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within the UICC World Cancer Congress

Azalea:
Effectiveness as a result of interaction between virtual and physical resources

G. Cognetti, A. Bogliolo, W. Russell-Edu, K. Bianchet and I. Truccolo

Azalea, the digital library for cancer patients, their relatives and citizens
www.azaleaweb.it

Alleanza contro il cancro
Synopsis

• Information as communication: before and after Internet
• Problems of effectiveness in online health care information
• Azalea’s answer to problems of information and communication
• Beyond Internet: the SICOP project
THE LACK OF COMMUNICATION IN AN EVERYDAY SITUATION...

Let’s first see your reflexes!

No reflex! Just a metallic sound!

I wanted to tell you...

Quiet! I’m thinking! Mumble...Like non-reflexive...something to do with metal!

Not me, but my uncle!
What has your uncle got to do with it? Stick out your tongue!

Ahhhh

Stick it further out!

UHHH...

Uh...

UGHH...

Pooh! How disgusting!

Okay! Now you can talk!

Ugh! Huff! As soon as I can! Gahhh!
Health care on the Internet: from the lack of communication to an excess of information

Biomedical information sites: more than 15,000

- Access to such sites: **37% of the total web access (43% in USA)**
- Users researching health care information on-line: almost 100 million, of which nearly **50% are from the general public, in 90% of the cases**, the person is searching information regarding their disease or that of a member of their family.
- Only 58% of Italians are able to find useful information in their language compared to **96% of Anglophones, 79% French and 89% Polish people** [www.hon.CH](http://www.hon.CH)
- Other statistics: North Europe, Greece, Spain, Portugal 15%, Italy 24% (Eurobarometer Data 2003 cited by Sole 24 ore, 122:18, May 5 2003)

“Europeans constitute the most numerous group using the Internet with 191 million, followed by people from Asia (187 million), North America (183 million), Latin America (33 million), Africa (6 million), and the Middle East (5 million)”

More recent data:

- There are approximately 20 million Internet users in Italy among those over 18-years old (42% - of the majority age population)
- 26% of the information searched for concerns health, i.e.
- 5 million Italians conduct health-related Web searches

Source: “The web as a worldwide health consultant”, CENSIS (Centre for Social Studies and Policies) survey, July 2005)

<http://www.censis.it/>
Effectiveness

Effectiveness =

• Information
  +
• Communication
  +
• Personalization (customization)

• Information must be effective in order to be communicative

• It is necessary to ‘demass’ communication for it to be efficacious (Chamberlain 1994)

• How to combine personalization
  • with electronic systems operating in a
  • stereotypical manner on the Internet?
Factors that reduce the effectiveness of online information (1)

- **Internet is anarchic**
  Information needs to be organized using metadata and international standards

- Search engines contain a great deal of useless information
- There is some risks of not finding necessary information
- Useful information is often found by chance, and in many cases it is not helpful to the patient
Factors that reduce the effectiveness of online information (2)

- Structured databases offer “easy to search” information but often require one to rephrase a question to obtain the necessary information.

- It is necessary to consult other sources to obtain full information (guidelines archives, clinical protocols, papers, journals and books).

- Information needs to be made accessible in an integrated manner (Dublin Core).
Buried under piles of books, journals, leaflets, web-sites and clinical trials!!
Ten ways of naming the same disease!!!
And in Italy some years ago?

- Before Azalea was launched, information for patients in Italy was not collated but rather scattered across virtual and physical sites, journals, pamphlets etc.
- This led to problems of access
- Patients were not in a position to validate the retrieved information
- Duplication of procedures existed as the number of papers regarding any disease, e.g. breast cancer, was unknown
Negative Effectiveness:
lack of quality evaluation of the information

- Invalid health information is potentially lethal

I Chalmers BMJ, April 21, 2001; 322(7292):998b-998
Lack of effectiveness

- **Linguistic barriers**
  make it difficult to use quality information produced in unfamiliar languages

- Only 58% of Italians are able to find useful information in their own language compared to 96% of Anglophones, 79% French and 89% of Polish people

(www.hon.CH)
Linguistic Barrier
Patients are not “empty buckets into which bits of data, treated like bricks, can be tossed” (L. Bunyan)
Last but not least
Internet divide

• Large swathes of population do not have access to the Internet or are unable to obtain online information from the Web.

(in Europe 60-65% do not use the computer/Eurostat data 2006)

“inverse information law”

• “access to high quality relevant information is particularly difficult for those who would need it most...people with low health literacy do not benefit from advance in consumer health informatics...”

G. Eysenbach  JMI R 3(2):e19
Azalea:
an Italian answer to the problems of “effectiveness”

- The Azalea Digital Library for cancer patients and their families

OR

- Effectiveness as a result of interaction between virtual and physical/human resources
What is Azalea?

An Italian multicenter collaborative project financed by the **Alliance Against Cancer**

coordinated by

Centro di Riferimento Oncologico (CRO) Aviano and Regina Elena Institute (IRE), Rome

**Alliance Against Cancer** (Alleanza Contro il Cancro, ACC) is the Italian network of the Oncology Institutes for Research, Hospitalization and Health Care

Created for sharing projects, finances and human resources
Behind Azalea: the international models (1)

CancerBacup
<http://www.cancerbacup.org.uk/Home>

Cancer.gov
<http://www.cancer.gov/cancer_information/pdq/>

Medlineplus

Caphis
<http://caphis.mlanet.org/>

CISMeF
<http://www.cismef.rouen.fr>

Internet Quality Internet resources
<http://biome.ac.uk/>
Behind Azalea: an Italian “real” experience (2)

Behind Azalea there is a non-virtual context:

☑ The Patients Library created at the Aviano National Cancer Institute, 1998, for meeting the information needs of Italian cancer patients in a tailored way.

1. quality validated documentation

2. intermediary expert

3. an assigned place.
Warranty of scientific level, neutrality, accessibility, and confidentiality

http://www.cro-sanita.fvg.it/biblioteca/bibpaz/txt_info_bibpaz.htm
“Mediterranean style” of communication

“Tailored way” means that the intermediary expert can answer the same question with a different package of materials according to the profile of a particular patient.

Physical users versus online

So, at the patients library:

➢ it is useful to hold many booklets about the same topic with different “nuances”

…and Azalea is the repository to be used and implemented

➢ it is fundamental to listen carefully to the users’ information requests …

…this also improves the Azalea search interface

Our aim is to transfer the ability to deal with physical patients to the online users
At present there are about 20 Patient Libraries/Information points in Italy

Some peculiarities and many similarities…

A survey is ongoing
Digital Library - Knowledge Center "R. Maceratini"
Regina Elena National Cancer Institute

Multimedial room

Patient library
Behind Azalea: the physical and electronic archive of the CRO Library for Patients (4)

Azalea’s first nucleus: the “Oncologic Data Bank of Literature for patients and common people” (CRO, ©2003)

about 900 records
So...What is Azalea?

An integrated database offering material on cancer, aimed at patients, their families and the general public: more than 3300 records in total.

Welcome to Azalea, the digital library for cancer patients, their families, and the general public.

Azalea is produced by the Alliance Against Cancer (Alleanza Contro il Cancro - ACC), a network of comprehensive cancer centres designated by the Italian government as Scientific Institutes of Hospital Admission and Treatment (IRCCS) under the auspices of the Ministry of Health, and founded in April 2002.

Azalea offers free access to quality information on cancer, available in print, electronically or on the Internet. The information is presented in a clear and readable style aimed at the lay person, and is mostly in Italian. Azalea is continually updated.
An integrated database means that… (cont’d)

searching for any topic, e.g. “fegato” (“liver”)…
...one can retrieve information not only about documents, but also clinical trials and associations or health care organizations working in that related field (in process)
Cancer on the Internet, July 9-10, 2006

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Clinical Protocol

Voluntary Associations

Full text doc

... about liver...
The Voluntary Associations database: not merely a list of descriptive records

The Voluntary Associations database is integrated into the documents database as a result of:

- Standardized description
- MESH/NLM subjects
- MESH subjects in Italian thanks to the translation by the Istituto Superiore di Sanità (ISS), Rome
The contact with the Associations…

We keep in touch with the Associations…

In this way, those who produce cancer information for patients

- can become better known to the public (see the Agenda)
- are easily contactable, irrespective of their Web presence or absence and regardless of their geographical location in Italy
Azalea in figures, June 2006

✓ **1892** records pertaining to informational material

✓ **614** full text, **229** websites, **89** clinical trials, **822** obtainable by request from holding library

✓ The materials available are: books, leaflets, articles, associations, web sites, clinical trials, dvds etc...

✓ The main language of the material is Italian
The Azalea Patient Forum

- 4 more Institutions collaborating beyond the 7 initial ones, plus other contacts

- **More than 400 documents** delivered on request by traditional and electronic mail (*since October 2004*)

- **Total 19,000 different Internet visitors** each month

- **Analysis of usage statistics to improve the database and make it more suitable to user needs**
An overview on the Azalea resources

New records alert

Search by subject

Results

Types of documents: print, electronic, websites, etc..

Clinical trials

Associations Database

Document Delivery among libraries

Cancer on the Internet, July 9-10, 2006

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Despite its complex back office...

Software Development Team
- database
- WEB languages
- liJAVA language
Etc...

Librarians Team
Quality Evaluation Staff

WEB SERVER
APPLICATION SERVER
DATABASE SERVER
Azaleaweb has a simple interface for facilitating information retrieval by those with little or no expertise …

**You can search by**

- simply typing one or more commonly-used terms in the search box
- or choosing a subject from a list
- or clicking on a body part
- or writing the name of an Association…
The patient can easily contact the Azalea Network Libraries

Any user can easily request the documents, or any kind of information if the document is not downloadable in full.
The Azalea way to support online information

Patients can obtain detailed, up to date and straightforward answers to their questions by:

✓ mail, telephone/fax OR
✓ coming to the nearest or preferred Library/Information Point of the Azalea Network OR
✓ coming to the nearest Association

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The Quality Evaluation of the Material in Azalea: some hints

- The three aspects of the Quality Evaluation of the material
  a) TECHNICAL-FORMAL ASPECTS
  b) COMMUNICATIVE STYLE
  b) CONTENT

Tools:
- A system of 3 evaluation grids for evaluating the 3 aspects
- The Materials Evaluation Committee
- Priority list criteria
- Patients opinion about quality
The Evaluation Circle in AZALEA

4th STEP
Patients' Evaluation
Patients with different cultural backgrounds complete a user satisfaction questionnaire to evaluate the document. 98% of the patients and their families interviewed by the CRO Aviano (84 questionnaires) judged the documents to be clear, comprehensible, complete and useful.

3rd STEP
Scientific Evaluation
A scientific committee examines the document and evaluates its scientific content by means of a purpose-built grid.

Information Provider:
Associations, scientific societies etc.

The evaluation of the document may be sent back to the information provider who can then improve on the quality of its information content and style.

1st STEP
Librarians' Evaluation
The Librarian evaluates the document by means of grids designed on the basis of internationally accepted criteria.

2nd STEP
Communication Evaluation
A team with expertise in the field of communication (psychologists and librarians) carry out a detailed assessment of the legibility and psychological impact of the document by means of specific evaluation grids.

The patient can directly read the evaluation of the document in AZALEA.

http://www.pa.izs.it/eahil/eahil_posters_docs/pdfcd/Cognetti-doc.pdf
The Result of the Quality process is a Quality Evaluation abstract

- **Readable online by the Internet users**
- **Physically deliverable to the “real” users of the Libraries**
- **The Quality Evaluation grids and guidelines are available online**

<table>
<thead>
<tr>
<th>Valutazione di qualità</th>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Stato valutazione di qualità</strong></td>
<td>Validato</td>
</tr>
<tr>
<td><strong>Data di valutazione</strong></td>
<td>01/04/2004</td>
</tr>
<tr>
<td><strong>Gruppo di valutazione</strong></td>
<td>Staff clinico-scientifico del CRQ</td>
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</tbody>
</table>
| **Sintesi della valutazione** | Il documento raggiunge un’ottima qualità di produzione, soprattutto per quanto riguarda la struttura e la chiarezza del testo. Gradevole nell’aspetto grafico, si individuano un unico design a tutto l’opera e le struture di riferimento in cui operarono gli autori. Il contenuto risulta ricco di utili informazioni, sia a scopo medico per specificazioni o approfondimenti, sia di carattere “amministrativo” per la gestione e la comprensibilità: i termini utilizzati sono chiari e precisi.
Il tono coloquiale e l’assenza di termini e acronimi eccessivi, contribuiscono a dare un’impressione positiva del lettore. Manca la presenza di un intervento diretto degli autori e delle strutture di riferimento per “fornire” ai lettori “lavori” o ossia a tutti coloro che si apprestano alla formazione o alla crescita professionale.
La suddetta valutazione si riferisce alla versione presente nel 2006. |
Patients opinions regarding quality of the written and electronic material: a survey is ongoing

✓ **Patients and citizens are asked their opinion concerning the quality of the material consulted and requested through Azalea**

✓ **An easy-to-answer questionnaire is downloadable**
A hint: patients opinions concerning quality of specific documents indexed in Azalea

<table>
<thead>
<tr>
<th></th>
<th>Clear/Simple</th>
<th>Comprehensible</th>
<th>Complete</th>
<th>Useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very</td>
<td>63%</td>
<td>57%</td>
<td>20%</td>
<td>44%</td>
</tr>
<tr>
<td>Enough</td>
<td>27%</td>
<td>34%</td>
<td>46%</td>
<td>39%</td>
</tr>
<tr>
<td>Sufficient</td>
<td>9%</td>
<td>10%</td>
<td>28%</td>
<td>15%</td>
</tr>
<tr>
<td>Poor</td>
<td>0%</td>
<td>0%</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>Not at all</td>
<td>0%</td>
<td>0%</td>
<td>1%</td>
<td>0%</td>
</tr>
</tbody>
</table>

...in a sample of 113 people, users of the CRO LP, 2004

Bianchet, K, et al. AIDAinformazioni, 3, 2005 <www.aidinformazioni.it>
Last but not least: the SICOP Project

Information System for Oncological Communication with Patients

- Approved by the Italian Ministry of Health in 2006
- Coordinated by IRE, Rome
- Participants:
  6 Cancer Research Institutes,
  3 Associations for patients
- Aim:
  to establish quality communication models for the supplying of information to patients
- Multidisciplinary equipes (librarians, psychologists, oncologists etc) are involved in the project
Conclusion

To quote Gertrude Stein, “A difference, to be a difference, must make a difference”, we believe that the Azalea information system can make a difference in the Internet world because of its formula:

- Digital library +
- Physical patient library +
- Voluntary Associations collaboration +
- Close Involvement of Healthcare Professionals in Evaluating Quality and Writing Materials for Patients
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⁶ National Cancer Institute Pascale, Naples, Italy
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(**on behalf of all the CRO Aviano Staff involved in the Quality Evaluation of the Material)
Thank you for your attention!

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