When the quality of health information matters: Health on the Net is the Quality Standard for Information You can Trust

Celia Boyer, Executive Director
Health On the Net Foundation, Geneva, Switzerland
London, at Campus Party, September the 5th, 2013
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Agenda

- Quality Health information: background
- Focus on the HONcode initiative
- Access to quality health information
- eHealth tendencies for delivering quality health information
  - Health avatar
  - Patient intelligence
  - mHealth
  - Serious games
- Perspectives and Conclusion
Health information online: a reality or a myth

The Internet is a mainstream media? 10 years ago, 360 million people reported using the Internet worldwide. Today, that figure is 2.4 billion people.

- In 2012, 16% of the African population has used the Internet; 84% of the UK population; 82% of the Swiss population; 70% of the Israeli population and 49% of the Saudi Arabia population; 81% of U.S. adults.

Looking for health info is the 3rd most common activity

72% say they have looked online for health information in the past year.

1 Internet Usage and World Population Statistics are for June 30, 2012.
2 Health Online 2013 Pew internet & American Life project
Controlling the Quality of Health Websites?

- 2.3 billion people (representing 32.7% of the world’s population) use the Internet for various purposes, one of them being health

- 3/4 of chronic patients do not check the source and date of the health information they find online

- Increased anxiety after consulting the Internet for health information

Sources:
- Cyberchondria: Studies of the Escalation of Medical Concerns in Web Search, Microsoft, Dec 2008
- Internet World Statistics, 2011 (Data up to Dec 31st, 2011)
- E-patients With a Disability or Chronic Disease, Oct. 2007, Pew internet & American Life project, pewinternet.org
Usage of health information online: a reality or a myth

35% of U.S. adults say they have gone online specifically to try to figure out what medical condition they or someone else might have.

When we asked respondents about the accuracy of their initial diagnosis, they reported:

- 41% of online diagnosers say a medical professional confirmed their diagnosis. An additional 2% say a medical professional partially confirmed it.
- 35% say they did not visit a clinician to get a professional opinion.
- 18% say they consulted a medical professional and the clinician either did not agree or offered a different opinion about the condition.
- 1% say their conversation with a clinician was inconclusive.
Delegates approved a resolution on eHealth standardization and interoperability. Member States noted the importance of standardized, accurate, timely data and health information to the functioning of health systems and services, while also highlighting that the security of this information, and privacy of personal clinical data, must be protected.

The resolution further emphasizes that health-related global top-level domain names, including “.health”, should be operated in a way that protects public health and is consistent with global public health objectives, and that names and acronyms of intergovernmental organizations, including WHO, be protected in the Internet Domain Name System.
“Eight in ten online health inquiries start at a search engine”
The Google problem

Google search for "natural cancer treatment"

Ads related to natural cancer treatment

- Alternative Cancer | embodiworks.com
  Learn about alternative cancer treatment

- Natural Cancer Therapies | annieappleseedproject.org
  Make more informed decisions (from the

- Alternative Cancer Treatments | cancer tutor.com
  24 Nov 2011 – Cancer Tutor Website, Cancer Treatments, also known as natural cancer
  The Treatment of Stage IV… - Lesson

Gerson Institute | gerson.org

CANCER TUTOR

The Cancer Tutor Website, Since 2003
by R. Webster Kehr

Cancer Options: The Surprising Power of Mother Nature!!

God has been good to His children by putting hundreds of natural substances in Mother Nature which can help all cancer patients in many different ways!! Mother Nature's cancer treatments are called "natural cancer treatments" or "alternative cancer treatments."

For example, the late Dr. William D. Kelley, a dentist by training, used alternative cancer treatments to treat more than 33,000 cancer patients. He used special diets, proteolytic enzymes, and other natural substances. Dr. Kelley was able to cure more than 90% of the cancer patients who went to him instead of using chemotherapy, radiation and surgery!!

Compare Dr. Kelley's cure rate of 90% to the overall cure rate of less than 3% of orthodox medicine!!

P. López-Jornet, F. Camacho-Alonso, The quality of Internet sites providing information relating to oral cancer, Oral Oncology, 2009.
What are the main problems in using the Internet for health?

Background
- Overload with information quantity
- Lack of skills to judge the information quality
- “Seen on Internet” seems to be a sign of quality

Outcomes
- Decision based on inadequate information
- Increased anxiety after consulting the Internet for health information
- Growing physician mistrust

Initiatives for accessing the quality of Web sites

Selection or referencing (the first approach):
Yahoo!, MedlinePlus (Miller et al, 2000), CISMeF (Darmoni et al, 1999)

Self-regulation:
IHC : eHealth Code of Ethics (Risk, 2000),
eEurope 2002: Quality Criteria for Health related Websites (European Union)

Evaluation/certification of web pages
HONcode (Boyer et al., 1996), URAC (2001, +20 Websites)
WMA (Bosch, 2002), TNO Health Trust : QMIC (Sheldon, 2002)
The Information Standard (Dec. 2010): +130 Websites accredited

Popularity of web pages (the most naturally used):
Google (Page et al., 1998)

Collaboration of users (the most democratic):
Outfoxed / Lijit, Google coop, Wikipedia

Education of users for quality evaluation (the most complementary):
Oxford University : DISCERN,
Mission: HON guides Internet users by highlighting reliable, comprehensible, relevant and trustworthy sources of online health and medical information, tackling the major obstacle of Web:

- the overwhelming quantity of information
- the uneven quality of health information available online
The Health On the Net Foundation: History

**1995**
*International Working Conference on the Use of Internet and World-Wide Web for Telematics in Healthcare*

**1996**
*State of Geneva...*

**1995**
*European Commission...*

**2002**
*NGO status granted by the United Nations*

**2004**
*eEurope Award eHealth*

**2007, France**
*Official certification body of all French health websites*

**2010**
*ISO TC 215 Health Informatics*
The HONcode

<table>
<thead>
<tr>
<th>Authoritiveness</th>
<th>Indicate the qualifications of the authors</th>
</tr>
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<tbody>
<tr>
<td>Complementarity</td>
<td>Information should support, not replace, doctor-patient relationship; Mission and Audience of site</td>
</tr>
<tr>
<td>Privacy</td>
<td>Respect the privacy and confidentiality of personal data submitted to the site by the visitor</td>
</tr>
<tr>
<td>Attribution</td>
<td>Cite the source(s) of published information and dating of medical and health pages</td>
</tr>
<tr>
<td>Justifiability</td>
<td>Site must back up claims relating to benefits and performance</td>
</tr>
<tr>
<td>Transparency</td>
<td>Accessible presentation, identities of editor and Webmaster, accurate email contact</td>
</tr>
<tr>
<td>Financial disclosure</td>
<td>Identify funding sources</td>
</tr>
<tr>
<td>Sponsorship</td>
<td>Clearly distinguish advertising from editorial content</td>
</tr>
</tbody>
</table>
The HONcode allow the web user to judge if she/he can trust the information found.
Example of certified website
Site not certified

Reference from 1983

Intentionally missing information

Tendentious

**HAIFISCH KNORPEL 740mg 100 Kapseln durch Puritan’s Pride®**

Regulärer Preis: 13,95 €
UNSER PREIS: 8,95 €

**Beschreibung**

Haifisch Knorpel: Natürliche Gelenkunterstützung direkt vom Meer!

- Rein, gefrier getrockneter Haifisch Knorpel
- Eine natürliche reiche Quelle von Chondroitinsulfat
- Unterstützt die Struktur und die Schmierung gesunder, flexibler Gelenke
- Ein natürlicher Weg Ihre Gelenke in optimaler Kondition zu halten
- Kann das Wachstum von Tumoren einschränken
- Kann Krebs Tumore verhindern
- Lindert Arthrose Schmerzen und Entzündungen

**Wieso sollten Sie Haifisch Knorpel nehmen?**

Health site of quality is possible only on the voluntary respect of ethical rules based on the transparency of the information.
The HONcode Certification

THE PROCESS
- The HONcode certification is requested by the Web publisher with a self-evaluation step.
- The HONcode Review Committee conducts a thorough inspection and provide recommendations.
- Transparency of the certification: excerpts of proof.
- Deliver the HONcode seal.
Dynamic, unique and dated seal
Certificate of compliance with the Code of Conduct HONcode

The health Website

Lab Tests Online UK is in compliance with the HONcode

Title of the site: Lab Tests Online UK
Web address: http://www.labtestsonline.org.uk/
HONcode PIN number: HONConduct995553
Date of initial review: 09 Jun 2004
Validity of certificate: 11 Jul 2013 - Jul 2015
Date of last visit: 16 Aug 2013
Show the HONcode seal on this site

This certificate confirms the revision of the site by the HONcode Team at the above date. It respects and pledges to honor the 8 principles of the HON Code of Conduct (HONcode).


Do you think the site is not respecting the HONcode? Do not hesitate to report a claim on this site

The Health on the Net (HON) Certificate serves as a guarantee that this website, at the date of its certification, complies with and pledges to honor the 8 principles of the HON Code of Conduct as drawn up by the HON foundation.

The responsible of the certified site commits to keep the site in compliance with the HON code principles for the duration of the certification.
Role of the certification

- A continuous quality audit process
  - initial certification with evidence collection
  - annual or biannual review
  - permanent citizen vigilance
  - loss of certification if non-compliance

- Process incorporating the regulatory environment
  - context, mission, site audience
  - regulation of the country concerned

- Accompanying measures to support sites
  - less than 5% of the sites requiring certification are in compliance at the first assessment.
  - support for certification
  - if reporting by citizen vigilance, investigation and follow-up until resolution.
The certified website is responsible for the content of its website, unless otherwise provided by law.

More information about the HONcode?

You will find below the elements identified by the HONcode team at a precise date to justify the respect of the 8 ethical principles.

The content of this certificate has been collected and written by the Health On the Net Foundation (HON) and should not be used without previous permission granted by HON. A request for permission can be sent to: HON.

1. Information must be authoritative
All the partners of Lab Tests Online have been listed.
Lab Tests Online-UK Editorial Team
(16 Aug 2013) - Link

2. Presentation of the site
Mission:
Lab Tests Online-UK has been designed to help you, the patient, to better understand the many clinical lab tests that are part of routine care as well as diagnosis and treatment of a broad range of conditions and diseases.
(11 Jul 2013) - Link

Audience: The website is intended to the general public.
(Webmaster)

Lab Tests Online-UK has been designed to help you, the patient, to better understand the many clinical lab tests that are part of routine care as well as diagnosis and treatment of a broad range of conditions and diseases.
(11 Jul 2013) - Link

Purpose of the website
The information provided through this service is not intended to be a substitute for a consultation with your medical doctor.
(11 Jul 2013) - Link

3. Confidentiality
The Association for Clinical Biochemistry and Laboratory Medicine (ACB) and its collaborating partners are committed to honouring the privacy of our visitors. We have designed the site to minimize the gathering of personal data; we will not do so without first alerting you to the fact.

We do collect non-personal data to help us understand how the site is being used and how we can improve it. We also collect the information you submit on forms found on our site. This information is invaluable and helps us provide a better service. Our web-server log collects non-personal information.

(16 Jul 2013) - Link

4. Information must be documented: Referenced and dated
Only data for one sample are displayed among those selected.

The Editorial team is responsible for all editorial content on this website. All pages are reviewed by a member of the team, each of whom works with other professional colleagues and various information sources to verify that the information is accurate and consistent with current UK practice. New pages are prepared by invitation from expert authors and subject to verification and editorial scrutiny by a member of the team.
(11 Jul 2013) - Link
Le Web n’a pas de frontière,
la certification non plus

« HONcode is the oldest and most-used ethical and trustworthiness code for medical and health-related information available on the Internet. »
The HONcode database

- Compliance with the HONcode principles
- Indexed with MeSH terms and HON labels
- +8'000 sites in 102 countries
  - correspond to more than 10 millions pages indexed by Google
  - 5 millions of webpages having the HONcode seal is visited per day
- +1800 sites in France
- +300 site in UK
- + 300 sites in Switzerland
Recognizing diversity in a globalizing world

- HON representation in Bamako, Mali for the French Speaking Africa
- Collaboration with the South African Medical Research Council (MRC) for English Speaking Africa
- Arabic Speaking countries with the collaboration with the King Saud Bin Abdulaziz University for Health Science and Saudi Association for Health informatics
HON representation in Bamako, Mali.

Focus on French speaking African countries

Created in 2006, under the auspice of the Republic of Mali
The MRC has entered into collaboration with the Health On the Net Foundation to become a HON Accreditation Centre for English-speaking countries in Africa.
Example of a HON accredited site

AfroAIDSinfo™

An HIV/AIDS information portal for southern Africa

Welcome to AfroAIDSinfo™

Call for editorial board members

Those interested to become members of the AfroAIDSinfo editorial board to review articles on HIV and AIDS are invited to complete the online application form.

AfroAIDSinfo Song of Hope

Download the ringtone or listen to the song.

Find us on Facebook
Follow us on Twitter
Perception of the respect of ethical principles

- A sample of 74 Web sites was drawn from a database of Health & Medical Web sites in English-speaking African countries.
Conclusion on the health English speaking African websites

- This study showed that Webmasters compiling health and medical information know that they should attend to accuracy, reliability and quality.
- However, less obvious criteria such as doctor-patient relationship, dating pages and respecting privacy which impacts on ePatients’ information-seeking are overlooked.
- This highlights the necessity for training of health and medical Webmasters.
MRC activities for the promotion of the quality

- Review health and medical Web site of English-speaking countries in Africa
  - Training on the review process completed and HONcode certification of websites

- Promotion activities
  - A Web site: Africa.org
  - An Africa-specific search engine
  - Present collaboration at conferences

- Educational activities
  - Integrated into the HON for Africa Web site:
    - an e-Learning module for African Web developers
    - an e-Guide for Consumers
Recognizing diversity in a globalizing world

- Out of the 122 Arabic health websites only 4.1% were compliant with HONcode principles.

- 79% of the 236 Arabic health professionals do not use the Arabic health websites in promotion of the production of quality health websites using quality criteria is necessary.

http://www.kaahe.org
Production of quality health websites using quality criteria: KAAHE.org

Statements Related to the Updates of the Novel Coronavirus

Saudi Ministry of Health - 2 Sep 2013 || The ministry of health announces the fully recovery of two patients who contracted the Coronavirus. The results of the tests carried out on the patient from Haf Al-Hasain aged twenty six and
Raising the Awareness of Users

المعلومات الطبية والصحية الموجودة على شبكة الإنترنت

كن حذرًا!

1. إسأل طبيبك!
لا تشتري أي أدوية على الإنترنت ولا تأخذ قراراتك من المعلومات الصحية الموجودة على الإنترنت قبل أي تغيير في استراتيجية الرعاية.... تحدث مع الطبيب!

2. مواقع المؤسسات العامة
خذ المعلومات من مواقع المؤسسات الموثوقة والمنظمة أولاً;
مثل:
www.kaahe.org
www.ngha.med.sa
www.ksau-hs.edu.sa

3. ابحث عن مواقع تقييمها من قبل مؤسسة HON
شعار HONcode حيث إن المواقع التي تحتوي على الشعار تعتمد على المبادئ الثمانية وهي من المواقع الموثوقة والتي تتم مراجعتها باستمرار.
Access to quality health information is fundamental for a wise decision making process
Identification of certified websites

Scholarly articles for **blood glucose monitoring**
- Anderson - Cited by 372
- DeMarzo - Cited by 456
- de Veciana - Cited by 496

**Blood glucose monitoring** - Wikipedia, the free encyclopedia
Blood glucose monitoring is a way of testing the concentration of glucose in the blood (glycemia). Particularly important in the care of diabetes mellitus, ...
Purpose - Blood glucose meters - Continuous blood glucose ...
en.wikipedia.org/wiki/Blood_glucose_monitoring - Cached - Similar

**Blood glucose monitoring** - MedlinePlus Medical Encyclopedia
Blood glucose monitoring refers to the ongoing measurement of blood sugar (glucose) Monitoring can be done at any time using a portable device called a ...
www.nlm.nih.gov/medlineplus/ency/article/003438.htm - Cached - Similar

Shopping results for **blood glucose monitoring**
Facilitate access to certified websites

<table>
<thead>
<tr>
<th>HONcode</th>
<th>sites Web</th>
<th>HONselect</th>
<th>News (on)</th>
<th>Conférences</th>
<th>Images</th>
</tr>
</thead>
</table>

## Asthme et Allergies | Le site de référence sur l’asthme et les allergies
Association à but non-lucratif qui apporte informations et soutien : brochures gratuites, bande dessinée, journal "Asthme infos", aide aux associations de patients ...

[asthme-allergies.org](http://asthme-allergies.org/)

## Asthme - Passeport Santé
L’asthme est une maladie caractérisée par une inflammation plus ou moins grave des voies respiratoires, et surtout des bronches et des bronchioles (voir ...) 

[www.passeportsante.net/fr/Maux/Problemes/Fiche.aspx?asthme](http://www.passeportsante.net/fr/Maux/Problemes/Fiche.aspx?asthme)

## OMS | Asthme
Asthme. L’asthme est une maladie chronique dont la gravité et la fréquence varient d’une personne à l’autre et qui se caractérise par des crises récurrentes où ...

[www.who.int/topics/asthma/fr/](http://www.who.int/topics/asthma/fr/)
European research project for improving the access of health information for the citizen and the health professionals
Search

About 27,000 results

By Disease Section

Overview (6)
Causes (1)
Symptoms (1)
Diagnosis (1)
Treatment (1)

By Topic

At Work Babies and Children Cancer Cardiovascular diseases Carers Consumer Safety Food Safety Medicines and Treatment Mental Health Nutrition Other Non-Communicable Diseases Patient Safety People with Disabilities Programmes Quality Assurance Research Social Environment Sports and leisure Vaccinations Women

With Filters

- All
- Forums
- Pages with video

Gluten intolerance
www.health.am/encyclopedia/more/gluten_intolerance/
Celiac disease is an inherited, autoimmune disease. The lining of the small intestine is damaged in response to ingestion of gluten and other proteins found in wheat, barley, rye, possibly oats and their derivatives. The intestines contain projections (called villi) that normally absorb nutrients.

More from this website : health.am (8)

Gluten
www.healthinsite.gov.au/topics/Gluten
Topics such as fitness, nutrition, drugs, preventing suicide, health insurance, women's health, disability includes links to State/Territory Health Services and other services. Follow the links for information about gluten in the diet. Coeliac disease can be managed.

More from this website : healthinsite.gov.au (5)

Gluten and gluten-free diet - myDr.com.au
Constipation, diarrhoea and digestion problems. Infectious Diseases Exclusion Periods Tool Travelturtle - personalised travel health reports. If you wish to share this article with a friend, please fill the fields below. They will be sent an email with these details and a link to this page. Gluten

More from this website : mydr.com.au (5)

Celiac and Gluten-Free Bloggers | NFCA
www.celiaccentral.org/Resources/Gluten-Free-Bloggers/125/
Talk about community building! The number of celiac bloggers increases by the day. There are people

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eHealth tendencies in delivering quality health information

- Quality Health information
- Health avatars
- Social web and communities
- Mobile health
- Serious games
Goal: A new way to deliver information direct to the user needs answered by trained physicians

Benefit: education and advice through ecommunication
Can Avatars Help Close the Doctor-Patient Communication Gap?

By Robert N. Charette

Posted 4 May 2013 | 4:00 GMT
The Health avatar:

- **Goal**: organize health information according to its relationships to the human anatomy.
- **Benefits**: enables patients and clinicians to find information quickly and intuitively (e.g. “show where it hurts”)

[Image: Health avatar diagram with interactive panels]
Patient-to-patient network
Health2.0

- Patient-to-patient communication is gradually increasing

- Allows comparison of different patient experiences, provides support and empathy, social network of like-minded persons.

- Enables patients with same medical condition to interact, share their symptoms, track their progress and connect in multiple ways.
Goal: Share and compare experiences between patients on common disease
Benefits: improve their decision making and help managing their disease
Seven in ten U.S. adults track a health indicator like weight, diet, exercise routine, or symptom. Of those, half track “in their heads,” one-third keep notes on paper, and 20% use technology to keep tabs on their health status.
87% US adults own a cell phone. 45% of them own smart phones.

31% of cell phone owners and 52% smart phone owners have used their phone to look up health/medical information.
mHealth offers patients easier access to care and control over their own health.

59% of those who use mHealth already say it has replaced visits to doctors or nurses.

64% worry that mHealth makes patients too independent.

**Problem:** who check the medical validity or the transparency of these apps?
Mhealth big expectation

And some resistance

- 64% worry that mHealth makes patients too independent.

To what extent do you expect mHealth applications and services will improve the following in the next three years?
Turn your Iphone into a heart monitor via a medical FDA approved device

HOW IT WORKS

1. The Device
   AliveCor Heart Monitor
   This Class II medical device snaps onto your iPhone 4, 4S or 5 like a case and wirelessly communicates with the app on your phone. No pairing between your iPhone and the Heart Monitor is required.
   BUY NOW

2. The App
   AliveECG
   Search for and download the AliveECG app from the Apple App Store. Once in the app, create an account and you’re ready to begin recording ECGs. It’s that easy to get started.

3. The Web
   AliveCor.com
   AliveCor.com provides you with anytime, anywhere, fully secure, HIPAA-compliant online access to all of your ECGs. Protected health information (PHI) and personally identifiable information are encrypted in transit and at rest.

Once you have the Heart Monitor and the AliveECG app you can create an account that gives you access to your protected ECG data.

Within the app and your online ECG hub, you are able to analyze ECGs as PDFs and print them. ECG data will sync between the app and your online ECG hub as data is consistent. Our online services will continue to expand based on customer feedback.
Serious Gaming

- Serious games are video games which are simulations of real-world events with the main intention of educating or training its user.
- Goal: increase better understanding / compliance
- Benefit: Through self valorisation, educate and change behavior

- Used in several sectors including healthcare and education
  - psychotherapy, healthcare training, physical rehabilitation
Psychology games can be used for emotional and cognitive training. Especially useful in adolescents.
Famille

Au travers de trois parcours de soins sous forme de jeux éducatifs en ligne, LudoMedic apprend aux enfants à se préparer à passer une IRM, subir une opération chirurgicale, ou encore suivre une chimiothérapie. Les parents quant à eux trouveront des explications claires et précises. Et tout ceci, gratuitement !
How has the Internet is changing healthcare?

Healthcare consumer perspective:
- Access to health information
- Patient empowerment
- Enables active participation in healthcare decision making
- Improved doctor patient interaction
- Access to co-sufferers (patient-to-patient communication).

Healthcare provider perspective:
- Better informed patients results in improved compliance
- Recognition of healthcare consumer as partner in healthcare decision making
- Improved access to health information
- Telemedicine and diagnostics
- Training and continuing education
- Minimally invasive procedures
HON Conclusion

- HON active for over 17 years
- Educate citizens to efficiently use the medical information
- Guide the information providers
- Automatic tools developed in order to support human expertise and tackle the large number of existing Web pages
- Collaboration with governmental and international organization (OMS)
- Adherence to the HONcode enhances a website’s overall quality

“Less than 1% of health websites that do not ask for HONcode certification do actually respect the eight HONcode ethical standards”

The HONcode an international reference

“In our experience, the HONcode provided the best overall guidance.”

“With added increased awareness of available resources, such as the HONcode, DISCERN and LIDA tools, the quality of health information on doctors’ websites can be improved.”


“Finally, 15 (63%) PHR systems were based on regulations or principles such as the US Health Insurance Portability and Accountability Act (HIPAA) and the Health on the Net Foundation Code of Conduct (HONcode).

CONCLUSIONS: Most privacy policies of PHR systems do not provide an in-depth description of the security measures that they use.”

Thank you very much for your attention!

Celia.Boyer@healthonnet.org