On quality benchmarking of online medical/health-related information resources

MN Kamel Boulos PhD, MSc (Med Inform), MSc (Derm), MBBCh

M.N.K.Boulos@bath.ac.uk

UNIVERSITY OF BATH School for Health

March 2004

Introduction: Why bother ourselves with information quality issues?

- On the Internet, anyone can publish anything. As the wheat grows with the tares and the sheep and the goats coexist, excellent and bad online medical/health resources also coexist.
- Extreme examples of bad quality medical/health information may be relatively easy to spot, but this is not always the case for many resources of questionable quality—their presentation can sometimes be very deceiving.

Bad quality information exists…

- Online medical and health-related information of dubious quality can be very dangerous and may even cost lives.
- Visit http://www.quackwatch.org/ for some examples.

Quackwatch℠
Your Guide to Health Fraud,
Quackery, and Intelligent Decisions

Many instruments exist…

http://www.hon.ch/HONcode/

http://www.chu-rouen.fr/netscoring/netscoringeng.html

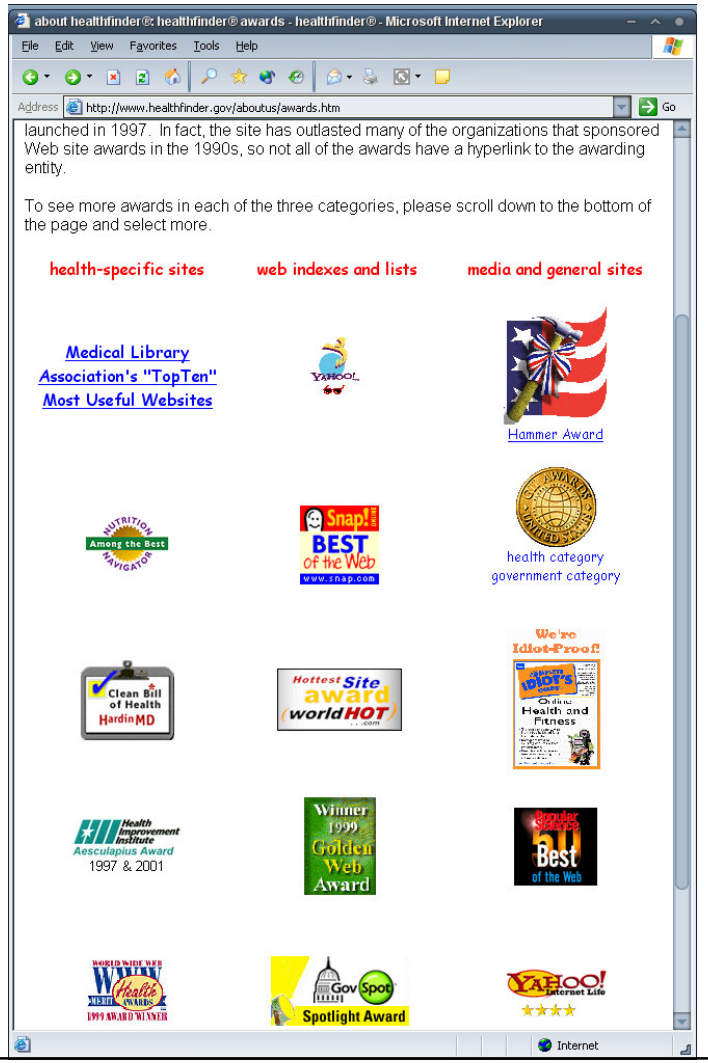
Some of these are just codes of ethics for resource providers, while others claim to be true quality-rating tools.

Some are geared towards the general public, e.g., http://www.quick.org.uk/, while others are mainly designed for use by healthcare professionals and librarians.

http://www.discern.org.uk

Some are “good”, others are of questionable utility

“*Surprisingly, many of these rating instruments, of questionable utility and without association to an operable entity, are featured on the US Department of Health and Human Services Healthfinder website* (*http://www.healthfinder.gov/aboutus/awards.htm*), *which uses a detailed and rigorous selection process for the development of its own content.*” (Gagliardi and Jadad, 2002)



They all suffer the same problems…

- Quality benchmarking of medical and health-related Web resources is an inherently subjective exercise (to some extent).
- Interobserver variability/reliability: how close would be the ratings by two independent observers using the same instrument to rate a given information resource?
- Rating the raters: how?

Just because it's *The Lancet* is not enough…

- Some have proposed rating information publishers instead of individual resources they publish, but should we, for example, blindly trust the quality of everything published in *The Lancet*?

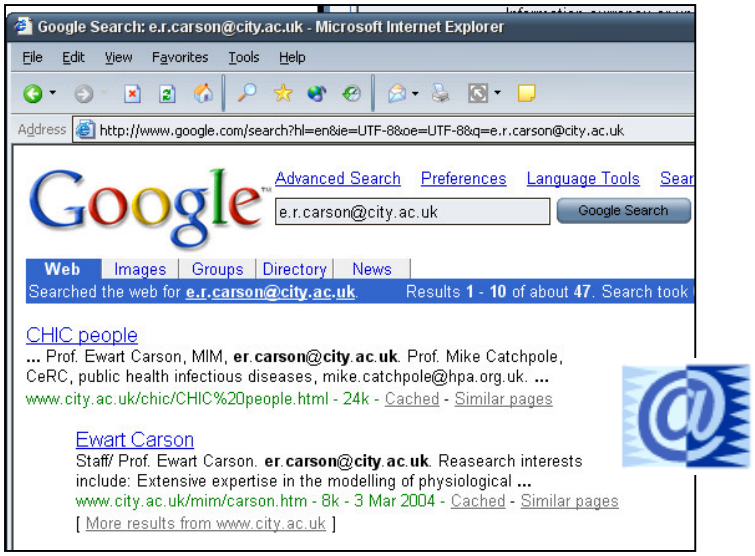
Essential information quality indicators

A list of the *least subjective* indicators

- Authorship (information about authors and their contributions, affiliations, and relevant credentials)
- Attribution (listing of references or sources of content)
- Disclosure (a description of Web site ownership, sponsorship, underwriting, commercial funding arrangements, or potential conflicts of interest)
- Information currency or up-to-dateness
- Resource accessibility/presentation/format issues
- Also read the provider's privacy policy (you may wish to use a P3P-enabled browser)

Carefully investigate authors' contact details

- ChiefScientist@hotmail.com
  (anyone can get a free Hotmail e-mail address)
- Scientist@cdc.gov
- Researcher@university.edu
- UndergraduateStudent@university.ac.uk
- Tip: You can use Google to investigate an e-mail address



Prune URLs to check the hosting server/organisation

- http://students.bath.ac.uk/username/
- http://staff.bath.ac.uk/username/
- http://www.geocities.com/mysite/
  (anyone can get a free Geocities Web site)
- http://www.commercial-company.com/scientific_papers/paper1.htm

Level of evidence

(Where applicable)

- For "sensitive information" (information found in documents published on the Internet, which could be used in a medical decision), an indication of the level of evidence could be the main criterion chosen for assessing the quality of the information (**Darmoni *et al*, 2003**).

  See also: http://www.cebm.net/levels_of_evidence.asp

Table 1 ANAES method to evaluate the level of evidence (for therapy issues)

Level of evidence from the literature	Type of studies	Grade of the guidelines
Level 1	Well-designed randomized controlled trials (adequate sample size) Meta-analysis of randomized controlled trials Decision analysis based on well-designed studies	Grade A: explicit scientific evidence
Level 2	Randomized controlled trials with poor power (non-adequate sample size) Well-designed non-randomized comparative studies Cohort studies	Grade B: assumption of scientific evidence
Level 3	Case controlled studies	Grade C: weak level of scientific evidence
Level 4	Comparative studies with important bias Retrospective studies Case-report studies Descriptive epidemiological (transversal or longitudinal) studies	Grade C: weak level of scientific evidence

ANAES=French Agency of Health Accreditation and Evaluation

Conflicts of interests

http://www.publicationethics.org.uk/

BBC NEWS UK EDITION

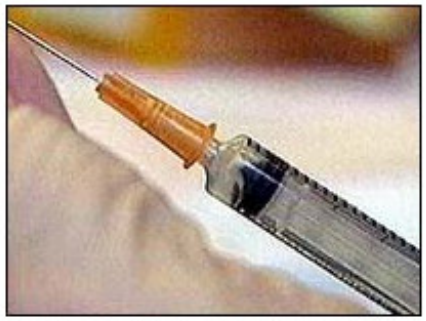
Last Updated: Friday, 20 February, 2004, 19:58 GMT

E-mail this to a friend Printable version

Journal regrets running MMR study

The medical journal that published a controversial study linking MMR to autism says, with hindsight, it would not have published the paper.

Richard Horton, editor of the Lancet told the BBC the researchers had a "fatal conflict of interest".



Children are vaccinated against measles, mumps and rubella

Last Updated: Friday, 27 February, 2004, 02:43 GMT

E-mail this to a friend Printable version

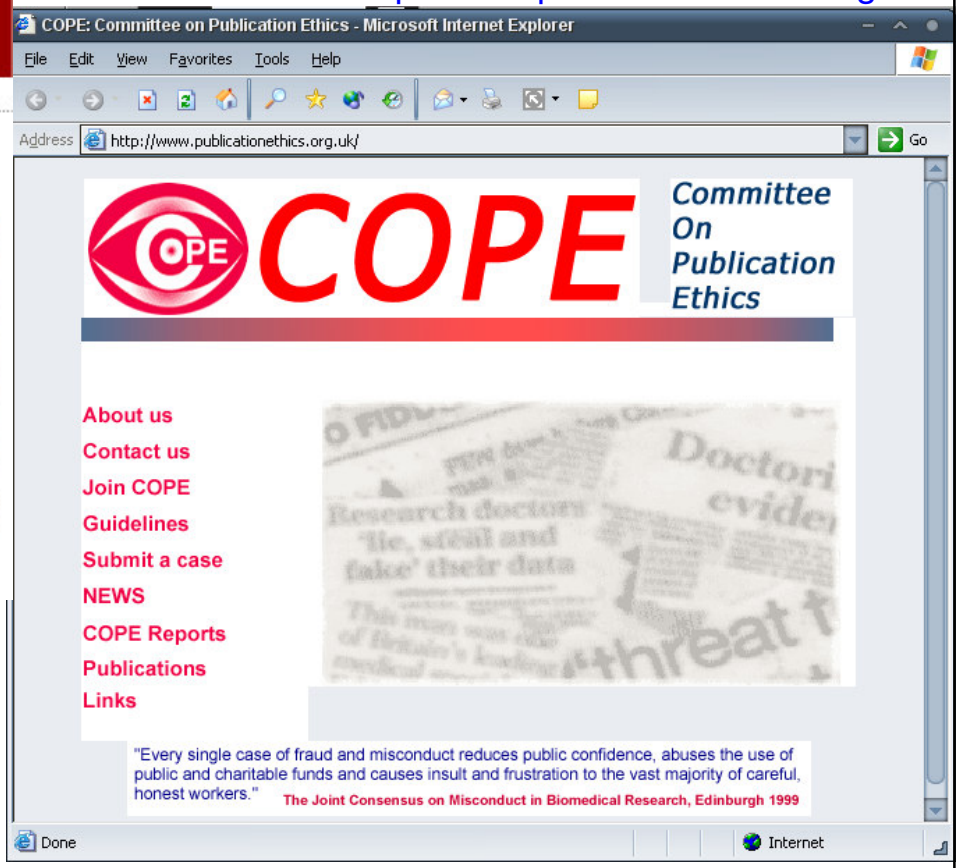
Journals plan regulation scheme

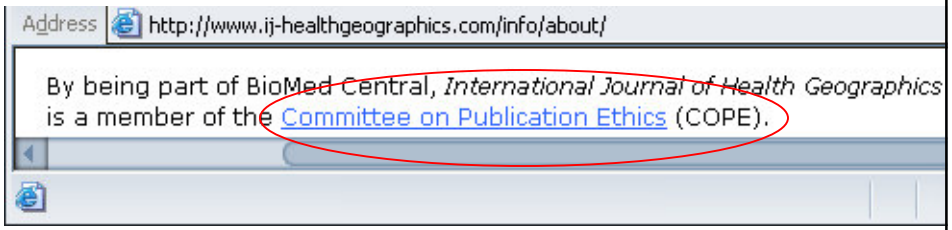
Medical journals should have a code of conduct, similar to that which governs newspapers, an ethics body has said.

A draft code has been set out by the Committee on Publication Ethics.

The code says journals must ensure they publish accurate material

British Medical Journal editor Dr Richard Smith, the code's author, said he hoped it would act as a "badge of trust" for readers.



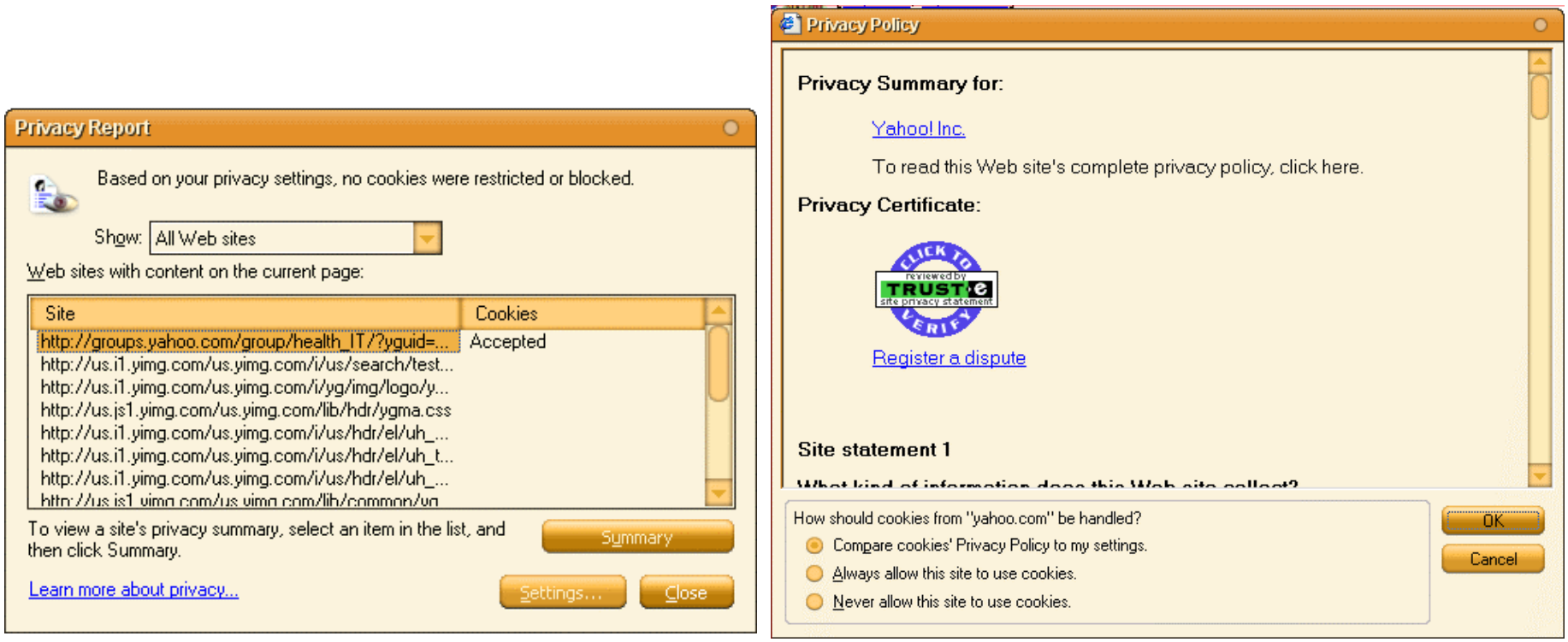


Last updated: *today*

- Some Web pages have scripts that automatically display today's date whenever they are visited making them appear as if they were updated during the last 24 hours (which in many cases is not the case).
- You can use Internet Archive to trace the update history of a resource: http://www.archive.org/

W3C Platform for Privacy Preferences (P3P) Project
http://www.w3.org/P3P/

- "Automated privacy management"
- Based on consumer's preferences
- Already built into Microsoft Internet Explorer 6 (http://www.microsoft.com/presspass/press/2001/mar01/privacytoolsiefs.asp)



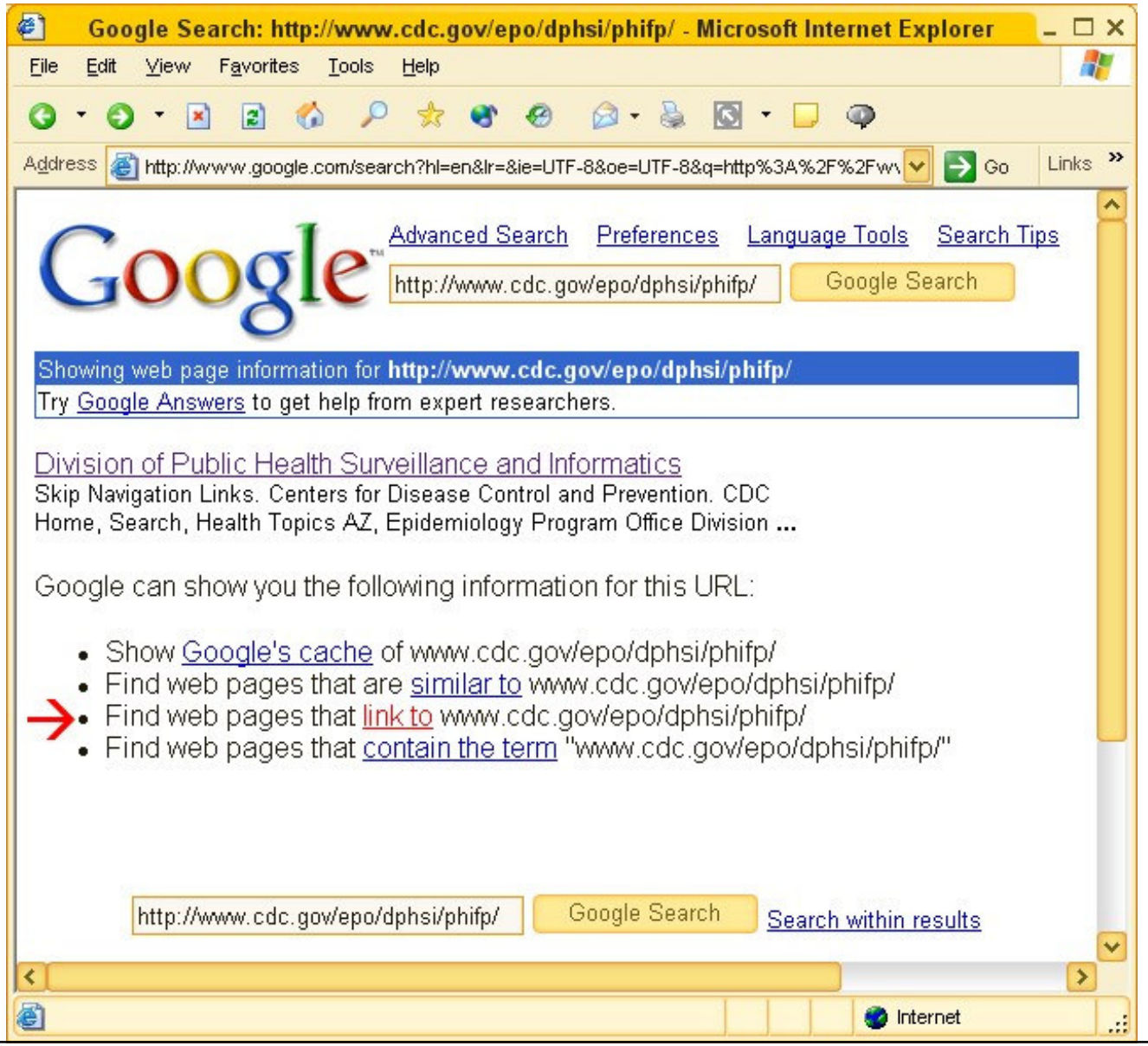
Is popularity an "indicator" of quality?

- Sometimes…
- Two measures of Web site popularity exist:
  - **Click popularity** (the frequency with which users have visited a site): drawbacks include incomplete data and marketing manipulation (esp. when tools like Alexa are used to measure it—see http://pages.alexa.com/prod_serv/traffic_learn_more.html)
  - **Link or "peer review" popularity** (the number of external links to a given resource—also known as back-links or Web impact factor)

Popularity (Cont'd)

- To measure the Web impact factor of say http://www.healthcare-informatics.info (and exclude internal links), type the following in Altavista's (http://www.altavista.com) search box:
  link:www.healthcare-informatics.info -host:www.healthcare-informatics.info
  (don't miss the '-' before host)
- Google can be also used for this purpose (see screenshot next slide).
- Please note that Google ranks its own results of searches by using a proprietary link popularity algorithm that takes into account the number of links and the "importance" of the linking sites.

Popularity (Cont'd)



How do consumers search for and appraise health information on the Web?

- *"Users of the Internet explore only the first few links on general search engines when seeking health information*
- *"Consumers say that when assessing the credibility of a site they primarily look for the source, a professional design, and a variety of other criteria*
- *"In practice, Internet users do not check the "about us" sections of Web sites, try to find out who authors or owners of the site are, or read disclaimers or disclosure statements*
- *"Very few Internet users later remember from which websites they retrieved information or who stood behind the sites"*

Eysenbach and Köhler, 2002

Box 1: Quotes from focus groups and in-depth interviews–criteria for credibility of healthcare information on the internet

Authority of source
"I want to know where that information comes from. Sometimes it is hard to detect who is responsible for the content, and this is bugging me"
"I consider it to be reliable if information is from public institutions or scientific publications"
"I certainly trust more an official website of an organisation or association rather than a private site"
"I would like to know whether this is the opinion of a single person or an institution, whether the content is selected according to scientific criteria or whether it is based on a personal experience"

Layout and appearance
"The presentation of the site is very important, so that it appears professional"
"The design and the advertising, the whole appearance must be pleasing. That's very important"

Advertising
"I have been on a [AIDS] site that was not too bad actually, but there have been some strange banners on top [advertising banners for pornographic websites]. This, of course, badly affected the credibility of that site"

Readability
"To me, the text shouldn't use too much professional terminology. It should appear in a language a medical layperson can understand without great difficulties"
"The text should be in a respectable and comprehensible diction, not too sensational."

Outbound links
"If a trustworthy site provides links to other sites, I assume they are trustworthy as well"

Picture of the site owner
"Perhaps a picture of the owner of the site would be helpful. It would be a plus if the site owner would have a pleasing face or appears likeable"
"I think it is the first impression. If there is a picture of a honestly smiling man, that would be very important"

Email
"One should have the ability to contact the provider, such as by email. And the owner should respond"

Credentials and qualifications
"If possible, the site owner should provide evidence of his credentials, that he is qualified to make such statements. For example, references to his previous work, or his curriculum vitae"

Updating of content
"I have seen pages that say 'Last updated in 1998.' In this case, I don't need to go any further. But I have seen on the site of that institute of tropical medicine that they were giving advice concerning anthrax. In this case I know that this site is updated frequently"
[The interview was conducted shortly after the first cases of mail contaminated with anthrax in the United States occurred]

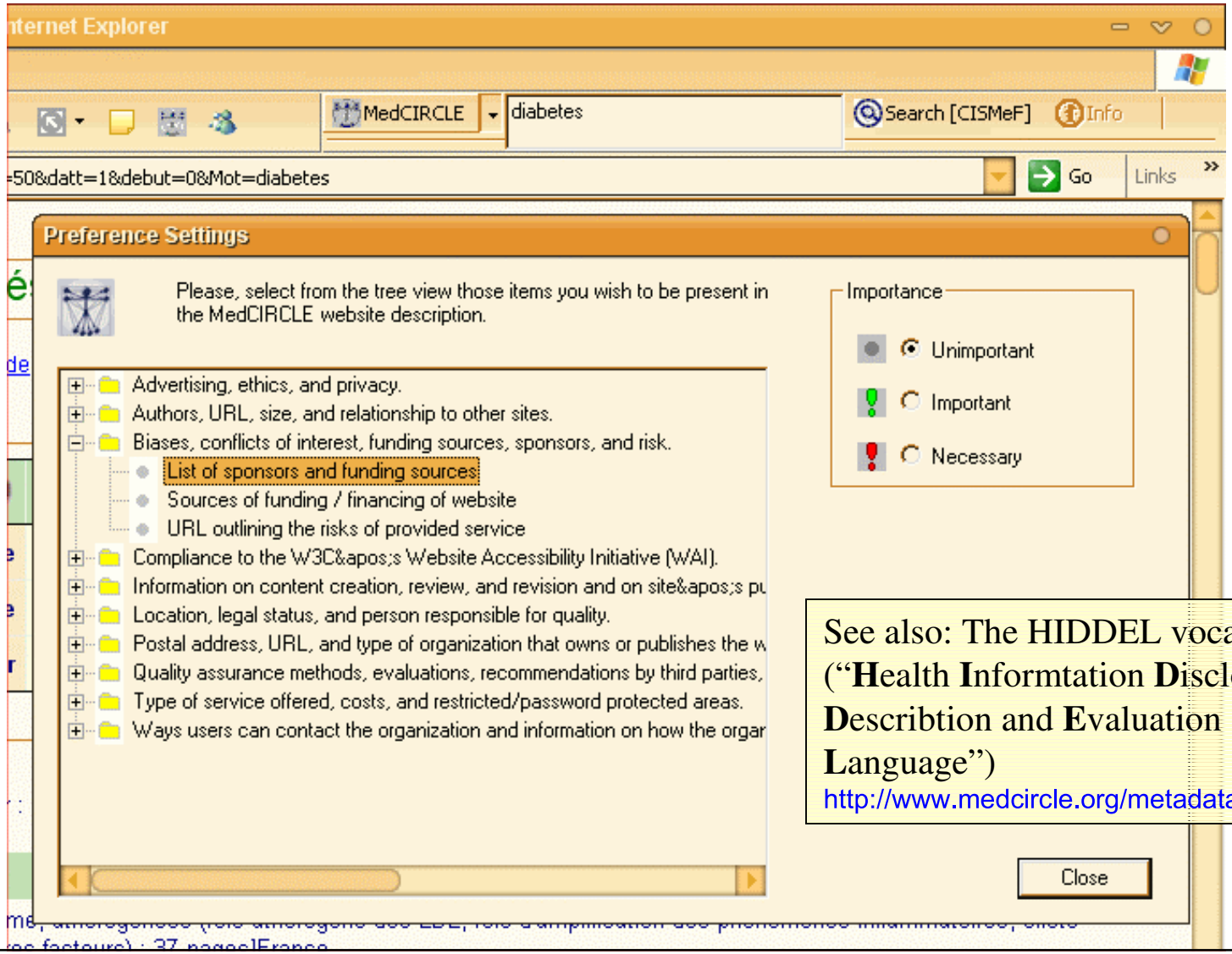
Quality seal and third party endorsements
"The content should be checked by the Federal Department of Health or any authority that can say 'Yes, this is OK.' "

One solution…

- Evaluative meta-information labelling and indexing (peripheral metadata embedded within resources and/or stand-alone/index metadata in a central catalogue or directory):
  - MedCIRCLE (http://www.medcircle.org/): The Collaboration for Internet Rating, Certification, Labelling and Evaluation of Health Information. The overarching aim of MedCIRCLE is to develop and promote technologies able to guide consumers to trustworthy health information on the Internet.
  - OMNI (http://www.omni.ac.uk)
  - Handpicked resources
  - Expert human resource-intensive
  - Scalability and coverage: limited

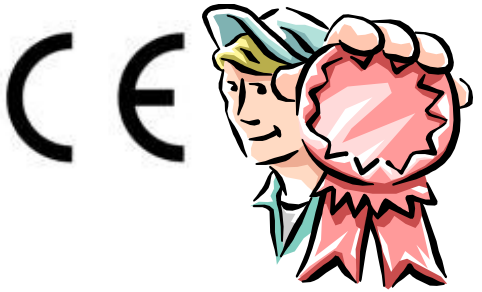
MedCIRCLE Infobar

http://www.medcircle.org/infobar/



See also: The HIDDEL vocabulary ("**H**ealth **I**nformtation **D**isclosure, **D**escribtion and **E**valuation **L**anguage")
http://www.medcircle.org/metadata/index.php

Solutions (Cont'd)



- EuroSeal: Rigby *et al* (2001) and Gagliardi and Jadad (2002) suggest the development of criteria that would be used by accredited agencies to self label conforming Web sites with a EuroSeal. Monitoring of integrity would be ongoing through cryptographic techniques.

  See also: eEurope eHealth Quality Criteria for Health-related Web sites:
  http://europa.eu.int/information_society/eeurope/ehealth/doc/communication_acte_en_fin.pdf

- WHO's proposal to ICANN* for .health Internet Top Level Domain (not approved yet):
  "*The World Health Organisation ("WHO") requests the .health TLD to provide the Internet public with screened health information. The WHO targets a restricted registrant base, large end user group and focuses primarily on non-commercial uses.*"
  (Quoted from http://www.icann.org/tlds/report/health1.html)
  * Internet Corporation For Assigned Names and Numbers—http://www.icann.org/

Conclusions

- Educate online medical/health information users
- When evaluating the quality of an online medical/health-related information resource, remember to check the following points:
  - Authorship
  - Attribution
  - Disclosure
  - Information currency or up-to-dateness
  - Resource accessibility/presentation/format issues
  - Appropriate measures to protect individuals' privacy
  - Popularity (not essential)

References

- Boulos MNK, Roudsari AV, Gordon C, Muir Gray JA. The Use of Quality Benchmarking in Assessing Web Resources for the Dermatology Virtual Branch Library of the National electronic Library for Health (NeLH). *Journal of Medical Internet Research.* 2001;3(1):e5 [http://www.jmir.org/2001/1/e5/]
- Darmoni SJ, Amsallem E, Haugh M, Lukacs B, Leroux V, Thirion B, Weber J, Boissel JP. Level of evidence as a future gold standard for the content quality of health resources on the internet. *Methods Inf Med*. 2003;42(3):220-5.
- Delamothe T. Quality of websites: kitemarking the west wind. *BMJ*. 2000 Oct 7;321(7265):843-4. [http://bmj.bmjjournals.com/cgi/content/full/321/7265/843]
- Eysenbach G, Kohler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *BMJ*. 2002 Mar 9;324(7337):573-7. [http://bmj.bmjjournals.com/cgi/content/full/324/7337/573]
- Gagliardi A, Jadad AR. Examination of instruments used to rate quality of health information on the Internet: chronicle of a voyage with an unclear destination. *BMJ*. 2002 Mar 9;324(7337):569-73 [http://bmj.bmjjournals.com/cgi/content/full/324/7337/569]
- Meric F, Bernstam EV, Mirza NQ, Hunt KK, Ames FC, Ross MI, Kuerer HM, Pollock RE, Musen MA, Singletary SE. Breast cancer on the world wide web: cross sectional survey of quality of information and popularity of websites. *BMJ*. 2002 Mar 9;324(7337):577-81. [http://bmj.bmjjournals.com/cgi/content/full/324/7337/577]
- Rigby M, Forsstrom J, Roberts R, Wyatt J. Verifying quality and safety in health informatics services. *BMJ*. 2001 Sep 8;323(7312):552-6. [http://bmj.bmjjournals.com/cgi/content/full/323/7312/552]