Access to Quality Information on Bioethics in Italy: an Analysis of Available Internet Resources

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Abstract

Background: Bioethics is an intensely discussed issue in Italy both in public debate and within academic and government institutions. Access to reliable and up-to-date information is essential in this field and the availability of information tools can ensure the exchange of knowledge and ideas, and stimulate research in relevant areas. Internet plays a key role in disseminating information and in the process of communication between citizens and governmental agencies.

Objectives: The purpose of this paper is to analyze the quality of Italian government, academic, educational and non-governmental organization websites in the field of bioethics; to verify Web availability of full-text documentation and to provide, in view of a future European network, a directory of Italian Internet information resources on bioethics that is similar to that provided by other institutions in their countries.

Methods: A Web search was performed using the main search engines and exploiting advanced search options. A sample of 44 websites was analyzed in terms of accessibility, reliability, usability, accuracy and exhaustiveness of information.

Results: The analysis of the identified websites showed that: 41% are official websites, 11% are academic or educational and 48% belong to non-governmental institutions. Significant information is concentrated on public source websites (67% of databases, 100% of terminological tools such as thesauri and glossaries). Compliance with accessibility regulations is incomplete for almost 90% of websites, of public or non-public origin. 94% of public source websites include the full-texts of laws, opinions and other documents. A dedicated website (SIBIL, www.iss.it/sibi ) was designed to provide links to quality Italian informational and educational resources.

Conclusions: Results of a questionnaire sent to Italian hospital ethical committees in 2003, showed that only 9.6% of responding centers has the possibility of consulting fee-based electronic resources. Internet and open access documents are therefore a key resource, especially for those regions where the information infrastructure is inadequate.
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KEYWORDS
Bioethics; information services; information storage and retrieval; Internet; Italy

Introduction

Bioethics is an intensely discussed issue in Italy both in public debate and within academic and government institutions. The issue of embryonic stem cell research, for example, has caused conflict within the research community: some scientists would like to see more liberal rules, while the Catholic and conservative coalition wishes to maintain the recently approved embryo-protection law, which is among the strictest in Europe [1].

Access to reliable and up-to-date information is essential in the field of bioethics and the availability of information tools can ensure the exchange of knowledge and ideas, encourage moral reflection on medicine and scientific progress, and stimulate research in relevant areas [2]. Internet plays a key role in disseminating information and in the process of communication between citizens and governmental agencies. There is an increasing demand for updated and reliable information which is necessary for today’s citizens; e-government is requested to provide not only online services but also full data access. Accordingly, the Italian Parliament has recently passed several important laws which are qualifying Italy as one of the most advanced countries in the field of e-government. Nevertheless, while Italian e-government policy, has been focusing attention on online interactive services, it has at times neglected the objective of making public sector information available in a simple, efficient and consistent way. Public information is scattered among many different websites, and it is therefore often difficult to find [3]. In this context, the Italian National Institute of Health (Istituto Superiore di Sanità - ISS) in 2001 launched a research project aiming at the creation of a website entirely devoted to bioethical information, through the joint work of bioethics experts, physicians and information professionals. The site is called SIBIL (Sistema Informativo per la Bioetica In Linea – Online Bioethics Information System), available on the Web since 2004 [4]. The site provides an updated overview of informative resources and educational activities in the field of bioethics, with links to the main sources of information.

Objective

The purpose of this paper can be summarized in the following three points:

1. To analyze the quality of bioethical websites of government, academic, educational and non-governmental organizations in terms of accessibility, usability, accuracy and exhaustiveness of information. The analysis was carried out according to the general principles proposed by MINERVA, a European network set up to create an agreed common platform for digitization of cultural and scientific content. MINERVA published a handbook which provides an accurate model of quality analysis of cultural websites [5]. The quality criteria proposed in the above-mentioned handbook were conceived for cultural websites, yet they are applicable to the field of bioethics, as well, since bioethics is interdisciplinary affecting science, law and philosophy.

2. To verify Web availability of full-text documentation such as laws, guidelines, position statements and reports, and of information tools such as databases, glossaries and e-journals.

3. To provide and update a directory of Italian Internet information resources on bioethics that is similar to that provided by foreign institutions in their countries [6,7]. The directory can be found on the above-mentioned SIBIL website. It represents a useful tool also in view of a future European network to be achieved through cooperation with parallel projects.

Methods

In order to select the available resources, a Web search was performed using the main search engines and exploiting advanced search options (i.e. searching the Italian term for bioethics in the title of pages, selecting only Italian language websites, finding pages that provide links to other significant pages). The Web search was performed during the period between 2006/01/01 and 2006/05/31. A sample of 44 bioethics-related websites was examined, distributed in six main categories: Official, University, Private, Ethical Committees, Bioethics Journals, European Commission and Vatican websites (see Figure 1). The last category was included in the sample since the information provided is in the Italian language.
The sample was analyzed according to four main criteria: reliability, accessibility, usability, quality of contents.

**Reliability**
The question of reliability is a key point in the e-health context and it constitutes a major priority for health-related websites. Many factors contribute to website reliability: first of all the attribution of authorship (all information presented on a website must be attributed to an author) and the transparency of sponsorship and funding sources; confidentiality of personal data relating to visitors must comply with an explicit policy. Before carrying out any kind of analysis, a careful evaluation of website reliability was performed. All the 44 websites included in our sample had to comply with a more than acceptable level of reliability.

**Accessibility**
Accessibility can be defined as the ability of anyone, including those who have disabilities, to access content and information on the Internet. "Accessible" means usable by a wide range of persons with disabilities, including blindness and low vision, deafness and hearing loss, learning difficulties, cognitive limitations, limited movement, speech difficulties, and combinations of these. The European Union is increasingly focusing on issues regarding access to information for all, promoting national policies which specifically address accessibility to the web by disabled people. In Italy, the so-called “Stanca Law on accessibility” [8], issued in 2004 and published in May 2005, obliges all Italian government authorities to make their websites fully accessible, as has been described by Mancini et al. [9]. The availability of technical guidelines on accessibility did not automatically lead to their application, as can be seen in the results of this study.

**Usability**
ISO 9241-11 standard defines usability as “the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use”. Usability is a measure of the ease with which visitors are able to use a website. Website usability is not just about making sure everything on the site works, but how quickly and easily visitors are able to make use of it. In the analysis of the website sample a usability index was constructed taking into consideration the presence of elements that could improve access to information and comprehension of contents.

**Quality of contents**
The quality analysis of the website sample contents was based upon the presence of elements that could improve the significance and the comprehension of the information provided. Presence on the website of glossaries, thesauri, databases, guidelines, news section, and discussion lists or forums were considered indicators of quality. Another factor taken into consideration was the presence and the number of links towards other relevant websites.

**Results**
The analysis of the identified websites showed that: 41% are official websites, 11% are academic or educational and 48% belong to non-governmental institutions. Significant information is concentrated on public source websites (67% of databases, 100% of terminological tools such as thesauri and glossaries). With regards to contents, 94% of public source websites include the full-texts of laws, opinions and other documents. All specialized bioethics journals are of non-public origin and 100%
of them have a website with a table of contents and abstracts. Only 14% of the articles are open-access.

**Accessibility**

In order to determine the website’s accessibility rating, a checklist based on WCAG 2.0 [10] was utilized. These guidelines cover a wide range of issues and recommendations for making Web content more accessible. The following criteria were adopted for evaluating accessibility levels:

- Use of HTML vers. 4.02
- Use of XHTML vers. 1.0-DTD strict
- Text alternatives for all non-text content
- Synchronized alternatives for multimedia
- Information and structure separated from presentation
- Distinction of foreground information from its background
- All functionality operable via keyboard interface
- Mechanisms to help users find content, orient themselves within the site and navigate through it
- Support compatibility with current and future user agents (including assistive technologies)
- Accessible alternative for all contents.

Web accessibility was validated through W3C Validator [11], a free service that checks Web documents in HTML and XHTML format for conformance to W3C Recommendations and other standards, and through CSS Validator [12].

The analysis results showed that compliance with accessibility regulations is not complete for almost 90% of websites, of public or not-public origin.

**Usability**

The analysis of website usability was based upon a quality indicator index of values ranging between 0 and 20. The index was built paying attention to the presence of tools which could improve the access to information. Special attention was paid to the availability of an internal search engine (Search function) and of a site map which are considered key factors for usability. The availability of an online glossary and the clarity of language were other elements considered.

In total four elements were taken into account: Site map; Search button; Glossary; Clarity of language.

A score of 5 points was assigned for each element. The total scores of the sites in a given category were summed up and then divided by the number of sites belonging to that category, thus providing a value for the average degree of usability.

The results of the usability analysis are summarized in Table 1.

<table>
<thead>
<tr>
<th>Website Category</th>
<th>Index (0-20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>European Commission and Vatican Website</td>
<td>13.75</td>
</tr>
<tr>
<td>Official Website Ethical Committee</td>
<td>16.25</td>
</tr>
<tr>
<td>Academic</td>
<td>10</td>
</tr>
<tr>
<td>Official Website</td>
<td>12.14</td>
</tr>
<tr>
<td>Private Website</td>
<td>7.91</td>
</tr>
<tr>
<td>Journal</td>
<td>7.22</td>
</tr>
</tbody>
</table>

The highest score was reached by the Ethical Committee websites, while private and journal websites have scores that are below average.

**Quality of contents**

Elements considered in evaluating the quality of contents of our website sample were the presence of databases, thesauri and glossaries, full-text documents and guidelines, news sections, possibility of participating in discussion lists and forum.

Percentages of these elements in the website sample are shown in Figure 2.

Worthy of notice is the high presence of a news section: this can be interpreted as a will to keep the website constantly updated and to offer users the possibility of following developments in the bioethics debate. The possibility of expressing one’s opinion through discussion lists and take part in public debate through a forum is still low. Informative and terminological tools such as databases, glossaries and thesauri, which require a large investment for their building and maintenance, are concentrated in institutional websites. The presence of full-text documents is distributed in a uniform way over all categories.
The presence and number of links to other relevant resources was another factor taken into account to evaluate the quality and the dynamism of a website. The results of the analysis, divided by category, are shown in Table 2.

### Table. Distribution of websites per category and number of links

<table>
<thead>
<tr>
<th>Number of links</th>
<th>European Commission and Vatican Website</th>
<th>Official Websites Ethical Committee Website</th>
<th>Private and Journal Website</th>
<th>Academic Website</th>
<th>Total per range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 to 7</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>8 to 15</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>16 to 50</td>
<td>1</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>More than 50</td>
<td>1</td>
<td>11</td>
<td>4</td>
<td></td>
<td>30</td>
</tr>
<tr>
<td>Total per category</td>
<td>4</td>
<td>11</td>
<td>11</td>
<td>4</td>
<td>30</td>
</tr>
</tbody>
</table>

Similar studies on link availability in health-related websites [13] showed that institutional websites usually provide a higher number of links to other resources, as compared with that offered by private sites, thus accomplishing the function of directories which orient users towards relevant information. Our study does not show a significant difference with regard to link number when comparing official or private websites.

### Discussion

In a previous study effected by the authors in 2004 [14], a survey was carried out by means of a questionnaire that was sent to ethical committees of hospitals and local health authorities and to other related institutions in order to verify their information sources. The results of the questionnaire showed that only 9.6% of the responding centers had the possibility of consulting fee-based electronic resources. Furthermore, the majority of ethical committees (65%) were located in the Northern and Central Italian regions, while 81% of clinical trials occurred in the same areas. Results of this paper clearly demonstrate that there is now in Italy, in the field of bioethics, a wide Web availability of full-text documents, guidelines and opinions. There is a lower but increasing presence of databases and terminological instruments, and a minimal availability of open access commercial journals.

Internet and open access documents therefore represent a key resource, especially for those regions where the information infrastructure is inadequate.

### Acknowledgments

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### Conflicts of Interest

None declared.
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