

Università degli Studi di Trieste

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Corso di Laurea Magistrale in  
INGEGNERIA CLINICA

# INFORMATICA MEDICA PERSONALIZZATA

Corso di Informatica Medica  
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**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



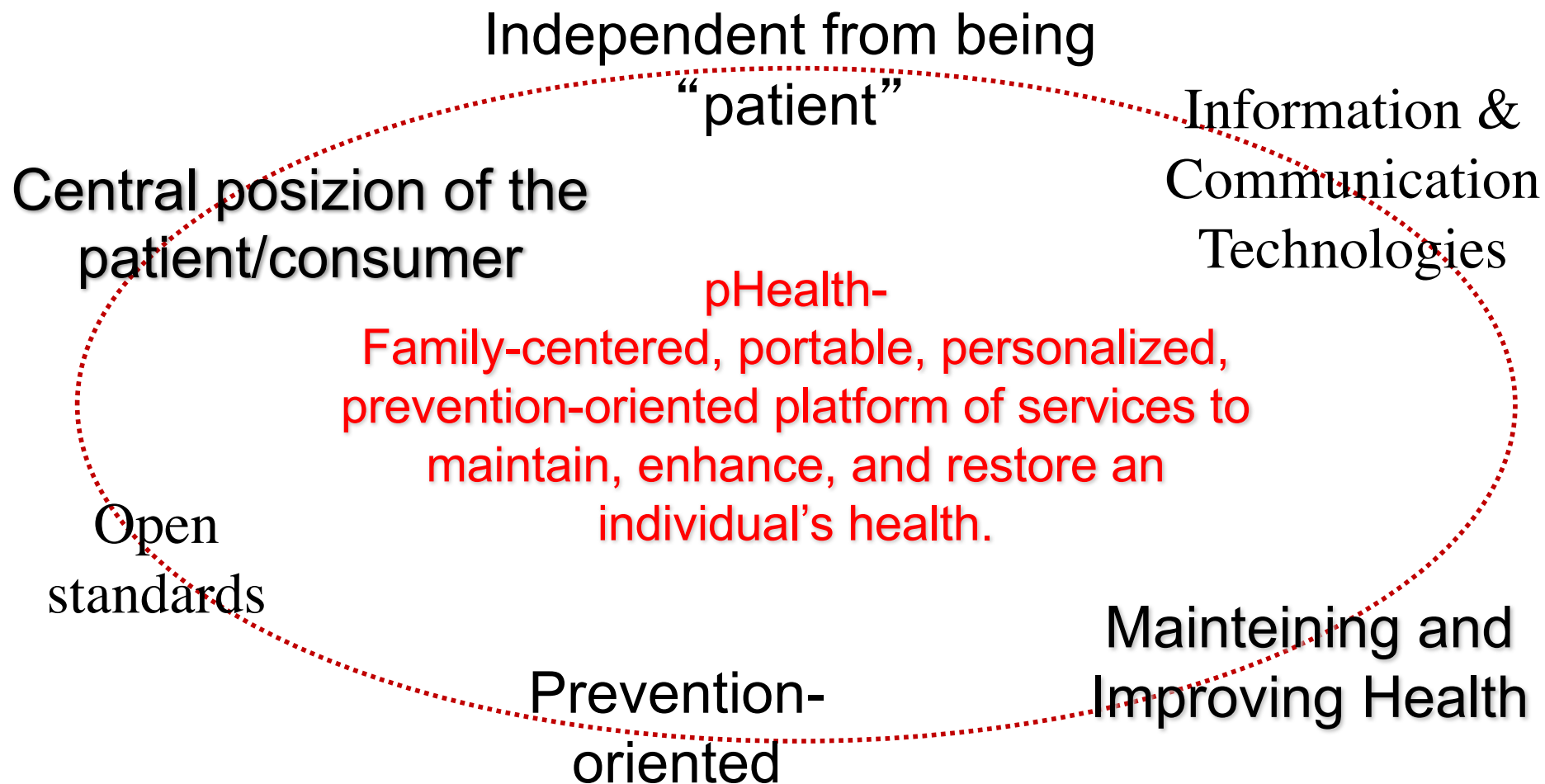
“the PATIENT is the most underused resource in the healthcare delivery system” [Slack W, 2001]

“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



# THE ACTIVE AND INFORMED PATIENT/CONSUMER



- **COMMUNICATES** with healthcare professionals → is able to establish an effective patient-physician interaction
- **ACCESS and MANAGES** health information and documents
- Has **HEALTHCARE KNOWLEDGE** → health literacy
- **MAKES DECISIONS** about personal health
- **SUPPORTS SELF-CARE** (also in the case of chronic illness)



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

# WHAT ACTIONS FOR THE ACTIVE PATIENTS?



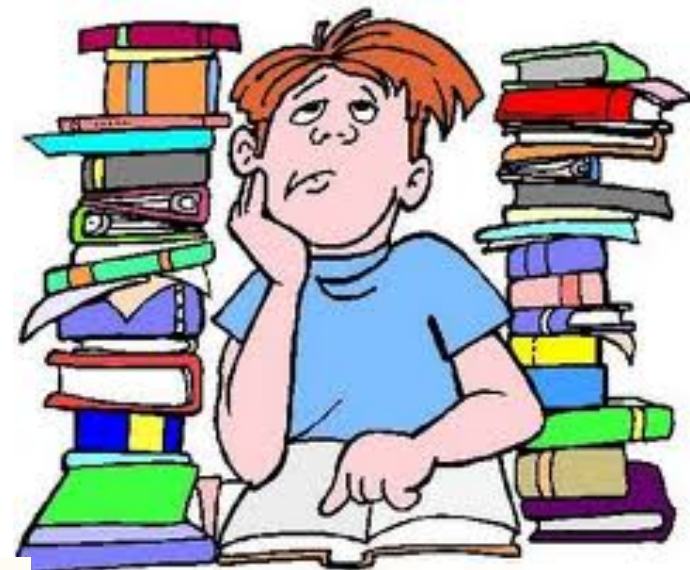
**Document  
archiving**



**Actions  
making**



**Content understanding**



**Decision  
making**



# 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 >

[< Previous Article](#)

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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

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<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.

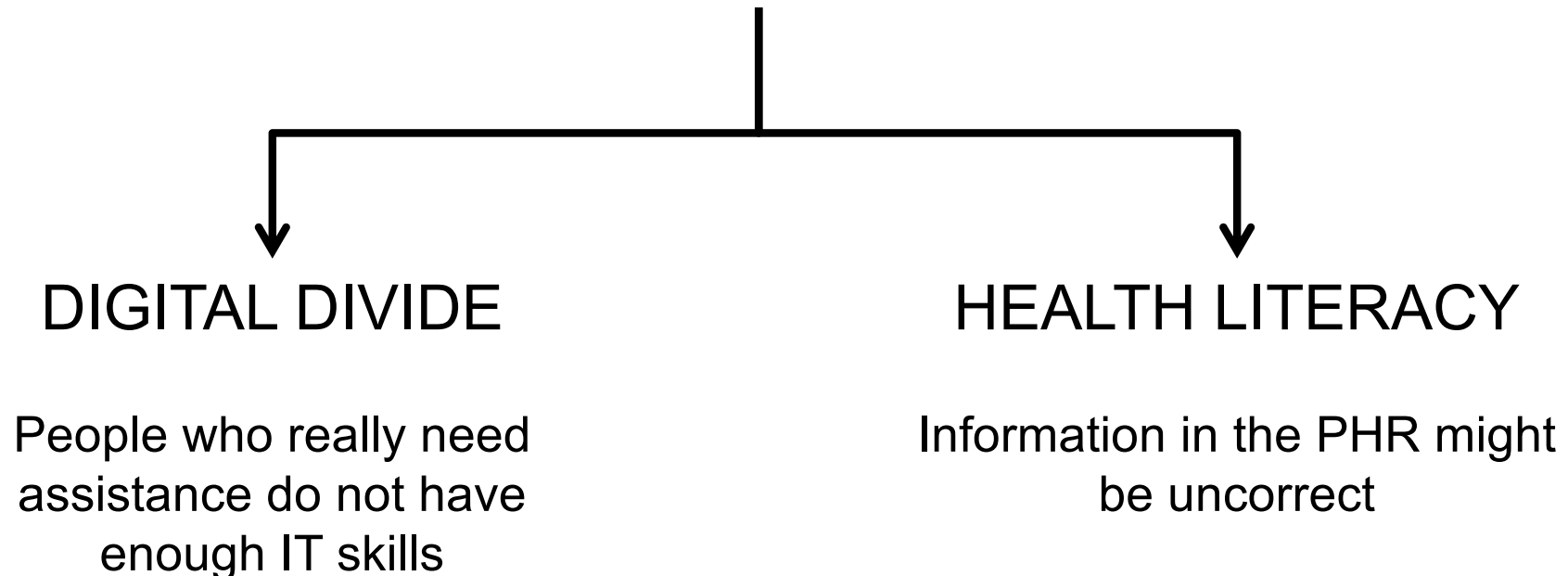
# PERSONAL HEALTH RECORD

# 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



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**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

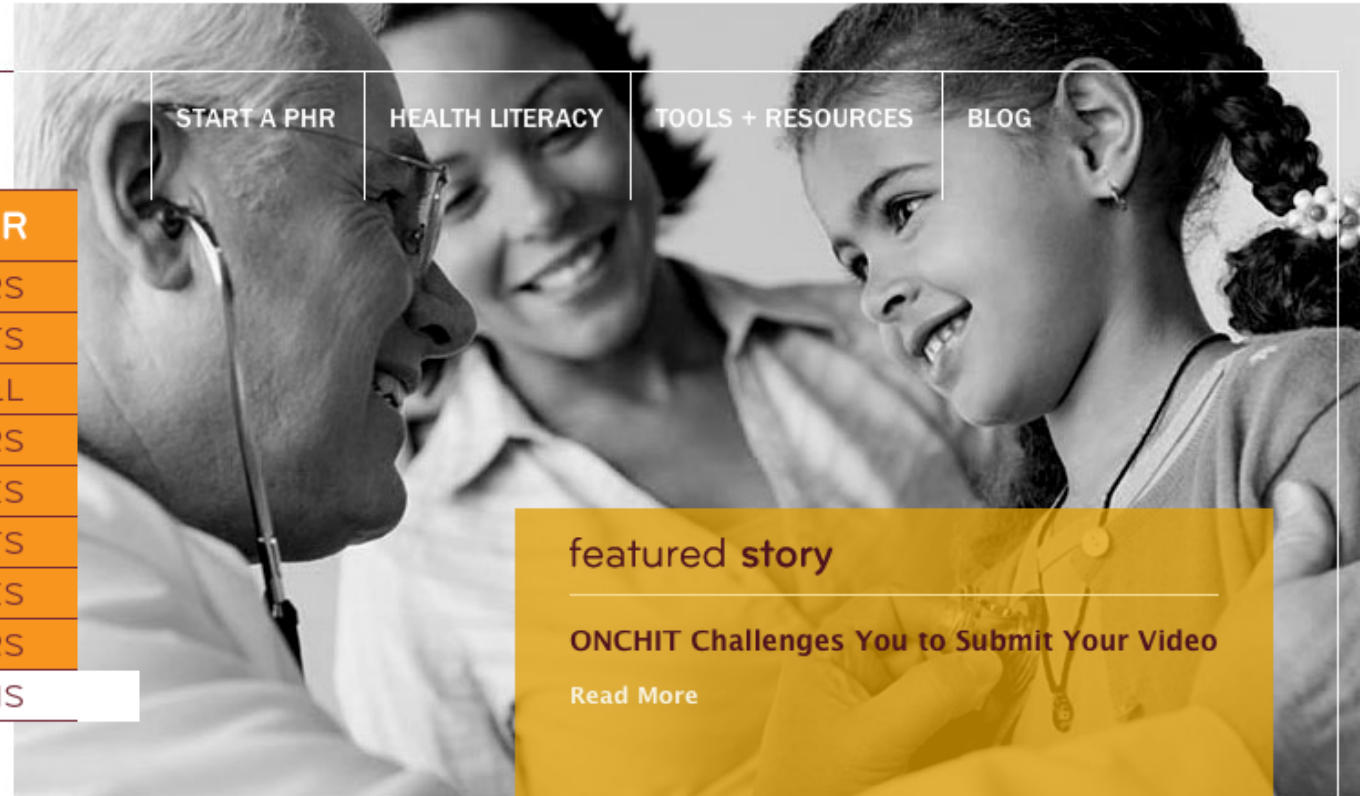
ABOUT US

CONTACT US

search

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



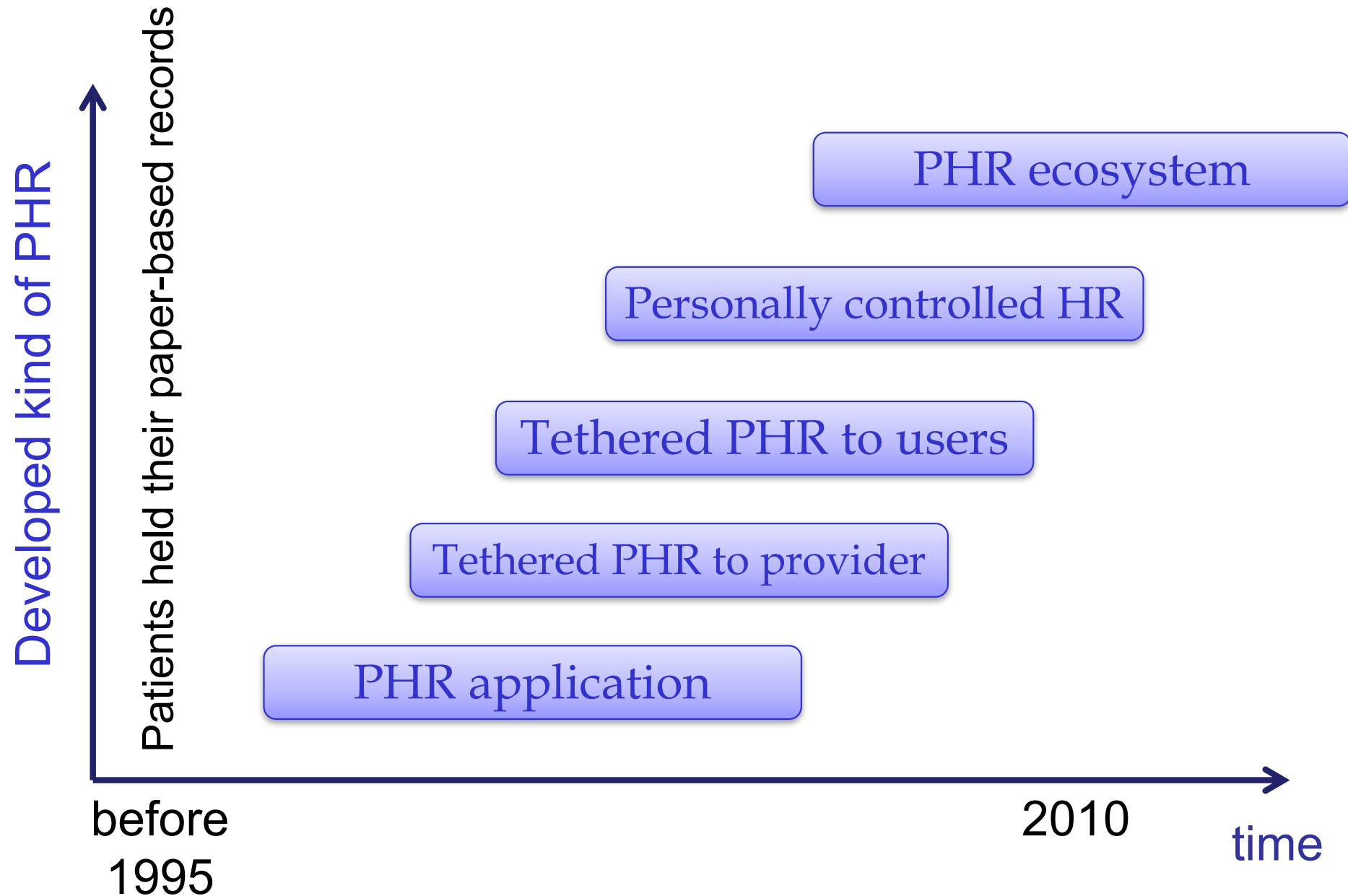
- > [Sex after hysterectomy](#)
- > [Top 10 diets review](#)
- > [10 myths about stop smoking treatments](#)

[More Live Well topics](#)

[Health A-Z](#)



# WHAT KIND OF PHR? (1)



# WHAT KIND OF PHR? (2)

## PHR APPLICATION

- transition to the vision of empowered patient
- experimental applications

## TETHERED PHR TO PROVIDER

- enhances the relationship between the provider and the patient
- aiming to fidelization

## TETHERED PHR TO USERS

- mainly from insurance: enhance the relationship insurer-subscriber
- Introduce rule engines to improve health (alerts, ...)

## PCHR – PERSONALLY CONTROLLED HEALTH RECORD

- unbinded to a healthcare provider, but are aimed to enhance the relationship to people
- introduces the problem of data standards

## PHR ECOSYSTEM

- more than simple applications
- aggregator PHR

# WHAT KIND OF INFORMATION CAN BE INCLUDED?



## CLINICAL DATA AND DOCUMENTS →

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

## 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, and 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



## PHRs: CRITICAL ASPECTS

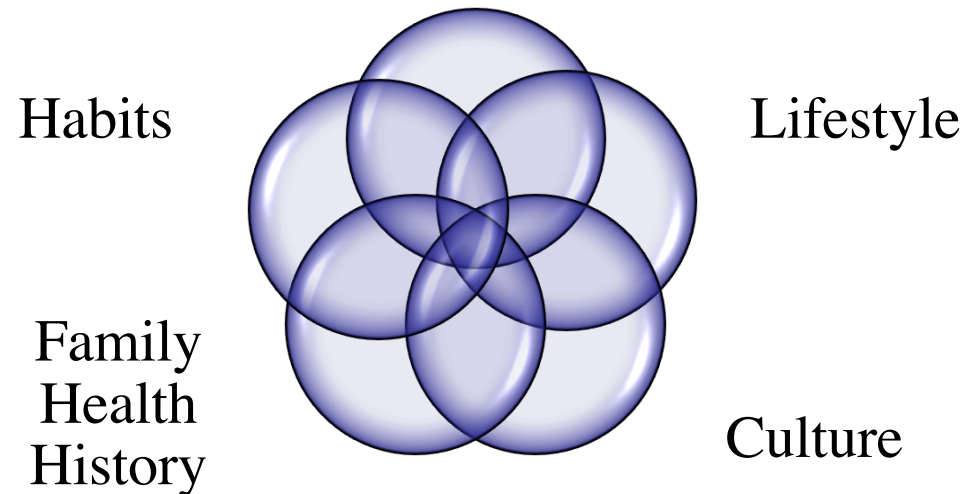
- **PERSONAL HEALTH RECORD** → enabling technology for pHealth
- PHRs alone are not enough to “empower” patients
- **THREE CRITICAL ELEMENTS**
  - Accessibility of health information
  - eSkills
  - Health literacy

**HOW TO COMPLEMENT PHR TO EMPOWER PATIENTS?**

# THE FAMILY ENVIRONMENT

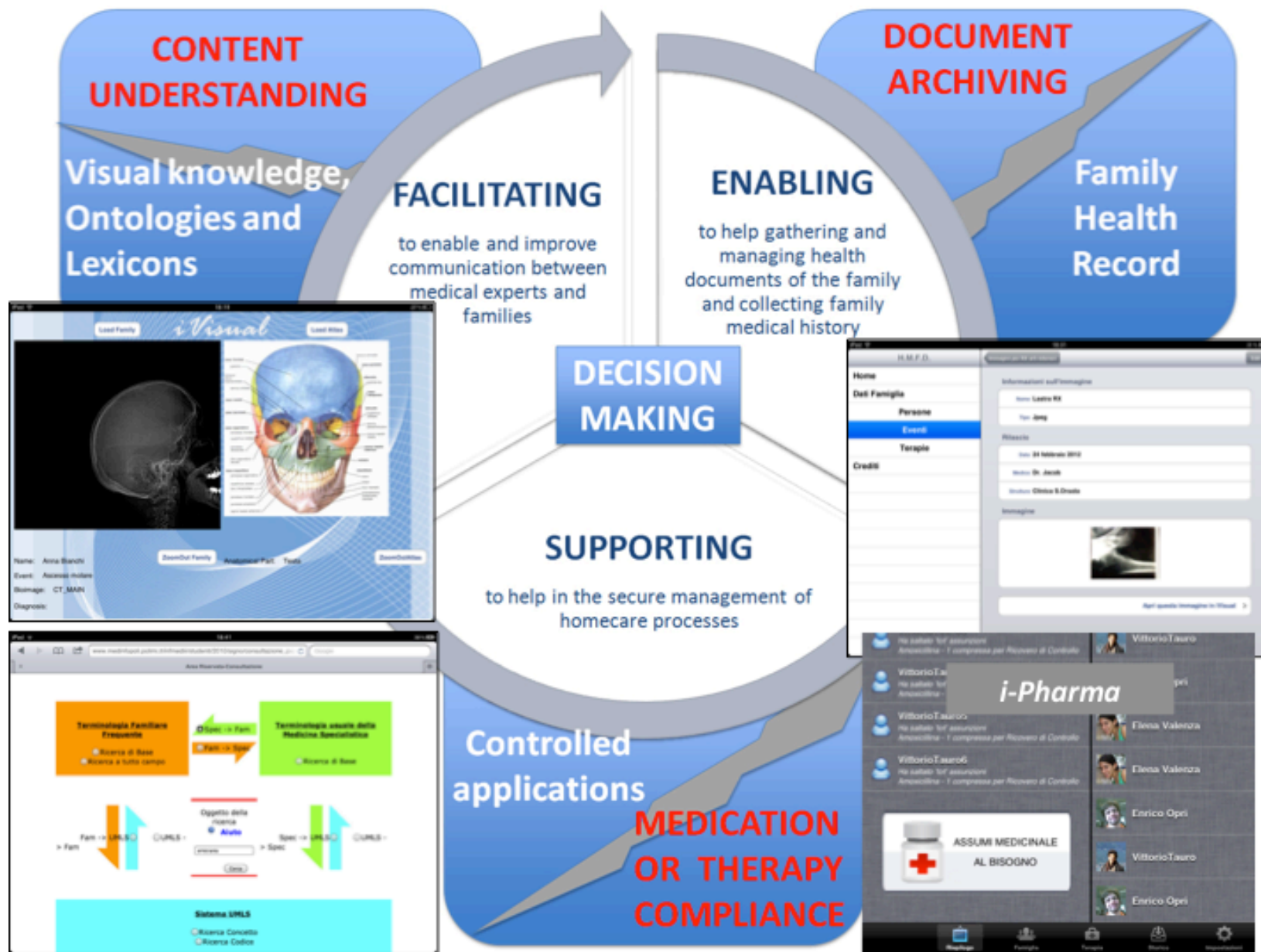


Context



- **Not** all the family members have **the same level of computer literacy or the same experiences** in healthcare
- Usually, in the family individual competencies and **experiences are shared** to globally increase “power”
- Usually, in the family environment **parents have the responsibility** of monitoring the health development of all their family members.

# A FAMILY PHR-BASED EMPOWERMENT APPROACH



# THE FAMILY HEALTH RECORD



1

HistoriaMedicaFamiliaeDigitalis

Edt

Informazioni Famiglia

Nome Famiglia: Bonacina

Indirizzo: Via Roma, 6

Città: Roma Provincia: RM CAP: 00100

Rodolfa Corti Luigi Bonacina Francesco Pincioli Marisa Bussandri

Stefano Bonacina Sara Marcegaglia

Simona Bonacina Lorenzo Bonacina Roberta Bonacina

2 Stefano Bonacina

Informazioni anagrafiche Anamnesi Fisiologica Anamnesi Patologica Eventi/Esami Terapie

Aggiungi Evento

07/03/2007 Titolo Evento: ECO APPARATO URINARIO COM

| Filename | Dimensione | Tipo |
|----------|------------|------|
|          |            |      |

| Codice | Etichetta | Data | Tipo Evento |
|--------|-----------|------|-------------|
|        |           |      |             |

3

Bonacina Stefano

SERVIZIO SANITARIO NAZIONALE REGIONE LOMBARDA

ECO APPARATO URINARIO COMPLETO

Conferma inserimento

HMFD - Historia  
Medica Familiae  
Digitalis

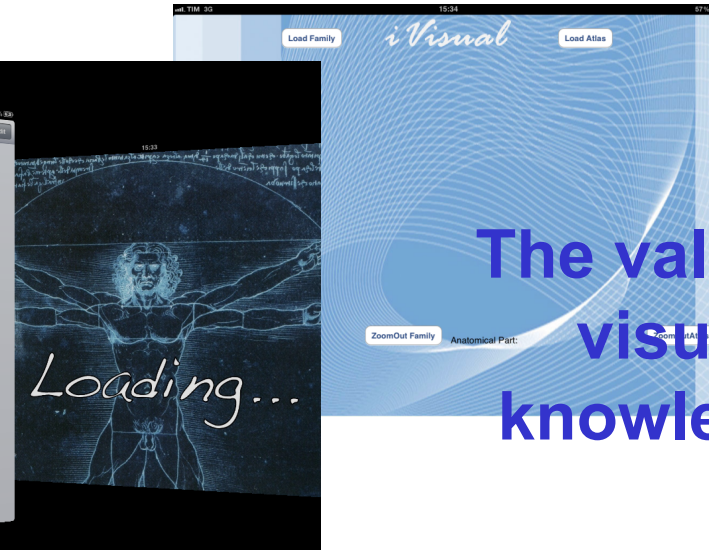
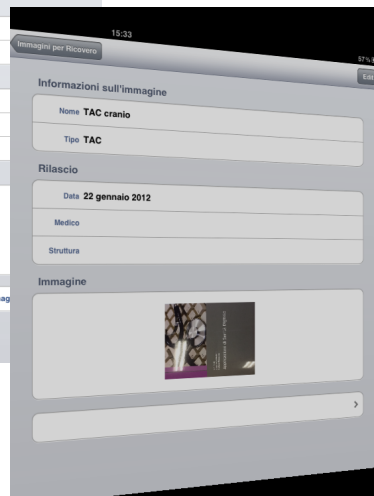
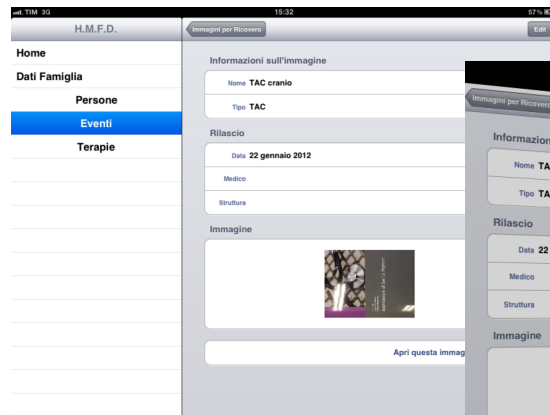
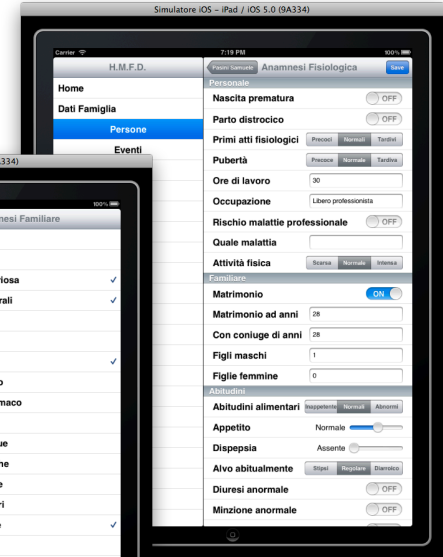
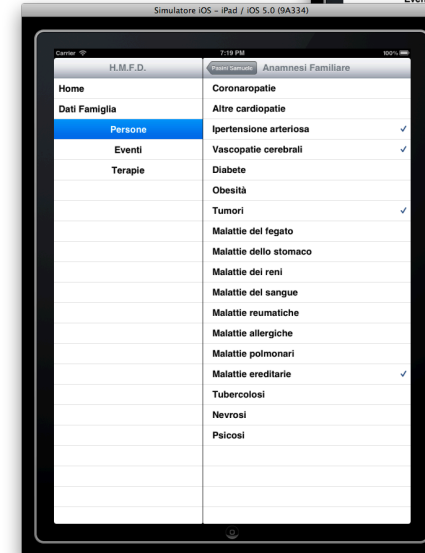
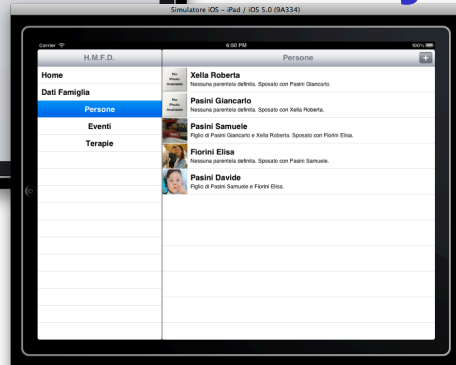
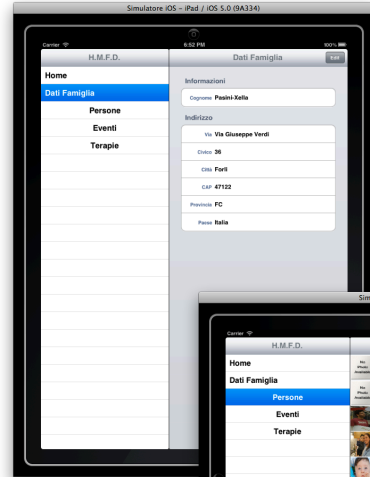




# H.M.F.D. for Tablets

## Family health data manager and family members

## Family history



## The value of visual knowledge

# FACILITATING TOOL: effective visualization of medical images



iPad 18:19 27%

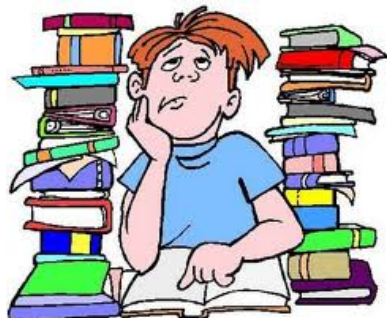
**Load Family** *iVisual* **Load Atlas**

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

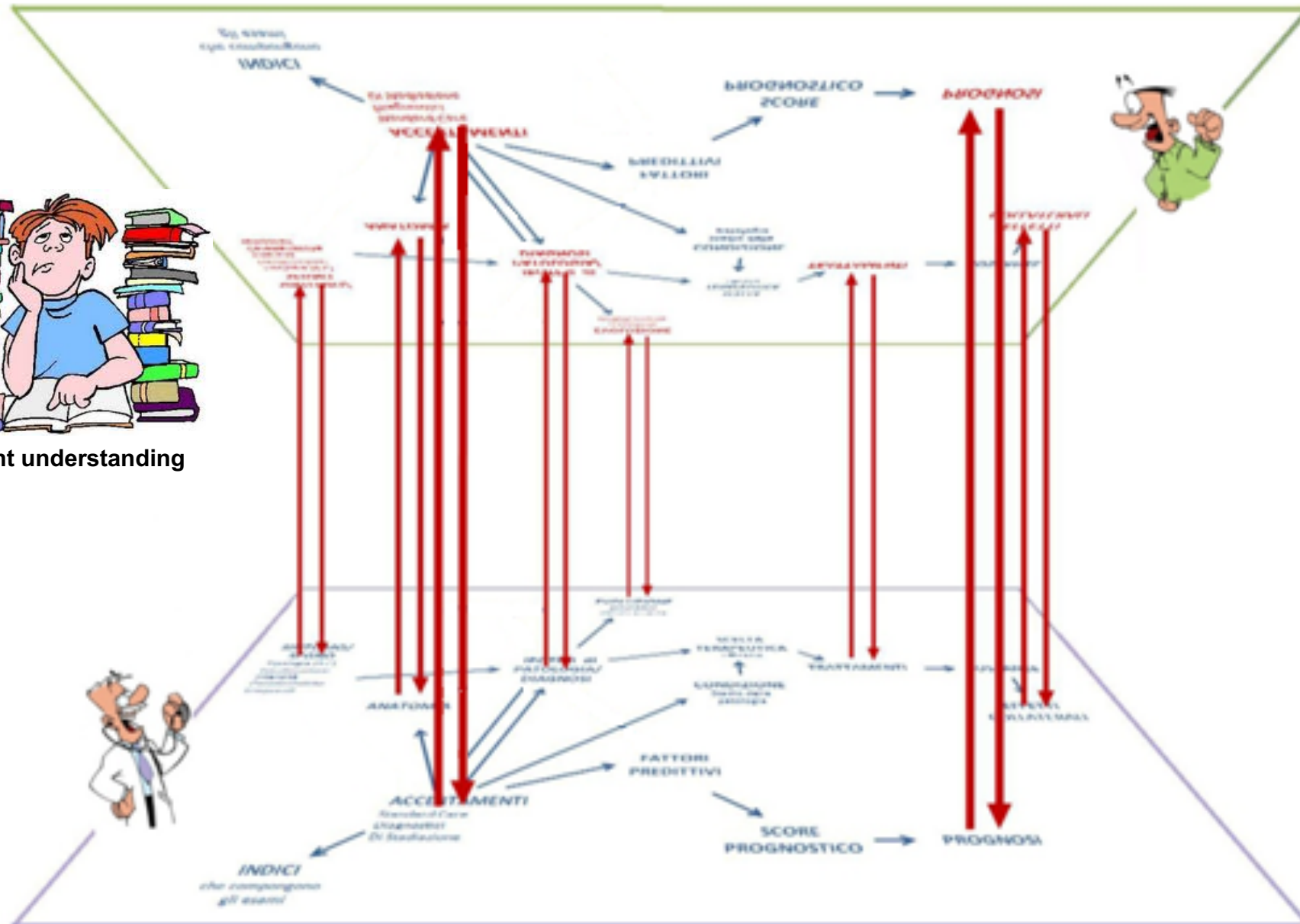
Name: Anna Bianchi  
Event: Ascesso molare  
Bioimage: CT\_MAIN  
Diagnosis:

## Comparing personal bio-images with anatomical atlases

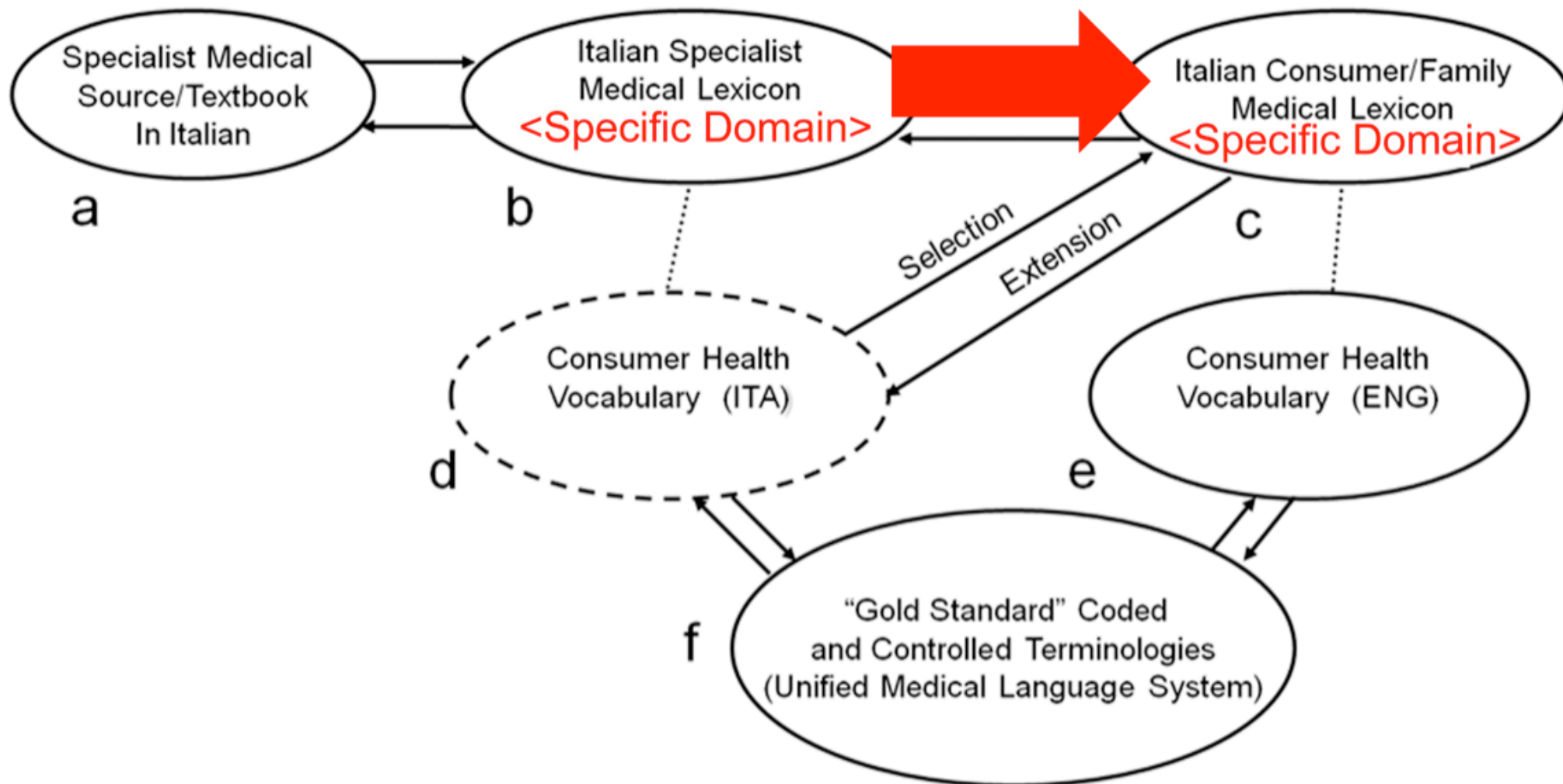
# FACILITATING TOOL: medical ontologies for patients



Content understanding



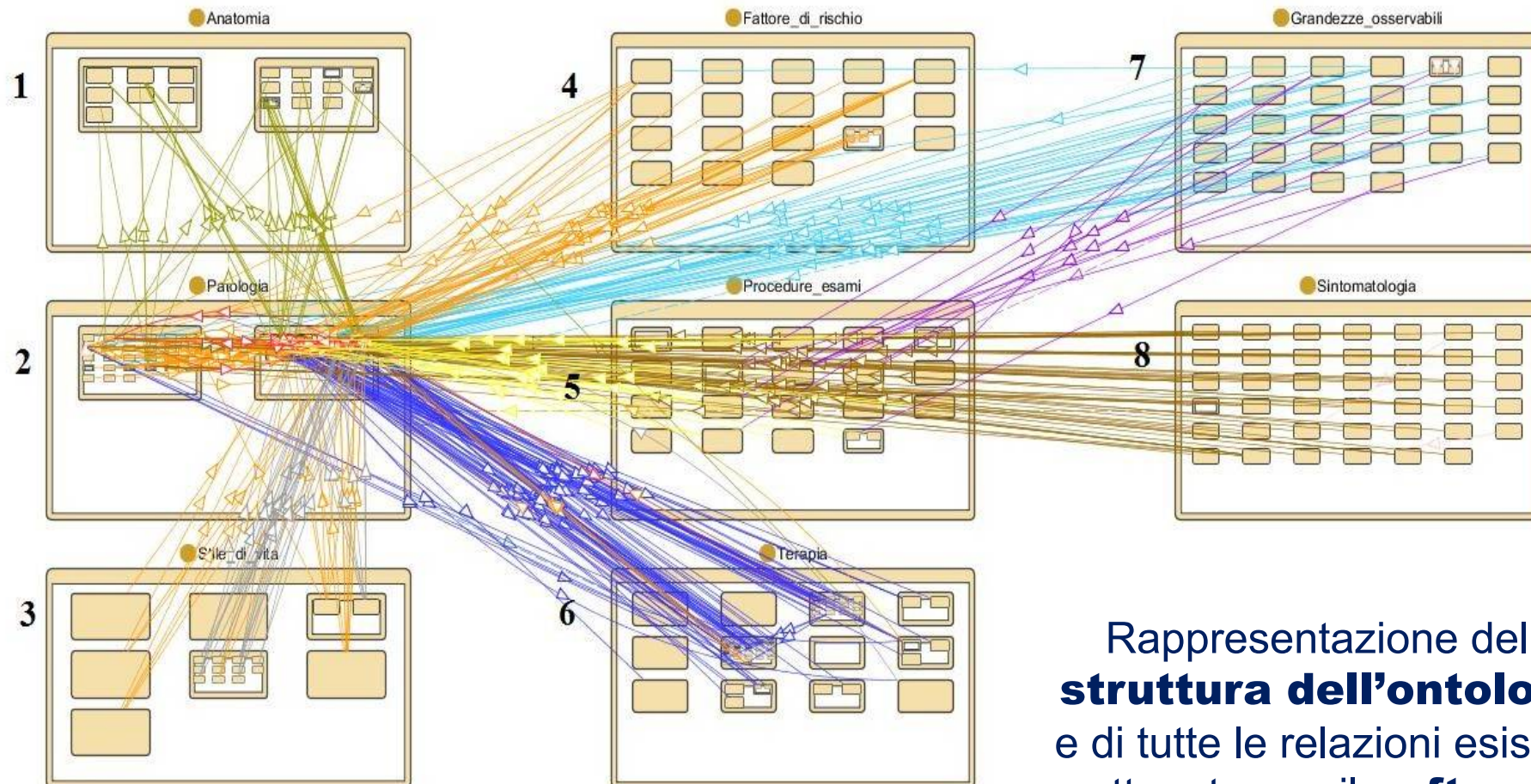
# THE MODELING APPROACH TO LEXICON CONNECTERS



# ESEMPIO: ONTOLOGY FOR CARDIOLOGY



owl:Thing



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

# ESEMPIO: ONTOLOGY FOR CARDIOLOGY



Firefox MedFam - Sezione dedicata al cittadino-...  
localhost:33390/Cittadino\_paziente/ricerca\_avanzata.cshtml

POLITECNICO DI MILANO  
DIPARTIMENTO DI BIOINGEGNERIA

Medical Lexicon Connector / Cardio  
Un connettore di lessici medici per il dominio cardiovascolare

sanità digitale  
Informatica BioMedica  
www.ehealth.polimi.it  
e-health Lab

Sezione dedicata al cittadino-paziente [Homepage](#) [Logout](#)

Clicca sul menù orizzontale qui di seguito per scegliere il tipo di ricerca desiderata.

Ricerca di base Ricerca relazioni **Ricerca avanzata** Descrizione servizio ↓

A seguito della compilazione del campo "OGGETTO DELLA RICERCA", è possibile:  
- ricercare i termini e le relazioni di tuo interesse cliccando su "Navigazione del dominio";  
- visualizzare le corrispondenze tra termini dei domini cliccando sulle frecce.  
Inoltre è possibile visualizzare tutti i termini appartenenti ad un dominio cliccando su "Visualizza i termini del dominio";  
per il lessico medico familiare inglese cliccando su "Vai al CHV" si aprirà il sito del Consumer Health Vocabulary.

**CONNETTORE TRA LESSICI MEDICI**

```
graph TD; A[LESSICO MEDICO FAMILIARE ITALIANO] <--> B[LESSICO MEDICO SPECIALISTICO ITALIANO]; C[LESSICO MEDICO FAMILIARE INGLESE] <--> D[LESSICO MEDICO SPECIALISTICO INGLESE]; A <--> C; B <--> D; S[OGGETTO DELLA RICERCA:];
```

Help

# SUPPORTING TOOL: SAFE DRUG ADMINISTRATION AT HOME



Step 1: the drug is taken in the Pharmacy

Step 2: automatic generation of the therapy schedule

Step 3: single administration event entered

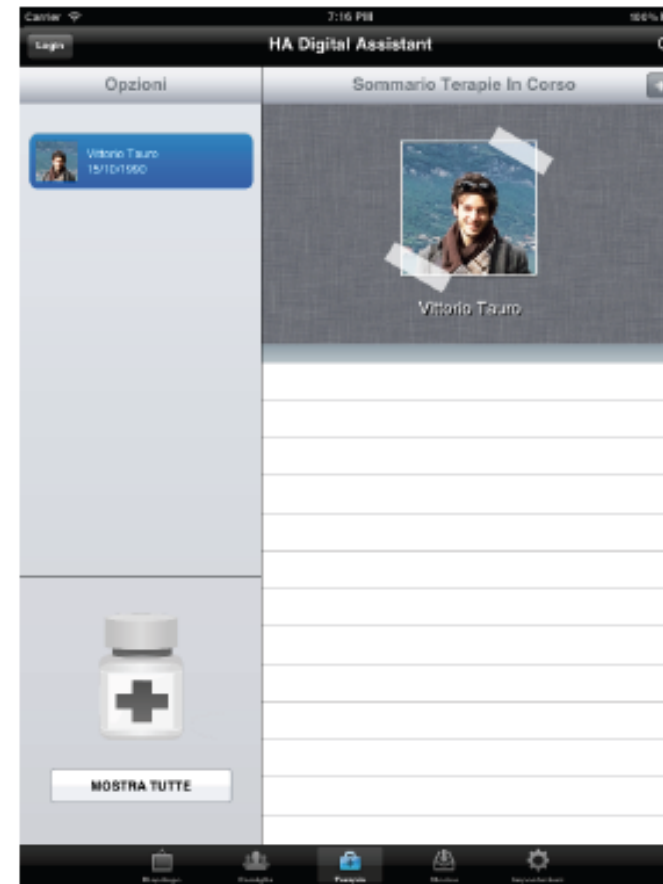
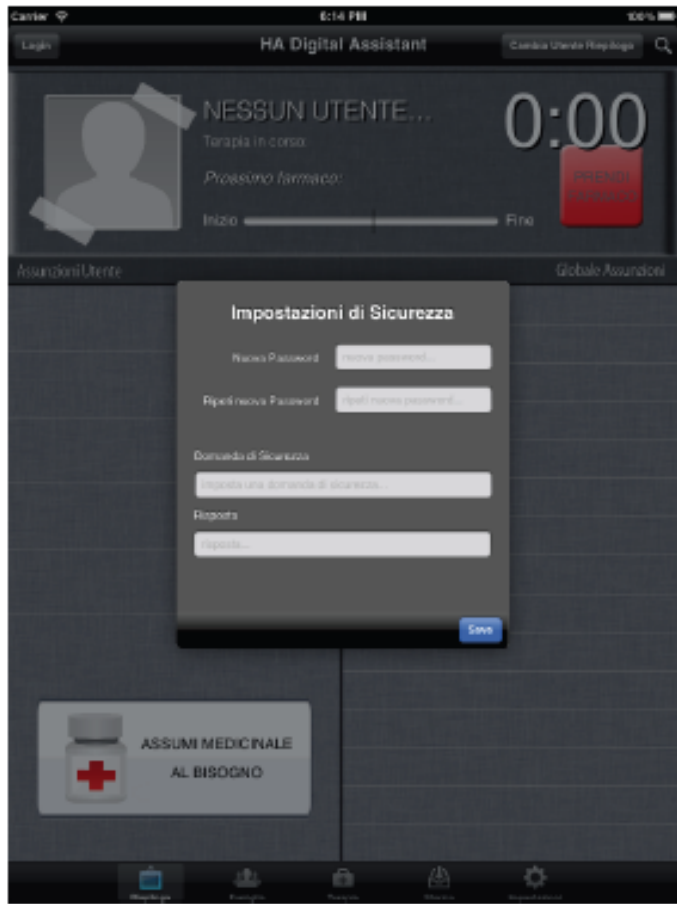
Step 4: checking of the administration process

- The application is managed by a family member caring for all the others
- The application is based on a complex data model to represent therapies, that are linked to the family health record
- The application contains the drug reference book and drug/drug interaction to check prescription information

Actions making



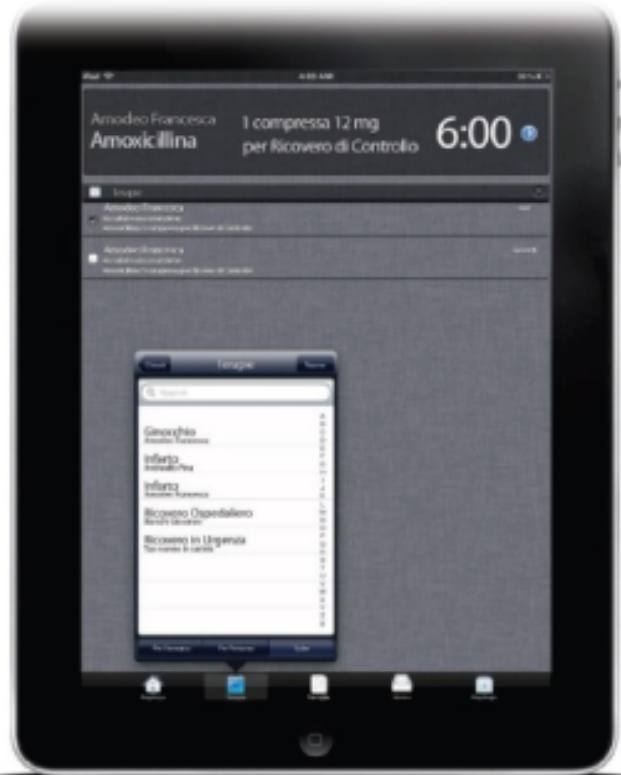
# THE iPHARMA PROTOTYPE



- Mobile application (iPhone/iPad) that can be linked to the mobile version of the family health record
- The use of mobile technologies increases the accessibility of healthcare information



# DRUG ADMINISTRATION AND HISTORY



When the time scheduled occurs, the system alerts you to take the medication

When the medication is taken, the history is updated

# “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

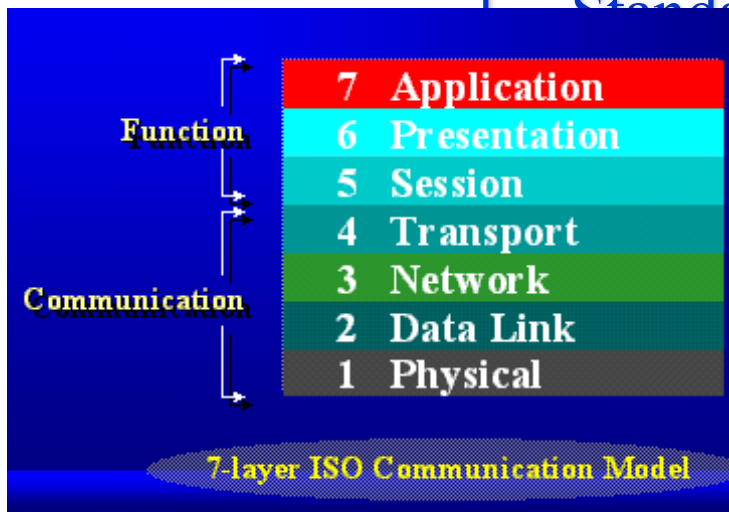


## CHARACTERISTICS OF LIFELONG HEALTH RECORDS

| Core Characteristics | Dimension   |
|----------------------|---|
| Interoperability     | Standardization                                       |
| Comprehensiveness    | Integrity<br>Accuracy<br>Completeness<br>Apomediation |
| Legal Value          | Privacy<br>Confidentiality<br>Auditability            |
| Availability         | Accessibility   |

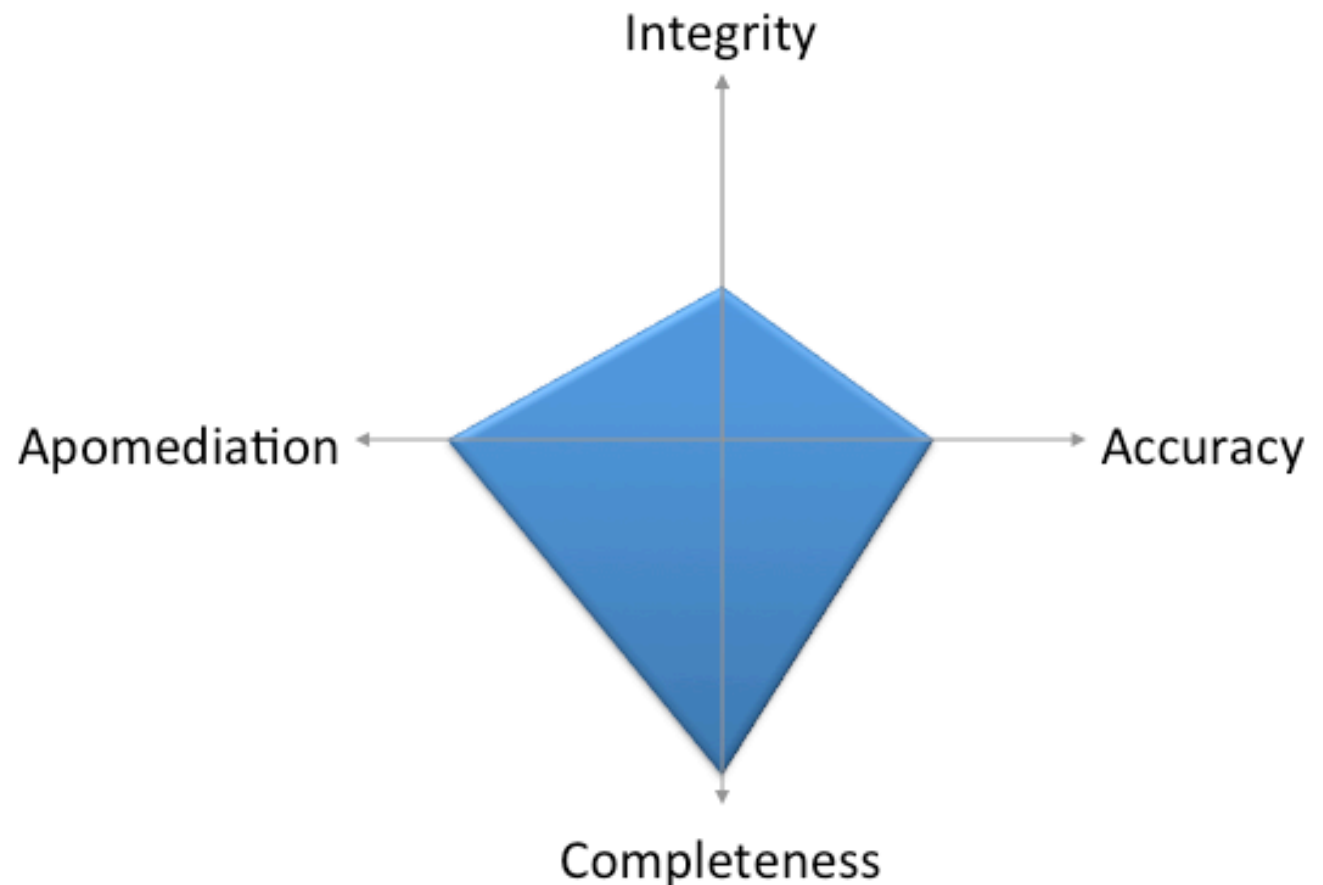
# INTEROPERABILITY

- The expectation of exchanging information/data/documents among different providers/systems
- Dimension →



# 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

