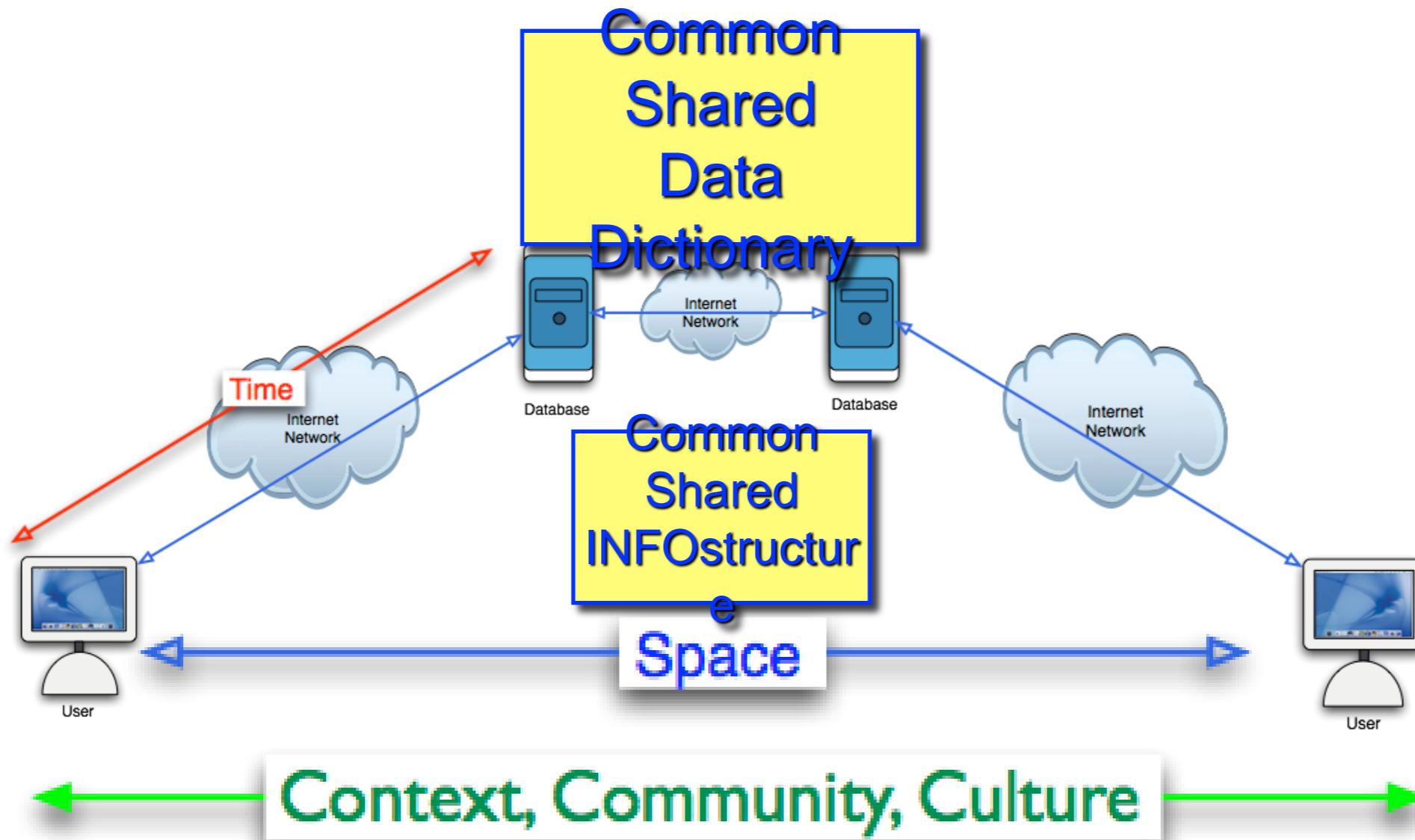
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eHealth Action Plan 2012-2020 - Innovative healthcare for the 21st century

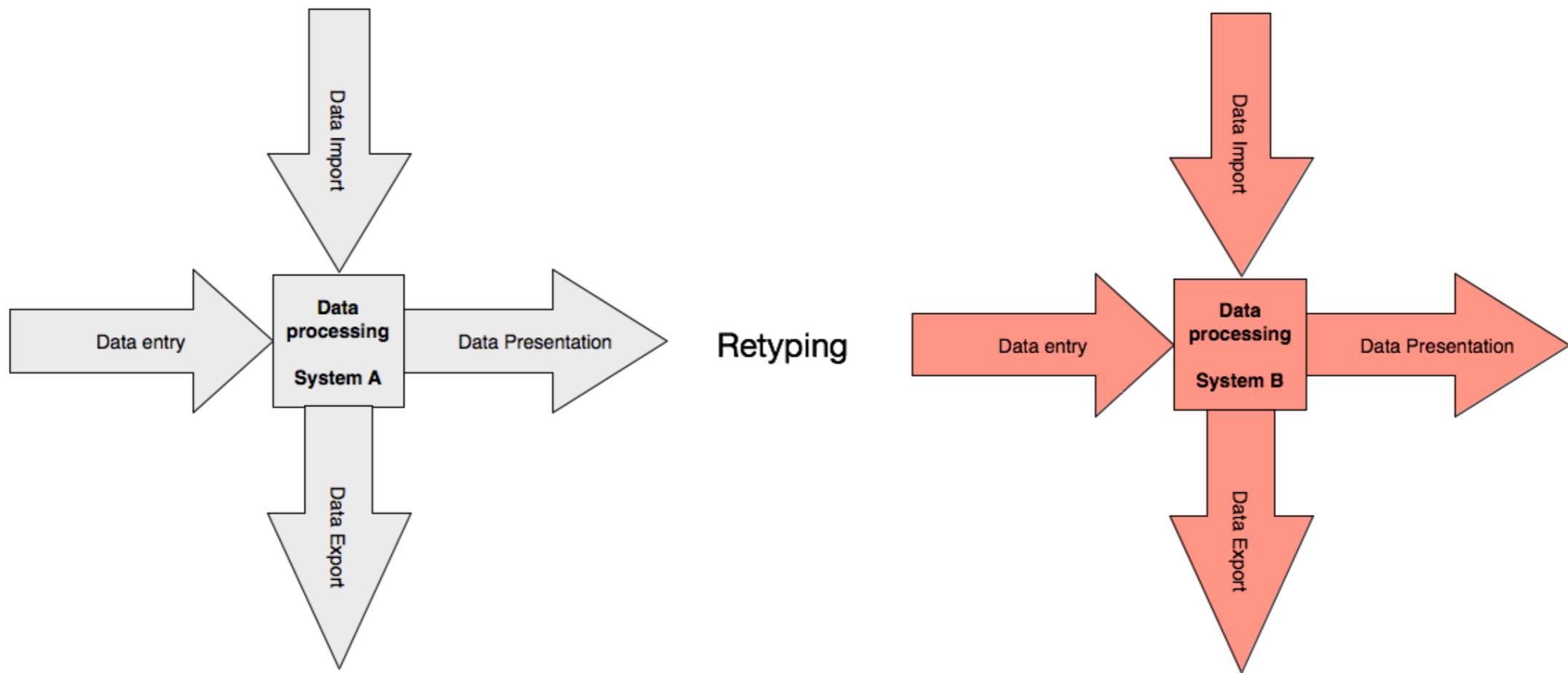
WHAT Exchange of Data

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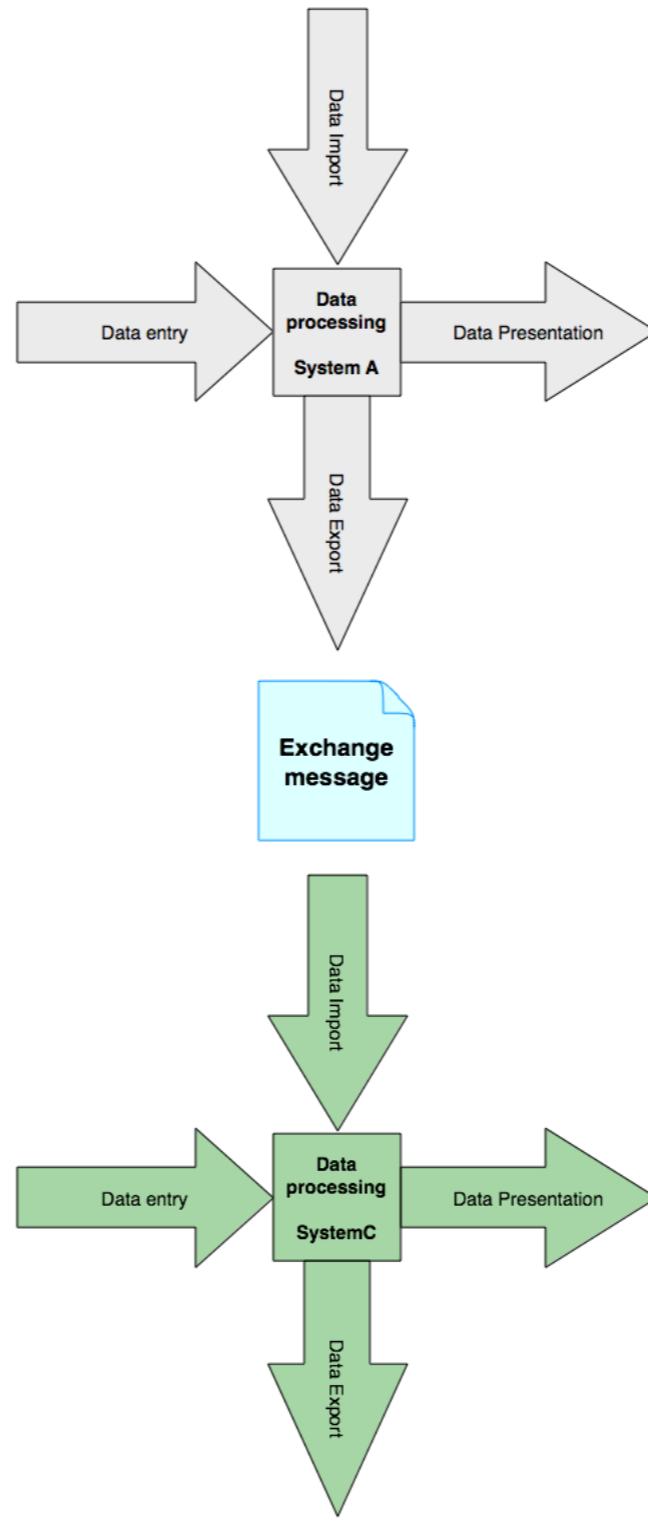
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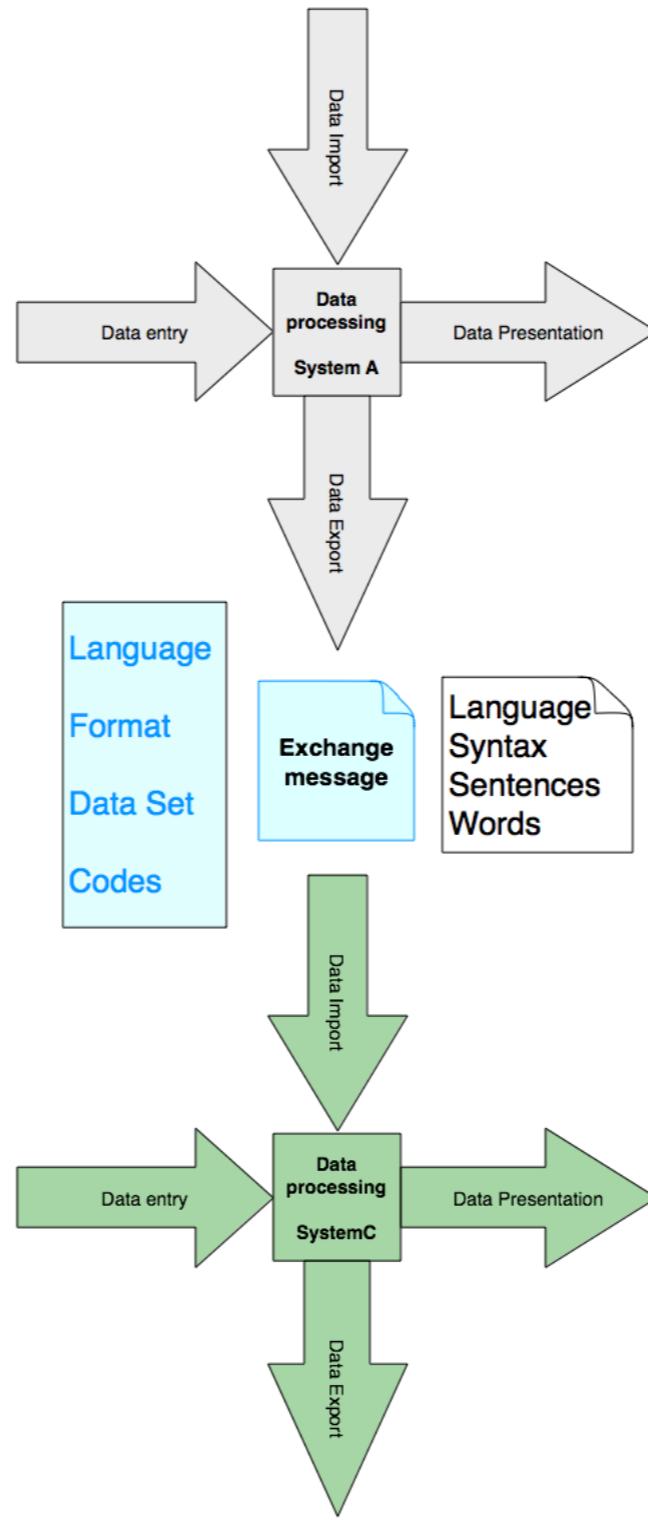
What Standards for IT-System Data Exchange



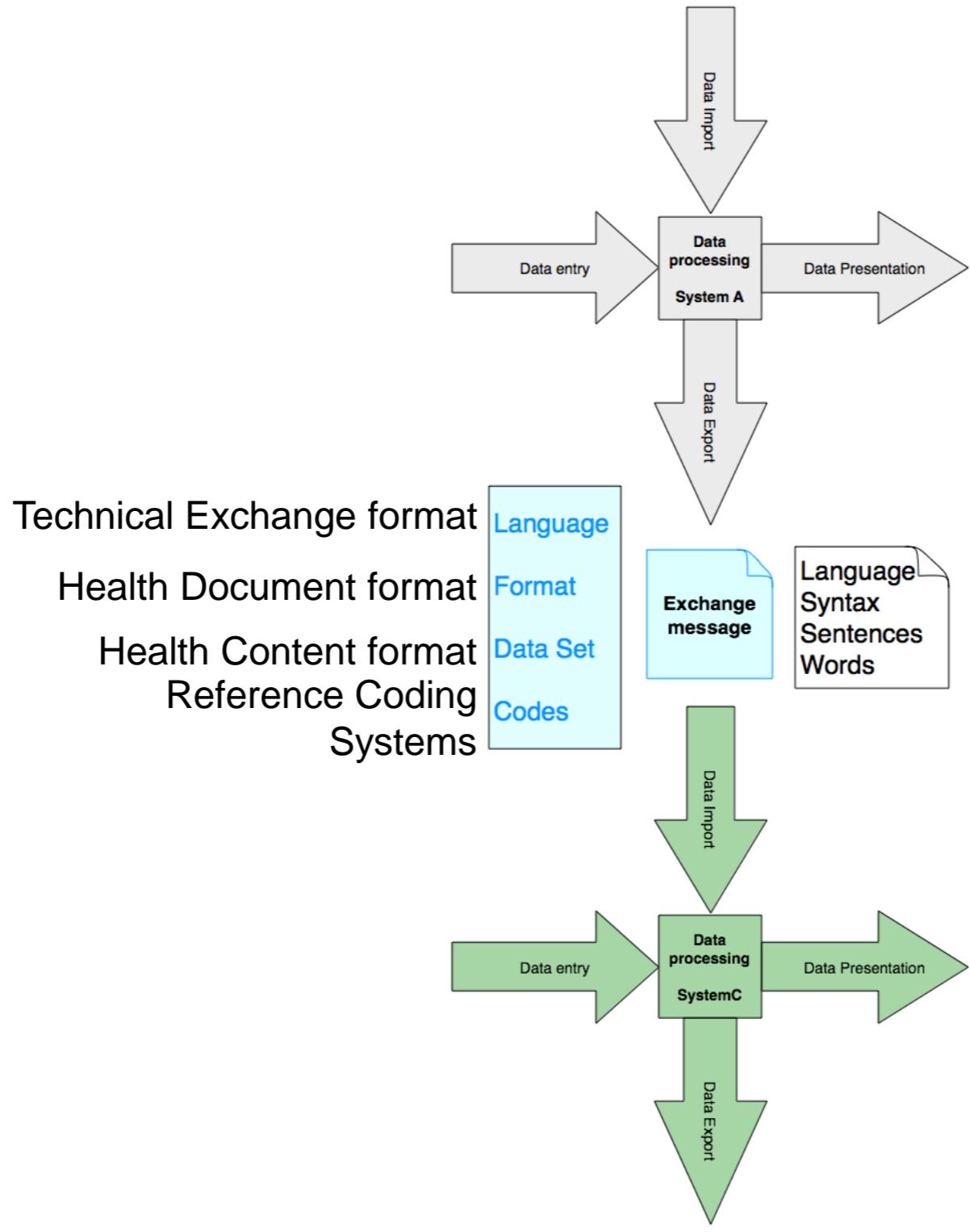
What Standards for IT-System Data Exchange



What Standards for IT-System Data Exchange



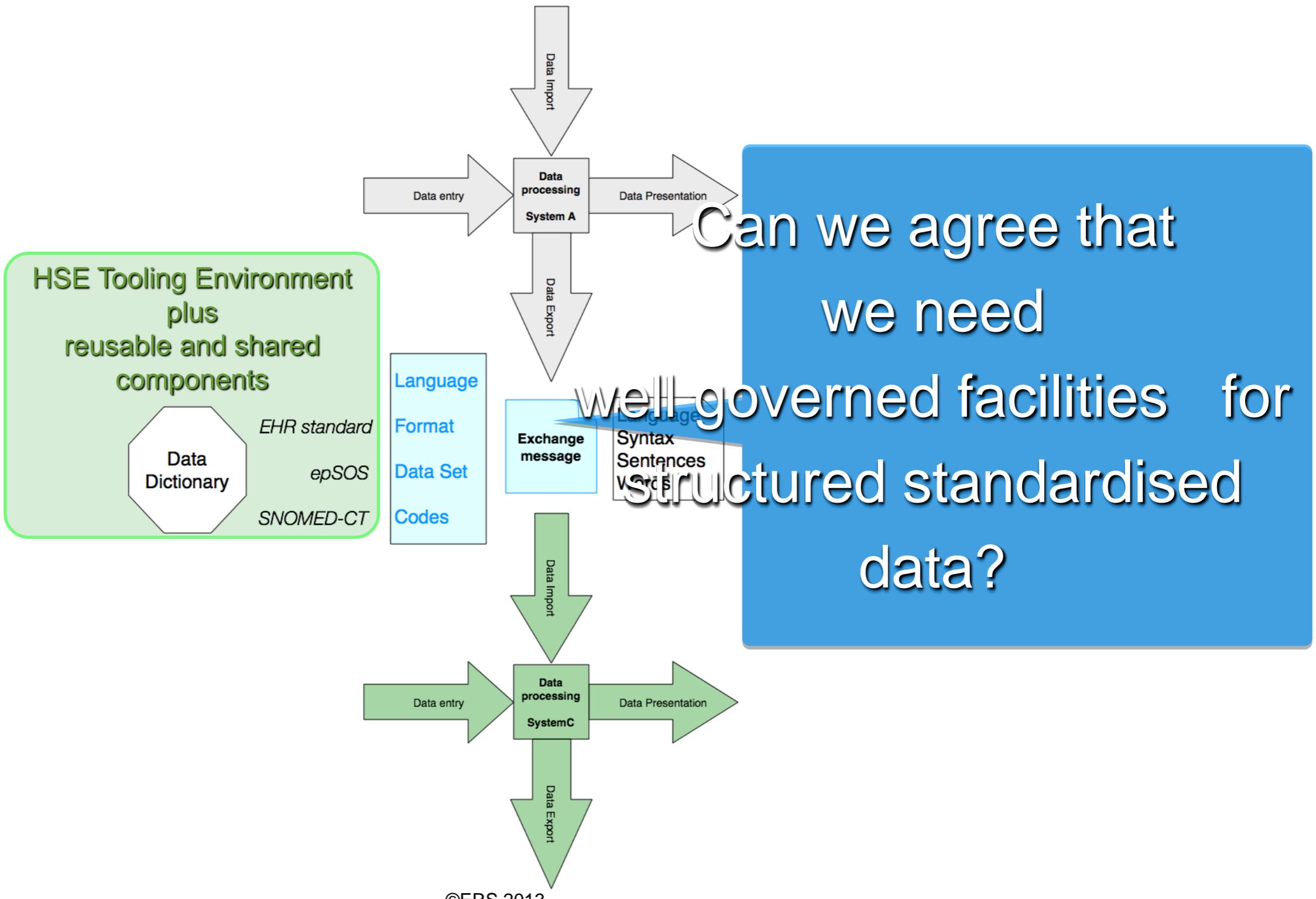
What Standards for IT-System Data Exchange



What Standards for IT-System Data Exchange

ERS

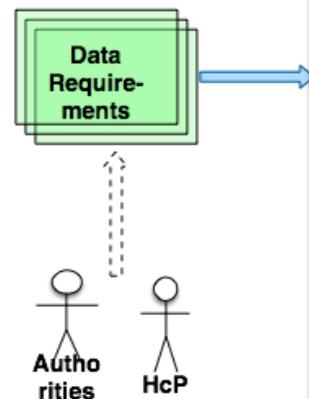
Electronic Record Services BV



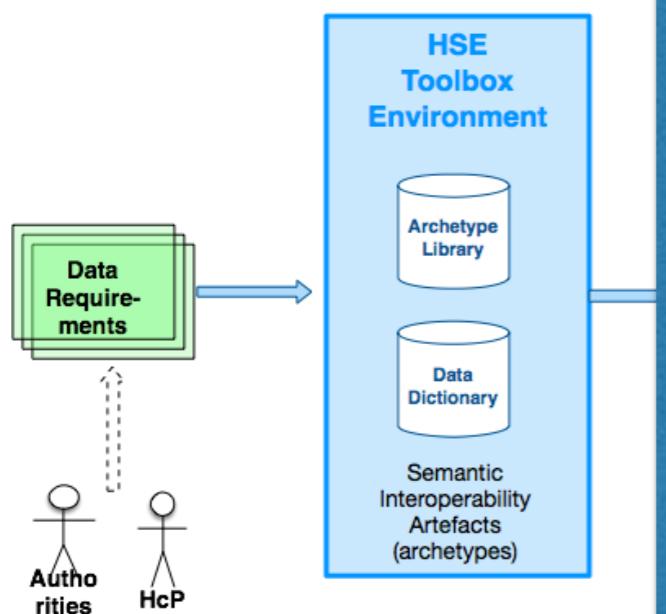
Benefits

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Co-operating Stakeholders
define Data Sets they need



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The HSE Tooling Environment
operated by a Health Information

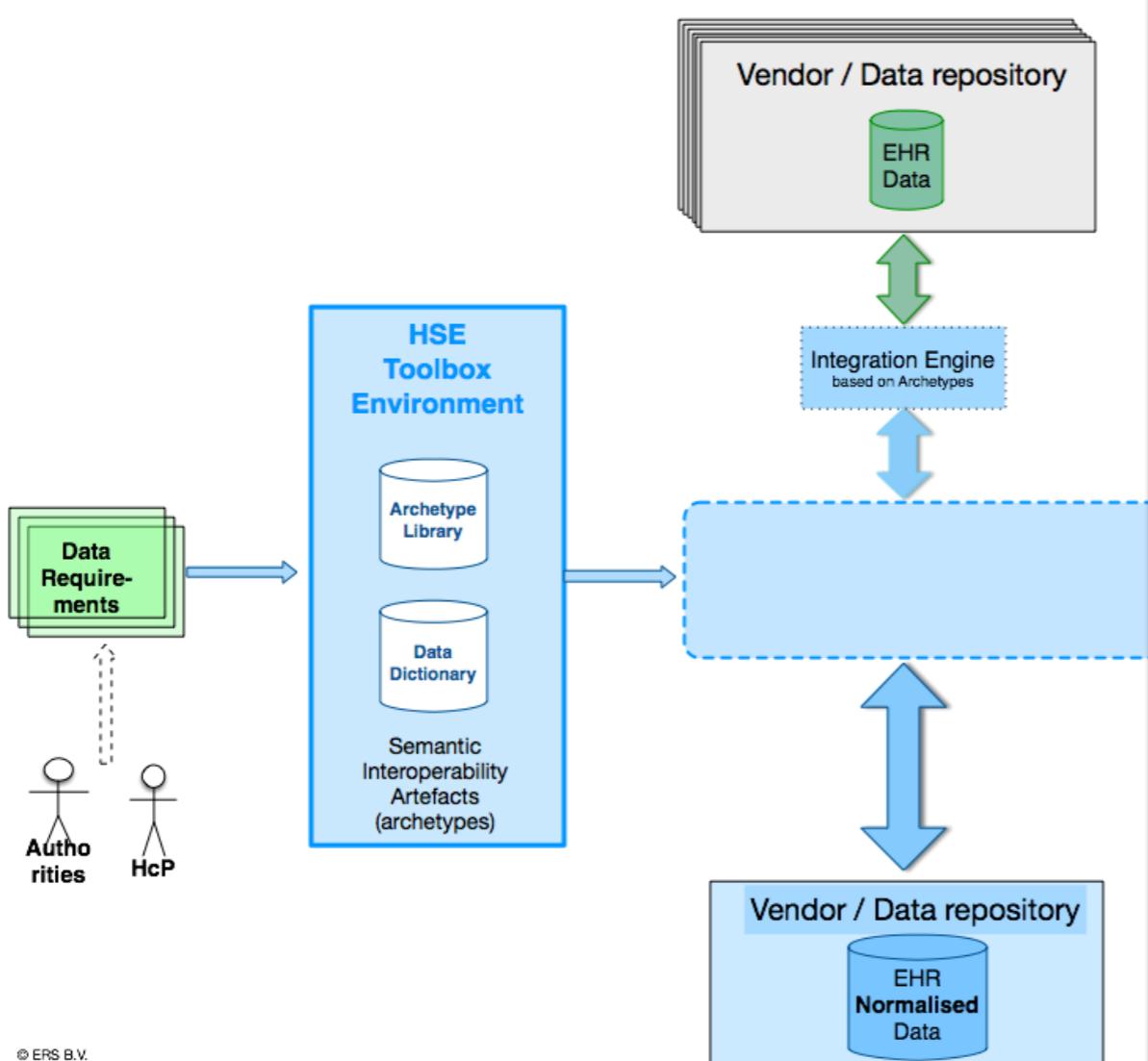
Expert:

1. Archetype Editor
2. Codes from a Reference Coding system (SNOMED-CT) attached
3. Data Dictionary with precise curated definitions

Benefits

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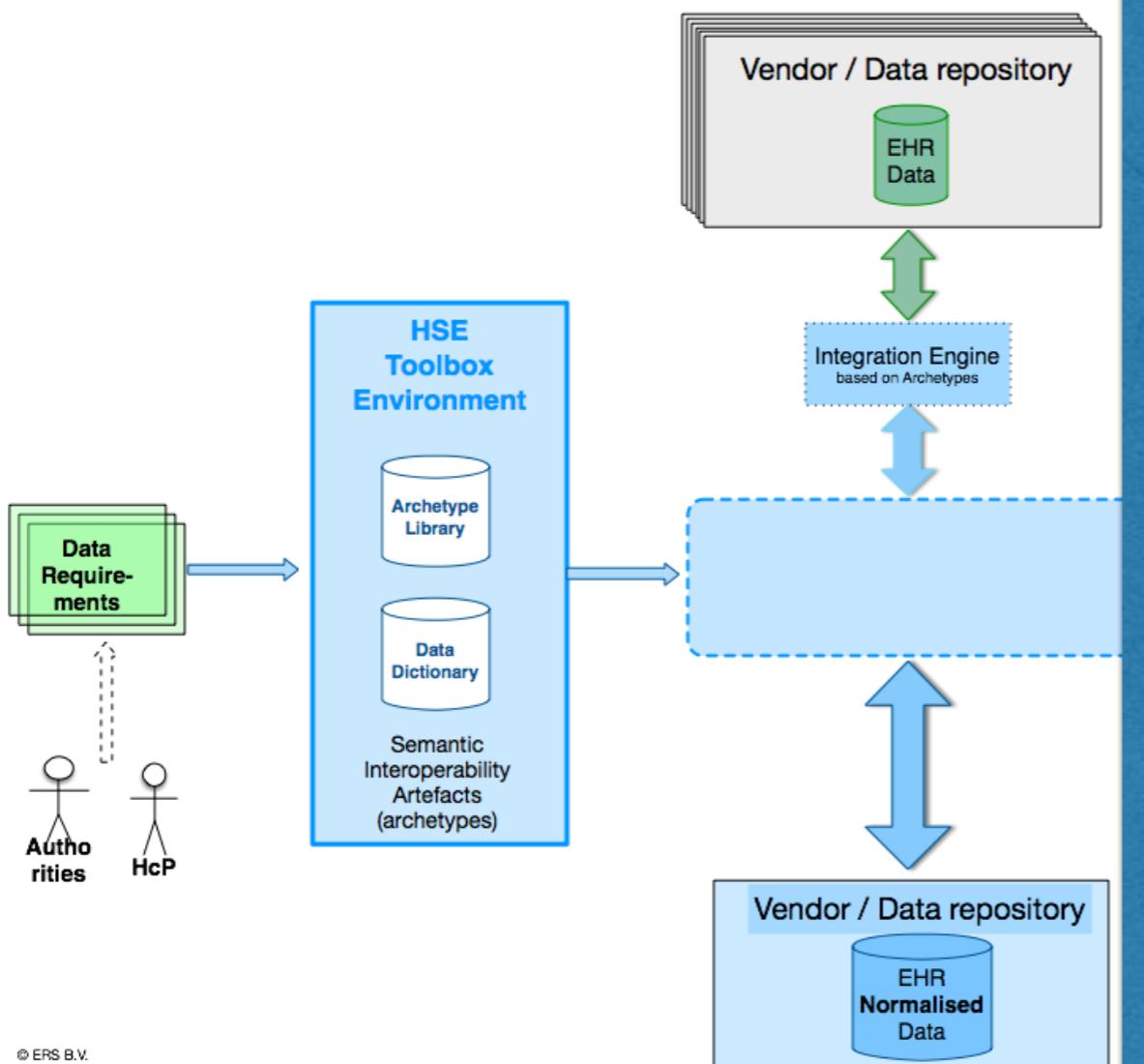


Possibilities:
The vendors can be informed
via procurement
requirements about the data
set the IT-system must be
able to support

Benefits

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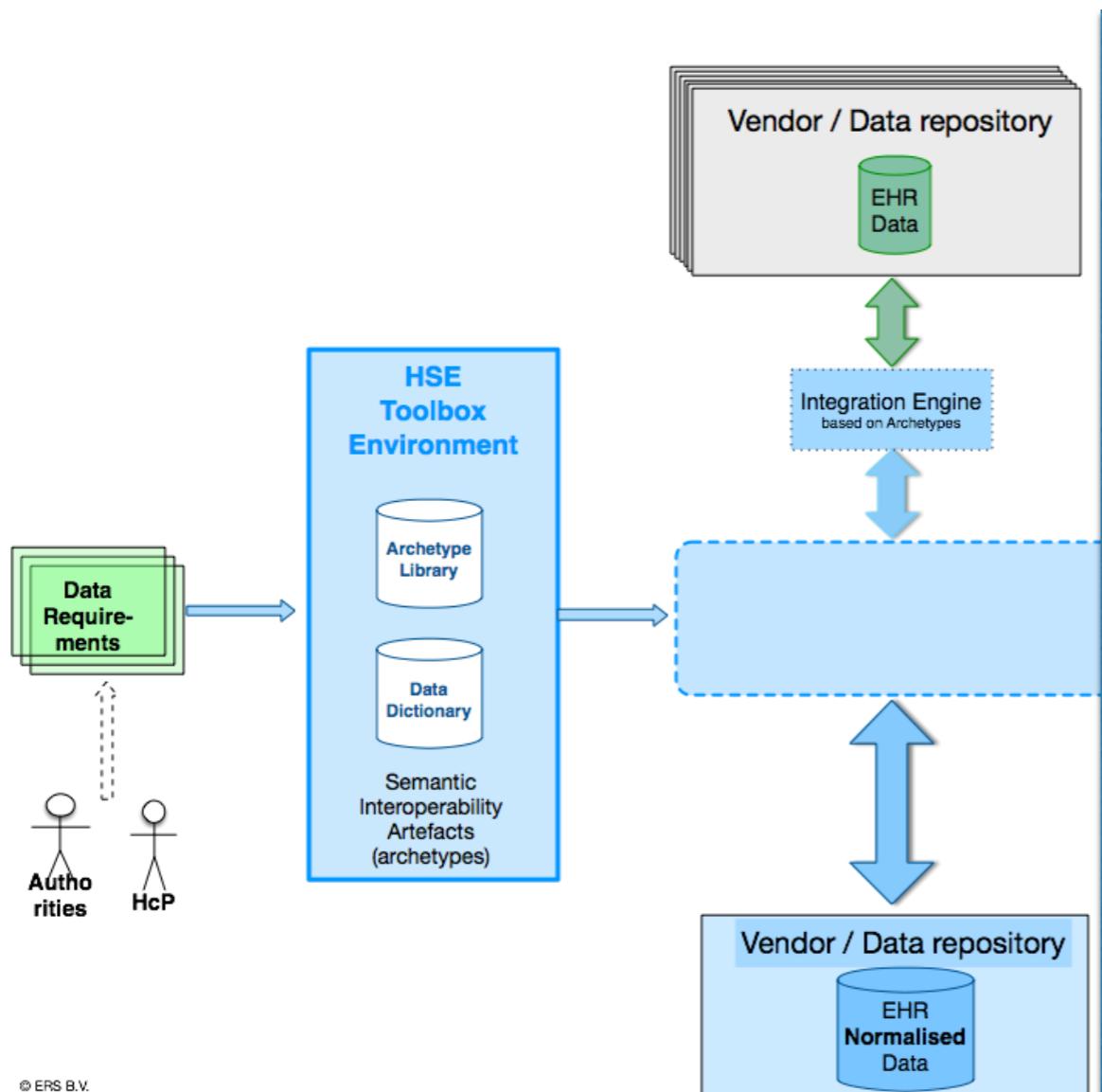
Possibilities:
Tools exist that help
integration of legacy systems
to the HSE INFOstructure

In the future IT-systems that
are conformant in side to
standards do not need the
Integration support

Benefits

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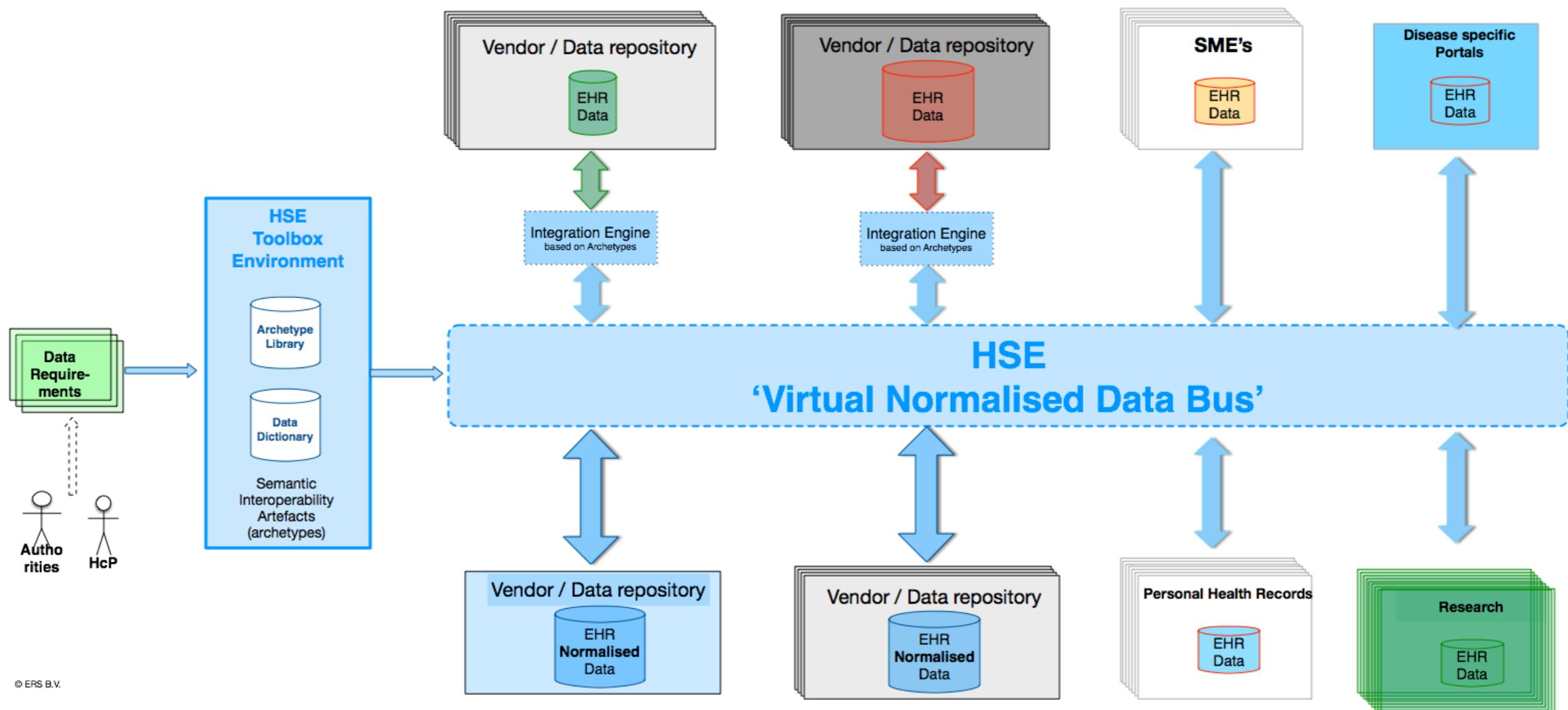
Because of the HSE Tooling Environment and re-usable components an ecosystem can emerge that encompasses:

1. Personal Health Records
2. Disease portals
3. Registries
4. eHealth Apps
5. Research
6. Reporting

Benefits

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Data sets

(for screens, reports, exchange, etc.)

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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?

Use Cases and Data Sets

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- 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.

Data Set Element	Comment	Formal Name	Type & Latency	Description	Parameter	Definition	Field No
		Irish Standards Based Diabetes Core dataset for Primary Care					
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

epSOS Data Set

Patient Summary

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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.

CEN/ISO EHR Communication **ERS** Important developments

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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,

Uniqueness

people, processes and organisations

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Each disease is unique



Each patient is unique

Each healthcare provider is unique

Each health organisation is unique

Each process is unique

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Presentatie
Functionaliteit
Code stelsels
Database





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National Integrated Services Framework

28-29 October 2013

Part 2

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

Recapitulation

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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

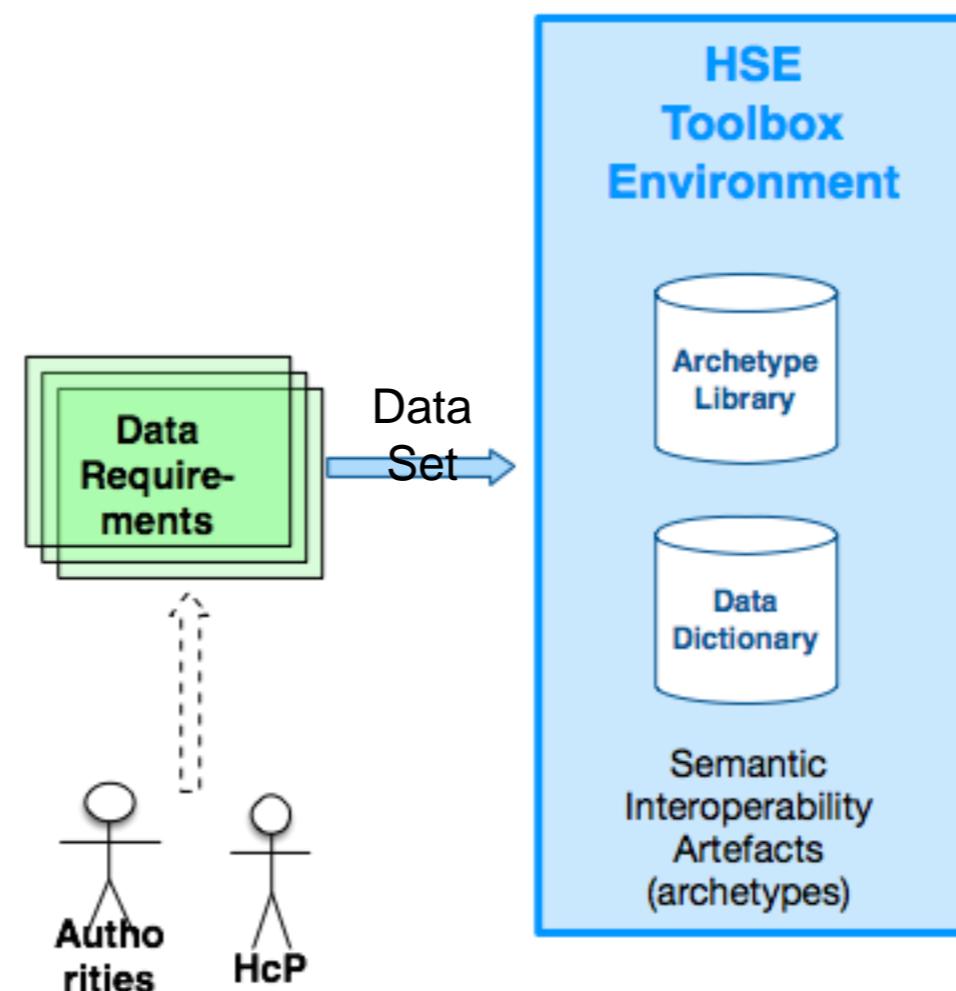
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Stakeholders	Activities
GP	Treats most common problems and needs to maintain an overview, Referral and discharge notes.
Pharmacists	Dispensing prescribed medicinal products and advice
Community Nurse	Monitoring the development new born, young children. 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



Collaboration platform

Archetype Editor

Archetype Library

Archetypes

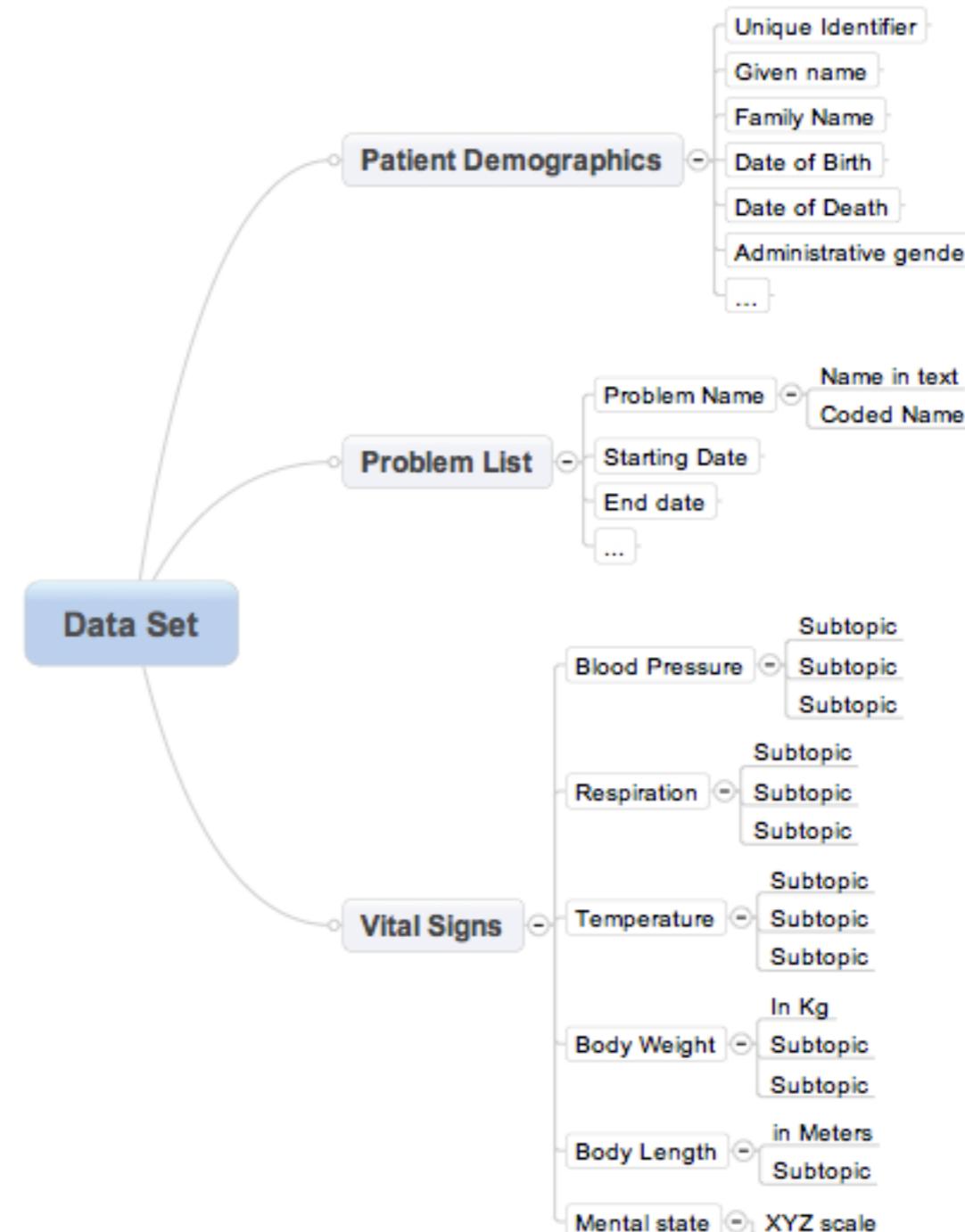
SNOMED-ct

Data Dictionary

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



HSE Tooling Environment

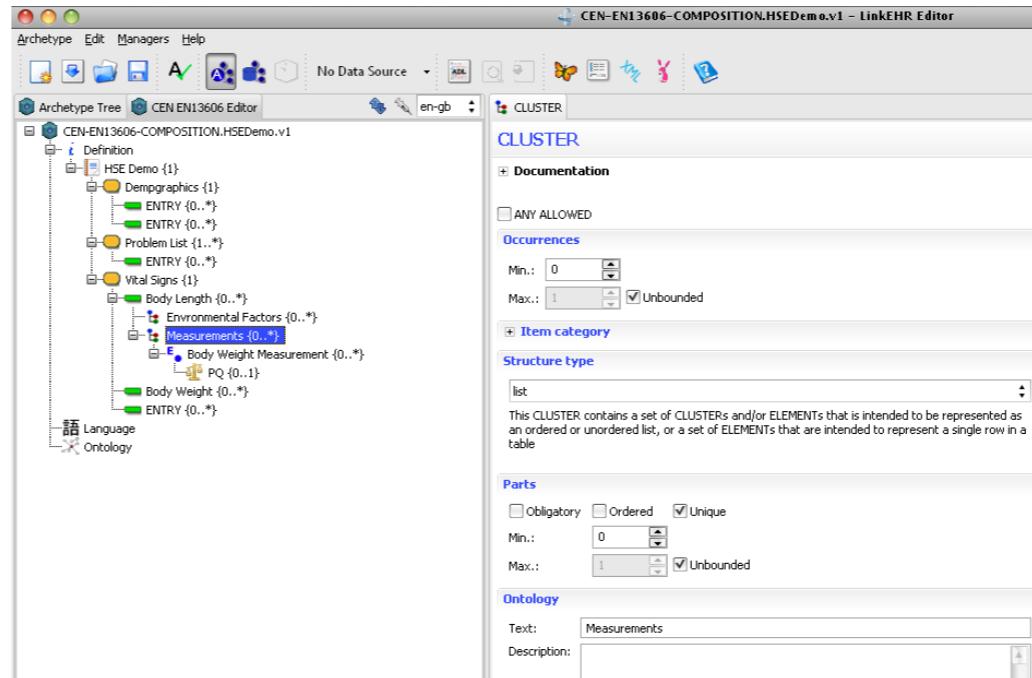
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The Archetype Editor uses pre-defined re-usable shared components from the HSE Archetype Library.

**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-EN13606-COMPOSITION.HSEDemo.v1.adl
1 archetype (adl_version=1.4)
2   CEN-EN13606-COMPOSITION.HSEDemo.v1
3
4 concept
5   [at0000]
6
7 language
8   original_language = <[ISO_639-1::en-gb]>
9
10 description
11   original_author = <
12     ["organization"] = <"ERS B.V.">
13     ["email"] = <">
14     ["name"] = <"GR">
15     ["language"] = <"en-gb English (United Kingdom)">
16     ["date"] = <"20131024">
17   >
18   lifecycle_state = <"Draft">
19   details = <
20     ["en-gb"] = <
21       language = <[ISO_639-1::en-gb]>
22     >
23   >
24
25 definition
26   COMPOSITION[at0000] occurrences matches (1..1) matches ( -- HSE Demo
27     content existence matches (0..1) cardinality matches (0..*; unordered) matches (
28       SECTION[at0001] occurrences matches (1..1) matches ( -- Demographics
29         members existence matches (0..1) cardinality matches (0..*; unordered; unique) matches (
30           ENTRY[at0008] occurrences matches (0..*) matches ( -- ENTRY
31             items existence matches (0..1) cardinality matches (0..*; unordered; unique) matches (*)
32           )
33           ENTRY[at0009] occurrences matches (0..*) matches ( -- ENTRY
34             items existence matches (0..1) cardinality matches (0..*; unordered; unique) matches (*)
35           )
36         )
37       )
38     )
39     SECTION[at0002] occurrences matches (1..*) matches ( -- Problem List
40       members existence matches (0..1) cardinality matches (0..*; unordered; unique) matches (
41         ENTRY[at0007] occurrences matches (0..*) matches ( -- ENTRY
42           items existence matches (0..1) cardinality matches (0..*; unordered; unique) matches (*)
43         )
44       )
45     )
46   )
47 
```

Why a Data Dictionary

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

Information entity

No Previous History:

Information entity

Past History: Yes No Unknown

Information entity

Past History:

1 History

Symptoms / Problems Choose ... Chest Pain

Family History Heart Failure Yes No Unknown

Diabetes Yes No Unknown

Organ Failure Diagnosis

Organ Heart Status Suspected

Caused by Physical Exercise Yes No Unknown

2 History

Symptoms / Problems Choose ... Symptom | Site Pain Chest

Family History Choose ... Heart Failure Yes No Unknown

Other diseases: Choose ... no diabetes

Diagnosis

Suspected heart failure caused by physical exercise

3 History

Symptoms / Problems Choose ... Chest Pain

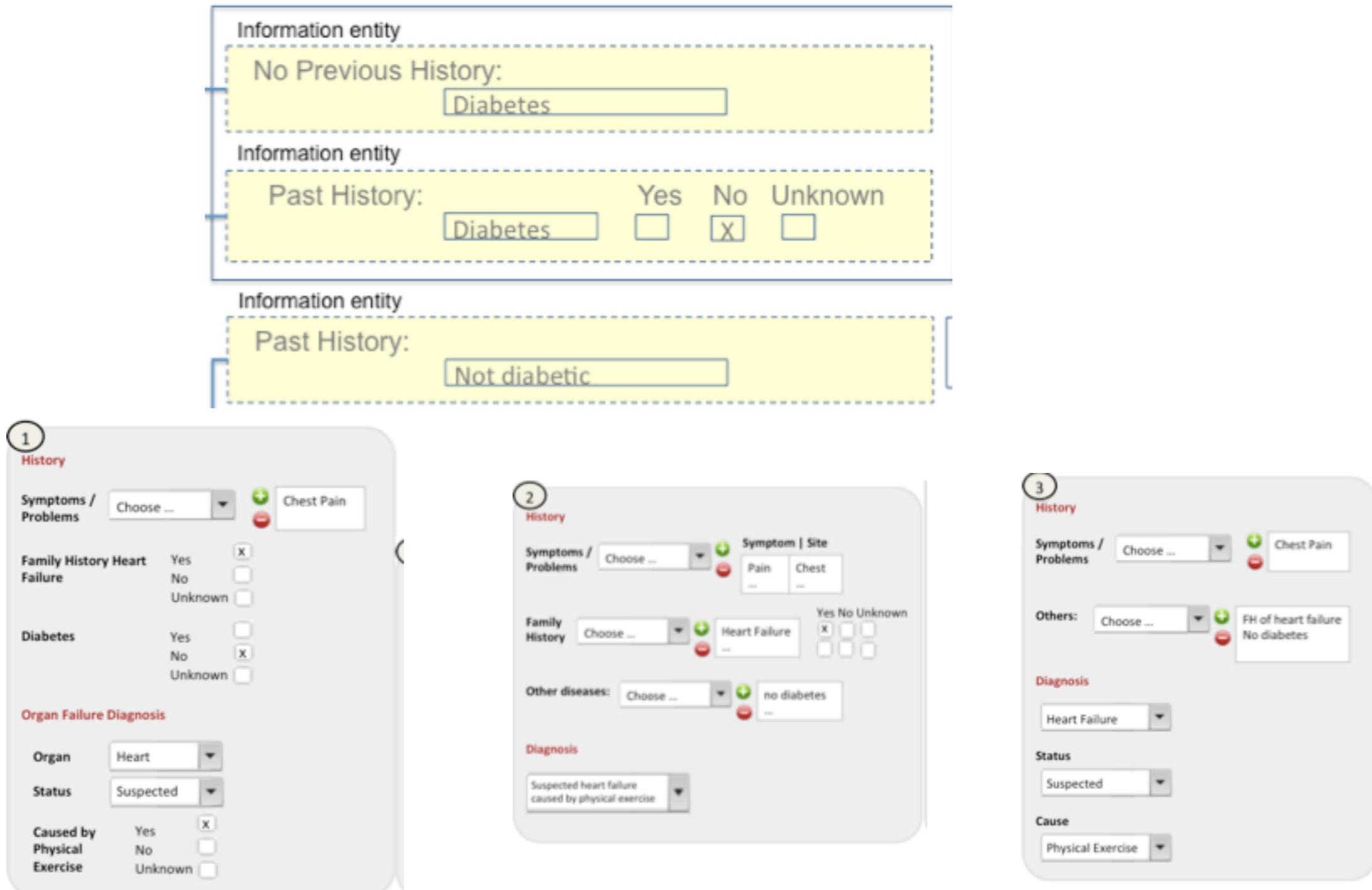
Others: Choose ... FH of heart failure No diabetes

Diagnosis

Heart Failure

Status Suspected

Cause Physical Exercise



Why a Data Dictionary

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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?