### Patient education: the experience of a project aiming at increasing the health literacy level in Italy

Maurella DELLA SETA, Rosaria Rosanna CAMMARANO, Paola FERRARI, Tania LOPEZ, Scilla PIZZARELLI, Letizia SAMPAOLO, Antonio SETTE, Corrado DI BENEDETTO

maurella.dellaseta@iss.it

### About the project

- Updated results of the project 'Health Literacy and Patient Empowerment through the development of an e-Health Information System'
- Duration of the project: 2012-2016
- Funded by the Italian Ministry of Health
- Grant of €258,500 (GR-2010-2313824),
- Lead by the Istituto Superiore di Sanità (ISS), the Italian National Institute of Health (ICT Service and Documentation Service)
- Sapienza, University of Rome, Department of Clinical Medicine

### Objectives of the project

- Increasing health literacy level and patient empowerment
- Collecting and organizing the large amount of health information available from quality-evaluated Internet sources
- Developing a Web Portal (MEDUSA Medicina Utenti Salute in rete)
- Providing indexing of selected resources using the Italian Translation of MeSH
- Developing a training pathway in order to enable participants to evaluate health information available on the web, and select relevant and reliable health information.
- Developing a patient-friendly educational multimedia toolkit on medical information for course participants, to be re-used at local courses.

### Main results of our project

- 1 WEB PORTAL
- 1 DATABASE (Dspace)
- 450 INDEXED DOCUMENTS
- 50 TUTORIALS
- 64 HEALTH MACRO-AREAS
- 500 MeSH TERMS IN ITALIAN
- 6 TRAINING COURSES
- 2 POSTERS
- 3 ORAL PRESENTATIONS
- 3 PUBLICATIONS









### Web Portal Home page - www.iss.it/medusa



## 50 Tutorials – Tryglicerides



## Training Courses addressed to patients associations representatives

#### Methods

- The training methodology combined faceto-face and hands-on sessions, ensuring a wide dissemination of information through the use of a **cascade** model.
- This approach is based on the principle that trainees have to coach and mentor other trainees who, in turn, will train others and so on, from level to level. Accordingly, soft and hard copies of teaching materials were delivered to all participants, to provide them with the necessary means to conduct training at local level.

#### The Cascade Model



## Training courses in five Italian regions













The last event will be in Catania, Sicily - October 21, 2016



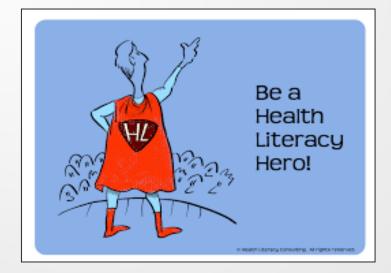
### Training Program aims

Specific training objectives were:

 To identify and assess potential lacks on the common level of highquality health information retrieval

To supply the tools to increase participants own awareness of health

literacy



### Topics of the training courses

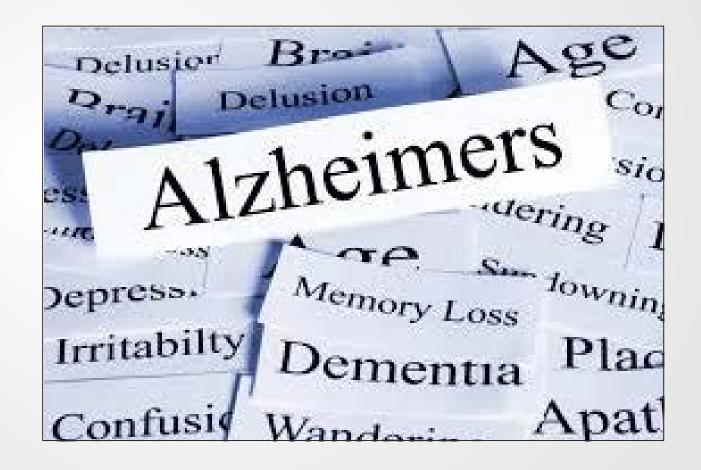
- Each course was divided into two sessions
  - One centered on pressing health topics
  - The other covering issues related to online health information
- Information specialists talked about:
  - Internet, search engines and patient empowerment
  - Quality criteria for the evaluation of health information available on the web
  - Web searching guidelines and tools

## The opening course focused on the Fetal Alcohol Spectrum Disorders

This video was produced to inform women on the importance of the abstention from the use of alcoholic beverages during pregnancy so as to prevent transmission to the fetus of serious conditions <a href="http://medusa.iss.it/handle/2198/211">http://medusa.iss.it/handle/2198/211</a>



## The second course (Reggio Calabria) was centered on Dementia, with special emphasis on Alzheimer Disease.



The Attention Deficit Hyperactivity Disorder (ADHD), a behavior disorder originating in childhood, was the main theme of the third course, in Milan <a href="http://medusa.iss.it/handle/2198/485">http://medusa.iss.it/handle/2198/485</a>



Difficulties in self-control and planning capabilities

## The fourth course (Aviano) was entirely devoted to the Cancer Patients Empowerment.

#### **Breast Cancer Diagnosis Tutorial**



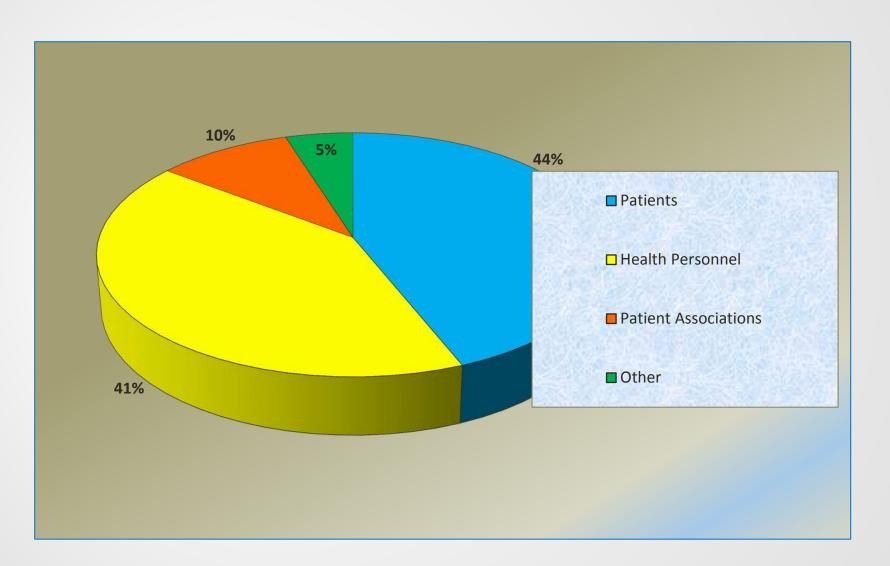
#### **Early diagnosis of Breast Cancer**

- Early detection greatly increases the chance of disease-free survival
- Self examination
- Clinical breast examination
- Ultrasound
- Mammogram

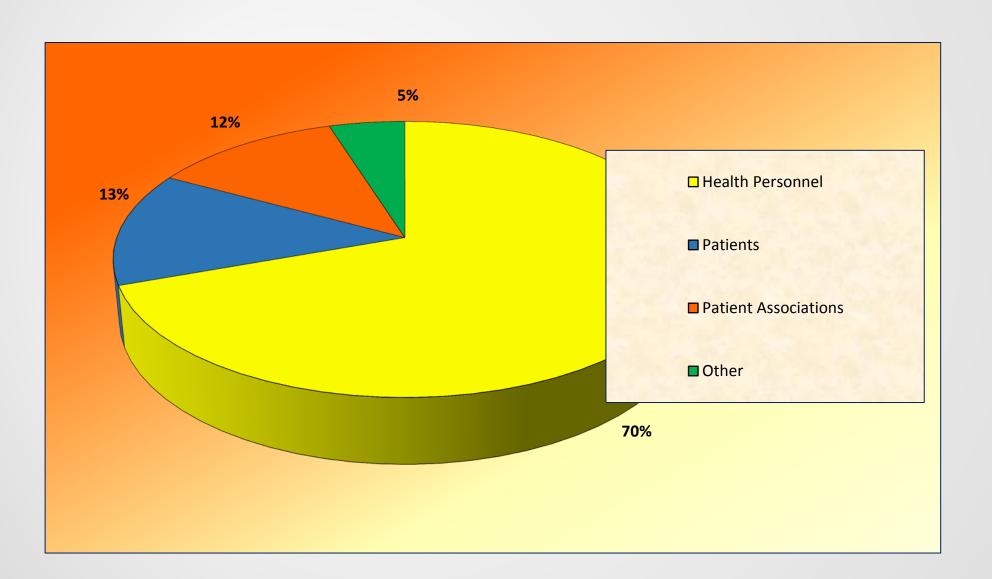
### Fifth course (Siracusa, Sicily) was about Communication in the Physician-Patient Relationship



### Non-CME Courses. Participant Categories



### CME Courses. Participant Categories



### Satisfaction Questionnaires (five courses)

Score	5	4	3	2	1
Overall impression					
The course content was appropriate for my level of knowledge/experience	46	75	12		
The course objectives were clearly defined	60	65	8		
The contents covered the course objectives	58	65	10		
The teaching method was effective	48	74	10	1	
The course has increased my knowledge	55	65	11	2	
The course has increased my skills	45	61	25	2	
I will be able to use what I have learned in the course	46	70	16	1	
Resources					
The course length was adequate to the objectives	30	89	13	1	
The time dedicated to the lessons was adequate	32	78	22	1	
The time dedicated to individual/group exercises was adequate	30	75	23	2	3
The quantity of learning materials distributed was appropriate	50	62	17	1	3
The quality of the learning materials distributed was good	51	72	6	1	3
The number of teachers/facilitators was appropriate	47	78	7	1	
The course was well-organized	68	58	7		

### Multiple-choice test was administered to assess the learning level achieved

- 1. In Google the most relevant results appear:
  - a) As first ones
  - b) As last ones
  - c) At the bottom of the page
  - d) In another window
- 2. What can be searched in Google with the word *define* followed by a term?
  - a) MeSH terms
  - b) Words in English
  - c) Words in Italian
  - d) Definitions of term
- 3. What is the FOG test?
  - a) A test for weather forecasts
  - b) A diagnostic test
  - c) A test for the analysis of texts readability
  - d) A test to measure reflexes

# Challenges and Opportunities of the Training Pathway

### Weaknesses

- It was planned at first to focus on Patient Associations
- Several organizations were contacted but not many were able to respond or meet the needs of our training proposal
- The Portal was built in Italian and that might rise some difficulties for foreigners and migrants living in Italy.

### **Strenghts**

- Specific sessions during the courses were scheduled to deepen pressing health issues
- Therefore several hot topics such as Dementia, Alzheimer Disease, Alcohol and Pregnancy, ADHD, cancer, were addressed by experts (medical doctors and allied health personnel), and patient association representatives. This initiative was highly and widely appreciated

### Conclusions

- Questionnaires administered during the courses resulted in a high level of satisfaction and learning level achieved, reinforcing the need of such initiatives in Countries with a poor Health Literacy level
- Health experts and patient representatives shared their knowledge and experiences in specific health topics
- Public Libraries may use the Portal for reference

