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MedCIRCLE: Collaboration for Internet Rating, Certification, Labelling and Evaluation of Health Information on the World-Wide-Web

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Abstract

We describe MedCIRCLE, an EU-funded semantic web project to implement the first steps towards a global, collaborative rating and guidance system for health information proposed in the MedCERTAIN project. In MedCIRCLE, three European gateway sites for consumer health information will implement the metadata vocabulary HIDDEL (Health Information Disclosure, Description and Evaluation Language). HIDDEL allows portals and gateways to make the results of their evaluations accessible as XML/RDF. The three participating national portals are: AQUMED (Agency for Quality in Medicine) patienten-information.de, COMB (Official Medical College of Barcelona) and CISMeF, a quality-controlled health gateway developed at Rouen University Hospital. Other health subject gateways, accreditation, or rating services are invited to join the collaboration simply by implementing HIDDEL on their gateways. Widespread implementation HIDDEL will allow intelligent agents or client-side software to harvest statements and opinions about the trustworthiness of other websites, assisting users in selecting trustworthy websites. The MedCIRCLE project builds on, expands and continues work on rating health information on the Internet piloted within the MedCERTAIN project. While MedCERTAIN provided the core technologies and software for rating and "trustmarking" health information, MedCIRCLE is built around these technologies and involves a wider medical community to assess health information, demonstrating the power of collaborative and interoperable evaluations in a semantic web environment. MedCIRCLE is a project with the overall objective to develop and promote technologies able to guide consumers to trustworthy health information on the Internet, to establish a global web of trust for networked health information, and to empower consumers to positively select high quality health information on the web. Other aims include refinement and expansion of HIDDEL, to become a standard vocabulary and interchange format for self- and third-party ratings of health information.

Keywords:
Internet; Semantic web; Health information; Rating services; Quality

Introduction

There has been considerable debate about the variable quality of health information on the world-wide-web and its impact on public health.[1] Several initiatives have been undertaken to define criteria to assess the quality of the increasing amount of health information on the Internet. As the number of health related websites continues to grow, and information technology and consumer health informatics are becoming integral parts of modern public health concepts and national health care policies in developed countries [2], implications of Internet information for public health are widely discussed.[3,4]

While central authorities to regulate, control, censor, or centrally approve information, information providers or websites are neither realistic nor desirable [5], public health professionals are interested in making systems available that direct patients and themselves to the best available information sources. The risk for an individual to encounter unsuitable information on the web is composed of the proportion of inappropriate sites on the web, times the risk (probability) of encountering inappropriate websites or avoiding them [1]. Thus, public health measures can either aim to reduce the proportion of unsuitable websites on the web or aim to enhance the ability of the user to find accurate, trusted information. The overarching aim of the MedCIRCLE project (http://ww.medcircle.org) is to establish a global web of trust for networked health information and to increase the accessibility and findability of trusted health websites using "semantic web" approaches, which essentially means to make "narrative" information on the web accessible in a machine processable format (RDF/XML) [6].

Providing trust related metadata

Health professionals have begun to recognise their responsibility to guide consumers and patients to the best available medical information on the web. Many national governments and medical societies have recognized their responsibility to help users to identify "good quality" information sources and have begun to develop national gateways, portal sites and other forms of infomediaries such as seals of approval ("kitemarks") or certification mechanisms in an effort to help consumers to locate trustworthy information resources.

However, current approaches mainly come from traditions outside of the Web and do not harness any of the advantages of the Web as a decentralized, distributed information system. There is a need for "next generation" tools, including intelligent knowledge-based tools, allowing consumers to positively identify reliable health information suitable for their needs. [7]

MedCIRCLE is a collaboration of trusted European health subject gateways, medical associations, accreditation, certification, or rating services, which all share the common goal to evaluate, describe, or annotate health information. The three partners of MedCIRCLE in Germany, Spain, and France are the following:

The Agency for Quality in Medicine (AQUMED, or *Ärztliche Zentralstelle Qualitätssicherung ÄZQ*) was founded in March 1995 as a joint institution of the German Medical Association (GMA = Bundesärztekammer) and the National Association of Statutory Health Insurance Physicians (NASHIP = Kassenärztliche Bundesvereinigung). AQUMED established an internet gateway (www.patienten-information.de) for lay persons, listing consumer health information sites which have been evaluated using the DISCERN instrument.

The Official Medical College of Barcelona (COMB) (http://www.comb.es) represents the medical profession of Barcelona. In the project "Web Medica Acreditada", COMB has to date accredited more than 300 Spanish health websites from Spain and Latin America [8].

The CISMeF (Catalog and Index of French-speaking resources) project is located at the Rouen University Hospital. CISMeF is a quality controlled subject gateway which is defined as an Internet service, which apply a set of quality measures to support systematic resource discovery (http://www.chu-rouen.fr/cismef) [9-11].

The three consortium partners are currently implementing the HIDDEL vocabulary (see below) on their sites and participate in the endeavour to define and standardise a common metadata vocabulary. MedCIRCLE will also encourage use of HIDDEL by health information providers to disclose information essential for consumers to assess the quality of websites themselves.

Brief description of the HIDDEL language

HIDDEL (Health Information Disclosure, Description and Evaluation Language) is a metadata language and ontology which allows expression of descriptive and evaluative annotations in XML/RDF (Resource Description Framework) [12]. HIDDEL evolved from medPICS [13], a basic rating vocabulary (rating system) for medical information conforming to the Platform for Internet Content Selection (PICS) [14]. PICS has been developed by the World Wide Web Consortium (W3C) as a technical standard so that people can electronically distribute descriptions of digital works in a simple, computer readable format.

From MedCERTAIN to MedCIRCLE

MedCERTAIN (MedPICS Certification and Rating of Trustworthy Health Information on the Net, http://www.medcertain.org/) [15] was an international project co-funded under the European Union's (EU) "Action Plan for safer use of the Internet" running from May 2000 through February 2002. MedCERTAIN established a fully functional demonstrator for a self- and third-party rating system enabling consumers and professionals to positively identify and select high quality information and proposed a global, collaborative system to evaluate and annotate health information. As the number of health related websites worldwide has been estimated as being around 100,000, complete coverage by a single third party evaluation body is impossible. Instead, a collaborative approach has to be promoted, whereby different rating services / organisations use comparable standards and a common metadata language.

The main conceptual difference between MedCERTAIN and MedCIRCLE is – apart from the fact that MedCERTAIN can be seen as the pilot phase and MedCIRCLE as the implementation phase – that MedCIRCLE is even less a "quality seal" than MedCERTAIN. Presence of a MedCIRCLE button on a health website does not imply in any way that the site meets minimum standards, in contrast to MedCERTAIN, where a 3-step approach towards obtaining a trustmark was proposed (self-disclosure – evaluation by non-medical expert – evaluation by medical expert).

Thus, in MedCIRCLE we do not speak about a "trustmark" any longer, and the MedCIRCLE logo is merely a button for consumers to access metainformation, while MedCERTAIN attempted to model the (in our view) most sensible 3-step approach towards evaluating a health website. This model included letting the health information provider declare certain things (level 1), check these declarations by non-medical (level 2) or medical experts (level 3), in this order.

In contrast, MedCIRCLE consortium takes a very neutral approach and does not impose (but merely recommends) certain procedures or minimum metadata, taking into account that collaborating gateways, accreditors, certifiers, raters may come from very different angles. Collaborating gateways in MedCIRCLE may for example directly check the content of a health website (level 3) without first asking the health information provider to self-declare certain site-attributes (level 1). Also, while in the MedCERTAIN approach health websites had to provide a minimum set of level-1 disclosure information in order to be allowed to carry the MedCERTAIN seal, this is not required for MedCIRCLE. MedCIRCLE is value neutral in respect to what needs to be disclosed or evaluated. This slight change in approach can be explained by realizing that – although there is a consensus on core quality criteria -, different gateways have different requirements and procedures (for example which elements are mandatory as opposed to desired) and it is unrealistic to assume that other organizations hoped to be partners in a global collaboration change their processes and criteria according to the MedCERTAIN recommendations.

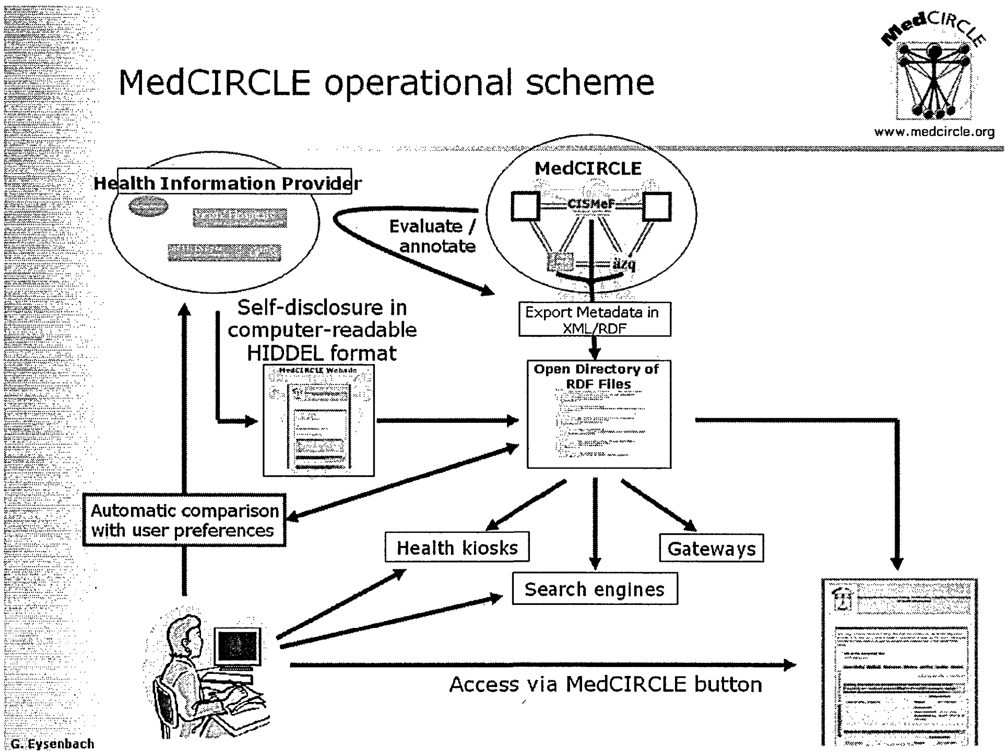

Figure 1. MedCIRCLE provides a model for a global, collaborative system to guide users to trustworthy health information. Participating gateways (portals, annotators, certifiers, third parties, rating organisations) in the MedCIRCLE consortium evaluate and annotate health information providers, and make the results of their evaluations explicit and accessible using RDF metadata. These can be exported or harvested into an Open Directory. Health information providers can also enter self-disclosure and descriptive data into the Open Directory using software developed by MedCERTAIN and MedCIRCLE. Users can access an aggregate view of what people say about a certain website by clicking on a MedCIRCLE button published on a health website, which opens up a "transparency label window" displaying and aggregating descriptive and evaluative metadata from different sources. Metadata from the Open Directory can also be fed into search engines and other gateways.

Taking into account these realities, the MedCIRCLE approach is therefore an even more open and bottom-up approach ensuring the widest possible collaboration and participation of different players, with the draw-back that it perhaps give less reassurance to consumers as different collaborating partners may do different things and may even fall behind a recommended standard for evaluating information.

MedCIRCLE is hoped to form the nucleus for a wider international collaboration, intending to help people, patients and professionals to identify health information useful to them [5], e.g. by ensuring interoperability of rating services, identifying common standards for recommending websites and exploring possibilities for decentralised, distributed rating systems by creating a network of evaluators, taking into account the power of the Internet as a networked environment.

The players and the collaboration model

In terms of providing or using health information or metainformation, four different types of "players" on the semantic web can be distinguished:

1. The "health information provider" can be referred to as "first party". In the semantic web / MedCIRCLE scenario, the health information provider makes various self-descriptive and self-evaluative statements about himself using RDF/HIDDEL.
2. An end user can be referred to as "second party". The user only uses HIDDEL metadata to set his requirements or preferences interacting with an intelligent agent or other kind of yet-to-be-developed client-side software able to filter appropriate information.
3. An independent "third party" is typically an individual or organization, e.g. a certification body, which feels special responsibility or knowledge to endorse, evaluate, validate, certify, recommend, approve, peer-review, comment on, or annotate information or services provided by health information providers. These third parties could be, for example, gateways, libraries, portal sites, or certifying institutions and may use HIDDEL metadata to express evaluations or endorsements in a machine-processable way.
4. An organization or association (group) of health information providers which sets up a code of conduct or guideline can be called a "fourth party". In a similar way as the "second party" (the user), such a group typically models requirements (for instance, saying that its members should make certain statements), or makes statements such as who is a member of the group.

In practice, each of these actors can have one or more of these roles simultaneously, for example, an evaluating third party can be identical to the actor that sets up guidelines (fourth party).

The vision

MedCERTAIN and MedCIRCLE attempt to create a critical mass of metadata, so that industry jumps in and develops intelligent Web browsers and agents able to aggregate and interpret this data. MedCIRCLE will be an open collaboration of organizations implementing the HIDDEL vocabulary. The semantic web will greatly magnify the challenges, but also the opportunities, created by the human-readable World Wide Web. On the opportunity side, the semantic web will give even greater power to the consumer to determine the trustworthiness of a given health information provider or service than the Web in its current form.

Semantic web approaches using intelligent software may open up new ways for educating consumers and reaching less-savy consumers, because part of the intelligence and knowledge currently required to critically appraise information on the consumer site could be built into search tools. The feasibility and use of this approach and the impact on consumers is subject of ongoing investigation within the MedCIRCLE project.

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References

[1] Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. JAMA 287 (20):2691-2700, 2002.
[2] Eysenbach G. Consumer health informatics. BMJ 320 (7251):1713-1716, 2000
[3] 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, 1469-1470.
[4] McLeod SD. The quality of medical information on the Internet. A new public health concern [editorial]. *Arch Ophthalmol* 1998; 116: 1663-1665.
[5] Eysenbach G, Diepgen TL.Towards quality management of medical information on the internet: evaluation, labelling, and filtering of information. *BMJ* 1998; 317: 1496-1500.
[6] Berners-Lee T, Hendler J. Publishing on the semantic web. Nature 2001;410:1023-1024.
[7] Eysenbach G. An ontology of quality initiatives and a model for decentralized, collaborative quality management on the (semantic) world-wide-web. *J Med Internet Res* 2001; 3: e34
[8] Sarrias R, Mayer MA, Latorre M. Accredited medical web: an experience in Spain. *J Med Internet Res* 2000; 2 (suppl 2): e5.
[9] Darmoni SJ, Leroy JP, Baudic F, Douyere M, Piot J, Thirion B. CISMeF: a structured health resource guide. *Methods Inf Med* 2000; 39: 30-35.
[10] Darmoni SJ, Thirion B, Leroy JP, Douyere M, Piot J, .The Use of Dublin Core Metadata in a Structured Health Resource Guide on the Internet. *Bull Med Libr Assoc* 2001; 89: 297-301.
[11] Darmoni SJ, Haugh MC, Lukacs B, Boissel JP. Quality of health information about depression on internet. Level of evidence should be gold standard. *BMJ* 2001; 322: 1367.
[12] Eysenbach G, Köhler C, Yihune G, Lampe K, Cross P, Brickley D. A metadata vocabulary for self- and third-party labelling of health web-sites: Health Information Disclosure, Description and Evaluation Language (HIDDEL). *Proc AMIA Annu Fall Symp* 2001; 169-173.
[13] Eysenbach G, Diepgen TL. Labeling and filtering of medical information on the internet. *Methods of Information in Medicine* 1999; 38: 80-88.
[14] Resnick P and Miller J. PICS: Internet access control without censorship. *Communications of the ACM*, 39(10):87-93, 1996.
[15] Eysenbach G, Yihune G, Lampe K, Cross P, Brickley D. MedCERTAIN: Quality Management, Certification and Rating of Health Information on the Net. *Proc AMIA Symp* 2000; 230-234.

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