

## **S6 : Web 2.0 and rare diseases : 13 mn**

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*In the early 2000s, new technologies and tools, like blogs, wikis, RSS, allowing more interactivity, information sharing, user participation, became popular on the Internet.*

*It was then suggested that the Web had initiated a new model, a second version, compared to Web 1.0, the original Web, more static. The term Web 2.0 was coined by Tim O'Reilly, a multimedia editor in the U.S., and defined as "a set of economic, social, and technology trends...characterized by user participation, openness, and network effects".*

### **S6.1 : Health 2.0 and Medicine 2.0**

#### **Définition**

*Between the two terms, little or no differences, according to medical literature reviews.*

*Health 2.0 and Medicine 2.0 can be defined as a set of services or tools, designed for patients, consumers, and health professionals, that use Web 2.0 technologies, like blogs and wikis, to allow interaction, real time information, exchange and share, collaboration, user generated content, for a better healthcare.*

#### **Web 2.0 tools : characteristics and examples**

##### **Interaction**

*Modern websites are more and more dynamic through interactive features with their users who can post comments on published articles.*

*RareDiseaseBlogs, the tool created by Eurordis and NORD, the U.S. National Organization for Rare Disorders aims to put online opinions of international leaders in the field of rare diseases and orphan drugs in order to develop interaction with the public.*

*A list of medical blogs can be found on Medworm website.*

##### **Real time information**

*Patients and health professionals, who need to keep up to date with the latest medical information, can use pushing devices like RSS.*

*RSS, which stands for Really Simple Syndication, is an easy-to-use technology which delivers real time information to a user's computer through a RSS reader, generally included in most browsers, like Firefox or Internet Explorer.*

*Pubmed provides such a service, helpful to stay tuned on the latest scientific articles.*

*Medworm proposes thousands of RSS feeds from medical websites and blogs.*

##### **Information exchange**

*Internet mailing lists are places where patients and families can discuss, by e-mail, about their problems, exchange their experiences, break their isolation, and find support. Working as an electronic form of support groups, they also provide members with useful and expert information.*

*Between 2006 and 2008, Eurordis launched 25 mailing lists concerning rare diseases and developed a Charter of good practice to optimize their management.*

##### **Share**

*Bookmarking and sharing information is less known than sharing photos or videos, but may be very helpful.*

*An example with this function on Orphanet. For each page, as for Fabry disease, a simple click on a Bookmark and Share icon adds the content to a social network like Facebook or to tagging and sharing tools, like Delicious.*

##### **Collaboration**

*The most popular collaboration tools are wikis, which are websites open to a community of authors. As anybody can contribute to a wiki like Wikipedia, the quality of the information may be low for some entries.*

*That's why wikis created by associations or health professionals are a source of relevant information as they use a closed environment, allowing editing only to selected and trustworthy authors.*

*For example, the two wikis from Genetic Alliance, a nonprofit advocacy in the U.S. : WikiGenetics, an encyclopaedia in lay language, and WikiAdvocacy, covering all aspects of managing an advocacy organization.*

*Medpedia is a free medical encyclopaedia where content is written by health experts, and where patients are invited to suggest changes based on their personal experiences.*

#### **Content and Quality**

*All these Web 2.0 tools gave the opportunity to create new forms of health content, directly produced by patients, families, associations, the **user-generated-content**.*

*But the open editing process of most wikis or the lack of scientific expertise from mailing lists subscribers clearly point the quality issue of this type of content and the risks of inaccurate, misleading and even harmful information.*

*However, scientific studies on cancer mailing lists showed that such tools could be self-regulated, most false statements being quickly corrected thanks to the combined knowledge of the whole subscribers.*

*A recent review of Wikipedia versus the online Encyclopaedia Britannica showed that similar amounts of errors were found in both of them.*

*In fact, user-generated-content, based on patients' expertise, tends to become a complement to health professionals' knowledge for providing a better healthcare.*

#### **Web 2.0 and innovation for healthcare**

*Web 2.0 applications lead to four major innovations for healthcare :*

*New patterns in information access*

*Reducing inequities between patients and health professionals*

*Patient empowerment*

*Social Networking*

##### **New patterns in information access**

*For patients, the traditional way for accessing to medical information goes through health professionals. A second possibility is to directly search on the Web.*

*Web 2.0 tools allow a new approach to identify information from blogs, wikis, or communication tools thanks to the experience, the expertise of other patients.*

##### **Reducing inequities**

*Open access to specialized information, for example on clinical research, RSS feeds help to reduce the asymmetry in the access to information between patients and health professionals. Such openness leads to more transparency in the information delivered to patients by health professionals.*

##### **Patient empowerment**

*Easier access to information and modified relationship with doctors help patients better understand the different care options. Patients are then more actively involved in all aspects of their care.*

*Patient empowerment due to Web 2.0 technologies lead to the emergence of participatory medicine in which "networked patients shift from being mere passengers to responsible drivers of their health".*

### **Social Networking**

*Social networks of persons or organizations, linked through social relationships or common interests, allow users to share ideas, activities or events with no specific discussion topic defined. On the Internet, they had become popular since the launching of Facebook, in 2004. Many patients' groups now exist on social networking sites. For example, Eurordis' Facebook group, counting about 1700 members.*

*A recent publication identified four main motivations for creating a social network : fundraising (45 %), awareness (38 %), support, and promote-a-site, to increase the visibility of a website.*

## **S6.2 : Social networks and online communities for rare diseases**

### **Social networks vs Online communities**

*On the first sight, Online communities look like social networks, they are "virtual social spaces where people come together to get and give information or support, to learn or to meet others", but online communities differ from social networks on three points :*

*a precise objective is defined : information exchange about a disease, psychological support,...*

*the membership system, with a controlled registration, allows the creation of a fairly close group in communities, roles gradually become defined among the subscribers. For example, animators, who post very frequently, and supply the group with information, "online patient helpers", who have an expert knowledge of their condition and go online to help other patients.*

*Here are two examples of online communities for rare diseases.*

### **Patients like me**

*PatientsLikeMe is a health data-sharing platform, launched in 2005, where members can enter their clinical data, describe their symptoms and treatments in natural language, in order to connect with patients like them, share their experiences, learn from others' outcomes.*

*The collected data are aggregated into reports. For example, on treatments, like Copaxone, a drug for multiple sclerosis. Access to most aggregated data and patients' profiles is open to any user of the site.*

*This project suggests how patients who choose to share health data within a community may benefit from the process.*

### **RareConnect**

*RareConnect, created by Eurordis, aims at connecting patients, families affected by a rare disease. The website is organized into disease specific communities. A set of features is implemented : testimonies from patients and families, communication tools, medical articles by experts, latest news from research,...*

*Two differences with social networks like Facebook : Eurordis RareConnect is independant from commercial interests and the exchanges between patients comply with Eurordis' Charter of good practice for discussion lists developed by a group of experts.*

*Patients are becoming more and more experts on their own disease. So the challenge of Eurordis RareConnect is to aggregate health professionals knowledge with patients' expertise in order to improve research, care, daily quality of life and contribute to scientific progress.*