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# Online communication of patients with rare diseases in Spain

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## Abstract

**Introduction:** This article presents the results of a study of the communication strategies used by organisations of patients with rare diseases on the internet. **Objective:** Identify the communication tools these organisations use in the internet to gain social and media visibility and to enable interaction between patients and families. **Methods:** The study is based on the content analysis of the websites, social networks and blogs of 143 national organisations of patients with rare diseases. In addition, 90 organisations of patients with rare diseases, which represented 63% of the sample of institutions, were interviewed via telephone. **Results:** 84% of the websites are managed by the organisations’ members, who lack specific training, and only the rest, 16%, are managed by professionals. The communication carried out on the internet by these organisations, be it on websites, social networks or blogs, target patients and their loved ones as well as the rest of the population with similar intensity. However, these organisations do not use tools that enable a more fluid communication for their members. **Discussion and Conclusions:** The results highlight the need for specialised staff and online spaces to communicate with media professionals and the rest of the population.

### **Keywords**

Rare diseases; health 2.0; web; blog, social networks and communication tools.

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Translation by **CA Martínez-Arcos** (PhD in Communication from the University of London)

## **1. Introduction. Patients with rare diseases and the importance of their organisations**

The concept of rare diseases appeared for the first time in the mid-1980s in the United States of America. Most of the diseases considered as rare are caused by genetic defects, although environmental causes are also possible. The first Programme of Community Action on Rare Diseases, of December 1999, defined “rare diseases” as “all those diseases with a prevalence under 5 cases for every 10,000 inhabitants in the European Community” (Posada, 2008:10). According to the World Health Organisation (WHO), there are about 7,000 rare diseases that affect 7% of the population. According to the Spanish Federation of Rare Diseases (FEDER), there are more than three million people with rare diseases in Spain.

Since the Government of Spain declared 2013 the Spanish Year for Rare Diseases, organisations of patients with these types of diseases have carried out intensive work in the area of communication. Through different communication platforms, people with rare diseases seek to educate and inform about these diseases, raise awareness of their problems and gain social legitimation to make their demands visible.

For people with rare diseases the internet is becoming the ideal medium to successfully carry out communication strategies as this medium breaks geographical barriers, can reach a large percentage of the population, and allows any content to reach any user immediately. In addition, communication campaigns in the internet do not require large budgets. Online communication campaigns, through social networks, crowdfunding or video websites like YouTube, can be an effective way to offer effective information to people with rare diseases and the rest of the population, and to request support for research.

### 1.1. Web 2.0 and e-health

The term Web 2.0 was introduced in 2004 by O'Reilly, who defined it as “a set of economic, social and technology trends that collectively form the basis for the next generation of the Internet -a more mature, distinctive medium characterized by user participation, openness and network effects” (quoted by Uribe, 2011: 7).

There are authors who consider that the main feature of the Web 2.0 is user involvement:

“The real revolution is the conception of the user: we have ceased to refer to users as consumers of information and have begun to acknowledge their participatory character in the production and management of content. This change is due to the development of the principles of radical trust on and use of the collective intelligence” (Cabrera, 2013: 30).

The Web 2.0 has its greatest exponent in the field of health based on the concept of knowledge generation, through collective intelligence and collaboration. Patients are the cornerstone of the evolution in communication and knowledge, and the development of new technologies has made this possible. A concept closely related to the rise and mass use of the internet in the field of health in recent years is “health 2.0”.

This research study focuses on the communication of the patients of rare diseases in the field of health 2.0 or e-health. In this regard, Basagoiti (2009:1) has considered that:

“The key aspect of the “revolution” constituted by the Internet, is issues such as the accessibility to information and resources, which is drastically reducing inequities caused by geographical, cultural, and organisational barriers.”

With regards to the use of the social web (Web 2.0) in the scientific community, in particular in hospitals, Zurbarán (2010) points out that: “52% of hospitals have websites while 14% use social networks” (2010: 4). The importance of the use of ICT is interesting for those governmental institutions and professionals that need more sophisticated tools to promote health communication.

“The development of activities in favour of health, education, training, e-consultation and research that may subsequently be applied in real life are some examples that open up a new world of possibilities that should result in a better health experience for internet users in general and for healthcare professionals and patients who can find in the internet a complementary tool in their daily activities” (Mayer and Lais, 2010:295).

Internet has strengthened ties between the medical community and patients, but it is necessary to achieve a new challenge: improve the communication 2.0 between organisations of patients with the rest of users, citizens and administrations. Fornieles and Bañón (2011) highlight the role of the Internet in the field of health, which has allowed the dissemination of information on diseases and has helped patients to share experiences and information. Despite advances, both authors considered

the achievements have been insufficient, since the population, in general terms, is unaware of these diseases.

Another important factor is that the patient has changed its profile as a result of the emergence of new technologies. According to the *White Paper on Medical Oncology in Spain*, the new patient profile corresponds to a user with a higher education level, a culture of consumer's rights, and greater access to health information published on the internet and the media (Muñiz *et al.*, 2007: 53).

Armayones and Hernández (2007) consider the internet is evolving to what they term the web 3.0, which is a more effective medium in the field of health, and particularly in the search and dissemination of information about diseases. The “counsellor” has emerged in the internet as a new element of e-health to support those people who have been diagnosed and do not find support in the physical world not information on what to expect in the not-too-distant future. The authors analyse some of the possibilities of the medium, like the application of virtual worlds such as *Second Life* and *Cyworld* to the field of health.

Torrente, Escarabill and Martí (2010) highlight the importance of these virtual spaces in this area, which offer people with specific health problems the opportunity to share experiences and to seek, receive and provide information, advice and even emotional support online. The authors refer to virtual health communities, online support groups, and varying organisational structures that do not depend on a single criterion (profile and number of members, purpose, activities, rules of access, etc.) but change according to existing networks. For patients and family members there is an emotional need because they feel isolated and discriminated against, even by the health system, given the lack of knowledge of the diseases even among medical professionals [1]. Although the use of virtual spaces by patients does not solve patients' basic deficiencies, it does respond to their needs for information and emotional support, because it encourages empathy with other patients who suffer from the same anguish and lack of information, support and understanding.

## 1.2. The evolution of communication tools in the digital era

The evolution of these organisations in the field of communication is linked to their use of communication tools on the internet. Among the new modalities of interaction with users and media professionals are the virtual press rooms which, according to Castillo and Almansa (2011: 136), “are defined as networked communicative spaces that contain tools and activities directed at media organisations”.

Press rooms facilitate and enhance communication between organisations and media professionals, but their use by patients has not developed due to lack of resources or knowledge.

The use of multimedia resources, such as the online video, is useful for the promotion of information exchange and empowerment among patients. Gabarrón and Fernández-Luque (2012: 197) discuss the use of the online video for the promotion of health and highlight the advantages of online platforms, such as their low cost and immediacy. Among the downsides are the lack of rigour and quality.

“In many cases you cannot identify the author of the video, its sources are not cited, personal opinions are presented as scientific facts and some aspects remain unanswered, so it may be difficult for users to rate the quality of its contents.”

This problem could be avoided by following guidelines and recommendations, such as those created by autonomous institutions such as those of Andalusia, and by international institutions like the US Centres for Disease Control and Prevention. The researchers identified 6,032 health-related videos in YouTube, and the 20 associations of patients with more viewed videos include the Spanish Association against Cancer and the Heart and Diabetes foundations.

Sánchez Blas *et al.* (2012) claim that 80% of Americans who use the internet seek health information and 25% has played online videos related to this field. In Spain, a study conducted by the consulting firm The Cocktail Analysis, in 2013 [2], for the biomedical company Pfizer, points out that “80% of Spanish internet users seek information to resolve their doubts about health and that the internet is, therefore, the first source of consultation among users”.

Patients need information, to share experiences, exchange and disseminate messages and in this sense the online video is one of the most attractive alternatives.

### **1.3. The empowerment of patients**

Potts (2008) argues that users of the knowledge society, and in particular the users of e-health, evolve more quickly than researchers and service providers. The author claims that in the United States there are more than ten million people taking part in online support groups that share resources.

As Muturi (2005:81) [3] emphasises, “communication empowers people by providing them with Knowledge and understanding about specific health problems and interventions”.

Patients with rare diseases are key to advancements in research and to the dissemination and exchange of information between patients and the scientific community. Especially, if we take into account that the majority of patients live far from one another, there are very few in the same area or country, there are few scientific works about their diseases and sometimes it is necessary to hear the support of other patients or family members to cope with the disease.

Rabeharisoa and Callon (2002:171) emphasise the role of the associations that promote the creation of “groups of mutual aid, the growing recognition of patients and their more active participation in the design of services targeting them”.

Therefore, these associations are fighting to make rare disease un-rare, at least in the eyes of the public administrations and other citizens, who are unaware of their symptoms, possible treatments and consequences. The empowerment of these groups is needed to achieve their goals and 2013 was the year to achieve two of the main objectives: to increase the visibility of these patients and obtain funding for research.

Moya (2012: 186) highlights the principle of subsidiarity in the empowerment of patients with rare diseases in Argentina. This concept is understood as the way to help those who need it the most and spending more on the sickest patients and those for whom the actions of patients themselves is key:

“People with rare diseases contribute to the optimisation of diagnostics, research, health care, treatment and the social integration of patients. Subsidiarity facilitates the establishment and development of values such as the promotion of health, respect for rights, equity and social justice in communities, through the recognition of their disease, education and the right to engage in their health care.”

Calvillo *et al.* (2013) identified different degrees of empowerment in patients. The first degree occurs when patients are informed by doctors and are aware of their health condition. The second degree occurs when the patients are more active, in terms of treatment, maintenance and prevention of potential risks. The third degree occurs when patients are trained in health, knowledge is democratised and patient and doctor work together on the same level. In the fourth degree patients are not only the recipients of information, but also sources of information. A new concept of empowerment arises from the moment in which their patients’ health experiences serve to help others.

The empowerment of patients is achieved through communication. Different strategies and the correct use of the communication tools can generate that needed attention so that the public administrations and citizens become aware of patients’ needs and their issues. This is how we achieve a higher degree of empowerment, in which patients are not only sources of information, but also encourage other citizens and patients to change their situation through of information and awareness or, in short, through communication.

Patients are a source of knowledge and their active and collaborative attitude influences developments in medical research. People with rare diseases and their families are carrying out vital work to collect information on these diseases and to share them with other patients and even the scientific community. Knowing how to manage all this information, how to transmit it and how to make it attractive to the media professionals is a priority so that patients with rare diseases can gain greater visibility and improve their public image.

The Spanish Federation of Rare Diseases has consolidated itself after 15 years of hard work, but most of the associations have very few members, which are usually patients or their family members and they usually hire poorly qualified personnel to manage communication.

Managing and disseminating information is a pending task for these organisations that aim to reach all citizens through various channels.

The empowerment of citizens through social networks in the field of health is a phenomenon that is acquiring increasing strength, given that the active patient and technologies complement each other to create a new concept: e-health. According to Eysenbach (2000:1-2):

“E-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology”.

## 2. Objectives

1. To know the extent to what organisations of patients with rare disease use communication tools on the internet.
2. To analyse the use of communication tools to achieve social and media visibility and to enable interaction between patients and families.
3. To study the degree of implementation of communication strategies 2.0 through social networks.

## 3. Methods

The population surveyed is composed of 143 organisations registered in the database of the National Reference Care Centre for People with Rare Diseases (CREER). The response rate to the invitation to participate in the telephone survey was 63%.

The study is based on the content analysis of each of the associations' websites, social network accounts and blogs. To complement the content analysis, we carried out telephone interviews. The questionnaire used for the interview was composed of multiple-choice and closed questions based on

a “reverse funnel sequence, in which basic questions are asked first and the details and associated ideas are posed at the end, to facilitate interviewees’ reasoning” (Ferrando, 1996: 171).

In addition, after identifying which associations had their own website, blog and social network accounts, we examined who managed the communication activities in these spaces, the target population, the number of followers and the published content (quantity and type). The analysis involved crossing the data of the analysis of the organisations’ online presence and the respective answers to the questions about their structures and communication strategies.

Content analysis focused on exploring the web-based communication tools, taking into account the following variables and categories related to communication 2.0:

- Type of website (1.0, 2.0)
- Requirement of user’s registration.
- Use of press rooms and communication resources (news, press releases, magazines, press dossiers).
- Use of audiovisual resources (pictures, videos, YouTube channels).
- Use of Really Simple Syndication (RSS).
- Access to forums.
- Presence in social networks and use of blogs.

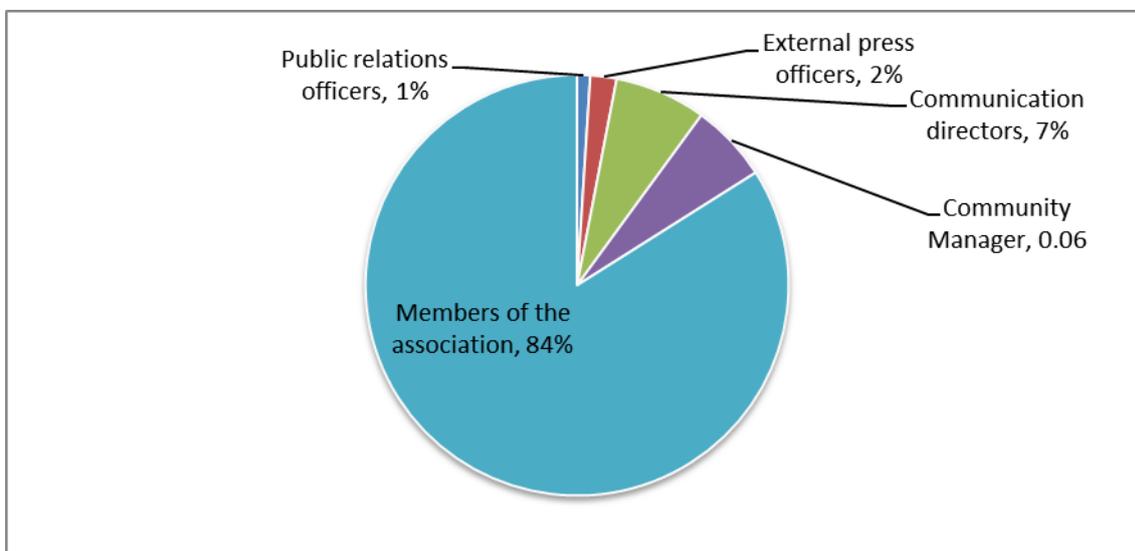
## 4. Results

### 4.1. The websites of organisations of patients with rare diseases

The first finding from the initial analysis is that 82% of the organisations has a working website. Despite the scarce economic resources of these entities, 58% has a website 2.0 while 24% continues to use the web 1.0.

Of the organisations, 84% manages the website and the communication activities by themselves, while the rest, 16%, hires professionals to perform these functions, which is divided in the following professions: public relations, communications director, community manager and external press office, as shown in Figure 1.

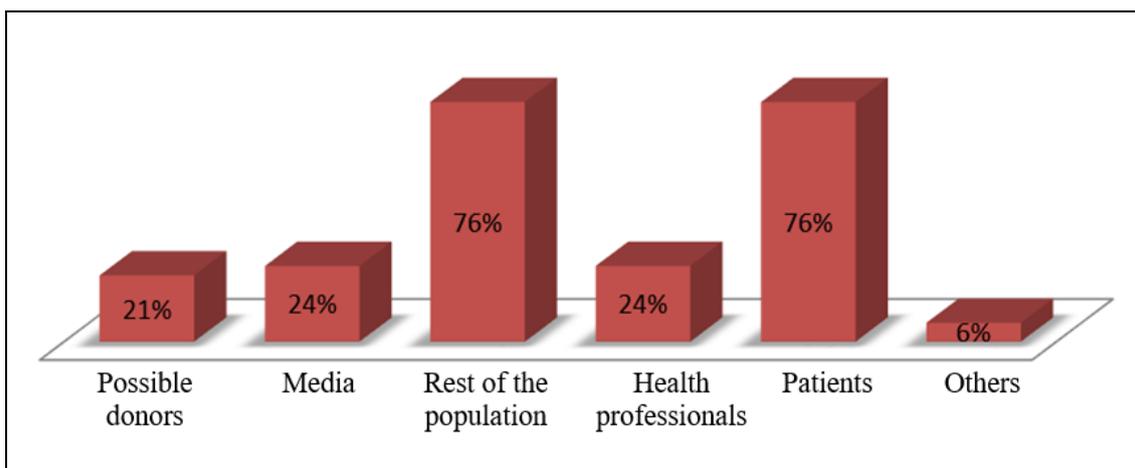
**Figure 1. Websites' communication management**



Source: Authors' own creation

Of the 16% of professionals who management communication activities, 69% are employees and 31% are volunteers.

**Figure 2. Targets of the information**



Source: Authors' own creation

30% of the websites request users to register, 37% use forums to exchange information, and 11% of these forums are open to the rest of users. The organisations tend to use email and forums restricted to members to communicate more sensitive issues related to the rare diseases, and use the traditional channels, email and phone, to deliver official communications.

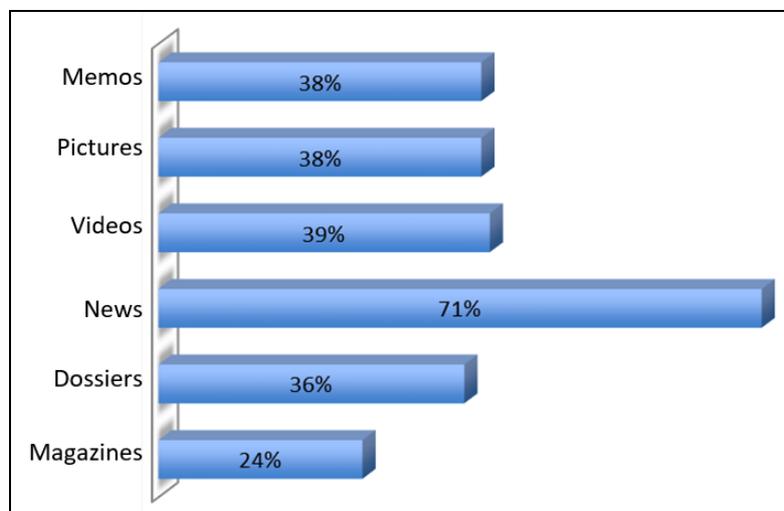
In the websites and social networks the organisations mainly target patients, their relatives and the population in general. The media and medical professionals are targeted to a lower degree, followed by potential donors and other sectors, as shown in figure 2.

#### 4.1.1. Use of communication tools

There is a very low percentage of press rooms: only 21% of the websites use them to communicate with the media. In addition, 1% of the websites have restricted access to these rooms.

The communication tools most used by these associations are the news stories on rare diseases, which are collected to make dossiers to be distribute them in the media. Other tools are used by around 30% of the associations, as shown in Figure 3.

**Figure 3. Communication tools**



Source: Authors' own creation

The percentage of the institutions that offers RSS in their websites to organise or share content on the web stands at 20%, while only 3% indicates that their website is accessible to people with disabilities.

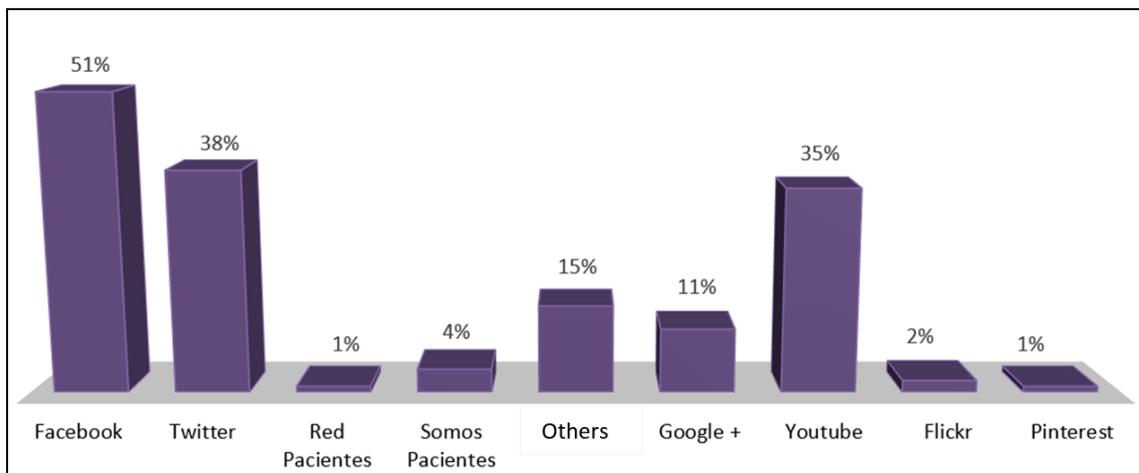
#### 4.2. Presence of organisations in social networks and blogs

More than half of the organisations of patients, 55%, prefer to use social networks. Of this percentage, 80% are managed by members of these organisations, while the rests is managed by external professionals: 8% by communication directors, 8% by community managers and 4% by other professionals.

The main reasons to use social networks are: to enable the provision of support among patients (74% of respondents) and to exchange information (63%), followed by connection with society (56%) and to establish contact with the media (28%). The main reasons some associations do not use social networks are the lack of resources and staff (73%) and the lack of time to manage them (64%).

Facebook is the most used social network, as half of these associations (51%) use it. The second most used network is Twitter with 38% and YouTube with 35%. 15% of these organisations uses other networks such as Rareconnect, Guiametabólica, RareShare and similar networks with the same goal. The whole distribution is shown in Figure 4.

**Figure 4. Social networks used by organisations of patients with rare diseases**



Source: Authors' own creation

These associations publish more frequently on Facebook. 38% of respondents said they post content on Facebook every two or three days, while 33% post on Twitter, between 10 and 20 times per month. Another network that used a lot is YouTube: 90% of YouTube users publish less than 5 videos per month due to the complexity involved in the creation of audiovisual content.

49% of these associations have more than 500 followers on social networks, while only 5% have less than 50.

29% of the associations uses blogs. 85% of these blogs are managed by members of these associations while the rest, 15%, are managed by communication specialists (11% are communication directors, 2% are other professionals, and 3% are community managers). The content reflects the experiences of fully-identified patients, which are narrated by patients themselves or their families. In the case of children with rare diseases, it is their mothers who explain the nature of the disease and the needs of the patient to the rest of the population, newly diagnosed people and other patients in similar situations.

Of the 29% of associations that use blog, more than half (55%) have this space linked to the website, and 45% use it as an independent space. This lack of re-directionality between the website and the blog is a waste of potential users of each platform. 68% of respondents published five times per month, 21% more than five, and 11% more than 10.

## 5. Discussion and conclusions

In order to fulfil the first objective of this study, which was to establish the extent to what the organisations of patients with rare diseases use web-based communication tools, we conclude the following:

- 82% of the organisations have a website, and of them 58% uses the web 2.0. There is a growing interest among these groups to take advantage of the opportunities provided by this type of website, although they still do not exploit this type of space to the fullest.
- Very few associations have websites with a press room or special news section where they correctly organise and use communication tools. Only 21% of the associations have a website with this section, and only 1% of these spaces has a restricted access. Therefore, one of the aspects these associations could improve is the use of press rooms to achieve a more effective communication with the media and, therefore, with society. To this we should add that a very low percentage of websites (20%) uses RSS, which is a tool that can make communication with patients or family members more fluid. Moreover, taking into consideration that 70% of people with rare diseases also suffer from a disability, it would be appropriate to make these websites accessible for people with disabilities. Currently, only 3% of the websites are accessible for disable people.
- Support and information exchange among patients are the two main purposes of the use of websites and social networks. The third most common purpose is to connect patients with society. Only 28% of the associations use the website to reach the media and to interact with media professionals. If one of the priorities of these associations is to reach the population, they should improve their relations with the media and reach the population through them.

With regards to the second objective, which was to analyse the use of communication tools to achieve social and media visibility and to enable interaction between patients and families, we reached the following conclusions:

- Among the communication tools, the most used, in 71% of the websites, are news, which are used to keep members informed. However, tools such as press release, notes and other instruments of external communication are not used. On the other hand, memos are presented as useful information to patients in the style of bulletin board.
- These entities dedicate a great deal of work to the production of dossiers, which are offered in 36% of the websites and are basically directed to their members. The organisations produce posters, pamphlets and other materials that could target the rest of the population, through the mass media. Pictures are also used to share information between members and on many occasions are part of informative galleries within the press room.
- 39% of these organisations produce or disseminate videos related to their objectives. Some associations post this material on the homepage or in home or through links on the YouTube channel. It is not common for these organisations to locate these videos in a multimedia gallery, the press room or the news section of the website.

Finally, to respond to the third objective, which consisted in studying the degree of implementation of communication strategies 2.0 through presence in social networks, we reached the following conclusions:

- In the case of social networks, 55% of these entities has a presence in them and their members manage them in 80% of the cases. Facebook and Twitter are the most used networks among the associations, with 51% and 38%, respectively. Social networks could be used as a means of communication with the media and as a way to increase the number of followers. Media professionals could be invited to follow these spaces so they could spread news and one-off events in a regular basis. The use of the networks specialised in rare diseases is very positive for the internal communication of the organisation, but their following and presence in these networks is still very low (20%).
- 29% of the associations use the blog because this tool is more appropriate to share the experiences and more intimate aspects of their members. 85% of these blogs are managed by members of the associations so the dissemination of content is carried out from a more subjective point of view. The improvement of the use of blogs would involve linking them to the associations' websites so that a greater number of people could use them.

In short, the communication strategies of these associations are conducted on the internet. These organisations should improve their communication strategies both on their website and on social networks in order to achieve their goals and reach their target audiences. The connection of these

associations with society would be easier through the media. Journalists would find it easier to obtain information directly from patients if communication with media professionals was taken into account by these organisations of patients. Each of these organisations faces very different problems and specific needs that cannot be treated in a uniform way. Communication with journalists would be more fluid if these organisations developed a virtual press room, which is space designed to deliver announcements, press releases, dossiers, graphic materials, video galleries and sound resources. This would greatly facilitate the work of the members of these organisations, who would find in this space an archive which could encourage the generation of collective knowledge by e-patients.

## 6. Notes

[1] Data of the Spanish Ministry of Health, Social Services and Equality, available at [http://www.creenfermedadesraras.es/crear\\_01/auxiliares/er/index.htm](http://www.creenfermedadesraras.es/crear_01/auxiliares/er/index.htm) (consulted on 1 February, 2015)

[2] Study included in Martín Fombellida A. B. M. *et al.* (2014: 148)

[3] Quoted by Schiavo, R. (2011:9)

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