



# Cancer on the Internet 3rd International Conference

ESO, 9-10 July, 2006

Washington - USA

within the UICC World Cancer Congress



*Azalea,  
the digital library for  
cancer patients, their  
relatives and citizens*  
[www.azaleaweb.it](http://www.azaleaweb.it)



Alleanza contro il cancro

Cancer on the Internet,  
July 9-10, 2006

©I. Truccolo;G. Cognetti

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

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



# 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...**



## THE LACK OF COMMUNICATION IN AN EVERYDAY SITUATION...

# Health care on the Internet: from the lack of communication to an excess of information

## Biomedical information sites: more than 15.000

Source: <http://us.deloitte.com/us/news/99april/eastudy.htm>

- 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)"

[http://www.nua.ie/surveys/how\\_many\\_online/](http://www.nua.ie/surveys/how_many_online/). 2003.



# **“The web as a worldwide health consultant”**

**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**
- **Information needs to be made accessible in an integrated manner (Dublin Core)**
- **It is necessary to consult other sources to obtain full information (guidelines archives, clinical protocols, papers, journals and books)**



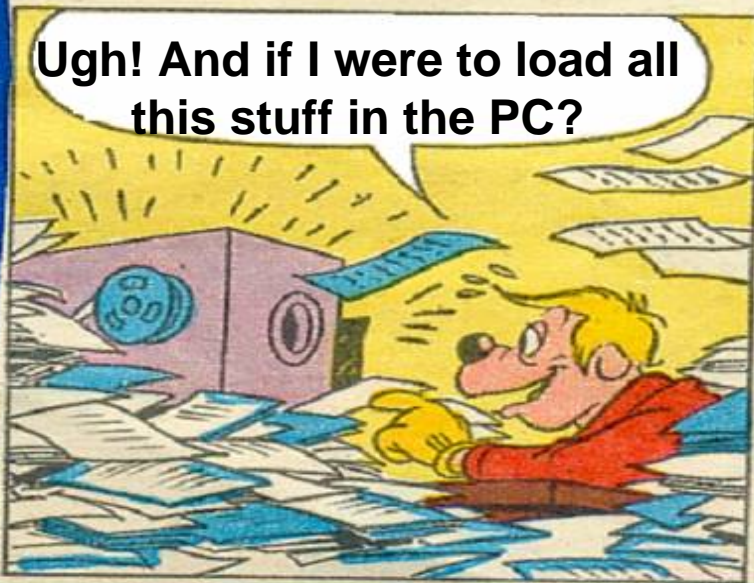
Maybe I am going mad!!

Buried under piles of books, journals, leaflets, web-sites and clinical trials!!  
Ten ways of naming the same disease!!!



Other limitations are the lack of integration of information

Ugh! And if I were to load all this stuff in the PC?



Anyway the Supercomputer swallows it all! ha! ha!



**THE INTERNET IS ANARCHIC: IT DOES NOT GUARANTEE  
THE EFFICIENT RETRIEVAL OF INFORMATION**

# 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](http://www.hon.CH))





# Linguistic Barrier

The screenshot shows the MedlinePlus website in English. The header includes the MedlinePlus logo and the text "A service of the U.S. NATIONAL LIBRARY OF MEDICINE and the NATIONAL INSTITUTES OF HEALTH". Below the header is a search bar and navigation links. The main content area is divided into several sections: "Start here with over 700 topics on conditions, diseases and wellness", "Drug Information", "Medical Encyclopedia", "Dictionary", "News", "Directories", and "Other Resources". Each section has a brief description and a link to the corresponding content.

The screenshot shows the National Cancer Institute website in Spanish. The header includes the National Cancer Institute logo and the text "National Cancer Institute U.S. National Institutes of Health". Below the header is a search bar and navigation links. The main content area is titled "Documentos sobre el cáncer" and contains several sections: "LINKS LINKS", "¿Por dónde empezar?", "Estadísticas de personas con cáncer", and "¿Dónde obtener información sobre el cáncer (PDF)?". Each section contains a list of links and brief descriptions.

The screenshot shows the CISM eF website in French. The header includes the CISM eF logo and the text "Catalogue et Index des Sites Médicaux Francophones". Below the header is a search bar and navigation links. The main content area is titled "5 modes de recherche" and contains several sections: "C'est de quoi se servir", "Accès aux Auteurs de la Bibliothèque", "Recommandations et avis", "Informations pour les patients", and "Essais cliniques et études". Each section contains a list of links and brief descriptions.







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 JMIR 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?



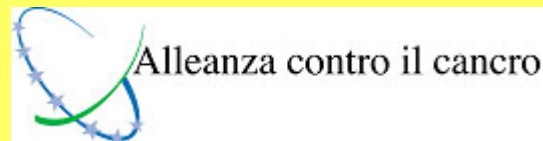
An Italian multicenter collaborative project  
financed by the Alliance Against Cancer

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/](http://www.cancer.gov/cancer_information/pdq/)>

## Medlineplus

<<http://www.nlm.nih.gov/medlineplus/medlineplus.html>>

## 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](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.

I. Truccolo et al. A pilot project of Cancer Patient Library in Italy: the results of a customer satisfaction survey and its products, *Health Info Libr J*, 2006 in press





## 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***



# The Network of Azalea's libraries (3)

## Information services in Italy



- ✓ 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. Macerani”  
Regina Elena National Cancer Institute



Multimedial  
room

Patient  
library



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



**Truccolo I et al . An Italian Oncology Data Bank for patients and common people. *EAHIL Newsletter* 2002, 2002 (61): 21-**

# So...What is Azalea?

**Azalea**  
Alleanza contro il cancro  
Biblioteca digitale in oncologia per malati, familiari e cittadini.

Home What is Azalea Editorial Committee Endorsement Contacts Collaboration Disclaimer

Newsletter News Link to Azalea

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.

Search

[Research tips] - [Subject search](#)

Search by bodyparts

Start your search from:

Nervous system Head and Neck

Endocrine glands

Prevention  
Environmental factors  
Treatment and rehabilitation  
Complementary therapies

First event in agenda

Washington, DC, 09/07/2006

[CANCER ON THE INTERNET](#)

conferenza

[Events Agenda] - [Suggest an event]

[DATABASE ASSOCIATIONS](#)

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

[www.azaleaweb.it](http://www.azaleaweb.it)

**Bogliolo et al. More information, more choice: an Italian database for oncology patients**  
*Ann Oncol.2005; 16: 1962-1967*

# An integrated database means that...(cont'd)

File Modifica Visualizza Preferiti Strumenti ?

Indietro Cerca Preferiti

Indirizzo [http://www.azaleaweb.it/pub/search?lang=en\\_EN&key=liver&submit.x=27&submit.y=8](http://www.azaleaweb.it/pub/search?lang=en_EN&key=liver&submit.x=27&submit.y=8) Vai

Adobe Y! digita chiave di ricerca Cerca Entra Y! Mail Il Mio Yahoo! Links

**Azalea** Alleanza contro il cancro  
Biblioteca digitale in oncologia per malati, familiari e cittadini.

[Home](#) [What is Azalea](#) [Editorial Committee](#) [Endorsement](#) [Contacts](#) [Collaboration](#) [Disclaimer](#)

**Search results**

Insert a word:

Ordina i risultati per

[Help](#)

Found: 24 documents, 0 clinical protocols, 2 [associations](#)

...one can retrieve...



### Risultati della ricerca

Inserisci un termine:

prostat\*

Ordina i risultati per

Rilevanza

Cerca

[Aiuto](#)

Trovati: 33 Documenti , 0 Protocolli clinici 3 [Associazioni](#)

#### Documenti



Pagina Web 1/33


[Tumori della prostata](#) / Urologia clinica .

Breve descrizione

**...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)**

**Azalea: Dettagli protocollo - Microsoft Internet Explorer**

Indirizzo <http://www.azaleaweb.it/pub/viewProtocollo?id=27592>



**Alleanza contro il cancro**  
Biblioteca digitale in oncologia per malati, familiari e cittadini.

Home Cos'è Azalea Comitato Editoriale Garanti/Valutazione Contatti Collaborazioni Avvertenze per l'uso

Newsletter **NEW** [Novità in Azalea](#) [Link ad Azalea](#)

**Dettagli protocollo**

**Protocollo clinico**

**Nemorubicina cloridrato (PNU-152243<sup>o</sup>) somministrata tramite arteria epatica in associazione a cisplatino in pazienti adulti con carcinoma epatocellulare non resecabile: studio di fase II preceduto da una fase di identificazione della dose. NEMA-0027-017. EUDRACT number 2005-000731-26, versione emendata 28 febbraio 2005 (CRO-19-2005) . Aviano : CRO , 2005**

**Descrizione**


- Obiettivo: determinare la dose massima tollerata e le tossicità dose-limitanti e raccomandare una dose della combinazione nemorubicina + cisplatino adatta; valutare l'efficacia antitumorale dell'associazione.
- Principio attivo del farmaco: nemorubicina cloridrato, cisplatino.
- Categoria: chemioterapico.
- Studio: sponsorizzato.
- Tipologia del paziente eleggibile: carcinoma epatocellulare non resecabile non suscettibile di trattamento ablativo con radiofrequenza; nessuna precedente chemioterapia sistemica o locoregionale.
- Controindicazioni (i criteri di esclusione): variante fibrolamellare di carcinoma epatocellulare; arruolamento in corso in un altro studio clinico; pazienti con invasione vascolare; diffusione tumorale extraepatica; precedente trapianto di fegato.
- Reclutamento: aperto.

**Contatti** Dott. Roberto Sorio, Oncologia Medica C. tel. 0434.659172. e-mail [rsorio@cro.it](mailto:rsorio@cro.it)

Operazione completata

**Informazione-Prevenzione - Scheda - AIOM - Associazione Italiana di Oncologia Medica - Microsoft Internet Explorer**

Indirizzo [http://www.aiom.it/InformazionePrevenzione/Itumoripiudiffusi\\_Scheda.asp?id\\_session=E9A04F68476244099D1AC8E1C1906FBC&id\\_BoxContent=190Selectionmen](http://www.aiom.it/InformazionePrevenzione/Itumoripiudiffusi_Scheda.asp?id_session=E9A04F68476244099D1AC8E1C1906FBC&id_BoxContent=190Selectionmen)



**Associazione Italiana di Oncologia Medica**

Associazione Iscrizione Attività Scientifica Event-Congressi News **Informazione-Prevenzione**

Martedì, Luglio 4, 2006 Home Deve stare Link utili Contatti Area Associati

Home > [Informazione-Prevenzione](#) > [Tumori più diffusi](#) > Scheda

**Tumore del fegato**

**I tumori più diffusi**

**I tumori infantili**

**Cartelle stampa**

**INCIDENZA**

Nel mondo si contano un milione di nuove diagnosi l'anno di tumori maligni del fegato. Si tratta di patologie frequenti in Asia e Africa, più rare nei Paesi Occidentali dove corrispondono al 3-5% di tutti i casi di tumore. Colpiscono in prevalenza maschi di media età.

I principali fattori di rischio per l'insorgenza di tumori del fegato sono: infezione da virus dell'epatite B o C, cirrosi (processo degenerativo del fegato), abuso di alcool. In alcune aree geografiche asiatiche e africane è stata evidenziata una correlazione con il consumo alimentare di aflatossine (prodotte da particolari funghi, chiamati aspergilli, che crescono nei depositi di grano) e di nitriti. Dati contrastanti riguardano l'esposizione ad ormoni steroidei e l'assunzione della pillola contraccettiva: ad oggi nessun dato certo depone per un aumentato rischio di tumore al fegato.

**CLASSIFICAZIONE**

L'epatocarcinoma è il tumore epatico maligno più frequente. Altre varianti più rare di tumori epatici maligni sono il carcinoma a cellule chiare, l'emangioendoteloma, il sarcoma a cellule di Kupfer e l'epatoblastoma (tipico dell'infanzia).

**CLINICA**

I sintomi sono pochi, aspecifici, per lo più tardivi. La presentazione più frequente è costituita dalla comparsa di dolore e senso di tensione addominale, calo di peso, stanchezza, diminuzione dell'appetito. Talora è presente ittero (pigmentazione giallastra della cute), spesso associato a prurito diffuso, urine scure (colore marsala) e feci chiare (ipocromiche).

**Clinical Protocol**

**Full text doc**

**Azalea** Alleanza contro il cancro

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**Associazione Prometeo**

**Abbreviazione:** PROMETEO

**Descrizione:** L'Associazione nasce presso l'Istituto Nazionale di Milano per iniziativa di un gruppo di ex-pazienti e dall'equipe medica dell'Unità Operativa di Chirurgia 1 e Trapianti di Fegato. I volontari offrono la loro disponibilità per sostenere la ricerca, finanziare progetti scientifici per la cura dei tumori del fegato, pancreas e vie biliari. E' parito il Progetto "Casa Accoglienza" che consiste nel raccogliere fondi per la costruzione di una casa di accoglienza per quei pazienti e i loro familiari che non risiedono nelle vicinanze delle terapie giornaliere.

**Attività:** Prometeo, organismo onlus, è un'Associazione, senza fini di lucro che opera a favore dei propri familiari prima e dopo il trapianto. L'altro suo obiettivo primario consiste nella prevenzione dei tumori del fegato del pancreas e delle vie biliari. E' sempre vicino ai pazienti e alle loro famiglie, per migliorarne la qualità di vita con l'aiuto di psicologi e volontari. Sostiene la ricerca sulle proprietà biologiche, molecolari e biochimiche delle neoplasie del fegato, del pancreas e delle vie biliari. Finanzia progetti scientifici per la cura di questi tumori attraverso borse di studio, pubblicazioni scientifiche, materiale informativo sull'argomento. Diffonde la cultura della donazione degli organi, l'organizzazione dei trapianti, lo sviluppo delle nuove

**Voluntary Associations**

**... about liver...**

# The Voluntary Associations database: not merely a list of descriptive records

**Associazioni**

**1/3 Associazioni**

[Europa Uomo \[EUROPAUOMO\]](#)

<b>Descrizione</b>	E'una libera associazione di cittadini, in grandis dedicata al raggiungimento degli obiettivi statuti hanno sperimentato o stanno sperimentando q segnare l'esistenza ma anche a tutti gli uomini informati su questa patologia.
--------------------	--

**2/3 Associazioni**

[LIFE \[ALIFE\]](#)

<b>Descrizione</b>	Life è un'associazione non profit per la prevenz Fondata nel 1986 e riconosciuta ente morale, s dei tumori più diffusi, avvalendosi di Medici qua codificati protocolli diagnostici. La prevenzione dell'utero, della pelle.
<b>Soggetti (italiano)</b>	<a href="#">Prevenzione di base</a> , <a href="#">Ricerca oncologica</a>
<b>Soggetti (inglese)</b>	<a href="#">Primary Prevention</a> , <a href="#">Oncology research</a>

**3/3 Associazioni**

[Associazione Volontaria Promozione e Ricerca Tumori \[AVOPRO\]](#)

<b>Descrizione</b>	L' Associazione è nata nel 1981 ed è iscritta al solo nel territorio di Parma e provincia. Promuc strumenti per la diagnostica, promuove screeni attiva l'assistenza domiciliare al paziente oncol
--------------------	--

**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**



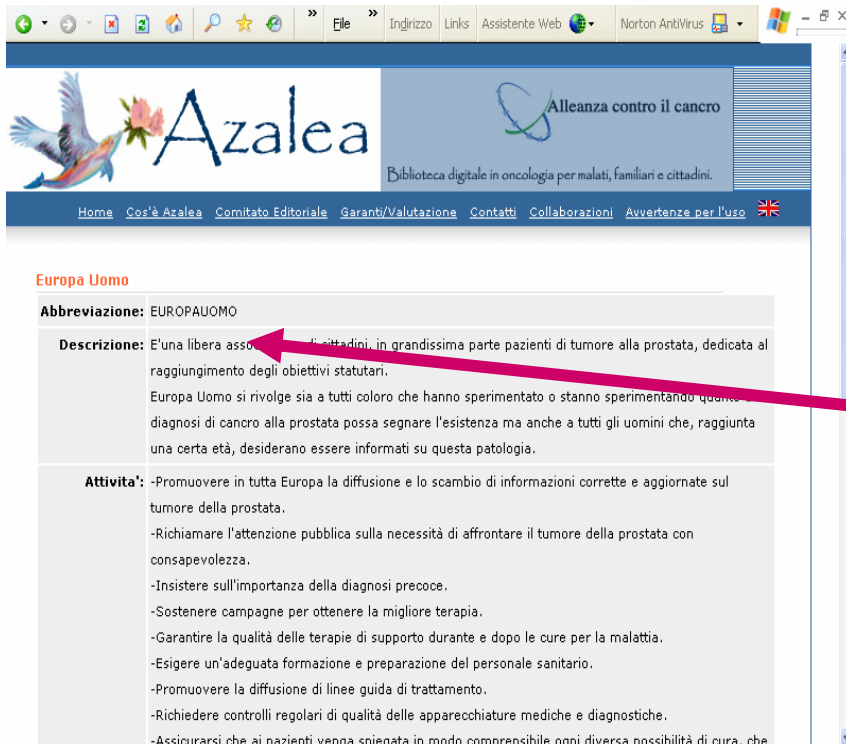
# The contact with the Associations

*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*



The screenshot shows a web browser window displaying the website 'Azalea' (Allianza contro il cancro). The page features a navigation menu with links like 'Home', 'Cos'è Azalea', 'Comitato Editoriale', 'Garanti/Valutazione', 'Contatti', 'Collaborazioni', and 'Avvertenze per l'uso'. Below the navigation, there is a section titled 'Europa Uomo' with the following details:

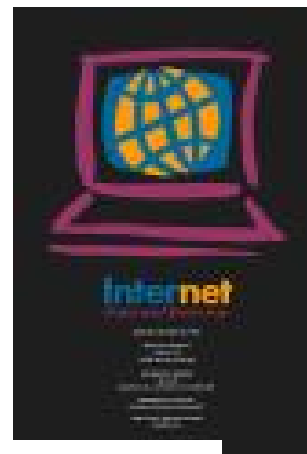
- Abbreviazione:** EUOPAUOMO
- Descrizione:** E'una libera associazione di cittadini, in grandissima parte pazienti di tumore alla prostata, dedicata al raggiungimento degli obiettivi statutari. Europa Uomo si rivolge sia a tutti coloro che hanno sperimentato o stanno sperimentando quanto la diagnosi di cancro alla prostata possa segnare l'esistenza ma anche a tutti gli uomini che, raggiunta una certa età, desiderano essere informati su questa patologia.
- Attività:**
  - Promuovere in tutta Europa la diffusione e lo scambio di informazioni corrette e aggiornate sul tumore della prostata.
  - Richiamare l'attenzione pubblica sulla necessità di affrontare il tumore della prostata con consapevolezza.
  - Insistere sull'importanza della diagnosi precoce.
  - Sostenere campagne per ottenere la migliore terapia.
  - Garantire la qualità delle terapie di supporto durante e dopo le cure per la malattia.
  - Esigere un'adeguata formazione e preparazione del personale sanitario.
  - Promuovere la diffusione di linee guida di trattamento.
  - Richiedere controlli regolari di qualità delle apparecchiature mediche e diagnostiche.
  - Assicurarsi che ai pazienti venga spiegata in modo comprensibile ogni diversa possibilità di cura. che

# 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**

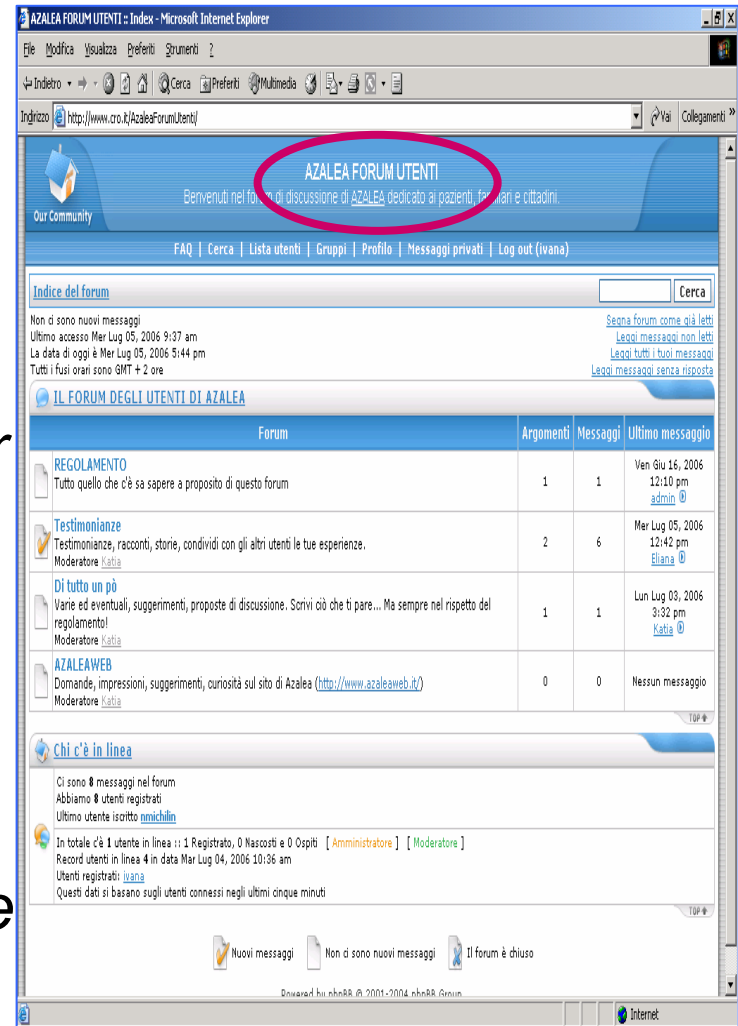


✓ *Print or other kinds of support are available*



# 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

English interface

Search by subject

Results

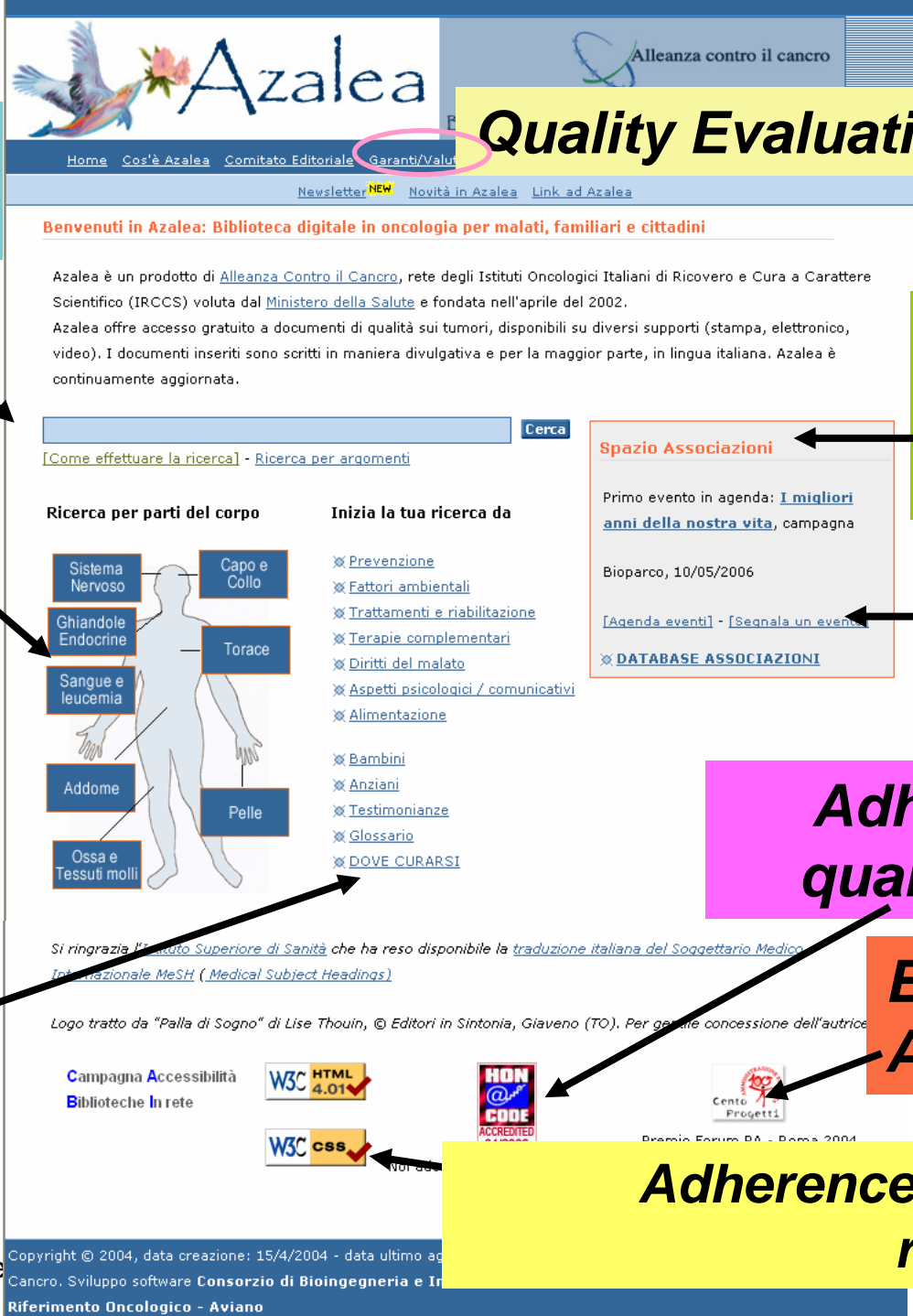
Types of documents:  
print,  
electronic,  
websites, etc..

Clinical trials

Associations Database

Document Delivery among libraries

The screenshot shows the Azalea website interface. At the top, there is a navigation bar with links: Home, Cos'è Azalea, Comitato Educativo, Garanti/Valutazione, Contatti, Collaborazioni, Avvertenze per l'uso, and a UK flag icon. Below the navigation bar, there is a search form with the text "Inserisci un termine:" and the input field containing "mammella". The search results are displayed in a table-like format. The first row shows "Trovati: 144 Documenti, 20 Protocolli clinici, 45 Associazioni". Below this, there is a section titled "Documenti" with a list of results. The first result is "La patologia della mammella" by Luca Rotunno and Malvini Stefania, 7th edition, LINFA, stamp 2003. The second result is "Il tumore della mammella" by Giotta Francesco and Schittulli Francesco. The page also includes a "Cerca" button and a "Richiedi il documento" link for the first result.



**Search by text words**

**Quality Evaluation Committee**

**Voluntary Associations Room**

**Events**

**Adherence to quality criteria**

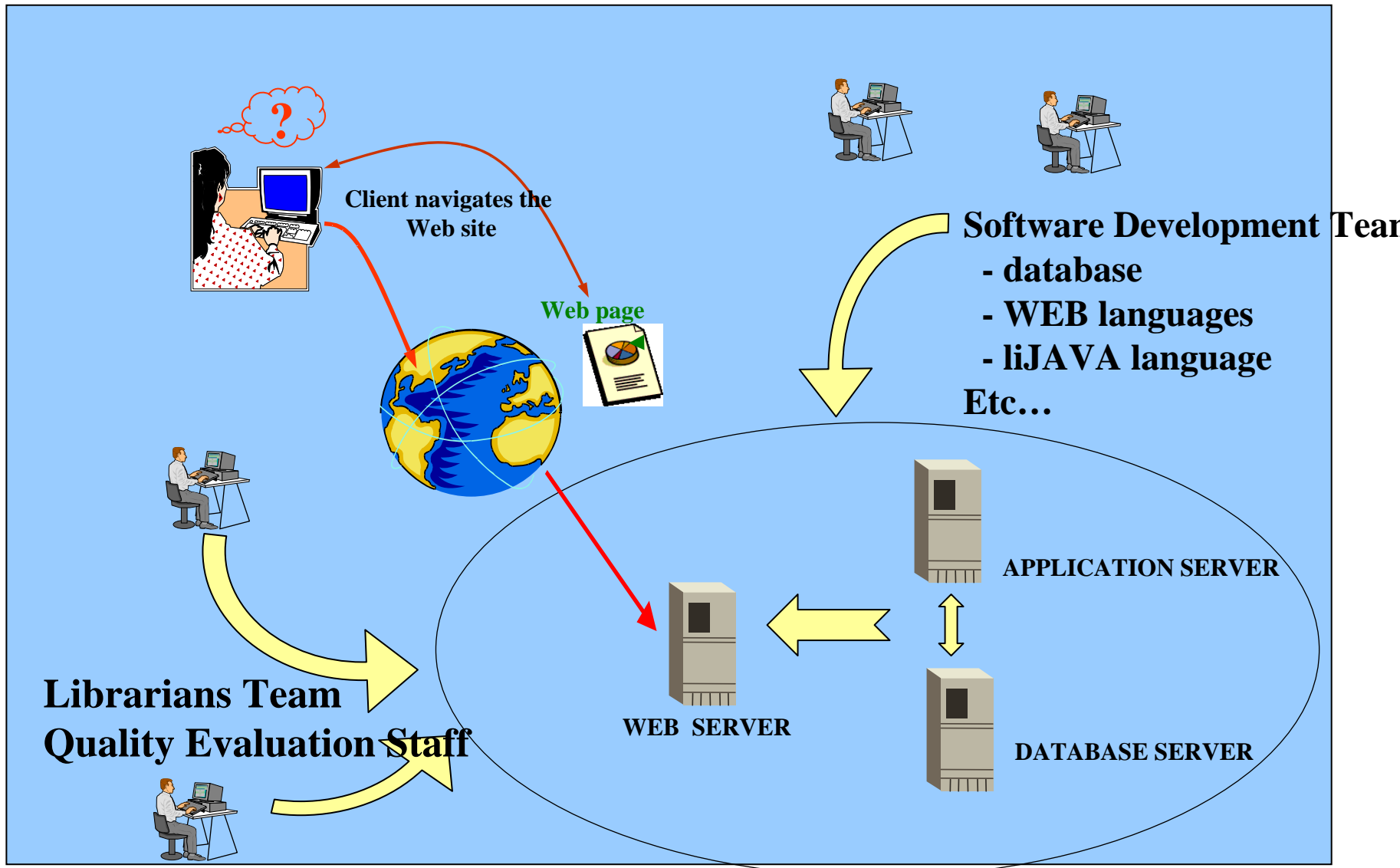
**Best Practices Award, 2004**

**Adherence to accessibility requirements**

**Search by body part**

**Search by Menu**

# Despite its complex back office...



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

**Modulo richiesta**

I dati raccolti vengono trattati in conformità al D.lgs. n.196/03. Leggi l'[infor](#)

I campi con l'asterisco\* sono obbligatori. Al fine di poter effettuare un monitoraggio pervenute, sono presenti dei campi non obbligatori che invitiamo caldamente a compilare. La compilazione di questi campi ci consentirà inoltre di fornire delle risposte personalizzate alle richieste pervenute.

Oggetto	Richiesta documento da AZA mammella
Seleziona la biblioteca	<input type="text"/>
Cognome	<input type="text"/>
Nome	<input type="text"/>
Indirizzo	<input type="text"/>
CAP	<input type="text"/> *
Città	<input type="text"/> *
Provincia	<input type="text"/> *
e-mail	<input type="text"/> *

*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

**Contatti**

✕ **Biblioteca Pazienti Centro di Riferimento Oncologico**  
Via Ped. Occ. 12 - 33081 AVIANO (PN)  
Tel. 0434/659467, Fax 0434/659358  
Ivana Truccolo, Katia Bianchet, Nancy Michilin. E-mail: [people@cro.it](mailto:people@cro.it)

✕ **Biblioteca Istituto Regina Elena**  
Viale Regina Elena, 291 - 00161 ROMA  
Tel. 06/52662216, Fax 06/52662216  
Gaetana Cognetti, Lucia Cecere. E-mail: [biblioire@ifo.it](mailto: biblioire@ifo.it)

✕ **Biblioteca Istituto Nazionale Ricerca sul Cancro**  
L.go Rosanna Benzi, 10 - 16132 GENOVA  
Tel. 010/5600077, Fax 010/352888  
Anna Bogliolo. E-mail: [anna.boqliolo@istgq.it](mailto:anna.boqliolo@istgq.it)

✕ **Biblioteca Istituto Nazionali Tumori**

*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*



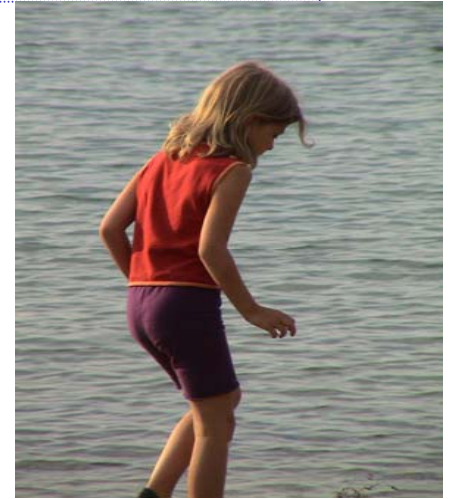
# The Quality Evaluation of the Material in Azalea: some hints

## ➤ 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 user satisfaction questionnaires to evaluate the documents. 98% of the patients and their families interviewed by the CRO Aviano (84 questionnaires) judged the documents to be clear, comprehensible, complete and useful.

I don't understand a word of it! Yuk yuk



Only 2% found the information difficult to follow or incomplete!

## 3rd STEP

### Scientific Evaluation

A scientific committee examines the document and evaluates its scientific content by means of a purpose-built grid.



#### Towards EBM?

The Librarian can supply evaluation literature, to support those carrying out content evaluation

## 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

#### Valutazione di qualità

Stato valutazione di qualità Evaluated

Data di valutazione 16 June 2005

Gruppo di valutazione CRO Scientific Staff

#### Sintesi della valutazione

Concise leaflet which clearly identifies the authors, date and sources, supported with a brief bibliography. The information contains much technical jargon which is not always explained. The presence of data and statistics could be overwhelming. Not appropriate as introductory material.



Documento a stampa [Richiedi il documento] 7/39

Prevenzione e diagnosi precoce dei tumori del colon-retto / Lega Italiana per la Lotta contro i Tumori - Roma : CSR, 1994

Soggetti (italiano) Neoplasie del colon e del retto - diagnosi, Neoplasie del colon e del retto - prevenzione e controllo

Soggetti (inglese) Colorectal Neoplasms - Diagnosis, Colorectal Neoplasms - prevention and control

Classificazione Q2 WS29

Read the quality assessment of the document

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

## 1st STEP

### Librarians' Evaluation

The Librarian evaluates the document by means of grids designed on the basis of internationally accepted criteria.

It's a nice web site, accessible, usable, but it doesn't say when it was last updated, where the information comes from or if someone is sponsoring it!



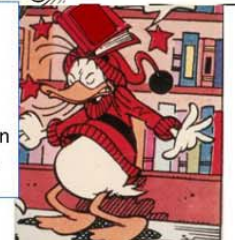
## 2nd STEP

### 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 documents by means of a specific evaluation grid.



Patients are not "empty buckets into which bits of data, treated like bricks, can be tossed." (L. Bunyan)



# The Result of the Quality process is a Quality Evaluation abstract

Valutazione di qualità	
<b>Stato valutazione di qualità</b>	Validato
<b>Data di valutazione</b>	01/04/2004
<b>Gruppo di valutazione</b>	Staff clinico-scientifico del CRO
<b>Sintesi della valutazione</b>	<p>Il documento raggiunge un'ottima qualità stilistica e aspetti tecnico-fo... Gradevole nell'aspetto grafico, si indiv... e le strutture di riferimento in cui oper... indice. Il contenuto risulta ricco di utili... medico per specificazioni o approfond... comprensibile: i termini utilizzati sono... Il tono colloquiale e l'assenza di termi... un'impatto positivo nel lettore. Mancan... degli autori e delle strutture di riferim... lavori" ossia a tutti coloro che si appr... competenze.</p> <p>[La suddetta valutazione si riferisce al</p>

✓ *Readable online by the Internet users*

✓ *Physically deliverable to the "real" users of the Libraries*

✓ **The Quality Evaluation grids and guidelines are available online**

# Patients opinions regarding quality of the written and electronic material: a survey is ongoing

Azalea: Richiedi un testo - Microsoft Internet Explorer

File Modifica Visualizza Preferiti Strumenti ?

Indirizzo [http://www.azaleaweb.it/pub/riciedi-doc?lang=en\\_EN&Inv=CRO007614&irccs=CRO](http://www.azaleaweb.it/pub/riciedi-doc?lang=en_EN&Inv=CRO007614&irccs=CRO)

Adobe Y! digita chiave di ricerca Cerca Entra Y! Mail Il Mio Yahoo!

**Azalea** Alleanza contro il cancro  
Biblioteca digitale in oncologia per malati, familiari e cittadini.

Home What is Azalea Editorial Committee Endorsement Contacts Collaboration Disclaimer

### How to request documents

All those requesting material present in the databank should be aware that:

- Up to 5 documents may be requested every 15 days
- If more than 5 documents are requested in this period, a photocopy fee is requested of €0.16 per page, payable by postal order (contrassegno)
- For manuals and textbooks, the index will be sent:
  - If the entire text is required, it will sent for a consultation period for a maximum of 8 days; [postal charges](#), payable by postal order are to be paid by the person making the request

Dear Sir/Madam,  
We would very much like **your opinion** regarding the quality of the material consulted and requested via Azalea. This will be of great help in **improving our service** and in particular the quality of the information supplied to patients, their families and the general public.  
[DOWNLOAD THE QUESTIONNAIRE](#)

✓ **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

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

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

Bianchet, K, et al. AIDAinformazioni , 3, 2005 <[www.aidainformazioni.it](http://www.aidainformazioni.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, psycologists,  
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





# The Azalea Project Research Group



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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!

Questions?

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