

Università degli Studi di Trieste

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



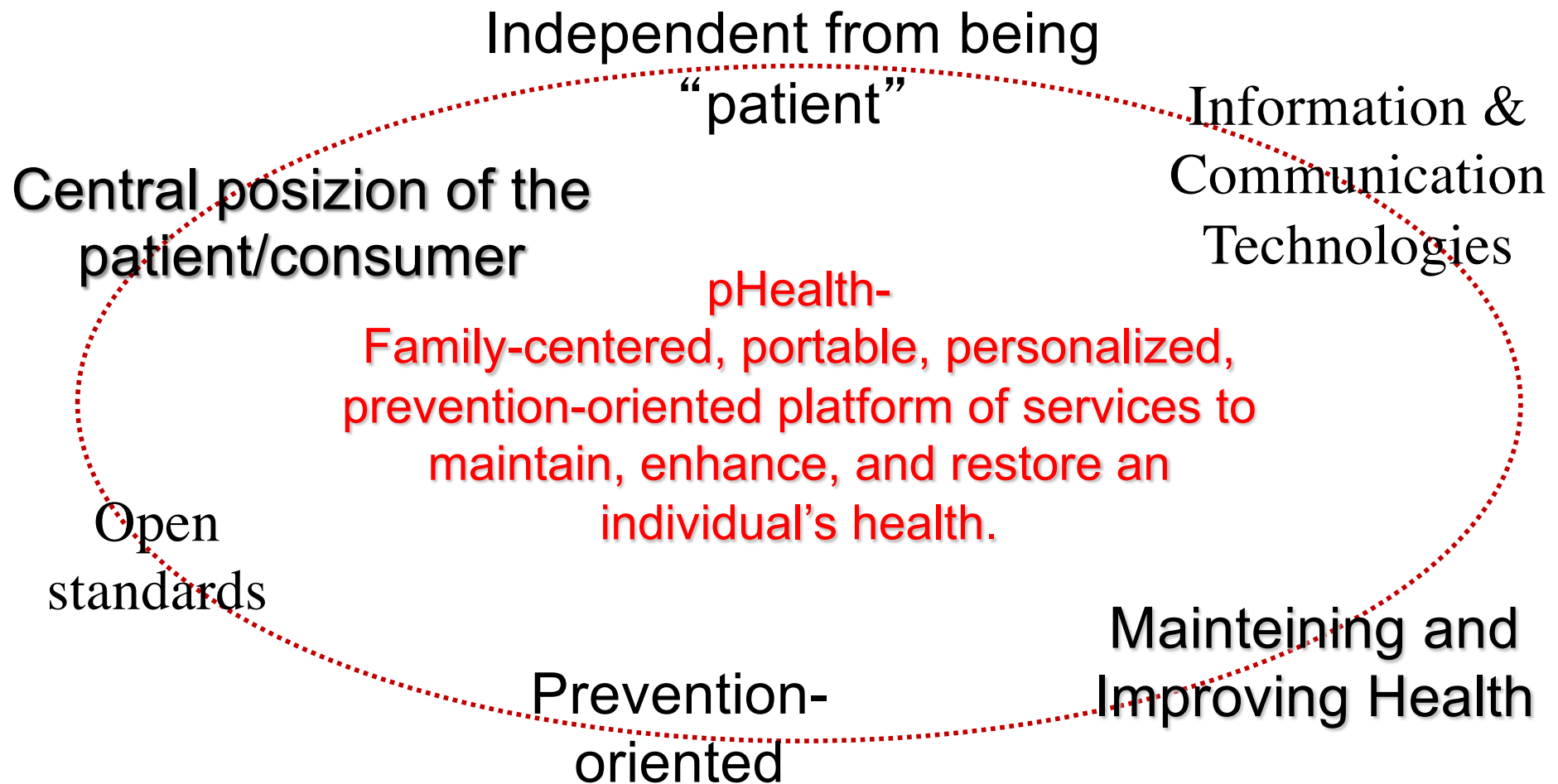
“the PATIENT is the most underused resource in the healthcare delivery system” [Slack W, 2001]

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

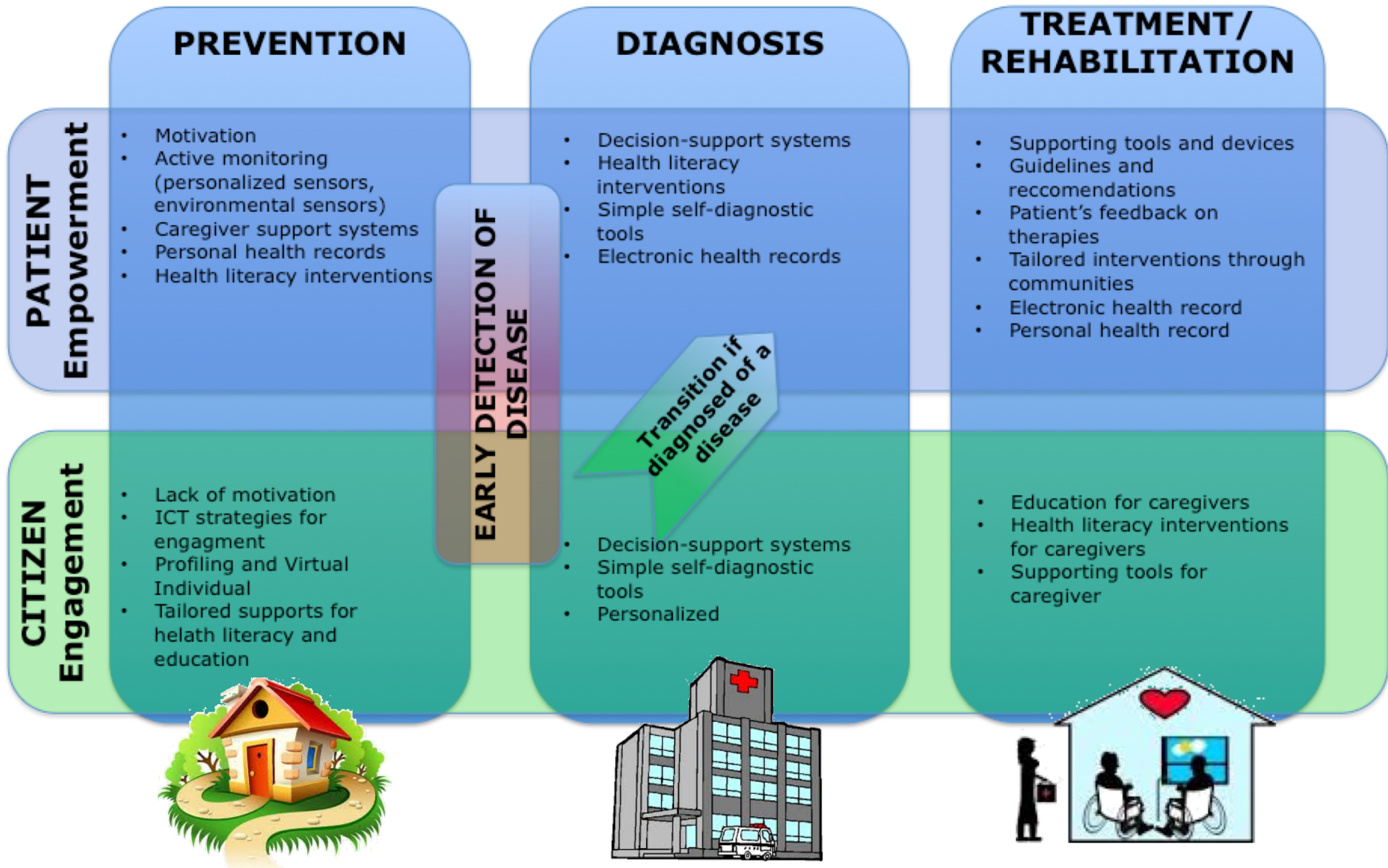
Cayton H. Better Information, Better choices, Better Health: Putting information at the centre of health. UK DoH Dec 16th, 2004

“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**

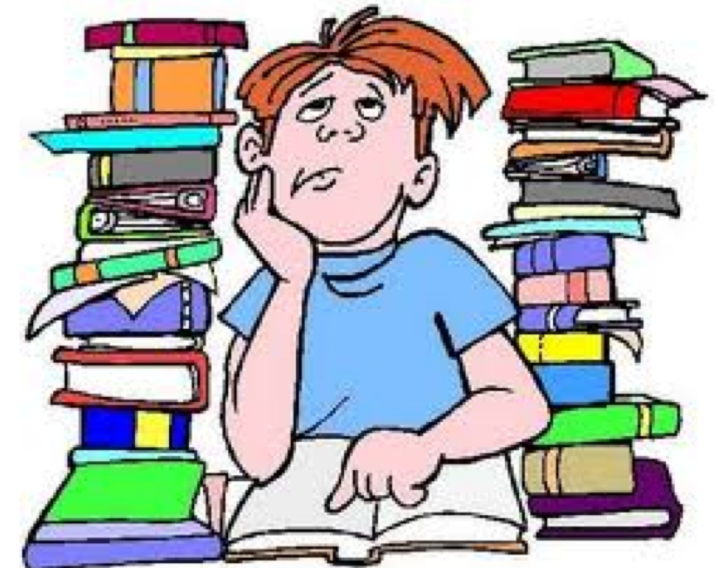


- Access health-related information
- Manage health-related information



**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

[Home](#) [Current Issue](#) [All Issues](#) [Online First](#) [Specialties & Topics](#) [CME](#) [Multim](#)

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

[< Previous Article](#)

Full Content is available to subscribers
[Subscribe/Learn More](#)

[Next Article >](#)

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

Home Current Issue All Issues Online First Collections CME Multimedia

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^{1,2}; Harlan M. Krumholz, MD, SM^{1,2}; Benjamin W. Moulton, JD, MPH³

[+] 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.

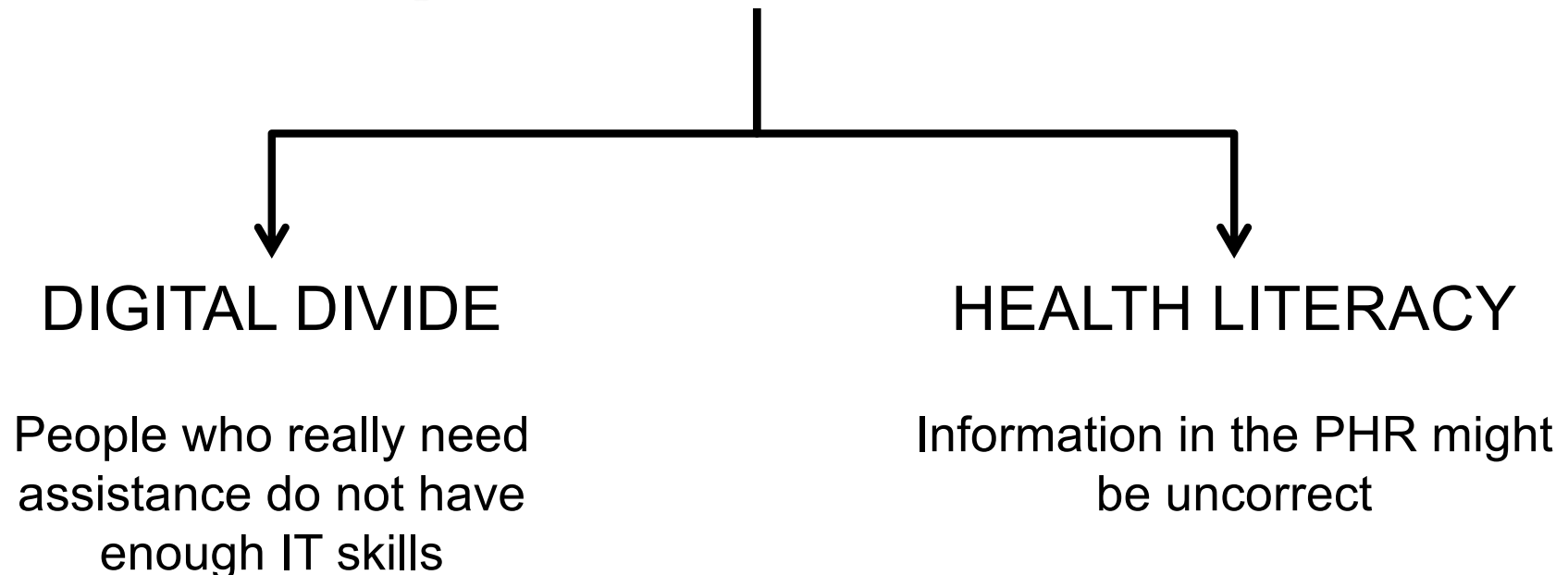
PERSONAL HEALTH RECORD

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



UNIVERSITÀ
DEGLI STUDI DI TRIESTE



**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)



twitter

REQUEST A PRESENTATION

FAQs

ABOUT US

CONTACT US

INCREASE TEXT SIZE

T+ T-



START A PHR

HEALTH LITERACY

TOOLS + RESOURCES

BLOG

RESOURCES FOR

SENIORS

PARENTS

CHRONICALLY ILL

CAREGIVERS

MILITARY FAMILIES

STUDENTS

ATHLETES

TRAVELERS

PHYSICIANS

featured story

ONCHIT Challenges You to Submit Your Video

Read More

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®

Microsoft

United States ▼ | help | sign in

track & manage

organize

get healthy

tools & devices

Search



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)



Find doctors & locations My profile Member assistance Español

Sign on

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

[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

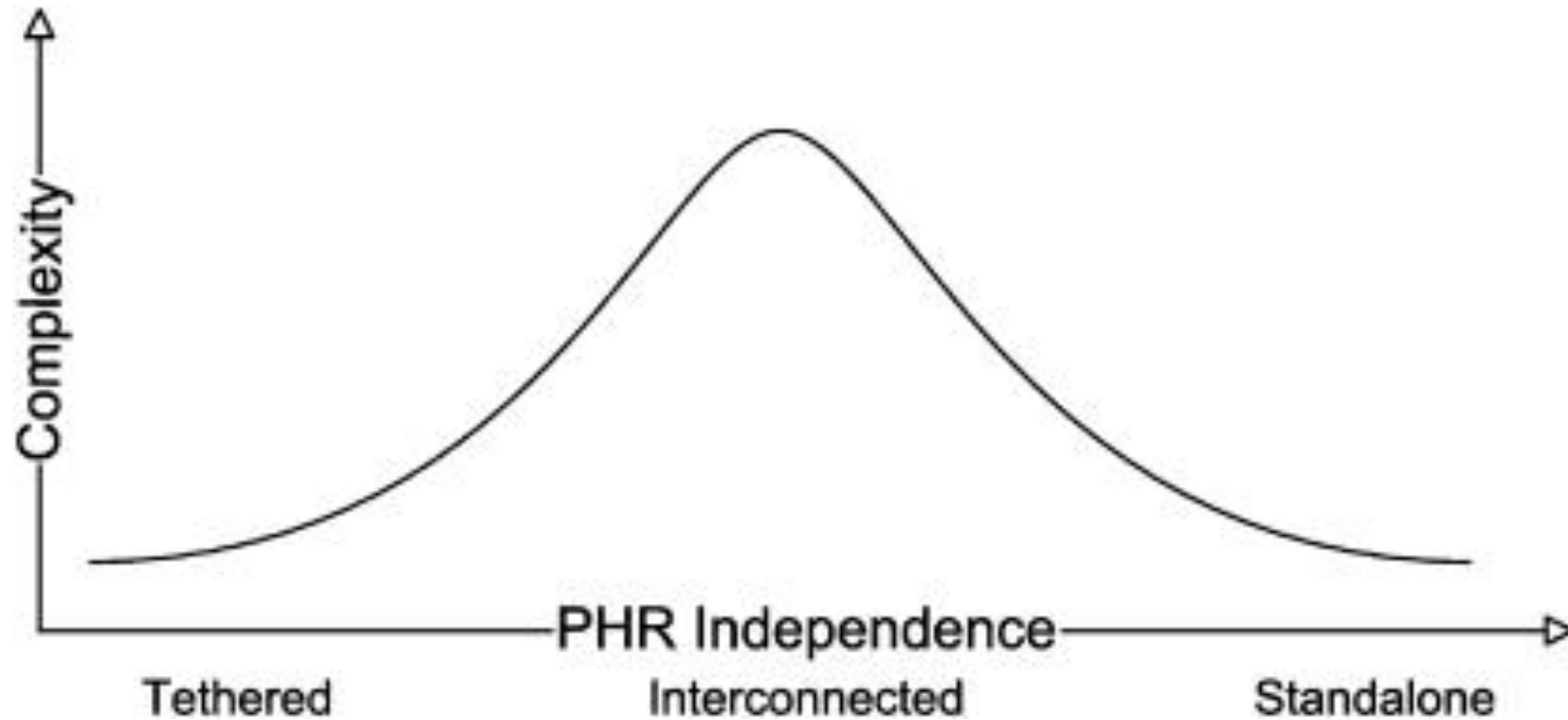


- [> Sex after hysterectomy](#)
- [> Top 10 diets review](#)
- [> 10 myths about stop smoking treatments](#)

[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 →

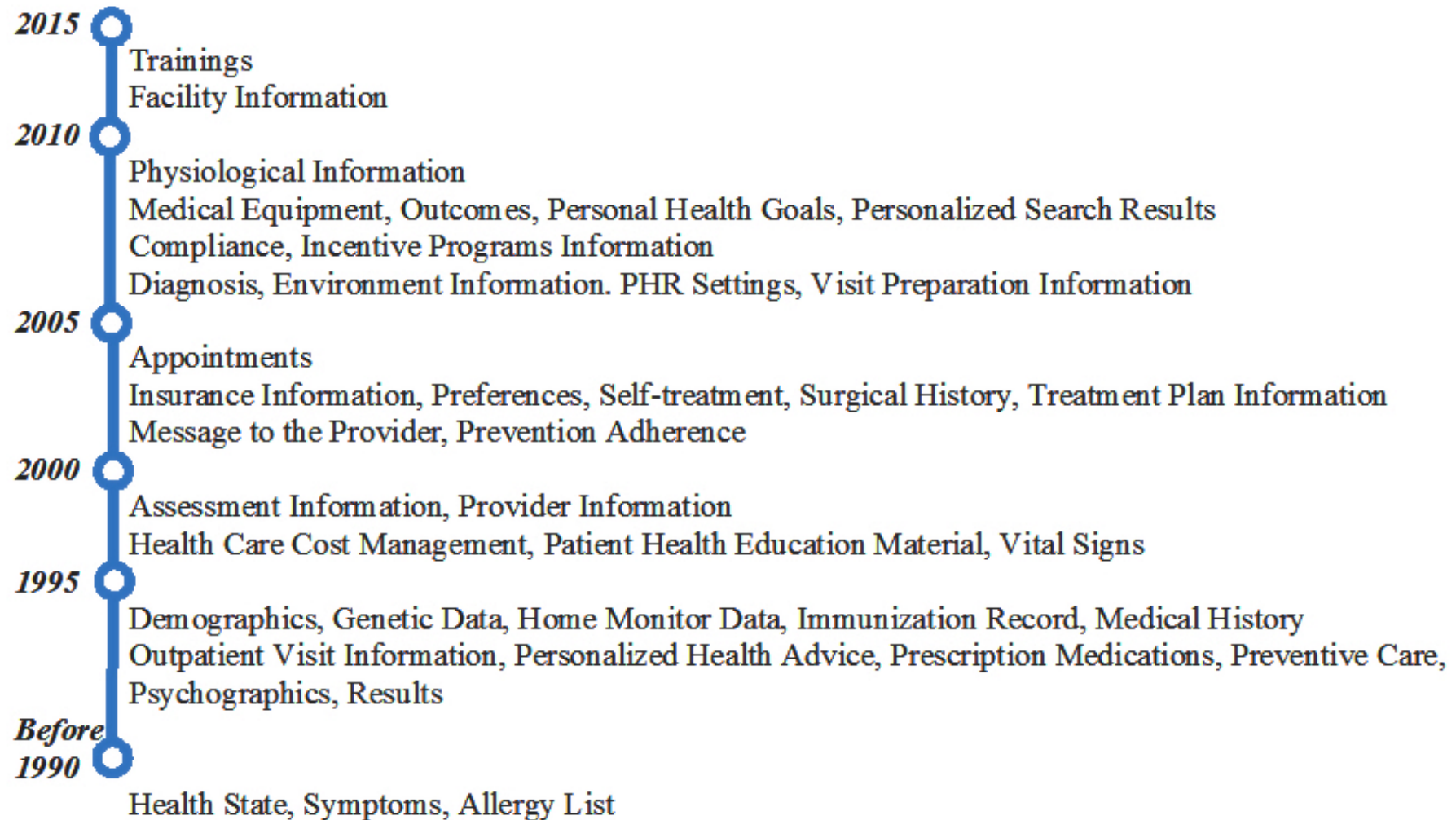
- book appointments
- reorder prescriptions
- communicate with healthcare professionals by email
- coordinate patient care between the physician's office, the hospital, radiology, the laboratory and the pharmacy
- authorize healthcare team members or caregivers can view, add, or update information
-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

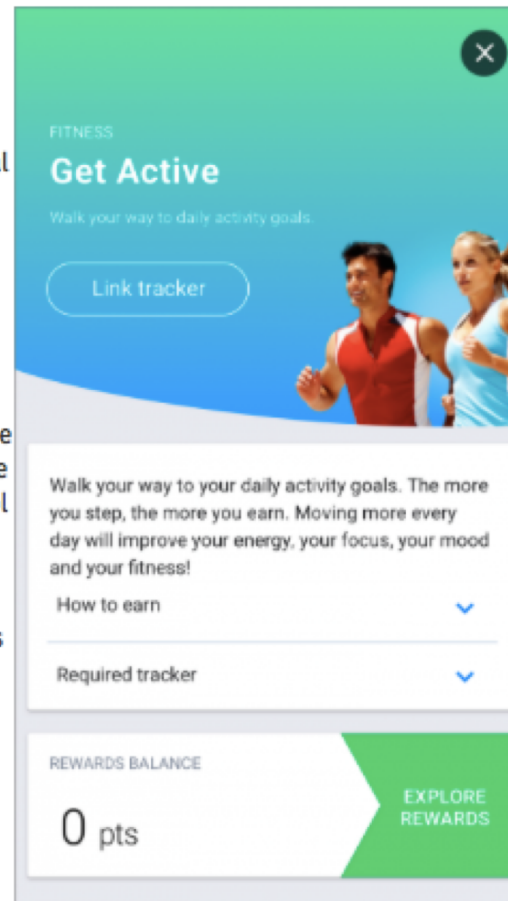


Anthem is launching a new comprehensive digital health platform for members nationwide. The platform, called Engage, comes out of the company's partnership with Castlight Health, **which began in 2015**. Going forward, it will serve as the foundation for the health plan's digital operations.

"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."



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%

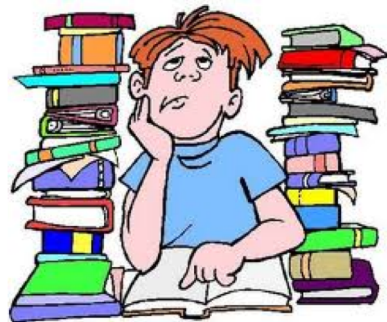
Load Family *iVisual* **Load Atlas**

ZoomOut Family Anatomical Part: Testa **ZoomOutAtlas**

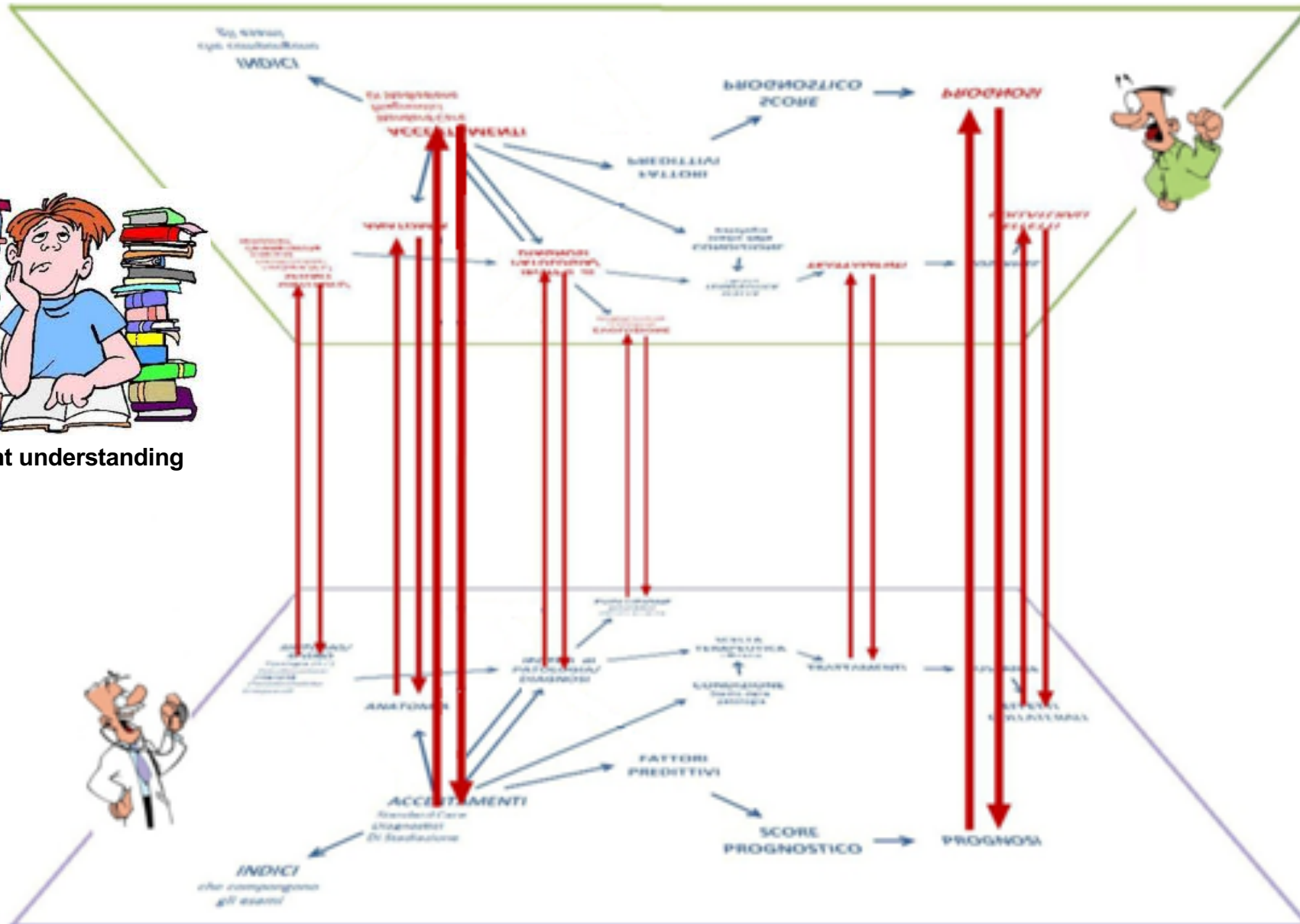
Name: Anna Bianchi
Event: Ascesso molare
Bioimage: CT_MAIN
Diagnosis:

Comparing personal bio-images with anatomical atlases

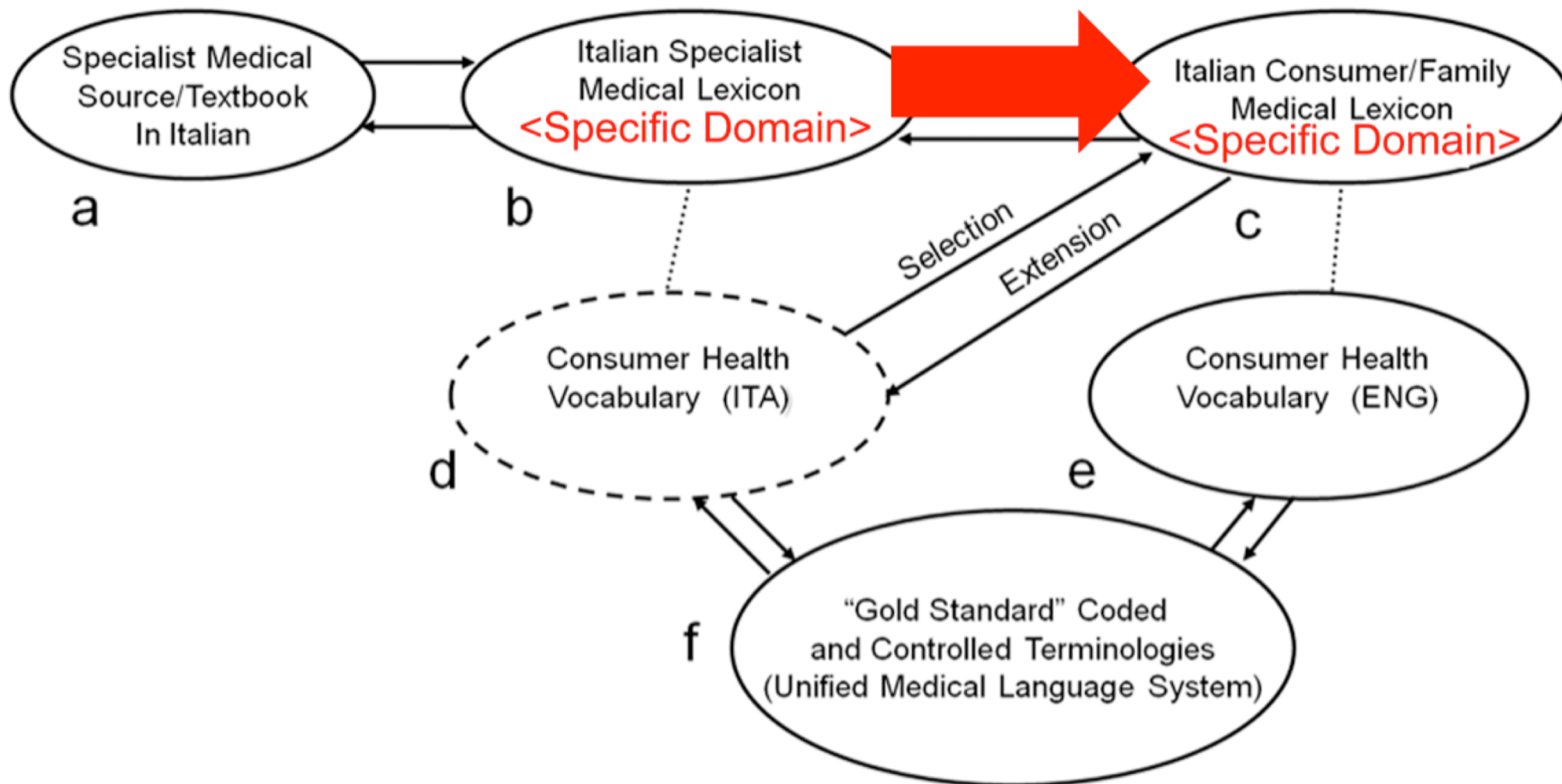
Medical ontologies for patients



Content understanding



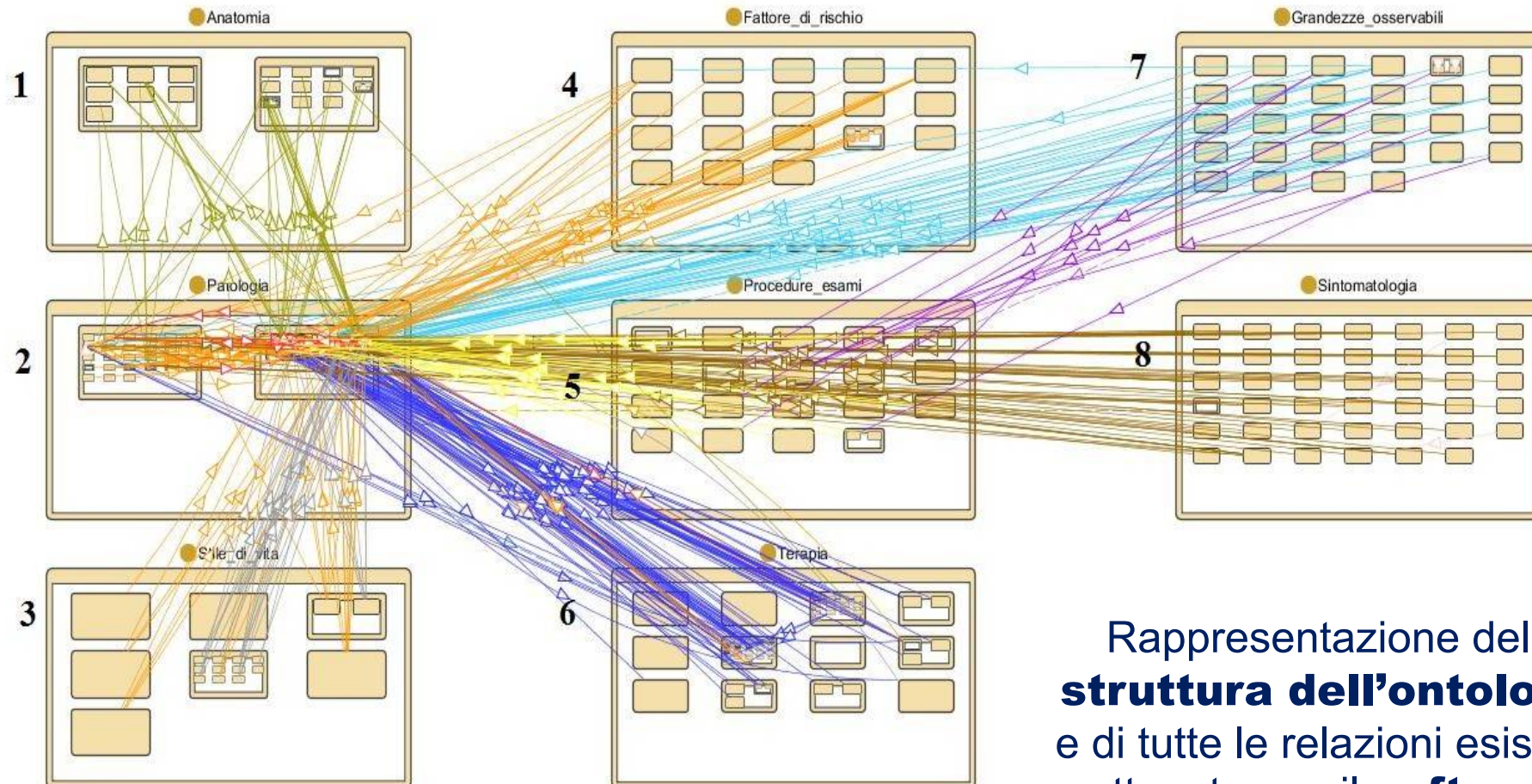
THE MODELING APPROACH TO LEXICON CONNECTERS



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

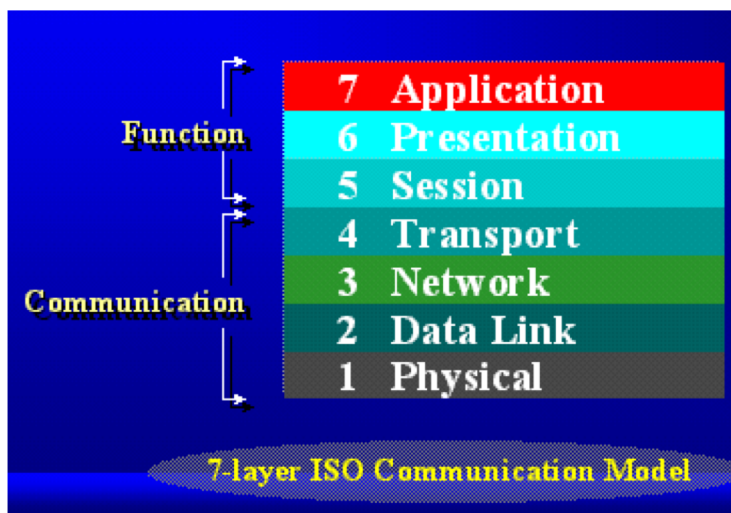


CHARACTERISTICS OF LIFELONG HEALTH RECORDS

Core Characteristics	Dimension
Interoperability	Standardization
Comprehensiveness	Integrity Accuracy Completeness Apomediation
Legal Value	Privacy Confidentiality Auditability
Availability	Accessibility

INTEROPERABILITY

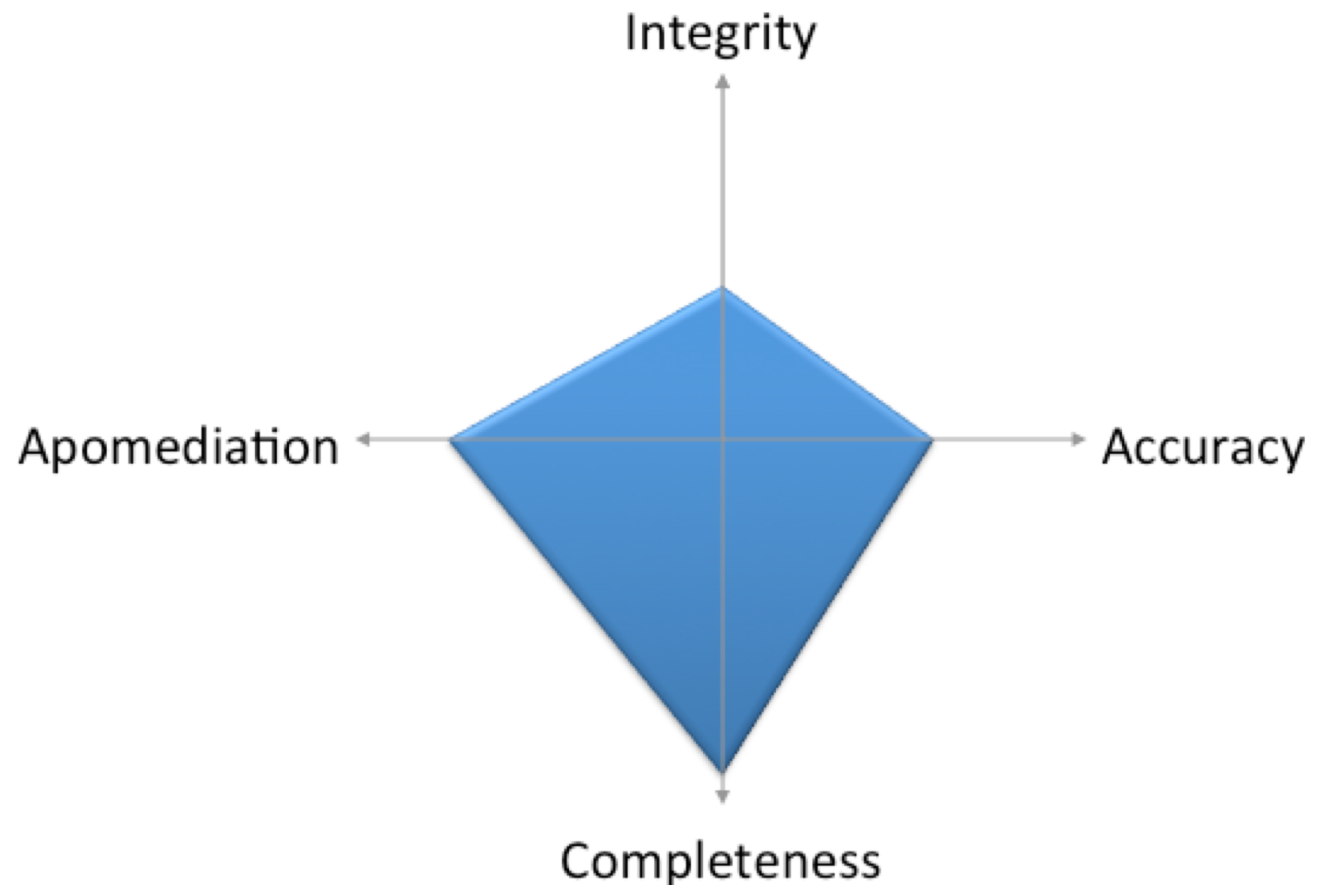
- The expectation of exchanging information/data/documents among different providers/systems
- Dimension →
 1. Standard adoption



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

