

UPDATE

The Quality of Online Health-Related Information – an Emergent Consumer Health Issue

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The Internet has become one of the main means of communication used by people who search for health-related information. The quality of online health-related information affects the users' knowledge, their attitude, and their risk or health behaviour in complex ways and influences a substantial number of users in their decisions regarding diagnostic and treatment procedures.

The aim of this review is to explore the benefits and risks associated with using the Internet as a source of health-related information; the relationship between the quality of the health-related information available on the Internet and the potential risks; the multiple conceptual components of the quality of health-related information; the evaluation criteria for quality health-related information; and the main approaches and initiatives that have been implemented worldwide to help improve users' access to high-quality health-related information.

Keywords: consumer health, health-related information, quality assessment criteria, e-health codes of conduct, automatic assessment of health-related information

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Introduction

The information and communication technology (ICT) has boosted the health care services and has transformed the doctor-patients, doctors-healthy people relationships, as well as the way healthy people relate with people afflicted by various medical conditions [1-3]. The Internet has become one of the main means of communication used by people who search for health-related information [4]. The quality of the health-related information that is available in the cyberspace affects the users' knowledge, their attitude, and their risk or health behaviour in complex ways [5,6]. The patients, some of whom suffer from serious diseases or are in critical life-or-death situations, can make decisions with irreversible consequences, based on recommendations obtained from these novel sources of information [7]. There are studies which show that the health-related information available on the Internet influences a substantial number of users in their decisions regarding diagnostic and treatment procedures [8-11]. An investigation of the latest developments in the specific area of vaccine-preventable diseases might bring valuable insights regarding the impact of online health-related information on public health considering that data from several countries with anti-vaccination media campaigns had significantly higher rates of some vaccine-preventable diseases compared to nations with fewer such reports, where vaccine coverage remained higher [12,13].

Aim

The aim of this review is to explore the benefits and risks associated with using the Internet as a source of health-related information; the relationship between the quality

of the health-related information available on the Internet and the potential risks; the multiple conceptual components of the quality of health-related information; the evaluation criteria for quality health-related information; and the main approaches and initiatives that have been implemented worldwide to help improve users' access to high-quality health-related information.

The Internet as a source of health-related information

The Health Internet

Computers and information networks have exerted a profound influence on the evolution of human society in the past and current centuries. Information technology and the Internet have had a strong and lasting impact on all areas of medicine, from research to medical education and medical practice [2].

There are three main reasons why users access health-related information online: to search information regarding various health issues, to participate in forum discussions within different support groups, and to seek medical advice from health professionals [3,14].

Health represents one of the main reasons why people access the Internet. According to the latest Pew Research Center's statistics, 59% of American adult citizens have looked online to find health information in the past year and 72% of American Internet users have searched online for health information during the past year [15]. An earlier survey conducted in the U.S. between August and September 2010 on 3001 adults has shown that 80% of Internet users (which represents 59% of the entire adult population) have searched online for information regarding approximately 15 health-related subjects, various diseases or treatments; 25% of users, meaning 19% of all adults in the

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USA, have watched a video online about health or a medical condition; 24% of users, meaning 18% of all adults, have searched online for opinions about a certain drug or medical treatment [16].

A study conducted in seven European countries reported that 44 % of the general population and 71% of the Internet users have searched the Internet for health-related purposes [17]. The percentage of Romanians who access the Internet for the same purpose increased to 19% in 2010 [18]. Another study conducted by a commercial company has shown that “the top categories about which Romanian users want to find information over the Internet include health (53.8%), education (50.8%) and entertainment (46.6%)” [19]. An IRES study published in May 2011 also has shown that health is one of the top three categories of information searched for by Internet users. The concern for health-related information seems to only be surpassed by that for politics and sports-related news [20].

The Internet has changed, more than any other communication channel, people’s relationship with information in general, as well as the way in which consumers and specialists access health-related information [21]. There are studies which have shown that one in four users who search for health-related information on the Internet also join a support group and part of these users believe that engaging in discussions within these virtual support communities is emotionally, financially and information-wise more useful than direct contact with doctors [3].

Regarding communication with medical personnel via the Internet, studies have shown that starting with the early 2000s one in five doctors were using the email to send information to their patients; 3.7 million patients send emails to their doctors and 33 million more would also like to do the same [3].

Studies indicate that there are differences between people who search for health-related information using the classic medical information sources (medical personnel, medical journals, printed media) and those who search for the same kind of information online. People who use the Internet to search for health-related information are younger, have a higher income and have a superior level of education than those who use traditional information channels [22-23]. Also, it appears that people who get their health-related information via the new electronic communication channels have higher levels of health-information orientation, stronger health beliefs, and healthier lifestyles than those who look for information elsewhere than online [23].

Benefits, challenges, and potential risks of using the Internet as a health-related information source

The Internet has great educational potential for both consumers and the medical personnel. Consumer health informatics, a new field of applied health-oriented research, is already providing many applications that enable patients and healthy people not only to access interactively and adaptively health-related information, but also promote

healthy behaviours and self-care, assist the users in making informed decisions, and provide increased and enhanced opportunities for peer information exchange and social support [24,25].

The most important advantages of the Internet as means of information over the traditional media include: widespread access to information, with no physical and geographical limitations other than the ones that are inherent to information technology, the possibility to quickly and frequently update the information, as well as improved access to personalized medical information upon request [3]. Other notable advantages include the interactivity, the reduce costs, the anonymity, and the possibility of obtaining interpersonal support within forums and online patient groups [3].

On the other hand, experts consider that the expansion of the consumer-oriented health web came along with an increased number unfounded health claims [26]. The health web is seen as a convenient platform for scammers, and researchers, professional organizations and governmental institutions have developed specific guidelines and have issued warnings to raise the awareness of consumers about the insidious but ubiquitous presence of unlicensed, unqualified online information providers, who offer from fraudulent mentoring or counseling services, to “miracle cures” or enticing life-enhancing products, frequently operating on the borderline or even completely outside the legal boundaries [27].

Probably the most commonly agreed upon source of concern is the fact that a large amount of health-related information that is shared over the Internet is of poor quality, exposing users to significant health risks [7]. During the last decade, there has been published a large number of studies scrutinizing the quality of online information related to most if not any known disease or medical condition. Various authors conclude that the Internet is not a reliable source of information and does not accurately inform patients about coronary heart disease [28], cardiac murmurs [29], varicose veins and the treatment options [30], gastric cancer [31], breast cancer [32,33], head and neck cancers [34], oral cancer [35], prostate cancer [36], urological oncology [37], hemangiomas [38], menopause [39], diabetes mellitus [40,41], parathyroid disease [42], healthy nutrition [43,44], vitamin B12 [45], depression [46], epilepsy [47] rheumatological conditions [48], osteoporosis [49], first aid for burns [50, 51], first aid in choking [52], cervical and lumbar disc herniation [53,54], scoliosis [55], vascular and other surgical operations [56,57], influenza [58], child fever [59], coeliac disease [60]. The concerns regarding the poor quality and many times even misguided health-related information available on the Internet have increased with the advent of Web 2.0 and its equivalents in the medical field (health blogs, health-oriented social media groups, YouTube), namely Health 2.0 and Medicine 2.0, which are characterized, among other traits, by an unprecedented increase in user-provided content [61-63].

Online health-related information can have undesirable health consequences for the users even when the information is of very high quality. This fact has been explained through the so-called “contextual deficit” which is characteristic to health-related information that is shared over the Internet [64]. A lack of context increases the risk of incorrectly applying information that is actually correct, like for instance when a message that was written for specialists is read by non-professionals, when a piece of information that is valid within a certain clinical context is transferred into a different context where it loses its validity, when a piece of information is outdated, or simply when the information is presented in a certain language and it is misunderstood by a user who does not have proper knowledge of that language [64].

Another concern is related to a growing number of interactive medical applications designed for the direct use of patients and healthy people, as well as of electronic patient registries that require collection of personal data, which raises sensitive personal data management and safety issues [65].

Last but not least, another challenging ethical issue is that the implementation of Internet and communication technologies in the healthcare field might lead to more discrepancies in the availability of health services for several disadvantaged groups of population (those affected by physical or psychological disabilities, people with low general health, and computer literacy, people with language barriers and low socioeconomic status). Experts are concerned that rapid advancements in health informatics and web, computer or mobile device based health communications might deepen the digital divide for individuals or groups with the poorest access to information and electronic technology [66].

Criteria for Assessing the Quality of Health Information on the Internet

A number of authors, professional organizations and governmental institutions have pointed out the questionable accuracy of online health-related information and the potential risks for users who make decisions relying on sources that don't comply with the basic ethical standards either because the providers of information are not aware of the applicable policies or because they deliberately engage in fraudulent activities [64, 67,70,71]. This concern has led to the launching of a significant number of initiatives focused on developing quality evaluation instruments for online health-related information.

The first initiatives towards developing guides for health websites creators and users were taken as early as 1996. Systematic reviews published over the last decade have identified between tens and hundreds of quality evaluation instruments for health-related information on the Internet [72-75].

Even though there are a number of technical and methodological differences between the various quality initia-

tives for the health Internet, they all have a common feature, which is the concept of normative criteria for best practices when it comes to sharing health-related information online [75].

In a systematic review, Kim et al classified the most frequently used quality criteria included in quality evaluation instruments for health-related information on the Internet and they found 165 criteria [76]. The majority of all considered criteria were grouped into the following categories:

- Content criteria (quality, validity, accuracy, completeness, depth)
- Design and aesthetic criteria (layout, graphics, the use of media)
- Credibility or ethical criteria (stating authors' names and their professional accreditations, disclosing sponsors, developers, specifying the purpose and character of the organization, mentioning financial sources, sources of information)
- Information currency (update frequency, whether the information is old or new, the degree to which the website has been updated)
- Source authority (the reputation of the source, its credibility)
- Ease of use (navigability, information accessibility on the website, functionality)
- Accessibility and availability (ease of access, access costs, whether the content is available with or without registration and/or fee, optimized for most common browsers and operating systems)
- Links (the quality of links, the use of links to other sources)
- Attribution and documentation (clearly stating the sources, a balanced presentation of evidence)
- The target audience (mentioning the target group, adapting the content to the declared target audience)
- Contact information or feedback system (displaying contact information, postal address, email address, phone number)
- User support (support availability, documentation availability)

The criteria that were not specific or were unique were included in a separate category, referred to as “other”. Up until now the multidimensionality and complexity of all criteria have rendered it impossible to define a complete, universally accepted evaluation system. The criteria sets which have been proposed thus far feature both areas of divergence and a significant common area.

Criteria for content quality

Investigating the quality of online health-related information has been frequently focused on two key dimensions: completeness or the degree to which the subject is covered, and accuracy or the degree to which the given information is correct [4]. To these primary aspects, some authors have added a third dimension, which aims to indicate whether a particular piece of information could expose the user to

a health risk by applying it. The assessment of the potential risk theoretically must include both the risk resulting from failing to mention important information pertaining to the topic (risk by omission) as well as actively conveying an information that is inaccurate or misleading (risk by commission) [77].

Although the methodologies for evaluating content completeness are varied from author to author, there are a few widely accepted methodological principles. One of the most common methods is computing the proportion of knowledge items covered on the website by comparing it against a normative list of knowledge items or a topic specific benchmark [4]. The number and nature of information items that are considered relevant for assessing health-related websites depend on the researchers' judgment. Another method of expressing completeness relies on calculating the percentage of websites which provide a minimal amount of information that is considered to be essential [9,46,59]. As regards the methods used to assess website completeness, the heterogeneity of the measures makes it difficult if not impossible to directly compare the result reported by different authors. A thorough examination of the evaluation methodology shows that in many studies researchers included completeness indicators which in addition to actual completeness per se, also included information accuracy criteria [4].

Accuracy, or scientific validity, was defined as the degree to which the information on the evaluated website followed the soundest available evidence or matched the information which was most widely accepted among specialists [4]. As with completeness, the way in which information accuracy is evaluated varies from one author to another. The reference base is usually developed during a preparatory step by bibliographic research from evidence-based medical guidelines, systematic reviews, expert published consensus documents or reference works. However, there are some studies in which the assessment of completeness is left at the evaluator's personal judgment and is not constrained by a predetermined benchmark. Furthermore, some researchers assess the accuracy of information based on standards outlined beforehand, while others develop the accuracy standards after collecting the information. The heterogeneous nature of the assessment methodology is also influenced by which information is considered as important [4].

Another important aspect regarding the quality of information on health-related websites refers to estimating the risk to which users could be exposed by uncritically applying some potentially harmful information. Walji et al have identified information that is potentially unsafe by either direct misinformation, or by omission [77]. Within the first category, authors distinguish risk-laden information because of toxicity (e.g., the recommendation of certain extracts containing active toxic compounds), because of side effects of unwanted interactions (e.g., the recommendation of supplements which could interfere with an-

tibiotics), because of delayed diagnosis or retarded/rejected conventional treatment. Within the category of risk by omission, the authors also defined four other subcategories of risk: failing to give a warning (e.g., not mentioning an important symptom necessary for identifying a serious medical condition), not mentioning certain substance interactions (e.g., not mentioning the interactions between the different medicinal preparations or extracts presented on the website, or between those recommended on the website and conventional medication taken by the patient in the mean time), not listing certain known side effects and finally not specifying known contraindications for certain treatments presented on the website [4].

Functionality Criteria

As far as functionality is concerned, the quality of a website depends on several factors, the most important of which being accessibility and navigability [78].

Accessibility refers to all aspects, chiefly the technical ones, which impact the optimal localization and display of searched-for information. The level of information accessibility on a website can be limited by browser incompatibility and the format in which the content is presented [78].

Another important aspect regarding accessibility is the website's visibility, that is, how readily search engines can find it when users search for information that is offered on its pages [78]. IT experts talk about an entire series of characteristics that pertain to website search engine optimization (SEO).

Information accessibility for people with disabilities is also a topical issue that is affected by website functionality. For visually impaired people, for instance, some important features include the possibility to adjust font size, the possibility to change the colour scheme for the website template, or in more severe cases the possibility to access the written information in audio format [79,80].

Navigability refers to how easy it is for the user to quickly go from one page to another to find the wanted information within the website. This includes the way menus and submenus are organized, the existence of a site map, how much information is displayed on the screen, and whether or not the website follows largely accepted conventions regarding elements (positional or visual) which facilitate navigation. An important complementary function which ensures quick access to the information within the website is an advanced internal search engine. Other functionality improvement features include the ones which memorize the user's navigation path within the website, website customization features and others [4,78].

Readability

Readability refers to how easy or how difficult it is to read a text. Readability shouldn't be mistaken for intelligibility. Understanding or comprehending a text depends, aside from readability, on a large number of factors (physiological, psychological, cultural, linguistic and others). Read-

ability evaluation is performed using mathematical formulas based on parameters such as sentence length and word length [81]. The most commonly used readability tests are Flesch-Kincaid Grade Level, Flesch Reading Ease, Simple Measure of Gobbledygook, Gunning-Fog index, and Coleman-Liau Formula. Studies suggest that common readability tests are inadequate for assessing the level of difficulty in written health-related materials [82]. Some authors have proposed readability tests specialized for health-related texts which in addition to syntactical and morphological parameters also included semantic ones to evaluate the degree of familiarity with the terminology within the analyzed texts [83,84]. The degree of readability is expressed either as scores or as the minimum level of education necessary to easily read the tested material. The published studies regarding the readability of online health-related texts have shown that these materials are generally difficult to read [85,86].

Aesthetic Criteria

Among the aesthetic aspects which some studies have examined about the quality of health-related websites include graphic layout, colour palette, dominant colours, contrasts and/or colour shades, design originality. Also, some authors include under these criteria a measure of the visual aids inserted in the website (static images, audio-vidéo material, and interactive media)[4]. The relatively small number of studies addressing the aesthetic criteria of quality was attributed to the subjective character of such undertaking. Some authors have noticed that the inter-rater reliability of the methods evaluating the aesthetic criteria of the health-related websites was much lower than in the case of evaluating navigability [87].

These criteria do not affect the quality of the content per se, however, the professional and attractive look of health-related websites seem to have a significant impact on the impression of credibility they convey to users. According to a qualitative study on user behaviour on health-related websites, the aesthetic aspect, the perception they gain at the first visual contact, within the first seconds of opening the homepage, are considered highly important by most users. Thus, an excessively busy design, a too complex structure, a lack of clear navigation clues, an excessive use of unattractive colours, pop-up advertisements, a font that is too small often cause users to no longer visit such websites and continue their search elsewhere [88].

eEurope 2002 Credibility Criteria

Considering Europeans' growing interest towards online health-related information, The Council of Europe has supported an initiative within "eEurope 2002" to develop a central set of quality criteria for health-related websites. Over the year 2001, as a result of a number of meetings attended by leading government representatives, international organizations representatives, nonprofit organiza-

tions representatives and industry representatives, a unified set of quality criteria was developed, according to which the Member States, the public, and the private sector could develop quality initiatives regarding health-related websites [78].

1. Honesty and transparency. These criteria require: stating the provider's identity (name, address, email, the website manager's/representative's address), transparency regarding the website's purpose and objectives (stating the target audience, describing the objective), transparency regarding all financial sources (grants, sponsorships, advertisement, donations, volunteer assistance) [78].
2. Authority. This criterion implies stating the source of published data/materials, indicating the name and professional accreditation for all individuals or institutions providing the information, including the date at which their professional accreditation was granted [78].
3. Confidentiality, privacy and personal data safety. This criterion implies clearly defining the confidentiality and personal data protection policy, which needs to comply with the European legislation [78].
4. Information updates. This criterion requires regular checks regarding the currency of the information for every page and regular updates, as well as clearly stating the date at which the last update was performed [78].
5. Responsibility. This criterion includes providing a feedback system for the users, clearly stating who is in charge of ensuring the website's conformity to the existing quality standards, taking all necessary measures to ensure that all linked websites, as well as all other partner websites follow the same Internet quality standards and a clear description of the content selection process [78].
6. Accessibility. This criterion requires ensuring physical access to the website as well as respecting the navigability and content readability standards [78].

In principle, the European quality criteria are independent of the website's content and medical specialty and they include metadata about how the content is displayed on the website. They are known by a series of names, such as "credibility criteria", "technical criteria", "general criteria" or "ethical criteria" [4]. The credibility criteria have been used as a basis for developing guides, codes of conduct, quality seals, certification systems or other initiatives for improving the quality of online health-related information [78].

Approach Strategies And Implementation Mechanisms

According to the core concept of the initiative and to the implementation mechanism, there are several categories of approaches that can be distinguished in evaluating health-related websites (Table I).

Table I. Classification of the initiatives by approach and implementation

Type of approach	Type of implementation	Examples
1. Code of Conduct	Guidance, direction	HONcode, e-Health Code of Ethics, HI-Ethics Code of Conduct, EC Quality Criteria for Health-Related Websites, IFPMA code
	Orientation, mentoring and quality mark/seal	HON
	Auto implementation on subordinate websites	AMA code
2. User guide	Assessment questionnaire applied by the user	DISCERN, HSWG IQ Tool
3. External certification	Fee-based evaluation, certification and rating process performed by a specialized entity	URAC, TNO QMIC
4. Filtering tools	Quality websites are manually selected and made available to users who are accessing them health and medicine directories	OMNI (INTUTE), Healthfinder, Healthsite, HardinMD
	Manually selected websites are accessed by users through search engines specialized in one or more medical fields	HONselect, MedHunt, HONmedia, HealthFinder, PudMed
	Filtering is automatically performed by a software application installed on the user based on certain measurable indicators provided by the developer.	Automated Quality Assessment (AQA) Automatic Indicator Detection Tool (AIDT) Support Vector Machines (SVMs)
	Complex filtering based on self-applied meta tags and implemented by third parties depending on the user's settings	MedCERTAIN (at present MedCIRCLE)

Codes of conduct

Codes of conduct try to solve the problem of the quality of health-related information on the Internet by elaborating recommendations or guidelines for website developers and users. The recommendations are based on a set of quality criteria. The Codes of conduct provide to health website developers a description of the self-evaluation process that must be implemented and explain to websites owners and users as well the best practices to be followed in disseminating high-quality health-related information, so that the website designers be able to respect the principles of website creation and the users be enabled to identify the websites not complying with the recommended practices [75].

The simplest implementation mechanism of the code of conduct is its voluntary use as a guideline for building the website by webmasters and all online health-related information providers.

Another implementation mechanism for codes of conducts is represented by those adopted by national professional associations or umbrella organizations for their own use. Certain organizations develop their own codes of conduct. In these cases, implementing the code is more secure and more complete since the founding forum of the association or organization can take disciplinary measures against members or subordinated entities that deliberately ignore or violate the code of conduct [78].

A complementary implementation mechanism practiced by some of the organizations which have developed codes of conduct is the so-called quality seal. The quality seal is a distinctive mark, an emblem or a logo, which displayed upon request on a website certifies that the health-related information provider has pledged to implement the specific code of conduct that the seal refers to. The code of conduct is voluntarily adopted by the administrator of the website and the quality seal is self-applied under the conditions imposed by the issuer. Basically, websites that would like to display a certain quality seal must make a prior approval request and will receive authorization to display it on their web pages only after the organization issuing the

seal verifies that the applicant complies with that code of conduct. The maintenance of the health-related information quality standards over time as required by the code of conduct is usually checked on a regular basis and in case a website has departed from the code that has committed to abide by, it is either warned to make the necessary steps to reinsure its compliance with the code or it is demanded to remove the seal. Users may also notify the organization in cases of fraudulent use of the label [75,78].

The development of a code of conduct is usually a low-cost undertaking, basically consisting of costs incurred by meetings of the expert group who develops the code of conduct and expenses with disseminating the recommendations. Furthermore, the cost of applying a quality seal is insignificant both for the developers and the owners of the health-related websites. Usually, the processing of membership applications, the random periodical checks of member websites' compliance and the targeted inspections initiated at the user's reports can be achieved by the organization issuing the quality seal with the help of a qualified team [75,78].

The major disadvantages of codes of conduct are represented by the lack of enforcement mechanisms and the difficulty of monitoring on a long term the compliance of registered entities to the respective code of conduct. As a result, codes of conduct may have a limited echo in time and thus their usefulness may be compromised [75,78].

On the other hand, just as with simple codes of conduct, the requirements to respect quality criteria when developing health-related websites will exclusively depend on the owner's / manager's will.

The benefit to users is that the displayed seal continuously draws attention to the importance of quality principles. Certainly, the actual usefulness is influenced by the extent to which website visitors understand the role of the seal and are interested in the values that it promotes [75].

Some of the best known codes of conduct are the following: the Health on the Net Foundation Code of Conduct (HONcode), the eHealth Code of Ethics of the Inter-

net Health Coalition, the HI-Ethics Code of Conduct, the code of the American Medical Association, eEurope 2002: Quality Criteria for Health related Websites, the code of the International Federation of Pharmaceutical Manufacturers & Associations and others [78,89-93].

User Guides

User guides are another approach to promote the quality of the medical Internet. These tools help visitors to appreciate themselves, based on a certain code and a set of quality criteria, to what extent and in what way the information on the visited websites meet quality standards. From a technical point of view, the evaluation guide is activated by just clicking a button or an icon displayed on the site. Then the user follows the guide that will prompt him to answer a series of questions related to the content of the website. At the end of the questionnaire, the user will be able to appreciate the quality of the visited website according to the score and the conclusions presented by the quality guideline. Quality guidelines can be general or specific to a medical subdomain or to a particular category of users (e.g. children) [75,78].

User guides are convenient for owners of websites as they do not involve any expenses from their part. Furthermore, the costs for developing and implementing guidelines are not high, usually having the same magnitude as the costs associated with the development of criteria and questions and the work of the programmers who write and test the source code of the application displaying the guide [78].

The extent to which guides contribute effectively to consumer orientation is strongly influenced by the fact that users are the ones who are totally responsible for launching and running the electronic guide. Some of the guidelines include a large number of questions so that their reading can take a lot of time given the fact that today's user is always in a hurry. Since this type of quality user guides requires a very high degree of motivation to be used effectively, the real benefits could be relatively small [78].

The most popular user guides for the quality assessment of health-related information on the Internet are DISCERN, NETSCORING and QUICK [94-96].

External certification

External certification or accreditation is a way to ensure quality in which the health information provider is assessed by an external, independent entity. The assessment is conducted according to a rigorous methodology, within the framework of a legal agreement between the health information provider and the assessing organization. During the accreditation process, the assessor and the applicant communicate and collaborate in order to achieve the ultimate objective of the certification. The accreditation process involves both an audit of the internal rules regarding the dissemination of health-related information by the owner of the website and an audit of the actual implementation of the regulations. Once the applicant meets all the

conditions for accreditation, the certification seal issued by the evaluator may be displayed on the applicant's website. This will certify that the health information provider meets all quality standards in the field and that the specific quality requirements are guaranteed by the accreditation company. The seal is actively linked to the external evaluator's database and thus the visitors are able to get an instant confirmation of the authenticity of the seal [97].

This type of initiative has emerged as a result of the providers' need to display on their websites a proof of quality that visitors would perceive as objective, independent, and professional. In fact, objectivity is ensured by entrusting the accreditation / certification process to a third party. Financially speaking, the cost of this outsourcing is really high. The level of quality assurance is directly proportional to the prestige of the company conducting the certification and of course, with costs supported by the health-related information provider. However, there are also evaluators who provide certification services at a relatively low cost [75].

It is quite obvious that from the user's point of view, this approach is very convenient because the guarantee of the quality of information is achieved without financial or time investment. Though, the utility is conditioned by the seriousness of the company that issues the quality certificate and the acceptance of the assessor's criteria by the consumer. Additionally, Eysenbach believes that external certification signalled by simply displaying a quality seal involves a regrettable reduction in data acquired by the laborious analysis of the qualities of the website to an ultra simple result, of binary type, achieved either by the presence or the absence of the certificate [97].

This type of quality initiative for health-related information quality includes URAC in the USA and TNO QMIC (in Europe) [98,99]. Although many external certification projects were started, few of them managed to operate for more than a relatively short period of time.

Quality filters

Quality filters are an approach that consists of selecting, manually or automatically, websites with quality health-related information based on predefined criteria. The health-related web resources selected in this way are stored in a database that is made available to users in various ways.

One of the most promising types of quality filters are the health-oriented web directories. They consist of a portal through which the users can access a selected universe of resources organized according to quality, relevance and topic [75].

One of the first quality filters of this kind is known as OMNI (Organising Medical Information Network) a project launched and supported by specialists from the UK. From 2006 it has been included in the medical and dental section of "Intute" which is a multidisciplinary portal. Since July 2011, the updating of this database has been discontinued due to funding difficulties [96,100].

Another quality filtered health information directory and portal is MedlinePlus, a service offered by the National Library of Medicine and the National Institutes of Health, USA [101].

The second type of implementation of the quality filters consists of specialized search engines. Their usage is similar to regular search engines but unlike the general ones those serving as quality filters, extract the results from a pre-selected database taking into account the quality criteria set by the developer of the filter.

Examples of such implementations are HONcodeHunt and HONselect (both of which provide two different versions, one dedicated to patients and the other for medical professionals), MedHunt, HONmedia and other search engines created by the HON Foundation [102-105]. Other important health oriented search tools are: HealthFinder a search engine created under the aegis of The United States Department of Health and Human Services (USDHHS) and PubMed, a search engine and highly specialized database for biomedical scientific publications made available to users by the National Library of Medicine and National Institutes of Health, USA [106,107].

Many quality initiatives that were based initially on only one of the two versions of filters have developed over time a complementary version, thus allowing users to access information both as a health information directory as well as a search engine.

From the users' point of view, it is obvious that quality filters are extremely convenient and are more advantageous than unspecialized search engines such as the well-known Google and Yahoo [75].

Despite the above-mentioned advantages, most people seeking health-related information start their search on a general search engine or unspecialized portal. A report published by the Pew Research Center highlighted that 89% of health-related information seekers in the United States begin their search at a general portal for instance Yahoo or AOL and only 8% initiate their search on a specialized website like WebMD.com [108].

In terms of costs for the author institution, the construction and especially the long-term development/maintenance of manually managed quality filters, either as directories or specialized search engines in one or more medical fields, is a real challenge. The dynamics of health-related information requires regular selection and sorting of websites which involves a large amount of work performed by experienced personnel in a field characterized by an extreme complexity.

The failure of many quality initiatives whose maintenance represented a Sisyphean task led to the exploration of new directions that hopefully could achieve the same goals with a more realistic human and technical apparatus. Therefore several authors have proposed projects to set up automatic filters in order to reduce or completely dispose of the human evaluators by transferring this task to software applications and computers.

A few authors tested automated quality assessment procedures implementing machine measurable quality parameters [109,110]. Griffiths et al have developed a quality ranking algorithm on a sample of depression websites using criteria based on current scientific evidence. The automation of the evaluation procedure is still difficult because the application requires pre-testing on a large number of training websites. Moreover, the replication or generalization of the automated quality assessment procedure to other health-related topics or fields requires renewed testing and training on a large number of websites relevant to each specific topic or field of interest [109]. Exploring in a similar line of research for the development of automatic filters, Wang and Liu have designed an Automatic Indicator Detection Tool (AIDT) which has shown a promising capability to automatically detect measurable quality indicators on health-related web pages [110].

The latest innovation in the line of automatic detection of health-related information on the Internet has been reported by Aphinyanaphongs et al and is based on machine learning models that were able to identify questionable cancer treatments on the web. The authors claim that their experimental model is not only accurate but could be generalizable to other treatments and scalable to the entire web [111].

Finally, the most comprehensive approach to the issue of quality filters for health-related websites is considered the filtering based on metadata linked to web pages, as tested in the international pilot project MedCERTAIN financed under the "Action Plan on promoting safe use of the Internet" supported by the European Union [64]. At this time the project is referred to as MedCIRCLE and it proposes a decentralized approach and interoperability of services and portals rating [112].

Quality Initiatives for Health-Related Information on the Internet

Health On the Net (HON)

The Health on the Net code was created by the Foundation bearing the same name, a Swiss nonprofit organization established in 1995 after an international conference on the use of the Internet and telematics in medical care. The code was developed for webmasters, health information providers and those who are responsible for health-related websites and aims to increase the quality of online health-related information by facilitating the identification of those websites which comply with ethical quality standards for health-related information [113].

The initial code consisted of eight very concisely formulated general principles. At the beginning, the authors of the code planned to circulate it on a wide scale and gain the support of any online health information provider who was in agreement with the principles of HON by displaying on the website the HON code logo. Subsequently, the idea of the HON quality seal was implemented which im-

plied prior verification of the candidate sites by a HON Foundation reviewer who scrutinized whether the applicant had indeed accommodated the HON principles on the website. For practicality reasons the initial criteria were operationalised so as to facilitate a consistent implementation [97]. Once the website's compliance had been validated, the applicant was required to display the HON seal of approval, usually on visible location on the homepage. The source code of the seal graphic was actively linked to the HON website.

The HONcode mainly includes the following ethical aspects of how health-related information are supposed to be shared via the Internet:

- clearly and visibly indicating the qualifications of the authors;
- displaying a clear disclaimer that the information provided on the website is intended to support, not replace, the doctor-patient relationship;
- ensuring the privacy and confidentiality of personal data submitted to the site by the visitors;
- clear attribution of published health-related information;
- any claims regarding the benefits or efficiency of a treatment or medical device must be backed up by scientific evidence;
- providing the visitors an easy way to contact the site owner/administrator by email;
- disclosing the website's funding sources;
- clearly distinguishing the advertising materials from the editorial content [114].

Over the years, the HON Foundation has become the most popular initiative for improving the quality of the health-related websites. Currently, it also provides users several other useful services for finding health-related information [115] such as:

- the MedHunt service - a specialized search engine that extracts information from sites certified by HON;
- the HonSelect service - a directory of medical resources and a search engine integrator for dedicated medical searches;
- the WRAPIN service - a complex feature that allows comparing health-related documents in any format (HTML, pdf, etc.) with an interconnected database to verify the existence and quality of the sought information in relation to the accepted standards;
- the HONmedia service - a search engine specialized in image searching on HON's visual database comprising almost 7,000 images covering 2,000 topics;
- the PROVISU service - a search engine for eye disease information; a service for diabetic disease – a search engine for accessing information about diabetes on all HON certified websites related to this disease;
- the ORPHANET service - a directory and search engine for information on rare diseases and orphan drugs.

DISCERN

The DISCERN project was launched in 1996, it is conducted by the Department of Public Health and Primary Care at Oxford University in collaboration with other governmental and nongovernmental institutions and is funded by the National Health Service Research and Development Program [116].

Originally it was developed as a tool to help consumers and health information providers to evaluate the quality of health-related information in printed publications regarding treatment options. DISCERN went through a rigorous development and testing process by a group of experts in the field of consumer health information. A pilot study conducted on a nationally representative sample showed that the tool is acceptable in terms of reliability and validity [117].

DISCERN is a tool that can be used to assess the quality of medical journals without the help of a specialist and without consulting other publications in the same specialty. The tool may reveal issues that subsequently require a more thorough investigation. The DISCERN tool was designed to help in assessing credibility but not the accuracy of the evidence presented in the publication if interest. DISCERN does not include criteria regarding the means of presentation, graphics, illustrations, readability and other characteristics of the content [94].

In 2003, DISCERN has been reviewed and tested so as to meet online health-related information and is available on the Internet [118]. DISCERN consists of 15 questions covering the same number of quality criteria. For example, question no. 4 helps customers realize the extent to which the consulted publication explicitly mentions the sources the presented evidence was extracted from. Question no. 5 draws the consumers' attention upon the possibility that certain information may not be updated. Question no. 6 highlights the possible omissions of some treatment options or the likelihood of bias in presenting treatment options. Each question is complemented by instructions that help the user to correctly apply the tool [94]. Users are provided with a manual containing general information, instructions and detailed explanations for the evaluation of each quality criteria included in DISCERN as well as a number of specific examples. The final score obtained based on the answers to the questions can be used to accept or reject information or to identify the weaknesses of the website [94]. More recently, a new, shortened version, namely the Brief DISCERN guide has been designed. The validation tests carried out on a sample of mental health-related websites have shown satisfactory results [119].

URAC

URAC (Utilization Review Accreditation Commission) is a nonprofit, independent organization having multiple ongoing accreditation, education and evaluation programs in health care. Initially, the organization was limited to ser-

vices aimed at checking the use of medical procedures for insured patients but later expanded its offer to a broader range of quality assessment and accreditation programs and services including those on the quality of health-related information disseminated on the Internet. In order to remove any reasonable suspicion of bias toward the health industry, URAC founders adopted several operating principles in the bylaws of the association that would ensure impartiality and avoidance of conflicts of interest. For this purpose, the association took the necessary steps regarding management and leadership representation and became an independent accrediting body including in its board of directors an equal number of representatives from all the stakeholders involved in the domain (consumers, providers, employers, government authorities, experts etc.) [120].

The accreditation program for health-related websites is based on the HI-Ethics code of conduct. Providers who are included in URAC's accreditation program of websites must disclose a series of information that can help consumers to evaluate the site. Disclosed information include among others: data about sponsors or other financial support, the site's privacy rules, the editorial policy and the advertising regulations. The health websites accredited by URAC must state the identity and qualifications of the authors and the information presented on the site should be based on scientific evidence. So as to ensure that accredited health-related information providers permanently comply with the assumed standards, URAC makes periodical reviews of the accredited websites and a thorough annual audit as well. URAC's certification program requires that all their clients set up a quality supervision committee composed of at least one specialist in the medical field and a person responsible for the confidentiality of personal data for each health-related website [98].

OMNI

"Organizing Medical Networked Information" (OMNI) was one of the first projects that provided users with a quality filter for accessing credible medical information. It was launched in 1996 by the Joint Information Services Committee (JISC) in the UK. The OMNI project was based on a quality filter approach, consisting of a database of medical resources which were selected based on quality criteria. The selection, categorization and reviewing of these resources were done by experts in the field of health-related information [99].

OMNI was mainly developed for specialized target groups such as students and teachers from the medical education system, researchers, and healthcare practitioner in the health care system. The service was for a while part of the BIOME service and in 2006 was integrated into the multidisciplinary portal Intute. The maintenance of the OMNI / Biome / Intute project database was a huge challenge. Unfortunately, in August 2010, the assigned budget to maintain Intute services was significantly reduced and from August 2011 the funding ceased. Although the data-

base is still available and can be accessed on the Intute site resources are no longer updated [122].

MedCERTAIN / MedCIRCLE

The two projects, MedCERTAIN and MedCIRCLE, aim at developing and promoting technologies able to guide consumers to credible health-related information on the Internet, creating a global Web network with reliable health-related information and enabling the consumers to assess and select high-quality health information. In the first phase, the MedCERTAIN project has developed tools and procedures that aimed to enable health information providers to apply for a transparency and credibility seal. From a technical perspective, MedCERTAIN is a technology-based approach assisting, on the one hand, the information providers to implement metadata tags and, on the other hand, allowing an external rating and certification of information using quality standardized vocabulary. MedCIRCLE is a continuation of the MedCERTAIN project and seeks to extend the descriptive meta tags applied by providers through the rating concept conducted by third parties. The MedCIRCLE project encourages the active involvement of some existing portals in various European countries to promote the implementation of a common vocabulary and to experience ways of exchange between heterogeneous entities, portals or rating services. MedCIRCLE brings together a consortium made up of three European health portals, located in Spain, France, and Germany. Two of them are supported by respected professional medical associations, namely, the German Medical Association and the Medical College of Barcelona [112].

The MedCERTAIN / MedCIRCLE strategy is based on three fundamental principles, namely:

- The technical criteria generally used to evaluate the trustworthiness of a website are not sufficient to assess the accuracy of the information, which can only be assessed by experts in the medical field [123].
- The quality standards of health-related information on the Internet can not and must not be controlled by a single central authority [123].
- The vastness of the field requires imperatively a collaborative, decentralized approach to the quality assessment of health-related information, which is subject to the adoption of a common standardized language [123].

The strategy of the MedCERTAIN / MedCIRCLE project exploits the combined contribution of information providers, users and experts in health-related information thus giving a more realistic chance of covering a field as vast as the health-related Internet. The MedCERTAIN / MedCIRCLE project opens the possibility of a nuanced assessment with more levels of credibility. The first level is based on the provider's own annotations, the second on annotations made by common users and the third one, on the assessment of an expert from the medical field [78].

However, the functionality of this type of complex filtering is subject to the adoption, by all potential partners,

of a unique metadata vocabulary called HIDDEL (Health Information Disclosure, Description and Evaluation Language) that allows the annotation of web pages with metadata information accessible to software applications used by the visitors of health websites [123].

Other initiatives

In 2000, the World Health Organization (WHO) proposed the creation of “.health” as a new Internet global top-level domain (TLD) name like other well-known TLDs such as “.com” or “.org” to help users locate websites related to their fields of interest. The proposal is supported by many national and international health organizations. Through this initiative, WHO wants to improve the level of online health-related information quality and increase the users’ confidence in health-related information on the Internet. It is thought that the WHO, as the funding organization, should have the responsibility to establish policies regarding the distribution and use of “.health” TLD names. WHO intends to make this domain available to health information providers who agree to abide by a set of health-related information quality criteria [124]. According to Internet Corporation For Assigned Names and Numbers (ICANN) the institution who coordinated and managed until October 1, 2016, coordination and management of generic TLDs, the .health domain name implementation is underway but it could take years until the new name might become available. Moreover, the process seems deadlocked in a deep controversy over the underlying philosophy that should guide the management of this domain. Consumer health experts seem to support some degree of content oversight and control while the opposing side espouses an unrestricted distribution based on commercial competition [125-127].

Romanian initiatives

The Romanian project which stands closest to the aims of a more credible and accurate health-related Internet is “Edusan” led by the National Institute for Research and Development in Informatics, Bucharest, the University of Medicine and Pharmacy “Carol Davila” and Valahia University from Targoviste. The project has been developed with European funding until the final phase of the experimental model. The project aims to develop a system of interconnected databases (about immunization, screening, prevention strategies and methods, risk factors, occupational health, environmental factors, institutions involved in public health, educational models on types of communities) as well as a library with health-related publications to facilitate the dissemination of expertise and the collaboration between institutions that have a role in the public healthcare system [128].

To the best of our knowledge, the only systematic and methodologically rigorous attempt to assess the quality of health-related information on the Romanian Internet was undertaken during 2008-2011 at the University of Medi-

cine and Pharmacy of Tirgu Mures, as a doctoral research by the author of this review [129]. Several results published during 2011-2016 have shown a poor compliance of the Romanian health-related websites to the credibility criteria, and modest completeness and accuracy scores [45,52,58,60].

Conclusions and practical implications

Improving the quality of health-related information on the Internet is definitely a long and hard to fight battle. Although measuring the credibility of the health websites is generally considered a tangible objective, the practicality of the tools is seriously questioned, and rightly so because no studies published so far have been able to find a correlation between the ethical and scientific criteria. Measuring content completeness and accuracy and thus estimating the degree of concordance with the evidence-based medical literature is also an elusive target as long as the gulf between the natural language used to disseminate the health-related information and the mathematical language used by computers is not bridged in.

Until a comprehensive strategy and an efficient automatic method for quality assessment is proposed, there are some steps that might be followed based on what already is accepted as empirically and scientifically sound:

- health professionals should be more aware that healthy or ill people that are exposed to poor quality health-related information might be at risk in a number of ways and should strive to reduce these potential risks by including this issue in the routine doctor-patient communication;
- at the health systems level, healthcare institutions and governmental organizations should invest more in providing high-quality health-related information to the general public and to specific categories of ill people;
- the educational strategies promoted by the governments should enable all people and especially children and adolescents to be equipped with a solid health literacy by complementing existing school curricula with health education that addresses the challenges of online health-related information;
- the global infrastructure and the stakeholders involved in the functioning of the Internet should find ways to promote the principle of free access to information without unnecessarily compromising the safety of users who search online for health-related information.

Conflict of interest

None to declare.

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