

## **S5 : Evaluating health information on the Internet**

### **S5.1 A complex definition for quality**

*Quality is a complex concept for various reasons : the definition of the term itself, the specificity of Internet health information, the different actors involved.*

#### **The definition of quality**

*The quality of a health website may refer to different items :*

*the content and its validation*

*the publication of original documents by experts*

*up-to-date information*

*organization of the information in the website*

*design*

*accessibility for disabled*

*optimization of the visibility on search engines*

*transparency on the funding sources,...*

*In addition, even for high-quality websites, there may be an unequal level of quality between the different information.*

#### **The specificity of Internet health information**

*Internet information is very different from traditional sources, like books or encyclopaedias. Internet is an unregulated network where anyone can publish without censorship.*

*So, different levels of Web pages may be found, from advertising to expert opinions.*

*And health information is more sensitive to misleading claims, unproven remedies, quack advices, or links to dubious websites.*

#### **The different actors involved**

*The websites are, of course, involved in the quality of their resources, including content, organization and visibility through search engine optimization.*

*Google helps Internet users by collecting and ranking Web pages in order to provide relevant information..*

*By selecting search terms, by building queries, by trying to evaluate the documents, Internet users are another actor of the quality of health information.*

*To help them identifying quality websites, some initiatives were taken these last years, which may be classified in three broad categories.*

**Catalogues** *are websites generally created by medical libraries or public organizations selecting the most relevant resources, organizing them in categories for a better orientation of users. The most known, MedlinePlus, created by the National Library of Medicine, in the U.S., is especially dedicated to the general public.*

**Guidelines** *are a set of criteria helping Internet users to assess information quality.*

*For example Trust it or Trash it, developed by a network coordinated by Genetic Alliance, a nonprofit health advocacy organization in the U.S.*

*The third initiative concerns **Quality labels**, the most known being HONCode.*

## **S5.2 HONCode (from Health On the Net)**

*A scientific publication from British Medical Journals in 2002 identified about one hundred rating tools, developed by public, private or non-profit organizations, used to assess the quality of health websites. Many of them are no longer functional but continue to be displayed on medical websites.*

*Currently, the most used is HONCode, initiated in 1996 by a Swiss foundation, Health On the Net, and adopted by about 8 000 websites in the world.*

*Information providers or webmasters who are candidate for the certification of their site have to complete an online questionnaire where they commit themselves to respect the eight principles of HONCode.*

*1. Authority : indicate the qualifications of the authors*

*Any medical or health information provided by the site will only be given by medical professionals. Otherwise it should be specified that a part of the information is from non-medically qualified persons.*

*2. Complementarity*

*Information should support, not replace, the doctor-patient relationship*

*3. Privacy*

*Respect the privacy and confidentiality of personal data submitted to the site by the visitor*

*4. Attribution*

*Cite the source of published information and its date. If the information proposed by the site is not the original source, the source of published information and its date have to be indicated.*

*5. Justifiability*

*Any information on a specific treatment will be supported by the source of information.*

*6. Transparency*

*Possibility to contact the webmaster for more complete information*

*7. Financial disclosure*

*Provide details on funding*

*8. Advertising policy*

*Clearly distinguish advertising from editorial content*

*A site complying with these principles is given a seal to place on its pages.*

*It is important to know that HONCode is not an award system that rates the quality of the information, of the content. It is only a set of standardized rules concerning editorial transparency.*

*In addition, it is quite impossible to guarantee a permanent quality for the whole information of a medical website due to the ever-changing nature of the content of electronic documents.*

*So quality seals are not the miracle solution to improve information quality. It's mostly the user by himself who has to evaluate the quality of the information and, at least, check a set of criteria; HON criteria are a good basis, but they have to be completed by others and also by the critical judgment of the user.*

## **S5.3 Some quality guidelines for Internet health information**

*Here are some tips to help you evaluating the quality of Internet health information.*

### **➤ Who runs the site? Who is the editor, the producer ?**

*The source of medical information is the first criteria for its credibility and quality and must always be displayed. Generally, search this information in a section named About us or Who we are. Some websites, like Orphanet, go further by displaying a Quality charter on their homepage.*

When evaluating a document found through a Google search, its URL often provides useful information. For example .gov identifies a government organization; .edu identifies educational sources,...

➤ **Who pays for the website?**

The source of a website's funding is important because it may affect what content is presented, how it is presented, what might be missing. It is also a potential source for conflicts of interest. Advertisement has to be clearly labeled as such and separated from the editorial content.

➤ **How is the information documented ?**

For an original source, the information should rely on a research basis, such as citations of articles in medical journals or links to the source.

If the information is not an original content, the source should be clearly identified.

➤ **What are the qualifications, the expertise of the authors ?**

Credentials must be disclosed. However, even when they are displayed, it sometimes may be difficult to evaluate them. Especially when authors provide medical information beyond their domain of expertise, for example concerning a rare disease.

A possibility to check this point is to search PubMed by crossing the name of the author with the topic for which he is cited. Here, for this search on *Osteogenesis imperfecta*, 14 articles from this author are found on Pubmed, including two Review articles, which are scientific summaries from experts.

➤ **How is the information reviewed ?**

Is there an editorial board ? What are the procedures for validating the information ? Are they clearly stated on the website ? On Medscape Reference, the names of editors are listed, as you can see here for dermatology.

➤ **How is the information updated ?**

Many resources do not provide a date of updating. It is important that medical information be current and updated on a regular basis. Even if the information has not changed, the last update has to be indicated to ensure users that it has been reviewed.

➤ **Be cautious with hyperlinks**

Hyperlinks are a major characteristic of the Web. They allow a continuous information, with the risk to be taken away from a validated information to a misleading source without being aware of it.

➤ **Accessibility**

Information on a website should be designed to be accessible to people with disabilities; for example, suitable space around links, pictures and symbols in addition to text, sufficient contrast between text and background colours.

In addition, information on a health website has to be :

Complete, exhaustive : be aware of information which may be missing, for example negative points on a treatment

Readable : easy-to-read, and, at least, rid of medical jargon

Useful : corresponding to the needs of users

And websites should pay attention to :

Organization of the information

Search engine optimization, to make the information more visible for users

And also Design

*In any cases, even if health information is provided by a trustworthy source, the critical judgment of Internet users is essential for its evaluation.*