

Facebook as a tool for raising awareness on rare diseases: the experience of Orphanet-Italy

Nutini M*, Battisti F*, Ciampa S.*, Pallotti P.*, Marino F°, Zamperini N°, Mingarelli R.*, Dallapiccola B.*

*Orphanet-Italy, Bambino Gesù Children Hospital, IRCCS, 00152 Rome, Italy;
°Digital Communication Division, Bambino Gesù Children's Hospital, IRCCS, 00165 Rome, Italy

Introduction

Social media are increasingly impacting into the way by which the public at large looks for health related information.

The Orphanet-Italy team trusted in the opportunity offered by Facebook (FB) to introduce the database services to a more wide audience, going beyond the key stakeholders: healthcare professionals, researchers, patients and caregivers. To this end, from September 2018, a dedicated social media team developed an editorial plan with the goal of "humanising" and bringing the database closer to the community of rare patients, without deviating from scientific rigor. Here we report the preliminary results of the FB network activity, and its impact into the Orphanet-Italy website, by:

- Comparing the demographic data of the FB followers and Orphanet website users;
- Illustrating the editorial strategy, based on topics covered by posts submitted to the FB page;
- Providing a figure of the social networking potential for guiding the public towards the Orphanet database.

Methods

Data was collected by Facebook Insights and Google analytics. Microsoft Excel was used for data analysis and graph representation. Time range. FB demographic data cumulative until 31st Dec 2019; Orphanet website's demographic data 1st Jan 2018 - 31st Dec 2019; editorial strategy 1st Sept 2018 - 31st Dec 2019; Facebook and Orphanet site's growth 1st March 2018 - 31st Dec 2019.

Facebook posts and website's users analysis. N = 5 pairs of posts were chosen and each of them was assigned to one of the two groups, with or without a link to Orphanet respectively. Each selected pair shared the number of Facebook users. The website's user number was collected according to the date of publication of each post, the time interval ranging from 1st Sept 2018 to 31st Dec 2019.

Results

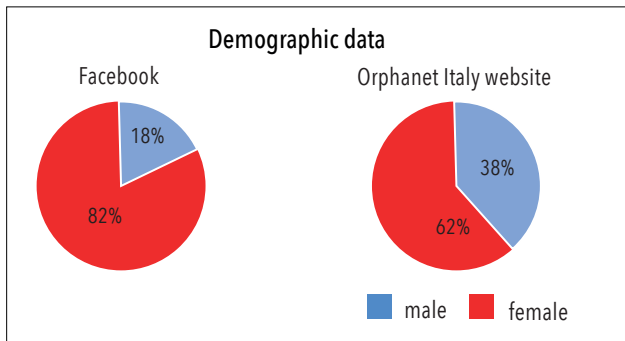


Fig. 1. Gender profile of the Facebook fans (left) and Orphanet website users (right).

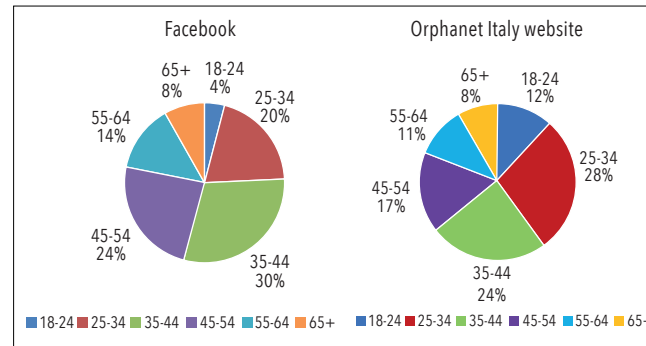


Fig. 2. Age distribution of Facebook fans ((left)) and Orphanet website users (right).

The majority of our FACEBOOK fans and Orphanet users were female (Fig. 1). The audience covered a wide range of people (aged 18 - >65 years), with a prevalence in the age range of 25-54 years for the site users, and 35-54 years for the FACEBOOK fans (Fig. 2). These results are in line with the average age of the majority of worldwide FB users, as shown by We are Social's Digital Report 2020.

Although the majority of our FB fans were Italian, altogether they are citizens of 10 different countries, differently from the Orphanet website users, which virtually all are Italian, taking advantage from the database translation in their own language.

Editorial strategy: posts' themes

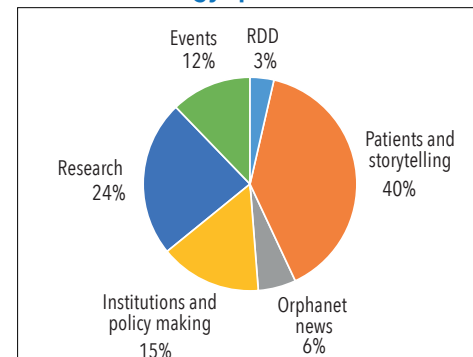


Fig. 3. Pie chart representing the number of published posts sorted by six main topics. The values are expressed as percentages

Facebook page and Orphanet site: a side by side growth

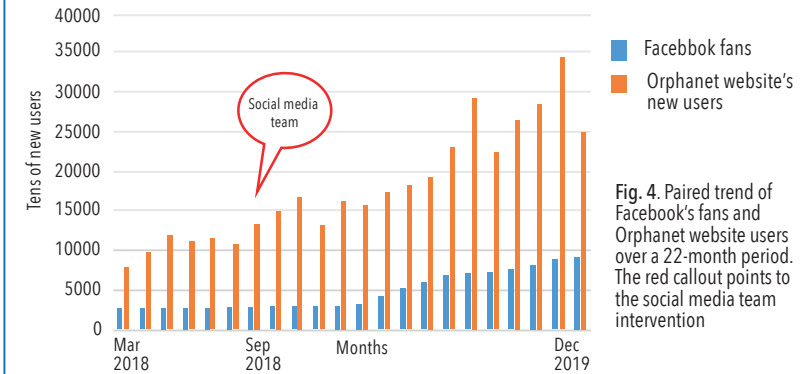


Fig. 4. Paired trend of Facebook's fans and Orphanet website users over a 22-month period. The red callout points to the social media team intervention

The followers' growth rate showed a remarkable increase (+210 % in 2019 vs 2018) starting from September 2018 when the social media team began the FB page management. Interestingly, the number of new Orphanet site users paralleled this trend, with a 32% increase in the total number of users in 2019, compared to 2018, or 2,888,018 vs 2,194,121 respectively (Fig. 4).

Conclusion

We cannot exclude that the views on the Orphanet site are not all attributable to the FB posts. With this limit in mind, the present results support us in:

- Creating a large community promoting Orphanet as a channel of certified and inside information in rare diseases;
- Deepening our analysis, in order to study the crosstalk between the social network growth and the Orphanet website success;
- Submitting the users a survey, to better understand their requirements and preferences.

Acknowledgement

The Orphanet team at INSERM (France) has provided us with data of the Orphanet-Italy website.

The effort to broaden our audience was evaluated on the users' response to six main topics of the posts: 1. rare disease day; 2. patients, empowerment and storytelling; 3. Orphanet news; 4. institutions and policy-making; 5. research, scientific findings and articles, innovations; 6. events, conferences, education. Not surprisingly, the posts with major engagement cover most published categories, including patients and storytelling (40%) and research (24%), as shown in figure 3.

In 2019, the posts referring to the Orphanet site reached 253,512 people, compared to 8,095 fans in 2018. This result well compares with the increased number of daily Orphanet users, whenever posts displayed a link to the website (Table 1).

	Posts with link to Orphanet	Posts w/o link
N. of users	10331 ± 1819,5	9133,4 ± 1270,9

Table 1. Average number of Orphanet users following the publication of posts either with or without a link to the website. Data are mean ± SEM; N=5.