

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

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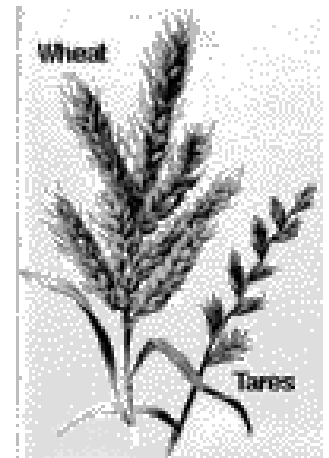


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Introduction: Why bother ourselves with information quality issues?

- 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.

QuackwatchSM
Your Guide to Health Fraud,
Quackery, and Intelligent Decisions



Many instruments exist...



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

We subscribe to the
HONcode principles
of the [Health On the
Net Foundation](#)

<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.

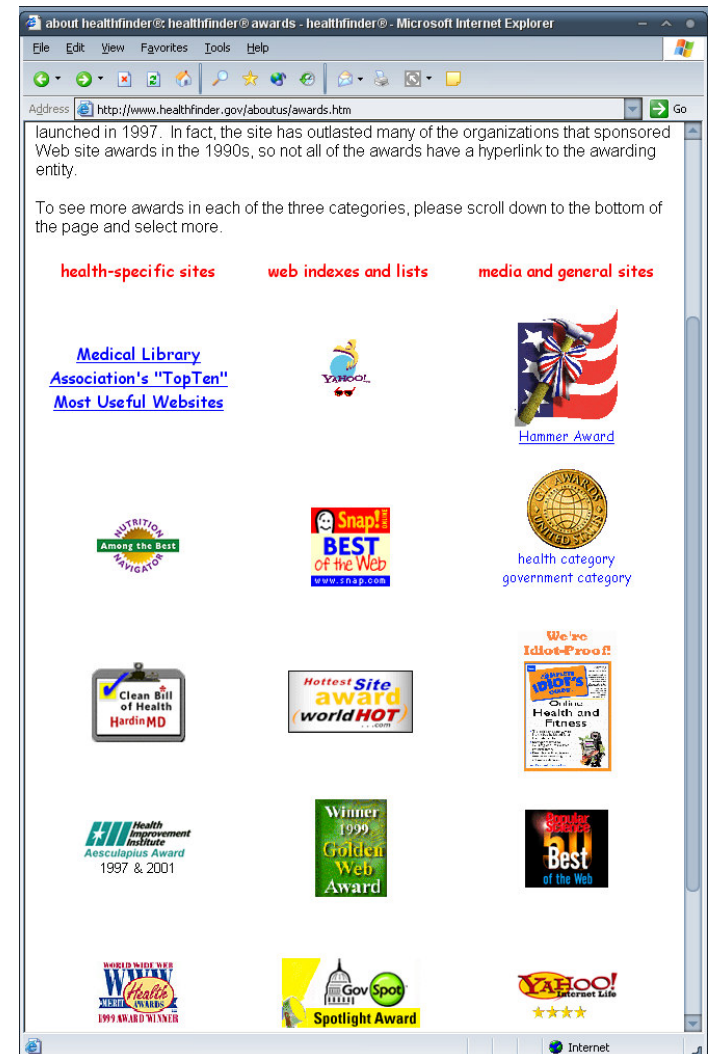
Some are geared towards the general public, e.g., <http://www.quick.org.uk/>, while others are mainly designed for use by healthcare professionals and librarians.



<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*?

The screenshot shows a Microsoft Internet Explorer browser window displaying a BBC News article. The address bar shows the URL: <http://news.bbc.co.uk/1/hi/health/3513791.stm>. The page title is "BBC NEWS | Health | Inside the world of medical journals". The article is dated Monday, 23 February, 2004, 17:52 GMT. The main headline is "Inside the world of medical journals" by Ray Dunne, a BBC News Online health staff member. The article discusses the MMR controversy and mentions that "One of the world's most respected medical journals says it should never have published a controversial paper on MMR." It also includes a sub-headline "What steps do journals take to ensure studies are robust and trustworthy?" and a photo of a copy of *The Lancet* newspaper. The article text states that Richard Horton, editor of *The Lancet*, sees thousands of research papers pass his desk every year and that in 1997, he received a paper from Andrew Wakefield, a doctor at the Royal Free Hospital in Hampstead, north London. The article also mentions that Dr. Wakefield and colleagues had carried out tests on 12 children, claiming a link between the MMR vaccine and autism and bowel disease. The page includes a navigation menu on the left with categories like World, UK, England, Northern Ireland, Scotland, Wales, Business, Politics, Health, and a sidebar on the right with sections for MMR Controversy, Key Stories, Background, Profile, Your Views, and Related Internet Links.

BBC NEWS | Health | Inside the world of medical journals - Microsoft Internet Explorer

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Address <http://news.bbc.co.uk/1/hi/health/3513791.stm>

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Last Updated: Monday, 23 February, 2004, 17:52 GMT

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Inside the world of medical journals

By Ray Dunne
BBC News Online health staff

One of the world's most respected medical journals says it should never have published a controversial paper on MMR.



The Lancet now has tougher rules on conflicts of interest

What steps do journals take to ensure studies are robust and trustworthy?

Richard Horton sees thousands of research papers pass his desk every year. As editor of *The Lancet*, he decides what is published in one of the world's most prestigious journals.

In 1997, he received a paper from Andrew Wakefield, a doctor at the Royal Free Hospital in Hampstead, north London.

Dr Wakefield and colleagues had carried out tests on 12 children. They claimed to have found a possible link between the three-in-one MMR vaccine and autism and bowel disease.

MMR CONTROVERSY

KEY STORIES

- ▶ Researchers issue retraction
- ▶ Top doctor wades into debate
- ▶ MMR study doctor calls for probe
- ▶ Journal regrets running study
- ▶ MMR uptake at record low
- ▶ 'No increased autism risk'

BACKGROUND

- ▶ How journals ensure standards
- ▶ Q&A: The MMR debate
- ▶ MMR research timeline

PROFILE

- ▶ Dr Andrew Wakefield

YOUR VIEWS

- ▶ Should there be an MMR inquiry?
- ▶ Are you concerned?

RELATED INTERNET LINKS:

- ▶ Committee on Publication Ethics
- ▶ The Lancet
- ▶ International Committee of Medical Journal Editors

BBC SPORT

BBC WEATHER

CBBC news

BBC ON THIS DAY

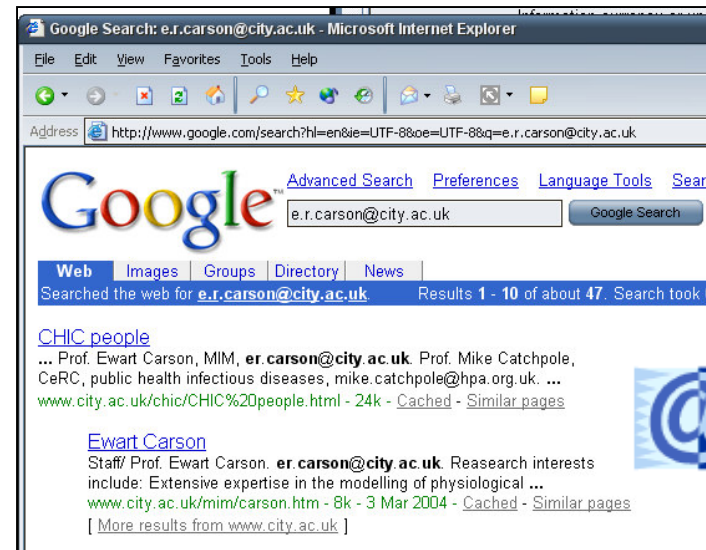
Essential information quality indicators

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

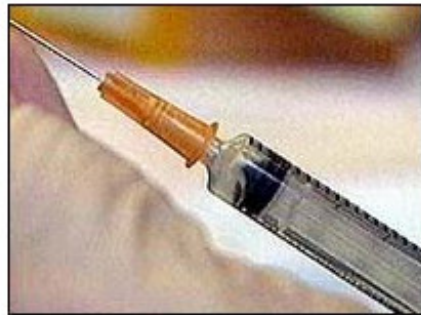
Last Updated: Friday, 20 February, 2004, 19:58 GMT

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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.



Children are vaccinated against measles, mumps and rubella

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

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

[E-mail this to a friend](#)

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Journals plan regulation scheme

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



The code says journals must ensure they publish accurate material

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

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

COPE: Committee on Publication Ethics - Microsoft Internet Explorer

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Address <http://www.publicationethics.org.uk/> Go

- About us
- Contact us
- Join COPE
- Guidelines
- Submit a case
- NEWS
- COPE Reports
- Publications
- Links

"Every single case of fraud and misconduct reduces public confidence, abuses the use of public and charitable funds and causes insult and frustration to the vast majority of careful, honest workers." **The Joint Consensus on Misconduct in Biomedical Research, Edinburgh 1999**

Done Internet

Address <http://www.ij-healthgeographics.com/info/about/>

By being part of BioMed Central, *International Journal of Health Geographics* is a member of the [Committee on Publication Ethics \(COPE\)](#).

Last updated: *today*

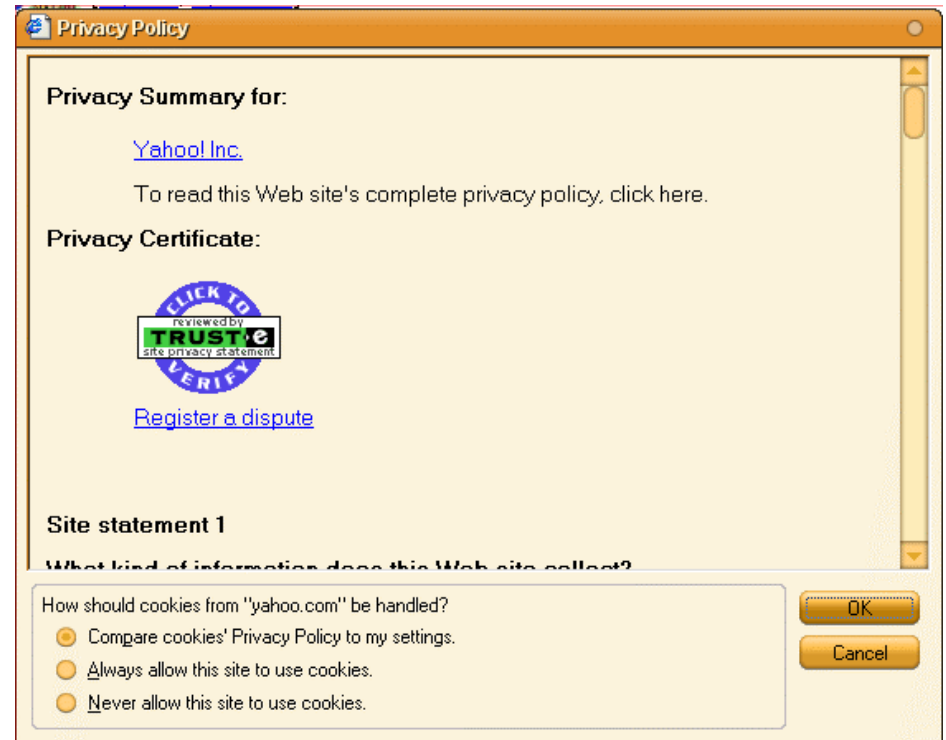
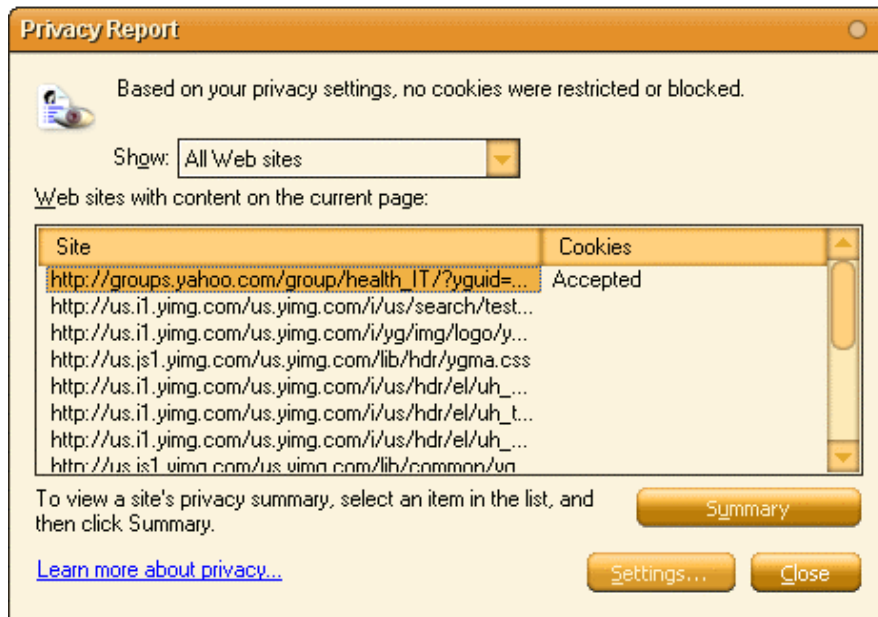
- Some Web pages have scripts that automatically display today's date whenever they are visited making them appear as if they were updated during the last 24 hours (which in many cases is not the case).
- You can use Internet Archive to trace the update history of a resource: <http://www.archive.org/>



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?

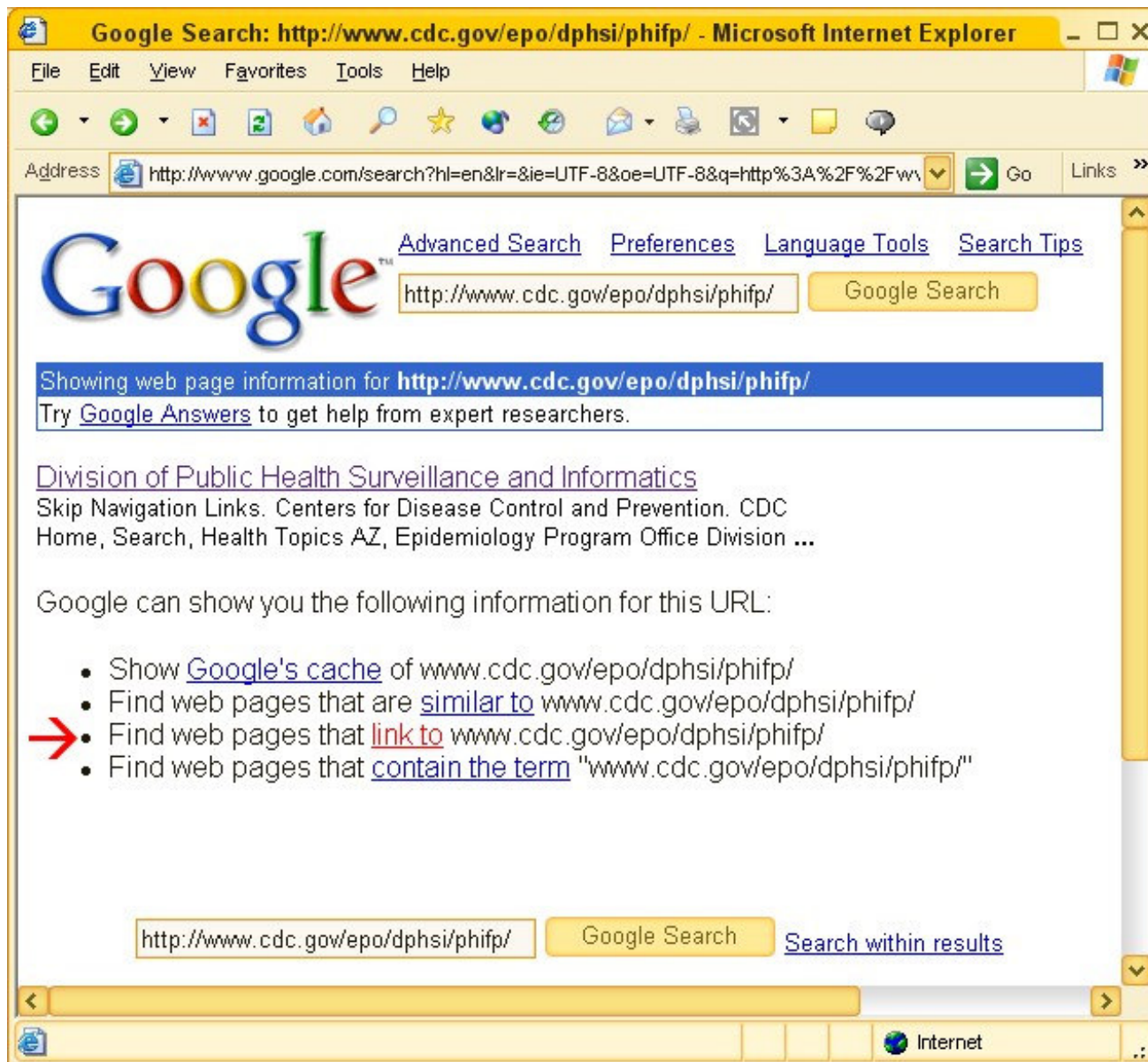
- Sometimes...
- Two measures of Web site popularity exist:
 - **Click popularity** (the frequency with which users have visited a site): drawbacks include incomplete data and marketing manipulation (esp. when tools like Alexa are used to measure it—see http://pages.alexam.com/prod_serv/traffic_learn_more.html)
 - **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)



Google Search: <http://www.cdc.gov/epo/dphsi/phifp/> - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Address <http://www.google.com/search?hl=en&lr=&ie=UTF-8&oe=UTF-8&q=http%3A%2F%2Fwww.cdc.gov/epo/dphsi/phifp/> Go Links >>

Google™ [Advanced Search](#) [Preferences](#) [Language Tools](#) [Search Tips](#)

Showing web page information for <http://www.cdc.gov/epo/dphsi/phifp/>
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Home, Search, Health Topics AZ, Epidemiology Program Office Division ...

Google can show you the following information for this URL:

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- Find web pages that are [similar to](#) www.cdc.gov/epo/dphsi/phifp/
- • Find web pages that [link to](#) www.cdc.gov/epo/dphsi/phifp/
- Find web pages that [contain the term](#) "www.cdc.gov/epo/dphsi/phifp/"

[Search within results](#)

Internet

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/>

Internet Explorer

MedCIRCLE diabetes

Search [CISMeF] Info

Go Links

Preference Settings

Please, select from the tree view those items you wish to be present in the MedCIRCLE website description.

- Advertising, ethics, and privacy.
- Authors, URL, size, and relationship to other sites.
- Biases, conflicts of interest, funding sources, sponsors, and risk.
 - List of sponsors and funding sources
 - Sources of funding / financing of website
 - URL outlining the risks of provided service
- Compliance to the W3C's Website Accessibility Initiative (WAI).
- Information on content creation, review, and revision and on site's pu
- Location, legal status, and person responsible for quality.
- Postal address, URL, and type of organization that owns or publishes the w
- Quality assurance methods, evaluations, recommendations by third parties.
- Type of service offered, costs, and restricted/password protected areas.
- Ways users can contact the organization and information on how the organ

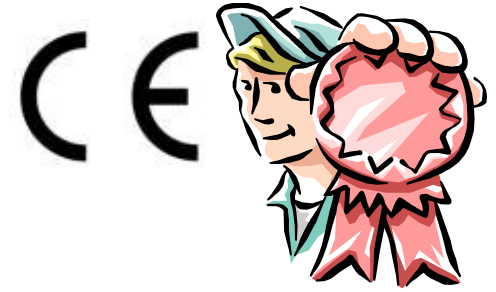
Importance

- Unimportant
- Important
- Necessary

Close

See also: The HIDDEL vocabulary (“**H**ealth **I**nformtation **D**isclosure, **D**escription 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/europe/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)

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