
Διαχείριση Ανοικτών Ερευνητικών Δεδομένων Υγείας

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Μέλος Advisory Board Κεντρικού ΟΚΦΝ

Twitter: @bamidis





Summary

- Open Data concepts
- Health Open Data
- Examples
 - Active and Healthy aging
 - Primary Health Care
 - Health Education



A note on openness ... from OKFN

- *Open means freely shared for anyone, anywhere, to use for any purpose - see OpenDefinition.org*
- “Here at Open Knowledge, we think the answer is clear: knowledge should be open not closed.
- We believe that our knowledge society must have at its heart collaboration not control, empowerment not exploitation and that everyone – citizens, scientists, entrepreneurs, activists – should have access to the information they need to understand and shape the world around them.”

<https://okfn.org/about/vision-and-values/>



Principles on Open Data from Philippines

DATA CATEGORY	EXAMPLE DATASETS
Agriculture	Crops, fisheries
Earth observation	Weather, earthquakes, disaster management
Economy	Lead economic indicators, commodity prices, energy consumption
Education	Number of students per school, school performance
Environment	Pollution levels, greening programs
Geospatial	National and local maps, hazard maps, topography
Health	Hospital location and services, medicines
Infrastructure	National roads, tourist spots, broadband penetration
Public finance	National budget, government payroll, awarded contracts, tax revenue
Public safety	Crime statistics
Research	Experiment results, social science surveys
Social Welfare	Housing, conditional cash transfer programs
Statistics	National statistics, census



EC, Horizon2020, Open Data...

In Horizon 2020 a limited **pilot action on open access to research data** will be implemented.¹ Participating projects will be required to develop a Data Management Plan (DMP), in which they will specify what data will be open.

Grant agreement / Pilot on Open Research Data in Horizon 2020

References to research data management are included in Article 29.3 of the Model Grant Agreement (article applied to all projects participating in the Pilot on Open Research Data in Horizon 2020).

Annex 2: Additional guidance for Data Management Plans
Research data management requirements for beneficiaries must:

- Scientific research data should be easily
- (a) *deposit in a research data repository and take measures to make it possible for third parties to access, mine, exploit, reproduce and disseminate — free of charge for any user — the following:*
1. Discoverable
 2. Accessible
 3. Assessable and intelligible
 4. Useable beyond the original purpose for which it was collected
 5. Interoperable to specific quality standards
- (ii) *other data, including associated metadata, as specified and within the deadlines laid down in the data management plan (see Annex I);*





HEALTH AND DATA: A LONG STORY



<http://www.epsiplatform.eu/content/open-health-care-data>

Maps of open data

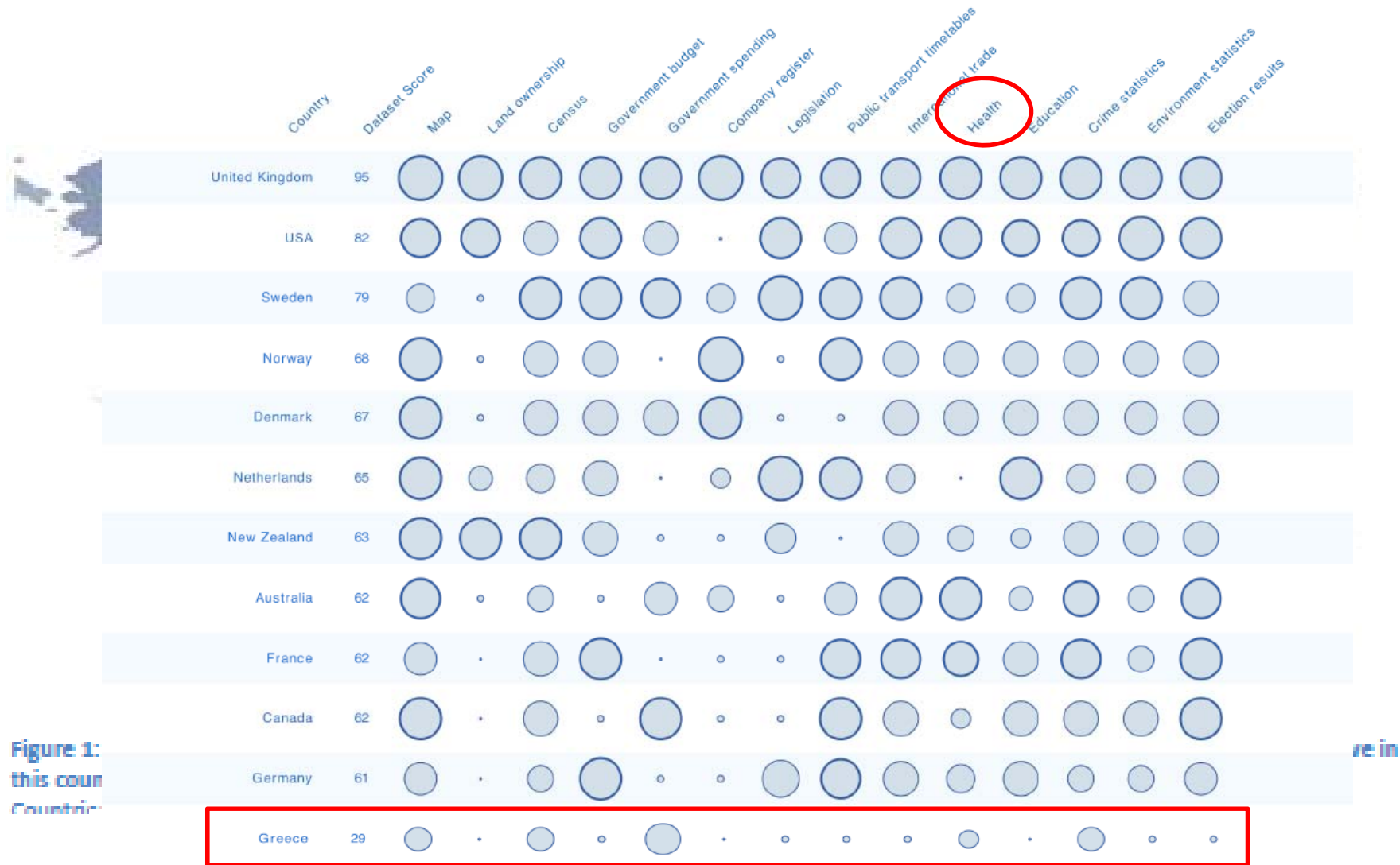


Figure 1:
this coun
Country

re in



Health care data

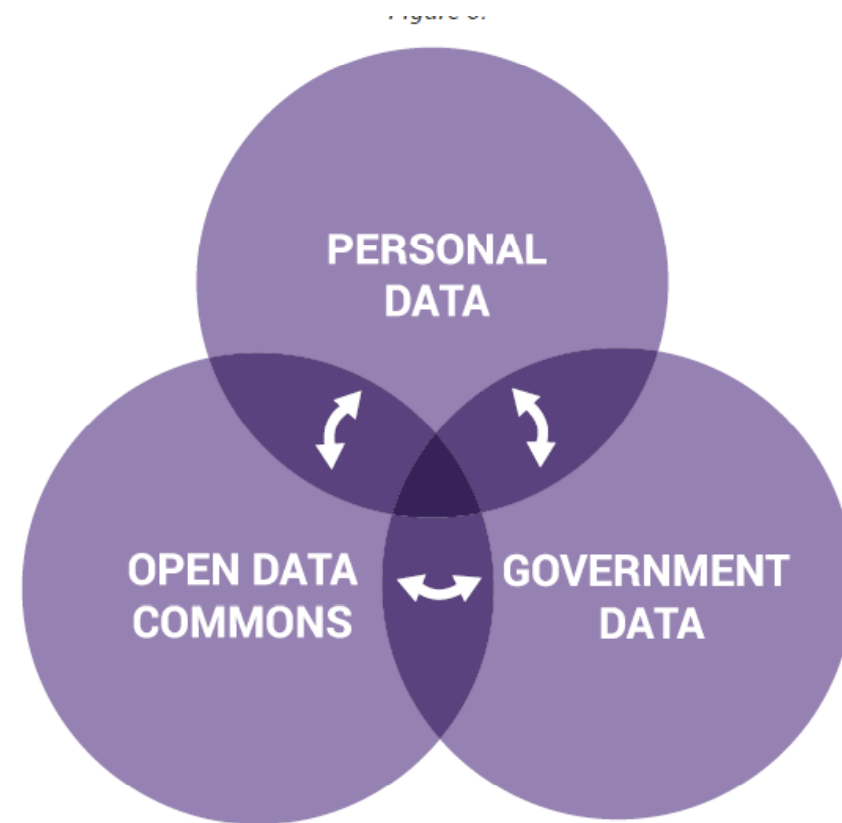
- exists in various forms with different added values:
 - Public spending and public policy on health care (very important for transparency and fight against recession...)
 - Performance indicators of individual health care providers (National Health System, Private Sector etc...)
 - General, anonymised information on population health statistics (e.g. data on occurrence of certain health conditions differentiated by age, income or location, morbidity, mortality etc...)
 - **Specific information about individuals (e.g. patient records)**

See more at: <http://www.epsiplatform.eu/content/open-health-care-data#sthash.UjDbulj7.dpuf>

Health Data type variations - an ecosystem

- combinations among big, government, and open data, all of which could fall in one of the three major categories below.
- big data (open or not) fall into:
 - personal or
 - proprietary data or
 - government secret data,

depending on the source of control.



Source: Pentland, A., et al. Big Data and Health: Revolutionizing Medicine and Public Health. December 2013.
<http://www.wish-qatar.org/app/media/382>

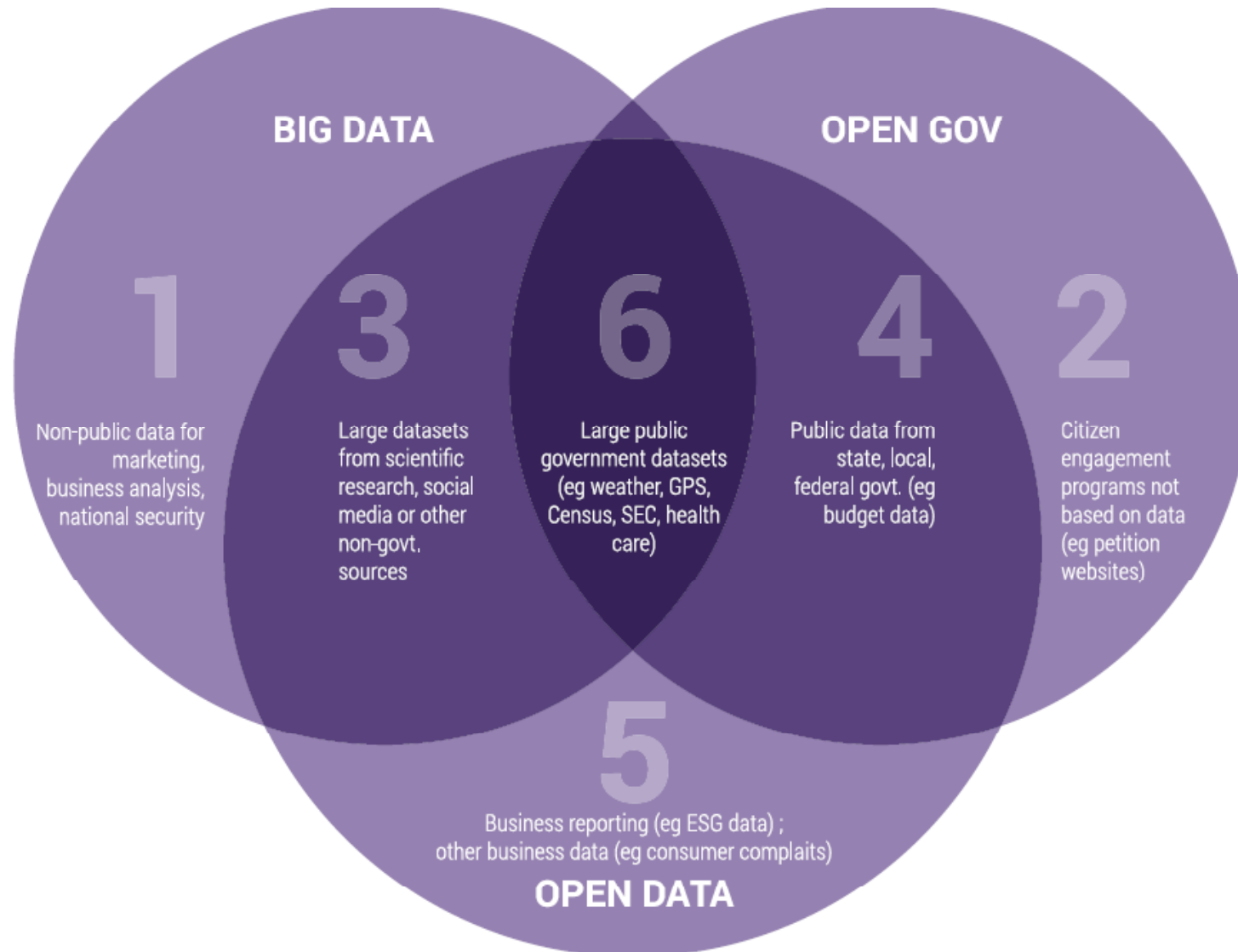


Big Data

- **Big data** are datasets whose **size is beyond the ability of typical database** software tools to capture, store, manage, and analyse.
- “maximizing computation power and algorithmic accuracy to gather, analyze, link, and compare large data sets; it is also about “drawing on large data sets to identify patterns in order to make economic, social, technical, and legal claims.”

Manyika, J., 2011. Big data: The next frontier for innovation, competition, and productivity.
Available at: http://www.mckinsey.com/insights/business_technology/big_data_the_next_frontier_for_innovation.

NOT ONLY OPEN GOVERNMENT DATA...



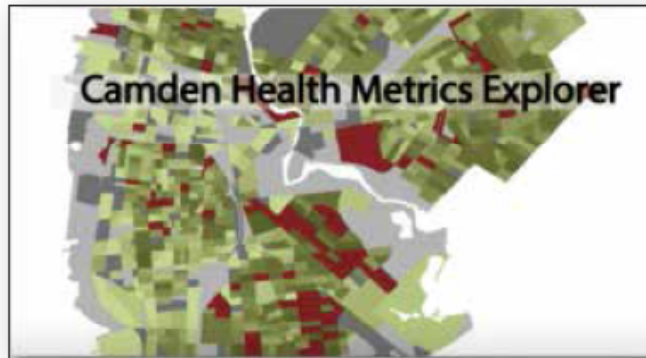
Source: Gurin, J. <http://www.opendatanow.com/2013/11/new-big-data-vs-open-data-mapping-it-out/#.Uv5w7newLP1>



UK - NHS - THE OPEN DATA ERA IN HEALTH AND SOCIAL CARE

In truth, health data—like all data—exists on a continuum from open to closed. In this paper, we suggest three categories

01



The Camden Health Metrics Explorer, created by the Camden Coalition of Healthcare Providers (CCHP) (based in Camden, NJ, USA) and BlueLabs, is leveraging open datasets linked to health exchange information and claims data, providing actionable metrics in real time. They place a focus on “hotspotting”—the identification of patients who are heavy users of the healthcare system--providing targeted interventions to address their needs and change their utilization patterns. Based upon a metrics dashboard, the Coalition seeks to reach out to high risk patients to coordinate the critical period following discharge and the transition back to primary care. The Camden Coalition also works with community groups to provide preventive care and health education.⁷⁰

and the original data files are not included in the release. An example of published data would be NHS patient satisfaction surveys.



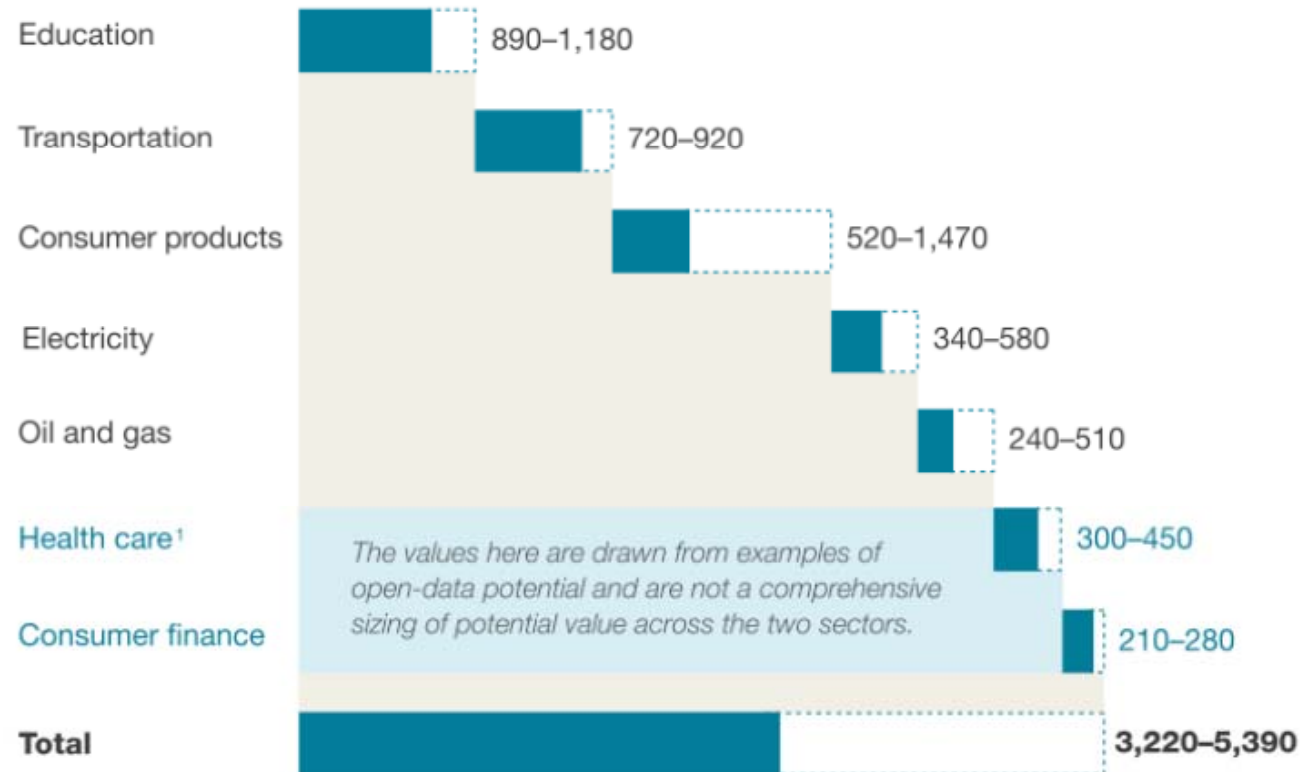
OPEN DATA & ECONOMIC VALUE

MCKINSEY



Open data can help unlock \$3 trillion to \$5 trillion in economic value annually across seven sectors.

Potential value in open data, \$ billion

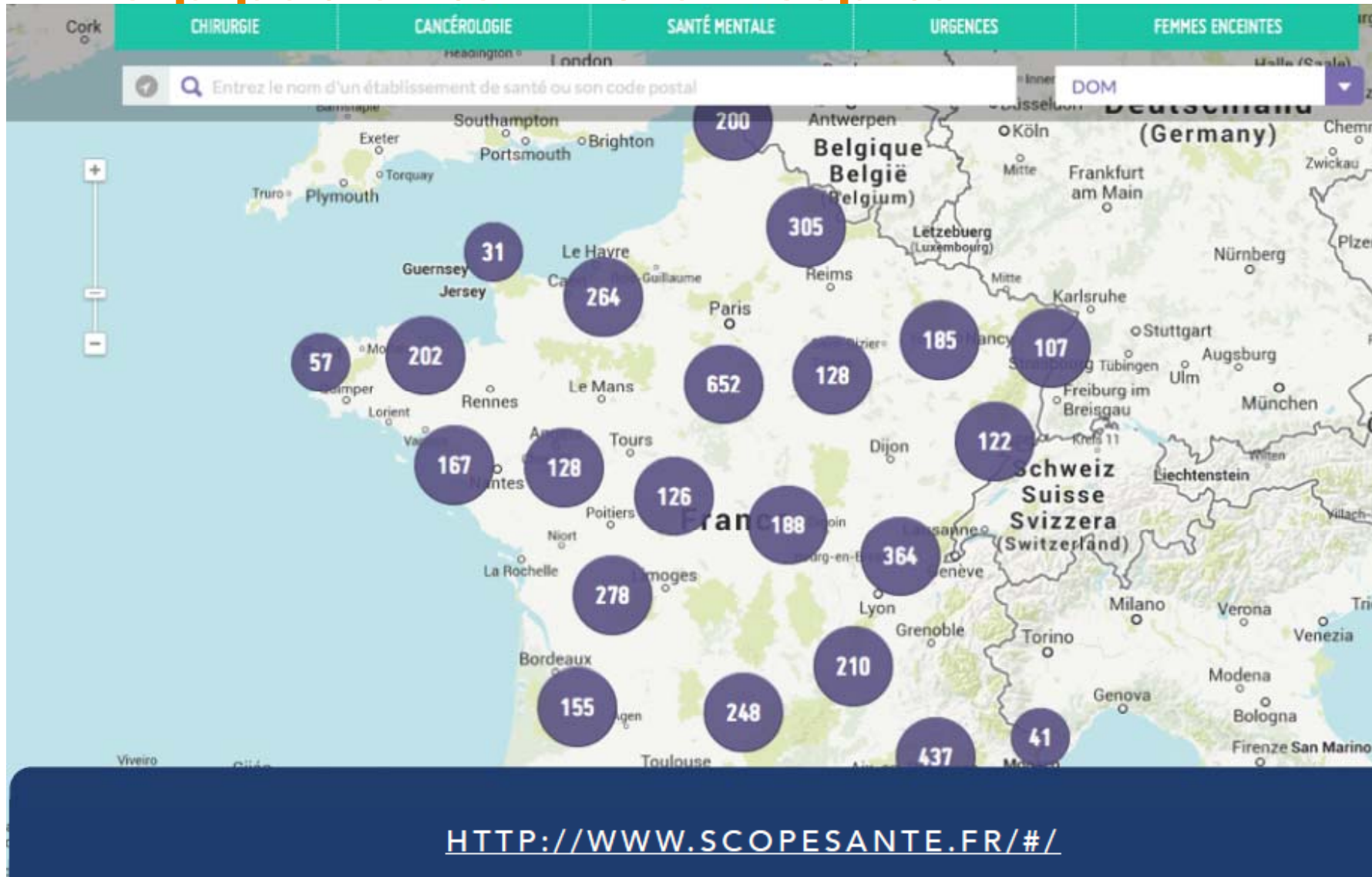


¹Includes US values only.

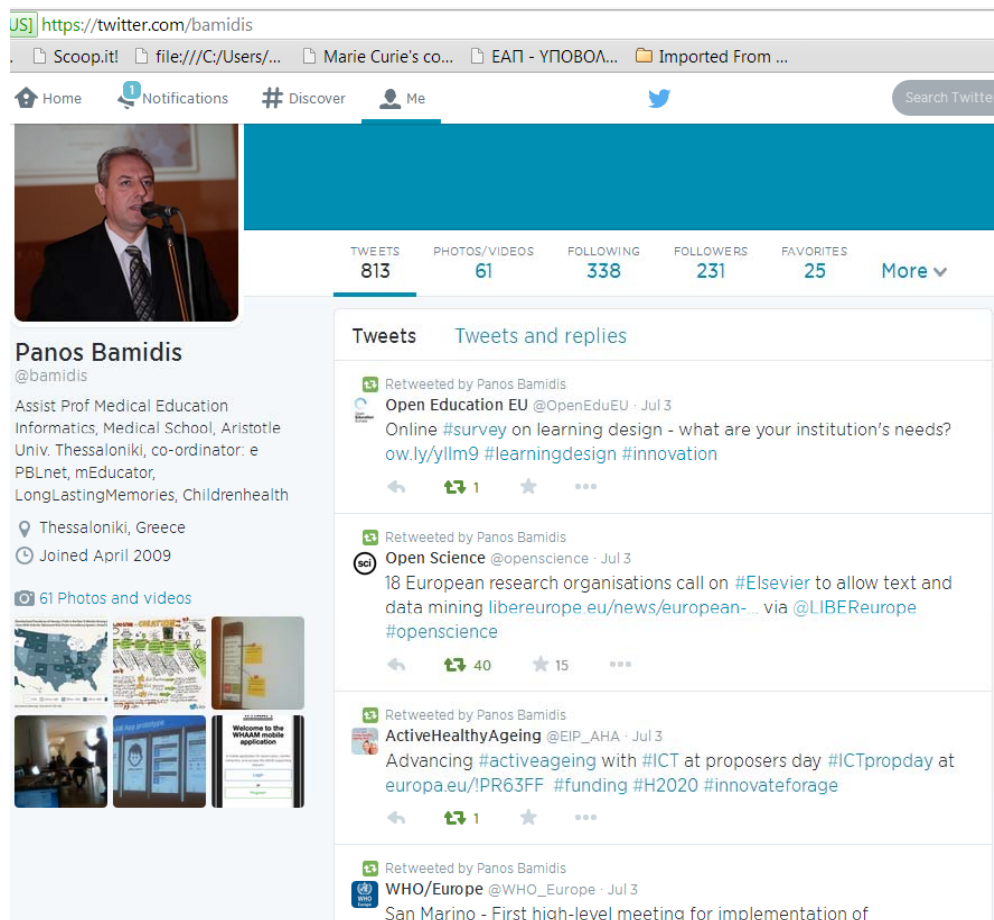
Source: McKinsey Global Institute analysis

[HTTP://WWW.MCKINSEY.COM/INSIGHTS/BUSINESS_TECHNOLOGY/
OPEN_DATA_UNLOCKING_INNOVATION_AND_PERFORMANCE_WITH_LIQUID_INFORMATION](http://www.mckinsey.com/insights/business_technology/open_data_unlocking_innovation_and_performance_with_liquid_information)

Help patients find a hospital



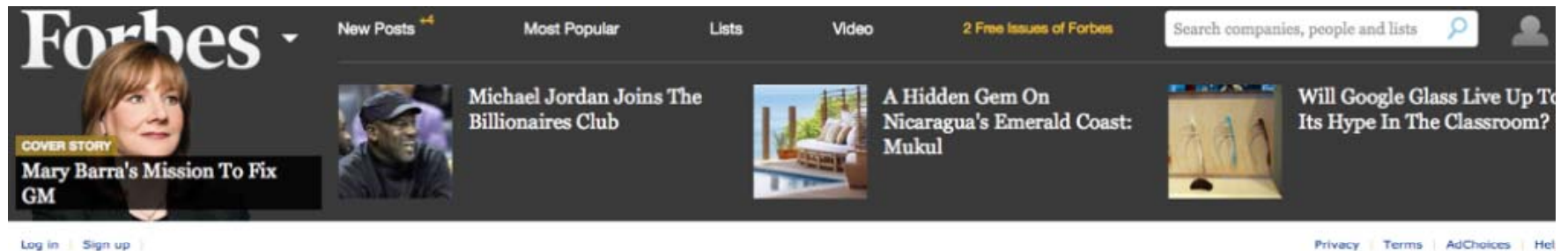
Current text and data mining (TDM) limitations



Eighteen European research and library organisations, are calling on [Elsevier](http://elsevier.com) to withdraw its current policy on text and data mining (TDM) Elsevier policy restricts researchers' abilities to perform TDM by requiring them to register their details and agree to a click-through license that can change at any time, and how it unfairly mandates conditions by which research outputs derived from TDM can be disseminated.

<http://libereurope.eu/news/european-research-organisations-call-on-elsevier-to-withdraw-tdm-policy/>

Google Fit



Parmy Olson
Forbes Staff

[FOLLOW](#)

I cover agitators and innovators in mobile.
[full bio](#) →

TECH 6/12/2014 @ 6:00PM | 51,585 views

Exclusive: Google Wants To Collect Your Health Data With 'Google Fit'

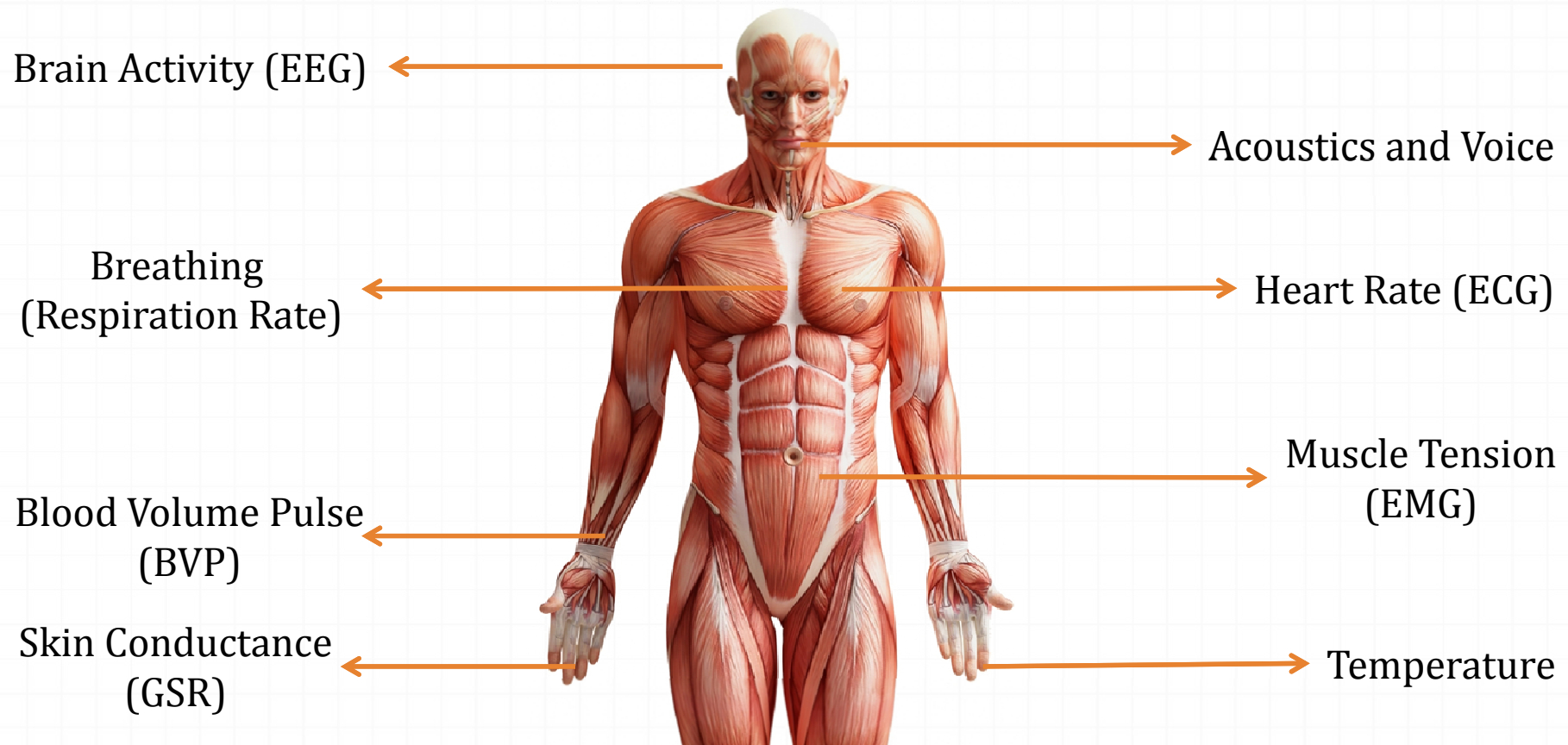
[+ Comment Now](#) [+ Follow Comments](#)

[HTTP://WWW.FORBES.COM/SITES/PARMYOLSON/2014/06/12/EXCLUSIVE-GOOGLE-TO-LAUNCH-HEALTH-SERVICE-GOOGLE-FIT-AT-DEVELOPERS-CONFERENCE/](http://www.forbes.com/sites/parmyolson/2014/06/12/exclusive-google-to-launch-health-service-google-fit-at-developers-conference/)

Source: Mateo Brunatti, ePSI platform

Examples from Active and Healthy Aging - Mobile Health

Different Modalities



A
notion
of the
‘quantified - self’



Mobile Sensor Platforms - HealthPAL

- HealthPAL™ is a personal health gateway that can connect to compatible medical devices using either a Bluetooth or wired connection.
- Through the HealthPAL data from these devices can be collected and transferred, via M2M, to an electronic health record (EHR)



Mobile Sensor Platforms – Basis

- The Basis is a wristwatch that is capable of tracking heart rate, movement with a 3-axis accelerometer, GSR and skin and ambient temperatures.
- Data are aggregated and various health and lifestyle indicators are extracted.
- Indicators are uploaded to a web portal for user access.



Vijay-Rozario S, James C, Amor J, Deliverable D2.4 - STATE OF THE ART OF TECHNOLOGIES, www.usefil.eu

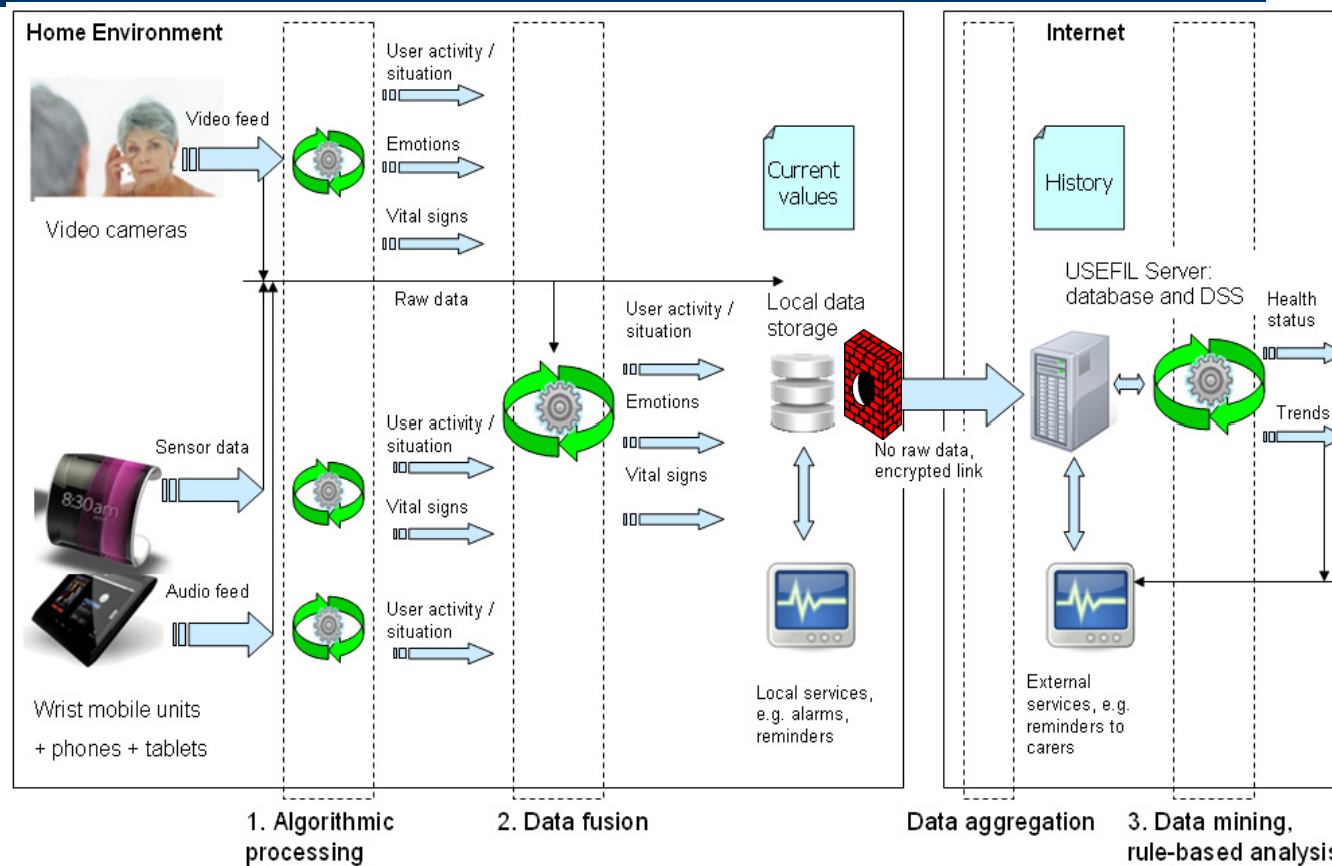


Sensor Platforms - Cameras



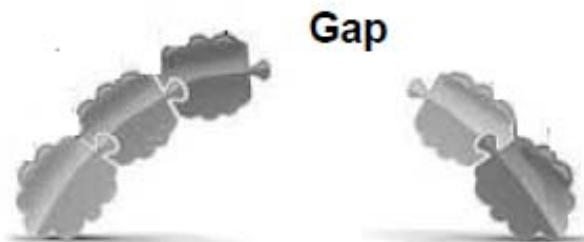


The USEFIL system





ICT Ecosystem



Needs of the elderly people

- We are not inventing new devices
- We are just trying to exploit the ICT Ecosystem for the benefit of the Elderly people.
- Our objective : Elderly people living independently for a longer time, feeling safe and socially connected

trial (alerts) 09:43

Health

Fitness

Events

Distance

Gait

Calories

Steps

Health

Fitness

Events

Memory Game

Agility Game

Dexterity Game

trialuser

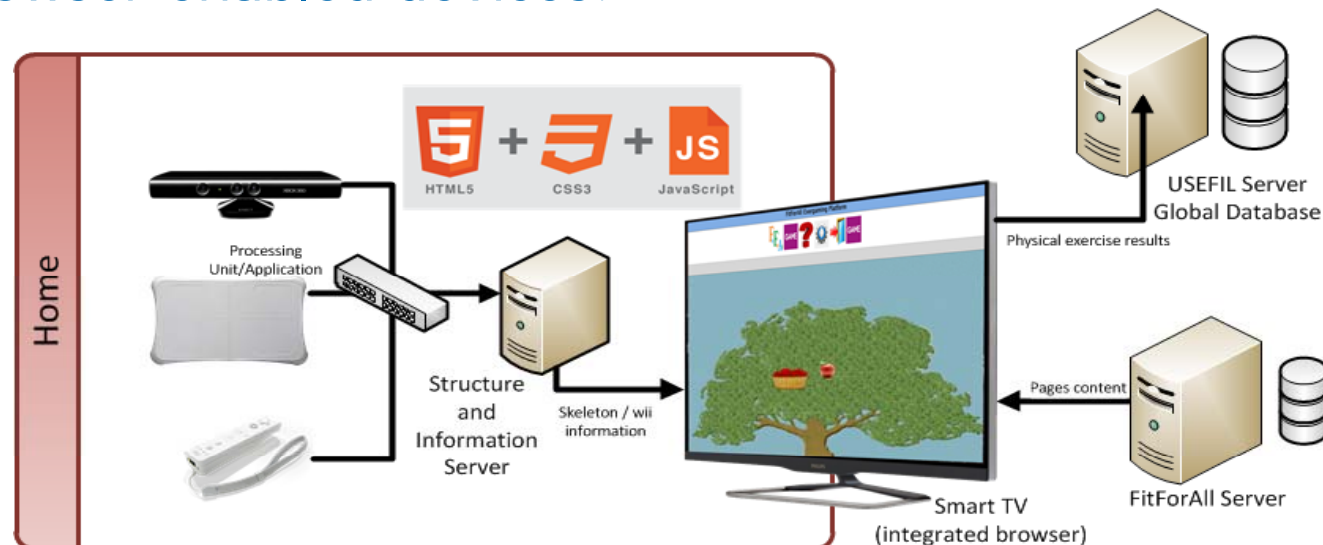
➔ Logout
 OK Select
 ↶ Return

The LLM Video

- http://www.youtube.com/watch?feature=player_embedded&v=ilABZtm8eGM

Expansion into real Active and Healthy Aging Apps

- *Developments to facilitate trials in the USEFIL project*
- *Self-therapy app*
- FitForAll, is suggested as a game playing activity to elders... to exercise and maintain their physical status and well-being... through an innovative, low-cost ICT platform (Wii Balance Board and MS kinect), Utilising the lightweight and extensible framework “Input devices sharing service”, it is accessible by web browser enabled devices.



<http://www.youtube.com/watch?v=IR-cEsuuOow>



eHome Experiments - Active & Healthy Aging

- Video demo



Can we leverage “Big Data” on Active and Health Aging?

- **Big data** are datasets whose **size is beyond the ability of typical database** software tools to capture, store, manage, and analyse.
- “maximizing computation power and algorithmic accuracy to gather, analyze, link, and compare large data sets; it is also about “drawing on large data sets to identify patterns in order to make economic, social, technical, and legal claims.”

Manyika, J., 2011. Big data: The next frontier for innovation, competition, and productivity.

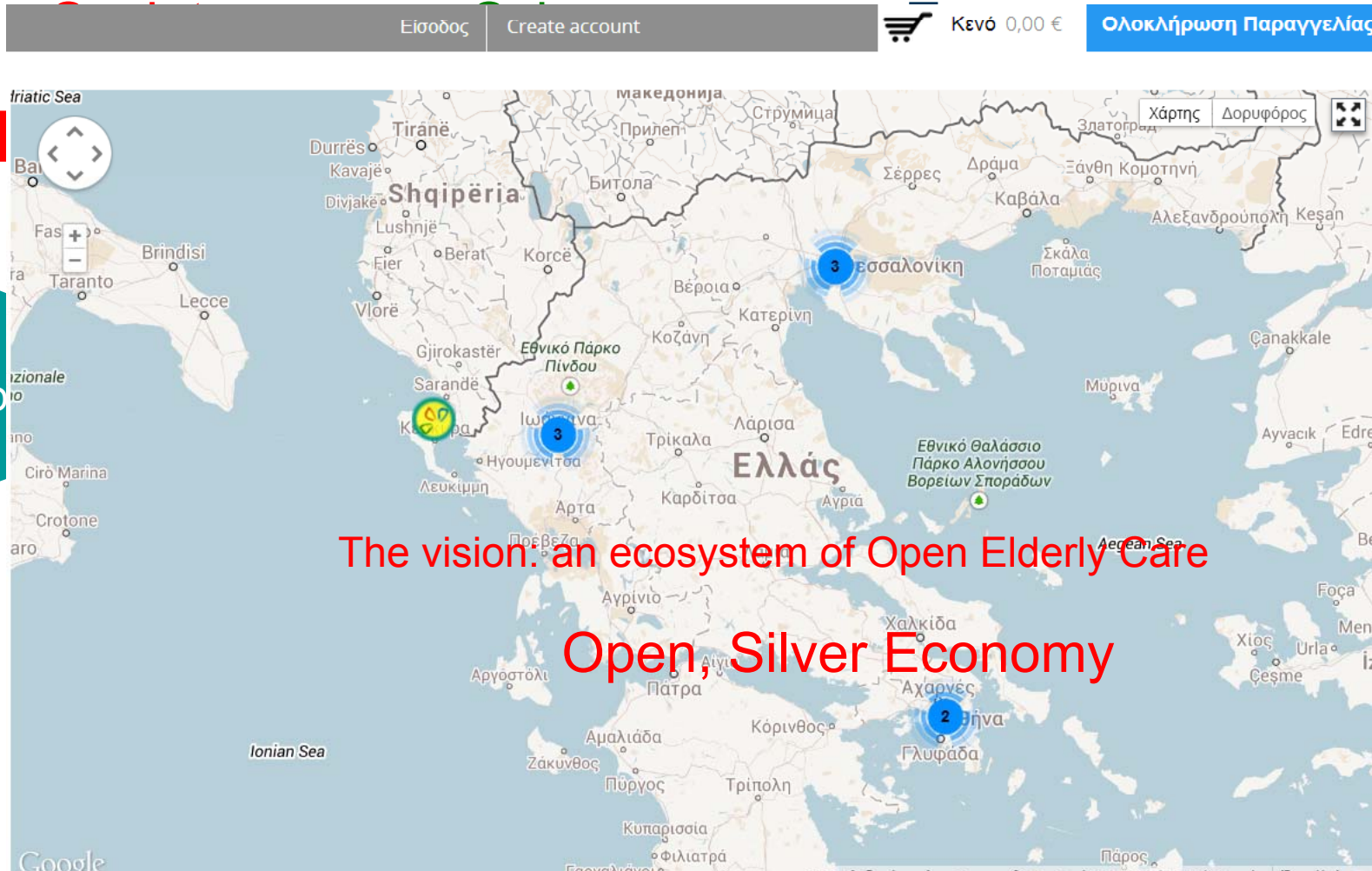
Available at: http://www.mckinsey.com/insights/business_technology/big_data_the_next_frontier_for_innovation.

If we make proper tools to exploit the richness of collected healthy aging data...
we will assist diagnoses and treatments

Aging

Silver

Silver



Idea
concept

loit

loit

loit

loit

The vision: an ecosystem of Open Elderly Care

Open, Silver Economy



The UNCAP project on Active & Healthy Aging

- UNCAP: Ubiquitous iNteroperable Care for Ageing People
- UNCAP delivers an interoperable platform based on open industrial standards
- ...leveraging on existing technologies for biosensing, indoor/outdoor localisation and home-automation.
- Result: an open source, scalable and privacy-savvy ecosystem compatible with existing Personal Health Record systems, that can deliver novel services that can help aging people (incl. those with cognitive impairments) live independently and with dignity.

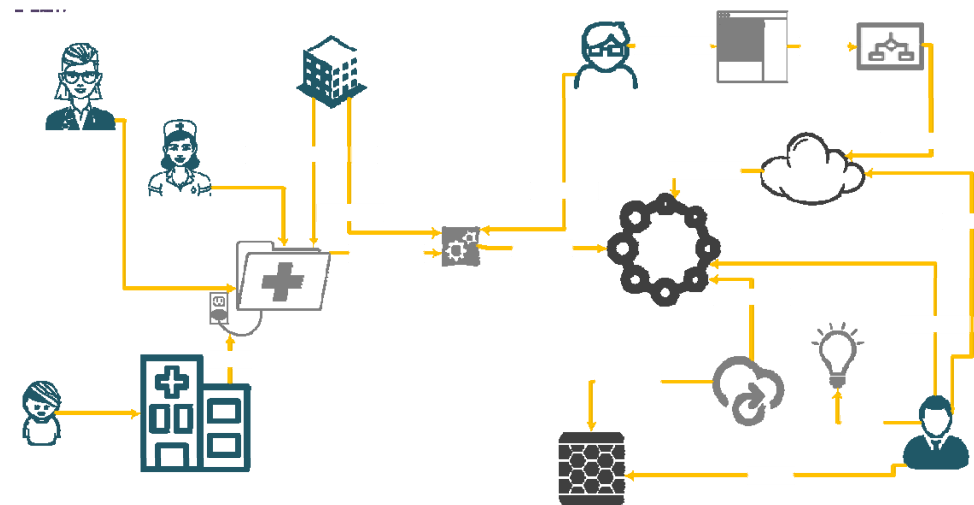


PHC-20-2014: Advancing active and healthy ageing with ICT:
ICT solutions for independent living with cognitive impairment



The eHiF project on Primary Health Care in Greece

- Δικτύωση Μονάδων Πρωτοβάθμιας Φροντίδας
- Συντονιστής ΕΠΙΣΕΥ, ΕΜΠ
- ΑΠΘ εταίρος έργου



Examples from Medical Education

Towards Open Learning

**Let us Opening up Learning,
Education and Training for ALL!**



**Open Research and Open Education –
The hidden treasures**

Christian M. Stracke (eLC / ICORE / University of Duisburg-Essen, Germany)
Ignasi Labastida (OEC / CC / University of Barcelona, Spain)

Bamidis Oct 2014



mEducator (www.mEducator.net)

- A Best Practice Network (BPN) co-funded by the
 - **eContentplus 2008** programme of the European Commission, Information Society and Media Directorate-General, Digital Content & Cognitive Systems
 - Contract Reference: ECP-2008-EDU-418006
- Run between May 2009 – April 2012 **but research keeps going**
- As a BPN, it developed and compared two different solutions/frameworks
 - Solution 1 = mEducator2.0 (based on Web2.0)
 - Solution 2 = mEducator3.0 (based on Web3.0/semantic web)
- Scope: to draw best practice recommendations

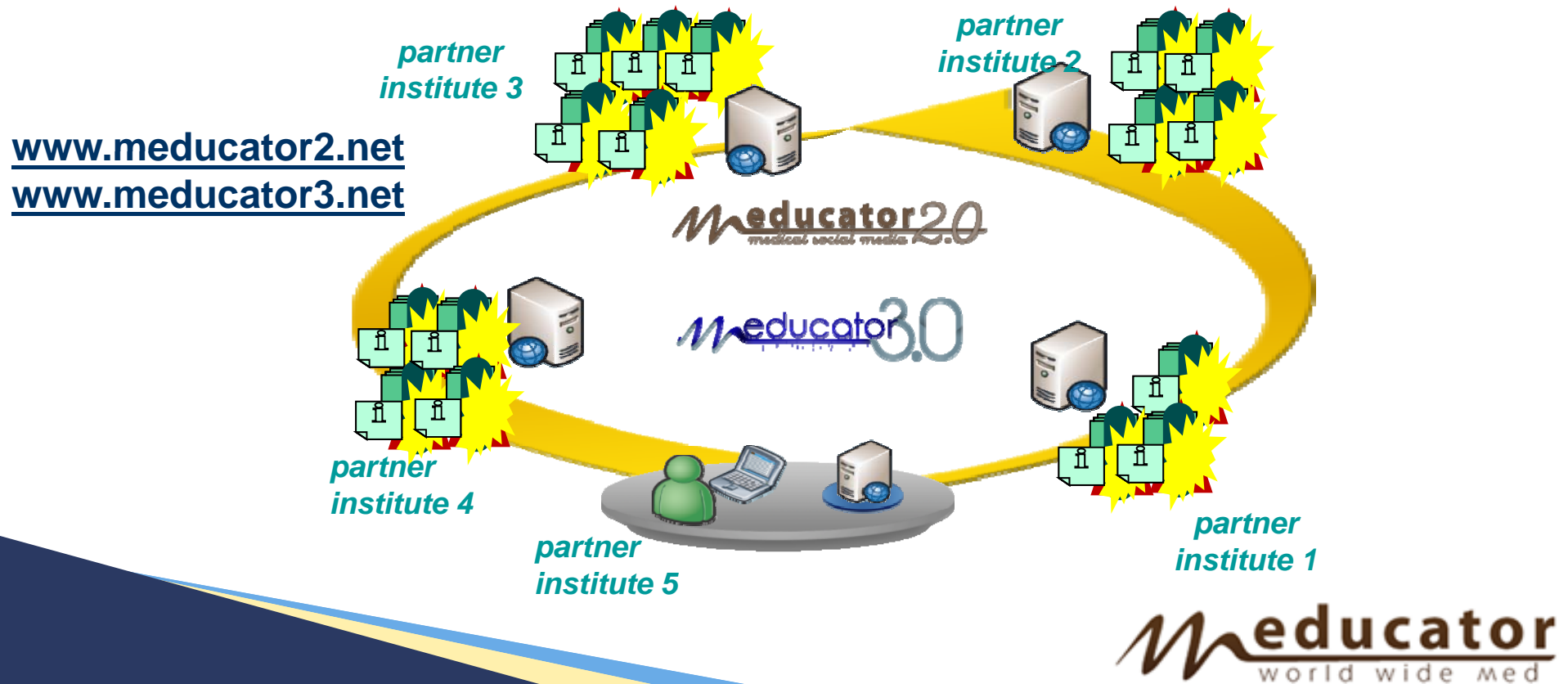
mEducator central idea

- discover, retrieve, use, rate, re-use and **re-purpose** educational content *irrespective* of any Learning Management System use
- Target 1: providers and users of such content:
 - expert instructors (academics / health professionals)
 - students / learners
- Target 2: technical providers of educational (health care) solutions



The main product/service

1. mEducator 2.0: loosely coupled LCMSs via mashup technologies (Web2.0)
2. mEducator 3.0: LCMSs linked via (semantic) linked services (Web3.0)





mEducator Video

<http://www.youtube.com/watch?v=HK5psY48kaQ>

MELINA+

(www.meducator3.net/melinaplus)

- **Medical Education LINKed Arena**
- MELINA+ is one of the implementations of the mEducator3.0 technologies.
- A content management system for medical educational resources.
- Based on **Drupal**, an open source content management system.



MELINA+



[Report an issue](#)



- [HOME](#)
- [EXPLORE](#)
- [CREATE](#)
- [COLLABORATE](#)
- [CONTACT](#)
- [ABOUT](#)

User login

Username or e-mail *

Password *

- [Log in using OpenID](#)
- [Log in using WebID](#)
- [Create new account](#)
- [Request new password](#)

User menu

mEducator

is a largely technical project which is developing ways to discover and share multi-type medical education content.



Explore

Either you are a **doctor** or a **medical student** explore a large collection of educational objects. Get rich related information via DBpedia spotlight annotation. Search across connected sites for other resources. All data are available through a SPARQL endpoint.

[Ways to explore](#) | [DBpedia spotlight](#) | [External search](#)



Create



MELINA+

Report an issue

MELINA+ MEDICAL EDUCATION LINKED ARENA

educator 3.0

HOME EXPLORE CREATE COLLABORATE CONTACT ABOUT

ALL CONTENT

Post date	Title	Author	Total views	Number of comments	Metadata language	Resource language
Wednesday, 4 April, 2012 - 16:24	Νοητική εξασθένηση και η άνοια στην Τρίτη ηλικία με αριθμούς Πρόληψη και αντιμετώπιση	Semetziadou Ana...	4	0	English	Greek, English
Wednesday, 4 April, 2012 - 13:29	Κλινικές δοκιμές και αποτελέσματα - Βελτίωση μνήμης, κατάθλιψη και φυσικής κατάσταση	Semetziadou Ana...	4	0	English	Greek, English
Wednesday, 4 April, 2012 - 12:50	Virtual Patients - a Swiss knife in medical education?	Anonymous (not verified)	10	0	English	English
Tuesday, 3 April, 2012 - 07:55	Long Lasting Memories (LEAM) - A unified solution for cognitive and physical health and autonomous living for senior citizens	Semetziadou Ana...	8	0	English	English
Monday, 19 March, 2012 - 01:09	Description of a game named DENTAL ADDRESS	Semetziadou Ana...	66	0	English	Greek, English
Sunday, 18 March, 2012 -	DENTAL WEBSITE (dewNEWS.net)	Semetziadou Ana...				

HOME EXPLORE CREATE COLLABORATE CONTACT ABOUT

Report an issue

MELINA+ MEDICAL EDUCATION LINKED ARENA

educator 3.0

HOME EXPLORE CREATE COLLABORATE CONTACT ABOUT

USERS

User login

sort by: ACCOUNT created date order: Desc Apply

ella Member since 05.04.2012	Kleanthis Nozikinos Member since 05.04.2012	Dimitra Rodia Member since 05.04.2012	Andreas Nozikinos Member since 05.04.2012
Gorgos Bamparo... Member since 05.04.2012	Dorian Gorgas Member since 05.04.2012		Kostas Boborkidis Member since 05.04.2012

HOME EXPLORE CREATE COLLABORATE CONTACT ABOUT

EDUCATIONAL OBJECTS ADVANCED SEARCH FORM

Title contains

Contains any word

Type

Is one of

URL
URN
ISBN
Okkam ID
ISSN

Identifier

Contains

Quality

Contains

Νοητική εξασθένηση και η άνοια στην Τρίτη ηλικία με αριθμούς

Πρόληψη και αντιμετώπιση

Submitted by Semetziadou Ana... on Wed, 04/04/2012 - 16:24

Content description:

This presentation sets the medical basis for dementia-related interventions.

Keywords:

dementia Alzheimer's disease

[Read more](#) [Log in or register to z](#)

Κλινικές δοκιμές και αποτελέσματα - Βελτίωση μνήμης, κατάθλιψη και φυσικής κατάστασης

Submitted by Semetziadou Ana... on Wed, 04/04/2012 - 13:29

Content description:

The aim of this presentation is to demonstrate scientific results derived from the neuro and fitness assessment before and after an intervention which combines cognitive with





MELINA+ : Advanced features

DBpedia spotlight annotation

Dbpedia Spotlight annotation

1. VIRTUAL

[score: 10%]

Linked Data: [Wikipedia link](#)

<http://dbpedia.org/resource/Virtual>

2. PATIENT

[score: 10%]

Linked Data: [Wikipedia link](#)

<http://dbpedia.org/resource/Patient>

3. SWISS ARMY KNIFE

[score: 12%]

Linked Data: [Wikipedia link](#)

http://dbpedia.org/resource/Swiss_Army_knife

VIRTUAL PATIENTS - A SWISS KNIFE I

View

Translate

Voting results



Submitted by Anonymous (not verified) on Wed, 04/04/2012 - 12:50

Language

English

▼ Identifier

URL <http://www.mei2012.org/content/virtual-patients-swiss-knife>

Educational resource:



[MEI2012_Zary_SpringSchool_dist.pdf](#)

Attribution CC BY



Resource language:

English

MELINA+ : Advanced features

Social learning collaboration

MY RELATIONSHIPS (RECEIVED REQUESTS)

Current

Received requests (2)

Sent requests

Picture	User	Relationship	Operations
	Theofilos Tsach...	Friend	Approve Decline
	Prodrimos Kouto...	Friend	Approve Decline

MELINA+ : Advanced features

Social learning collaboration

Share content

Content access based on your relationships to other users

Relationship Type	view	update	delete
Post to Coworkers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Post to Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Post to Group teammates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Save



REPURPOSE OF SERIOUS GAMES IN HEALTH CARE

View Quality control Translate Voting results

This clone will not be saved to the database until you submit.

Title *

Repurpose of Serious games in Health Care

Main identifier

This property is used to identify the resource by means of one of the next options.

Please select *

- I want to upload my learning object
- My learning object exists already online or is a physical object (e.g. a book) and I'll provide a unique identifier

IPR Licenses

Type of IPR License granted for legally using this medical learning resource. The adopted license can be either one of the Creative Commons Licenses, or a different one.

Please select the appropriate IPR License (experienced users only) *

Attribution-NonCommercial-NoDerivatives CC BY-NC-ND

Dbpedia Spotlight
annotation

1. SERIOUS GAME

[score: 35%]

Linked Data: [Wikipedia link](#)

http://dbpedia.org/resource/Serious_game

2. HEALTH CARE

[score: 18%]

Linked Data: [Wikipedia link](#)

http://dbpedia.org/resource/Health_care



User menu

My account

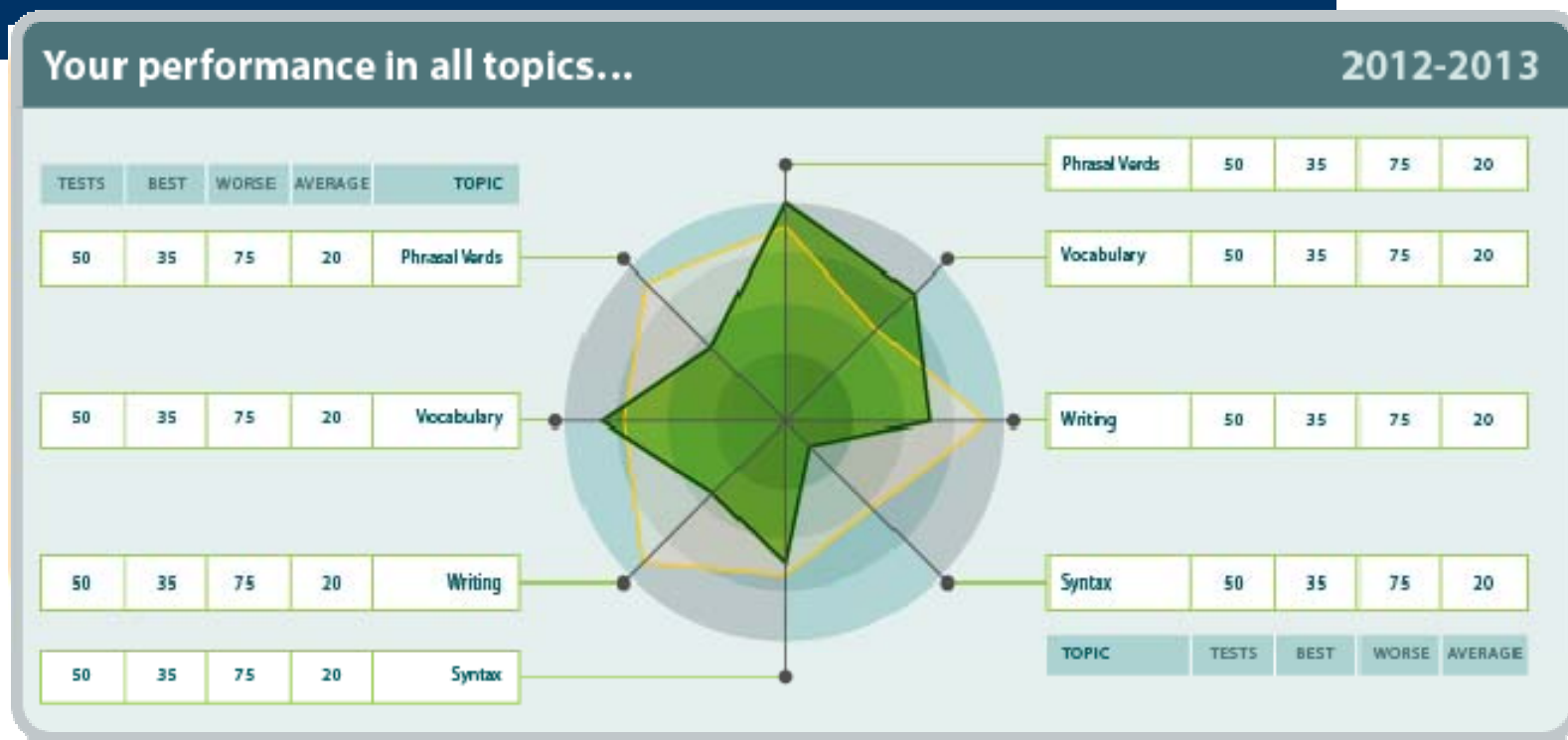


Big (Educational) Data (1)

- Data coming from:
 - online learning environments (e.g. LMS), learning platforms, learning software
- includes log-in information, rates of participation in specific activities, time students spend interacting with online resources or others in the class, and, in some cases, grades (Norris 2011).



Some examples





Medical Learning Analytics (MLA)

- a completely new field, under-researched...
- encompasses the leverage of **Learning Analytics** technologies for boosting **medical educational** practices
- *...and establishing best practices in obtaining student interaction quality*
- *...by optimising learning in medicine and health sciences and fostering those activities that achieve clinical competency.*



An example from
Problem **B**ased **L**earning and
Virtual **P**atients



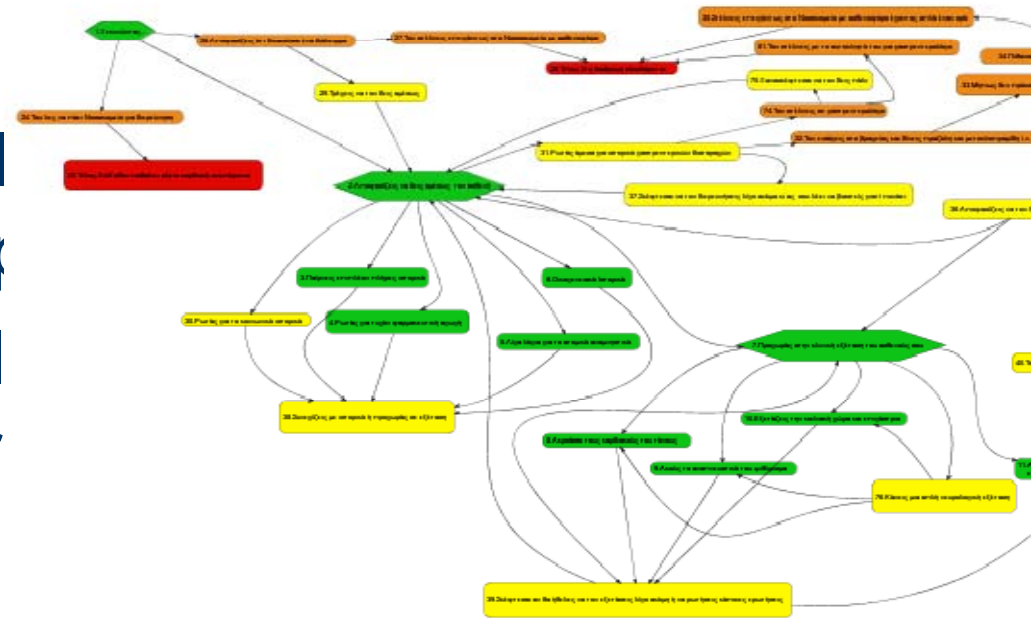
Virtual Patients

- Interactive simulation of health care incidents
- The learners take the role of the professional, being able to:
 - diagnose
 - make therapeutic decisions
- Medical errors challenge the learners without being harmful or fatal to any real person



Open Labyrinth

- Web-based Virtual
- allows users to build pathway-based applications
- Pathways may be built in any other sequence for
- Virtual patients are used because of the many pathways
- Object referencing model allows for easy use and reuse of media, questions, avatars etc.





ARISTOTLE
UNIVERSITY
OF THESSALONIKI

ePBLnet: Establishment of the Supra-Regional Network of the National Centres in Medical Education, focused on PBL and Virtual Patients.

Panagiotis Bamidis
Project Co-ordinator
Aristotle University of Thessaloniki



Tempus

www.epblnet.eu

DISCOVER – Skills for Carers

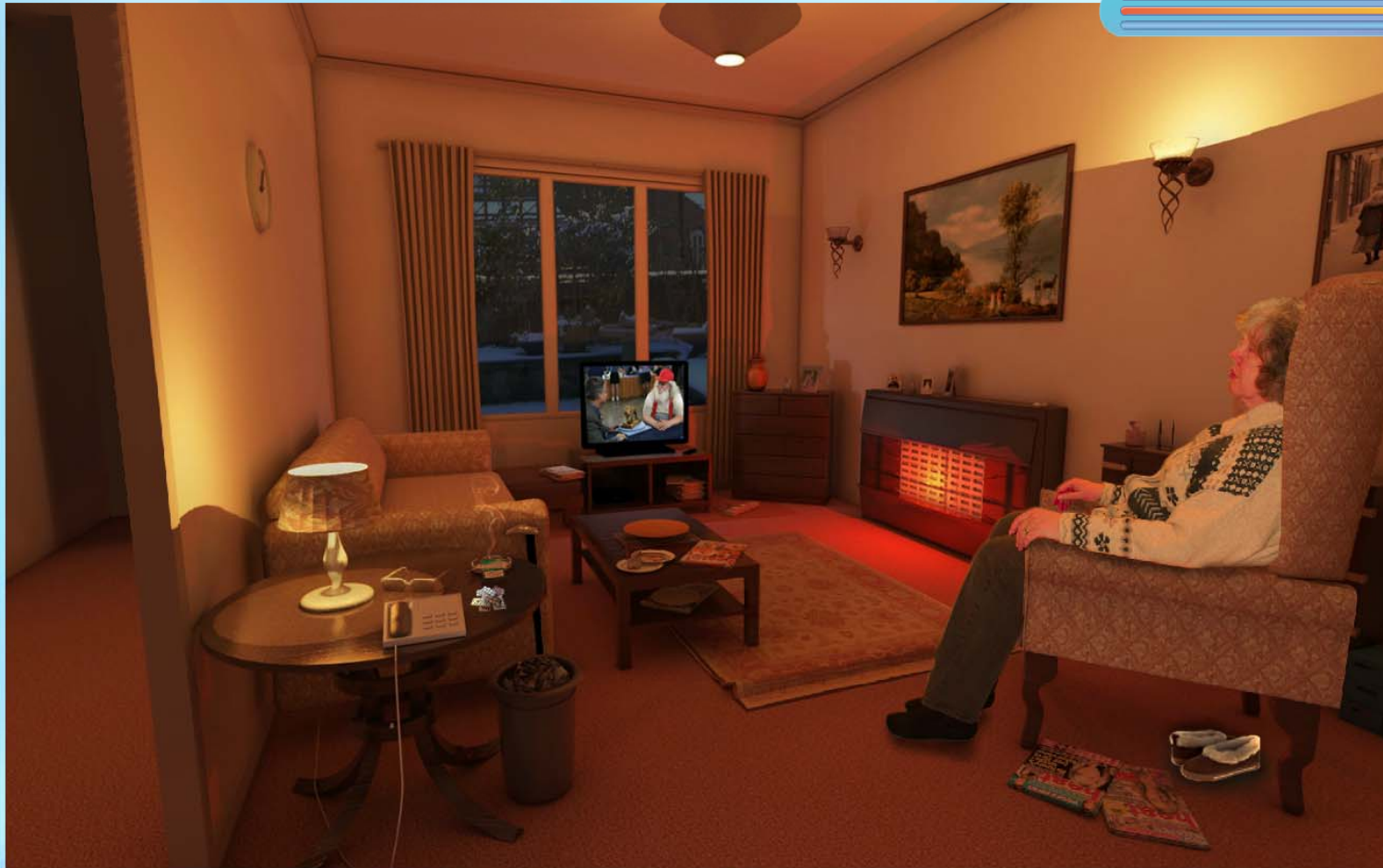
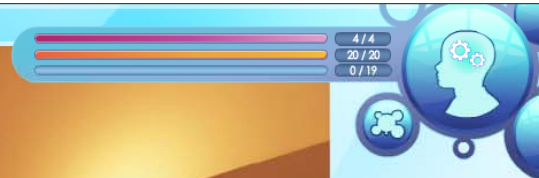
<http://www.discover4carers.eu/>



- Pan-European project, offering **information, advice, guidance** and **training** to support the **wellbeing of carers** in their caring role.
- Fostering a **shared learning environment** for communities of carers; to share experiences, knowledge, challenges and questions.
- Using **everyday technologies** like the internet, mobile phones and other digital devices to reach carers in the comfort of their own home as well as through the use of community locations.
- **Raising awareness** of the **benefits** of acquiring digital based skills for carers as well as sharing this with those they care for, all of which will be done in a mutually supportive way.

Sample eLearning content

4 / 4
20 / 20
0 / 19





Skills needed?

- EU-US collaboration project:
- CAMEI
EU FP7 project

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

The screenshot shows the CAMEI EU Project website. At the top, there is a navigation menu with links for Home, The project, Meetings, Partners, Associated Partners, Upcoming events, and Contact. Below the menu is a user login section with fields for Username or e-mail and Password, and a Log in button. To the right of the login section is a welcome message and a list of main activities. Below the login section is a section for S&I FRAMEWORK, a 'Who's online' section showing 0 users, and a 'Keep me informed!' section with an email field and a Submit button. On the right side, there is a 'Project presentation' section with a 'Share' button and the text: 'CAMEI Coordination Actions in the scientific era of Medical Education Informatics for fostering IT skills for healthcare workforce in the EU and USA'.



Info:

- **mEducator:**
 - YouTube [mEducatorproject](#) channel
 - The project final video is in YouTube:
<http://www.youtube.com/watch?v=HK5psY48kaQ>
 - Follow us in Facebook and twitter (meducator, @meducator)
- **LLM and LLMcare**
 - www.longlastingmemories.eu
 - www.llmcare.gr
- **USEFIL**
 - www.usefil.eu
- **DISCOVER:**
 - <http://www.discover4carers.eu/>
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