iHEALTH – Health and Innovation in Europe

Transfer of knowledge from science to health practitioners and to citizens

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Knowledge Society Agency

Ministry of Science, Technology and Higher Education, PORTUGAL
Knowledge Society Agency Mission

To coordinate information society policies and its mobilization through research, qualification and awareness activities

Incubated eGovernment coordination and large scale projects (Citizen’s Portal, Enterprise Portal, Full Creation of Enterprises Online, e-ID Citizen Card, Interoperability Platform) spinned off to the recently created Agency for Public Services Modernization, in 1\textsuperscript{st} May 2007

Incubated the National e-Procurement Program spinned off to the recently created National Agency of Public Procurement in the Minister of Finance, in 9\textsuperscript{th} May 2007

Now other major challenges:

- e-Science
- international partnerships in S&T with worldwide leading institutions
- health and biomedical sciences information for citizens
- emerging technologies such as sensor based networks and nanotechnology (including nanomedicine)
Transfer Health and Biomedical Research Knowledge to the Public

Rationale:

Research over the past 30 years has demonstrated that

- people can powerfully protect their own health through adopting healthy lifestyles
- people with chronic illnesses can partner with health professionals to help monitor their illnesses

The interest of the general public in health and in the implications of biomedical research for health has risen greatly.

There is great potential in a nationwide initiative to improve the availability of health information for the general public, and thereby to improve the health of the public.
Transfer Health and Biomedical Research Knowledge to the Public

Further on the rationale:

- Improving the health of the public not only reduces suffering, but it is also a stimulus to the economy through improving the productivity of the work force.

- A decision by a nation to invest in biomedical research requires public understanding and support.

- The next generation of practicing health care professionals and biomedical scientists are today’s children. A properly-designed health education program can ignite their interest in health and biomedical research at an early age.

- The development and public dissemination of high quality health information in Portuguese on the Internet can be valuable to people in all Portuguese speaking countries, especially in Africa and Brazil, impacting outside of Portugal.
Transfer Health and Biomedical Research Knowledge to the Public

Goal of program:

To promote the literacy of the public at large about health and biomedical science, through information provided in the Internet and by a network of individual and institutional intermediaries.

- physicians, nurses, psychologists, pharmacists, journalists, secondary school teachers
- Health Family Units, Ciência Viva centers (science hands on museums for the promotion of the scientific and technological culture)
- family members, particularly younger members of extended families
Participating Portuguese Institutions

- All the 7 Portuguese Medical Schools
- All the 5 Biomedical Research Associate Laboratories and other leading research units
- National Institute of Health (INSA)
- Knowledge Society Agency (UMIC)
- Ciência Viva – Agency for Scientific and Technological Culture
- High Commissariat for Health
- Directorate-General of Health
- National Authority for Medicines and Medical Devices (INFARMED)
Other Portuguese Institutions Expected to Join the Program

- Health Family Units
- Scientific Societies
- Hospitals

International Partnership

- Harvard Medical School
National Platform on Health and Biomedical Research Knowledge

BACKOFFICE

CONTENT EDITION AND CREATION TOOL

LINGUISTICS REVISION

SCIENTIFIC/TECHNICAL REVISION

INTERNET, PHONES

SCIENTIFIC COMMITTEE

PARTICIPATION

FRONTOFFICE

Medical Schools
Associate Labs and Research Centers
INSA – National Institute of Health
Directorate General of Health
High Commissariat of Health
Pharmaceutical Approval Agency
Harvard Medical School
Context of Very High Growth of Science System

Nº of new PhD and PostDoc fellowships every year

Nº of new PhDs every year

Nº of scientific publications (ISI-Thomson)

×4  ×4  ×7.5
The Editorial Agenda

- Initially focused in main priorities of the National Health Plan: heart disease and cancer (prevention, diagnosis and treatment)

- Subsequently, other priority areas in National Health Plan: mental health, HIV/AIDS, neurodegenerative diseases such as Alzheimer and Parkinson, neurovascular diseases, certain genetic diseases
Target Populations

- The general public, with special attention to teenagers and the elderly
- Medicine and other health professions students (open courseware)
- Intermediaries: physicians, nurses, psychologists, pharmacists, journalists, teachers
Multiple Content Formats and Delivery Devices

- Internet-connected devices: PCs at home and at work, handheld devices, health kiosks with screens and earphones in intermediary institutions (e.g., medical practices, pharmacies, science museums)

- Not just text. Also drawings, interactive tools and quizzes, animations and video

- Spoken content, to reach population with limited literacy

- “Push” as well as “pull” through RSS feeds
Online Communities

- **Online communities** have great potential to link health professionals, biomedical scientists, and the general public, and to attract the interest of a major target population: teenagers and young adults. They will be established in priority topics.

- **Ask a scientist communities** will engage scientists and health professionals with expertise in a particular topic area and citizens.

- **Blogs** will be initiated in some mature online communities by health professionals, to stimulate public discussion.

- **Breaking health news** included in RSS feeds will also be published in online communities.
Content for Citizens with Limited Literacy

The program will experiment with providing information for citizens with limited literacy, using spoken voice and images, delivered via the Internet and telephone.

A substantial fraction of Portuguese adults have low educational attainment, particularly people over age 60 – who are also the people with the greatest burden of illness.
Digital Inclusion in Portugal in One Slide

% Internet users by educational attainment
population 16-74 years old, 2007 (1st Quarter)

➔ 7th (90%) of UE27 in people with higher education
(following Netherlands, Luxembourg, Denmark, France, Finland, United Kingdom) average UE27 = 86%

➔ 5th (81%) of UE27 in people with secondary education but no higher education
(following Netherlands, Luxembourg, Denmark, France) average UE27 = 63%

digital divide

➔ 21st (24%) of UE27 in people without secondary education
(only better than Italy, Cyprus, Malta, Bulgaria, Romania, Greece) average UE27 = 36%

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<tr>
<th>Age Group</th>
<th>Internet Users</th>
<th>In 2005 was</th>
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<tbody>
<tr>
<td>age 55-74</td>
<td>5%</td>
<td>2%</td>
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<tr>
<td>age 25-54</td>
<td>24%</td>
<td>15%</td>
</tr>
<tr>
<td>age 16-24</td>
<td>78%</td>
<td>59%</td>
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Source: EUROSTAT
Internet and Broad Band Penetration in the Population (%)
Internet and Broad Band Penetration in Households (%)
Competitive Grant Program for Research Projects on Citizen-Centered Health Information Systems

Assessment of the program impact, in particular regarding the role of intermediaries, to be conducted through a set of research projects

An innovative and comprehensive program such as this, at the scale of a whole nation, provides a valuable opportunity for developing unique knowledge on citizen-centered health information systems
Evaluating the Impact of the Program

Citizen-centered health information systems are likely to become important tools for health literacy and for the empowerment of citizens on health matters.

It is therefore important to design and conduct evaluations of the different interventions.

Assessment of the impact of interventions with intermediaries will be conducted through a series of competitive research grants, solicited by a call for collaborative research proposals.

The lessons learned may have implications for other nations.
5 General Practical Rules for Success in the Knowledge Society

- Develop human capital
- Foster partnerships and knowledge networks
- Aim at outcomes and measure them
- Leave room for bottom up creativity
- Promote internationalization