Διαχείριση Ανοικτών Ερευνητικών Δεδομένων Υγείας

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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

<table>
<thead>
<tr>
<th>DATA CATEGORY</th>
<th>EXAMPLE DATASETS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agriculture</td>
<td>Crops, fisheries</td>
</tr>
<tr>
<td>Earth observation</td>
<td>Weather, earthquakes, disaster management</td>
</tr>
<tr>
<td>Economy</td>
<td>Lead economic indicators, commodity prices, energy consumption</td>
</tr>
<tr>
<td>Education</td>
<td>Number of students per school, school performance</td>
</tr>
<tr>
<td>Environment</td>
<td>Pollution levels, greening programs</td>
</tr>
<tr>
<td>Geospatial</td>
<td>National and local maps, hazard maps, topography</td>
</tr>
<tr>
<td><strong>Health</strong></td>
<td>Hospital location and services, medicines</td>
</tr>
<tr>
<td>Infrastructure</td>
<td>National roads, tourist spots, broadband penetration</td>
</tr>
<tr>
<td>Public finance</td>
<td>National budget, government payroll, awarded contracts, tax revenue</td>
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<tr>
<td>Public safety</td>
<td>Crime statistics</td>
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<tr>
<td>Research</td>
<td>Experiment results, social science surveys</td>
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<tr>
<td>Social Welfare</td>
<td>Housing, conditional cash transfer programs</td>
</tr>
<tr>
<td>Statistics</td>
<td>National statistics, census</td>
</tr>
</tbody>
</table>
In Horizon 2020 a limited **pilot action on open access to research data** will be implemented. 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**

Regarding the data management plan general tasks, the beneficiaries must:

- **Scientific research data should be easily**
  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

- **Other data, including associated metadata**, as specified and within the deadlines laid down in the data management plan (see Annex I);

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HEALTH AND DATA: A LONG STORY

TEMPERATURE AND MORTALITY OF LONDON For every week of 11 years (1840-50).

HTTP://VISUALOOP.COM/17808/DATA-VIZ-NEWS-43

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

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Maps of open data

<table>
<thead>
<tr>
<th>Country</th>
<th>Dataset Score</th>
<th>Map</th>
<th>Land Ownership</th>
<th>Government Transparency</th>
<th>Government Spending</th>
<th>Budget</th>
<th>Library</th>
<th>Public-transport datasets</th>
<th>Education</th>
<th>Health</th>
<th>Sound</th>
<th>Crime statistics</th>
<th>Environment &amp; Health</th>
<th>Election &amp; Results</th>
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Heath 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.

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.”

NOT ONLY OPEN GOVERNMENT DATA...

1. Non-public data for marketing, business analysis, national security
2. Citizen engagement programs not based on data (eg petition websites)
3. Large datasets from scientific research, social media or other non-govt. sources
4. Public data from state, local, federal govt. (eg budget data)
5. Business reporting (eg ESG data); other business data (eg consumer complaints)
6. Large public government datasets (eg weather, GPS, Census, SEC, health care)

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

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. The original data files are not included in the release. An example of published data would be NHS patient satisfaction surveys.
Open data can help unlock $3 trillion to $5 trillion in economic value annually across seven sectors.

Potential value in open data, $ billion

- Education: 890–1,180
- Transportation: 720–920
- Consumer products: 520–1,470
- Electricity: 340–580
- Oil and gas: 240–510
- Health care¹: 300–450
- Consumer finance: 210–280
- Total: 3,220–5,390

¹ Includes US values only.

Source: McKinsey Global Institute analysis

HTTP://WWW.MCKINSEY.COM/INSIGHTS/BUSINESS_TECHNOLOGY/OPEN_DATA_UNLOCKING_INNOVATION_AND_PERFORMANCE_WITH_LIQUID_INFORMATION
Help patients find a hospital

Source: Mateo Brunatti, ePSI platform
Current text and data mining (TDM) limitations

Eighteen European research and library organisations, are calling on Elsevier 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.


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Google Fit

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

Source: Mateo Brunatti, ePSI platform
Examples from Active and Healthy Aging - Mobile Health
Different Modalities

Brain Activity (EEG)

Breathing (Respiration Rate)

Blood Volume Pulse (BVP)

Skin Conductance (GSR)

Acoustics and Voice

Heart Rate (ECG)

Muscle Tension (EMG)

Temperature

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.

Sensor Platforms - Cameras
The USEFIL system
What is USEFIL trying to do?

ICT Ecosystem

• 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.
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.

Silvergaming Demo video

http://www.youtube.com/watch?v=lR-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.”


If we make proper tools to exploit the richness of collected healthy aging data… we will assist diagnoses and treatments
The vision: an ecosystem of Open Elderly Care

Open, Silver Economy

www.LLMcare.gr
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.
The eHiF project on Primary Health Care in Greece

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

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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)

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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)

www.meducator2.net
www.meducator3.net
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.
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+ : Advanced features

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**

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

**Language**

English

**URL**

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

**Educational resource:**

MER2012_Zary_SpringSchool_clst.pdf

**Resource language:**

English
## MELINA+ : Advanced features

### Social learning collaboration

#### MY RELATIONSHIPS (RECEIVED REQUESTS)

<table>
<thead>
<tr>
<th>Picture</th>
<th>User</th>
<th>Relationship</th>
<th>Operations</th>
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<tbody>
<tr>
<td><img src="image1" alt="Profile" /></td>
<td>Theofilos Tsech...</td>
<td>Friend</td>
<td>Approve Decline</td>
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<td>Prodromos Kout...</td>
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<td>Approve Decline</td>
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</table>
MELINA+ : Advanced features

Social learning collaboration

Share content

Content access based on your relationships to other users

<table>
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<tr>
<th>Relationship Type</th>
<th>view</th>
<th>update</th>
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<tr>
<td>Post to Friends</td>
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<tr>
<td>Post to Group teammates</td>
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Save
REPURPOSE OF SERIOUS GAMES IN HEALTH CARE

1. **SERIOUS GAME**
   [score: 35%]
   Linked Data: [Wikipedia link]
   http://dbpedia.org/resource/Serious_game

2. **HEALTH CARE**
   [score: 19%]
   Linked Data: [Wikipedia link]
   http://dbpedia.org/resource/Health_care

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**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 4.0 International (CC BY-NC-ND 4.0)
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 Based Learning and Virtual Patients
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 linear, branched or any other sequence format.
- Virtual patients are called labyrinths, because of the many pathways.
- Object referencing model allows for easy use and reuse of media, questions, avatars etc.
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

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
Skills needed?

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

http://www.camei-project.eu/
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)

- **LLM and LLMcare**
  - [www.longlastingmemories.eu](http://www.longlastingmemories.eu)
  - [www.llmcare.gr](http://www.llmcare.gr)

- **USEFIL**
  - [www.usefil.eu](http://www.usefil.eu)

- **DISCOVER:**
  - [http://www.discover4carers.eu/](http://www.discover4carers.eu/)
  - Follow @DISCOVER4carers in twitter

- **ePBLNet**
  - [www.epblnet.eu](http://www.epblnet.eu)

- **CAMEI**
  - [http://www.camei-project.eu/](http://www.camei-project.eu/)

- **pdbbamidis@gmail.com** Follow me @bamidis