

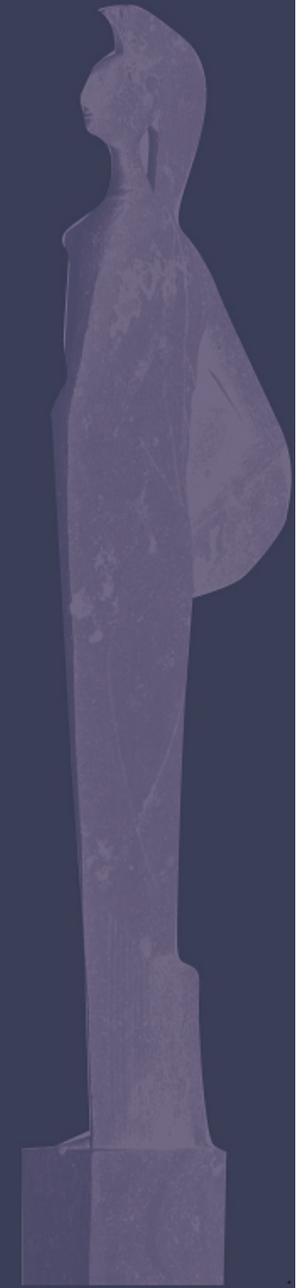
Università degli Studi di Trieste

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Corso di Laurea Magistrale in  
INGEGNERIA CLINICA

# INFORMATICA MEDICA PERSONALIZZATA

Corso di Informatica Medica  
Docente Sara Renata Francesca MARCEGLIA



Dipartimento di Ingegneria e Architettura



UNIVERSITÀ  
DEGLI STUDI DI TRIESTE



# p-HEALT: personalized eHealth

## PERSONALIZED HEALTHCARE

The process of tailoring health interventions, services, and information to the needs of individual

## pHealth

## eHealth

**e-health** is a field of **medical informatics**, referring to the organisation and delivery of health services and information **using the Internet** and related technologies

# PERSONALIZED HEALTH INFORMATICS: DEFINITION



“**Personalized Health Informatics** is a comprehensive set of Internet-based tools that offer a **personally centred**, prevention-orientated platform of services to maintain, enhance, and restore an individual’s health”.

•[Lacal, 2006, adapted]

# The PATIENT as the centre of the healthcare process



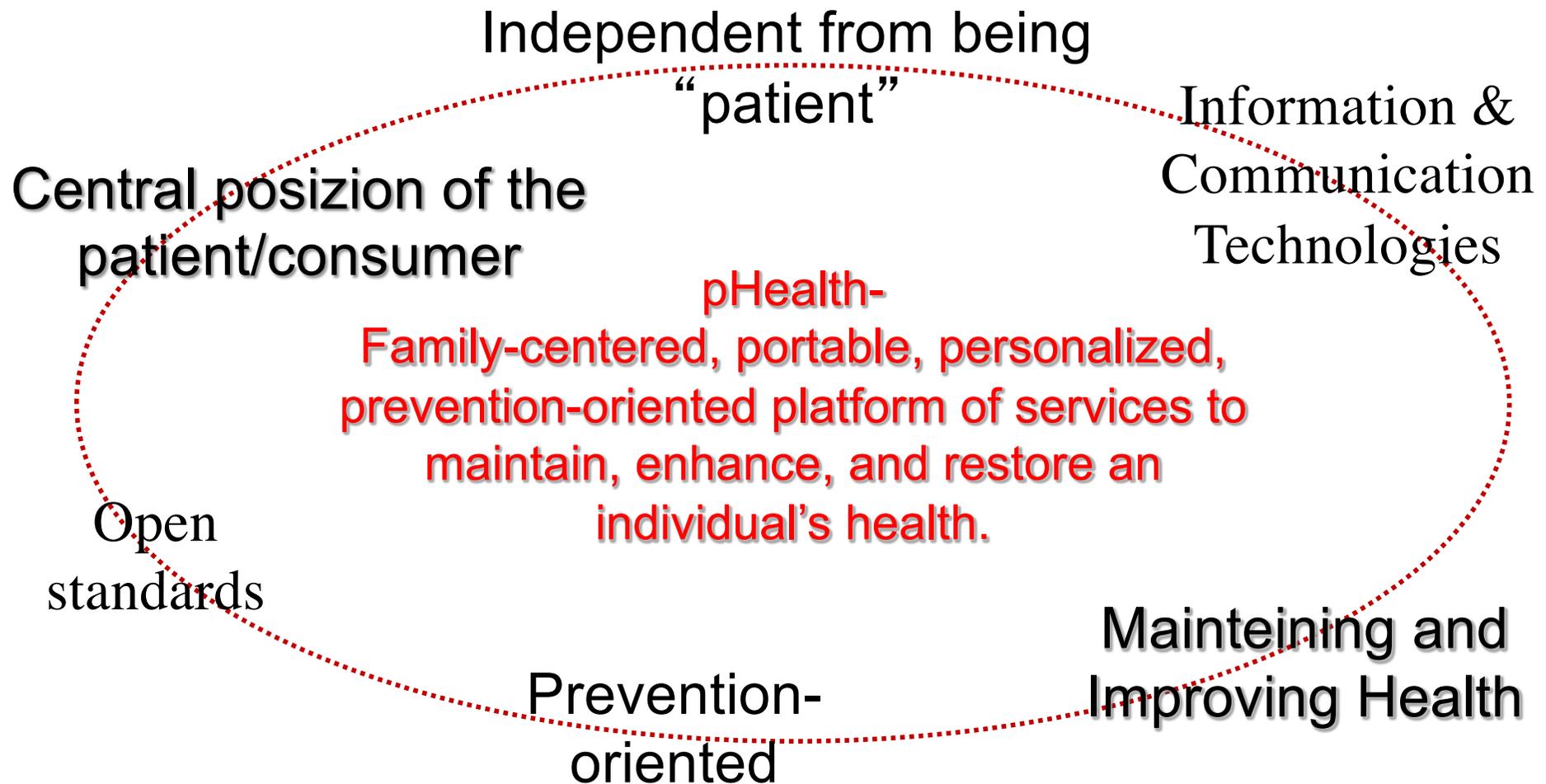
“the PATIENT is the most underused resource in the healthcare delivery system” [Slack W, 2001]

“Without information there is no choice.... The future is about sharing information, sharing decisions and sharing responsibility”

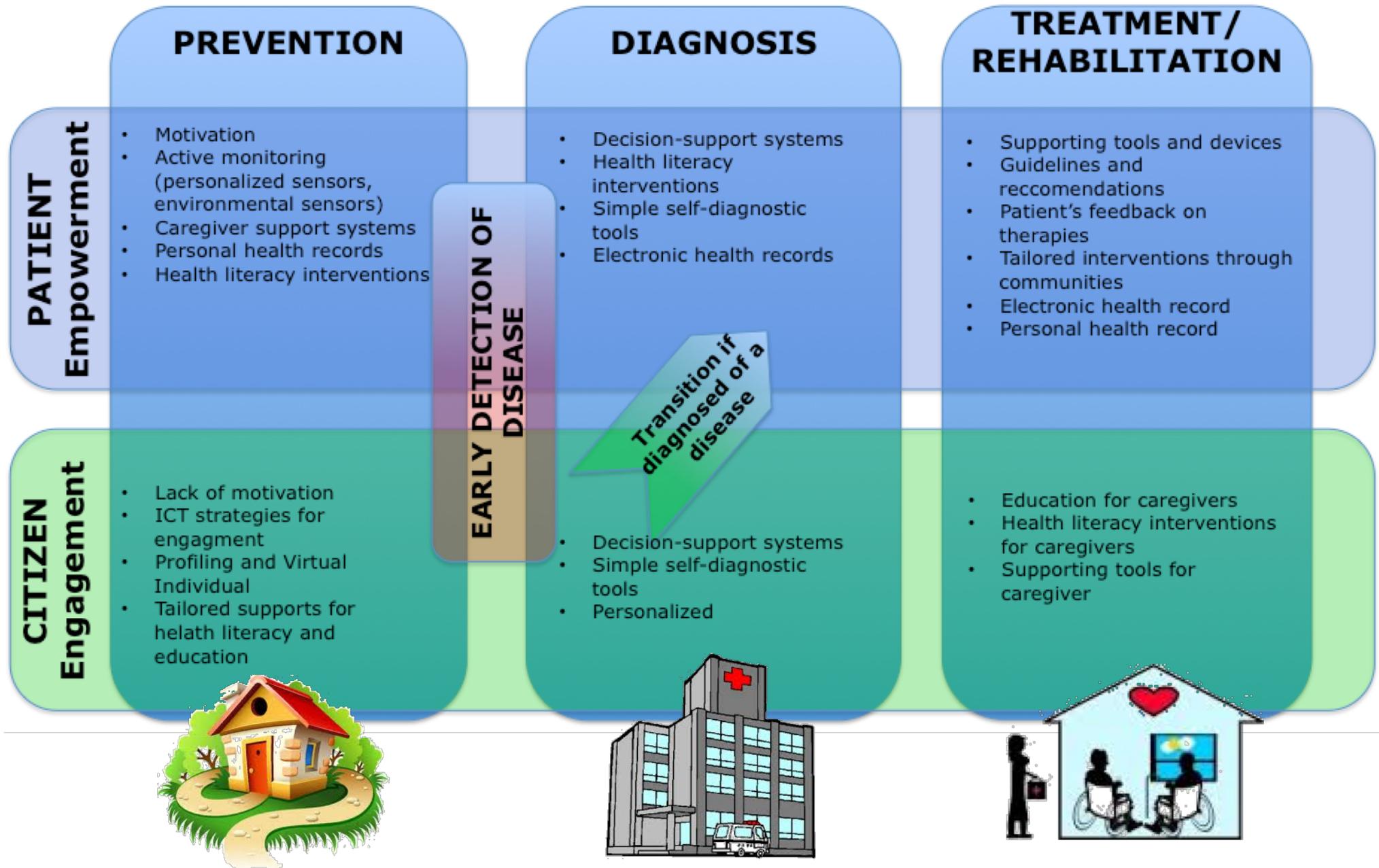
Cayton H. Better Information, Better choices, Better Health: Putting information at the centre of health. UK DoH Dec 16th, 2004

“Improving a person’s ability to understand and manage his or her own health and disease, negotiate with different cadres of health professionals, and navigate the complexities of health systems is crucial to achieving better health outcomes.” [Lancet, 2012]

# Personalized Health Informatics: scenario



# EMPOWERMENT vs ENGAGEMENT



# EMPOWERMENT vs ENGAGEMENT



**Empowerment can be intended as the process through which the patient/consumer becomes an “active and informed patient”**



**Engagement can be intended as the process through which the citizen/consumer becomes active in preserving his/her health**

# DECISION MAKING IS THE CORE

Support  
selfcare



- Care actions
- Prevention actions

Document  
archiving

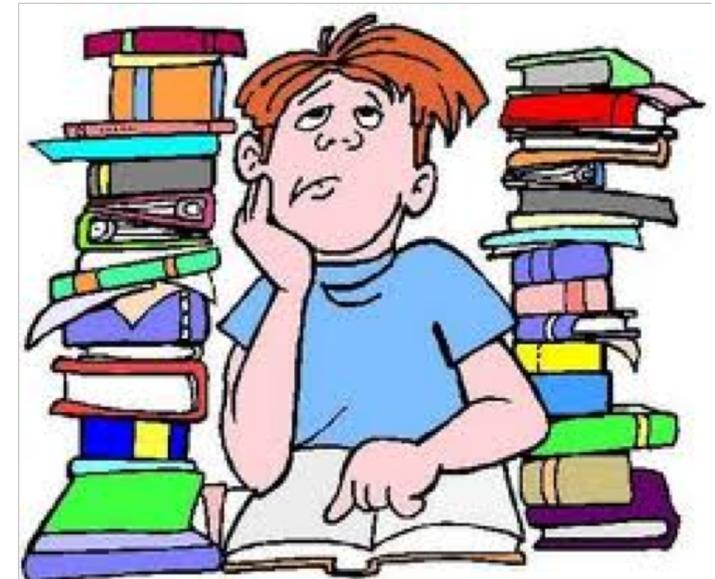


- Access health-related information
- Manage health-related information



## Decision making

## Communication with professionals



- Content understanding
- Fast/real time communication

**BOTH EMPOWERMENT AND  
ENGAGEMENT AIM TO  
PROMOTE INFORMED  
DECISION MAKING ON  
PERSONAL HEALTH**



# Shared Medical Decision making (1)

**Collaborative communication process between clinicians and patients that integrates the best evidence available with the patients' values and preferences, to promote high-quality health care decisions.**



## JAMA The Journal of the American Medical Association

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November 24, 2004, Vol 292, No. 20 >

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Commentary | November 24, 2004

### Shared Medical Decision Making Problems, Process, Progress

Robert A. McNutt, MD

JAMA. 2004;292(20):2516-2518. doi:10.1001/jama.292.20.2516.

Text Size: [A](#) [A](#) [A](#)

[Article](#)

[References](#)

It is easy to march behind the banner of shared medical decision making. Sharing with a patient who faces tough choices when he or she is ill is one of the true gifts of being in the medical profession. The patient-physician relationship is the sacrosanct epitome of professionalism with the goals of ensuring that patients receive the treatment best for them (science) and that the best treatment is carried out in the most efficient and compassionate manner (quality and safety).

# Shared Medical Decision making (2)

**JAMA** The Journal of the American Medical Association

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May 17, 2016, Vol 315, No. 19 >

< Previous Article Next Article >

Viewpoint | May 17, 2016

**The New Era of Informed Consent**  
**Getting to a Reasonable-Patient Standard Through Shared Decision Making** **FREE**

Erica S. Spatz, MD, MHS<sup>1,2</sup>; Harlan M. Krumholz, MD, SM<sup>1,2</sup>; Benjamin W. Moulton, JD, MPH<sup>3</sup>  
[+] Author Affiliations

JAMA. 2016;315(19):2063-2064. doi:10.1001/jama.2016.3070. Text Size: A A A

- In its final decision, the UK Supreme Court ruled that the standard for what physicians should inform patients about the risks, benefits, and alternatives of treatment will no longer be determined by what a responsible body of physicians deems important but rather by **what a reasonable patient deems important**.
- In rendering this decision, the court swept away decades of medical paternalism in the United Kingdom to embrace a **new patient-centered standard**.
- In the United States, approximately half of the states have adopted the **reasonable-patient standard**.
- The reasonable-patient standard views the **informed consent communication process from the patient's perspective**. It requires physicians and other health care practitioners to disclose all relevant information about the risks, benefits, and alternatives of a proposed treatment that an objective patient would find material in making an intelligent decision as to whether to agree to the proposed procedure.



The idea of individuals keeping files on their personal medical information is not new [Moen and Brennan, 2005].

The widespread diffusion of the ICTs has made this idea feasible using personal computers, media tablets or smart-phones.

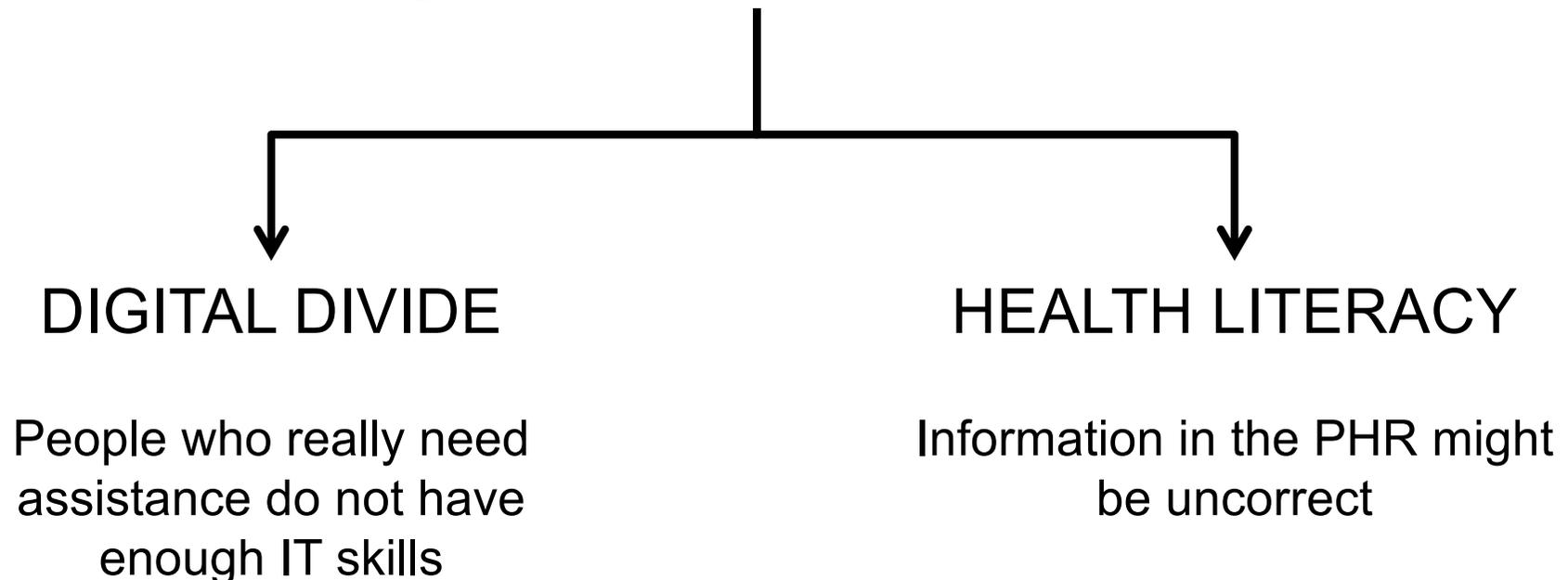
# PERSONAL HEALTH RECORD

# Personal Health Record



## PERSONAL HEALTH RECORD

An electronic application through which individuals can **access, manage and share** their health information, and that of others for whom they are authorized, in a **private, secure, and confidential environment**.



# AMIA-AHIMA JOINT STATEMENT



**The Value of Personal Health Records  
A Joint Position Statement for Consumers of Health Care  
by  
American Health Information Management Association  
American Medical Informatics Association  
February 2007**

## **Position**

The American Health Information Management Association (AHIMA) and the American Medical Informatics Association (AMIA) advocate empowering individuals to manage their healthcare through the use of a personal health record (PHR). The PHR is a tool for collecting, tracking and sharing important, up-to-date information about an individual's health or the health of someone in their care. Using a PHR will help people make better health decisions and improves quality of care by allowing them to access and use information needed to communicate effectively with others about their healthcare.



# PHR – EXAMPLES (1)



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INCREASE  
TEXT SIZE

T+ T-



[START A PHR](#)

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## RESOURCES FOR

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[PARENTS](#)

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[PHYSICIANS](#)

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## IN THE BLOGS

[Complicated Family Tree  
Further Complicates Family  
Health History](#)

[Behavioral Health Breakdown](#)

[Alzheimer's: A Long Journey For  
Caregivers And Sufferers Alike](#)

## PHR VIDEOS



## QUICK GUIDE TO CREATING A PHR

[Click here for 7 easy steps to a PHR.](#)



# PHR – EXAMPLES (2)



## Health

### Google Health has been discontinued

You can download and delete the data you have stored in Google Health through **January 1, 2013** by signing in to the right, but you will no longer be able to view, edit, share, or enter new data.

Any data remaining in Google Health after January 1, 2013 will be irretrievably **deleted** shortly after that date.

- To learn more about this announcement, see our [blog post](#).
- To learn more about how to download and continue using your data outside of Google Health, see our [Help Center articles](#).
- See also our answers to [frequently-asked questions](#).

[Report a problem](#) accessing Google Health

Google uses sophisticated security techniques to help keep your information secure and private, and you always control how it's used. We will never sell your data. You are in control. You choose what you want to share and what you want to keep private. View our [privacy policy](#) to learn more.

### Google Health privacy policy

Google respects the privacy of your health information. [Learn more](#)

Sign in

Google

Email

Password

Sign in

[Can't access your account?](#)

Microsoft Outlook

# PHR – EXAMPLES (3)



Microsoft®  
**HealthVault®**

United States ▼ | help | [sign in](#)

Search

**track & manage**   **organize**   **get healthy**   **tools & devices**

HealthVault helps you  
**monitor**  
chronic conditions  
and share data with  
your doctor.

[Get started](#)

sign up for your **free**  
**account!**

[sign up](#)

**What is HealthVault?**

A trusted place for people to organize, store, and share health information online.

[See how it works](#)

**Welcome, Google Health Users**

**Did you know?**  
You can create wallet cards with your emergency medical information



# PHR – EXAMPLES (4)

**KAISER PERMANENTE** Find doctors & locations My profile Member assistance Español

Sign on Search our site

My health manager Health & wellness Health plans & services Locate our services

My doctor My medical record Pharmacy center Appointment center My plan & coverage My message center

**Act for a family member**  
View health information and use features on behalf of your child and other family members.

E-mail my doctor Act for a family member Past visit information Order an ID card Sign up for e-newsletters

**My message center**  
Exchange secure e-mail with your doctor's office in [my message center](#). You also can go there to contact our Member Services and Web manager.

**Appointment center**  
Wondering if you should book a visit? Consult our [interactive symptom checker](#), or go straight to scheduling in the [appointment center](#).

**My medical record**  
See test results, immunizations, and more health information in [my medical record](#).

**Manage my plan & coverage**  
Get the facts about your plan and

**Pharmacy center**  
You can manage your prescriptions here.

# PHR – EXAMPLES (5)



[Accessibility](#) | [Feedback](#) | [Help](#) | [Sitemap](#) | [Features](#) | [What's New](#)



## HealthSpace

Search >

HealthSpace

Overview

Health and Lifestyle

Calendar and Address Book

Library

Summary Care Record

You are here: [HealthSpace](#) » Overview

## Welcome to HealthSpace

HealthSpace is a free, secure online personal health organiser. It can help you to manage your health, store important health information securely, or find out about NHS services near you.

There are a variety of features you can take advantage of and anyone living in England, aged 16 or over, with a valid email address can [register for a HealthSpace account](#).



### Health and Lifestyle information

Manage your health and lifestyle by keeping track of information like your weight, blood pressure, cholesterol levels and medications.



### Calendar and Address Book

Use the calendar to keep track of appointments and events, or the address book to store your NHS contacts like your GP, dentist or local pharmacy.



Please log in or register.

[Login](#) | [Register](#) | [Forgotten Details](#)

Related health information from:

**NHS choices**

### Live Well

Healthy living for everyone

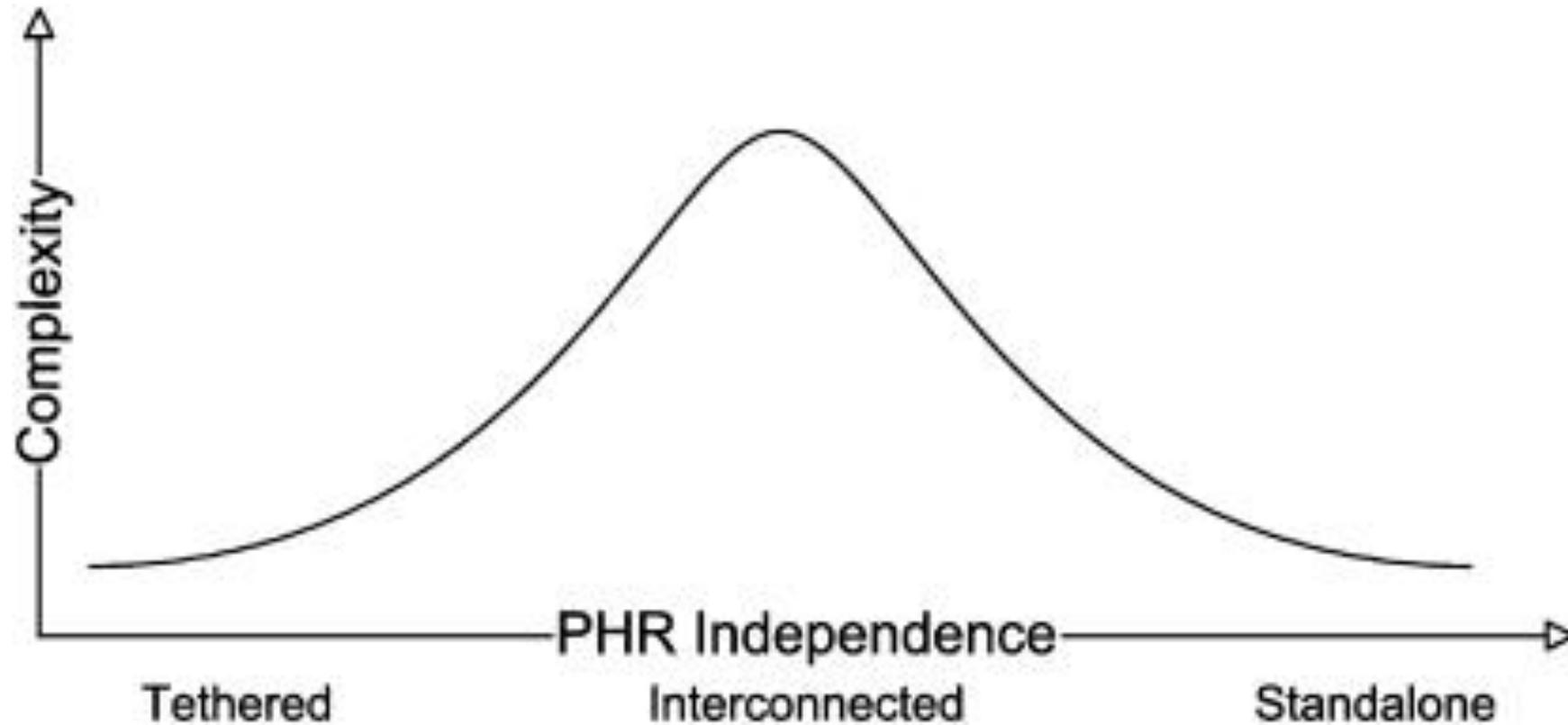


- > [Sex after hysterectomy](#)
- > [Top 10 diets review](#)
- > [10 myths about stop smoking treatments](#)

[More Live Well topics](#)

[Health A-Z](#)

# WHAT KIND OF PHR? (1)





## WHAT KIND OF PHR? (2)

### STANDALONE

- The patient can enter and access his or her health data through an application
- The stand-alone application does not connect with any other system.

### TETHERED

- PHR functionality Provided by allowing patients to view their own health care provider's EHR.
- The EHR-based systems may include additional functionality, such as allowing the patient to request appointments and prescription renewals and providing a communication channel to clinicians
- Patients may add supplemental information that may or may not subsequently be incorporated into the provider's EHR

### INTERCONNECTED

- Hybrid PHR systems connected to various health care data sources to acquire and transmit data.
- This latter approach overcomes the limitations that result from using a PHR integrated in a single health care provider or organization, but is much more complex.

# WHAT KIND OF INFORMATION CAN BE INCLUDED?



## CLINICAL DATA AND DOCUMENTS FROM HOSPITALS/EHRs →

- records of allergies, immunisations, weight, blood pressure, cholesterol levels
- diagnoses, laboratory results, medical history, images
- instructions from past visits
- Medications, refill

## AGENDA →

- future appointments and events
- address book to store helpful contacts, including the general practitioner (GP), the dentist or local pharmacies.

## FUNCTIONS →

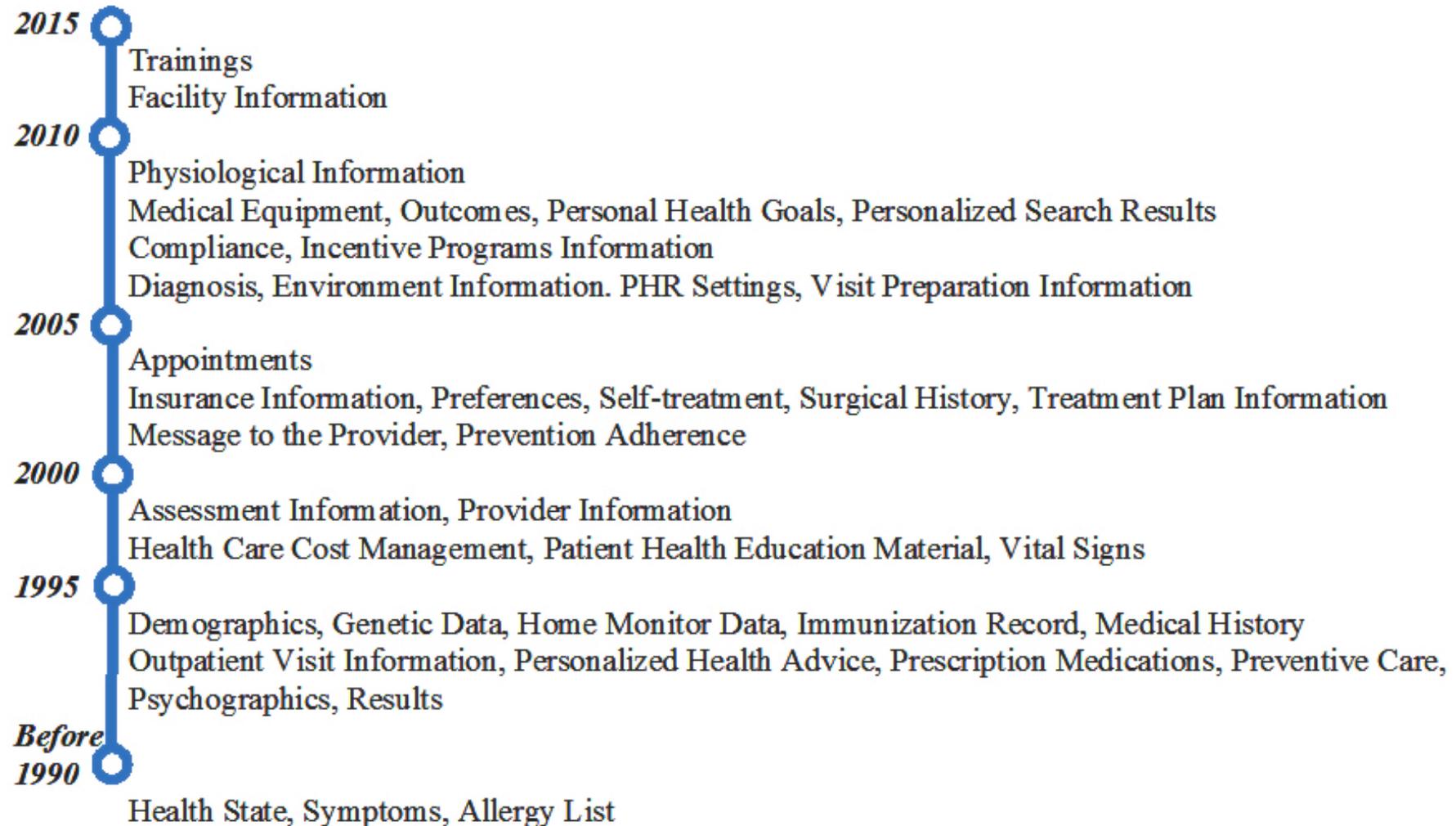
- book appointments
- reorder prescriptions
- communicate with healthcare professionals by email
- coordinate patient care between the physician's office, the hospital, radiology, the laboratory and the pharmacy
- authorize healthcare team members or caregivers can view, add, or update information
- Decision support systems through analytics

## CLINICAL DATA SOURCE

- Patient-reported outcomes
- Physician ratings
- Medication adherence
- Social support & communities



# EVOLUTION OVER TIME (1)





# EVOLUTION OVER TIME (2)

## Early 1970s: Accessing Comprehensive Patient Data

Source:

EHR

Data Type(s):

Text/number

Functionalites Type:

Read

Purpose:

Assist patient/providers in decision making

## 2000s - 2005: Extending the Patient-Provider Experience

Source:

Interactive web/mobile

Data Type(s):

Image, voice, video, relational

Functionalites Type:

Create/update

Purpose:

Improve access

Improve care coordination

Improve healthcare management

## 2005 - present: Tracking Patient Health Information

Source:

Decision support tools

Data Type (s):

Time series

Functionalites Type:

Tracking/monitoring

Purpose:

Disease prevention

Health promotion

# BEYOND PHR

## Anthem to launch Engage, a new digital hub

By [Jonah Comstock](#) | October 19, 2017

SHARE

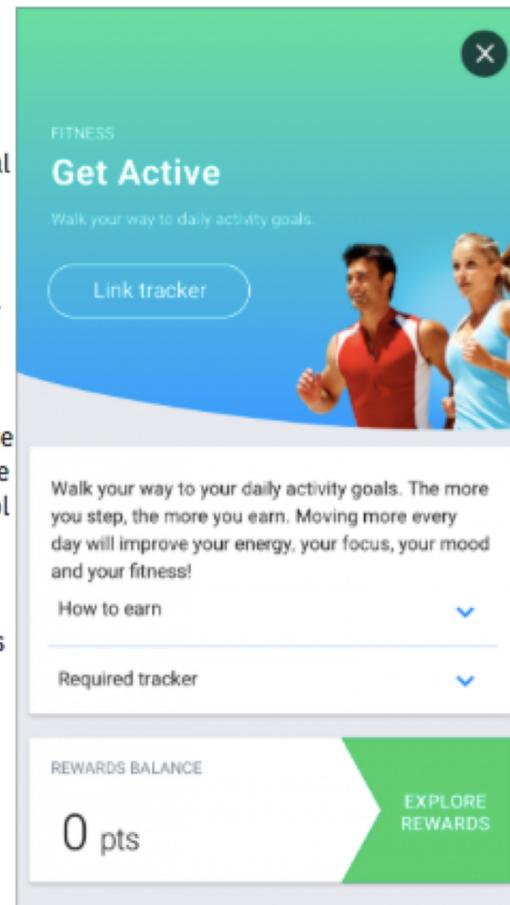


Anthem is launching a new comprehensive digital health platform for members nationwide. The platform, called Engage, comes out of the company's partnership with Castlight Health, **which began in 2015**. Going forward, it will serve as the foundation for the health plan's digital operations.

"So much is moving into the digital and mobile modalities," Morgan Kendrick, Anthem's head of national accounts, told *MobiHealthNews*. "The days of outbound telephonic engagement strategies are certainly limited. The population that wants to be reached that way is waning. [Moving toward digital engagement] allows us the opportunity to augment those technologies with machine learning and personalization to create a curated web tool for this person, which creates a greater trust level, which allows efficacy to happen in a different way."

At launch, Engage will include three major functionalities according to *Jonna Kurucz*, staff VP of Sales.

"The first one is creating a digital hub," she said. "Large accounts often choose to do business with multiple vendors, but that crates complexity for them. We're able to offer a single-sign on approach across all those benefits."



FITNESS  
**Get Active**  
Walk your way to daily activity goals

Link tracker

Walk your way to your daily activity goals. The more you step, the more you earn. Moving more every day will improve your energy, your focus, your mood and your fitness!

How to earn

Required tracker

REWARDS BALANCE  
0 pts

EXPLORE REWARDS



# CRITICAL ELEMENTS



- **Understanding health data (health literacy)**
  - Data visualization
  - Representation models targeted to patients
- **Data quality (patient-entered data)**
  - Standardized measures and guidelines
  - Verify accuracy through triangulation of multiple sources
- **Interoperability between components/systems**
  - Need of standards (interconnected PHR)
- **Data-related issues**
  - Heterogeneity
  - Openness
  - Security, scalability, transparency
  - Data generated by sensors and devices
  - Terminology used by patients differs from that used by providers (ontologies for patients)

# Data visualization



iPad 18:19 27%

**Load Family** *iVisual* **Load Atlas**

**CT Scan Labels:**  
giabella  
incisura (foro) supraorbitale  
lamina orbitale  
osso nasale  
osso lacrimale  
osso zigomatico  
processo frontale  
superficie orbitale  
processo temporale  
foro zigomatico-faciale  
osso mascellare  
processo zigomatico  
superficie orbitale  
foro infraorbitale  
processo frontale  
processo alveolare  
spina nasale anteriore

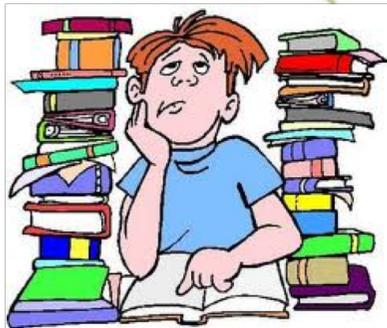
**Anatomical Atlas Labels:**  
sutura coronale  
osso parietale  
stenoide  
grande ala  
osso temporale  
etmoide  
superficie orbitale  
lamina perpendicolare  
conca nasale media  
conca nasale inferiore  
vomere  
mandibola  
ramo  
corpo  
foro mentale  
proluberanza (tuberosità) mentale

**ZoomOut Family** Anatomical Part: Testa **ZoomOutAtlas**

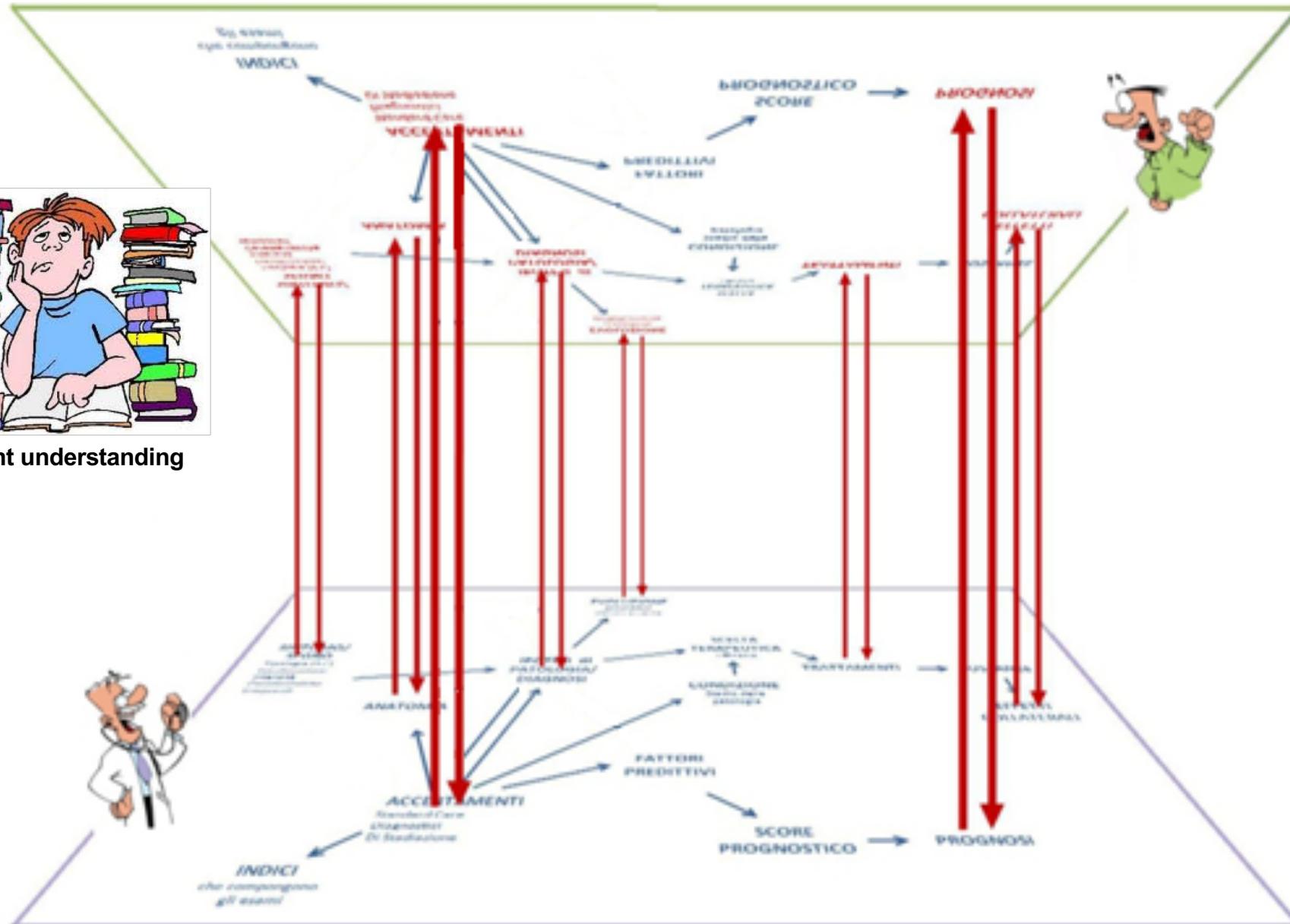
Name: Anna Bianchi  
Event: Ascesso molare  
Bioimage: CT\_MAIN  
Diagnosis:

## Comparing personal bio-images with anatomical atlases

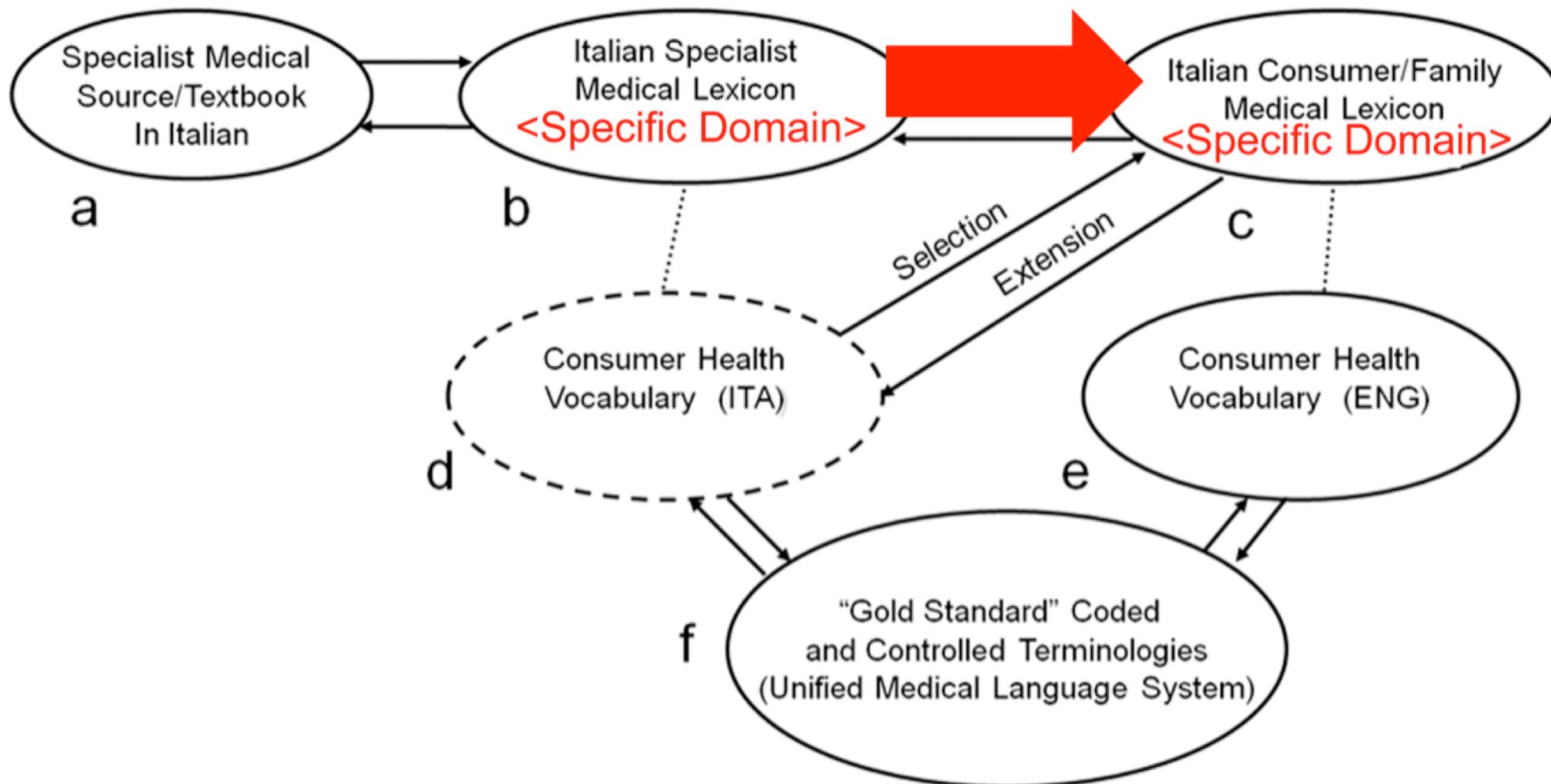
# Medical ontologies for patients



Content understanding



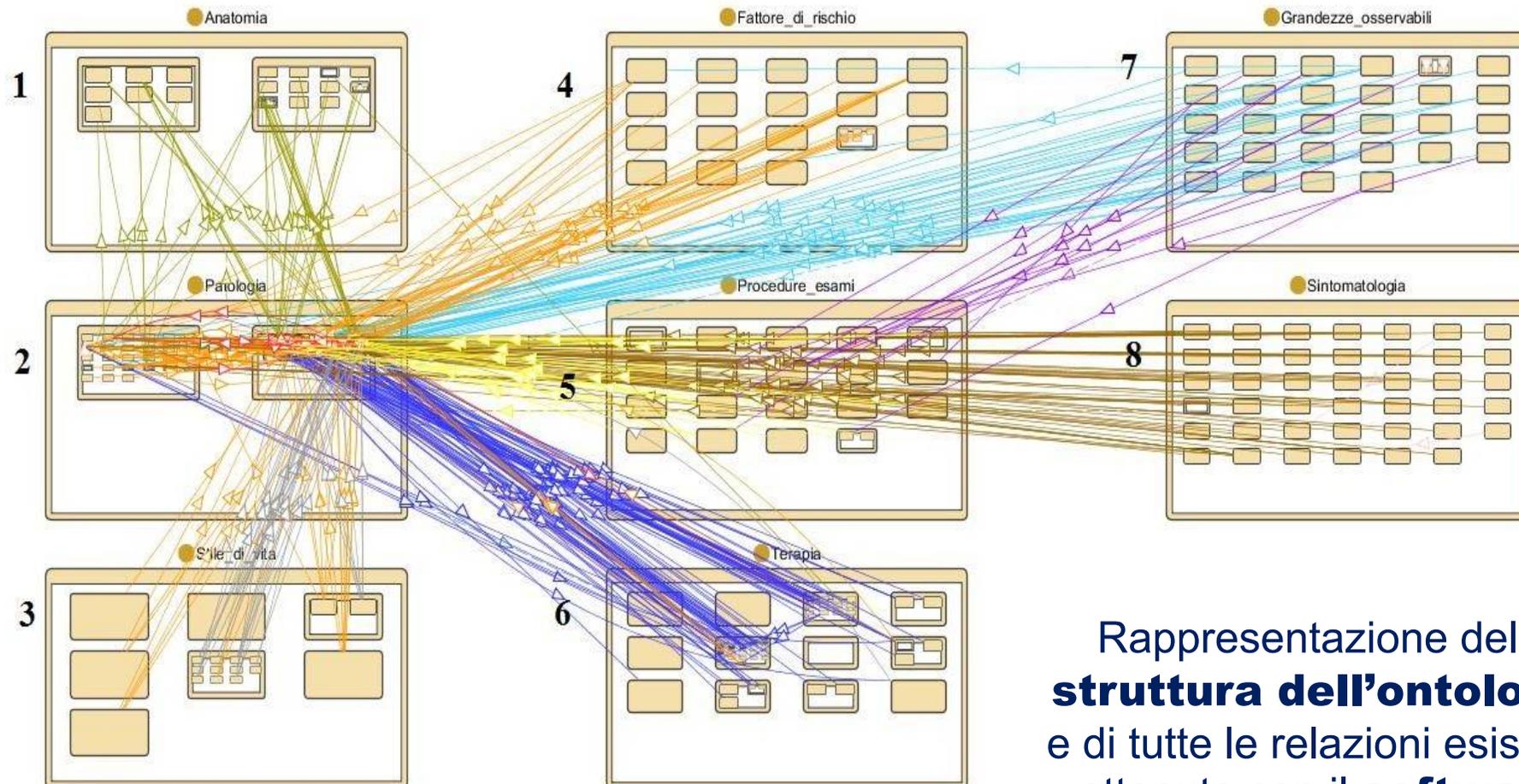
# THE MODELING APPROACH TO LEXICON CONNECTERS



# ONTOLOGY FOR CARDIOLOGY



owl:Thing



Rappresentazione della  
**struttura dell'ontologia**  
e di tutte le relazioni esistenti  
ottenuta con il **software**  
**Jambalaya**

# “ELECTRONIC HEALTH RECORD” vs “PERSONAL HEALTH RECORD”



| EHR   | FEATURE             | PHR   |
|---|---------------------|---|
| Single healthcare provider                    | Owner               | Citizens  |
| Clinical data and documents                   | Kind of information | Data, documents and information on health and wellness    |
| Time during which the patient is hospitalized | Observation time    | Life-long   |
| Healthcare workers and patients               | Addressee           | The citizen + All the subjects taking care of the patient |
| Within hospital information system            | Interoperability    | Global  |
| Only healthcare professionals                 | Accuracy of data    | The citizen can upload data and documents                 |
| Within hospital intranet                      | Security            | Citizen's PC and generic servers                          |
| All the healthcare workers of the provider    | Accessibility       | citizen   |

# ENVIRONMENT FOR THE QUALITY EVALUATION OF PHR



## CHARACTERISTICS OF LIFELONG HEALTH RECORDS

### Core Characteristics

### Dimension

Interoperability

Standardization

Comprehensiveness

Integrity  
Accuracy  
Completeness  
Apomediation

Legal Value

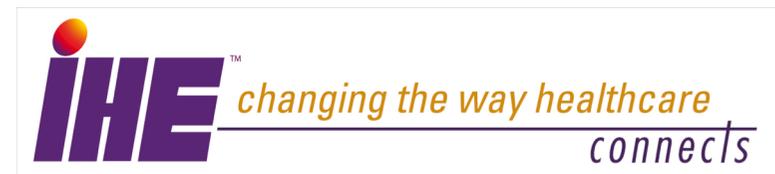
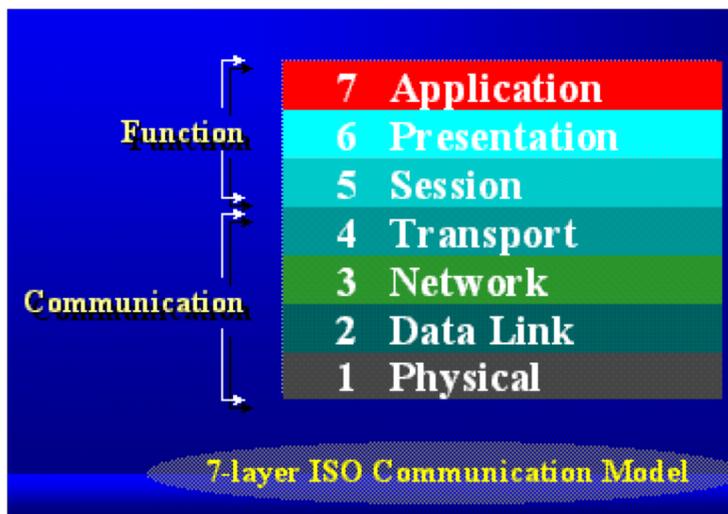
Privacy  
Confidentiality  
Auditability

Availability

Accessibility

# INTEROPERABILITY

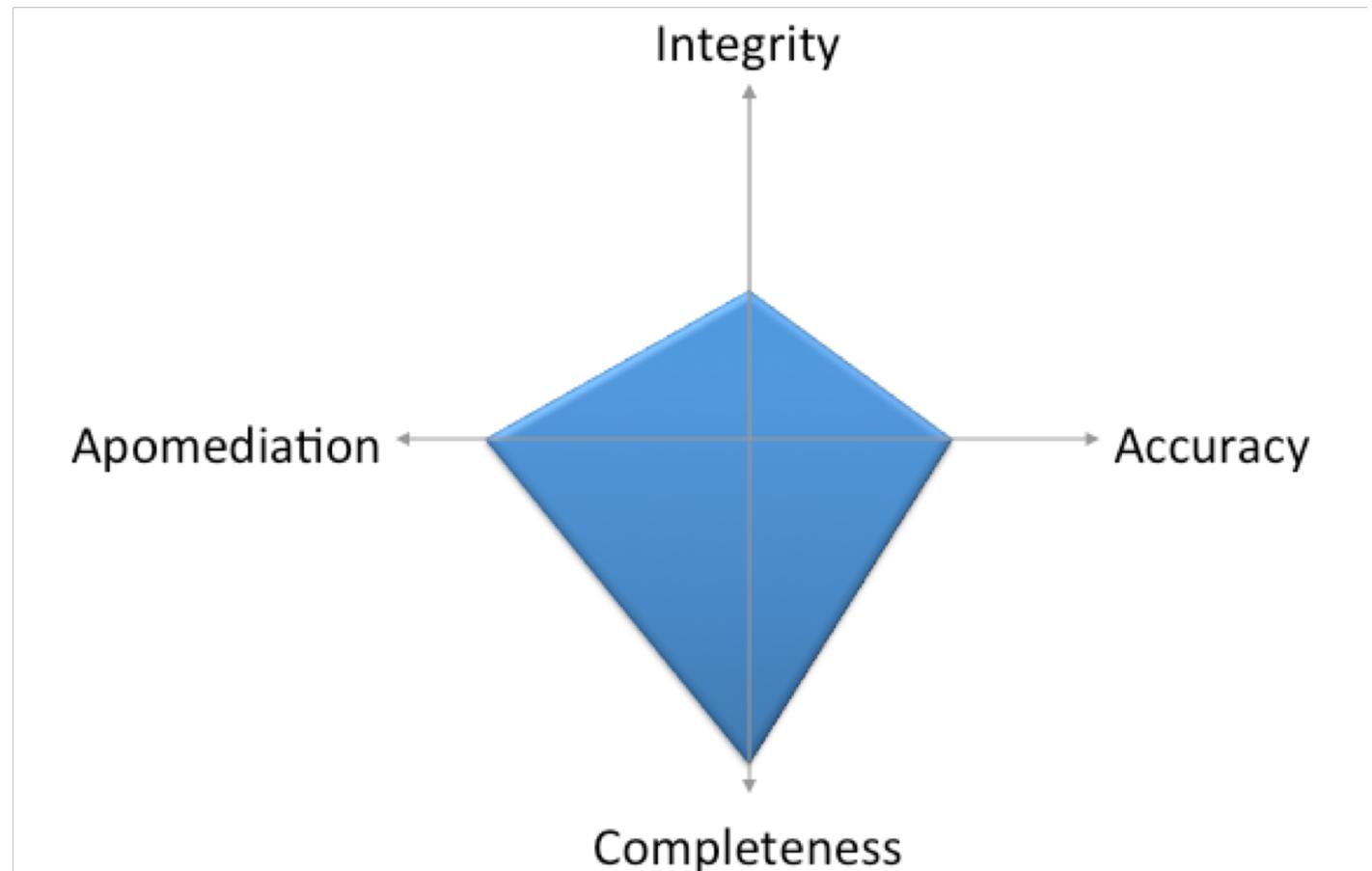
- The expectation of exchanging information/data/documents among different providers/systems
- Dimension →
  1. Standard adoption



# COMPREHENSIVENESS

- Data/documents/information contained should be comprehensive to be used also by healthcare professionals in caring the patient

- **Dimensions**





## LEGAL VALUE

- Data/documents/information contained should be legally valid to be used also by healthcare professionals in caring the patient.
- **Dimensions** →
  1. **Privacy** (patients consent is needed to make information available to healthcare professionals)
  2. **Confidentiality** (information should be protected by unwanted access)
  3. **Auditability** (the system should provide tools to verify access/use of information)

# AVAILABILITY

- Expectation → information should be available at the right place and at the right time

- Dimensions

1. Access policies and user profiles

