Quality of Online Health Information
A Critical Ingredient for the Use of the Internet in Health

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Why be Concerned About Quality?

Welcome to CureCancer.com

With 100 Case Histories
Goal
To promote a quality Internet health experience...
...and protect against a bad experience
How Can We Ensure Success?

- Ethics
- Excellence
- Education
- Enforcement
Ethics

Four Reasons:

- Protect from harm
- Create ethical environment
- Pride, not embarrassment
- Fairness/Synergy

Source: Tom Murray
Purpose

“...The goal of the "e-Health Code of Ethics" is to ensure that all people worldwide can confidently, and without risk, realize the full benefits of the Internet to improve their health.”
eHealth Code of Ethics

- Eight Principles
  - Candor
  - Honesty
  - Quality
  - Informed Consent
  - Privacy
  - Professionalism in Online Health Care
  - Responsible Partnering
  - Accountability
Background: Initiatives

- Internet Healthcare Coalition
- Hi-Ethics
- Health On the Net Foundation
- etrust
Code of Ethics

eHealth Code

Translation & Implementation

Self-Regulation
URAC, HON, Hi-Ethics, AMA

Domain Name Restrictions
WHO (dot.health)

Regulation
FTC, FDA...+
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The Starting Point: Defining Excellence

Quality Criteria for Internet Health Information – Developed by the Health Summit Working Group representing all stakeholders
What is Quality?

- Gold standard – peer-review?
- Does it include outcome/effectiveness?
Key
⇒ Uniform Set of Criteria
⇒ Implementation Vehicle

Focus of the Health Summit Working Group
Quality Criteria

- Basic criteria
  - Health Summit Working Group
    http://hitiweb.mitretek.org/hswg
    Policy paper available
    Internet based educational tool (beta) available

- Additional criteria for risk assessments
Health Summit Working Group
What makes this effort unique?

● All stakeholders
  – health care providers, international, pharmacists, consumers, librarians, academicians, government (FTC, NLM, NCI, ODPHP, OAM), IHC, AMIA, HON, Science Panel

● International scope
  – White paper and policy paper translated into numerous languages
Health Summit Working Group
What makes this effort unique?

- Developed through consensus
- Implemented
  - Policy Paper broad endorsements
  - IQ Tool
Quality Criteria:
Health Summit Working Group

- Credibility
- Content
- Disclosure
- Links

- Design
- Interactivity
- Caveats
Quality Criteria:
Criteria Specific to Health Assessments

- Source of algorithm
- Testing of algorithm
- Algorithm availability
- Privacy and security
- Appropriate questions
- Appropriate results
Interactive Applications: Evaluation

Evaluation Reporting Template For Interactive Health Communication Applications,
Version 1.0, Science Panel On Interactive Communication And Health

This is an evaluation reporting template for developers and evaluators of interactive health communication (IHC) applications to help them report evaluation results to those who are considering purchasing or using their applications. Because the template is designed to apply to all types of applications and evaluations, some items may not apply to a particular application or evaluation. Complete only those items that apply. This and subsequent versions of the template and other resources on evaluation of IHC are available at: URL: www.scipich.org

I. Description of Application:

1. Title of product/application:
2. Name(s) of developer(s):
3. Relevant qualifications of developer(s):
4. Contact(s) for additional information:
5. Funding sources for development of the application (e.g., commercial company, government, foundation/nonprofit organization, individual):
6. Category of application (e.g., clinical decision support, individual behavior change, peer support, risk assessment):
7. Specific goal(s)/objective(s) of the application (What is the application intended to do? List multiple if applicable)
8. Intended target audience(s) for the application (e.g., age group, gender, educational level, types of organizations and settings, diverse groups, cultural/ethnic/population groups):
9. Available in languages other than English? No Yes (specify):
10. Technological/resource requirements of the application (e.g., hardware, Internet, on-site support available):
11. Describes how confidentiality or anonymity of users is protected:
12. Indicates who will potentially be able to get information about users:

II. Formative and Process Evaluation:

1. Indicate the processes and information source(s) used to ensure the validity of the content (e.g., peer-reviewed scientific literature, in-house “experts,” recognized outside “experts,” consensus panel of independent “experts,” updating and review processes and timing)
2. Are the specific original sources of information cited within the application? Yes No
3. Describe the methods of instruction and/or communication used (e.g., drill and practice, modeling, simulations; reading generic online documents, interactive presentations of tailored information, specifying methods used):
4. Describe the media formats used (e.g., text, voice/sound, still graphics, animation/video, color):
5. For each applicable evaluation question below, indicate: (a) the characteristics of the sample(s) used and how they were selected, (b) the method(s) of assessment (e.g., specific measures used), and (c) the evaluation results:

http://www.scipich.org
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Education

- Educate Internet Website developers on what “quality and ethics” mean
- Educate site evaluators on what to look for
- Educate the consumer on what to look for
Interactive Education Online
The Information Quality Tool (IQ)
Welcome to the IQ, the Health Information Quality Assessment Tool!

The IQ Tool helps you become and educated consumer by helping you ask the right questions. Based on your answers IQ will evaluate the site's strengths and weaknesses. All you have to do is enter the site's URL to begin! Then it is up to you to find the answers.

Begin using IQ!

We'd like to hear what you have to
HSWG Information Quality

General Questions

Address: http://kidshealth.org/parent/healthy/fever.html

If this is promotional site selling a product, click here.
If this is promotional site selling a service, click here.

Note: Scroll down to see more questions. If a question is not applicable, click on the button beside the question. To comment on

1. Is the author identified in the article?  
   - Yes  
   - No

2. When the author refers to another source, are appropriate references provided?  
   - Yes  
   - No

3. If the author is not referring to a source, does he/she clearly state this?  
   - Yes  
   - No

4. Are the site author's credentials listed?  
   - Yes  
   - No

5. Does the site author's credentials relate to the knowledge of the field?  
   - Yes  
   - No

Burning Up: Facts About Your Child's Fever - Netscape

Are fevers dangerous? What should you do when your child has a fever?
duPont Hospital for Children pediatrician David West, M.D., explains the basics.
# HSWG Information Quality

## Score & Explanations


#### Summary of responses:

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author was identified</td>
<td>LEFT BLANK: No source references given</td>
</tr>
<tr>
<td>Author's credentials listed</td>
<td>LEFT BLANK: Did not state that non-reference information was opinion</td>
</tr>
<tr>
<td>Credentials are related</td>
<td></td>
</tr>
<tr>
<td>Experience relevant to topic</td>
<td></td>
</tr>
<tr>
<td>Contact information provided</td>
<td></td>
</tr>
<tr>
<td>Sponsorship identified</td>
<td></td>
</tr>
<tr>
<td>Conflict or bias explained</td>
<td>LEFT BLANK: Sponsors have not been disclosed</td>
</tr>
</tbody>
</table>

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### Final Score: 76.60%

Your assessment of the site has been saved. The computed score does not necessarily reflect the overall assessment outcome of a particular site.

**Details of negative or missing criteria:**

- If a source is not cited, then it should clearly state that the information is only based on opinion and not necessarily based on sound research.
- If a site is honest about where it gets its money or why it is biased, it helps you to determine how to use the information given. It is difficult to believe information found on a site if these conflicts or biases are not explained.
- If a contributor or sponsor has control over the content of a website, the information is more than likely biased.
- An explanation of what will be done with your information is very important. If you do not know what information and being gathered and what it will be used for, BE CAREFUL!
IQ - One Tool for Education

- Reminder - Internet presence does not give automatic credibility
- Introduce and reinforce attributes of quality
- Foster common vocabulary
How Can We Ensure Success?

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Enforcement

- Already established law in the US.
- What about the international community?
The Critical Pieces

- Code of Ethics
- Definitions
- Accreditation
- Regulation & Law
- Country specific laws (FTC, FDA); International law/agreements
- URAC/Hi-Ethics
- AMA, HON, Hi-Ethics, HSWG
- eHealth Code of Ethics (IHC)
Excellence, Ethics, Education and Enforcement:

Ensuring a safe and rewarding experience for the Internet in health