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Health On the Net's 20 Years of Transparent and Reliable Health Information

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Abstract. The Health On the Net Foundation (HON) was born in 1996, during the beginning of the World Wide Web, from a collective decision by health specialists, led by the late Jean-Raoul Scherrer, who anticipated the need for online trustworthy health information. Because the Internet is a free space that everyone shares, a search for quality information is like a shot in the dark: neither will reliably hit their target. Thus, HON was created to promote deployment of useful and reliable online health information, and to enable its appropriate and efficient use. Two decades on, HON is the oldest and most valued quality marker for online health information. The organization has maintained its reputation through dynamic measures, innovative endeavors and dedication to upholding key values and goals. This paper provides an overview of the HON Foundation, and its activities, challenges, and achievements over the years.

Keywords. Quality standard, Ethics, e-health, Health information technology, Certification

1. Introduction

Steadily increasing internet access - now 85% of the population in North America and 70% in Europe [1]– leads people to resort to web searches for health information or to gain access to health services. A 2012 Pew survey found that 72% of internet users had investigated health information online the previous year [2]; 77% began their pursuit through Google or Bing [3]. Search engines rank results according to popularity, not by trustworthiness. Reliability of health information that laypersons obtain via search engines cannot be guaranteed. Abundance of content (1 billion websites in 2014 [4]), suggests the problem is not finding health information, but in evaluating its trustworthiness [5]. It is surprising that a foundation would be established after a September 1995 conference “*The Use of the Internet and World-Wide Web for Telematics in Healthcare*” by a handful of visionaries and impact the health internet field over the next two decades.

The Health On the Net Foundation (HON) registered in May 1996 as a not-for-profit International Foundation in Geneva. It works to develop realistic and applicable

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solutions related to its mission: "to promote the effective and reliable use of the new technologies for telemedicine in healthcare around the world.". Over the past two decades, HON has identified two main challenges for which it develops schemes, takes actions, and collaborates with other entities for multiple projects: 1) how to discern reliable health content; and 2) how to provide access to trustworthy resources.

2. Methods: Actions implemented by the Foundation

2.1. Promote the creation of quality content through the HONcode and its certification

The HONcode criteria for health websites & collaborative platforms: In 1996, the Foundation elaborated the HON Code of Conduct (HONcode), summarized in Table 1., to help promote the quality and reliability of medical and health information provided on the World Wide Web [6]. The HONcode is a process metric that determines if website construction and maintenance conform to standards of excellence. The HON Foundation does not evaluate the reliability or quality of website information content directly. Studies have demonstrated that websites that conform to the HONcode quality standards contain more reliable health information than randomly selected health-related websites [7]. Presence of the HONcode symbol on a website helps a citizen to make a decision when faced with multiple, contradicting and sometimes questionable information. The HONcode standards help webmasters and information providers to adhere to quality information provision practices, especially considering the endless controversies of medicine. Editors of health-related Internet sites require simple, broadly-accepted rules to structure their construction and maintenance processes - the HONcode meets this need.

Table 1. The eight HONcode criteria for medical and health websites also available in 35 languages.

| HONcode seal | Criteria name | Detail at hon.ch/HONcode/Guidelines/ |
|---|---------------|--|
|  | HC1 | Authoritative |
| | HC2 | Complementarity |
| | HC3 | Privacy policy |
| | HC4 | Attribution |
| | HC4 | Reference criteria |
| | HC4 | Attribution Date |
| | HC5 | Justifiability |
| | HC6 | Transparency |
| | HC7 | Financial disclosure |
| | HC8 | Advertising policy |

When Web 2.0 appeared early 2000 [8] the Foundation responded to the needs by collaborating with the French National Authority for Health (HAS) in 2008 to adapt HONcode principles for Web 2.0 specific needs - focusing on dynamic interactions between internet users and developers [9].

Certification process: Websites voluntarily apply for the HONcode seal and are evaluated manually by an expert medical team according to the eight HON principles and associated published guidelines. As the result of the audit, an evaluation report helps health editors render content HONcode compliant and transparent. Once a website has been validated, it is delivered a dated dynamic and unique logo it can display to boast its annual certification and illustrate the trustworthiness of its

construction and maintenance (see [10]). The seal is located on HON servers, so its status can be monitored and adapted. When appropriate, the HON emblem on a website can show another logo mentioning *Reexam* or *Invalid* when necessary [10]. The seal of each site is linked to its corresponding HONcode certificate. The latter summarizes why and for how long the website has been certified [10]. Furthermore, because internet health content evolves constantly, the HONcode relies on three mechanisms:

1. The complaint mechanism: HON promotes the opportunity for any user to submit a complaint via the HONcode certificate or directly on the HON website which leads additional HONcode reviews to be carried out in an ad hoc manner. Submission of a complaint triggers HON to open an investigation after which the website must comply with any ensuing request for amendment - or lose its right to display the HONcode seal.
2. Automatic surveillance: The pages of the certified websites are stored in an HON database. Any new content is retrieved on regular interval and stored with prior content to enable experts to compare data. This mechanism helps to automatically identify significant changes to the previous pages used to justify HONcode compliance.
3. Manual surveillance: Every year the certified websites are re-assessed by the HONcode team through in-depth analysis of the website and focuses on new content and services. Re-review requires an average of one hour and a half.

Methodologies for certification have evolved over time. The measures for internal and external quality assurance, established for years, were updated in 2007. HON improved the system by incorporating standards such as the ISO/IEC 17065 norm and requiring inspection by independent accrediting organisations. To improve its services, HON set up procedures to monitor certification, complaint management, re-evaluation, and internal audits. Thus, HON has furthered the reproducibility of certification independently of revisers by more than 74% according to the principles [11].

2.2. Increase the access to trustworthy information online: topical search engine of online trustworthy health content

A European Union funded HON-related project (2010 to 2014), Khresmoi for Everyone (K4E, <http://everyone.khresmoi.eu>), targeted the general public by developing a search engine for identifying quality online health information [12]. It enables EU citizens and healthcare professionals to find the most recent and relevant medical information through a state-of-the-art semantic search. Within K4E, HON provides access to a large database of trustworthy health information consisting of over 8,000 certified and manually selected web portals in over 27 European languages. The HON contributions help to guide the end user toward health content according to the complexity of the terminology used. After the project ended in 2014, HON began working on new venues to provide even more intuitive semantic solutions to the citizen, via financing from the European Commission and the KConnect project (KConnect.eu). Raise awareness of the uneven quality of health information online

A website can be completely reliable and conform to HONcode criteria without being HON certified. The number of such sites that gain certification is limited due to limited manual resources. Therefore, HON developed an automated system to detect HONcode criteria conformance of health websites [11]. This tool was implemented in the K4E search engine as a feasibility test; it will become a plugin for a general search engine. It will assist in detecting health uncertified websites as HONcode candidates.

3. Results

Over the past 20 years, HON has evaluated over 20'000 websites; 20% had Web 2.0 components. Some 30% of websites in general disappear over a 10 year period. Nevertheless, over 13% of HON-certified websites have requalified for over 10 years (e.g., Rouen CHU has been certified for 19 years, MedlinePlus for 16, the Canadian Paediatric Society and Cismef for 17 years, WebMd for 15 years).

Not all websites achieve certification: 20% are rejected after HON initial inspection - and 7.5% in 2010. Increasing refusal rates may reflect stricter, more binding guideline criteria. Reasons for exclusion vary: site outside the scope of certification, inappropriate content, inability to respect the HONcode, or non-certifiable content. A comparative study found that only 0.6% of randomly chosen health websites that did not apply for HON certification conformed to eight ethical standards [13]. Certification motivates behavioural changes in the production process of health websites, thus gradually influences the website's transparency and trustworthiness [14].

Some 12,000 users now access the HONcode certificate daily through health certified websites. This demonstrates the demand for reliable information. A 2010 study mandated by the French National Medical Council and conducted by IPSOS Public Affairs showed that 26% of participants responded that they were aware of HONcode certification when browsing information on the net [15]. Thanks to public funds, the certification procedure was initially a free service. In 2014, due to economic instability worldwide, HON sought greater financial sustainability, and implemented an annual fee for recertification. HON deemed unacceptable the alternative of using advertisements for funding. The recertification payment scheme considers the type of website, its visibility, and its usage; fees range from 50€ to 325€. So far, of the 50% of certified websites contacted to pay, 32% done so.

4. Discussion and Conclusions

Over the past 20 years, many organizations have tried to guide internet users to transparent, high quality health websites [16]. Not many are still active. The HONcode is not only eight criteria but a commitment to inform users in a responsible and honest manner. Health websites applying for HONcode certification recognize that health information is unique. Websites requesting the HONcode voluntarily make changes to their production processes [13]. HON plans new ways to educating health website editors, e.g. providing quality tutorials.

HON gained non-governmental organization in official relation status with the World Health Organization (WHO). This demonstrates that HON is fulfilling its goal. In 2010, HON established a liaison with the International Standard Organization Technical Committee for Health informatics TC215. HON's goal remains to ensure the unrestricted and easy access to all for trustworthy online health information. HON hopes to continue to offer innovative solutions which integrate collective intelligence to address this global issue.

Several independent third-party studies on the effects of the HONcode certification demonstrated the importance of the HONcode [17]; others showed limitations depending on the health domain [18]. The HON Foundation addresses an issue ignored and abandoned by public and government services. Countries have minimal ability to legally restrict online health information. France regulated health websites in 2007, but stopped in 2013 due to other priorities [19].

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