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Twenty Years of Health On the Net: Committed to Reliable Information

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Abstract. In 1996, at the beginning of the World Wide Web, a group of health specialists anticipated the need for trustworthy health information online. Thus the Health On the Net Foundation (HON) was born. HON was created to promote the deployment of useful and reliable health information online and to enable its appropriate and efficient use. Two decades on, HON is the oldest and most valued quality marker for health information online. For a number of years under the guidance of the late Jean-Raoul Scherrer, the foundation has established its reputation through dynamic measures, innovative endeavors and a dedication to upholding key values and goals. This panel discussion provides an overview of the HON Foundation, its activities, challenges and achievements over the years.

Keywords. quality standard, ethics, e-health, health information technology, certification

1. Panel Organization

The proposed speakers are:

- Antoine GEISSBÜHLER, President, Health On the Net Foundation Council
- Célia BOYER, Executive Director, Health On the Net Foundation

2. Panel Description

Format. This panel discussion gets into the nitty-gritty aspects of the HON Foundation's work, and most importantly the challenges and opportunities inherent in both providing trustworthy health information online and its appropriate and efficient use. It will also explore how certification motivates behavioural changes in the production process of health websites, gradually influencing the website's transparency and trustworthiness

- Introduction to HON and the HONcode certification, and the challenges and opportunities of providing trustworthy health information online and its appropriate and efficient use 30 minutes
- Panelists position presentation (30 minutes)
- Questions & answers (30 minutes)

Sample debatable questions

- Discuss the possibility of worldwide access to HONcode.
- Sustainability of HON into the future.

3. Description

The majority of the adult population in both Europe and North America has access to the Internet. More than 70% state that they have used the Internet to look for health information and the majority started their search at a search engine. Given that search engines list sites according to popularity and not quality, it is imperative that users have a means of separating trustworthy and honest information from non-reliable health information. The abundance of content (1 billion websites in 2014, according to internetlivestats.com) suggests that the problem does not lie in finding health information, but in evaluating its trustworthiness.¹

Numerous challenges and pitfalls are inherent in accessing high-quality health and medical information on the Internet. One approach to meeting the challenges is through HONcode certification, the longest standing and respected quality guideline for health information online. It consists of eight quality factors that health websites should comply with, ensuring access to standardized, trustworthy health information that can be used as a tool to guide consumers.

HONcode seal		Criteria	Detail
HON @** CODE	HC1	Authoritative	Indicates the qualifications of the authors
	HC2	Complementarity	Information supports, does not replace, the doctor- patient relationship
	HC3	Privacy policy	Discloses and respects the privacy and confidentiality of personal data submitted to the site by the visitor
	HC4	Reference and date	Cites the source(s) of published information Dates medical and health pages
	HC5	Justifiability	Backs up claims relating to benefits and performance
	HC6	Transparency	Presentation is accessible; email contact is accurate
	HC7	Financial disclosure	Identifies funding sources
	HC8	Advertising policy	Clearly distinguishes advertising from editorial content

The HONcode is a process metric that determines if a website's construction and maintenance conform to standards of excellence. The HONcode standards help webmasters and information providers adhere to quality information provision practices through simple, broadly accepted rules. The presence of the dated, dynamic and unique HONcode symbol on a website helps users make a decision when faced with multiple, contradicting and sometimes questionable information.

The HON Foundation does not evaluate the reliability or quality of website information content directly. 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 website editors render content HONcode compliant and transparent.

Methodologies for certification have evolved over time. The measures for internal and external quality assurance were updated in 2007, improving the system by incorporating standards such as the ISO/IEC 17065 norm and by requiring inspection by independent accrediting organizations. To improve its services, HON set up procedures to monitor certification, complaint management, re-evaluation, and internal audits. When a website is granted certification, HON monitors and adapts the website's status. Because health content on the Internet evolves constantly, the HONcode relies on three mechanisms for this monitoring: the complaint mechanism; automatic surveillance; and manual surveillance. Thus, HON has furthered the reproducibility of certification independently of revisers by more than 74% according to the principles.²

Not all websites achieve certification: 20% are rejected after initial inspection. Increasing rejection rates may reflect stricter, more binding guideline criteria. The 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 the eight ethical standards, while 89% of certified websites did.³ Certification motivates behavioural changes in the production process of health websites, gradually influencing the website's transparency and trustworthiness.

Through Khresmoi for Everyone (K4E, <u>http://everyone.khresmoi.eu</u>), a HONrelated project funded by the European Union, HON has targeted the general public by developing a search engine that identifies high-quality online health information. It enables the public and healthcare professionals in the European Union to find the most recent and relevant medical information through a state-of-the-art semantic search. Within K4E, HON provides access to a database of trustworthy health information consisting of over 8,000 certified and manually selected Web portals in some 27 European languages.

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 a lack of manual resources. Therefore, HON has also developed an automated system to detect health website HONcode criteria conformance. This tool was implemented in the K4E search engine as a feasibility test and will become a general search engine plugin. It will assist in detecting uncertified health websites as HONcode candidates.

Over the past 20 years, HON has evaluated more than 20,000 websites. Some 30% of websites in general disappear over a 10-year period. Nevertheless, 13% of HON-certified websites have re-qualified for over 10 years. Some 12,000 users now access the HONcode certificate daily through these certified health websites. This demonstrates the demand for reliable information. Thanks to public funds, the certification procedure was initially a free service. In 2014, HON sought greater financial sustainability and implemented an annual fee for recertification. The recertification payment scheme considers the type of website, its visibility, and its usage. Fees range from $50 \in$ to $325 \in$. So far, 50% of previously certified websites have been contacted and asked to pay; 32% have done so.

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