



**JUNE 7 - 12 • 2015 • TORONTO**  
**WORLD CONGRESS**  
ON MEDICAL PHYSICS & BIOMEDICAL ENGINEERING

SP169 - Self Engagement, Patient  
Empowerment and mHealth

# Empowering Patients through Information Technologies

**Eleni Kaldoudi**

Associate Professor, School of Medicine  
Democritus University of Thrace, Greece

[kaldoudi@med.duth.gr](mailto:kaldoudi@med.duth.gr)

# patient empowerment

a process where

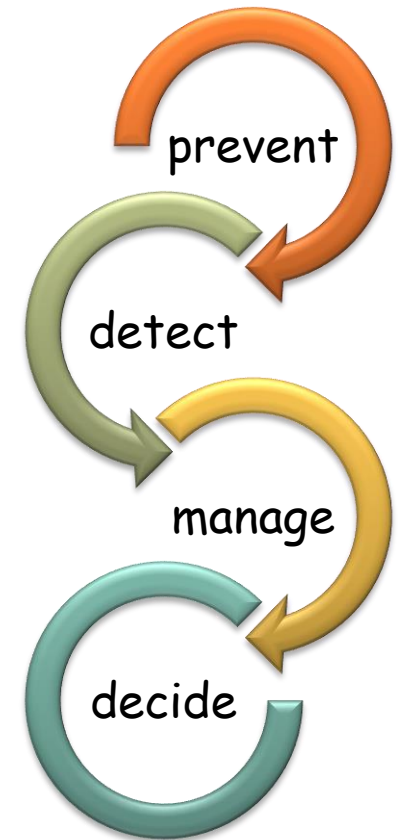
patients are encouraged to **think critically** and **act autonomously**

promotes **self-regulation**, **self-management** and **self-efficacy**  
in order to achieve maximum health and wellness

**empowerment:** a process by which people, organizations, and communities  
**gain mastery over their affairs**

# “why” empower

- **sustain** good health and **prevent** health deterioration
  - ↳ lifestyle related disease, e.g. cancer, cardiovascular and respiratory chronic disease
- recognize **early signs** of disease
  - ↳ new disease or disease progression or transition to comorbid situation
- **manage** every day practical issues
  - ↳ manage a common, chronic, progressive, costly, health burden at home
- gain **control** and **co-decide** on treatment and disease management options



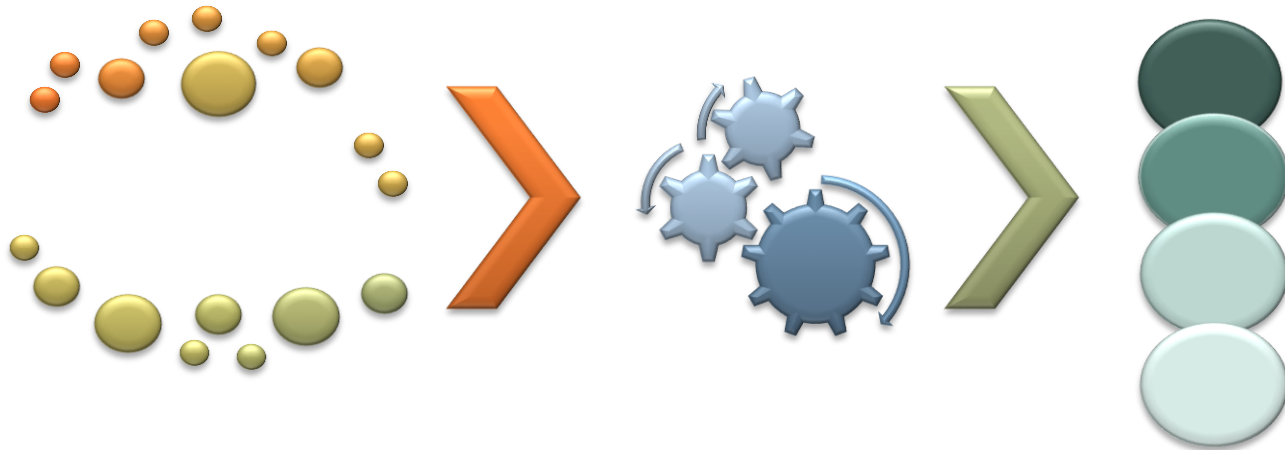
# “who” is to be empowered

- healthy citizens
  - ↳ to adopt and sustain a healthy lifestyle and detect disease early
- chronic patients
  - ↳ autonomously manage everyday practical issues
  - ↳ adhere to therapy and monitoring
  - ↳ detect disease progression and transition to comorbidities
- all patients
  - ↳ cope with disease
  - ↳ co-decide on treatment and disease management

also involved

- ↳ family and social environment: to cope and to be able to care
- ↳ healthcare providers: to be aware and support when needed

# “how”



# “how”



educational resources  
for patients



medical evidence



knowledge

quantified self



personal  
sensors



personal  
health  
records



intentions,  
plans,  
beliefs, etc.

data integration

analytics

semantics

predictive  
systems

decision support  
systems

web pages

social media

personal health  
applications

...

*so, we have a good grasp of...*

### the context

- ↳ **who:** healthy citizen, chronic patients, all patients, family, healthcare providers
- ↳ **why:** prevent, detect, manage, decide

### the process:

- ↳ **how:** educational content, medical evidence, sensors, personal health and other systems, data integration, semantics analytics, predictive systems, decision support systems, web technologies, mobile devices, smart phones, ...

*but, it is still unclear...*

### the content:

- ↳ **what** is to be designed and evaluated in a patient empowerment intervention

R. Bengoa,  
Regional Minister for Health and Consumer Affairs  
for the Basque Country of Spain (2012):

*“Suppose I am a patient:*

*I have 12,000 apps about chronic disease, access to my  
records and a battery of gadgets for home support.*

*Am I more empowered?”*

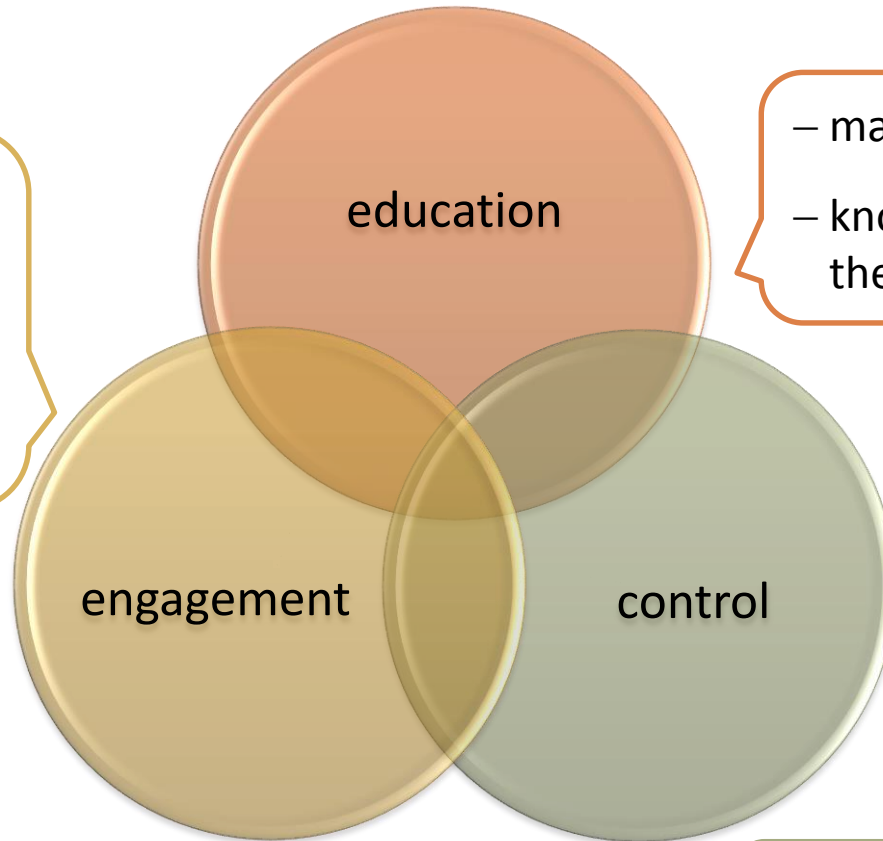
The WHO, Empowering Patients, 17-4-2012

<http://www.euro.who.int/en/what-we-do/health-topics/noncommunicable-diseases/sections/news/2012/4/empowering-patients>



# patient empowerment so far ...

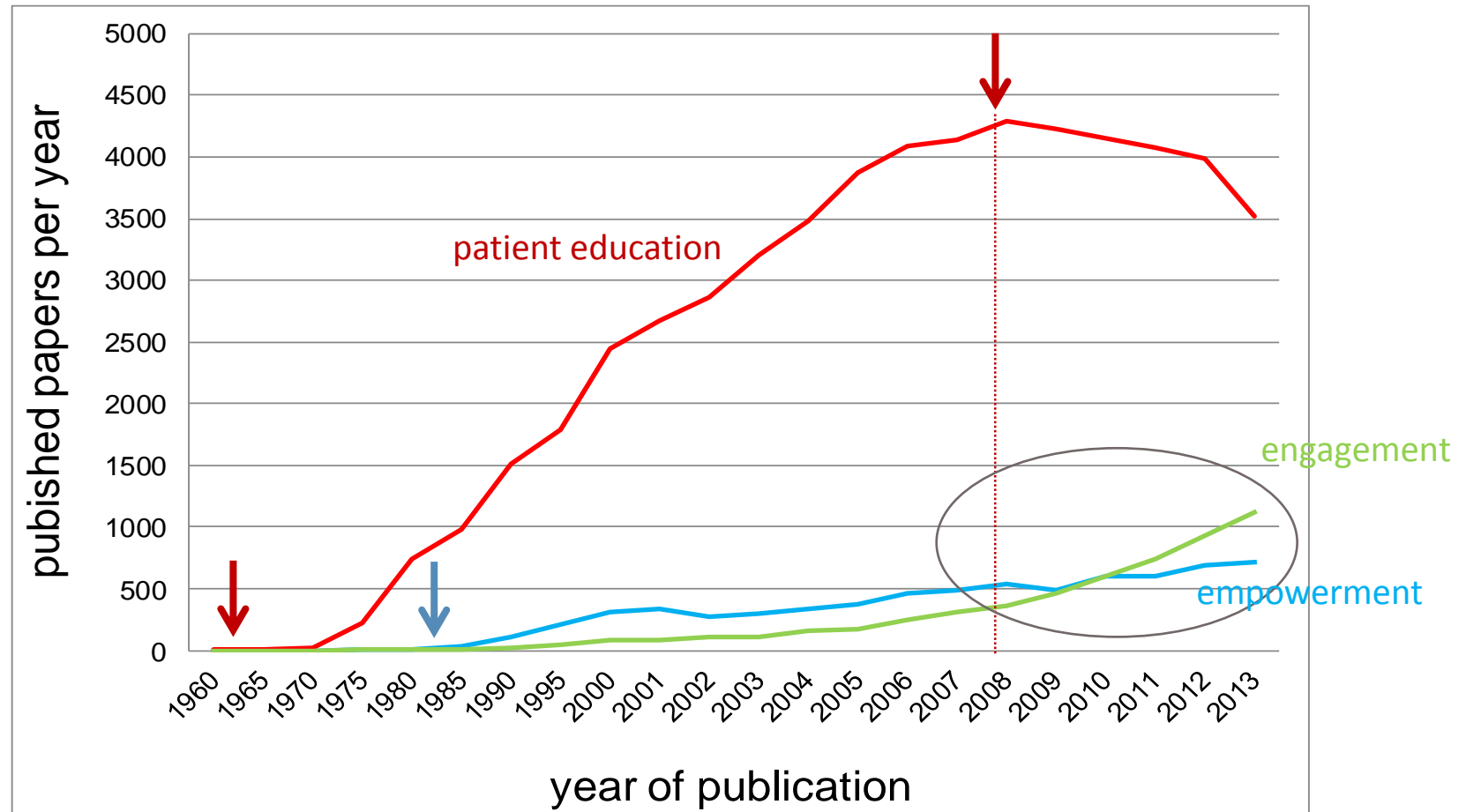
- cooperate with health professionals
- actively engage in disease self-management



- maintain or improve health
- know how to care for themselves

actively participate in health related decisions

# searching PubMed



# empowerment as a cognitive process

empowerment  $\Leftrightarrow$  control on one's own actions

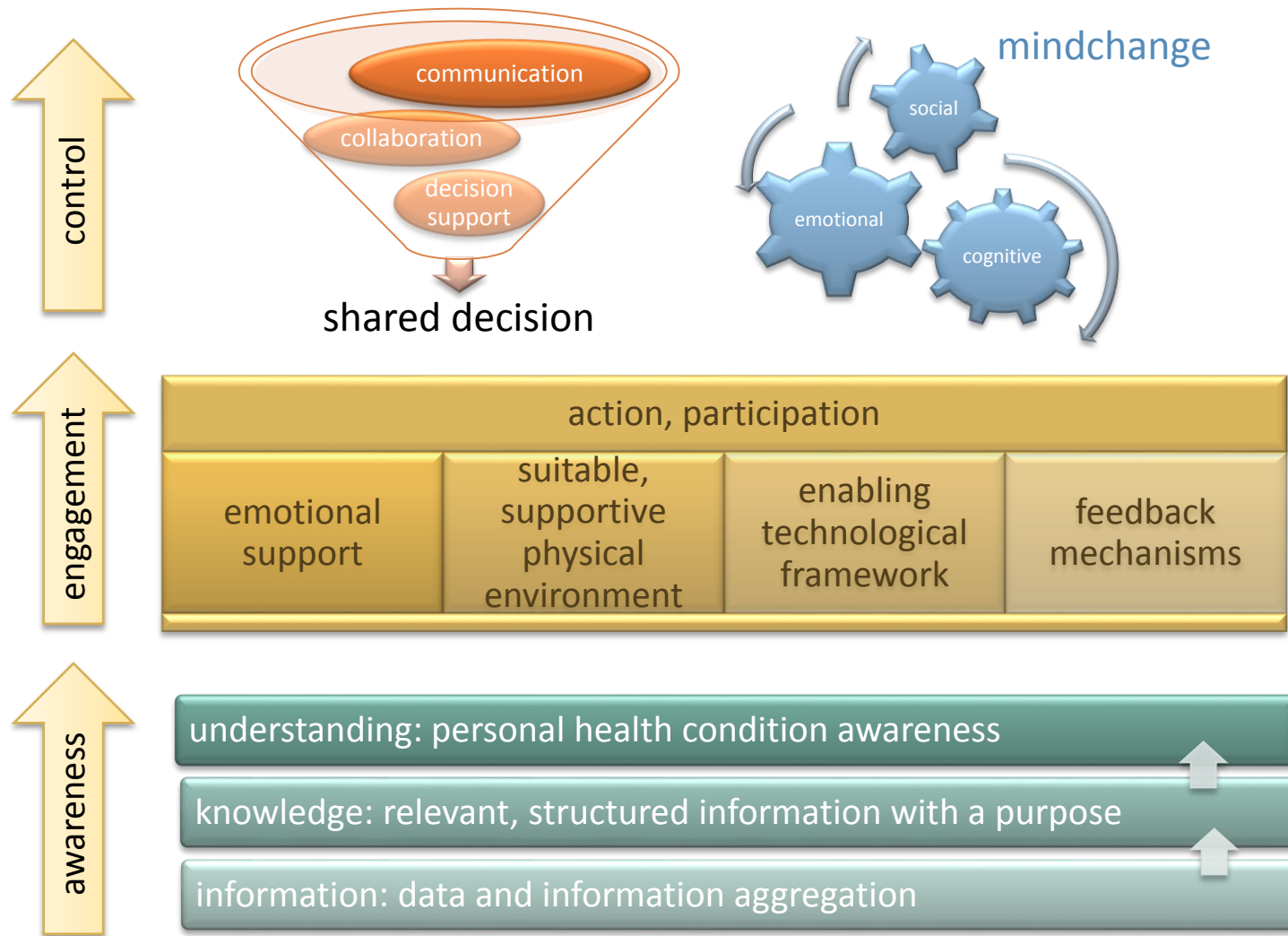


complex construct that involves various **cognitive** processes and skills

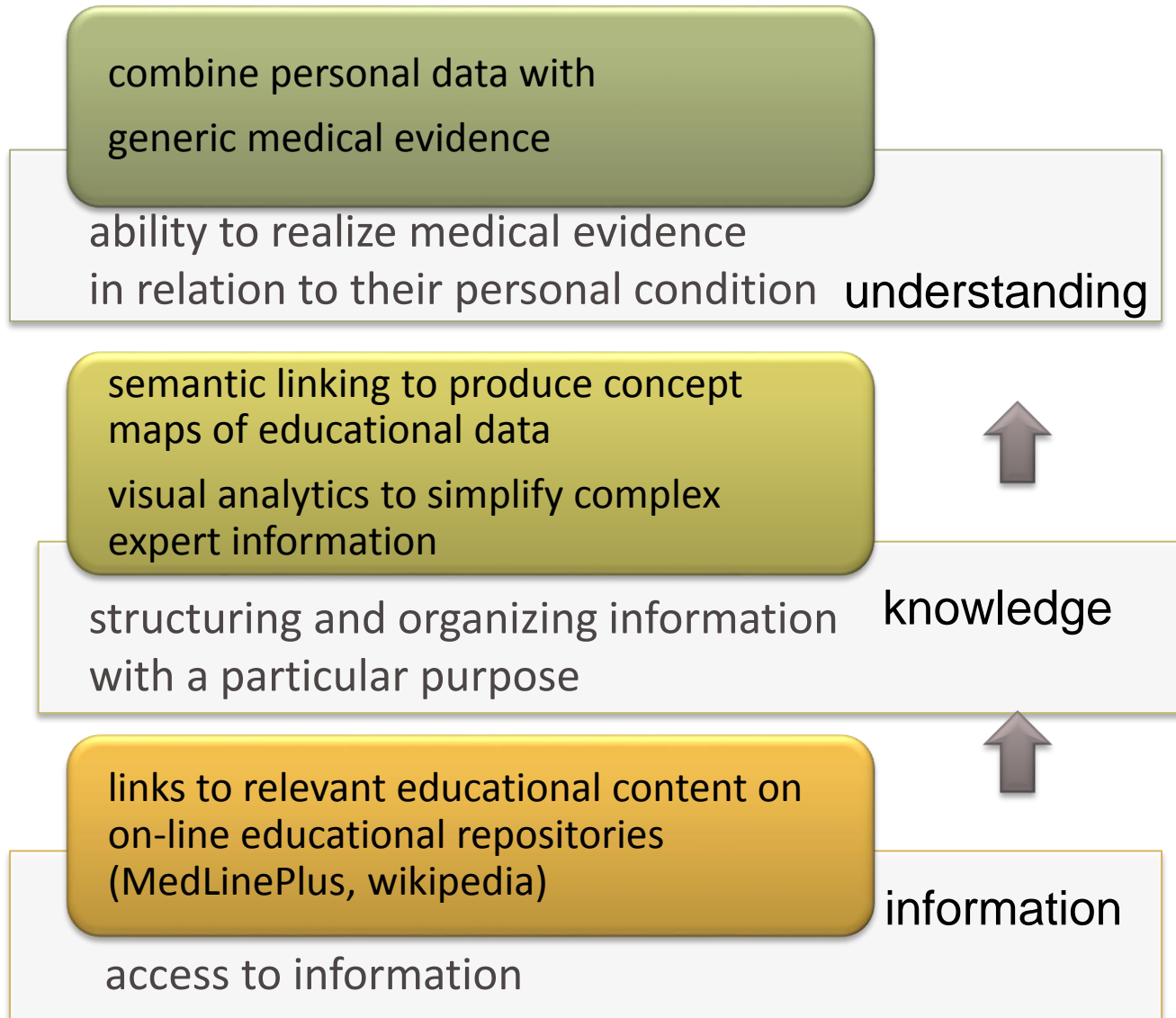
- ↪ knowledge acquisition, through perception
- ↪ thinking and learning
- ↪ awareness of one's own current conditions and /or needs
- ↪ active participation in the management of the current or future condition and in the relevant decision making

*thus, following the overall approach of cognitive psychology...*

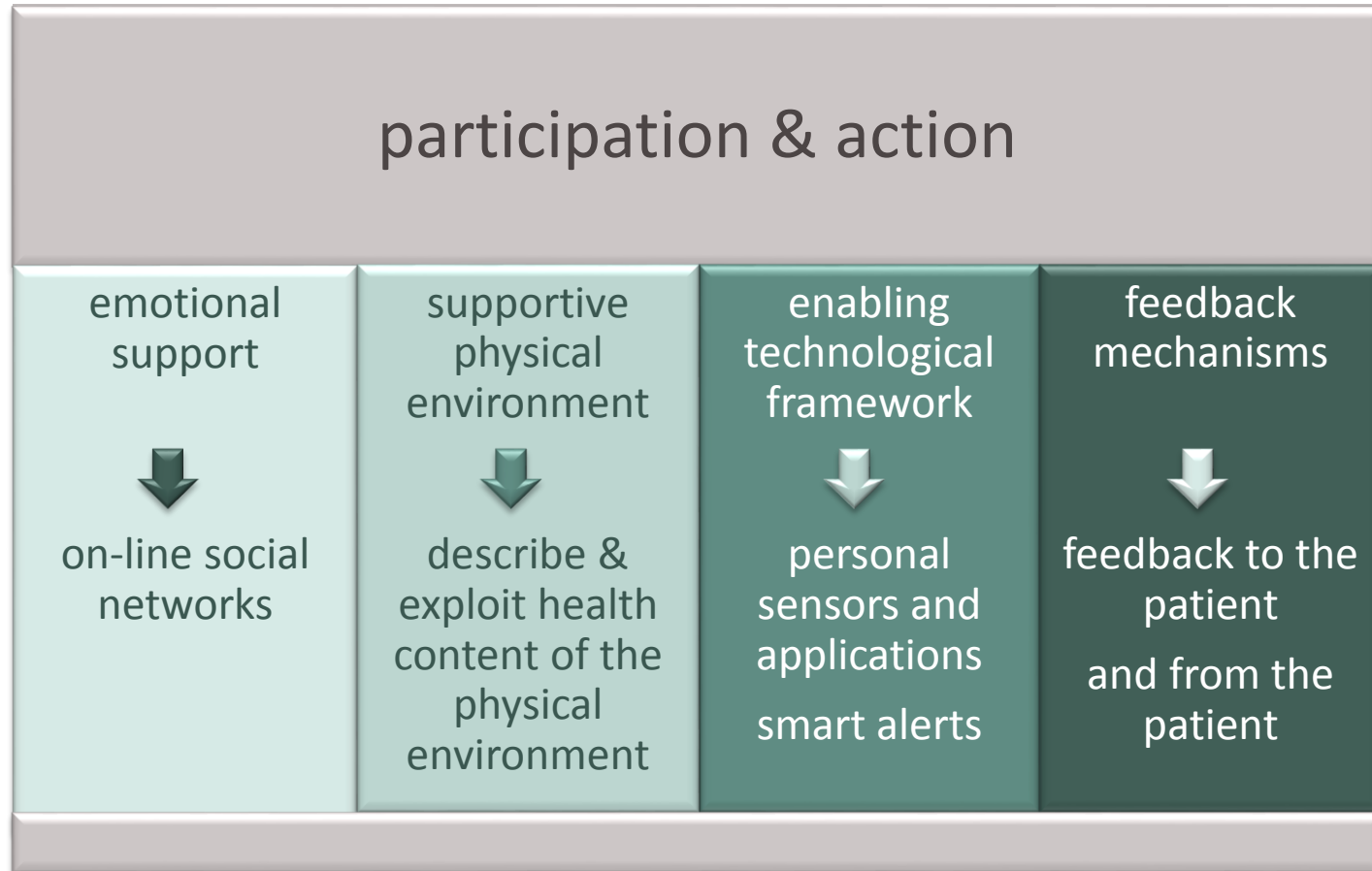
# empowerment as a cognitive process



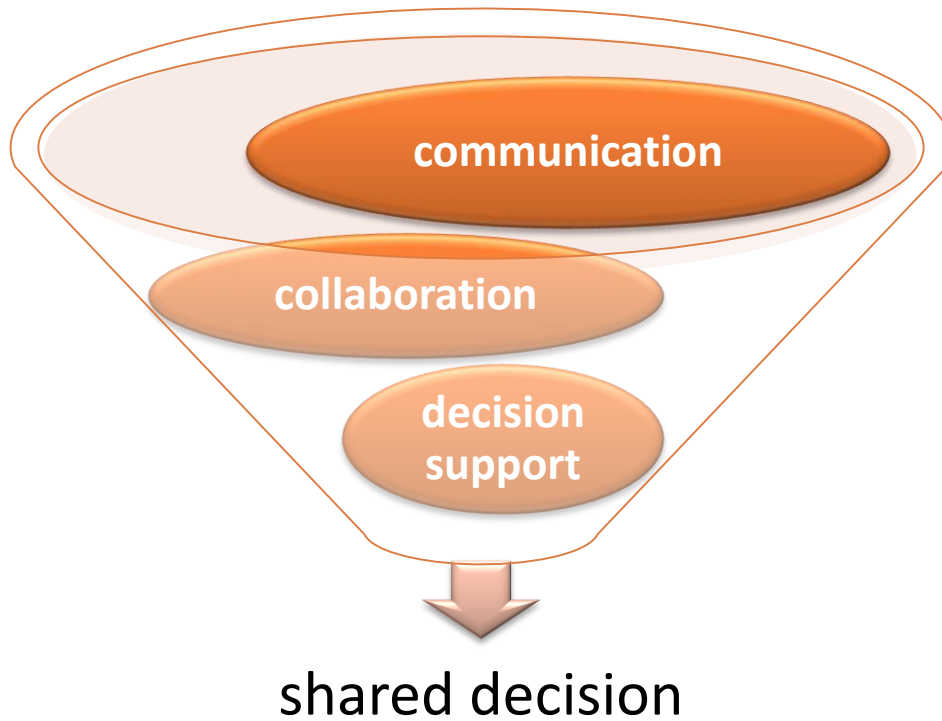
# awareness: understand own health condition



# engagement



# control: decision making



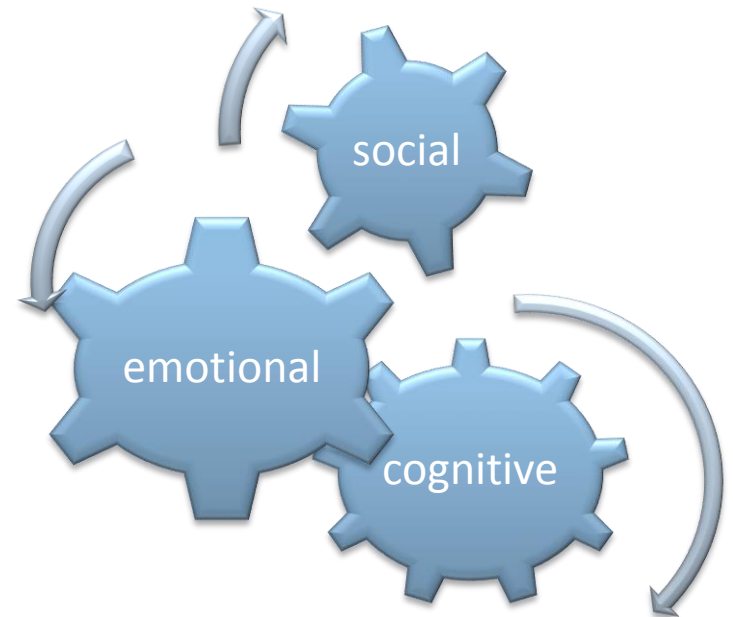
collaborative spaces  
personal health records  
decision support systems

# control: mind change

modify one's own mental states, e.g. beliefs, emotions, intentions, and thus achieve and maintain a healthy behavior

- identify motivation, attitude, habits
- design interventions to change first representations then behaviours

requires highly interdisciplinary research

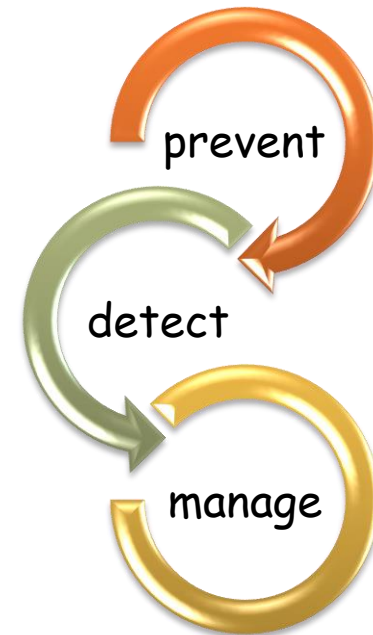




# a case example: empowering the chronic comorbid patient

## facts:

- significant **increase** in the **prevalence** and **incidence** of chronic disease
- ½ of all chronic patients present **comorbidities**
- the chronic patient is mostly an **outpatient**
  - ↳ needs to care for herself at home
  - ↳ mainly away from continuous professional care
  - ↳ while trying to lead a normal life



# cardiorenal disease & comorbidities

## *some numbers...*



- ↳ hypertension ⇒ 1/3 of adults (US 2008)
  - ↳ diabetes ⇒ 8% of overall population
  - ↳ chronic kidney disease ⇒ 9-16% of overall population
  - ↳ 44% of chronic kidney disease is due to diabetes
  - ↳ 86% of chronic kidney disease has at least 1 comorbidity
  - ↳ most patients with chronic kidney disease develop cardiovascular disease
- 
- ⇒ chronic heart failure ⇒ 1-2% of total healthcare costs
  - ⇒ end-stage renal disease (dialysis) ⇒ >2% of total healthcare costs



FP7-ICT-2013-611140

consortium: 6 partners from 4 EU countries

coordinator: Eleni Kaldoudi (DUTH)

duration: Nov 2013 – Oct 2016

budget: 3,210,470€

<http://carre-project.eu/>

# CARRE

Cardiorenal  
comorbidity management  
via **empowerment** and  
shared informed decision



DUTH



The Open  
University, UK



Univ. of Bedfordshire



Vilnius Univ. Hospital

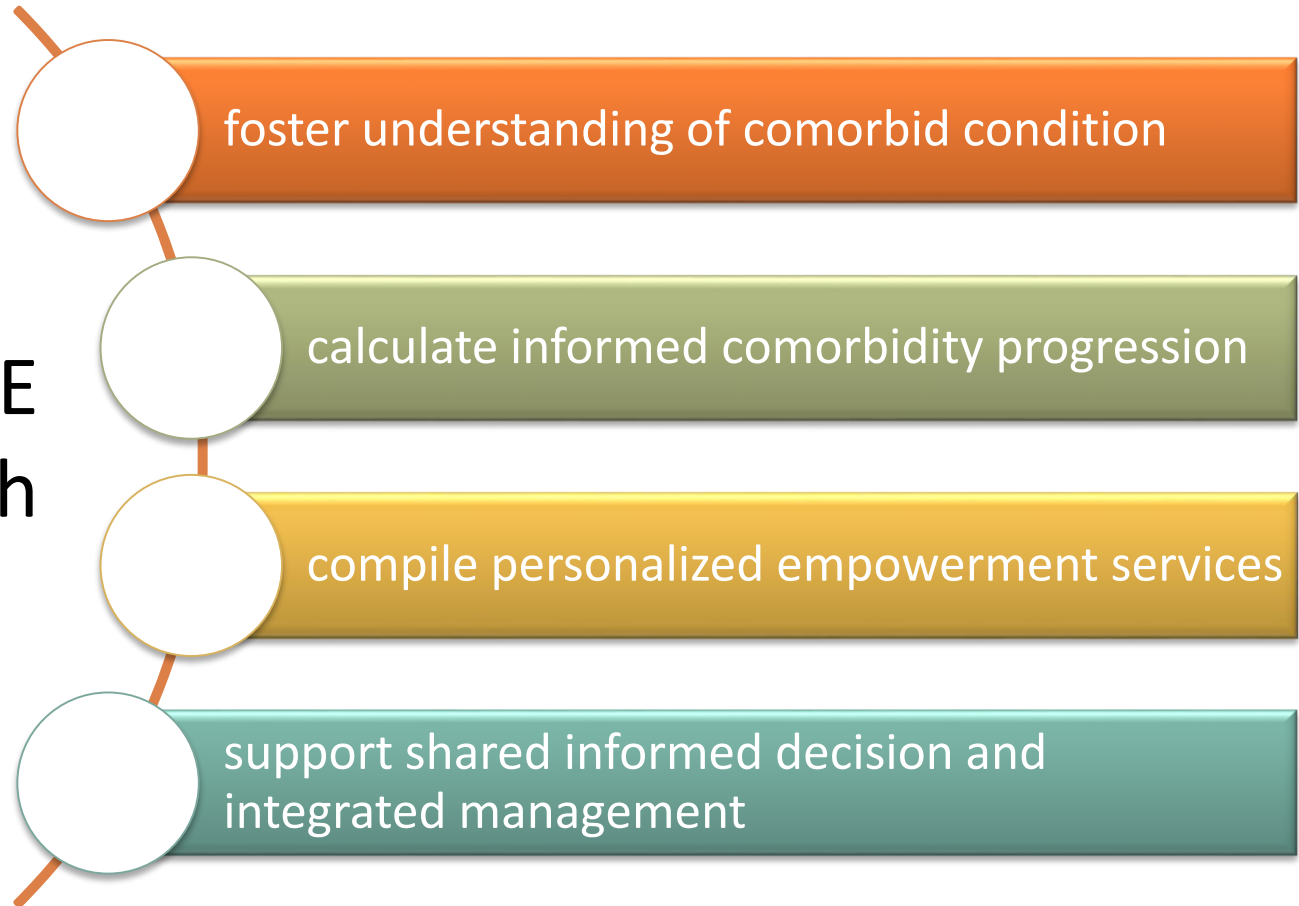


Kaunas Univ.

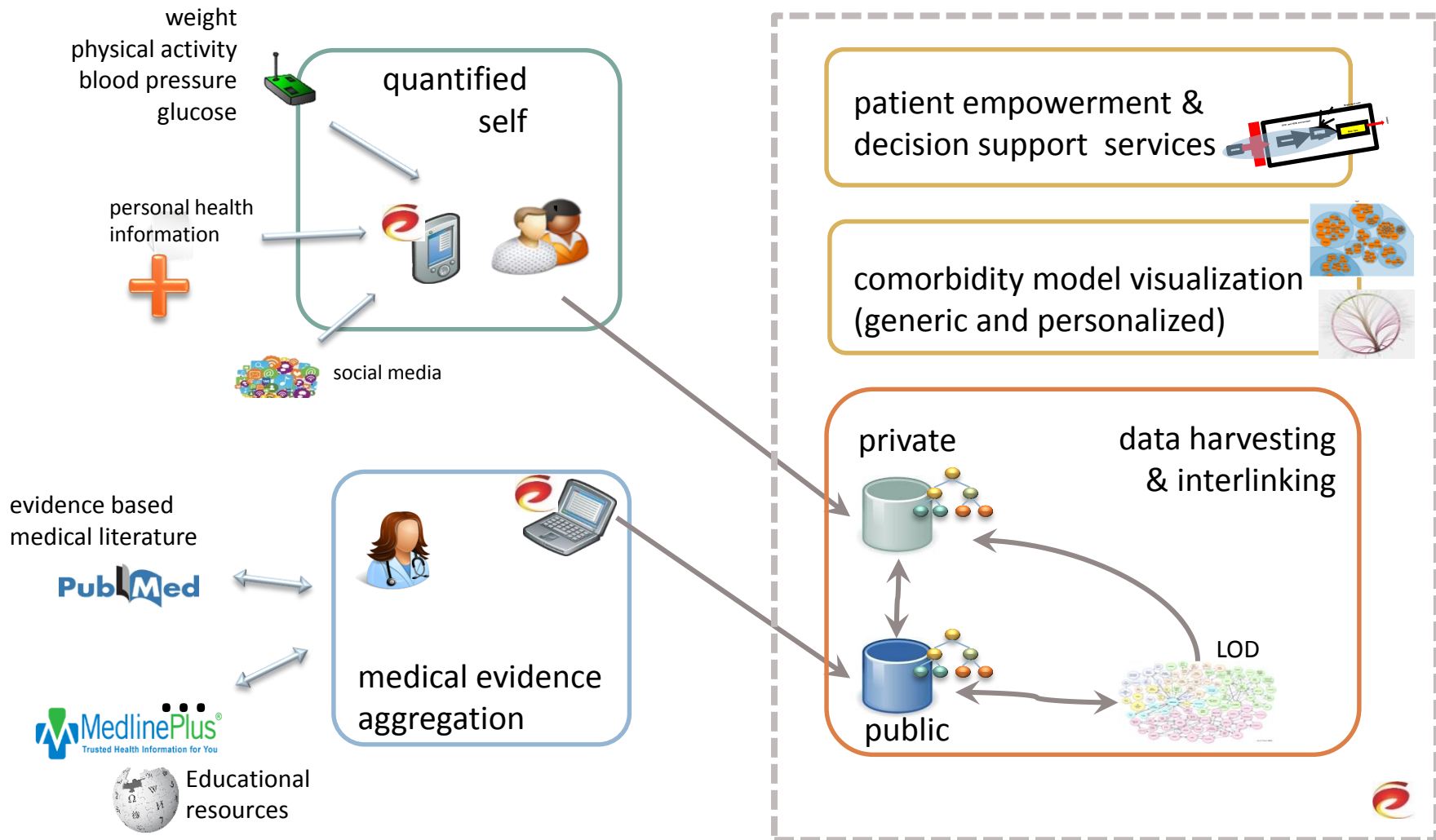


Industrial Research Institute  
for Automation & Measurements

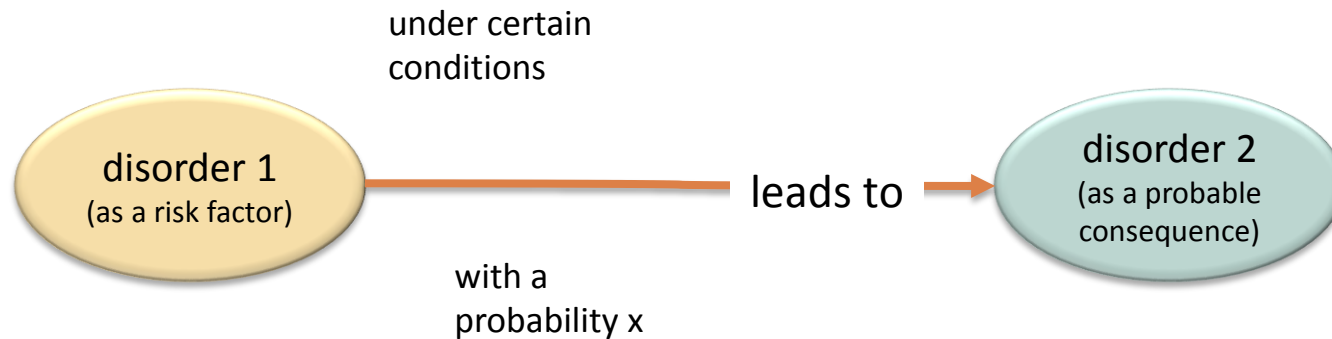
## CARRE approach



# CARRE approach

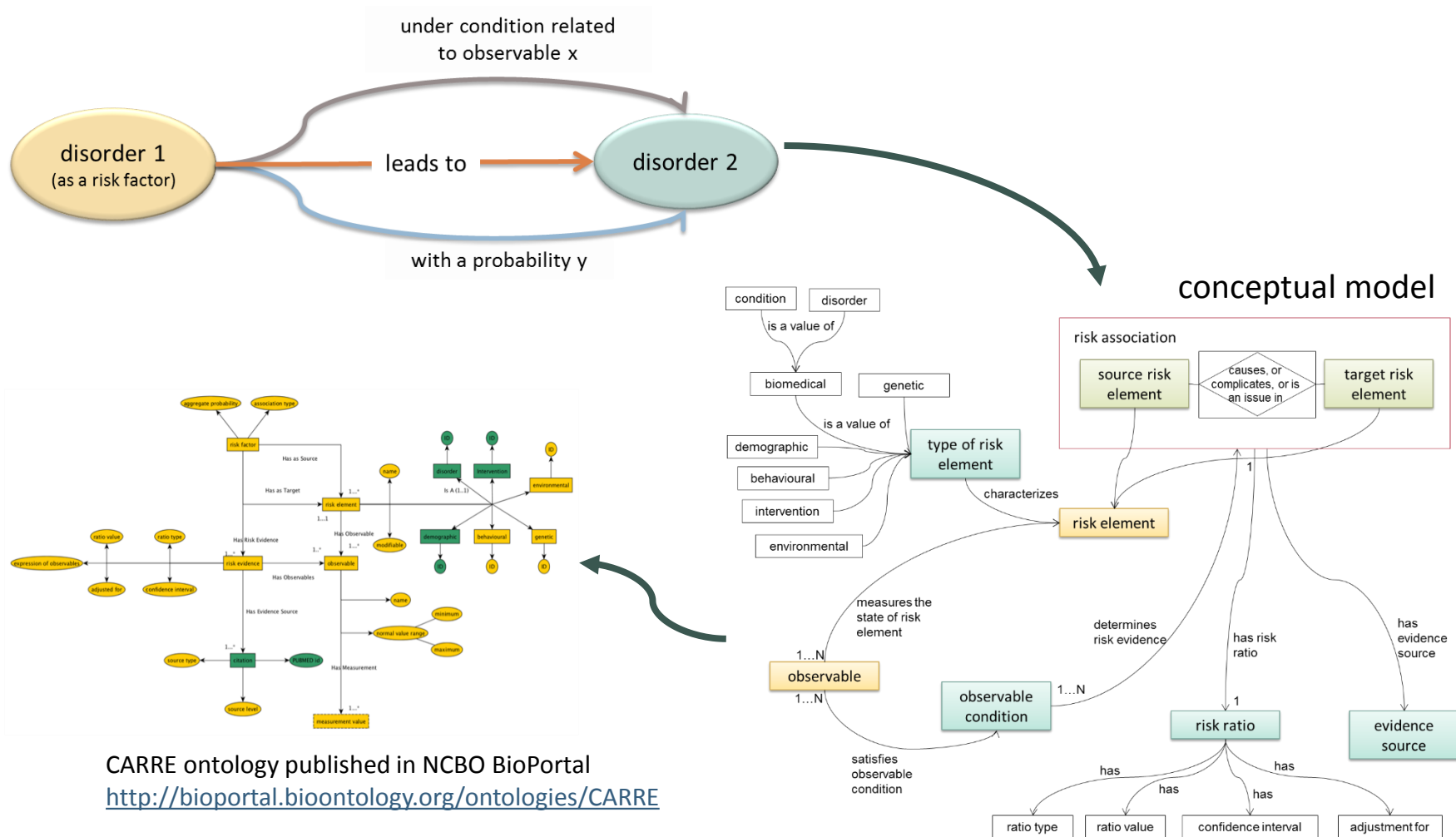


# risk factor as a central concept



risk factors derived from clinical studies and reported in medical literature  
(top level evidence: systematic reviews with meta-analysis)

# risk factor as a central concept



CARRE ontology published in NCBO BioPortal  
<http://bioportal.bioontology.org/ontologies/CARRE>

http://bioportal.bioontology.org/ontologies/CARRE

BioPortal Browse Search Mappings Recommender Annotator Resource Index Projects Sign In Help Feedback

## CARRE Risk Factor ontology

Summary Classes Properties Notes Mappings Widgets

### Details

ACRONYM	CARRE
VISIBILITY	Public
BIOPORTAL PURL	<a href="http://purl.bioontology.org/ontology/CARRE">http://purl.bioontology.org/ontology/CARRE</a>
DESCRIPTION	Clinical risk factors, evidence and observables
STATUS	Beta
FORMAT	OWL
CONTACT	Allan Third, <a href="mailto:allan.third@open.ac.uk">allan.third@open.ac.uk</a>
HOME PAGE	<a href="http://www.carre-project.eu">http://www.carre-project.eu</a>
PUBLICATIONS PAGE	
DOCUMENTATION PAGE	
CATEGORIES	Health
GROUPS	

### Metrics

We have not yet calculated metrics for this ontology.

### Visits

Download as CSV

Month	Visits
Oct 2013	0
Nov 2013	0
Dec 2013	0
Jan 2014	0
Feb 2014	0
Mar 2014	0
Apr 2014	0
May 2014	0
Jun 2014	0
Jul 2014	0
Aug 2014	0
Sep 2014	5
Oct 2014	10
Nov 2014	0
Dec 2014	20
Jan 2015	5
Feb 2015	25
Mar 2015	28

### Reviews

Add your review

No reviews available.

### Submissions

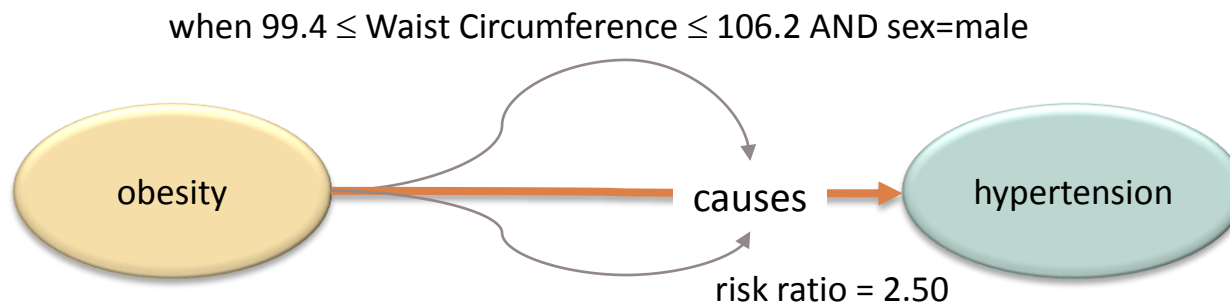
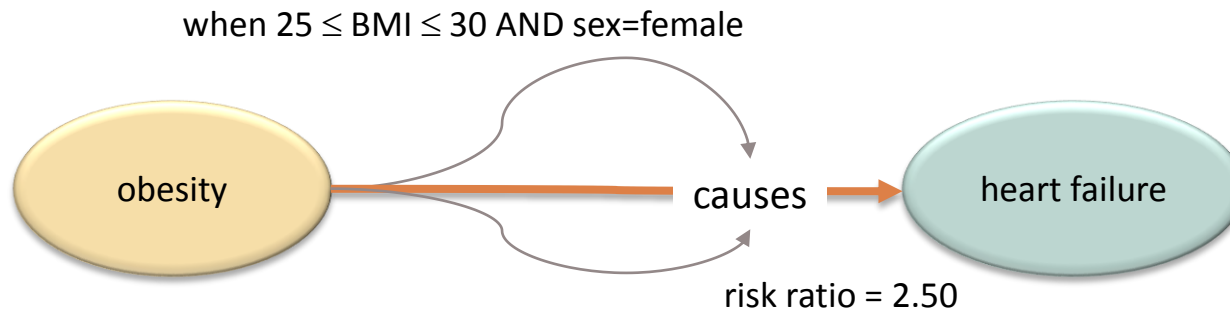
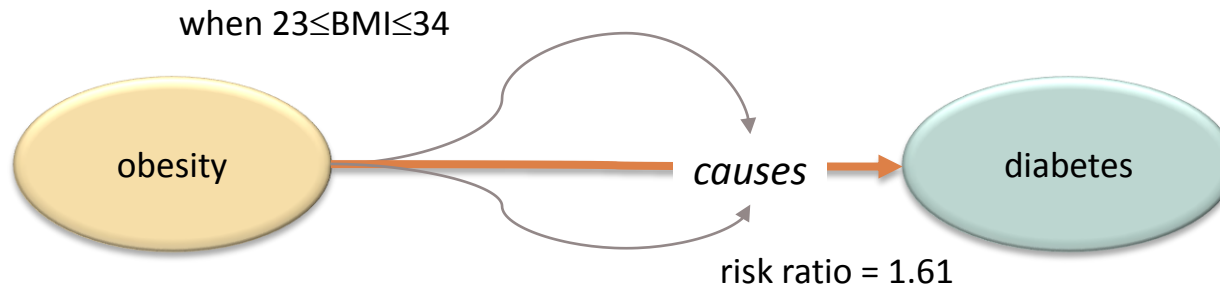
SUBMISSION	RELEASE DATE	UPLOAD DATE	DOWNLOADS
0.2 (Parsed, Indexed, Metrics, Annotator)	09/30/2014	12/08/2014	<a href="#">OWL</a>   <a href="#">CSV</a>   <a href="#">RDF/XML</a>   <a href="#">Diff</a>
0.1 (Archived)	09/30/2014	12/08/2014	<a href="#">OWL</a>   <a href="#">Diff</a>
0.1 (Archived)	09/30/2014	09/30/2014	<a href="#">OWL</a>

CARRE ontology published in NCBO BioPortal  
<http://bioportal.bioontology.org/ontologies/CARRE>



# some of the **major** related conditions

1. *Acute kidney injury*
2. *Acute myocardial infarction*
3. *Age*
4. *Albuminuria*
5. *Anaemia*
6. *Angina pectoris*
7. *Asthma*
8. *Atrial fibrillation*
9. *Chronic kidney disease*
10. *Chronic obstructive pulmonary disease*
11. *Cholelithiasis*
12. *Colorectal Cancer*
13. *Coronary and carotid revascularisation*
14. *Death*
15. *Depression*
16. *Diabetes*
17. *Diabetic nephropathy*
18. *Drugs*
19. *Dyslipidemia*
20. *Family history*
21. *Heart Failure*
22. *Hyperkalemia*
23. *Hypertension*
24. *Hyperuricemia*
25. *Hypoglycaemia*
26. *Ischemic heart disease*
27. *Ischemic stroke*
28. *Left ventricular hypertrophy*
29. *Obesity*
30. *Obstructive Sleep Apnoea*
31. *Myocardial infarction*
32. *Osteoarthritis*
33. *Pancreatic Cancer*
34. *Peripheral Arterial Disease*
35. *Physical activity*
36. *Smoking*
37. *...*



```
graph LR; A(hypertension) -- causes --> B(chronic renal disease); B -- "risk ratio = 2.00" --> A
```

A causal diagram illustrating a relationship between smoking and chronic renal disease. A yellow oval labeled "smoking" is connected by a thick orange arrow to a teal oval labeled "chronic renal disease". The word "causes" is placed between the two ovals. Below the arrow, the text "risk ratio = 2.40" is displayed. Two curved arrows form a loop around the word "causes", indicating a causal link.

http://carre.kmi.open.ac.uk/

Home Risk Factors Risk Elements Observables Citations

Navigation

- [SPARQL endpoint](#)

Search PUBMED



Add Citation as PUBMED ID



User login

Username \*

Password \*

- [Request new password](#)

Risk Elements

## Home

Choose from the following options:

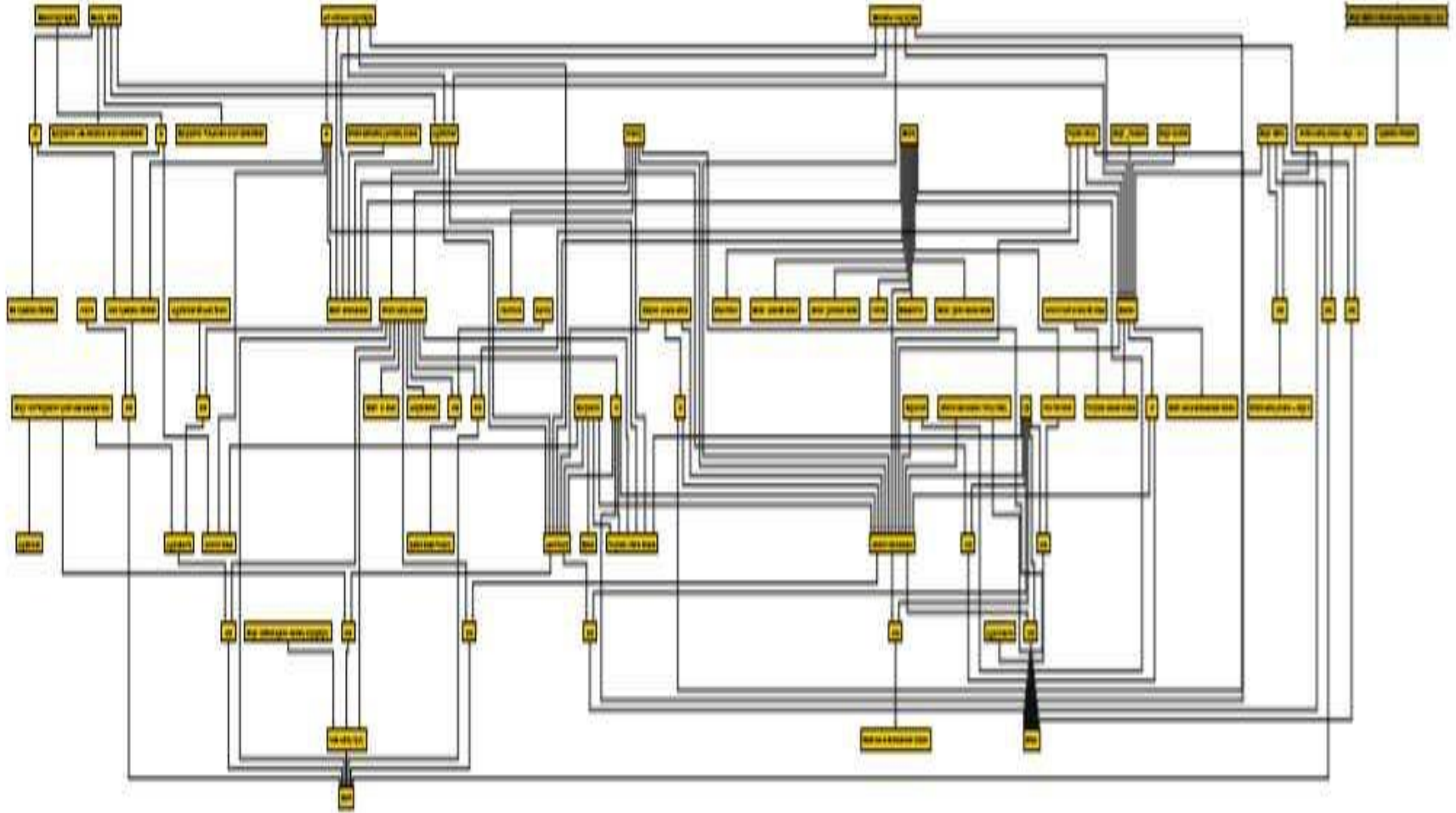
- [Add a new risk factor](#)
  - Add a new risk evidence
- [Add a new risk element](#)
- [Add a new Observable](#)
- [Add a new citation \(PUBMED\)](#)
  - [Search PUBMED](#)

```

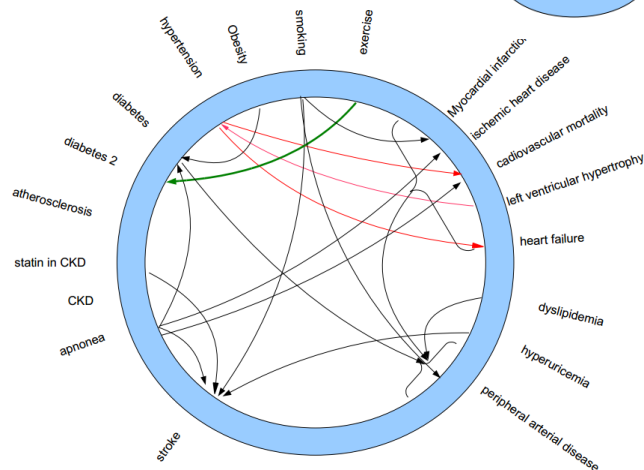
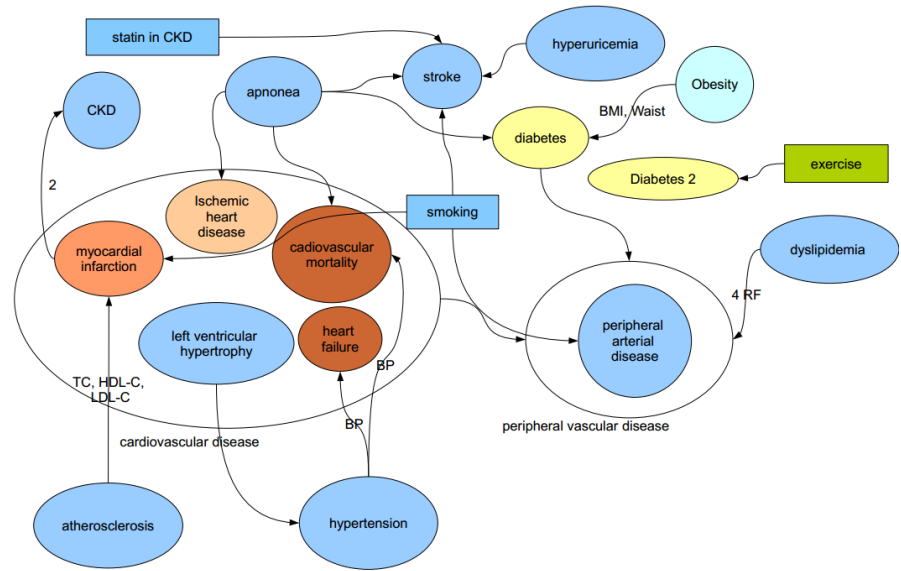
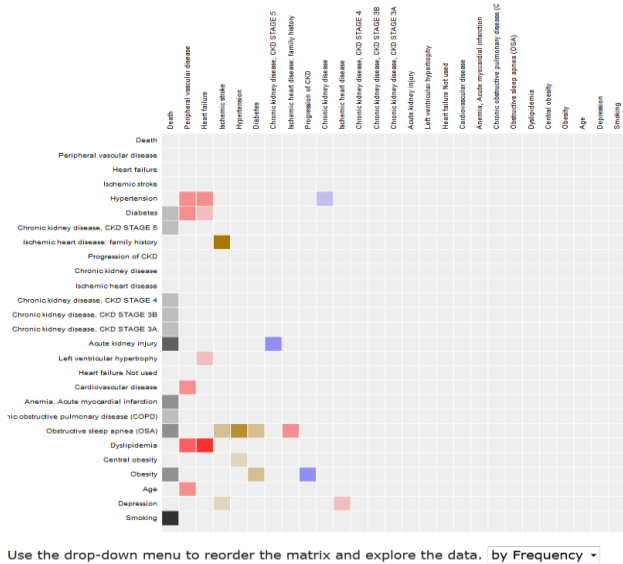
graph TD
    condition -- is a value of --> biomedical
    disorder -- is a value of --> genetic
    biomedical -- is a value of --> type_of_risk_element[type of risk element]
    genetic -- is a value of --> type_of_risk_element
    type_of_risk_element -- characterizes --> risk_element[risk element]
    observable[observable 1..N] -- measures the state of risk element --> risk_element
    observable -- satisfies observable condition --> observable_condition[observable condition 1..N]
    observable_condition -- determines risk evidence --> risk_evidence[risk evidence]
    observable_condition -- has --> risk_ratio[risk ratio 1]
    risk_element -- has --> risk_ratio
    risk_ratio -- has --> evidence_source[evidence source]
    risk_ratio -- has --> risk_association{risk association}
    risk_association -- causes, or complicates, or is an issue in --> source_risk_element[source risk element]
    risk_association -- causes, or complicates, or is an issue in --> target_risk_element[target risk element]
  
```

## CARRE risk factor database and predictive model

*a partial view of the graph...*

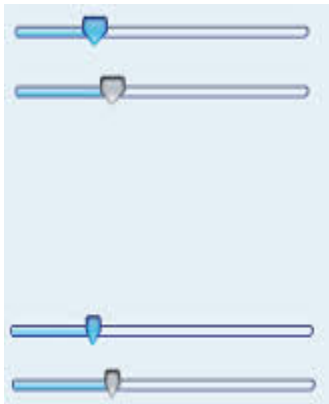


# intuitive presentations for patients

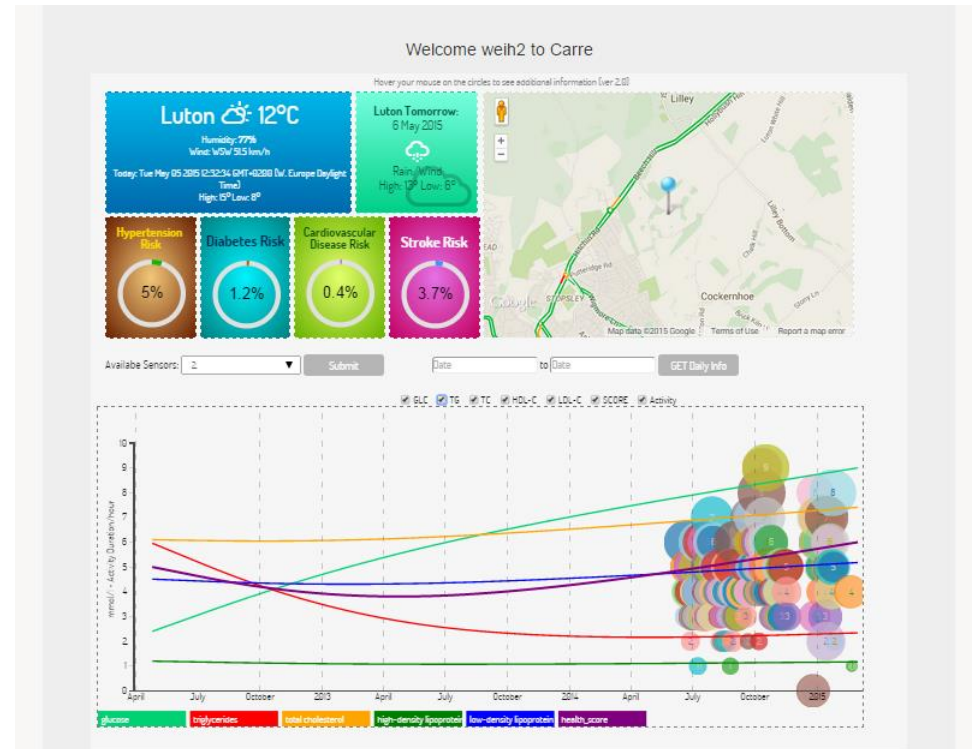


# interactive risk prediction and planning

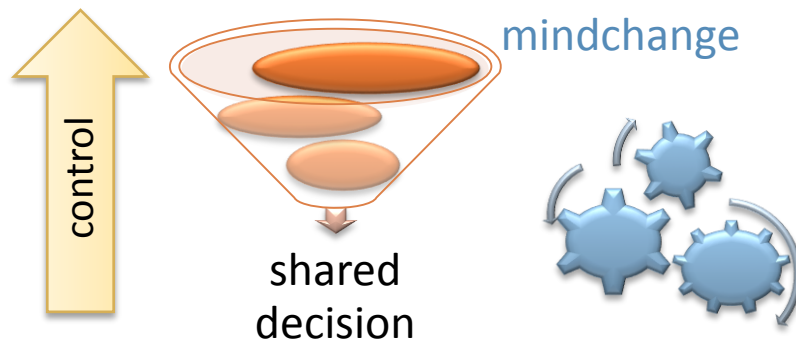
weight  
exercise



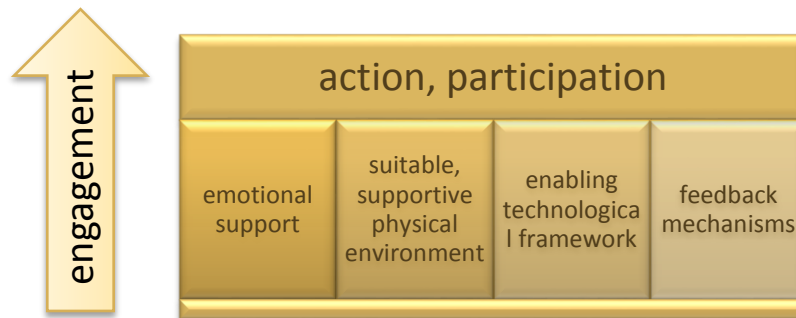
blood pressure  
blood glucose



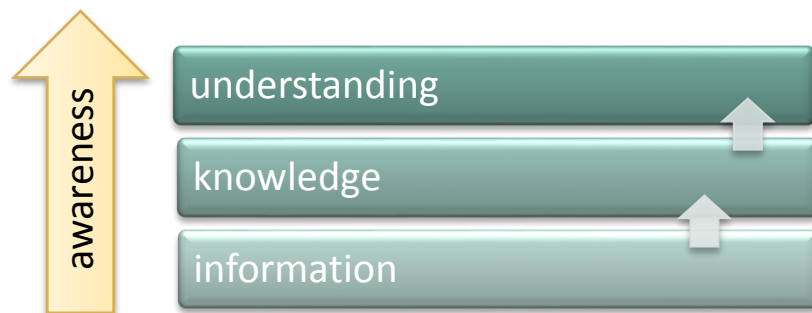
## empowerment in CARRE



advanced decision support services and **mindchange** interventions based on the real-time coupling of medical evidence, personal health status and intentions and beliefs, as deduced from social web data mining



enabling framework:  
**interactive model** to allow **planning** and a **set of alarms** to enable patient **engagement** and give **feedback**

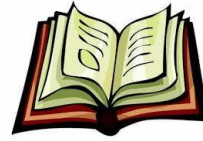


**personalized, interactive risk model** of disease progression and transition

**generic model of disease** progression pathways and comorbidities trajectories, based on current **medical evidence**



# to summarize...

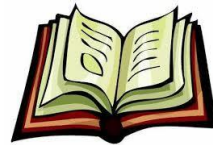


health education  
for the public

1



+



customization for  
relevant and meaningful  
health information

2

*medical evidence*



self awareness for  
engagement & control  
in health and disease  
prevention & management

3



*quantified self*



*personal  
decision support system*

# to summarize...

1

general health information for the public

2

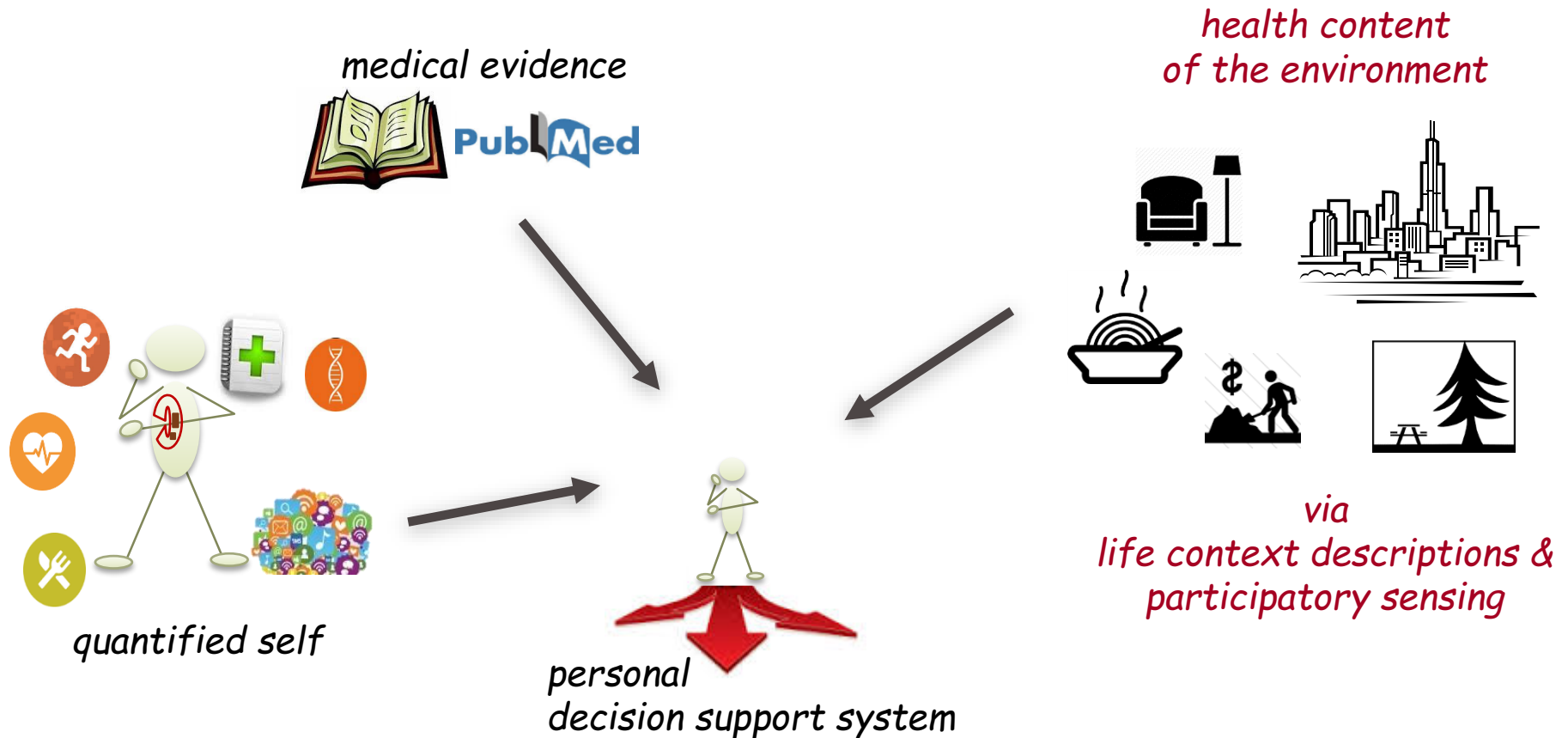
customized health information and guidelines for the individual

3

self-awareness for informed decision and control

*but, are we still missing out on something?*

# change of paradigm: making environments work for people



# acknowledgment

work funded under project CARRE

co-funded by the

European Commission under the

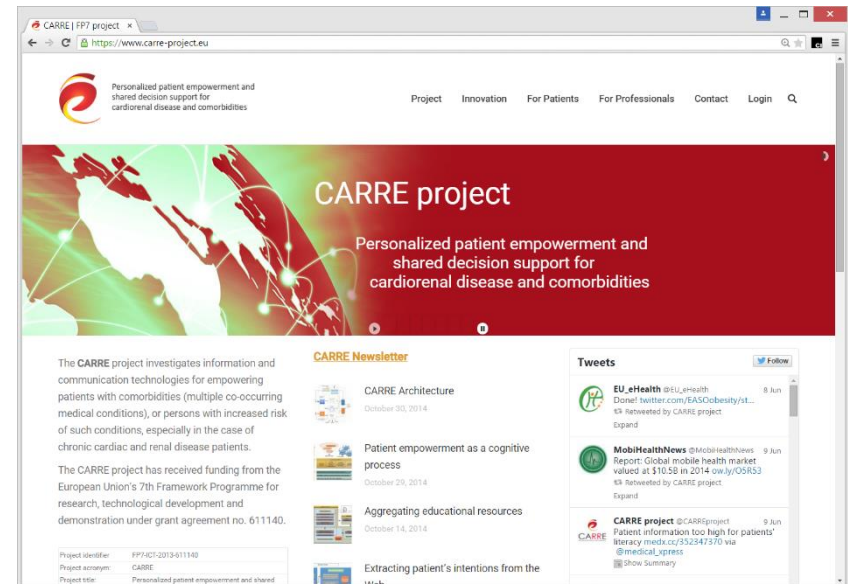
Information and Communication Technologies (ICT)

7<sup>th</sup> Framework Programme

Contract No. FP7-ICT-2013-611140

CARRE: Personalized patient empowerment  
and shared decision support  
for cardiorenal disease and comorbidities

<http://www.carre-project.eu/>



---

## Cite as

Eleni Kaldoudi

Empowering Patients through  
Information Technologies

Keynote Speech

IUPESM World Congress 2015  
Toronto, Canada  
June 7-12, 2015

<http://wc2015.org/>

---

## Contact

Eleni Kaldoudi

Associate Professor  
School of Medicine  
Democritus University of Thrace  
Dragana, Alexandroupoli  
68100 Greece

Tel: +302551030329

Tel: +30 6937124358

Email: [kaldoudi@med.duth.gr](mailto:kaldoudi@med.duth.gr)

Email: [carre@med.duth.gr](mailto:carre@med.duth.gr)