

Records of

Revolutionizing healthcare through
independent lifetime health records

Health

Standards of

Towards a universal
health information language

Translational & Interoperable Health Infostructure - The Servant of Three Masters

Abridged Presentation

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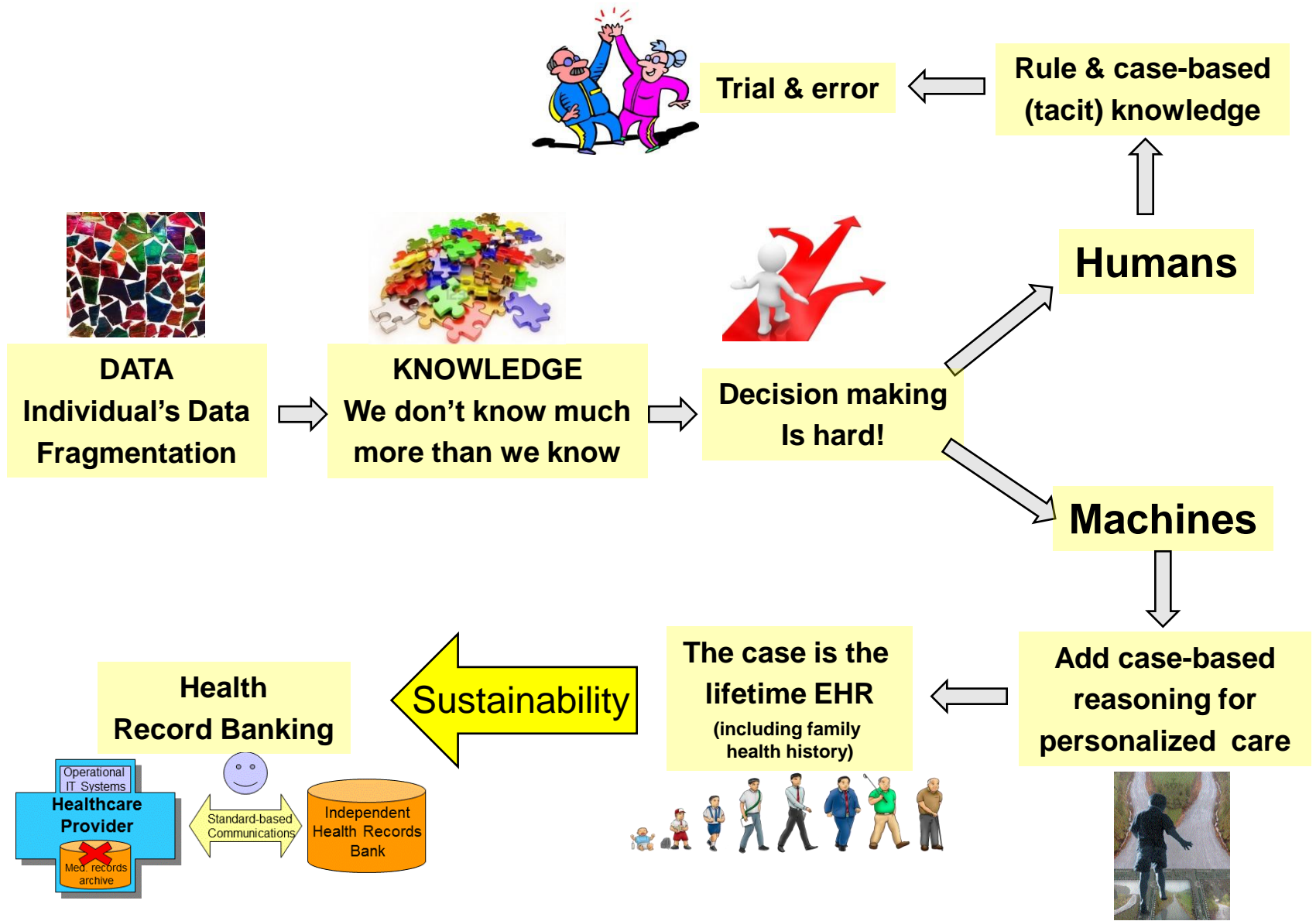
Chair, EFMI Translational Health Informatics Work Group

Chair, IMIA Health Record Banking Work Group

Co-chair, HL7 Clinical Genomics Work Group

Research Fellow, University of Haifa

Motivation and Passion...



Foundations of Informatics for CBR

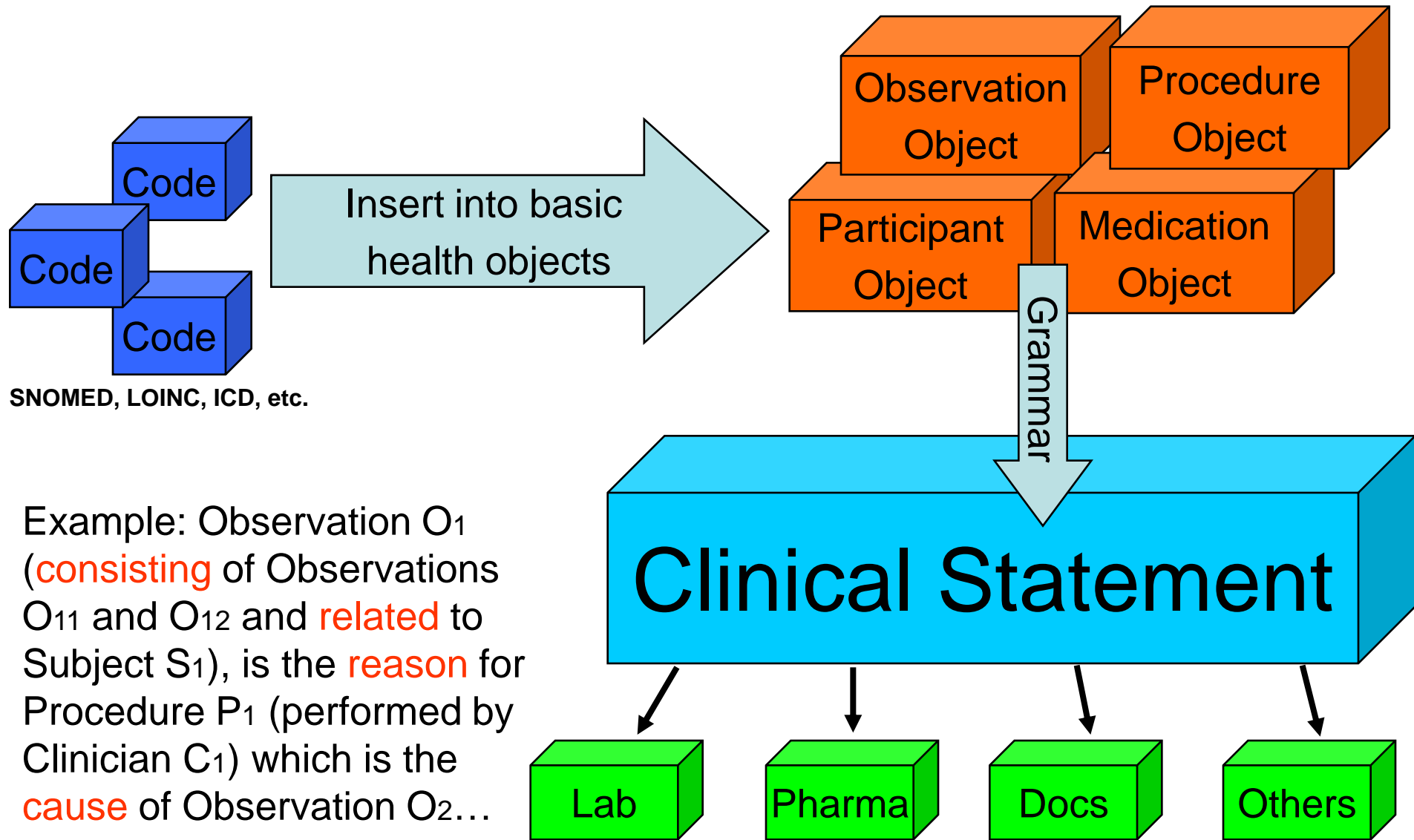
- **Cased-based Reasoning (CBR) requires ontological comparison of cases**
- **Ontological comparison requires the following foundations of health informatics:**
 - **Explicitly represent contextual data**
 - **Strike a balance of Narrative – Unstructured data**
 - **Use base language in a model-driven approach**
 - **Encapsulate raw data into clinical structures**
 - **Use EHR as best organizer of patient (case) data**
 - **Include family health history as part of the EHR**
 - **Warehouse health data by richest & standard form**
 - **Emerge the lifelong EHR in an information mart**
 - **Give rise to independent health record banks**

Flat representations are flat tires!

Key Principle

Health data semantics and context cannot be faithfully represented using flat structures (e.g., a list of entries), rather, it requires a compositional language that associates data entries into a meaningful statement

Need a Compositional Language



SNOMED, LOINC, ICD, etc.

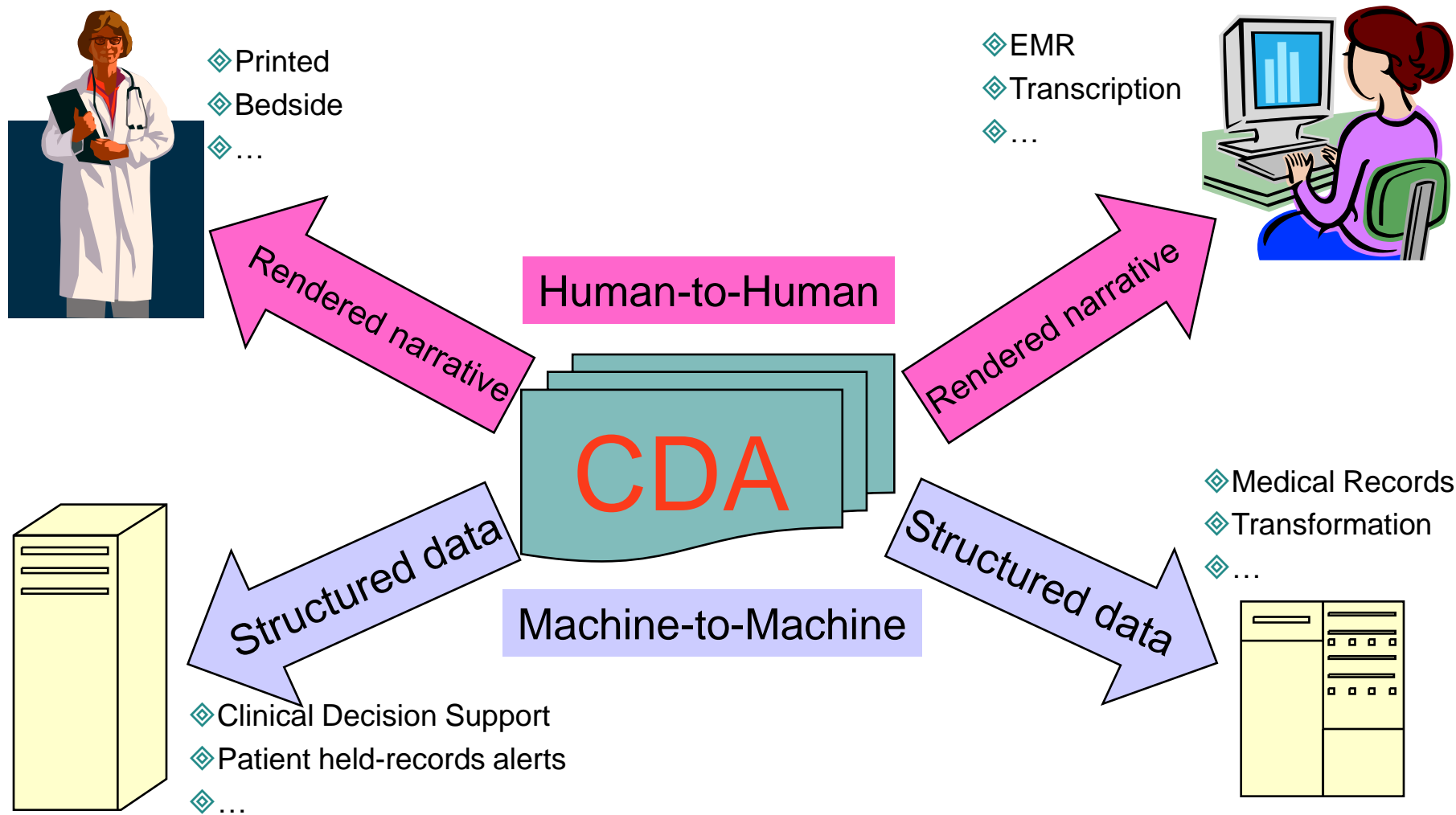
Example: Observation O_1 (consisting of Observations O_{11} and O_{12} and related to Subject S_1), is the reason for Procedure P_1 (performed by Clinician C_1) which is the cause of Observation O_2 ...

It's available through the new generation of standards!

Key Principle

Health information language needs to accommodate unstructured data (e.g., clinician's narrative or patient's story), while maintaining interlinks to structured data entries corresponding to contents that have been structured

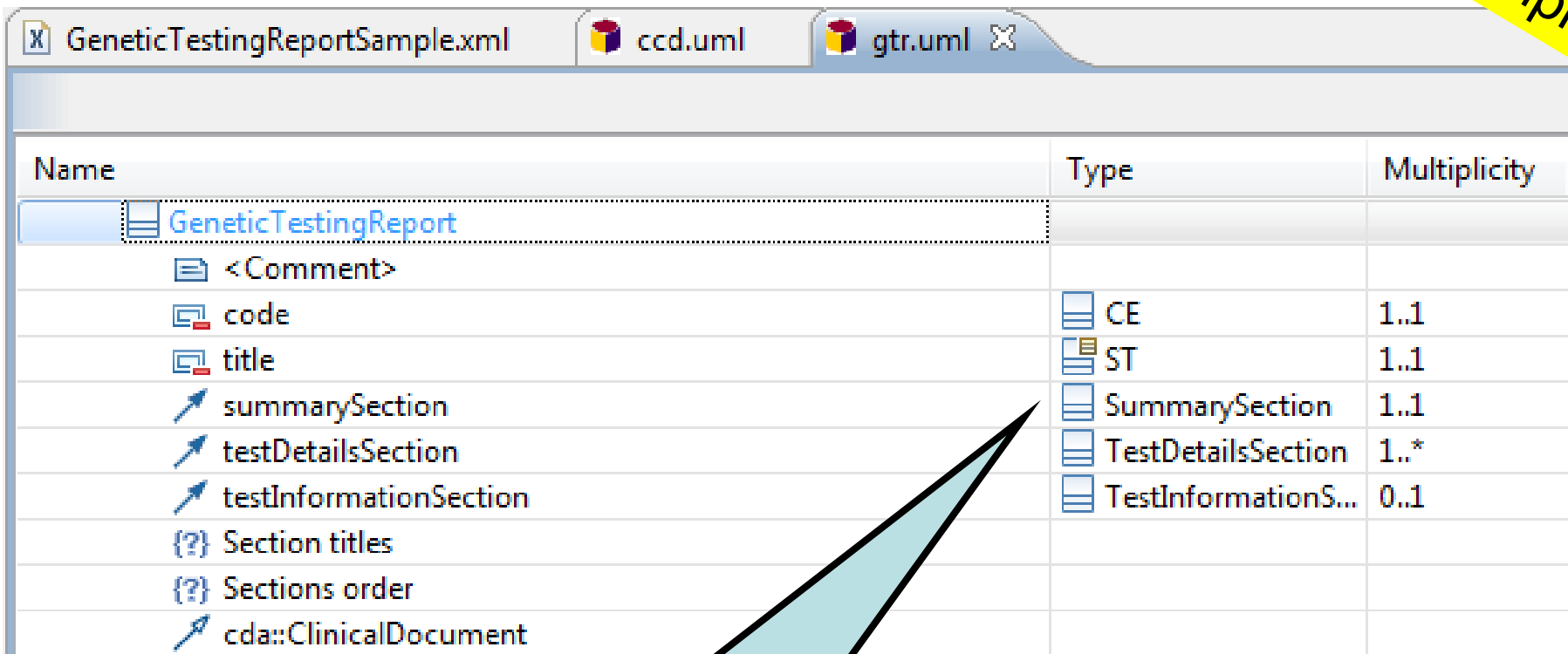
HL7/ISO CDA (Clinical Document Architecture)



Use Model Driven Tools to Ensure Consistency

Key Principle

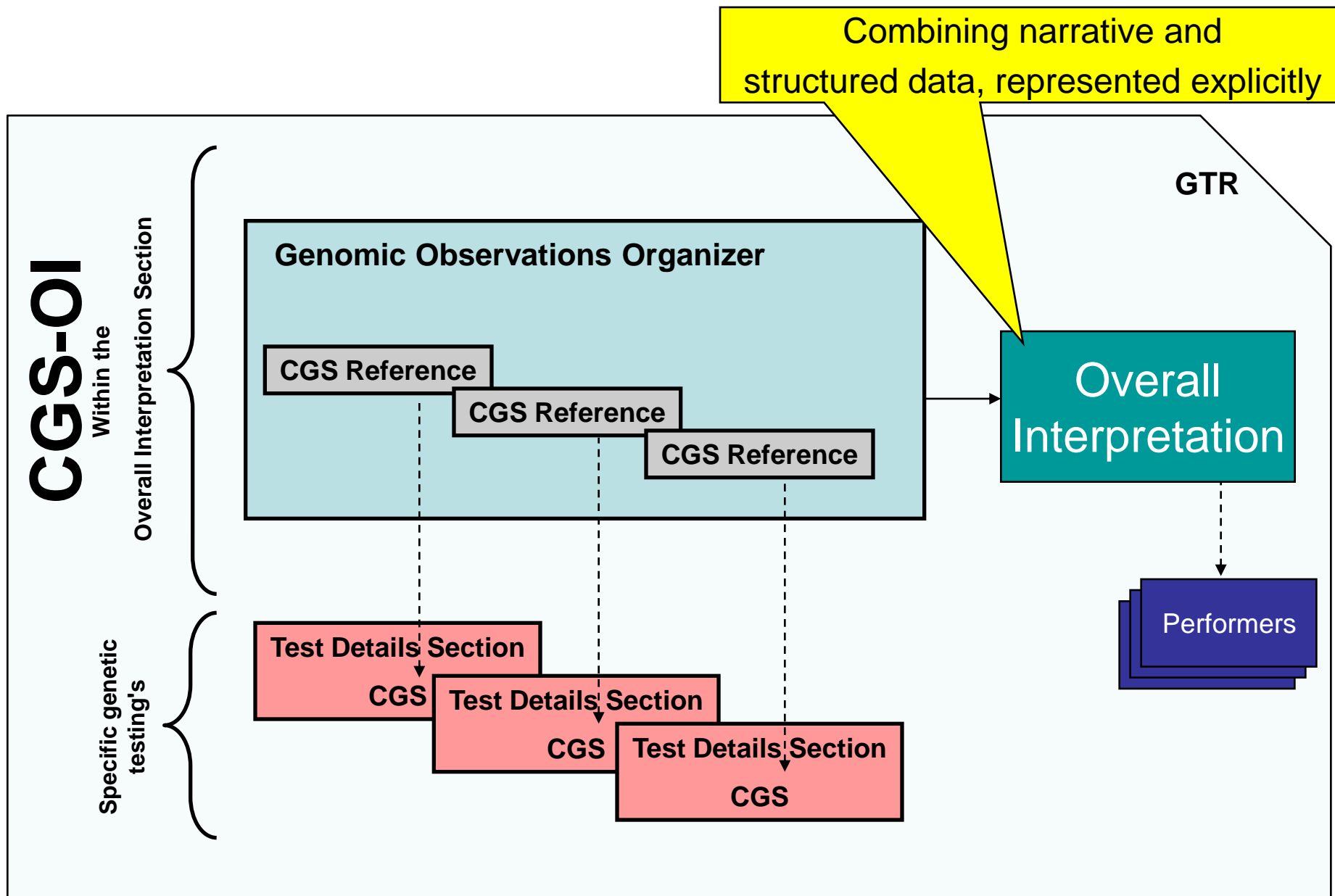
Design of the CDA-based Genetic Testing Report (GTR) using CDA UML Model in the Model Driven Health Tool



Name	Type	Multiplicity
GeneticTestingReport		
<Comment>		
code	CE	1..1
title	ST	1..1
summarySection	SummarySection	1..1
testDetailsSection	TestDetailsSection	1..*
testInformationSection	TestInformationS...	0..1
{?} Section titles		
{?} Sections order		
cda::ClinicalDocument		

Sections multiplicity:
Summary SHALL appear exactly once
TestDetails SHALL appear at least once
TestInformation MAY appear once

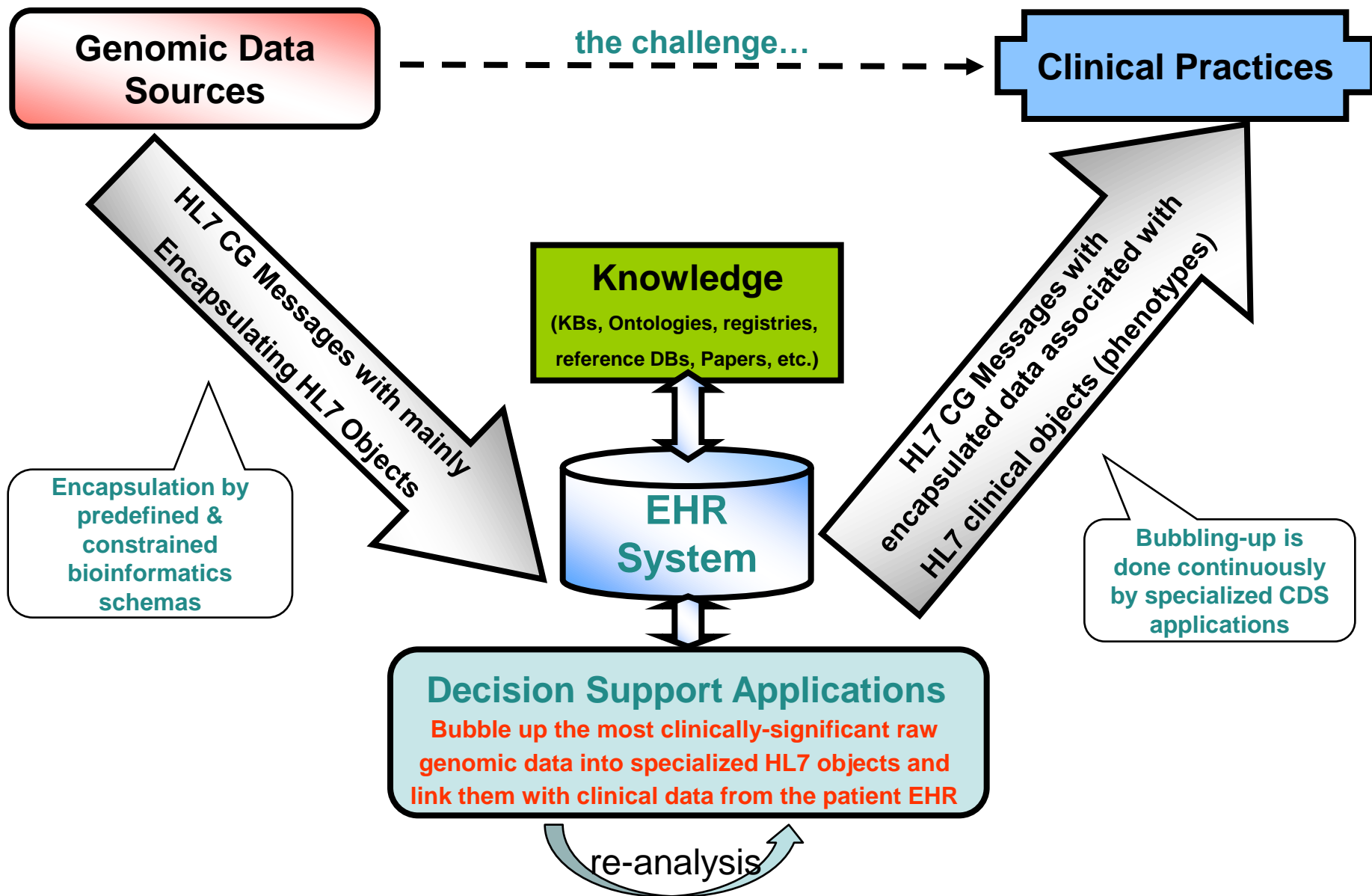
Clinical Genomic Statement - Overall Interpretation



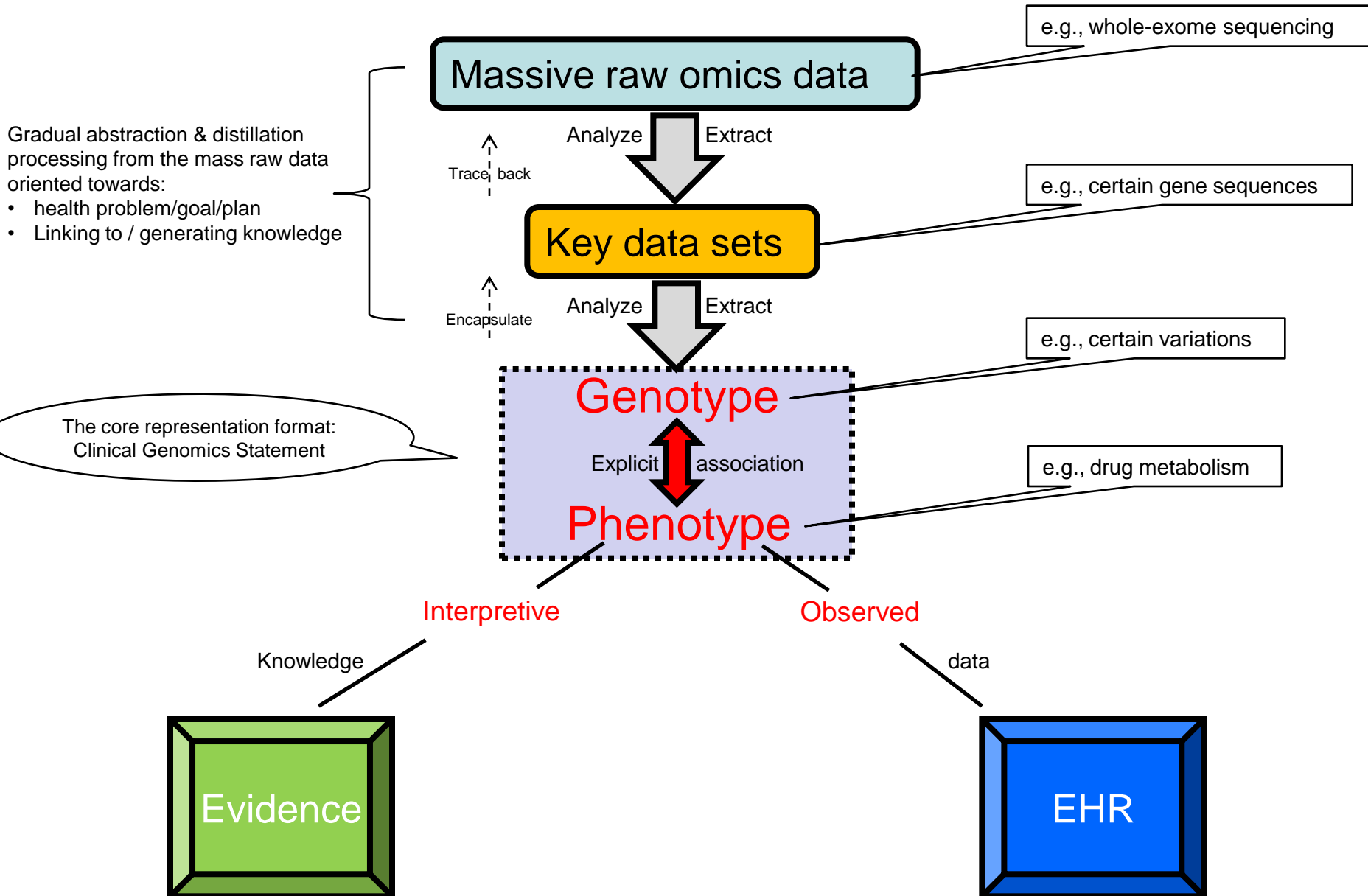
Key Principle

Key data out of raw/mass data sets pertaining to an individual should be encapsulated in its native format into clinical data structures, where 'bubbled-up' items could be associated with phenotypic data (using clinical data standards)

HL7 Clinical Genomics: Encapsulate & Bubble-up

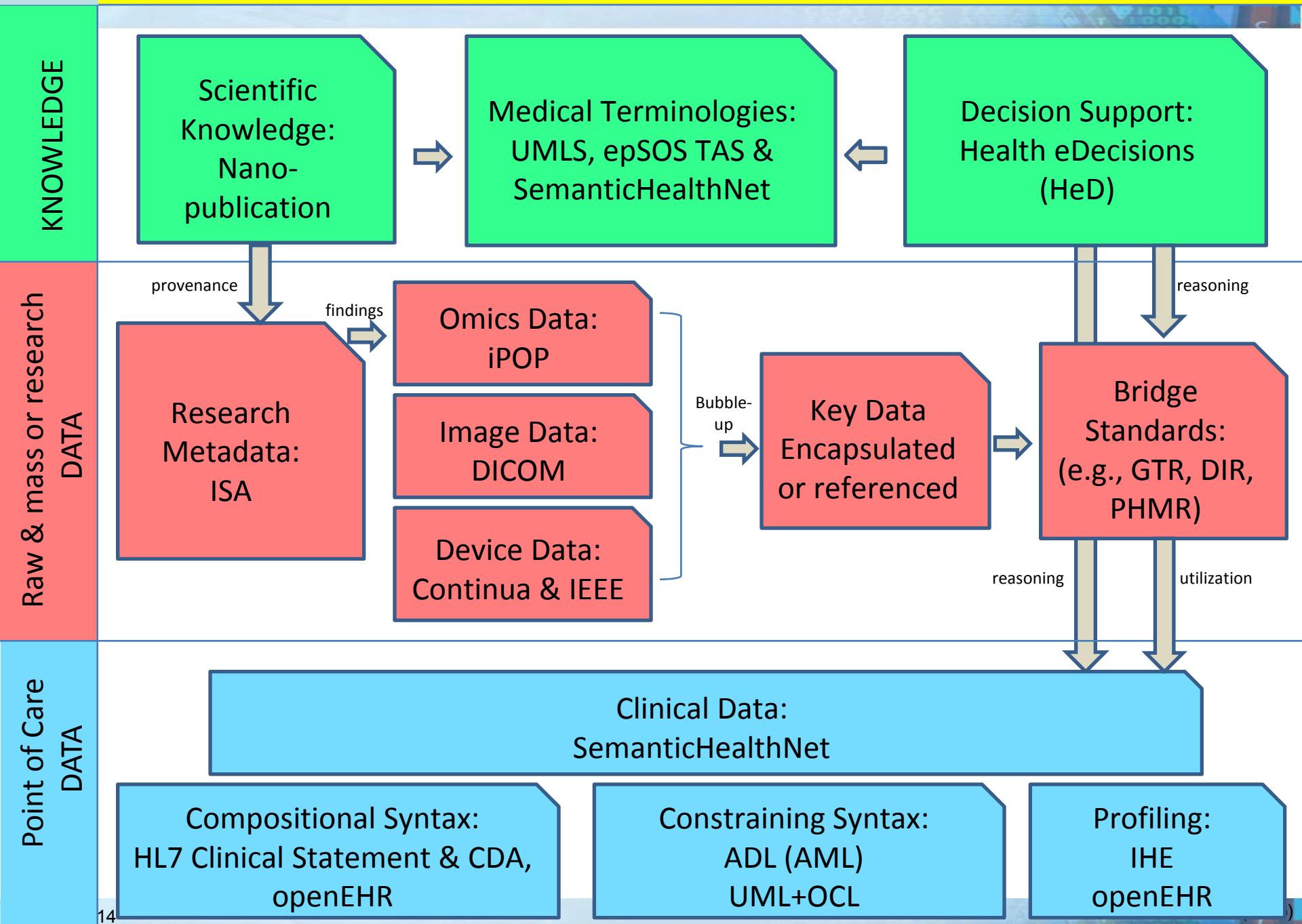


Gradual Distillation of Mass / Raw Genomic Data



- **Rethinking Domain Specific Standards**
 - Wouldn't it be better if we strive to a universal health information language?!
 - Domain standards will then be just different usages of that language
 - Current situation is that various domain standards are semantically inconsistent
- **Are standards for exchange only?!**
 - Natural languages are used for both communication between people and self communication
 - Similarly, standards could be used beyond exchange for internal representation
 - Differences between representations for exchange and internal needs often make the exchange of data not fully semantic interoperable

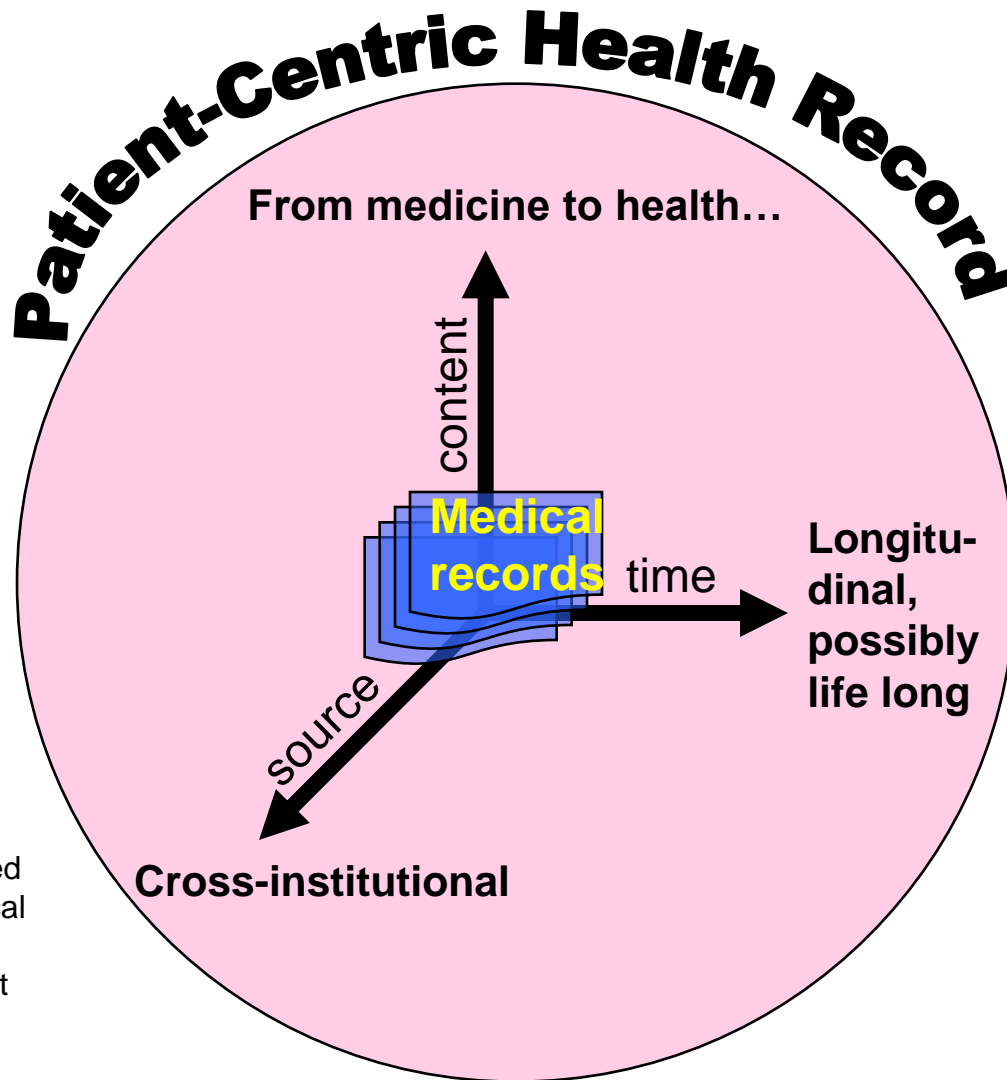
Towards a Translational Health Information Language



Key Principle

Various types of healthcare and life sciences data should be fused into a single & coherent information entity representing health information of an individual – a.k.a - the Electronic Health Record (EHR)

From Medical Records to the EHR...



Health record

Any data items related to the individual's health (including data such as genetic, self-documentation, preferences, occupational, environmental, life style, nutrition, exercise, risk assessment data, physiologic and biochemical parameter tracking, etc.)

Should Also include genetic data

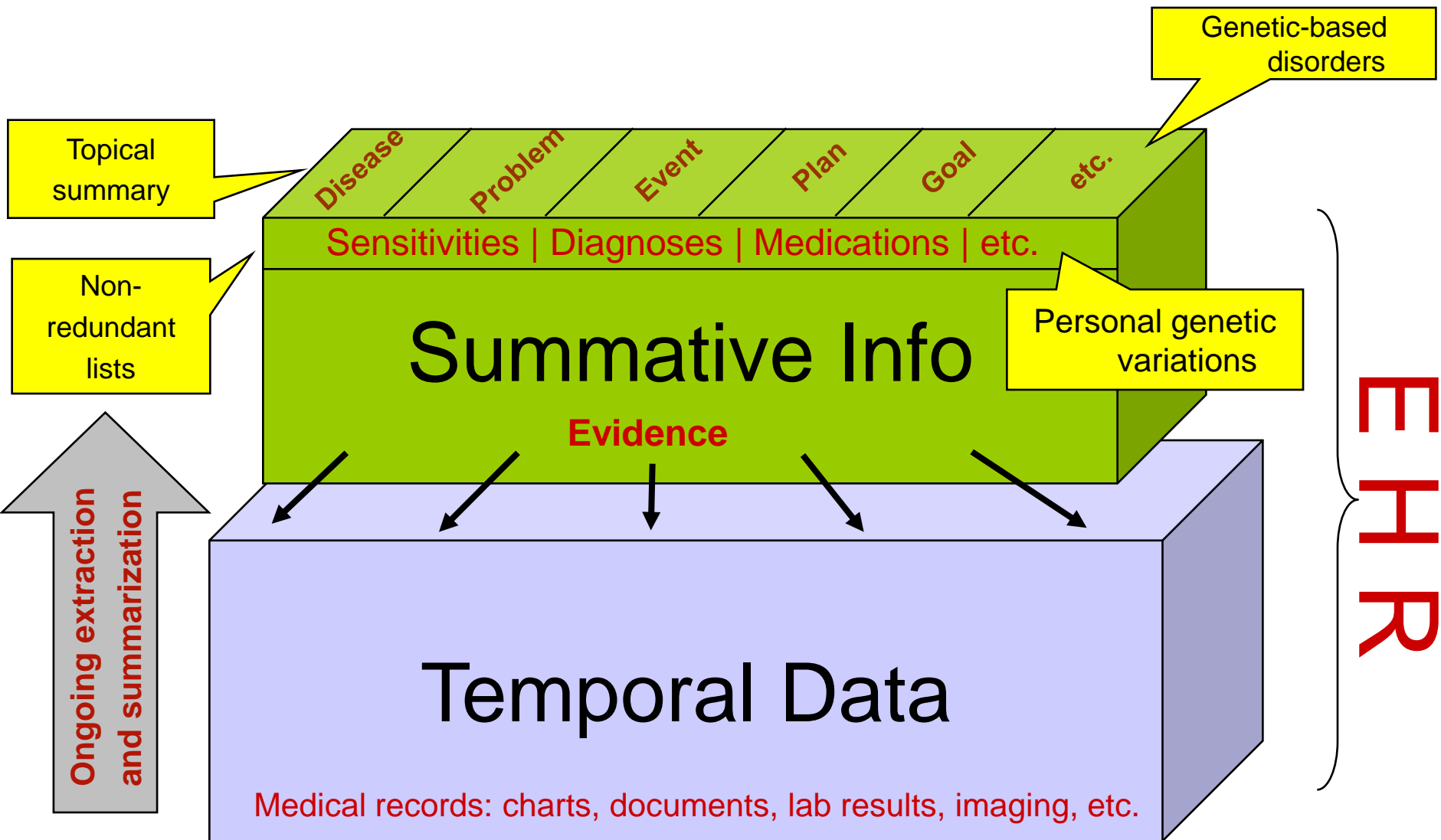
Medical record

Every authenticated recording of medical care (e.g., clinical documents, patient chart, lab results, medical imaging, personal genetics, etc.)

Longitudinal (possibly lifetime) EHR

A single computerized entity that continuously aggregates and summarizes the medical and health records of individuals throughout their lifetime

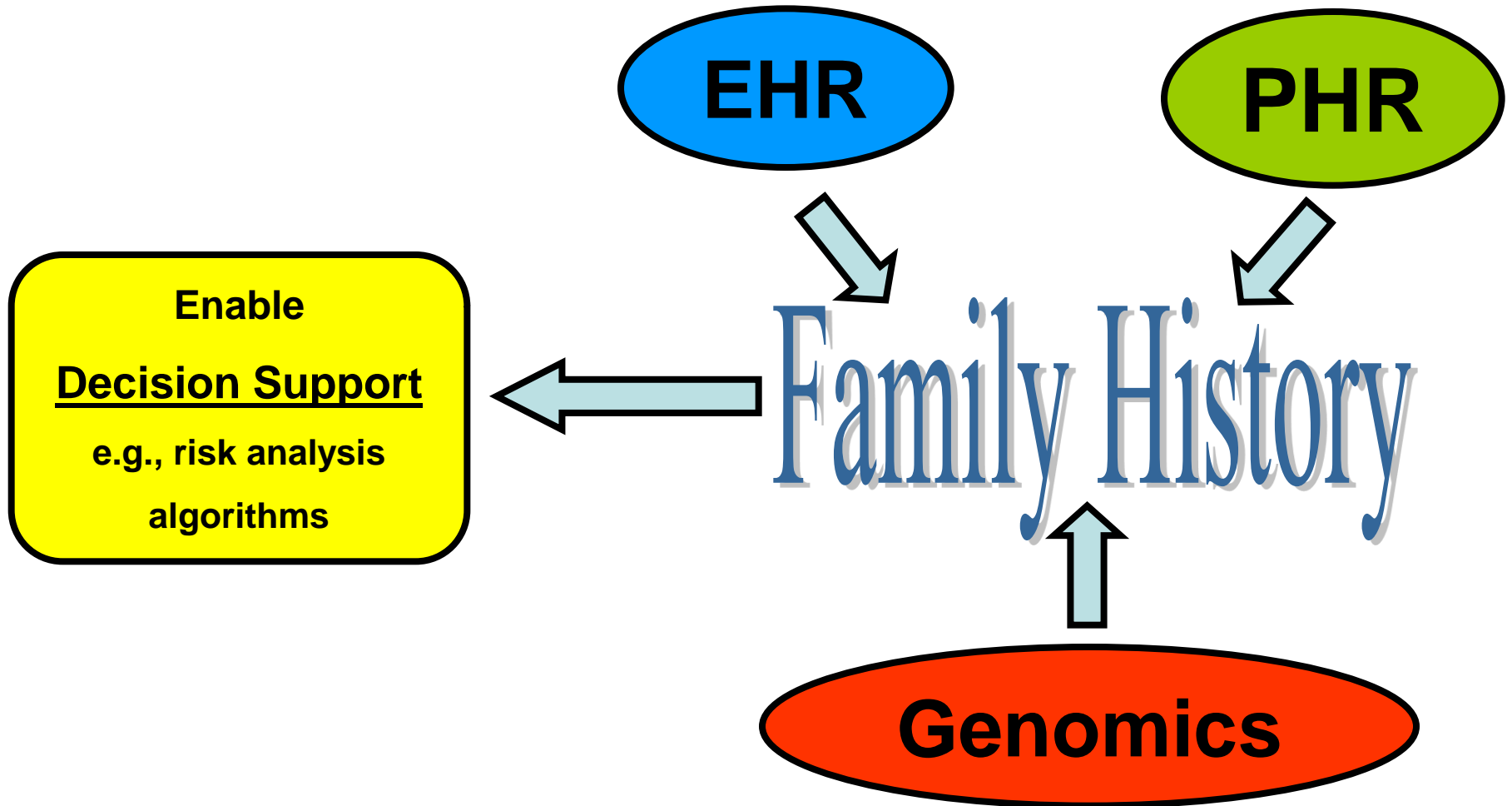
EHR – layers of temporal and summative data



Key Principle

- Even at the dawn of the genomics era, FHH is still very relevant, being a proxy for genetic, environmental, and behavioural risks to health
- FHH is considered the most unused resource in clinical practice and thus the case is incomplete, hindering CBR (case-based reasoning) power

Family Health History – A Convergence Test Case

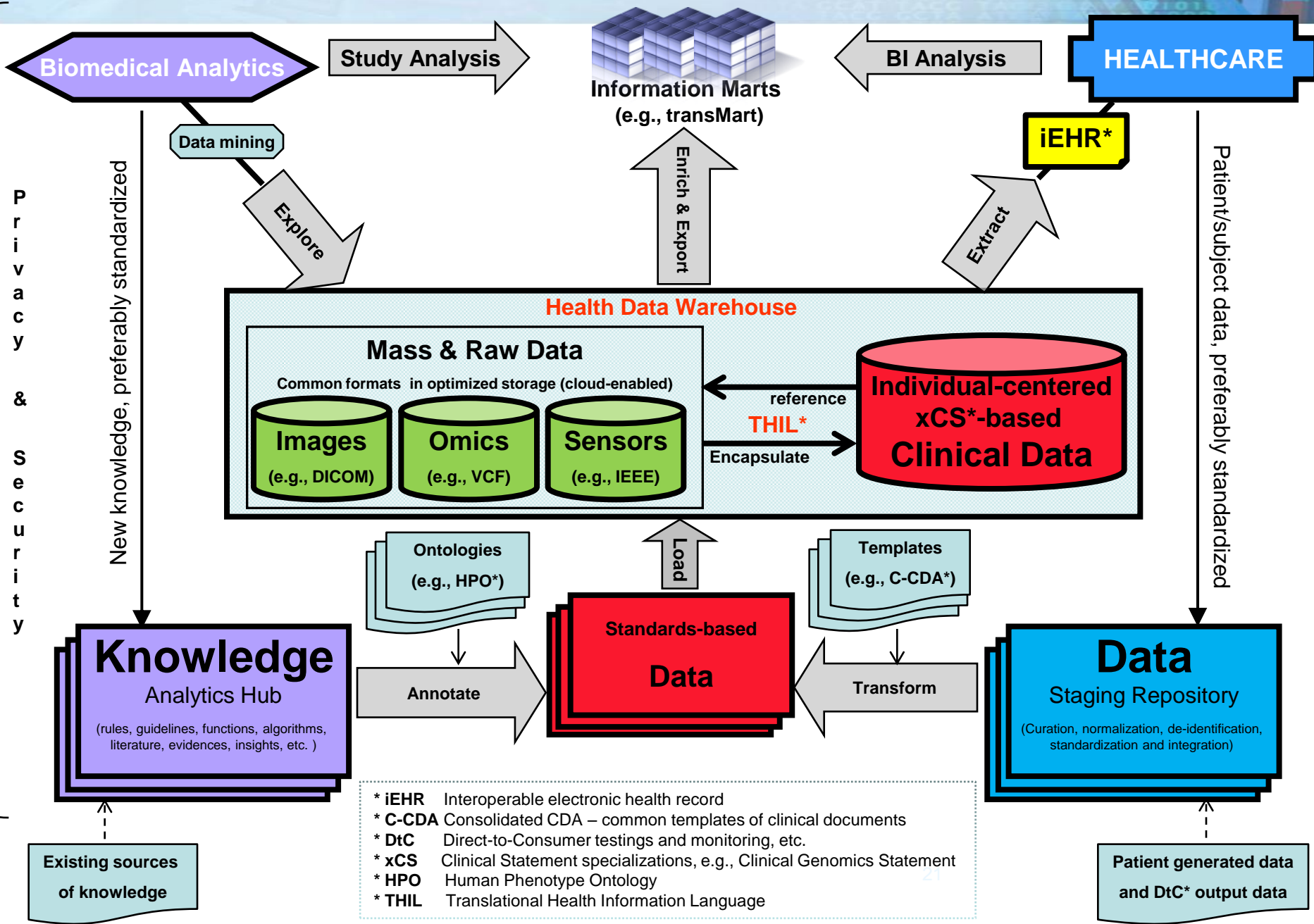


Warehouse Information Models

Key Principle

- A warehouse can have multiple information models, each dedicated to a specific solution/project
- A warehouse information model is created based on selection of generic standards such as HL7 CDA and
 - **Constraining the standards**
 - **Interrelating the standards**
- A warehouse information model can also be an EHR and this can support case-based reasoning for further personalization of care

Translational Health Info-structure



EHR Sustainability Constellations

Risk

e.g., UK

**Government
Centric**

Big brother

e.g., Canada

**Provider
Centric**

Partial data

**Non-Centric:
Independent
EHR Banks
(IHRBs)**

e.g. USA

**Regional
Centric**

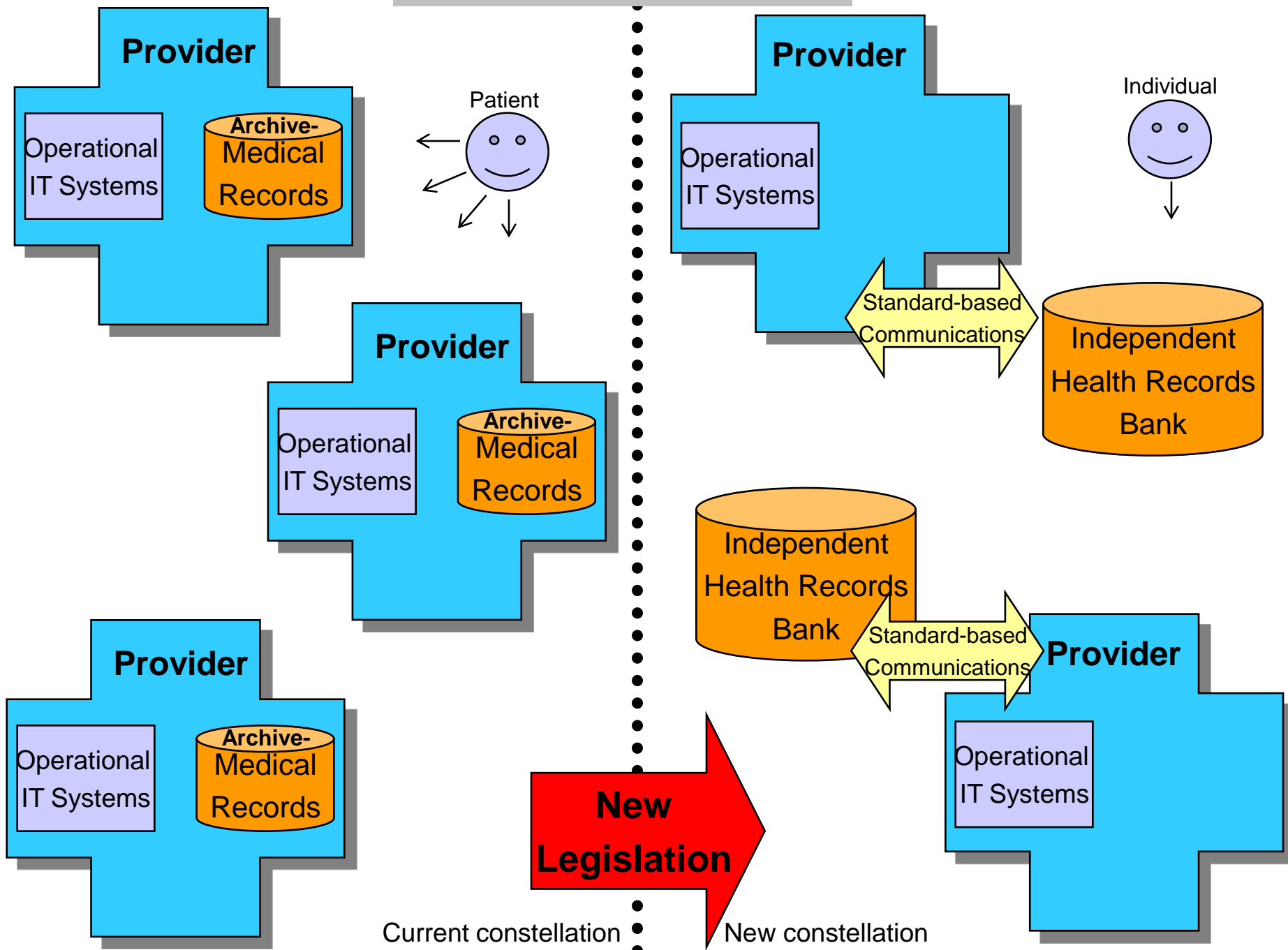
Limited

e.g., Google Health

**Consumer
Centric**

Non-reliable
Data

The Conceptual Transition



The End

- ◆ Thanks for your attention!
- ◆ Questions?
- ◆ Comments: amnon.shvo@gmail.com

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