

# E-Oncology and Health Portals: Instructions and Standards for the Evaluation, Production Organisation and Use

G. Cognetti and L. Cecere

Scientific Library, Regina Elena National Cancer Institute, Rome, Italy

*"We must find ways of producing, validating and diffusing appropriate information in a manner that involves users (consumers) in order to guarantee a non-authoritarian practice, access for all to healthcare information, and high quality information on the Internet".*

G. Eysenbach (1)

In 2002 the Italian Ministry of Health promoted the institution of a network and a web portal, E-oncology (2), for the seven NHS research institutions specialising in oncology (Istituti di Ricovero e Cura a Carattere Scientifico - IRCCS). One of the aims was to gather and provide information on tumoral pathologies to operators and the public. For an optimum organisation of a health web site it is necessary to uniform the standards internationally approved. The World Wide Web Consortium (W3C) has developed guidelines for accessibility and usability of the sites, implemented in Italy through governmental issues. Many international organisations adopt rules and codes of conduct to validate biomedical information and have organised quality portals such as NLM, OMNI, MEDCIRCLE, HON etc.. Some terminological standards, such as the MESH thesaurus and UMLS, have been produced by the libraries for a correct management and an effective information retrieval, and are currently used by the most important biomedical web sites. The Dublin Core, metadata standard for the integration of information deriving from heterogeneous archives, has also been developed by the libraries. The easy access to information dims the complex architecture necessary for the construction of a web site. The contribution of different professionals is necessary to guarantee the production of quality medical/health web sites, among them librarians have always been involved with the management of knowledge and their skills are extremely valuable. Furthermore, the libraries' network is essential in order to guarantee universal access to health information, mostly still against payment, and to contribute to overcoming the 'digital divide' and 'second-level digital divide'.

**Key Words:** E-oncology, Health web site, Healthcare information, Health information standards, Digital divide, Medical libraries

On April 5<sup>th</sup>, 2002 the Association "Alleanza contro il Cancro" (Alliance against Cancer) joining the seven NHS research institutions specialized in oncology (Istituti di Ricovero e Cura a Carattere Scientifico - IRCCS), was held in Italy, in order to gather and spread information for operators as well as the general public through the 'E-Oncology' web site.

The improvement and guarantee of uniformity on prevention, diagnosis and treatment of tumors and the decrease in patients' health care migration are amongst the benefits to be gained from this service (3).

What are the criteria and standards required for the construction and organisation of health web sites? To

understand the delicate problems involved it is necessary to evaluate the phenomena of the Internet in sectors such as this. In recent years we have witnessed a huge development of the Internet. In particular, in the biomedical sector, where more than 100,000 sites connected to biomedicine (4) are to be found, and the growth has been exponential. Researches (5) showed that of 40.6 million adults using the Internet in the United States, 17.5 million (43%) were downloading information on health care. This percentage applies also to the countries of Northern Europe, while in the countries of Southern Europe; Greece, Spain, Portugal, it does not exceed 15%; however, Italy, with 24%, is a

major user of health web sites (6). Many of the navigators are patients or members of the general public. This highlights the problem of a control and selection of valid information, keeping in mind the potential danger of providing health care information which is not updated, lacks sources or context. Many international organisations are involved in producing codes of conduct, quality control, guidelines, norms and regulations for the management of biomedical information. Last but not least on December 7<sup>th</sup>, 2002 the European Commission published the long awaited political document on the quality criteria for health web sites (7).

### **The portals of the National Library of Medicine and the National Cancer Institute**

The most important health web site on the Internet is produced by the National Library of Medicine (NLM) of Bethesda (USA). Since 1997, thanks also to the government efforts, almost 40 databases (Medlars System), once only available on payment, are now free services. Amongst them, the most important is the bibliographic data base Medline (PUBMED), which has been greatly expanded and has been available on the Web since 1997 (8). The Medlars archives on bioethics, Aids, health care organisations, population studies, space medicine etc., have all recently been added to PUBMED. Created some years ago, NLM Gateway (9), allows access through a unique query interface to different sources of information, including PUBMED, abstracts from medical congresses held by the NLM (Locatorplus), catalogues of books and videos and data banks for patients. One of the resources of some note, directly available to the so called 'health consumer', is MEDLINEPLUS (10). Established in 1998, it is a mega-container of documents, mostly full-text. The central body of MEDLINEPLUS, apart from dictionaries, encyclopaedias and health care guides, contains: well organised information (health topics) on 600 pathologies, including educational material ('interactive tutorials'), news from press agencies (e.g. Reuter) and links to other material for patients, produced by the most important health care institutions. It also contains nearly 9000 clear and very informative drug summaries. Moreover, it permits an automatic retrieval of updated bibliographies for patients in PUBMED. MEDLINEPLUS can therefore be considered the 'portal of the portals' overcoming the problems of fragmentation, dispersion and therefore, difficult access to information created by a great number of sites offering patient information. How does

MEDLINEPLUS work? For instance, when researching tumors, people are able to access multiple and well structured information published on important health sites, e.g. Cancernet (11) produced by the National Cancer Institute. This is the most important oncology web site for health care professionals and patients. The central nucleus is the PDQ (Physician Data Query) data bank, founded in 1984, once only available on payment, today it is a free service. In fact the oncology sector, more than any other in medicine, has to deal with the dramatic problem of information. In this field, delays in the transmission of information in clinical practices leads to 'mortality' in hundreds of patients, as seen in some important epidemiological researches (SEER Program). PDQ, updated monthly, had to guarantee the immediate spread of data, such as state of the art therapy, protocols as well as specialists and institutions operating in the field. In PDQ the information for health workers (physicians, nurses, etc.) and patients are different but are found alongside each other. Patient information is clearer and more popular, being handled by a committee experienced in communication. The importance attached to information in the oncology sector (for the most part PDQ) had been freely available on the Internet before the Medlars system. Further, for those without the Internet, access to the system is also guaranteed by automatic/numerical access procedures via fax or via e-mail (12). In 2002 the site was restyled with the creation of a large number of connections: for example patient information is linked to online glossaries, permitting improved accessibility and understanding of the information for the public.

### **Defining the target**

The first problem in the construction of a health web site, is the definition of the target (physicians, nurses, general public etc.) and their information needs. This is pointed out in the criteria set up by the European Commission '...target audience clearly defined...' (Table I). The most advanced experiences in the creation of portals or databases are always preceded by studies in this regard (5). The co-operation of professionals such as computational linguists or other experts in communication, who, for instance, define the legibility of texts available to people with different scholastic levels, is also desired. In this regard, the European Commission document states, "where a particular type of audience is targeted (e.g. children), the presentation and content of information should be

**Table I** - COM (2002) 667 Communication from the commission to the Council, the European Parliament, the Economic and Social Committee and the Committee of the regions: eEurope 2002: Quality Criteria for Health related Websites

### 1. Transparency and Honesty

- Transparency of provider of site - *including* name, physical address and electronic address of the person or organisation responsible for the site (see Article 5 and 6 Directive 2000/31/EC on Electronic Commerce).
- Transparency of purpose and objective of the site
- Target audience clearly defined (further detail on purpose, multiple audience could be defined at different levels).
- Transparency of all sources of *funding* for site (grants, sponsors, advertisers, non-profit, voluntary assistance).

### 2. Authority

- Clear statement of sources for all information provided and date of publication of source.
- Name and *credentials* of all human/institutional providers of information put up on the site, including dates at which credentials were received.

### 3. Privacy and data protection

- Privacy and data protection policy and system for the processing of personal data, including processing invisible to users, to be clearly defined in accordance with community Data Protection legislation (Directives 95/46/EC and 2002/58/EC).

### 4. Updating of information

- Clear and regular updating of the site, with date of up-date clearly displayed for each page and/or item as relevant. Regular checking of relevance of information.

### 5. Accountability

- *Accountability* - user feedback, and appropriate oversight responsibility (such as a named quality compliance officer for each site).
- Responsible partnering - all efforts should be made to ensure that partnering or linking to other websites is undertaken only with trustworthy individuals and organisations who themselves comply with relevant codes of good practice.
- Editorial policy - clear statement describing what procedure was used for selection of content.

### 6. Accessibility

- *Accessibility* - attention to guidelines on physical accessibility as well as general findability, searchability, readability, usability, etc.

appropriate to the chosen target audience" (7). An example of this is, 'The quick guide to checking information quality' (13) aimed at children looking for health information on Internet.

### Guidelines for the evaluation of information

After defining the target, it is necessary to evaluate the reliability of the information. Every institution which seriously approaches the problem of offering

information on health care must produce or stick to guidelines for its selection. Many initiatives have been undertaken in this regard attempting to control the quality of information. Many organisations have produced seals, outlined codes of behaviour and quality control and often the sites are checked by a kind of 'peer review'. In some cases they are awarded a point system (e.g. Medical Matrix (14)). In others, such as Discern (15), standard questionnaires by which the users can personally carry out a quality evaluation of the site, have been developed. Other initiatives tend to

incorporate the elements of evaluation of the information through the use of a standard language and so-called evaluative 'metadata'. So the same tools produced to evaluate the web, have become part of the explosion of information which they attempt to control (16).

### **Organisation of information: towards the semantic web. How to avoid finding 'Mickey Mouse' along with lab mouse**

*1. Metadata.* The use of metadata is recommended in the document of the European Commission 'To make health data more findable' (7). The application of metadata (literally: data regarding other data) allows one to structure the information from books, articles, clinical records, etc. (even multimedia documents) selecting some interesting research profiles (e.g. authors, arguments/subject, title, abstract etc.). This way greater precision in information retrieval will be possible. When looking for the author of a document a search will be conducted in metadata regarding the authors and not in the 'abstract' metadata where only the author might be cited. According to the principles of information science, a document is not inserted 'sic et simpliciter' in an archive; when creating catalogues or databases, it is carefully studied, examined and structured by also adding information. A more structured archive e.g. PUBMED permits a more precise research, avoiding the retrieval of non pertinent documents. Not only does metadata permit effective searching as well as storing and management of information, it can also be used to evaluate information, e.g. the date of updating describes a resource but also permits to verify its obsolescence.

*2. Integrating the information on the sites: The Dublin Core as standard metadata.* Nowadays, the trend is towards integration, i.e. the retrieval of information by searching different sources or archives, using gateways such as that of NLM or digital libraries. Therefore, all kinds of documents or archives, e.g. catalogues, bibliographic databases, images, full text, can be found in a single integrated library tool.

All kinds of information are usually attached to different types of metadata, "In the metadata garden, truly a thousand flowers are blooming" (17). The clinical protocol will contain as metadata: the head of research, a description, patient enrolment, drug dosage, etc. In a journal article or in a monography, the metadata are:

the author, the abstract, the subject etc.

In an integrated archive the metadata regarding different kinds of documents must interrelate. It is therefore necessary to apply a *koinè*, in other words a standard metadata allowing one to surf through various metadata with different types of information. The Dublin Core (18) created by the American scientific librarian community has now become the standard metadata, also in the health field (e.g. for guidelines or clinical records etc.). The Dublin Core is characterised by a limited set of 15 elements which permit one to write different types of information resources in a 'minimal' but 'sharing' manner. In this way, searching 'Mario Rossi' as the 'creator' of a document, we will be able to obtain clinical protocols in which he has co-operated as well as any video production he has directed and the articles and books he has signed as an author.

*3. Indexing by subject: the MESH/UMLS as international standard.* It is essential to standardise the subject metadata. In order to efficiently access data in a library one uses controlled terminology (subject headings or thesauri). In this way it is possible to avoid the phenomena of 'noise' (an excess of non pertinent documents) or silence (non-retrieval of useful documents), often associated with the Internet research engines which operate by searching free words (text words). If the concept of tumor is being searched for, using the text word 'cancer', it will not be possible to find all the documentation on that subject. In an automatic search of the words in the title or the abstract all the information containing synonyms of 'cancer' such as neoplasm, tumor, neoplasia etc. would be lost.

Instead, using a thesaurus, a single controlled term such as '*neoplasms*' will find all documents regarding that subject, through the indexing process made by the experts. Furthermore, one can also move from one concept to another related concept or from a generic to a specific concept. In fact, all subjects are inserted in a classified structure and are related to other subjects.

The international standard for subject indexing is MESH (Medical Subject Headings) created by the National Library of Medicine for MEDLINE, translated into various languages. MESH is the nerve centre of UMLS (Unified Medical Language), also created by the National Library of Medicine, a bridge between about one hundred standard terminologies in the medical and nursing fields. Beside the standard terms, UMLS also includes terms and expressions of natural language (Specialist Lexicon). UMLS identifies biomedical concepts through the so called 'unique concept identifier' which maps terms used in the different

fields of biomedicine (ICD, SNOMED etc.). The system has a wide application in biomedical databases, such as PUBMED, Embase, Biosis, etc., and in the most important biomedical web portals. In PUBMED and other NLM databases the user's questions are automatically 'mapped' towards the appropriate MESH in order to render the retrieval of information friendly and efficient. UMLS, along with its concept relationship (Semantic Network) and the Dublin Core, are basic instruments for setting up an 'ontology', a term recently adopted from philosophy, representing the newly acquired technology of the semantic Web. The aim is to build a system of knowledge which permits world wide navigation across biomedical documents through the relationship between the concepts. For example the information on a virus can be connected to that of diseases deriving from it and so on through the web of semantic connections, setting up a true 'research environment', a powerful source of new knowledge.

A tool for the construction of such a semantic web is RDF (Resource Description Framework), based on XML and recommended by W3C to represent connections of various types (19).

### **Criteria for accessibility and usability**

Organisation through metadata and the use of standard terminology, with mapping of the natural language, will facilitate access and use of information for all citizens. To realise this goal, W3C (World Wide Web Consortium) has produced guidelines on accessibility (WCAG: Web Content Accessibility Guidelines 1.0 (20) and the more recent UAAG: User Agent Accessibility guidelines 1.0 (21)). These guidelines have been assimilated in Italy, in a circular from the Department of Public Function No.3 13<sup>th</sup> March 2001 and an AIPA circular 6<sup>th</sup> September 2001 (22). Currently, several laws are under project to enforce the guidelines for web sites in the Public Administration in Italy.

Accessibility means that information systems can be used without discrimination caused by a disability; the requirements for access are linked to those of use (usability), meaning a web site can be accessed by anyone no matter the type of computer, the speed of connection, the browser, user interface or the kind of software (23). For example it is important not to weigh down a web page with graphics that are difficult to access without the use of a 'super computer', it is necessary for each image to have a textual description to permit an automatic translation into Braille or sound

through screen readers. The use of frames or colours to differentiate the information or signal the commands is not advisable (access might not be possible for those who have monochromatic screens or are visually challenged). Accessible sites will contain a label (autocertification) available from W3C with three levels of certification represented by a minimum of one to three A's (AAA = web sites, which adhere to all conditions of accessibility). It is also possible to find free software on Internet to test the accessibility of sites.

### **Interoperability and choice mark-up language: standard XML**

Interoperability is defined by a European decree (91/250/EC) as: "functional interconnection and interaction"... "the ability to exchange information and mutually use the information which had been exchanged" (7). Beside a standard metadata and terminology, the use of a standard mark-up language is required. To date, Internet mainly makes use of the HTML mark-up language. However, HTML is now being taken over by XML because of its greater extensibility, permitting documents to be well structured, incorporating specific metadata.

Access and saving of information is not tied to owner systems.

### **Best practices: codes of conduct and quality control**

As mentioned, in this field there are many initiatives amongst which: the e-Health code of Ethics, created by the Internet Healthcare Coalition (24) which contains fourteen criteria; WHO and many other organisations have also developed codes and quality seals. One of the first initiatives was developed by the Health on the Net Foundation (25) which was set up in September 1995. A research group, consisting of approximately sixty experts and representatives of important organizations (NLM, WHO, ISTU, CERN, UE, G7 etc.) decided to form a permanent association, with the aim of promoting the use of new information and communication technology (ICT). The new-born 'Health on the Net Foundation' produced the Honcode, a brief but clear and concise 'vademecum' for the creation of medical and biomedical web sites (Table II). Those adhering to this code can make use of the Honcode seal on their site. The HON organisation controls the observation of HONCODE principles. The seal is

---

**Table II** - Honcode principles (Version 1.6 April 1997)

---

**1. Authority**

Any medical or health advice provided and hosted on this site will only be given by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a non-medically qualified individual or organisation.

**2. Complementarity**

The information provided on this site is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her existing physician.

**3. Confidentiality**

Confidentiality of data relating to individual patients and visitors to a medical/health Web site, including their identity, is respected by this Web site. The Web site owners undertake to honour or exceed the legal requirements of medical/health information privacy that apply in the country and state where the Web site and mirror sites are located.

**4. Attribution**

Where appropriate, information contained on this site will be supported by clear references to source data and, where possible, have specific HTML links to that data. The date when a clinical page was last modified will be clearly displayed (e.g. at the bottom of the page).

**5. Justifiability**

Any claims relating to the benefits/performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in Principle 4.

**6. Transparency of authorship**

The designers of this Web site will seek to provide information in the clearest possible manner and provide contact addresses for visitors that seek further information or support. The Webmaster will display his/her E-mail address clearly throughout the Web site.

**7. Transparency of sponsorship**

Support for this Web site will be clearly identified, including the identities of commercial and non-commercial organisations that have contributed funding, services or material for the site.

**8. Honesty in advertising & editorial policy**

If advertising is a source of funding it will be clearly stated. A brief description of the advertising policy adopted by the Web site owners will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.

---

interactive with the HON site so long as the site observes the HONCODE rules. Approximately 3,000 sites make use of the seal. In October 1999 to improve the information retrieval of these sites, the foundation adopted an innovative system, HONSELECT, based on MESH. The multilingual system upgrades the search functions using this thesaurus in English,

French, German, Spanish and Portuguese (26).

**Best practices: other projects using metadata standard and MESH/UMLS**

· *OMNI (Organising Medical Networked Informa-*

tion)(27): recently merged with other archives and biomedical web sites forming BIOME (28), holding nearly 6,000 quality information resources. OMNI was created by a team of specialists in information at the University of Nottingham Greenfield Medical Library, in co-operation with other important English organisations. OMNI describes the health websites, selected on the basis of criteria of quality, using the Dublin Core standard (metadata) and the MESH thesaurus. Along with this general instrument, other thesaurus (e.g. for nursing: the 'Royal College of Nursing thesaurus'), are used for better and more in depth information retrieval. Besides the National Library of Medicine Classification, the catalogued resources are also classified using various other international classifications (LCC: Library of Congress Classification; DDC: Dewey Decimal Classification etc.) produced by libraries.

· *MedCIRCLE* (29) : originally Medpics, started out with the development of PICS (Platform for Internet Content Selection), developed by World Wide Web Consortium, as a technical standard for distributing the description of texts in a machine-readable format. Later on, it became an instrument for controlling and selecting dangerous web sites for children. MEDPICS, based on the Dublin Core metadata, and the use of UMLS/MESH for indexing, became the international project, MedCERTAIN (i.e. MedPICS Certification and Rating of Trustworthy Health Information on the Net), financed by the European Union's "Action plan for safer use of the Internet" (2000-2002). The website of MedCERTAIN is actually no longer active, having again been converted into the new project, MedCIRCLE (Collaboration for Internet Rating, Certification, Labelling and Evaluation of Health Information). The project actually joins three European partners:

- Germany, represented by the mentor of the project G. Eysenbach of the Department of Clinical Social Medicine (Heidelberg University) and by two other German institutions.
- France participates with the CISMef (30) (Catalog and index of French-language health resources), a portal collecting health resources on the Internet, using the standard MESH and Dublin Core.
- Spain participates with the Official Medical College of Barcelona (COMB), which in 1999, produced a quality seal for Spanish and South American biomedical web sites.

The MedCIRCLE project reaffirms the necessity for international co-operation between the multiplicity of organizations, amongst them also consumer and

professionals associations, in order to deal with the issue of biomedical information.

MedCIRCLE and its partners share a single model of evaluative and descriptive metadata: HIDDEL (Health Information Disclosure, Description and Evaluation Language) made up of standard elements and sub-elements of XML (Table III). Essential information such as; author/provider, data of publication and updating, target, level of evidence, etc., necessary in order to certify the validity of a biomedical web site, is thereby incorporated in the web page.

Through these metadata, the research engines should automatically be able to signal potentially dangerous or misleading, uncontrolled information (31).

### **The Italian situation: e-government without government?**

In Italy there are very few initiatives using standards and guidelines for the quality and accessibility of information, among these:

· *Azalea* (2), multi-centre project of a digital library for patients, their relatives and the general public, was developed from the database originally created for the library for patients at the Centre for Oncological Reference (CRO) of Aviano. The original databases now available on the E-oncology portal, contain almost 1,000 records; 600 bibliographical citations, 100 web site descriptions, 350 oncological associations, and full-text documents for patients. The Azalea team, a pool of professionals coming from the seven research institutes specialized in oncology, is working to implement the digital library in a co-operative way. Azalea is a 'hybrid' library which integrates different kinds of documents; books, brochures, articles, interactive tutorials, links to web sites, associations schedules etc. Furthermore the clinical trials, in a friendly/readable version for patients, will be included in the archive. The project will be carried out using an evaluation scheme (HON-CODE enriched) for selecting the documents.

Azalea uses international standards and MESH for indexing information and is studying the application of the Dublin Core. The Azalea team is also working on the availability of the thesaurus MESH, translated into Italian by the National Health Institute Documentation Sector, but is as yet unpublished.

· *Elisir* (32) (Electronic Library International of Selected Internet Resources) is another interesting library project, developing a catalogue of Internet

**Table III** - Sample from MedCircle: <http://www.medcircle.org/metadata/index.php> (accessed 2003 Oct 10). Evaluation can be carried out on three levels: Level 1 means a self-evaluation, the provider certifies the elements (name, address, e-mail, etc.); Level 2 means that a non-medical expert has reviewed the site: in the example above, the rater verified the lack of feedback ("E-mail was bounced"). A Level 3 can be added if a medical expert has provided an opinion.

Row Data	Level 1: Structured data with the application of XML/Hiddel tags	Level 2: Level 1 + the check provided by an external rater (in this example, a Medcertain expert)
<b>Address:</b> Bergheimer Str. 58, 69115 Heidelberg	<infoprovider> <feedback> <address> Bergheimer Str. 58, 69115 Heidelberg </address>	<infoprovider> <feedback> <address> Bergheimer Str. 58, 69115 Heidelberg <checked by="medcertain">Positive</checked></address>
<b>e-mail:</b> feedback@mysite.com	<email>feedback@mysite.com</email>	<email>feedback@website.com <checked by="medcertain" creator="Expert" date="22.1.2001">Negative <reason creator="MedCERTAIN">Email was bounced!</reason> </checked></email>
	</feedback> </infoprovider>	</feedback> </infoprovider>

resources for doctors, nurses and the general public in the paediatric and gynaecological field. This also uses enriched Honcode, Dublin Core, MESH, for the selection, evaluation and organisation of information.

- *Oncocare* (33), like *Cardiocare*, *Gastrocare*, *Neurocare*, *Dermacare*, and *Pneumocare*, which evaluates and describes specialized Internet resources also using an enriched HONCODE scheme.

Some Italian databases produced by information services and libraries are also available:

- *BIBIT/BIBLIT/RIBIT* (34) produced by the Istituti Zooprofilattici Sperimentali (research institutes specialized in veterinary science) is a database of Italian journals in biomedical and veterinarian fields. Almost 1,600 journal titles were collected and many indexed.

- *Sibil* (35) (Online informative system of bioethics) produced by the Documentation Sector of the National Institute of Health, contains nearly 3,600 bibliographic references and full-text concerning monographs, articles, laws, ethic codes and guidelines, web sites, etc, mostly in Italian.

In order to avoid duplications and to permit access

to all the information on health, all these efforts must be co-ordinated. Moreover, about 250 medical libraries and documentation centers figuring in the 2000 census run by BDS Association, have to be connected in a NHS network. Unfortunately in Italy the policy of 'E-government' is still lacking the 'government' element.

### Conclusions: Guess who is coming to dinner?

*"Evaluating an Internet resource is not a single act, like that of filling in a form. It is a process, indeed. It is also a work in progress, because a resource must be followed and examined during its entire existence, to highlight changes. During this process different skills are required and different points of view and backgrounds have to interact."*

P. Gardois (36)

The management of the health information is more complex today than in the past. It requires the cooperation of various professions, amongst these, the librarian, who for centuries has developed methods and



standards for the knowledge management. Basically, the semantic web is nothing else but the transposition on to the web of the organization of information which has been put into practise by the librarians for some time in the biomedical databases. Although this study is limited to the problems of accessing biomedical information through the web, it is necessary to do away with a widespread prejudice; "Internet is everything, there is nothing beyond the Internet". According to the Gale Directory of Databases (37) in 2002, there were 1,957 databases available in the health/life science fields, the majority of which are not free. For instance, Embase database which offers almost 70% of supplementary information compared to PUBMED. Furthermore, it should be kept in mind that, not all can access the online resources (Internet divide) and not all are capable of efficiently finding useful and valid information, a phenomenon recently highlighted in literature with the term 'second level Internet divide' (38). In the famous movie 'Guess who is coming to dinner' Spencer Tracy calls a public library to ask for information regarding the coloured doctor his daughter intends to marry. He gets an immediate answer telling him that he is a famous doctor, author of many publications. Maybe the library used the Medline database. As such, non specialised libraries can also give access to health information. The National Library of Medicine experimented a trial (39) co-operating with the public libraries found throughout the country, for the dissemination of health information to the general public. Through the library network all citizens, like all professionals, may have access to the best and most updated, customized health information in order to guarantee the quality and uniformity of medical/health services within the country.

**Acknowledgements:** We thank L. Maida, I. Reverberi, students of the Scuola Speciale per Archivisti and Bibliotecari dell'Università La Sapienza, who, during their training in the library of the Regina Elena National Cancer Institute have contributed some synopses on quality international web sites, in particular the HON one, which has proved very useful for this essay.

## References

1. Eysenbach G., Diepgen T. D.: Towards quality management of medical information on the Internet: evaluation, labelling and filtering of information. *British Medical Journal* 317: 1496-1502, 1998.  
<http://bmj.bmjjournals.com/cgi/content/full/317/7171/1496> (accessed 2003 Oct 2).
2. <http://www.e-oncology.it> (accessed 2003 Oct 2).
3. Bufalino R.: E-Oncology: il portale e rete informativa oncologica per gli operatori e pazienti. Intervento presentato al Bibliocom Meeting: La buona informazione è la migliore medicina(3). Portali sanitari: gestione e contenuti, Roma, 2002: <http://www.aib.it/aib/com/bc02/bds.htm3> ; <http://crs.ifo.it/Biblioteca/Bibliotecaire/ital/Abstract7.htm> (accessed 2003 Oct 2).
4. Eysenbach G., Sa E.R., Diepgen T.L.: Shopping around the internet today and tomorrow: towards the millennium of cybermedicine. *British Medical Journal* 319 (7220):1294-1298, 1999. <http://bmj.com/cgi/content/full/319/7220/1294> (accessed 2003, Oct 2).
5. Miller N., Lacroix E.M., Backus J.E.: MEDLINEplus: building and maintaining the National Library of Medicine's consumer health Web service. *Bulletin Medical Library Association* 88: 0011 0017, 2000. <http://www.pubmedcentral.gov/articlerender.fcgi?tool=pubmed&pubmedid=10658959> (accessed 2003 Oct 2).
6. Sondaggio Eurobarometro: la nuova cura si cerca sul Web. *Sole-24 ore*, 122: 18, May 5 2003.
7. Commission of the European Communities: eEurope 2002: Quality Criteria for Health related Websites. *Journal Medical Internet Research* 4: e15, 2002.  
<http://www.jmir.org/2002/3/e15/index.htm> (accessed 2003 Oct 2).
8. <http://www.ncbi.nlm.nih.gov/PubMed/> (accessed 2003 Oct 2)
9. <http://gateway.nlm.nih.gov/gw/Cmd> (accessed 2003 Oct 2)
10. <http://www.nlm.nih.gov/medlineplus/> (accessed 2003 Oct 2)
11. [http://www.cancer.gov/cancer\\_information/](http://www.cancer.gov/cancer_information/) (accessed 2003 Apr 17)
12. Cognetti G., Paradiso B., Truccolo I., Ugolini D., Santi L.: Information oncological tools produced by the U.S. National Cancer Institute: how much are they known and used? Results of an enquiry in Italy. *Tumori* 81: 347-350, 1995.
13. <http://www.quick.org.uk/> (accessed 2003 Oct 2)
14. <http://www.medmatrix.org> (accessed 2003 Oct 2)
15. [www.discrim.org.uk](http://www.discrim.org.uk) (accessed 2003 Oct 2)
16. Terry N.P.: Rating the "Raters": Legal Exposure of Trustmark Authorities in the Context of Consumer Health Informatics. *Journal of Medical Internet Research* 2:e18, 2000.  
<http://www.jmir.org/2000/3/e18/> (accessed 2003 Oct 2)
17. Caplan, P.: International metadata initiatives: lessons in bibliographic control. *Proceedings of the Bicentennial Conference on Bibliographic Control for the New Millennium*, Washington, DC : Library of Congress, 2001. [http://lcweb.loc.gov/catdir/bibcontrol/caplan\\_paper.html](http://lcweb.loc.gov/catdir/bibcontrol/caplan_paper.html) (accessed 2003 Oct 2)
18. <http://www.iccu.sbn.it/dublinco.html> (accessed 2003 Oct 2)
19. Kamel Boulos M.N., Roudsari A.V., Carson E.R.: Towards a semantic medical web: healthcybermap's Dublin Core Ontology in Protege-2000. Fifth International Protégé Workshop, Sowerby Centre for Health Informatics at Newcastle , University of Newcastle upon Tyne, Newcastle, England (Wednesday 18th July 2001) [http://protege.stanford.edu/ontologies/dublin-core/hcm\\_dc\\_in\\_protege\\_newcastle.pdf](http://protege.stanford.edu/ontologies/dublin-core/hcm_dc_in_protege_newcastle.pdf) (accessed 2003 Oct 2)
20. Web Content Accessibility Guidelines 1.0: W3C Recommendation 5-May-1999 <http://www.w3.org/TR/WAI-WEBCONTENT/> (accessed 2003 Oct 2)

21. User Agent Accessibility Guidelines 1.0: W3C Recommendation 17 December 2002 <http://www.w3.org/TR/2002/REC-UAAG10-20021217/cover.html> (accessed 2003 Oct 2)
22. Policella E. O.: Internet e disabili. Diritto & Diritti: rivista giuridica on line, Apr 2003. [http://www.diritto.it/articoli/dir\\_tecnologie/policella4.html](http://www.diritto.it/articoli/dir_tecnologie/policella4.html) (accessed 2003 Oct 2)
23. Norme per il diritto d'accesso ai servizi e alle risorse informatiche pubbliche e di pubblica utilità da parte dei disabili e per favorire la loro integrazione con le nuove tecnologie. Campa's, Palmieri's Bill, 2002 Dec 16. [http://www.camera.it/\\_dati/leg14/lavori/stampati/sk3500/articola/3486.htm](http://www.camera.it/_dati/leg14/lavori/stampati/sk3500/articola/3486.htm) (accessed Oct 2).
24. <http://www.ihealthcoalition.org/> (accessed 2002 Dec 31)
25. <http://www.hon.ch/> (accessed 2003 Oct 2)
26. Boyer C., Baujard V., Griesser V., Scherrer J.R.: Honselect: a multilingual and intelligent search tool integrating heterogeneous web resources. International Journal of Medical Informatics 64: 253-258, 2001.
27. <http://omni.ac.uk/> (accessed Oct 2)
28. <http://biome.ac.uk/> (accessed 2003 Oct 2)
29. <http://www.medcircle.org> (accessed 2003 Oct 2)
30. <http://www.chu-rouen.fr/cismef> (accessed 2003 Oct 2)
31. Eysenbach G.: Collaboration for Internet Rating, Certification, Labeling and Evaluation of Health Information (MedCIRCLE). <http://www2002.org/CDROM/alternate/T4/index.html> (accessed 2003 Oct 2)
32. Gardois P., Grillo G., Bassi C., et al.: Planning with users: a catalogue of Internet resources for clinicians, nurses and citizens. 8th EAHIL Conference - paper 101. <http://www.zbmed.de/eahil2002/proceedings/gardois-proc.pdf> (accessed 2003 Oct 2).
33. <http://www.oncocare.it/it/default.htm> (accessed 2003 Oct 2) ,
34. Lazzari L.: LexVet e BiBIt due banche dati realizzate dagli Istituti Zooprofilattici Sperimentali. Webzine Sanità Pubblica Veterinaria® 2002 (16) [http://www.pg.izs.it/arretrati/numero\\_16/lazzari.html](http://www.pg.izs.it/arretrati/numero_16/lazzari.html) (accessed 2003 Oct 2)
35. <http://www.sibil.iss.it/> (accessed 2003 Oct 2)
36. Gardois P.: Evaluating the quality of medical information on the Internet: a brief bibliography. 8th International Congress on Medical Librarianship <http://www.icml.org/posters/post28/poster28.htm> (accessed 2003 Oct 2)
37. Gale directory of databases. Volume 1: Online databases. 2003, part 1. Detroit: Gale Group, 2003.
38. Hargittai E. Second level digital divide: differences in people's online skills. First Monday, 7: 2002 [http://www.firstmonday.org/issues/issue7\\_4/hargittai/index.html](http://www.firstmonday.org/issues/issue7_4/hargittai/index.html) (accessed 2003 Oct 2)
39. Wood F.B., Lyon B, Schell M.B., Kitendaugh P, Cid V.H., Siegel E.R.: Public library consumer health information pilot project: results of a National Library of Medicine evaluation. Bulletin of the Medical Library Association 88:314-22, 2000 <http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=11055298> (accessed 2003 Oct 2)

Received: March 10, 2003

G. Cognetti  
Regina Elena National Cancer Institute  
Scientific Library  
Viale Regina Elena, 291  
00161 Rome, Italy  
Tel.: 0039 06 52662613; Fax: 0039 06 52662216  
E-mail: g. cognetti@ifo.it