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Illustration of the diversity and heterogeneity in health information sources on Internet

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Abstract—In France, there are thousands of information sites dedicated to health. Ranging from the simple popularisation of medical facts to institutional sites, including sites for associations of patients and professionals, sites freely available or requiring a free or paid-for access code, medical Net is growing fast. Ranking these information sources is difficult because most of these sites present several of the above characteristics. For example, many of the sites originally intended for healthcare professionals are easily viewed by the public, where scientific articles can be readily found but which cannot be exploited by the layperson. In order to reduce the problems linked to the quality of information found on the internet, the Health ON the Net (HON) Foundation established a quality charter, the Hon Code, for health sites. Moreover, in the medical field the terminology used by authors is complex and each database has its own thesaurus and its own terminology.

Index Terms—health information, internet, quality, terminology

I. INTRODUCTION: THE DIVERSITY OF INFORMATION SOURCES ON INTERNET

THE attempt to classify what I am presenting here illustrates the difficulty involved in categorizing health Web sites, and thus the difficulty for an uninformed public to access to relevant, reliable, independent information, taking into account the latest scientific data productions. An attempt of categorization could be as follows:

- Search engines:

*Google of course! [1]

*SearchMedica.com, the "Google medical search engine", which declares itself as the search engine for doctors, but which can be consulted by everyone after registration. [2]

- **Consumer health portals:** A lot of advertising (health food, diet, beauty, etc.) and their forums, often a source of anxiety leading to Internetitis:

*Doctissimo (in collaboration with doctors) [3]

*Medisite (Internet in the service of health) [4]

*e-sante.fr (Your daily health) [5]

*SantéAZ (The world of health online) [6]...

- "**Professional**" health portals but accessible to all or with a large part for the general public:

*CISMEF (Rouen Hospital catalogue and index of French-speaking medical sites) with information intended for patients [7]

*Critical directory of sites of the BDSP (public health database), managed by EHESP (school for advanced studies in public health), accessible to all [8]

*Health On the Net (HON) is an NGO that can be accessed by professionals, patients and webmasters [9]

*RechercheSante.fr [10]

*Univadis, a truly professional website (medical registration number required) but sponsored by MSD laboratories, with free access, particularly to Vidal [11]

- Specialist health sites, databases:

*MedicFrance (public medicine portal, Thesorimed) [12]

*Thériaque (independent reference database) [13], Claude Bernard: drug database for professionals, but accessible to all after registration [14]

*EurekaSanté (particularly drugs: Vidal for everyone) [15]

- **Patient groups** whose aim is to support, inform and defend their interests:

*AFD (French Association for Diabetics) [16]

*Asthma and Allergy [17]

*Orphanet (the portal for rare diseases and orphan drugs, international site) [18]

- Institutional sites:

*AMELI [19], WHO [20], HAS (French health authorities) [21], AFSSAPS [22], Pasteur Institute [23], etc

*Pharmaceutical industry: the very powerful pharmaceutical industry lobby [24]

- Bibliographic databases:

*Free access: dozens listed in the CISMEF [7]

PubMed-Medline (the most used non-exhaustive, MesH little used by doctors) [25], Banque de Données de Santé

Publique [26], Toxibase [27], Nosobase [28], Pharmadoc [29], etc

Access to a number of scientific journal articles freely available to the public

*Access fee: Embase-Elsevier (European Medline), Pascal, International Pharmaceutical Abstracts, Cochrane, Web of Sciences, ScienceDirect-Elsevier, accessible to researchers from universities and research organizations.

Ultimately, there are RISKS:

*For the public: many heterogeneous information sources, uneven in quality, not always up to date and mostly accessible free of charge, hence a significant risk of persons seeking information about their health, but without the ability to discriminate.

*For health professionals (and therefore patients): little training in documentary research (no systematic exhaustive search, poorly developed search strategies, lack of critical thinking on the origin of the information and the aim of the author, which may present a conflict of (pharmaceutical industry) interest)..

II. A CODE OF CONDUCT: THE HONCODE OF THE HEALTH ON THE NET FOUNDATION [9]

The Health On the Net Foundation is the leading organization promoting and providing online information about health and drugs, as well as their appropriate and effective use. Founded in 1995, HON is a non-governmental, non-profit making organization, accredited by the United Nations Economic and Social Council. For twelve years, HON has focused on one key issue, providing health information to citizens, information that respects their code of ethics. To cope with the amount of health information available online, the HON Code of conduct provides a varied consensus on the standards to protect citizens from misleading health information

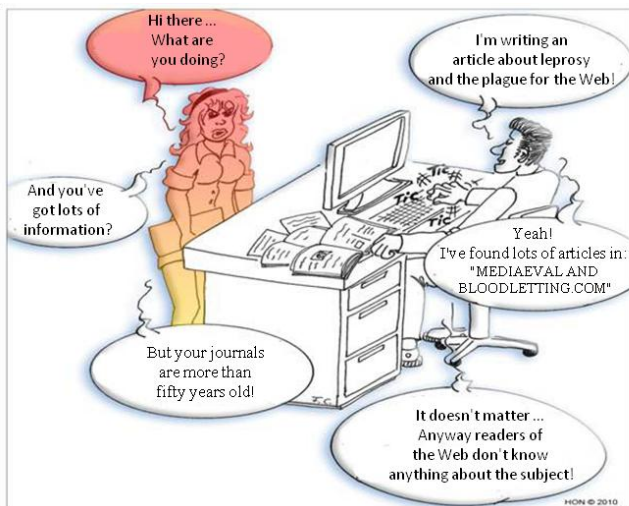


Figure 1: a joke on the quality of health information on the Internet by HON

The HONcode is a quality charter developed by the Health On the Net Foundation and adopted in France by the Health Authorities in 2007. It addresses the public demand for a site webmaster for medical health. Created in 1995, it has continued to grow to become the most widely used and most popular ethical code for health websites:

A health site with the HONcode "label" has the following logo on its homepage :



Figure 2: the HON Code "label"

The HONcode addresses one of the key issues on the Internet: reliability and credibility of the medical and health information. HONcode certification is free of charge. The certification conducted by HON involves a thorough evaluation of the websites, based on application of the HONcode. There is ongoing monitoring throughout the year and a systematic annual review of HONcode certified sites.

The HONcode is not a system that rewards sites. The fact that the site is not certified does not mean that it is of poor quality.

The HONcode - Eight quality criteria:

A. *Authoritative*

Indicate the qualifications of the authors

Any medical or health advice provided and hosted on this site will only be given by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a non-medically qualified individual or organisation.

B. *Complementarity*

Information should support, not replace, the doctor-patient relationship.

The information provided on this site is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her existing physician.

C. *Privacy*

Respect the privacy and confidentiality of personal data submitted to the site by the visitor.

Confidentiality of data relating to individual patients and visitors to a medical/health Web site, including their identity, is respected by this Web site. The Web site owners undertake to honour or exceed the legal requirements of medical/health information privacy that apply in the country and state where the Web site and mirror sites are located.

D. Attribution

Cite the source(s) of published information, date and medical and health pages.

Where appropriate, information contained on this site will be supported by clear references to source data and, where possible, have specific HTML links to that data. The date when a clinical page was last modified will be clearly displayed (e.g. at the bottom of the page).

E. Justifiability

Site must back up claims relating to benefits and performance. Any claims relating to the benefits/performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in Principle 4.

F. Transparency

Accessible presentation, accurate email contact. The designers of this Web site will seek to provide information in the clearest possible manner and provide contact addresses for visitors that seek further information or support. The Webmaster will display his/her E-mail address clearly throughout the Web site.

G. Financial disclosure

Identify funding sources. Support for this Web site will be clearly identified, including the identities of commercial and non-commercial organisations that have contributed funding, services or material for the site.

H. Advertising policy

Clearly distinguish advertising from editorial content. If advertising is a source of funding it will be clearly stated. A brief description of the advertising policy adopted by the Web site owners will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.

Another way to illustrate the heterogeneity of health information on the Internet and its difficulty of access can be achieved by comparing the different thesaurus databases

III. HETEROGENEITY OF TERMINOLOGY USED BY THE DOCUMENTATION TOOLS

In the medical field, the terminology used by authors is complex, superfluous and not very standardized, hence creating difficulties in documentary research:

- Synonyms: beta-blocking agent, beta-blocker, beta-adrenergic, beta-inhibitor

- In writing: betablocking agent, betablocker, beta adrenergic, beta inhibitor
β-blocking agent, β-blocker, β-adrenergic, β-inhibitor

So, fairly elaborate thesauri have been developed for the databases. However, these still remain complex to use by researchers seeking specific information. Furthermore, each database has its own thesaurus and its own terminology.

I present here an illustration using the term "ANTIBIOTIQUE".

*MeSH for Medline, also used by CISMEF in its French version:

Terme en français :
antibactériens

Terme en anglais :
anti-bacterial agents [NLM](#)

Définitions :
- **MeSH en anglais :** Substances that reduce the growth or reproduction of BACTERIA.
- **Vidal de la famille :** Substance capable de tuer certaines bactéries. Le spectre d'un antibiotique est l'ensemble des bactéries sur lesquelles ce produit est habituellement actif. Contrairement aux bactéries, les virus sont toujours insensibles aux antibiotiques. Les premiers antibiotiques furent extraits de cultures de champignons : pénicillium (pénicilline), streptomycetes (streptomycine). Ils sont actuellement fabriqués par synthèse chimique. Les antibiotiques sont divisés en familles : pénicillines, céphalosporines, macrolides, tétracyclines (cyclines), sulfamides, aminosides, lincosanides, phénicolés, polymyxines, quinolones, imidazolés. Un usage inapproprié des antibiotiques peut favoriser l'apparition de résistances : n'utilisez un antibiotique que sur prescription médicale, respectez sa posologie et sa durée, ne donnez pas et ne conseillez pas un antibiotique que l'on vous a prescrit à une autre personne.

- **FNCLCC :** Définition

Synonyme(s) CISMef :
ab; antibiotiques peptidiques; ATB

Synonyme(s) MeSH Français :
Agents antibactériens; Agents antibiotiques; Agents antimycobactériens; Agents bactéricides; Anti-bactériens; Antibiotiques; Anti-mycobactériens; Antimycobactériens; Bactéricides; Médicaments antibactériens; Médicaments antibiotiques; Médicaments antimycobactériens; Médicaments bactéricides

Synonyme(s) MeSH Anglais :
agents, anti-bacterial; agents, antibacterial; agents, anti-mycobacterial; agents, antimycobacterial; agents, bacteriocidal; anti bacterial agents; anti mycobacterial agents; antibacterial agents; antibiotics; anti-mycobacterial agents; antimycobacterial agents; bacteriocidal agents; bacteriocides

[Produits chimiques, biologiques et pharmaceutiques]

- actions chimiques et utilisations **CISMef26022**
- actions pharmacologiques **CISMef21583**
- utilisations thérapeutiques **CISMef17928**
- anti-infectieux **CISMef4688**
 - anti-infectieux locaux **CISMef492**
 - anti-infectieux urinaires **CISMef95**
- antibactériens **CISMef1947**
 - antibiotiques antituberculeux **CISMef37**
 - antituberculeux **CISMef35**
 - antituberculeux **CISMef**
 - antituberculeux + **CISMef138**
- antifongiques **CISMef630**
- antiparasitaires + **CISMef424**
- antiviraux + **CISMef918**
- désinfectants + **CISMef375**

Figure 3: example of vocabulary of MesSH used by CISMEF in French.

*Emtree for Embase (Elsevier), paid access, not available:

Table 1: information given by Elsevier

Emtree	Mesh	Emtree value (for the user)
“Natural language terminology” (e.g. <i>myeloid leukemia</i>)	Has many “inverted terms” (e.g. <i>leukemia, myeloid</i>)	Intuitive and recognizable terms for ease of use
Has more than 230,000 synonyms (incl. over 144,000 drug synonyms)	Has far fewer synonyms (exact number unknown)	High probability that term used by user is in Emtree
Includes all MeSH terms (many as synonyms)		Emtree can easily be used by MeSH users
Relies upon “meaning” invested in terms by authors using them	Has many scope notes to describe how terms are used	No dependence on or need to look up scope notes
Larger (over 56,000 preferred terms)	Smaller (ca. 24,000 preferred terms)	Best chance of finding both drug and non-drug terminology

*The BDSP thesaurus:

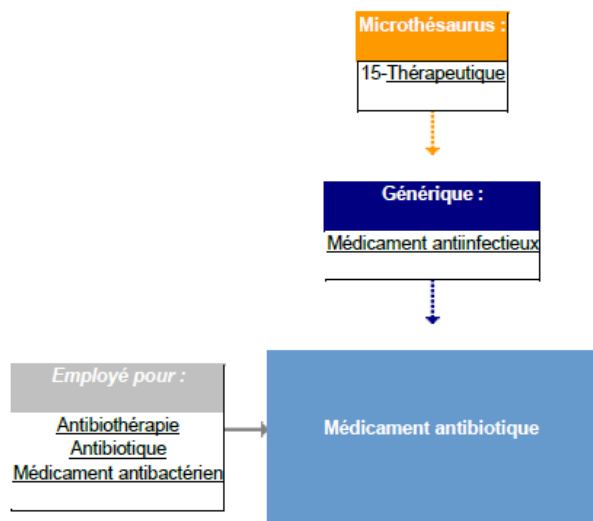


Figure 4: : example of vocabulary of BDSP

*Nosobase

AGENT ANTI-INFECTIEUX Spécifique ANTIBIOTIQUE
 ANTIBIOTHERAPIE Préférentiel ANTIBIOTIQUE
 ANTIBIOTIQUE Spécifique ACIDE FUSIDIQUE
 ANTIBIOTIQUE Spécifique AMINOSIDE
 AMINOGLYCOSIDE Préférentiel AMINOSID
 ANTIBIOTIQUE Spécifique BETALACTAMINE
 BETALACTAMINE Spécifique PENICILLINE
 PENICILLINE Spécifique CARBOXYPENICILLINE
 PENICILLINE Spécifique UREIDOPENICILLINE
 BETALACTAMINE Spécifique CARBAPENEME
 BETALACTAMINE Spécifique MONOBACTAME
 BETALACTAMINE Spécifique CEPHALOSPORINE
 CEPHALOSPORINE Spécifique CEPHALOSPORINE
 PREMIERE GENERATION
 CEPHALOSPORINE Spécifique CEPHALOSPORINE
 DEUXIEME GENERATION
 CEPHALOSPORINE Spécifique CEPHALOSPORINE
 TROISIEME GENERATION
 ANTIBIOTIQUE Spécifique FOSFOMYCINE
 ANTIBIOTIQUE Spécifique GLYCOPEPTIDE
 GLYCOPEPTIDE Spécifique VANCOMYCINE
 ANTIBIOTIQUE Spécifique LINCOSAMIDE
 ANTIBIOTIQUE Spécifique MACROLIDE
 ANTIBIOTIQUE Spécifique NITROFURANE
 ANTIBIOTIQUE Spécifique NITRO-IMIDAZOLE
 ANTIBIOTIQUE Spécifique NOVOBIOCINE
 ANTIBIOTIQUE Spécifique PHENICOLE
 PHENICOL Préférentiel PHENICOLE
 ANTIBIOTIQUE Spécifique POLYMYXINE
 ANTIBIOTIQUE Spécifique POLYPEPTIDE
 ANTIBIOTIQUE Spécifique QUINOLONE
 QUINOLONE Spécifique FLUOROQUINOLONE
 QUINOLONE Spécifique QUINOLONE DE PREMIERE
 GENERATION
 ANTIBIOTIQUE Spécifique RIFAMYCINE
 ANTIBIOTIQUE Spécifique SYNERGISTINE
 STREPTOGRAMINE Préférentiel SYNERGISTINE
 ANTIBIOTIQUE Spécifique SULFAMIDE
 SULFANAMIDE Spécifique SULFAMIDE +
 TRIMETHOPRIME
 ANTIBIOTIQUE Spécifique TETRACYCLINE
 ANTIBIOTIQUE Spécifique INHIBITEUR DE BETA-
 LACTAMASE

*The Toxibase thesaurus:

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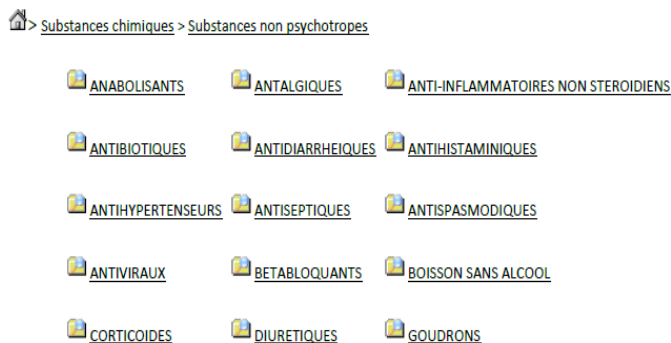


Figure 5: example of vocabulary of Toxibase

*Pharmadoc and Thériaque

ANTIBACTERIAL ANTIBIOTIC

This examples of heterogeneous terminologies used by different databases can explain the difficulties to find health information in databases. One solution could be that each health database take systematically the Mesh thesaurus and adapt it to its microfield if necessary.

IV. CONCLUSION

Through these few examples, it should be clear to everyone that the diversity and variety of documentary sources, and the lack of standardization of terminology in the field of health, pose a major problem for access to reliable, comprehensive information taking into account the latest scientific advances. Whether it is the general public, professionals of information or health, all benefit greatly from the pooling of documentation tools and procedures. This would undoubtedly provide better access to health information, and thus better support for the health of every sick person.

[add references here]

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