

MedCERTAIN: Quality Management, Certification and Rating of Health Information on the Net

Gunther Eysenbach¹⁾, Gabriel Yihune¹⁾, Kristian Lampe²⁾, Phil Cross³⁾, Dan Brickley^{3) 4)}

- 1) Dept. of Clinical Social Medicine, Unit for Cybermedicine, University of Heidelberg, Germany, email: ey@yi.com
- 2) FinOHTA / STAKES Finnish Office for Health Technology Assessment, Finland
- 3) ILRT Institute for Learning and Research Technology, United Kingdom
- 4) W3C Metadata Interest Group, MIT, Boston

MedCERTAIN (MedPICS Certification and Rating of Trustworthy Health Information on the Net, <http://www.medcertain.org/>) is a recently launched international project funded under the European Union's (EU) "Action Plan for safer use of the Internet. It provides a technical infrastructure and a conceptual basis for an international system of "quality seals", ratings and self-labelling of Internet health information, with the final aim to establish a "trustmark" for networked health information. Digital "quality seals" are evaluative metadata (using standards such as PICS=Platform for Internet Content Selection, now being replaced by RDF/XML) assigned by trusted third-party raters. The project also enables and encourages self-labelling with descriptive meta-information by web authors. Together these measures will help consumers as well as professionals to identify high-quality information on the Internet. MedCERTAIN establishes a fully functional demonstrator for a self- and third-party rating system enabling consumers and professionals to filter harmful health information and to positively identify and select high quality information. We aim to provide a system which allows citizens to place greater trust in networked information, exemplified in the domain of health information, whilst also making a significant contribution for similar projects with different target domains. The project will demonstrate how PICS-based content rating and filtering technologies can automate and exploit value-adding resource description services. It further proposes standards for interoperability of rating services.

Background

The evolution of the "information age" is mirrored in the exponential growth in the number of web sites and online accessible databases, and expanding services and publications available on the Internet.¹ Many consumers and patients directly apply the information they have read on the Internet to their own lives². A well-known concern is the extremely variable quality of health related informa-

tion on the Internet, which ranges from beneficial to harmful. Several studies have evaluated the quality of medical information on various venues of the Internet such as the World-Wide-Web³, newsgroups⁴ and email consultations⁵⁻⁷. As information technology and consumer health informatics are becoming integral parts of modern public health concepts and national health care policies in developed countries⁸, implications of Internet information for public health are widely discussed topics^{9;10}.

Misinformation can lead patients with life-threatening conditions to lose trust in their provider, take actions that undermine the effectiveness of their treatment (e.g., by taking substances that interact in a negative way with prescribed medications). Patients may use their limited time with their healthcare provider unproductively in ways that ultimately increase costs of care, and even abandon a provider delivering high-quality care to pursue ineffective therapies. People with inadequate capabilities in critical thinking may also be victimized by biased or incomplete information from those with a financial interest in the information they provide¹¹.

Such risks are present in most media, but on the World-Wide-Web this problem reaches a new dimension. Therefore new technologies and services, which allow consumers to filter high-quality information, are needed to shift the balance towards more effective utilisation of trustworthy and beneficial health information.^{8;12}

Quality management of health information on the Internet

To realize the full potential of the Internet for self-help, self-care and patient empowerment, it is necessary to ensure the quality of information. As on the Internet any centralized body to assure quality is unrealistic and undesirable, one current challenge of consumer health informatics is to develop applications that help consumers to assess the quality of information and to automatically filter information according to their needs.¹²

Quality management of health information on the Internet essentially rests on four pillars – the four big E's^{8;13}:

- **E**ducating consumers so that they are better able to identify and find good quality information
- **E**ncouraging health information publishers to self-regulation and self-labeling (disclosure, content description with metadata). This also involves educating publishers so that they are better able to provide high quality information
- **E**valuating information by independent external third parties,
- **E**nforcement of existing legislation, in the case of fraudulent or harmful information.

We describe the ongoing implementation of these four pillars in an ongoing EU project named MedCERTAIN (MedPICS Certification and Rating of Trustworthy Health Information on the Net), funded by the European Union under the „EU Action Plan on promoting safer use of the Internet by combating illegal and harmful content on global networks“ (<http://www2.echo.lu/iap/>). The Action Plan and this project are pulling together academics, industry, consumers, and professional organizations in order to establish a comprehensive quality management system on the Internet, which includes a network of hot-lines, support for self-regulation, development of technical measures for rating and filtering, and awareness initiatives. This paper will focus on the conceptual, organizational and technical framework of the project.

Concept

The MedCERTAIN project follows up from the idea that the quality of health information and interactive applications on the Internet cannot and should not be controlled by a central body or authority, but instead information and applications must be evaluated and be “labelled” in a decentralised manner^{12;14;15}. Labelling means to provide meta-information, i.e. to provide information about information. We have previously pointed out that meta-information can be descriptive or evaluative. In 1997, we proposed a medical core metadata set based on the W3C PICS (Platform for Internet Content Selection) standard, which we called medPICS¹⁶. Proposed descriptive metadata included authorship, qualification of authors, sources of funding, content keywords based on UMLS/MeSH etc.¹⁶ Compared to other approaches, such as the provision of Dublin Core Metadata in HTML metatags, which allow only the use of descriptive meta-information supplied by webauthors¹⁷, the idea behind medPICS was to make use of the fact that the PICS standard allows for metadata to be assigned by third parties. In the health field this can be used to evaluate information on other websites^{12;16}. The combination of descriptive and evaluative ratings can be used by consumers to filter information according to their needs and help them to make informed health decisions¹⁸.

From PICS to RDF/XML

The PICS standard is currently migrating towards becoming an application of the XML/RDF technology of the W3C. The successor standard, RDF (the Resource Description Framework), grew out of work on expanding PICS (then called PICS-NG) to provide for more flexible descriptive capabilities (e.g. textual comments). RDF is a W3C Recommendation for Web “resource description” which includes labelling, classification, cataloguing, rating etc. RDF in turn adopts the W3C XML Recommendation as a new file format for exchanging such data, replacing the PICS 1.1 format.

Organizational framework for rating and labeling information

The MedCERTAIN consortium is not rating health information itself, but builds an organizational and technical infrastructure which allows individuals and organizations to evaluate information on other websites and creates standards for collaboration and interoperability among rating services. This evaluative meta-information coming from different sources, together with descriptive meta-information voluntarily assigned by the webauthors, can be used by consumers to filter high-quality information for their needs. Meta-information can either be provided by webauthors themselves or provided from a third-party rating service (or simply “label bureau”).

Approaches to deliver evaluative meta-information

The most common approach to provide evaluative meta-information is “self-labelling” by means of putting a static “award” logo on a webpage to show endorsement by third parties (or to provide this information as text or by providing meta-tags). A problem of these “first generation” approaches is that such awards and logos can be included by webmasters themselves and therefore are more suited for marketing purposes rather than to provide reliable reassurance to consumers.

Second generation approaches make such logos or awards “clickable” and allow consumers to check the current standing of a website by directly linking to the third-party site which would display a dynamic record. Examples for services using this approach are VeriSign, E-trust, or VIPPS (Verified Internet Practice Sites) of the National Association of Boards of Pharmacy). The Health on the Net (HON) Logo¹⁹ is currently transiting from a first- to a second generation approach.

Both first and second-generation approaches allow webauthors to publish selectively “awards” or evaluative meta-information with no possibilities for rating services to bring this information directly to consumers. While such approaches make sense for descriptive meta-information (e.g. information about the authors, date of publication, qualification of authors etc.^{16;17} provided in

metatags) they are problematic for evaluative metainformation.

Third generation approaches would allow consumers to directly retrieve metainformation from one or more rating services in real time while accessing a website.

Two complementary approaches will be tested for the MedCERTAIN project to convey evaluative metainformation to consumers:

- PICS (RDF/XML) labels (Fig. 1).
- Dynamic quality “seals” (Fig. 2):

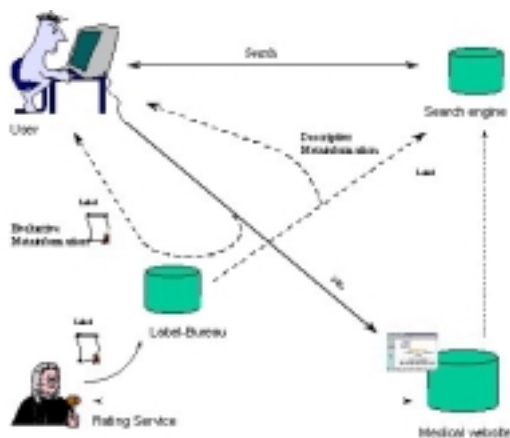


Figure 1 – The medPICS standard can be used to transmit metainformation directly to consumers, for example to mark fraudulent websites

PICS (RDF/XML) labels

The advantage of the medPICS approach¹⁶ is that consumers can receive PICS (RDF/XML) labels (Fig. 2) (metadata) directly from a third-party label bureau, without the rated website having to co-operate or having the possibility to tamper with the rating, which is a prerequisite for being able to deliver critical or disapproving comments, in extreme cases they would allow “blacklisting” harmful websites, such as websites making fraudulent health claims, by appropriate bodies such as the FTC (US Federal Trade Commission).

Dynamic quality “seals”

Dynamic third-generation quality “seals” (Fig. 2) are primarily useful for “whitelisting” and labelling trustworthy health websites, who agree to a consensus e-health Code of Ethics²⁰, are in “good standing”, and volunteer to disclose certain information, e.g. authorship, sources of funding, internal quality control mechanisms etc. The web publisher includes an IMG SRC tag in his HTML code which remotely loads a dynamically generated from the MedCERTAIN website. The “seal” can contain current information and logos generated “on-the-

fly” from the MedCERTAIN database, for example the logos of the societies endorsing the website, a timestamp and the URL of the site. In addition, users can (similarly to the second generation approach) click the logo to display the disclosed information (loaded from the MedCERTAIN website), such as rating information provided by professional raters or feedback comments from other users.

Both approaches – MedPICS labels and dynamic quality seals – can be used simultaneously and are not mutually exclusive. Evaluative medPICS labels and dynamic quality seals are generated from the same label database containing evaluative metainformation about the website in question.

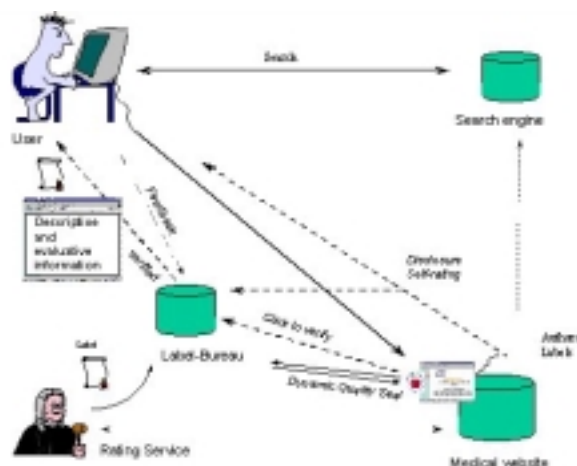


Figure 2 – Dynamic quality seals, which are linked to a dynamic MedCERTAIN page, providing additional descriptive and evaluative information about the website, can be displayed by trustworthy health websites

Levels of accreditation

The MedCERTAIN consortium is evaluating the use of different levels of certification for publishers of health information on the web.

- Level 1 labels indicate that the site is in “good standing” (no complaints are filed), that the information provider has agreed to follow an consensus E-health Code of Ethics²⁰ and that basic disclosure information has been submitted. The disclosures can be retrieved by the consumer either by clicking on the seal (a new webpage opens, generated by the MedCERTAIN site), or by means of medPICS metainformation.
- Level 2 labels indicate that the website has been checked by a third party (a member of the MedCERTAIN collaboration) and fulfills the formal criteria of the eHealth Code of Ethics
- Level 3 labels indicate that the content of a website has been evaluated by an individual rater (expert) or

a rating organisation, who are content experts (medical organisations). Based on these evaluations the rater would make a general judgement on the trustworthiness of the publisher.

Level 4 labels indicate that the content of a document (a webpage) has been peer-reviewed by an independent third party. This level will only be used in special cases (such as clinical guidelines) and also involves that the content needs to be re-evaluated if significant changes have been made.

Who rates the information?

A number of organizations, institutions and individual experts are already in the business of evaluating, accrediting, or endorsing information. Some (for example professional societies) are just publishing links as endorsements on their websites, others (such as Medical Matrix) maintain databases with evaluative information. The problem is that all these efforts are made in a non-coordinated way and that no common rating criteria are used. Many of the rating criteria commonly in use are not even validated.²¹

Goal: Interoperability of rating services

A basic idea of MedCERTAIN is to foster cooperation and interoperability of these services. If all health information rating services on the Internet would use a common, standardized "language" (evaluative metadata) to describe and rate health information on the net, and if this data can be exchanged and communicated to the consumer in a standardized way, then the user will have a huge resource of meta-information at his fingertips, helping him to assess the credibility of any health information he finds.

Consensus rating criteria for collaborative evaluation

In September 2000 a group of experts gathered in Heidelberg, to draft the "Heidelberg recommendations", which contain a basic set of reliable consensus quality criteria for health related websites, that can be used for assessment by a third party; a rating vocabulary (a computer-readable representation of these rating categories and their scales); a set of descriptive metadata categories, which will allow health websites to disclose essential information required in the Washington Code of eHealth Ethics²⁰ in a standardized, computer-readable way; and a data exchange structure which assures interoperability of rating services. A "Collaboration for Critical Appraisal of Internet Health Information", proposed already in 1997,¹² is currently being formed, which brings together organizations and individuals who are active in the field of reviewing, appraising, rating, evaluating health information on the web, based on the consensus criteria, and to further develop methods and to exchange data. Together with the Cochrane Collaboration, this initiative hopes to

improve dissemination of evidence to consumers on the Internet and thereby to advance evidence-based decision making in health care in empowering consumers to make informed, evidence-based decisions.

Acquisition of ratings

A rating organisation can be for example a trusted medical society who chooses to certify websites relevant to their work, or a library attempting to collect high-quality resources on the web.

If a publisher wishes a level-3 or level-4 certification from any or a specific society or body he would contact the MedCERTAIN collaboration, which would forward the rating request to the respective society/body (Members of the MedCERTAIN collaboration can decide whether they rate information for free or whether they charge a fee to the publisher).

Raters are individual experts, working either independently or are affiliated with a rating service/organisation. The MedCERTAIN rater database currently contains more than 100 experts, who voluntarily or for a fee evaluate health information on the Net.

Rating services, such as professional societies or libraries, collaborating with the MedCERTAIN project, can supply ratings through two different venues: Either, rating services publish their meta-information in XML on their site, and the MedCERTAIN database will automatically harvest these ratings, or a rating service (such as a professional society wishing to endorse a website) uses tools which will be supplied by the MedCERTAIN consortium, such as bookmarklets, the RDF what's-related menu, the HTML forms interface, bookmark uploads, remote bookmark storage (in LDAP repositories or JAVA-Applets. Digital signatures may ensure the authenticity of these ratings.

How does the metadata come to the user?

The ratings gathered in the MedCERTAIN database constitute a RDF "open directory" will be redistributed and can reach the consumer through different channels. With PICS technology, consumers will be able to use their browsers, or additional software, to retrieve this meta-information automatically in the background whenever they access a website. Similarly, health kiosks (publicly accessible Internet terminals for use in libraries and hospitals) may use this infrastructure to limit access to quality assessed content on the web, or to display disclaimers if the consumer is leaving the "evidence-based" (rated) subset of the web. Search engines may also access the MedCERTAIN RDF data and may for example display this information already when listing the search results. In addition, the collaborating rating services may publish this information on their site. Finally, web publishers themselves may publish a dynamically generated seal described above which will make visible relevant

information from the MedCERTAIN database to users when they access the website.

Acknowledgements

MedCERTAIN is funded by the European Union, Action Plan for safer use of the Internet.

References

1. Eysenbach G, Sa ER, Diepgen TL. Shopping around the internet today and tomorrow: towards the millennium of cybermedicine. *BMJ* 1999;**319**:1294.
2. Eysenbach G, Diepgen TL. Patients looking for information on the Internet and seeking teleadvice: motivation, expectations, and misconceptions as expressed in e-mails sent to physicians [see comments]. *Arch Dermatol* 1999;**135**:151-6.
3. Impicciatore P, Pandolfini C, Casella N, Bonati M. Reliability of health information for the public on the World Wide Web: systematic survey of advice on managing fever in children at home [see comments]. *BMJ* 1997;**314**:1875-9.
4. Culver JD, Gerr F, Frumkin H. Medical information on the Internet: a study of an electronic bulletin board [see comments]. *J Gen Intern Med* 1997;**12**:466-70.
5. Eysenbach G, Diepgen TL. Evaluation of cyberdocs. *Lancet* 1998;**352**:1526.
6. Eysenbach G, Diepgen TL. Responses to unsolicited patient e-mail requests for medical advice on the World Wide Web [see comments]. *JAMA* 1998;**280**:1333-5.
7. Sandvik H. Health information and interaction on the internet: a survey of female urinary incontinence. *BMJ* 1999;**319**:29-32.
8. Eysenbach G. Consumer health informatics. *BMJ* 2000;**320**:1713-6.
9. Coiera E. Information epidemics, economics, and immunity on the internet. We still know so little about the effect of information on public health [editorial; comment]. *BMJ* 1998;**317**:1469-70.
10. McLeod SD. The quality of medical information on the Internet. A new public health concern [editorial]. *Arch Ophthalmol* 1998;**116**:1663-5.
11. Science Panel on Interactive Communication and Health. Wired for health and well-being; the emergence of interactive health communication. Eng, T. R. and Gustafson, D. H. 1999. Washington, DC, US Department of Health and Human Services, US Government Printing Office. Ref Type: Report
12. Eysenbach G, Diepgen TL. Towards quality management of medical information on the internet: evaluation, labelling, and filtering of information [see comments]. *BMJ* 1998;**317**:1496-500.
13. Eysenbach G. Towards ethical guidelines for e-health: JMIR Theme Issue on eHealth Ethics. *J Med Internet Res* 2000;**2**:e7.
14. Patrick K, Robinson TN, Alemi F, Eng TR. Policy issues relevant to evaluation of interactive health communication applications. The Science Panel on Interactive Communication and Health. *Am J Prev Med* 1999;**16**:35-42.
15. Gustafson DH, Robinson TN, Ansley D, Adler L, Brennan PF. Consumers and evaluation of interactive health communication applications. The Science Panel on Interactive Communication and Health. *Am J Prev Med* 1999;**16**:23-9.
16. Eysenbach G, Diepgen TL. Labeling and filtering of medical information on the Internet. *Methods Inf Med* 1999;**38**:80-8.
17. Malet G, Munoz F, Appleyard R, Hersh W. A model for enhancing Internet medical document retrieval with "medical core metadata.". *J Am Med Inform Assoc* 1999;**6**:163-72.
18. Eysenbach G. Rating information on the internet can empower users to make informed decisions. *BMJ* 1999;**319**:385B.
19. Boyer C, Selby M, Scherrer JR, Appel RD. The Health On the Net Code of Conduct for medical and health Websites. *Comput Biol Med* 1998;**28**:603-10.
20. e-Health Ethics Initiative. e-Health Ethics Draft Code. *J Med Internet Res* 2000;**2**:e2.
21. Jadad AR, Gagliardi A. Rating health information on the Internet: navigating to knowledge or to Babel? [see comments]. *JAMA* 1998;**279**:611-4.