# ORPHANET-ITALY: BECOMING SOCIAL TO GENERATE NEW KNOWLEDGE

Mingarelli R., Di Giacinto M., Ciampa S., Radio FC., Ruotolo R., Dallapiccola B.

Orphanet is the reference portal for information on RD and orphan drugs (OD), for all audiences, and its aim is to help improve the diagnosis, care and treatment of patients with rare diseases. In 2001 it was started in Italy and, during its first ten years of activity, it disseminated data mainly through two means of communications: an international website and paper publications (leaflets and books).

Ten years later, in 2011, in order to give more evidence to national news on RD and OD, a national website specific for Orphanet-Italy (http://www.orphanet-italia.it) was created in February and the Italian version of the OrphaNews Europe newsletter, OrphaNews Italia, was launched in December. Orphanet-Italy.it includes information on national events, news and access to national policy documents concerning rare diseases and orphan drugs. OrphaNews Italia is the Italian version of the electronic newsletter of the RD-ACTION Joint Action (www.rd-action.eu), which is published on-line, and sent to over 6,000 subscribed readers, twice a month, presenting an overview of scientific and political news about rare diseases and orphan drugs. In the meantime, several other services and documents were made available online: a classification of rare diseases; an encyclopaedia of rare diseases in Italian; an inventory of orphan drugs at all stages of development; a directory of expert resources in the field of rare diseases, in Italy; an encyclopaedia of recommendations and guidelines for emergency medical care and anaesthesia (Orphanet Urgenze); a collection of thematic reports, the Orphanet Reports Series; a website providing the scientific community with a comprehensive, high-quality and freely-accessible dataset related to rare diseases and orphan drugs, in a reusable format (Orphadata); and the Orphanet Rare Disease Ontology (ORDO).

Despite the wide, valid and diverse range of information provided, we noticed a decrease in Orphanet-italia.it users' interest that could be allegedly due to a far too dispersive and little user-friendly data dissemination mode.
Therefore, we decided to use social media to reach as much stakeholders as possible and made them discover the added value of our data: we collect and disseminate highly valuable, expert-validated and updated scientific data on rare diseases, which are conditions typically characterized by a deficit of medical and scientific knowledge. In 2013, for that reason, a Facebook page for Orphanet-Italia was created and in the same year the Orphanet mobile application was launched. In 2014, Orphanet-Italia YouTube channel was created and, a year later, in 2015, a mobile application for OrphaNews Italia was developed. This effort was driven by our commitment in overcoming isolation and lack of information related to rare diseases (RD) and social media platforms can represent a powerful instrument in that direction: stakeholders use them for interaction and networking, education, information dissemination and search, research funding, experience sharing.


1.
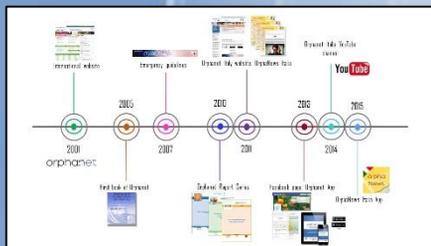
Firstly, we analyzed Orphanet-italia.it users' habits (number of sessions, session duration, pages viewed per session, returning visitors) to assess their interest in a non-interactive web-page. Analyzing Orphanet-italia.it users' habits (considering the period 2011 to 2015), it was reported a general and constant decrease in their interest: -21.84% for number of sessions, -24.69% for session duration, -36.38% for pages viewed per session and -41.89% for returning visitors.

	Number of sessions	Session duration (hours/minutes/seconds)	Pages viewed	Returning visitors
2011	7,562	00:01:32	15.291	26.5%
2012	19,220	00:01:21	32.964	32.3%
2013	13,218	00:01:05	20.946	25.9%
2014	13,823	00:01:07	20.820	17.6%
2015	14,819	00:01:01	20.985	18.4%
2016 (till April)*	5,007	00:01:03*	7.558*	16.4%*
*Partial data				

We registered the highest values for number of sessions, pages viewed and returning visitors in 2012, a year after the website creation. While in 2011 the national website could be little known because of its novelty, in 2012 it seems to have expressed its full potential with a good start. Unfortunately, those standards were no longer reached over the next years and we witnessed a significant decrease in our public interest that we thought crucial to tackle as well as it could be in order to disseminate our knowledge further.

The structure of our national website is quite rigid: there are mandatory sections for all Orphanet partners in different countries (general information; Orphanet international services; international news; national events; team; governance; governance) and a specific main section for all national news which appears to be quite similar to that of a blog but, unlike this tool, it do not allow users to comment or share its contents. Information is provided in a passive way.

2012 user satisfaction survey of the Orphanet website gave us an important insight about what kind of information our users are looking for when they use our database:
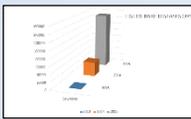

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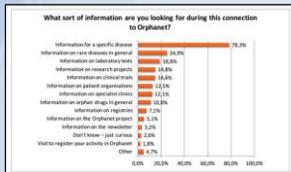
We thought that the specificity of their information requests (78.9% of them were looking for information on a specific disease) could be correlated to the low values for returning visitors: in other words, once their information request was fulfilled, they rarely returned to use our website. Therefore, what we had to do was to inform them about the variety of our documents and services and the regularity of their updating: they had to know that every time that they came back to our website they could find more information.

Orphanet documents download: Then, we analyzed data for Orphanet documents download: in particular, Orphanet Emergency guidelines and Orphanet Report Series. All the documents included in these two collections were posted and shared on our Facebook page.

Orphanet Emergency guidelines in Italian	Average download
2015	4,000
2014	4,000
2014	3,500
2012	1,500
2011	1,000

Orphanet Report Series (ORS) are texts providing aggregated data covering topics relevant to rare diseases. New reports are regularly put online and are periodically updated. These texts are published as PDF documents accessible from the homepage and from every other page of Orphanet's website. New versions of these publications are advertised in OrphaNews Italia and Orphanet-Italia's Facebook page. After the creation of our Facebook page, we found a general increase in ORS download: in particular, the download increase for the list of rare diseases ORS was astonishing.

The social media technology allows to better meet RD stakeholders' needs, which can be directly expressed through interaction and engagement with specific topics. In particular, it helped us to overcome a sort of detachment we experienced from our users: as a matter of fact, thanks to these new ways of communication, now we are able to reach with our knowledge more and more stakeholders every day, with a direct and fast approach, eliciting their participation and supporting their empowerment (in particular for RD patients) in the meantime. Orphanet mission is not only to provide information on rare diseases but also to disseminate it and create the conditions for its reuse in different and heterogeneous settings, in order to create new knowledge. Information sharing, confrontation and co-construction of knowledge in the field of rare diseases is the way that social medias can support and Orphanet represents a powerful tool to exploit for that purpose.

Healthcare services providers are struggling to find new ways of communicating as many existing tools (like pamphlets, newsletters, non-interactive webpages) are proving to be obsolete and inadequate by now. We started our study taking into account our means of communication and parting them in two main categories: non-interactive and interactive tools. We valued most the interaction parameter since it is strictly correlated to the users' willingness to sharing contents and therefore making information available to as many stakeholders as possible, so that information shared can represent a cue for new knowledge to be generated.

Orphanet-Italia's non-interactive tools are our national website (Orphanet-Italy.it) and the OrphaNews Italia newsletter; our interactive tools include Orphanet-Italia's Facebook page and YouTube account.

We analyzed statistics concerning our means of data dissemination in order to understand how to increase access to our services and documents. With the help of Google Analytics we first considered Orphanet-italia.it users' habits and Orphanet documents download, finding a decrease in our public's interest. As regards our Facebook page, post reach, engagement (referring to post clicks, reactions, comments and shares) and fans' gender and age related to the Facebook page were analyzed, in order to better understand trends and stakeholders' needs while seeking information. To assess the most valued themes we considered as criteria a post reach ≥ 800 and the higher values for post engagement. We also determined the success of our videos on YouTube according to the number of visualizations.

We have parted the results of our analysis into four sections:

1. Orphanet-Italia national website
2. Orphanet documents download
3. Orphanet-Italia Facebook page
4. Orphanet-Italia YouTube page

3.

We created a Facebook page with the primary aim of bringing our scientific knowledge to patients, health professionals and all the stakeholders in need of information on RD and OD. In particular, we published on our Facebook page all the contents of the Orphanews Italia newsletter.
The reference period for all the Facebook data taken into account goes from September 22, 2013 to April 30, 2016.
We first analyzed our users' profile: out of a total of 1,249 Facebook fans 79% are women, 21% men, women and men aged 35-44 are the largest segment. For the most part, our Facebook public is composed of patients and their entourage (including patient organizations, alliances and support groups).

To assess the most valued themes we considered a post reach ≥ 800.
According to this criterion, we identified 83 successful posts and we classified them into 8 main themes:

Rare Disease Day
Patients, Empowerment, Storytelling
Orphanet documents (ORS List of rare diseases, ORS List of orphan drugs, ORS Prevalence)
Institutions, Policy-making
Campaigns, Fundraising
Research, Scientific findings and publication, Innovations
Events, Conferences, Education
Centers proving medical management

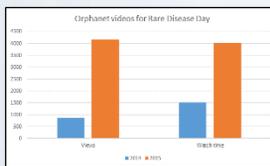Here follow the results of the data analysis (the most relevant data are in red):

Themes	Number of posts per theme (with a post reach ≥ 800)	Average post reach per theme*	Engagement (post clicks, reactions, comments and shares)*
Rare Disease Day	8	3,212.1	177.4
Patients, Empowerment, Storytelling	14	1,524.1	64.9
Orphanet	12	1,664.7	55.5
Institutions, Policy-making	9	1,389.4	78.9
Campaigns, Fundraising	5	1,066.0	82.4
Research, Scientific findings and articles, Innovations	20	1,401.5	58.3
Events, Conferences, Educations	13	1,320.5	52.4
Centers	2	800.5	43.6
*Average post engagement per theme			

According to the table above, the most valued themes from our Facebook users are the following:

Theme with the highest number of post (with a post reach ≥ 800)	Theme with the highest average post reach	Themes with the highest engagement (post clicks, reactions, comments and shares)
Research, Scientific findings and articles, Innovations	Rare Disease Day	Rare Disease Day; Institutions, Policy-making, Campaigns, Fundraising

The most valued themes are news and events on Rare Disease Day (with an average post reach of 3,212.1), research, scientific findings and innovations (with the highest number of posts going beyond the post reach of 800), national campaigns and fundraising and policy-making and institutional news (with an engagement of 82.4 and 78.9, respectively). This analysis allowed us to understand what type of information our users appreciate, as a result, to offer them what the information they need the most.

4.

You Tube: The creation of our YouTube page gave us more insights about the best way of communicating in the field of RD and OD: direct, simple and patient-centered. The Orphanet video for 2015 RDD reached 3,956 views with an increase of 371.51% compared to the 2014 one, highlighting some success factors (short duration, simple and immediate theme-based message).

The social media technology allows to better meet RD stakeholders' needs, which can be directly expressed through interaction and engagement with specific topics. In particular, it helped us to overcome a sort of detachment we experienced from our users: as a matter of fact, thanks to these new ways of communication, now we are able to reach with our knowledge more and more stakeholders every day, with a direct and fast approach, eliciting their participation and supporting their empowerment (in particular for RD patients) in the meantime. Orphanet mission is not only to provide information on rare diseases but also to disseminate it and create the conditions for its reuse in different and heterogeneous settings, in order to create new knowledge. Information sharing, confrontation and co-construction of knowledge in the field of rare diseases is the way that social medias can support and Orphanet represents a powerful tool to exploit for that purpose.

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