

EAHIL Workshop

Implementation of quality systems and certification of biomedical libraries

Palermo, June 23-25, 2005

SMIL – Scandinavian Medical Information for Laypersons

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The database

SMIL is a database of links to quality assessed web pages on medical information, understandable for laypersons, in the three Scandinavian languages: Swedish, Norwegian or Danish. URL: <http://www.smil.uio.no>

The information in the database can be retrieved by free text searching, or by browsing the subject headings. The words in the alphabetical list are in three different fonts: Main headings are in bold and subheadings are in normal font. References (synonyms) are in italics. When clicking a main heading, all subheadings related to the main heading are displayed.

It is possible to switch from one language to another at any time by clicking the flag-logos representing the three languages.

A record gives a short description of the web page, in addition to the title, author and URL. When clicking the URL, the web page will be displayed in a new window.

In 90% of the cases we get the full text article right away. We do not have to click any further to find the information we are looking for.

The project

Background and needs

1. In libraries and information centers we experience that patients and the general public are requesting information about diseases and conditions in their own language, and that it often is difficult or time consuming to find what they are asking for.
2. We all know that information on the Internet is not always of good quality.
3. Many libraries and organizations establish and maintain collections of links on their web-pages. A lot of duplicate work is being done.

The vision of the project was to create a common, easy-to-use gateway to quality assessed medical information in the three Scandinavian languages – which are different languages, but mutually understood.

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We wanted the information to be retrievable by free text searching and through a system of subject headings. The subject headings are very important because they enable retrieval of information in all three languages. Free text searching alone would only retrieve information in the other languages in the cases where the word searched is written identically in more than one language.

We put quality before quantity. Our ambition is not to make the database as big as possible.

A short history

In 2000 Eva Alopaeus and Elisabeth Husem prepared a project plan and sent applications for financial support to several parties.

In 2001 the project was granted 50 000 SEK, approximately 5700 Euro, by the Swedish Library Association, and a project group of 10 librarians and nurses from Sweden and Norway was established.

In 2002 we found a technical solution, we got a contribution of 3.280 Euro from the Nordic Council for Scientific Information and we got a participant from Finland.

Finland is involved in the project because of their minority of 300 000 Swedish-speaking people (5.6 % of the total population), and they contribute with high quality information which would be hard to find if it was not registered in SMIL.

Database registration started in December 2002 and SMIL was launched in Norway in January 2004.

Contents and extension

When the project group first met we had several topics to discuss. One was the contents and extension of the database, and we decided that we would focus on patient information, and to a lesser degree on more general consumer health information.

With “patient information” we mean information on diseases, disabilities, diagnostics and treatment. To make the information as readily accessible as possible, we agreed to mainly register web pages in the database.

However we do also register web sites: Homepages of organizations and institutions, newsletters, portals and so on.

The target group of the database is the general public, and therefore the name SMIL – Scandinavian Medical Information for Laypersons. And by the way: SMIL means smile.

The information suppliers for SMIL are non-profit and humanitarian organizations, governmental and other public institutions, like the National Social Insurance Office, hospitals and different centers, and commercial health information services.

Quality criteria

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We looked at different sets of quality criteria, and decided to adopt the then newly established criteria from the European Commission: “eEurope 2002: Quality Criteria for Health Related Websites”(1).

There are six elements in this set:

1. Transparency and honesty – which includes name of the provider and transparency of purpose and of all sources of funding.
2. Authority – which includes sources for information and name of information providers.
3. Privacy and data protection policy, and system for the processing of personal data.
4. Updating of information.
5. Accountability – which includes editorial policy, responsible partnering and facilities for user feed back.
6. Accessibility, such as readability and searchability. Only information free of cost is included in SMIL.

After more than two years of registration it is time to ask if the criteria are suitable for our purpose. We soon learned that quality assessment is not the same as quality assurance. When launching SMIL in Norway we described it as a database of quality assured links, but this was soon brought into question by the public.

The SMIL group does of course not have the competence to assure that all the information in all the web pages we register is accurate. That is why we need a set of criteria suitable for non-medicals. Unfortunately, studies show that information filling all of the criteria is not available in our languages (2-4).

Another study, by England and Nicholls 2004 (5), examined whether the Internet is a useful resource for people with celiac disease and whether transparency criteria can be used in identifying accurate sites. The surprising result of this study is that it found that there was no correlation between sites that scored highly for accuracy and those that scored highly for transparency. So what should we do? We still need criteria, but for two reasons they can not be absolute:

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1. No information fills all the criteria
2. Even if the information seems to be OK according to the criteria, it may be inaccurate.

So what we do when assessing the web pages for SMIL may be compared to the assessment a librarian does when guiding a user to web pages in the library. However, the assessment has a better chance of being of good quality when we don't have a user impatiently waiting by our side.

Another advantage is the fact that the work we do is saved in a database for others to use.

SMIL today

By June 2005 there are more than 6500 records in the database, and more importantly: There are more than 1400 different subject headings. There is information from Sweden, Norway, Denmark and Finland. Approximately 90% of the records are web pages, the rest are web sites.

Statistics show an increase in use. We now have approximately 1400 users daily. These are not unique users.

The vast majority of users come from Norway, with Sweden second, followed by Denmark and Finland. We also have occasional users from almost everywhere in the world.

SMIL is indexed by Google and the other major search engines, and an interesting question is to what degree users find their way to SMIL intentionally or accidentally.

We know that SMIL is well known in Norway and most public libraries and medical libraries and a lot of hospitals and other institutions have a link to SMIL on their web pages. In Norway we had nothing like SMIL before SMIL.

In Sweden, the other heavy contributor to the project, SMIL is not completely unique. That may be the reason why it is less known, less linked to, and less used than in Norway.

The statistics are difficult to read on this matter, but there is reason to believe that the majority of users find SMIL by way of the search engines.

Cooperation

The University of Oslo Library, Library of Medicine and Health Sciences is hosting the system and covers all costs in this connection.

The SMIL-group now includes 20 persons, of which 15 are registrators. All participants do the SMIL-work as part of their normal working hours.

The group meets once or twice a year – to discuss different topics and not least to maintain a personal network. Since we live far apart and mainly communicate by email, this is very important.

One person is responsible for the consistency of the indexing, and all new registrations must be approved by this person.

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Reference List

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