Citizens Centered Health Information:
A view from Portugal

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February, 2011
Health and digital literacy workshop -
Diabetes association of Barreiro, Portugal
1. Health and literacy survey for members of the diabetes association;
2. Program for improving digital/health literacy: “learning diary”;
3. Prototype design;
4. Prototype implementation and testing.

A SMALL SCALE EXPERIMENT
(2007-2009)

With a personal health information system

Diabetics Association in Barreiro (a town, across the Tagus river from Lisbon) with approximately 1050 members
– 500 active ones
– 50 participated in the experiment (age 40 to 80; low socioeconomic condition)
A SMALL SCALE EXPERIMENT

Joint development and evaluation of PHR prototype
1. We can do it! ... useful way to organize personal health information

2. ... can inputting be simplified?

3. ... how to fit it in our daily living?

4. ... currently outside mainstream thinking in health services

2009 evaluation
Personal health information systems: Portuguese experience II

From a small scale experiment
To a large scale implementation and evaluation program
A partnership between Portuguese Telecom (PT) and the N School of PH

MEU Sapo Saúde
Personal Health Information System
Personal Health Information Systems

MEU. SAPO.SAUDE

Tech potential
Internet
Mobile
TV
Personal Health Information Systems
MEU. SAPO. SAUDE

Tech potential

- Internet
- Mobile
- TV

Expanding/promoting utilization – next step

PT h. services = 100.000
NHS phc = 100.000
Diabetes Ass = 1.000
Personal health information systems: **main objectives**

**EMPOWERMENT**
Repositioning citizens in the health system

**HEALTH LITERACY**
Using information intelligently in day-to-day health related decisions

**COMMUNICATION**
Interacting with others

**INFORMATION MANAGEMENT**
Capturing, annotating, storing and processing data and information

**INFORMATION and HEALTH PROTECTION**
Ensuring readability and information transfer

Adapted from: Sakellarides, C, Pedro, AR. Mendes, MS. Knowledge-centered health innovation - The case for citizen health information systems, 2009
Promoting health literacy through Personal health information systems

Development strategy in “unprepared” environment: 8 complementary approaches?
1. Linking with EHR
Personal health information system

Citizen centered and managed health information

Electronic health records across all NHS services

2009-2012 project

Citizen centered information

Professional managed information

Early pilot proposed
Personal health information systems structure

Personal and family health
- Self – recording
- Self - measurement
- Self – management

Support systems

Health care
- Import/export health care information
- Information exchange with health care providers, caregivers, family
1. Linking with EHR

**Opportunity:** makes sense – right timing

**Limitations:** hierarchical view: providers first
2. Knowledge support and evaluative research
Electronic health records
Citizen centered information
Professional managed information

Knowledge support systems
Knowledge translation and dissemination

Personal health information system
Citizen centered and managed health information
PHIS performance evaluation

- Usability
- Access
- Literacy
- Awareness
- Utilization

Quality

Outcomes

Cost effect.

PHIS Governance

Users as stakeholders

Level 1

Level 2

Level 3

Level 4

Level 5
2. Knowledge support and evaluative research

Opportunity: need recognized

Limitations: too many opportunistic impulses – funding difficulties
3. Participatory innovation and shared ownership
Electronic health records
Citizen centered information
Professional managed information

Knowledge support systems
Knowledge translation and dissemination

Social networks
Web 2.0

Personal health information system
Citizen centered and managed health information
3. Participatory innovation and shared ownership

Opportunity: broaden social base
Limitation: corporate culture not yet attuned
4. Emphasis on customization ... starting with the patient
2. Information export/import communication capacities

1. Basic Module (display, reminder systems)
   Basic problem list
   Selected health monitoring: weight, blood pressure, and others
   Diagnostic tests results (Eye and dental records)
   Medicines in use; immunization
   Allergies and other emergency information (break-the-glass rules)
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2. Information export/import communication capacities

3.1 Organize personally relevant information
   Health services navigation

3.2 Organize personally relevant information
   Social, behavioral, environ. health determinants

3.3 Organize personally relevant information
   Biomedical determinants
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4. Financing and payment information:
Regular mandatory contribution
Private insurance; Direct payments

5.1 Organize personally relevant information

6. Choice and voice opportunities

7. Health risk profile

8. Personal health statements
Living will and advanced orientations;
Organ donation authorization;
Permission, consent forms

9. Personal health management
Advanced problem list
Personal health and health care program
4. Emphasis on customization

**Opportunity:** adaptation to complexity and personalized health information

**Limitation:** not seen as an “early” issue
5. Community and public health support
Local Health Strategies

- Context
- Local Situation
- Targets
- Health Resources
- Action Strategies
- Action Plans
- Monitoring/ Evaluation

Experimental work in 8 community health centers
5. Community and public health support

**Opportunity:** broad community involvement – focus on outcomes, local partnerships and communication strategies

**Limitations:** early development stage
6. Health information governance
Governance: Defensive scenario

- Individual focus
- Payer
- Vendors packaging
- Innovation
- Public policies
- Service providers
- Interoperability priorities
- Community focus
Governance: Unbalanced development scenario

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6. Health information governance

Opportunity: need of an overview
Limitation: no clear locus for governance debate
7. New “social contract”
Health literacy and empowerment as critical elements of a new social contract for health Systems and micro level

Institutionalism

John Rawls  *Theory of Justice* (1971)
“The justification and prescription of perfectly just institutions”

Engaged deliberative incrementalism

Amartya Sen  *The Idea of Justice*  2009
Dynamic “agreements based on public reasoning on ranking alternatives that can be realized”
7. New “social contract”

**Opportunity:** intellectual challenge for a crises period

**Limitations:** small constituency too close to “politics”
8. International cooperation
Tectonic Shifts in the Health Information Economy
Mandl, K, Kohane, I.

Join the Boston CH, Harvard, MIT INDIVO family
8. International cooperation

Opportunity: Learn, adapt, exchange
Limitations: ... “too soon for us”
Promoting health literacy through Personal health information systems

Development strategy – a summary
Promoting health literacy through Personal health information systems - Next step?
Promoting health literacy through Personal health information systems - Next steps?
... maybe the issue is not how much a hostile place the world is but rather that we are not just SMART ENOUGH (yet) to face these challenges!

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