

**HEALTH INFORMATION FOR THE LAY PERSON ON THE INTERNET: A SURVEY OF THE ITALIAN EXPERIENCE**

**Abstract**

At the present time, the importance of informed consent has been globally recognised and even sanctioned by legal decisions. Hence, health professionals and institutions are now required to appropriately inform patients on benefits and adverse effects of medical treatments. In order to assess whether health information available on the Internet could be a useful tool for lay people, a survey on a sample of 30 Italian user-oriented web sites has been carried out. An evaluation has been made of types of producers, kind of information provided, intelligibility of language and accuracy of presentation, also with regard to graphics and value-added services offered to consumers. Reliability of web sites has been estimated according to basic standards established by the literature. Our analysis shows that Italian health consumers have now at their hand on the Internet a broad range of user-oriented tools, although medical information provided should still be checked for accuracy and currency.

**Introduction**

In today's society the consumer's right to be informed about health-concerning decisions is now well established. Lay people have a basic need to increase their health knowledge, and have the right to be as much informed as possible, both to maintain health and prevent disease, and to exactly know the risk of proposed therapies, benefits and adverse effects deriving from medical treatments. The importance of informed consent has been recognised also in Italy where recent legal decisions have been taken in this direction<sup>1</sup>. It is worth mentioning the decision No. 471/1990 of the Constitutional Court concerning the inviolability of the individual person and the recent decision No. 364/1997 of the Court of Cassation that states the duty of the surgeon to inform the patient not only on the risk of the operation itself, but also on problems that may arise in any of its phases,

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<sup>1</sup> Fucci S. *Informazione e consenso nel rapporto medico-paziente: profili deontologici e giuridici*. Milano: Masson, 1996.

starting from the anaesthesia to the rehabilitation. Furthermore, the Italian medical Code of Conduct approved in June 1995 pays specific attention to the issue of informed consent, underlining on the one hand the importance of the patient's will and on the other the duty of the practitioner to provide the most accurate and objective information about diagnosis and possible therapeutic options.

In this changeful scenario, medical libraries and information centres are usually seen as a source for information. They should be ready to play the role of mediators between physicians and lay people, patients or patients' families, to disseminate adequate information tools for the provision of consumer health information<sup>2</sup>. These tools may range over a wide variety of media: traditional printed material, such as textbooks and encyclopaedias; leaflets prepared by support groups or self-help consumer organisations; telephone helplines for specific health problems, as the national AIDS helpline; electronic information systems designed for public access, such as Physician Data Query (PDQ) which contains cancer information for both lay readers and health professionals; information available on the World Wide Web. Nevertheless, health information, no matter on which media it is disseminated, should always be tailored to the individual needs, taking into account, besides the reliability of the information itself, its psychological and ethical implications. Health-related information should be targeted to age brackets, to cultural level of consumers, and should have an high index of readability, that is lay people must be able to easy read and understand it<sup>3</sup>. Health information on the Internet has recently been soaring, thanks to its peculiarity to allow the diffusion of information at a relatively low cost in an environment of great freedom; anyone in fact may be author, editor or publisher of medical resources. That is why the information provided should always be checked for accuracy and currency. The purpose of this paper is to monitor the Italian situation on a sample of Web sites, to assess on the basis of previous established parameters whether the Italian consumer has the possibility of finding on the Internet adequate health-related information.

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<sup>2</sup> Stevens CA. Morris A. Sargent G. Internet health information sources. The Electronic Library 1996; 14 (2): 135-47.

<sup>3</sup> Wyatt JC. Commentary: Measuring quality and impact of the world wide web. BMJ 1997; 314: 1879-81.

## Methods

In order to identify the location of health information addressed to Italian consumers, a search has been performed on the Internet during the months of June, July and August 1997. Microsoft Explorer was used as a browser and relevant web sites were located by the search engines Altavista (<http://www.altavista.digital.com>), Yahoo (<http://www.yahoo.com>) and Excite (<http://www.excite.com>). Italian terms for health, medicine, physician and patient were employed and the search was limited to Italian language based sites. Moreover, our search was performed on the Italian Web Pages (<http://www.iwp.it>), a directory of Italian web sites, arranged into categories. Under the voice Medicine there were 332 Web pages, distributed into 28 sub-categories, which included both medical specialties such as surgery, cardiology, orthopaedics, etc., and public health related fields of interest (e.g.: substance dependence, bioethics, disabilities). The Italian General Subject Tree (<http://www.mi.cnr.it/IGST/Medicina/Medicina.html>) was also consulted.

## Results

A whole amount of 78 possibly relevant health-related sites was selected, 30 ones of which offering user-oriented information: some of them were completely devoted to health information end-consumer, while others, even if including a consumer-targeted section, were basically conceived for health professionals. The analysis of the 30 selected web sites was carried out according to the following criteria:

- Producers of the site
- Kind of information provided
- Readability of the language used and presence of graphics or animations
- Value-added services offered.

With regard to the first point, most of web pages were prepared by individual health professionals; the remaining were developed by academic or research institutes, by governmental or regional organisations and by commercial firms; in two cases authorship was not clearly indicated (see table 1). Information ranged over a wide variety of health-related topics, the management of chronic diseases being obviously the focus of most sites. A lot of information was found, therefore, on diabetes, cancer, heart diseases, AIDS, neurologic diseases such as multiple sclerosis and Parkinson disease,

including preventive measures, diagnostic and therapeutic procedures, sometimes notice of hospitals or specialised centres for the treatment of the disease. Among other topics, contraceptive methods, organ transplantation and a site devoted to homeopathy could be mentioned. As far as it concerns the third point, the index of readability was very good in 57% of the sites, good in 30% and inadequate in only 13% of the cases (4 sites): the intelligibility of the language used in these four sites was considered low because in one case information was basically given in English, although the site was addressed to Italian users; in another case the language used was too specialised for patients; in the last two cases information provided was judged too synthetic.

Information on the web may be communicated also through graphics, animations and diagrams which are considered to be an important factor to improve legibility and comprehension<sup>3</sup>. 50% of the Italian sites analysed used graphics as means of communication: attention should be paid to drawings explaining exercises for preventing low back pain, and pictures of teeth in an orthodontic page aimed at children.

**Table 1** Authorship of 30 health-related Italian Web sites providing consumer-oriented information  
No. (%) of web sites

Individual health professionals	12 (40%)
Academic institutions or research institutes	6 (20%)
Commercial firms	6 (20%)
Governmental or regional organizations	3 (10%)
Professional associations	1 (3%)
Not clearly indicated	2 (7%)

As regards to the value-added services offered by the examined web sites, the results of our analysis are summarised in table 2. The possibility of sending an e-mail with specific health questions to specialists, able to answer within the next two or three days was a popular option. Among other services offered, access to online databases such as PubMed and links to

<sup>4</sup> Silberg WM, Lundberg GD, Musacchio RA. Assessing, controlling and assuring the quality of medical information on the Internet. JAMA 1997; 277: 1244-45.

other medical web sites were quite widespread, as well as calendars of conferences or courses. Among additional services it is worth mentioning the possibility of measuring one's sight on the web through an interactive service provided by the Eye-Web site (<http://www.dada.it/eyeweb/>); a direct electronic helpline to cope with toxic substances related emergencies, offered by the Anti-poisons Centre of the Catholic University of Rome (CAV) (<http://www.tin.it/anriuscsc/cav/>).

**Table 2** Value-added services offered by 30 health related Italian web sites providing consumer-oriented information  
No. (%) of web sites.

Links to other web sites	14 (47%)
Direct dialog with public through e-mail	11 (37%)
Links to online databases	8 (26%)
Other services (Conferences, newsgroups, medical translator)	10 (33%)

Besides analytical criteria adopted for the evaluation of the web sites, basic standards have been established<sup>4</sup> to estimate the reliability of web sites and electronic resources present in the Internet. Such core standards include indication of authorship and relevant credentials, clear listing of references and sources for all contents, full disclosure of Web site ownership, sponsorship and of potential conflicts of interest, dates in which content was posted and updated. Our sample of 30 Italian web sites was examined according to these criteria and the results of our analysis are presented in table 3. Only two sites were found to meet all the four above mentioned standards:

- MALINF (<http://www.sanita.interbusiness.it/malinf/>) - prepared by the Prevention Department of the Ministry of Health. It provides easy searchable official and validated data concerning infectious diseases in Italy and gives information about international prophylaxis;

<sup>5</sup> Impicciatore P. Pandolfini C. Casella N. Bonati M. Reliability of health information for the public on the world wide web: systematic survey of advice on managing fever in children at home. *BMJ* 1997; 314: 1878.

- VIRTUAL HEALTH SERVICE (<http://www.cilnews.unige.it>) developed by the Laboratory of Clinical Informatics, Department of Internal Medicine of the University of Genoa. It is an educational site, with a section called Telematic Virtual Hospital providing non-professional health information in almost any medical specialty.

**Table 3** Compliance to standards established by literature as indicators of reliability in 30 Italian web sites providing consumer-oriented health information

	<u>No. (%) of web sites</u>
Indication of authorship	28 (93%)
Indication of reference sources	13 (43%)
Disclosure (sponsors, conflicts of interests)	13 (43%)
Indication of currency of information provided	13 (43%)

Three other sites - DEMATEL (<http://www.dematel.com>), CAV (see above), PSYCHIATRY ONLINE (<http://publinet.it/pol/>) did not clearly indicate the dates in which information was updated, but matched the other criteria. In three other cases reference sources were not mentioned, while in two others there was no full disclosure about web site ownership or sponsorship. It is worth remarking that there were also two sites in which no standard at all was met, and other four sites in which only authorship was indicated, although relevant credentials were not pointed out.

### Conclusions

The results of our survey confirm findings similar to those of other recent international studies which, with regard to the problem of medical information present on the Internet, suggest that "there is an urgent need to check public oriented healthcare information for accuracy, completeness and consistency"<sup>5</sup>. Undoubtedly, the Italian consumer is able today to find on the Web a large variety of health information, with a language that in most cases is accessible to lay persons and with many helpful services. Nevertheless, only very few sites offer warranties of quality as regards content and updating of information provided. There are still too few sites developed by

official organisations and addressed to the general public: an effort should be made by public agencies to provide reliable data and information accessible to everybody - at least everybody connected to the Internet! Which role medical librarians are then asked for in this changing scenario? They should certainly become the customer's guide in the new electronic information world, by preparing directories of resources aimed at their library's users. This printed matter should not be limited to a mere list of sites, but give exhaustive information on contents, updating and services offered in order to sustain consumers in their hard way towards information.