

The associations of rare diseases: the structure of their networks and identification of opinion leaders through the technique of social network analysis

Las asociaciones de enfermedades raras: Estructura de sus redes e identificación de los líderes de opinión mediante la técnica del análisis de redes sociales

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ABSTRACT

Introduction. This research has used the technique of Social Network Analysis to analyze the structure of network relationships that surrounds on Twitter the three more important federations of associations of rare diseases and identify key actors in their communications. **Methodology.** NodeXL software has been used, with visualization as a key component, to capture the network of connections of the accounts under study, represent their interaction patterns, and find out the position occupied by users within the network. **Conclusions.** The results indicate that these associations use social networks to raise awareness, educate and inform about RD and its problems. They are very influential accounts with a high degree of connection and a great capacity for prescription due to the interest aroused in a part of the population by these pathologies and everything that surrounds them.

KEYWORDS: Social Network Analysis; SNA; Rare Diseases; Twitter; NodeXL.

RESUMEN

Introducción. Esta investigación ha empleado la técnica del Análisis de Redes Sociales para analizar la estructura de relaciones de red que envuelve en Twitter a las tres federaciones de asociaciones de enfermedades raras más importantes e identificar a los actores clave en sus comunicaciones. **Metodología.** Se ha utilizado el software NodeXL, con la visualización como un componente clave, para capturar la red de conexiones de las cuentas objeto de estudio, representar sus patrones de interacción y averiguar la posición que ocupan los usuarios dentro de la red. **Conclusiones.** Los resultados indican que estas asociaciones emplean las redes sociales para sensibilizar, educar e informar sobre las ER y sus problemáticas. Son cuentas muy influyentes con un alto grado de vinculación y una gran capacidad de prescripción debido al interés que despiertan en una parte de la población estas patologías y todo lo que las rodea.

PALABRAS CLAVE: Análisis de Redes sociales; ARS; Enfermedades Raras; Twitter; NodeXL.

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Translation by **Paula González** (Universidad Católica Andrés Bello, Venezuela)

1. Introduction

Social networks have become an increasingly present actor in our lives. As O’Keeffe and Clarke-Pearson (2011: 800) point out, an important part of our social and emotional life already takes place on the Internet -especially on social networks- and through tools such as tablets or mobile phones. For this reason, it is of interest for the academic world to research those interactions that occur online in social media and to identify the main actors that manage the flow of social influence and information within a relational system. These opinion leaders are classified as social media influencers (SMIs) (Freberg et al., 2011: 90) and to recognize them it is necessary to study the position and links with third parties that members of a social network have. The problem is that most of the research that has studied SMIs has shown limitations by focusing only on quantifying aspects such as the times a message is shared or the number of followers (Del Fresno, 2014). “Since influence is essentially qualitative, these strategies can only be accepted as mere starting points (Basille, 2009; Straley, 2010). Identifying SMIs only through their activity and/or through the counting of followers or friends is not a valid approach and will lead to poor results” (Del Fresno et al., 2016: 29).

To do this, researchers must make the network that surrounds a person or organization visible, that is, a graphic representation with all the relevant ties that connect the studied nodes. This is where the analysis of social networks shows its usefulness since it is related to the development of computer tools that allow the collection, monitoring, analysis, and visualization of data from social networks to discover the invisible structure of online relationships, extract useful patterns, and understand their complexity (Fan, 2014: 74). For example, it has been used successfully in epidemiology to understand how diseases spread (Martin et al., 2011; Berkman et al., 2014; Lichoti et al., 2016) or how information is disseminated (Pfeffer, 2014; Dhar et al., 2016, Ahmed and Lugovic, 2019).

This article will focus on Twitter as a research field and will use social network analysis (SNA) as a methodological instrument to identify SMIs and study the network structures that surround three rare disease organizations: FEDER, EURORDIS, and NORD. It is “a scientific method aimed at optimizing social media research, replacing anecdotal approaches (number of friends, followers, likes, etc.) and providing significant results in the identification of key actors in communication within online social platforms” (Del Fresno et al., 2016: 28).

2. State of the issue

2.1. The analysis of social networks and social media

According to Liu (2011: 270), social network analysis is useful for the web because the Internet “is essentially a virtual society, and therefore a virtual social network, where each page can be considered as a social actor and each hyperlink as a relationship. Many of the social media results can be adapted and expanded for use in the web context. The ideas of analysis of social networks have been decisive in the success of online search engines”. In the same sense, researchers such as Del Fresno et al. (2016: 29) point out that the SNA is the appropriate instrument to scientifically identify the models of information dissemination on online social platforms.

In the last ten years, a series of academic papers have addressed the issue of diffusion in online networks in general, and the attributes and roles of social media influencers (SMI). Following Bakshy et al. (2011: 66), the first studies analyzed the dissemination of information between groups of bloggers. Shortly after, Leskovec together with Adamic researched the networks of recommendations that emerged (‘link cascades’) on an online commerce site (Leskovec et al., 2007). Then the research was extended to other platforms. For example, Sun et al. (2009) will analyze the networks in the Facebook fan pages, and authors such as Kwak et al., (2010) focused on the Twitter networks to identify the most influential users. In this case, since its appearance in 2006, the microblogging platform created by Jack Dorsey “has provided a rich set of data for researchers, which has led to the publication of more than a thousand academic articles” (Williams et al., 2012: 384). In this sense, the most recent studies on Twitter focus on emotion analysis (Salinas et al., 2017; Zambrano et al., 2016); the dissemination of information in various events (Lee et al., 2015; Shin et al., 2016; Groshek and Tandoc, 2017), the study of hashtags (Zappavigna, 2015; Fink et al., 2016), or the use of the platform by different groups or organizations (Einwiller and Steilen, 2015; Meijer and Torenvlied, 2016; Gil de Zúñiga et al., 2016, Hanusch and Bruns, 2017), among other aspects.

2.2. The rare diseases

Medicine and health are the topics that most interest Spaniards according to the 2018 survey on Social Perception of Science and Technology carried out by the Spanish Foundation for Science and Technology (FECYT by its acronym in Spanish). Furthermore, the Internet (40.3%) and social networks (48%) are cited in this work as the first source of scientific information for a large part of citizens, something that becomes more evident regarding rare diseases (hereinafter RD). In this sense, already in 2016, the survey of the National Observatory of Telecommunications and the Information Society (ONSTSI by its acronym in Spanish) collected that 6 out of 10 Spaniards used the Internet to find out about health.

The concept of RD was developed for the first time in the US in the mid-1980s and referred to those pathologies that have a low prevalence in the population, are potentially fatal, and carry a degree of disability, dependency, and a deterioration of the quality of life (Posada, Martín, Ramírez, and Abaitua 2008: 1). According to the World Health Organization (WHO), 300 million people around the world

live with some of the 7,000 RD cataloged until 2018 (7% of the world population). According to the Spanish Federation of Rare Diseases (FEDER by its acronym in Spanish), to be considered rare, each specific disease can only affect less than 5 out of 10,000 inhabitants. In total, it estimates that in Spain there are more than 3 million people with rare diseases (Castillo et al., 2015: 674). In Europe, however, a disease is considered rare when it affects 1 person in 2,000. According to the European Organization for Rare Diseases (EURORDIS), there are 30 million people affected. In the US, it is classified as such if it affects less than 200,000 and it is estimated that there are 30 million throughout the country.

They are diseases that are difficult to diagnose and that imply a radical change in the quality of life of those affected and their families (Huerta et al., 2012). From the FEDER website, they explain that these patients wait an average of 5 years to obtain a diagnosis (in 20% of cases it takes 10 or more years) and, while in 40.9% of cases, the affected person does not receive any support or treatment, 26.7% receive some inappropriate treatment due to lack of knowledge about their pathology, and in 26.8% of cases their disease has worsened. Furthermore, their situation worsens due to the lack of adequate medications for their ailments and the high cost involved. According to the FEDER, the coverage of health products by Public Health is scarce or null in 36% of the cases. They calculate that each family spends more than 350 euros a month on their illness (purchase of medicines, medical treatment, adapted transport, personal assistance, and adaptation of the home) and that more than 70% of those affected have a disability certificate.

In this context, “Internet is emerging as the ideal medium for this group to successfully carry out its communication strategies. It is a medium in which it is not necessary to have a high budget to carry out a campaign, it breaks geographical barriers, and any content reaches the user immediately, which can be accessed by a large percentage of the population. Through campaigns on the internet, on social networks, crowdfunding campaigns, or through the dissemination of videos on channels such as YouTube, effective information can be offered to those affected and to other citizens, besides requesting research support” (Castillo, et al., 2015: 675).

The Internet and social networks allow RD sufferers to overcome existing geographical barriers, share experiences, and information. “This need to share information and knowledge is especially relevant in the case of rare diseases, these people being the most active Internet users due to the very characteristics of the diseases: their high number (around 7,000), their low prevalence, their incapacitating nature, and the serious threat to life that they pose” (Armayones et al., 2015: 336).

The use of the Internet and social networks is also of interest to health professionals who can carry out virtual consultations, train, inform and collaborate in studies and research (Guo, et al., 2017; Benetoli, Chen, Aslani, 2018).

In terms of research, there are numerous studies related to health in the media (Costa, 2008; Dalley, Buunk, and Umit, 2009; Roberts and Good, 2010; Schumaker et al., 2014; Jacobs, et al., 2016; Cavaca et al., 2016 and Emerich et al., 2017). Likewise, other works focus on specific diseases such as influenza A (Camacho, 2009); HIV-AIDS (Terrón, 2012); obesity (Yoo and Kim, 2012); mental health (Peñafiel et al., 2014), or anorexia (Gúzman and Rodríguez, 2016). On the other hand, studies have also been carried out focused on RD and the media (Díaz, 2007; Solves and Bañon, 2014; Villa et al., 2014, or Sánchez, 2016). Other recent research focuses on the communication strategies of RD patient organizations (López-Villafranca, 2016), their strategies on the Internet (Castillo, López, Carretón, 2015), the use of social networks by RD patient associations (Armayones, et al., 2015), and the framing of RD in the Spanish media (López and Castillo, 2018).

Therefore, it is a topic of current interest that helps to sensitize public opinion "and give visibility to a serious health problem by providing a general and different vision of the treatment given in the general information newspapers to RD" (Santos and Pérez, 2019).

2.3. Federation of associations of rare diseases

The media play an important role when it comes to the visibility of RD (Adekunle and Adnan, 2016). In this sense, Castillo, López, and Carretón (2015: 676) point out: "The Internet has strengthened ties between the medical community and patients, but it is necessary to achieve a new challenge, which is the one posed by patient organizations with the rest of the users". These entities such as FEDER, EURORDIS, or NORD, faced with the reality that the population is unaware of the existence of most of these pathologies, try to educate and inform about them, raise awareness about their problems "making their common needs visible and proposing solutions to improve their quality of life, representing their interests, defending their rights, and promoting concrete improvements to achieve their full social inclusion", as detailed by the FEDER through its website (<http://www.enfermedades-raras.org>). According to Armayones et al. (2015: 335), the associations are using social networks "to raise awareness about rare diseases in general and their own in particular, as well as to exchange content related to psychological, medical, and social support, the promotion and dissemination of research, and fundraising".

Patient organizations, as mentioned above, together with associations, provide advice and emotional and therapeutic support by sharing common experiences (Huerta et al., 2012) since many times those affected feel abandoned due to the existing ignorance about their pathologies among the medical community. At the international level, the American National Organization for Rare Disorders (NORD) and the European Organization for Rare Diseases (EURORDIS) are a reference. In Spain, the Spanish Federation of Rare Diseases (FEDER) must be mentioned.

- NORD emerged in 1983 when the leaders of several rare disease patient organizations in the United States came together. Today it represents 280 associations. It has been present on Twitter since October 2009.
- EURORDIS was created in 1997 and is defined as a non-governmental alliance of patient organizations that represents 837 organizations of people affected by rare diseases in 70 countries, covering more than 4,000 diseases. It joined Twitter in March 2009.
- FEDER was born in 1999 to be the speaker of the more than three million people who live with any of these pathologies in Spain. Throughout these 20 years, they have gone from 7 to 337 associations and represent more than 1,097 pathologies and more than 95,500 people. According to their latest published activity report, in 2017 they helped 123,719 people (information and guidance, psychological care, or legal advice, among others). It has been present on Twitter since January 2009.

The activity carried out over the years by these organizations has proved fundamental when it comes to raising public awareness, promoting medical research, and providing services to patients and their families. Something that recent research such as that of López and Castillo (2018: 136) shows: "The results show that the visibility and knowledge about these pathologies have increased and a proactive image of this group is reflected thanks to their initiatives and demands."

3. Objectives

The generic objective of this research is to analyze the structure of network relationships woven around the accounts of the Spanish (@FEDER_ONG), European (@eurordis), and American

(@RareDiseases) federations of rare diseases associations using the social network analysis (SNA) technique. It contains the following specific objectives:

- O1- Find out the position of users within the network and identify the main actors or SMIs.
- O2- Study the type of links that have arisen in the network.
- O3- Research semantic networks and discover hidden patterns in tweets.

4. Hypothesis

H1- Among the profiles with the greatest structural advantage in the network (related to O1), the associations, foundations, biopharmaceutical companies, and research centers that use the networks to promote their activities and offer useful information to those affected stand out above those affected.

H2- The activity carried out by these entities to inform and guide has been fundamental and has made them a benchmark with a high level of commitment to their followers. It is based on the hypothesis that the main way to create an interaction that is detected in the structure (O2) will be through links of the type mention or retweet because those affected consider these publications of great interest to be shared with third parties.

H3- Regarding the associations of words that create networks of meanings (related to O3), the most relevant threads of conversation are related to the dissemination of their campaigns or events that are organized to raise awareness, educate, and inform about the RD and their problems, or request help for research.

5. Methodology

This article is part of a line of research on the presence of rare diseases in the media and refers to the analysis of the structure of their networks using the SNA technique. For this article, the profiles of the Spanish Federation of Rare Diseases (FEDER), the European Organisation for Rare Diseases (EURORDIS), and the American National Organization for Rare Disorders (NORD) were analyzed. In their selection, criteria such as their representativeness –they group the majority of associations–, having a different geographic coverage, or presenting common objectives in terms of coordination tasks of patients, public administration, scientists, etc., to improve the quality of care for the sick were taken into account.

To make the network that emerged around these associations of rare diseases under study visible and identify the central nodes (main actors or SMIs), Twitter was chosen, taking as reference research such as that of Del Fresno et al. (2016: 29) where they point out that the research interest of the platform lies in the fact that it is a “medium in which there is a massive exchange of interpersonal communication and two types of key explicit connections: retweets (RTs) and mentions and responses (MTs). These two types of explicit connections are more significant than follower/friend relationships. For Wu et al. (2011: 706), the microblogging network offers an interesting context in which to address Lasswell's maxim (who says what to whom), especially since Twitter makes it easy to observe the information flows between the users of its application. Williams et al. (2012: 385) –whose research found almost a thousand academic texts related to the platform- point in the same direction and point out that this abundant scientific production is because it is an open platform, and that availability of messages published on Twitter provides a rich data set for academic researchers from various disciplines ranging from statistics to anthropology. Along the same lines, Bakshy et al. (2011: 65-66) emphasize that Twitter presents a perfect natural laboratory for the study of dissemination processes because, unlike other networks such as Facebook, Twitter is expressly dedicated to disseminating information.

To capture the network of connections of the accounts @FEDER_ONG, @eurordis, and @RareDiseases and make visible their patterns of interaction and/or dissemination, the NodeXL program was used, "one of the main open-source analysis software for analysis and visualization of networks." (Lieberman, 2014: 3), designed by the sociologist Marc Smith to facilitate the learning of the concepts and methods of social network analysis with visualization as a key component (Hansen et al., 2010: 54; Smith, 2014: 1153) and that has been used successfully in different research such as those of Lichoti et al. (2010) –which provided information on the epidemiology of African swine fever-, Verweij (2012) –which examined the connections between politicians and journalists-, Choi et al. (2014) –which analyzed the political discussions of Korean Twitter users-, Dossis et al. (2015) -who studied the diffusion of various hashtags during the recent Greek crisis-, Perez, Meso, and Mendiguren (2018) -who researched what Spanish political leaders talk about with the media and journalists- or Ahmed and Lugovic, (2019) -which studied the dissemination of news-.

The extraction was carried out at the beginning of February 2019, taking as a reference the research on the representation of RD in the Spanish press by Santos and Pérez (2019), which revealed that February was the subject with the highest activity.

The program represented each user as a vertex or node and translated as edges the relationship that the messages kept between the users. The software downloaded 1,551 vertex and 7,384 relationships between vertex that allowed us to understand and visualize the network woven around these organizations.

Table 1: *Vertex and relationships*

Speaking of:	Relationships (edges)	Vertex
@FEDER_ONG	4,864	746
@eurordis	1,075	323
@RareDiseases	1,445	482
Total	7,384	1,551

Source: Self-made

Likewise, this research was based on the concept of centrality, composed of a group of metrics that measure the importance of nodes in a network (Scott, 2012). Taking as reference the research of Hansen et al. (2010) and Smith (2014), and following Lieberman, these centrality metrics were classified as:

Table 2: *Centrality*

Centrality	Interpretation on social media
Intermediation	What is the probability that this person is the most direct route between two people on the network?
Closeness	How fast can this person reach everyone on the network?
Prestige or eigenvector	How well is this person connected to other well-connected people?

Source: Lieberman (2014: 8)

- Degree of intermediation (betweenness centrality): It allows to measure how important a node is and is related to how the position of a user in a network conditions their access to information. According to Hansen et al. (2010: 150), it is calculated as the number of times a person is on the shortest path between two other actors. If an actor has a high value, this means that a large amount of non-redundant information passes through him and turns him into a 'bridge', a gatekeeper, or regulator that can exercise control over the flow of information. Actors with a high value of intermediation can filter, distort, or block information for other parts of the network. On the contrary, the actors with a low value in intermediation are those that provide redundant content.
- Degree of closeness (closeness centrality): The average of the shortest distances from a node to all other actors. It can be understood as the speed with which information spreads from one node to all the others (Brandes, Borgatti, and Freeman, 2016).
- Prestige or eigenvector (eigenvector centrality): It measures the influence or authority of a node in a network. For Hansen et al. (2010: 72) a connection with a popular or leading actor (well-connected) is more important than a connection with a loner. This metric takes into account not only the number of connections that a node has (degree centrality) but also how many of those links are with well-connected people.

6. Results

The account with the most followers is @FEDER_ONG (29,400), followed by @RareDiseases (28,200), and @eurordis (20,700). This metric, which indicates the potential reach that these organizations' messages can achieve, is conditioned by the degree of activity, syndication of their messages, or received 'likes'. Along these lines, the most active profile is that of the Spanish federation with 12.2 daily tweets, double than NORD (5.48 messages per day), and six times more than EURORDIS (1.98 tweets). Besides, the results show that they are all accounts with a high degree of linkage (engagement) since more than 60% of their tweets are forwarded to third parties because their followers consider them relevant to be made known among their friends. NORD achieves a forwarding rate of 70.72% with an average retweet of 7.61 times per message. EURORDIS gets 62.33% and 8.09 forwardings per message. FEDER's messages are also very successful among users and, although it occupies the third position, it achieves a syndication rate of its contents of 61.24% and 4.4 retweets per publication. Therefore, approximately two out of three of the messages from these organizations achieve a significant impact. Proof of this is also the significant number of 'likes' obtained by the three accounts. 77.94% of the publications made by the North American association are marked as favorites by internet users. The Spanish federation follows closely behind with 65.49% of its tweets receiving a 'like'. 61.43% of what EURORDIS publishes is also liked by users.

6.1. The North American Organization for Rare Disorders (NORD)

The @RareDiseases account was created in October 2009 and describes itself as “the voice of the rare disease community”. It has 28,200 followers and has posted more than 11,800 messages.

6.1.1. Actors with more favorable positions in the network

The structure of the network woven around the NORD obtained with the software shows a dozen groups according to their relationships. According to the degree of intermediation (betweenness centrality), among the individuals who provide non-redundant information in the network that surrounds the North American RD organization, the presence of a group of four accounts is striking (@shashanktyagi05, @LSDSS, @sudhee26, @thezbfoundation) based in India and Pakistan, among which the neuroscientist Dr. Sudheendra Rao (@sudhee26) stands out. Along with them, as 'bridges'

to the flow of information, there are also profiles of Dr. Joan Fallon, director of the biopharmaceutical company Curemark (@curemarkceo) or the activist and expert in RD Tracy Zervakis (@ChiariTracy), among others. Furthermore, in the conversations collected during the research, it is also necessary to mention three other users who functioned as intermediaries in the communications between the actors that shape the structure: @roneawkard (whose publications contain up to 48 mentions per message), @ionisdisrupts (affected by an RD), and @lagunagy (affected by another RD).

When studying the interaction and communication patterns on Twitter when talking about NORD, it is also interesting to pay attention to the degree of closeness, which measures the ability of an account to access the rest of the accounts on the network. A profile with a high degree of closeness is important because it can quickly connect with the rest (Del Fresno et al., 2014). They are accounts that, despite having few connections, allow reaching all the nodes of the network faster than from any other point and, therefore, constitute a good position to monitor the flow of information throughout the structure (Kuz, et al., 2016).

The people who can reach others on the network faster (structural advantage), besides NORD, are the following:

1. @RareDiseaseDay: Rare Disease Day account (February 28th). Its objective is to sensitize patients, families, and caregivers around the world affected by RD.
2. @bsyngap: Bridge the Gap Foundation - SYNGAP Education & Research Fnd. To serve, educate, and fund research for families coping with the effects of SYNGAP1 mutations.
3. @lseiders3: Lydia L. Seiders, NORD Ambassador in Maryland. She coordinates the 200 members of the network in Maryland to raise awareness of the approximately 600,000 patients affected by a rare disorder.
4. @ncats_nih_gov: Official Twitter account of the National Center for the Advancement of Translational Sciences of the National Institutes of Health (NIH).
5. @GlobalGenes: Leading patient advocacy organization working to eliminate RD challenges faced by 350 million people around the world.
6. @eurordis: European Federation of Associations. An alliance of more than 800 RD patient organizations working together to improve the lives of the 30 million people living with a rare disease in Europe.
7. @KirkBrazeau: Father whose son, Archer, was diagnosed with Recessive Dystrophic Epidermolysis Bullosa (RDEB). His story became famous for being one of those chosen by the NORD to show how the life of a family changes and how it can be overcome with hope and love.
8. @DrPas84Ele: Doctor Eleonora Passeri, consultant in science and social networks.

Another of the metrics studied is the degree of authority (eigenvector), which is related to the influence that a profile acquires in a network and which, besides counting the number of connections of a profile (degree of centrality), studies how many there are with people who are well connected. In this case, the actors with more favorable positions (who have a structural advantage in the network) are almost the same as those obtained with the degree of closeness. This suggests that, in general, there are no large inequalities in the centrality or power of the account when measured in this way.

The positions change and two new actors to take into account appear:

- @mlweldon5: Monica Dudley Weldon is a speaker and activist whose son Beckett was one of the first diagnosed worldwide with SYNGAP1, and since that day, she has been talking about it.
- @NIH: Official Twitter account of the United States National Institutes of Health.

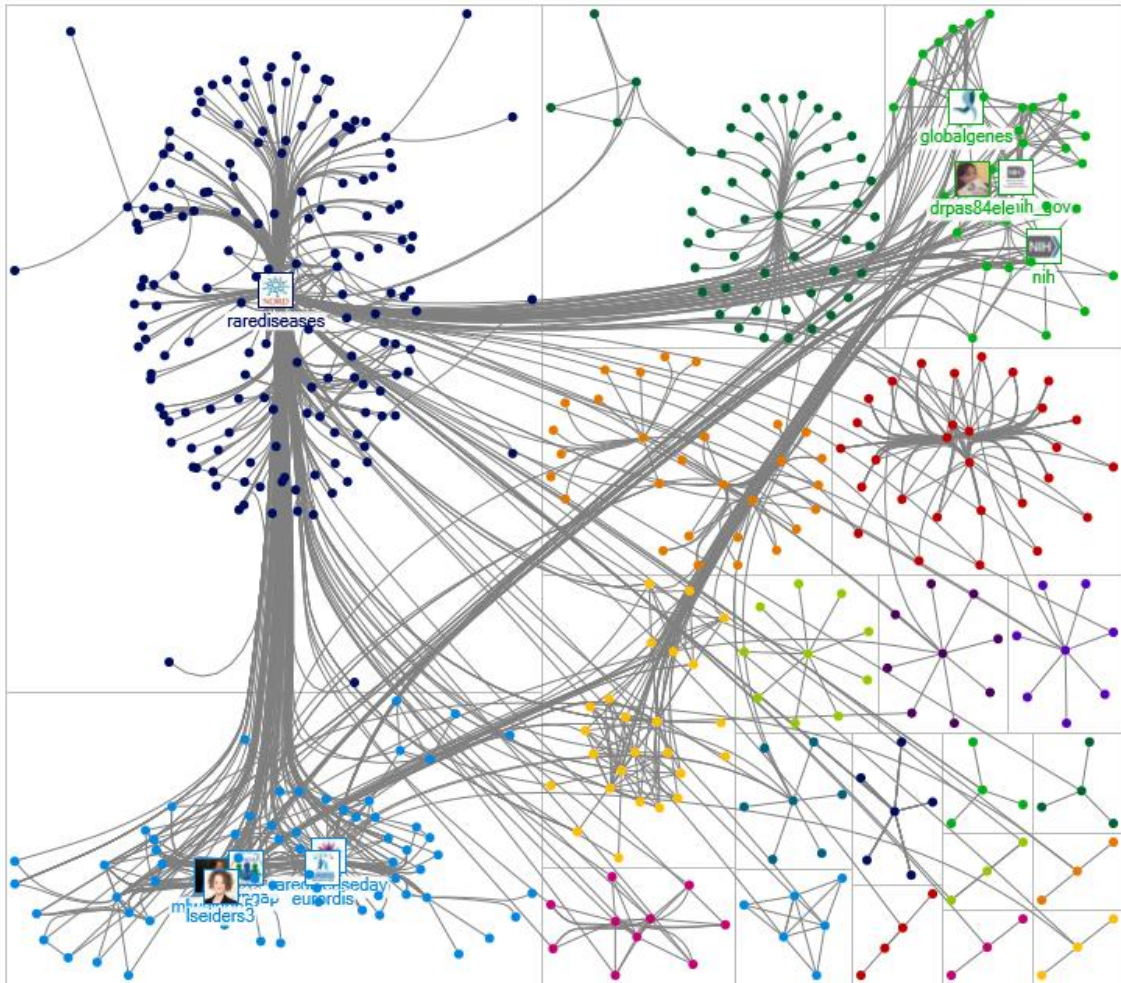


Figure 1: Visualization of the degree of authority
Source: Self-made

6.1.2. Interactions on the network

The network of interactions that surrounds the North American organization is made up of 72.66% of mentions, 21.45% of retweets, 4.295 of responses, and only 1.59% of tweets. The mention predominates as the majority form of relationship with publications such as the message from @runwayofdreams1 to @RareDiseases:

“I am #rare. I am one of approximately 100 people in the United States with #Mucopolysaccharidosis Type VI. Also known as Maroteaux-Lamy (#MPS-VI). #RareDisease #RareDiseaseDay #showYourStripes #CareAboutRare @SanfordCoRDS @RareDiseases @GlobalGenes @rareDiseaseday #MPSVI <https://t.co/gtruRq0uux>”.

Besides NORD, the most mentioned actors were:

1. @RareDiseaseDay: February 28th is celebrated as Rare Disease Day and the research was conducted at the beginning of that month, so it is not surprising that this account accumulates a good number of mentions.

Example: “Are You Ready!?! #RareDiseaseDay @RareDiseases @rareDiseasefdn @eurordis @rareDiseaseday #SYNGAP1 #neverstopping <https://t.co/fp06Jn7e9Z>” (28/01/2019, 4:36).

2. @eurordis: The European Federation of Associations closed a strategic partnership agreement with NORD in 2010, thus laying the foundation for key joint initiatives and further transatlantic collaboration.
Example: “Did you know that #RareDiseaseDay was founded by @eurordis in 2008? Learn more abt the international campaign on their Twitter account @rare diseaseday and visit their website for global campaign resources at <https://t.co/scuXryKFZq> <https://t.co/xqARgwjGLr>” (31/01/2019, 21:13:12).
3. @RareAction: American network that fights at the federal level to improve the lives of the 30 million Americans with RD.
Example: “Advocates are learning the ins & outs of the #orphandrugact Good stuff at #PARare day today. @RareAction @RareDiseases #RareDisease #Pennsylvania <https://t.co/svmyj0Kyu2>” (01/02/2019, 16:17).

6.1.3. Most relevant conversation topics

In addition to studying the structure of network relationships, the software has also been used to analyze the most repeated words in the information flow and their association with other terms. In this way, the most relevant threads of conversation have been discovered (see figure 4). The most important conversation line (in dark blue) refers to February 28th, the international day of RD, and is complemented by the second most significant association (in light blue in the image). Example:

“Raise awareness for #rare diseases! #ShowYourStripes with NORD on #RareDiseaseDay, coming up on Thursday, February 28! Learn how to get involved at <https://t.co/TfUgm5FA4i> <https://t.co/XOBI2le0yx>” (26/01/2019, 9:55).

The other main thread of conversation also refers to the day of rare diseases, specifically the zebra that is the symbol of RD in the USA (in dark green, orange, and red). Example:

“It's #InternationalZebraDay! 🐎 DYK that the zebra is the symbol of #rare diseases in the U.S.? Similar to how each zebra's stripes are unique, each of the 25-30M Americans living w/ #rare disease are unique. In honor of #RareDiseaseDay, #ShowYourStripes! <https://t.co/p0g5CEy1W0> <https://t.co/eb63sAvnpx>” (01/02/2019, 1:21).

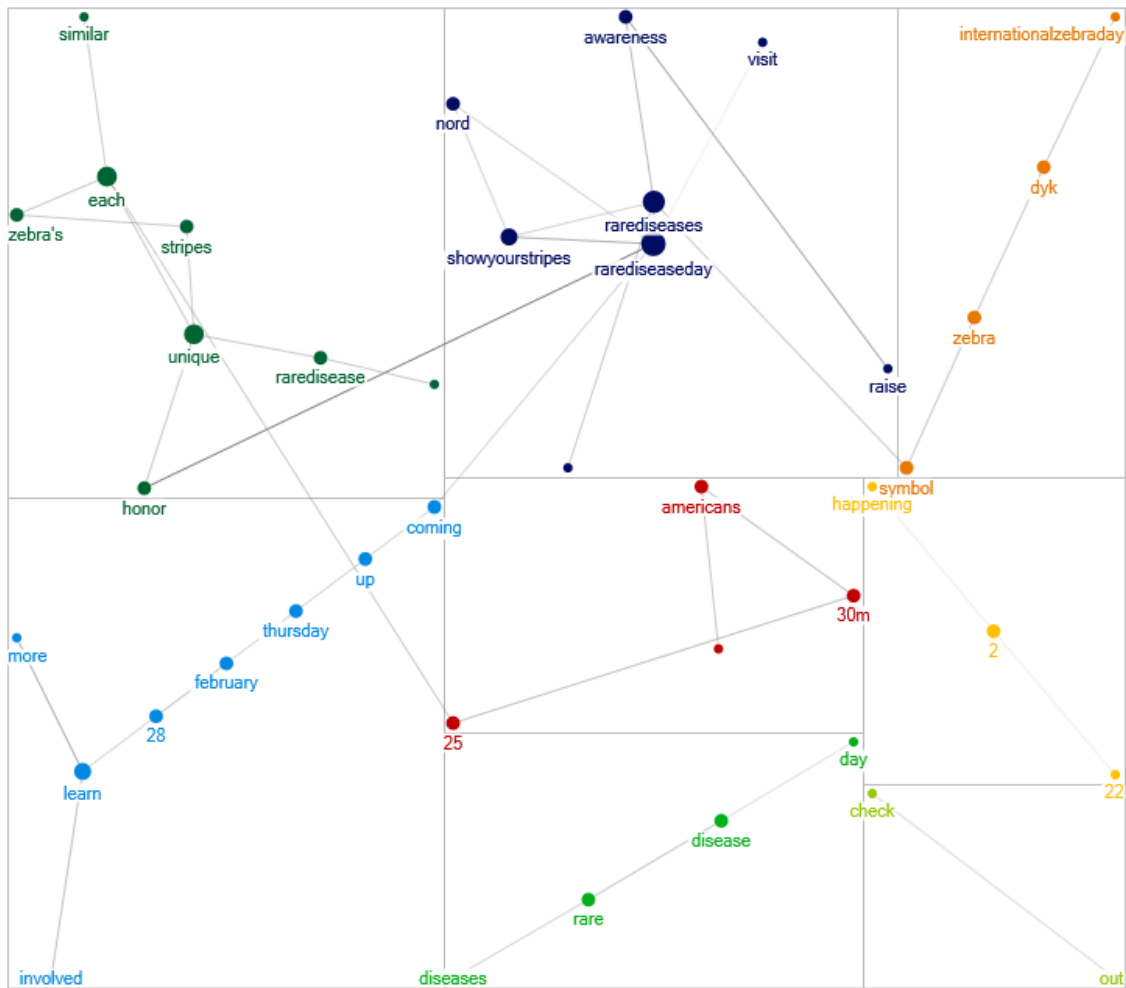


Figure 2: Most relevant conversation threads in the network surrounding NORD
Source: Self-made

6.2. The European Federation of Rare Disease Associations (EURORDIS)

The @eurordis account was created in March 2009 and is described as "An alliance of more than 800 rare disease patient organizations working together to improve the lives of the 30 million people living with a rare disease in Europe." It has 20,700 followers and has posted more than 4,469 messages.

6.2.1. Actors with more favorable positions in the network

Regarding the degree of intermediation, in the network relationship structure that surrounds EURORDIS, the profiles that have the greatest structural advantage belong to RD associations and foundations (@thezbfoundation, @ifsbh, @ERNithaca, and @bsyngap) or their leaders such as Jacqui Browne (@abrihouse) or Marleen aka Sparkles (@patientexpert). Likewise, a publication on health (@healtheuropa) or the account of the international day of RD (@rare diseaseday) should be noted.

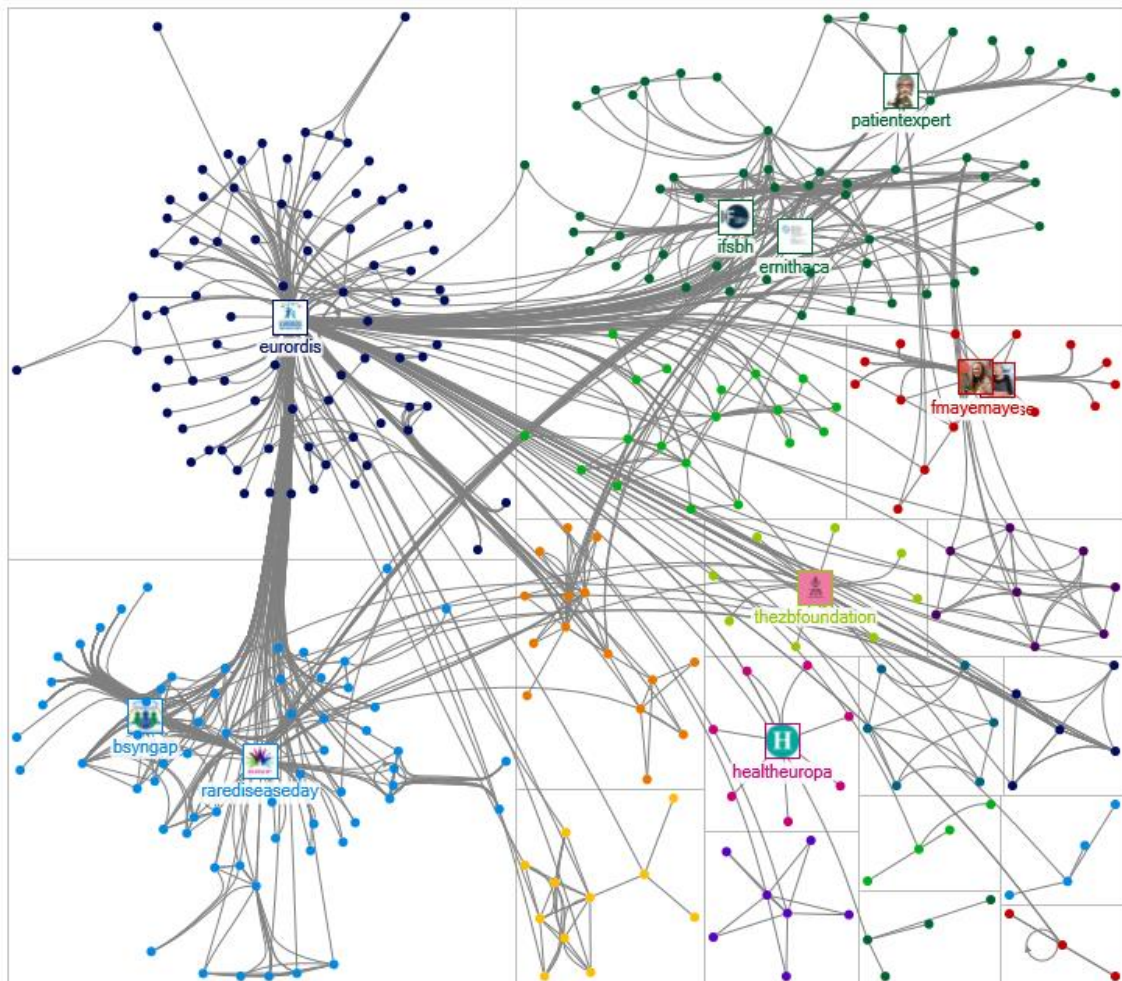


Figure 3: Visualization of the degree of intermediation
Source: Self-made

Another aspect of an advantageous structural position is the degree of closeness. The people who can reach others the fastest on the network surrounding @eurordis (besides itself) are shown below. In this sense, it is observed that the majority correspond to federations and reference networks of RD. It should also be noted that the account with the greatest degree of closeness is the RD Day account (@RareDiseaseDay), something that coincides with the NORD network and is related to its celebration on February 28th (the research was held three weeks before its commemoration). Likewise, the relationship between EURORDIS and the North American Organization for Rare Disorders is once again manifested, which, as mentioned, joined forces in 2010 and, among other things, agreed to promote Rare Disease Day as an event of international recognition.

1. @RareDiseaseDay: Rare Disease Day account (February 28th).
2. @RareDiseases: North American Organization for Rare Disorders
3. @ERNithaca: European reference network on congenital malformations and rare intellectual disability (ERN-ITHACA).
4. @ifsbh: World Organization for Spina Bifida and Hydrocephalus Associations.
5. @ERN_RARE_LIVER: Patients with rare liver diseases in Europe.
6. @RareDiseasesEU: It has been the Twitter account of 2 Joint EU Actions for RD: RD-ACTION and EUCERD JA.
7. @EU_Health: EU Commission on Health and Food Safety (SANTE). They work to protect the health, prevent diseases, and strengthen health systems.

8. @Metab_ERN: The European Reference Network for Rare Hereditary Metabolic Diseases.
9. @ern_reconnet: European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases.

Regarding the degree of prestige or authority, eight of the actors that occupied the first positions in the closeness metric are also the profiles with the most influence and, therefore, have a structural advantage in the network woven around EURORDIS. This indicates that there are no major inequalities in the centrality of the account when the degree of prestige is measured. Some positions change and it is necessary to mention two new actors:

- @SjogrenpowerAna: Ana Vieira. Patient with Sjögren's syndrome, which is an autoimmune disorder in which the glands that produce tears and saliva are destroyed. Member of the European League Against Rheumatism (EULAR).
- @bsyngap: Bridge the Gap Foundation. Related to SYNGAP1 mutations. This is one of the actors that occupied the top positions in the NORD network.

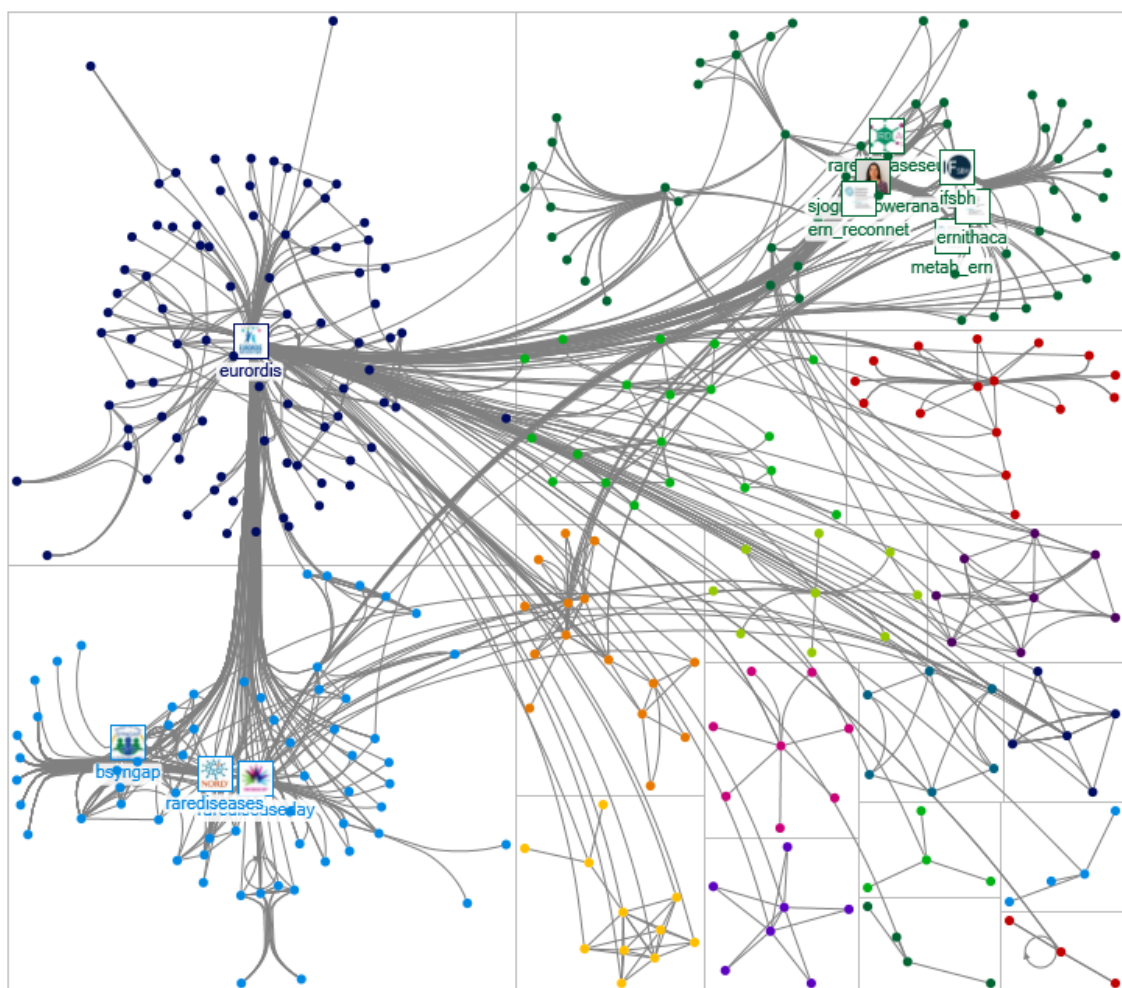


Figure 4: *Visualization of the degree of authority*
Source: Self-made

6.1.2. Interactions in the network that arose around EURORDIS

The graphs above allow us to easily observe the information flows that occur between users. 79.16% are mentions, 17.67% are retweets, 2.79% are responses, and 0.37% are tweets. The mention is the

majority form of relationship between the actors and the most mentioned (not counting @eurordis) were:

- @RareDiseaseDay: Rare Disease Day account.
Example: “Did you know that #RareDiseaseDay was founded by @eurordis in 2008? Learn more abt the international campaign on their Twitter account @rarediseaseday and visit their website for global campaign resources at <https://t.co/scuXryKFZq> <https://t.co/xqARgwjGLr>” (31/01/2019, 20:50).
- @RareDiseases: NORD’s account.
Example: “@GeneticAlliance @GeneticsGSA @_GeneTherapy @TheEllenShow @GlobalGenes @RareDiseases @eurordis @rarediseaseday @RareConnect @RareDR @raredisorders @McGill_rareDIG” (31/01/2019, 6:42).
- @rarediseasefdn: Rare Disease Foundation.
Example: “Are You Ready!? #RareDiseaseDay @RareDiseases @rarediseasefdn @eurordis @rarediseaseday #SYNGAP1 #neverstopping <https://t.co/fp06Jn7e9Z>” (26/01/2019, 17:45).

Again, the similarities with the network created around NORD should be noted. RD Day also occupies the first position here, followed by mentions of the North American Federation (they mention each other).

6.2.3. Most relevant conversation topics

In the network that surrounds EURORDIS, semantic networks have also been researched. The word associations present in the tweets have discovered different networks of meanings. The most important conversation line (in light green) refers to access to therapies to combat RD and presents a very strong connection with a symposium organized by the European federation on the subject. Example:

“Are you a clinician working within a European Reference Network? Register for the 3rd EURORDIS Multi-Stakeholder Symposium to learn more about the crucial role that #ERNs play in improving access to rare disease therapies. #RareEU2019 <https://t.co/0gxdDQrj8s> @ERNIthaca @Metab_ERN <https://t.co/UOmlv9KQSe>” (26/01/2019, 16:56).

The other main conversation thread (in dark green and completed with the light blue) is about how collaboration between different networks at the EU level can make a real difference in the lives of people living with a rare disease. Example:

“The European Reference Networks show that collaborating at EU level can make a real difference to the lives of people living with a rare disease #ERNs <https://t.co/ztxXqyRBuR>” (30/01/2019, 16:41).

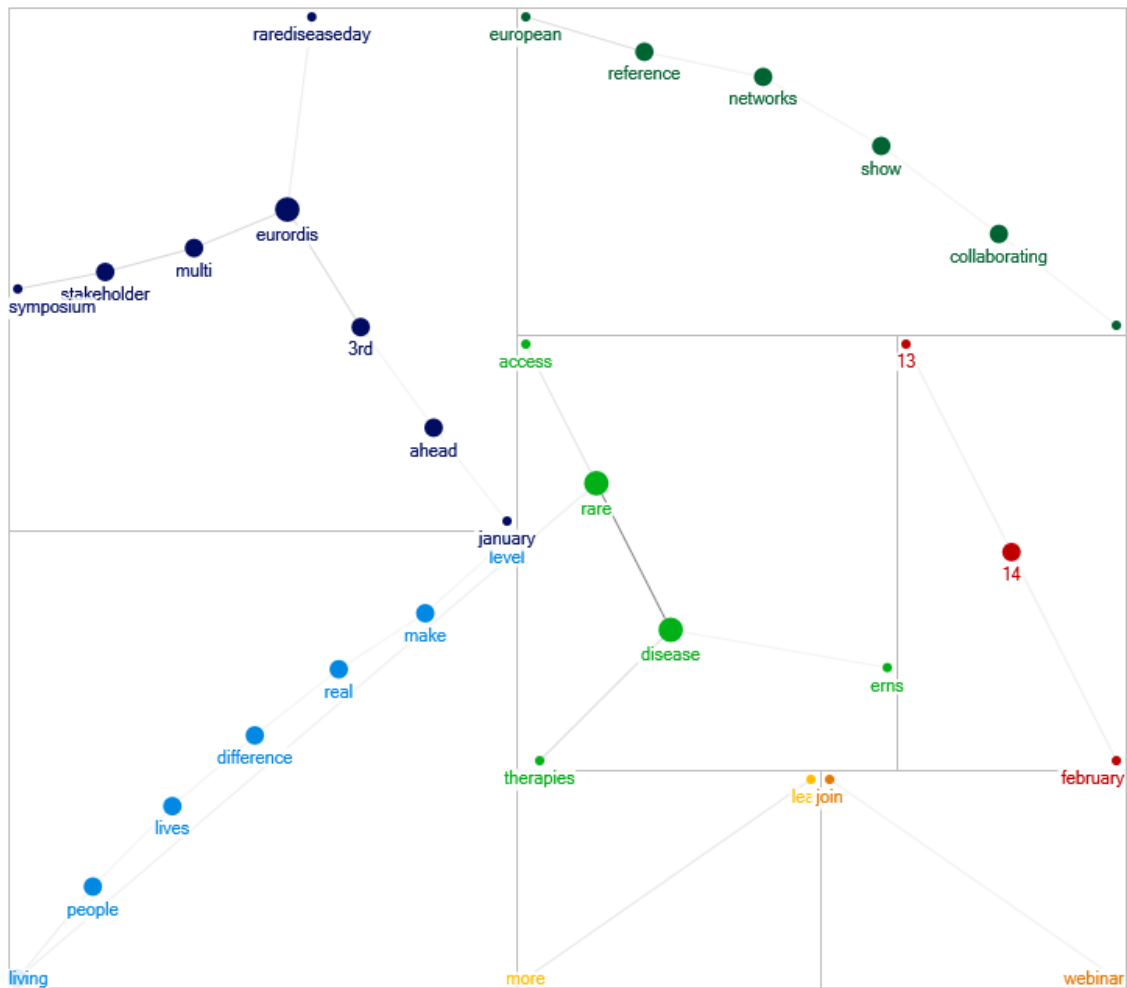


Figure 5: Most relevant conversation threads in the network surrounding EURORDIS
Source: Self-made

6.3. The Spanish Federation of Rare Diseases

The @FEDER_ONG account was created in January 2009, it has 29,400 followers and is the most active profile of the three studied since it has published more than 63,300 messages (six times more than NORD and 14 more than EURORDIS).

6.3.1. Actors with more favorable positions in the network

As mentioned above, the network that surrounds the Spanish federation is made up of 746 nodes. The actors that occupy the most favorable positions in terms of their degree of intermediation –that is, for a profile to be able to link to another with which it does not have a direct connection, it would have to resort to one of these intermediary actors- are the following: a runner related to the race for hope on March 3rd (@DavidRumbao); the founder of the National Association of Matrimonial Lawyers (@CesarMartAbgdo); the *Fundación Oír es Clave*/AG Bell International foundation (@oiresclave); a Catalan pediatrician (@crevertebover); the communication agency Sombradoble, author of a documentary about RD (@NoInvisibles); the biopharmaceutical company Sanofi Genzyme, the third-largest in the world (@RarasReales); an association of patients (@ffpaciente), or a nurse (@marisabarcelo), among others. These accounts had a high intermediation value, so it is considered that a large amount of non-redundant information passed through them.

If we consider the network in terms of the closeness of the actor –since the closeness and distance are a structural advantage– the accounts that can connect more quickly with the rest in the distribution that surrounds FEDER (besides itself) are:

1. @NoInvisibles: Account belonging to the ‘Rare but not invisible’ project, which began as a documentary to give visibility to minority diseases, people, and related research. It was a work carried out by the Sombradoble agency that currently tries to bring science, medicine, and technology to the public.
2. @RarasReales: Account created by Sanofi Spain, a company that is part of Genzyme Corporation, a biotechnology company based in Massachusetts and considered the third largest biotechnology company in the world.
3. @sanidadgob: Ministry of Health, Consumption and Social Welfare.
4. @ffpaciente: Patient association.
5. @nh487: Noah Higón Bellver. Jurist and political scientist affected by RD.
6. @Fundacion_ONCE: Foundation of the National Organization of the Spanish Blind.
7. @CIBERER: Center for Biomedical Research on the Network of #RareDiseases (CIBERER), dependent on the Carlos III Health Institute.
8. @lou_cordon: Lourdes Cordón. Biologist Ph.D., specialized in flow cytometry.
9. @espinmesado: David Mesado. Laboratory technician at the La Fe Health Research Institute.

In this case, contrary to EURORDIS and NORD, the proximity of the International Day of RDs does not reach the same relevance. First appears the profile of a documentary on RD, followed by a company that belongs to the third-largest biotechnology company in the world. In the third position is the Ministry of Health. The rest belong to patient associations, foundations, research centers, and their researchers or technicians.



Figure 6: *Visualization of the degree of closeness*
Source: Self-made

If we consider the network in terms of prestige –if a node is linked to important nodes, it will have a high "eigenvector" or "authority"- the best-connected accounts in the network that surrounds FEDER (besides itself) are almost the same that had a greater degree of closeness. This indicates that there are no major differences in the centrality of the network when the degree of prestige is measured. Some positions change and two new actors to be considered appear:

- @LFdCesmas: *La Fuerza del Corazón* is a network that brings together the various social causes that are supported by the singer Alejandro Sanz, including FEDER.
- @ilunion: ONCE business group for the social insertion of people with disabilities. It has a staff of 32,000 workers.

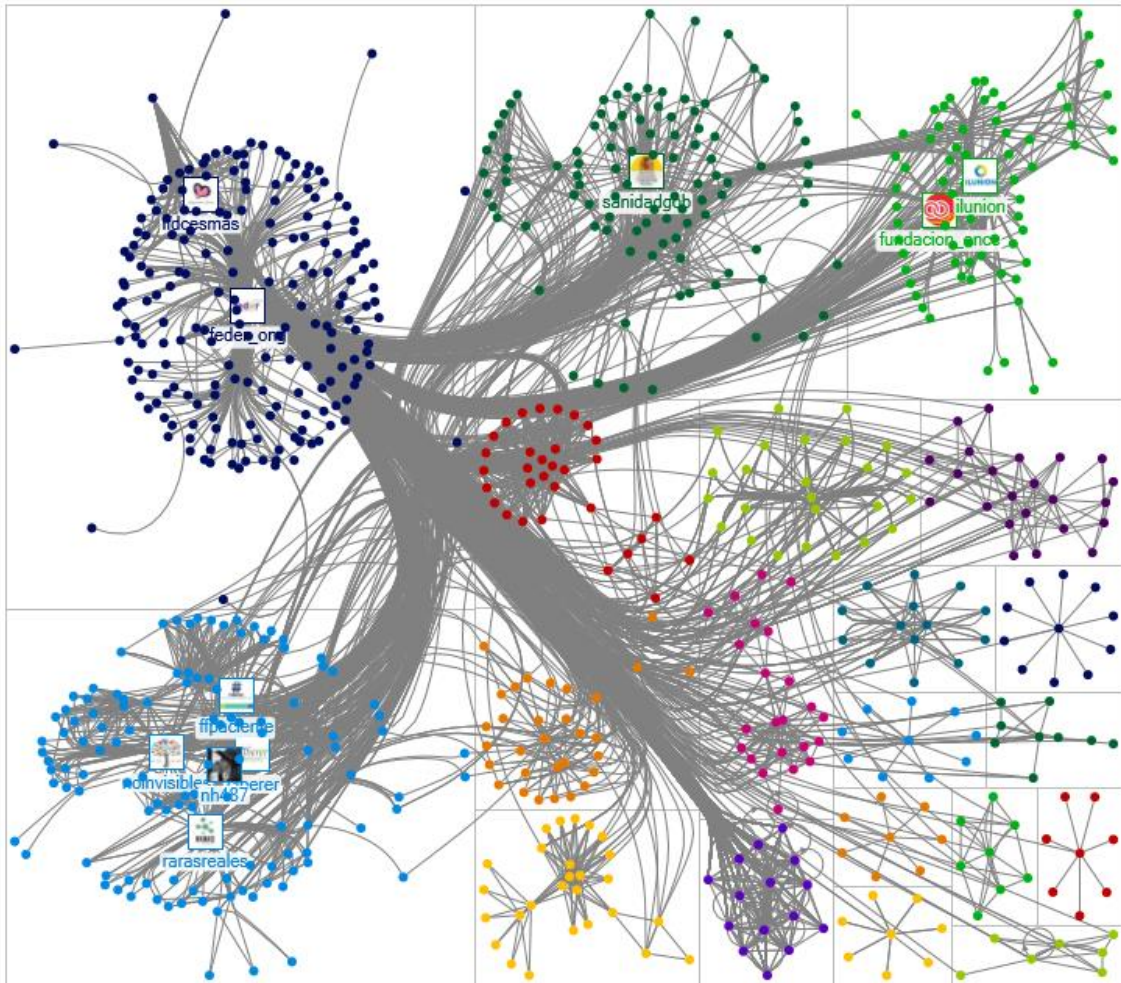


Figure 7: Visualization of the level of authority
Source: Self-made

6.3.2. Interactions in the network that arose around FEDER

In the @FEDER_ONG account, mention stands out as a preferred form of relationship (73.23%), followed by retweets (22.03%), responses (3.61%), and tweets (1.11%). If we exclude the account under study, the most mentioned actors were:

- @AlejandroSanz: Spanish singer who has sold millions of records worldwide and has won multiple Grammy Awards. Example:
“Lo estabais esperando y ya está aquí, el cartel oficial de la X Carrera 🏃🏃🏃🏃 por la esperanza de las #EnfermedadesRaras ¡El 3 de Marzo te esperamos en la Casa de Campo de Madrid! @FEDER_ONG @LFdCesmas @alejandrosanz <https://t.co/yDHEl7JWyf> <https://t.co/YgqfTGfKTx>” (27/01/2019, 10:22:23).
- @LFdCesmas: Network that brings together the various social causes supported by the singer Alejandro Sanz, including FEDER. Example:
“Están todos invitados @FEDER_ONG #enfermedadesraras @AlejandroSanz @VienedelAireARG @LFdCesmas #JuntosSomosMás <https://t.co/6ZVHQFCqdm>” (27/01/2019, 14:54).
- @NoInvisibles: Account belonging to the documentary ‘Rare but not invisible’. Example:

“Este viernes 1 de Febrero tendrá lugar una Jornada sobre la Enfermedad de #Huntington en Las Palmas de Gran Canaria. Os animamos a que asistais y acompañéis a parte de nuestra junta directiva que participará y asistirá a dicho evento. @FEDER_ONG @NoInvisibles RT <https://t.co/Pr8CgxEPur>” (29/01/2019, 12:37).



The results show that the network of relationships that surrounds FEDER is similar to that of EURORDIS and NORD, with mention as a form of interaction predominant in the three studied profiles. In contrast, there is no reference to the account of the International Day of RD, despite its proximity in time.

6.3.3. Most relevant conversation topics

In the network that surrounds FEDER, semantic networks have also been researched, which have made it possible to represent through an image how words are interrelated. Figure 10 offers an idea of the connections between different terms where the nodes are the concepts or words and the semantic or meaning links are shown by lines. In the image, you can see that some words are more connected than others. The association (in orange) of FEDER with @RarasReales (the third largest biotechnology company in the world), @NoInvisibles (the documentary 'Rare but not invisible'), @ALBA_albinismo (association to help people with albinism), @FundacionMehuer (foundation for orphan medicines and RD), @CIBERER (RD Biomedical Research Center), @ffpaciente (association of patients), and @fundacionhp (foundation against pulmonary hypertension) stand out. Example:

“Comienza la cuenta atrás para el Congreso #MHER19. El acceso equitativo a los tratamientos, los avances en nuevas terapias o los casos sin diagnóstico, entre los contenidos más relevantes de esta cita, que organizamos junto a @FundacionMehuer y @FEDER_ONG. <https://t.co/DXDIwKFx4Q>” (01/02/2019, 9:21).

The second association of words present in the tweets refers to the X Race for Hope of people with RD that was going to be held on March 3rd (the color red), where the singer Alejandro Sanz and his foundation to support solidarity causes appear, and which is completed with information about the official poster (in light blue). Example:

“@FEDER_ONG Lo estabais esperando y ya está aquí, el cartel oficial de la X Carrera  por la esperanza de las #EnfermedadesRaras ¡El 3 de Marzo te esperamos en la Casa de Campo de Madrid! #JuntosSomosMás @AlejandroSanz  <https://t.co/FgiHXCiibY> <https://t.co/DtHBUAGWjG>” (28/01/2019, 3:04).

At the same time, another group that presents a strong connection (in dark green) refers to World RD Day that is celebrated on February 28th. Example:

“Comienza la cuenta atrás, quedan 28 días para celebrar el Día Mundial de las Enfermedades Raras <https://t.co/DfY2OyCyFm>” (31/01/2019, 10:34).

Another significant conversation thread (in dark blue) is related to the solidarity payroll program ‘*Gracias a Ti*’, a project to support the work of the Spanish Federation of Parents of Children with Cancer, the Josep Carreras Foundation, and the REMAR Association. Example:

“Hoy con una parte de mi sueldo, apporto mi granito de arena junto al programa de nomina solidaria #GraciasATi a seguir trabajando por un mundo mejor. Enhorabuena a las entidades @FEDER_ONG @AlzheimerEsp @FundAladina <https://t.co/V378Xneouy>” (04/02/2019, 11:39).

This initiative is related to the ONCE Foundation and its ILUNION hotels since it was their workers who participated in the activity. Example:

of indicators allowed to specify the three analyzed accounts' ability to influence since they provided information on the high level of commitment (engagement) and amplification of the message that they achieved among their users due to the interest that these pathologies arouse and everything that surrounds them.

The most active profile was that of the Spanish federation, despite having a tenth of those affected by rare diseases than Europe or the United States. In any case, the other two also registered adequate levels of activity, something that is important because publishing updated content is the best way to retain users and make a profile influential (Pérez, Santos, and Meso, 2015).

Using NodeXL it was possible to capture the virtual communities gathered on Twitter around these issues. When considering the network in terms of intermediation, closeness, or authority, the study demonstrated H1 as it found that among the profiles that presented the greatest structural advantage in the network, patient associations, foundations, biopharmaceutical companies, research centers, and their researchers or technicians who used the networks to make visible promotional activities, raise funds, or disseminate the research predominated (above those affected).

Likewise, the relationship between EURORDIS and NORD was made manifest, which, as mentioned above, joined forces in 2010 and, among other things, agreed to promote Rare Disease Day as an event of international recognition. The time proximity of this event (there was less than a month left for its celebration) made it the protagonist of a large part of the publications in both entities. In FEDER, concerning the degree of intermediation, unlike with EURORDIS and NORD, the proximity of the International Day of RD did not reach the same relevance, nor did the other two organizations appear in the first positions. In the Spanish case, the presence of Sanofi Spain should be highlighted, a company that is part of Genzyme Corporation, the third-largest biotechnology company in the world.

If we consider the network in terms of authority, the best-connected accounts in the network that involved the three studied profiles were almost the same ones that obtained a greater degree of closeness. This indicates that there were no major differences in the centrality of the network when the degree of prestige was measured.

In this specific study, by mapping the network of the three RD federations, besides identifying the Twitter users who were the most influential, the visualization showed how users in different groups had specific conversations in which they talked about different topics. The software allowed to represent through an image how the words were interrelated and demonstrated the H3 since these associations used social networks to sensitize, educate, and inform about RD and their problems. In NORD the most connected terms were related to the publicity of the International Day of RD and in EURORDIS it was with a symposium about access to therapies to combat RD. Finally, in FEDER the main words included the promotion of the race for the hope of the RD, where one of the most relevant actors were the singer Alejandro Sanz and his foundation.

Finally, it is hoped that this work will serve as a valuable resource for future researchers who can use the SNA technique to obtain information on how users talk about certain topics and study how networks are structured. It should be mentioned that this work has focused on NodeXL, but that other tools can be used for the analysis of social networks such as DMITCAT (Felt, 2016) or Gephi (Mochon, 2016), among many others.

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Text for the video (form 500)

In this work, SNA has been used as a methodological instrument to study the network structures that surround the rare disease associations NORD, EURORDIS, and FEDER and identify the most influential users on Twitter.

The three entities have profiles that bring together between 20,000 and 30,000 followers, an amount that may be small if one takes into account that it is estimated that in Spain there are 3 million individuals with RD, 30 million affected people in Europe, and another 30 million in the U.S.A. But having or not a broad base of followers only offers an approximate orientation of the influence that a profile can reach and, in this sense, it is of greater interest to examine metrics such as the number of mentions, retweets, or likes achieved by these profiles. In this case, all three accounts are very successful with users, as between 60 and 80% of their messages are marked as favorites and achieve similar forwarding and mentioning rates. In this sense, and regarding the type of links that emerged in the network, the use of the mention as a mode of interaction between users prevailed (it included the retweet following Suh, et al., 2010). These types of indicators allowed to specify the three analyzed accounts' ability to influence since they provided information on the high level of commitment (engagement) and amplification of the message that they achieved among their users due to the interest that these pathologies arouse and everything that surrounds them.

The most active profile was that of the Spanish federation, despite having a tenth of those affected by rare diseases than Europe or the United States. In any case, the other two also registered adequate levels of activity, something that is important because publishing updated content is the best way to retain users and make a profile influential (Pérez, Santos, and Meso, 2015).

Using NodeXL it was possible to capture the virtual communities gathered on Twitter around these issues. When considering the network in terms of intermediation, closeness, or authority, the study found that among the profiles that presented the greatest structural advantage in the network, patient associations, foundations, biopharmaceutical companies, research centers, and their researchers or technicians who used the networks to make visible promotional activities, raise funds, or disseminate the research predominated (above those affected).

Likewise, the relationship between EURORDIS and NORD was made manifest, which, as mentioned above, joined forces in 2010 and, among other things, agreed to promote Rare Disease Day as an event of international recognition. The time proximity of this event (there was less than a month left for its celebration) made it the protagonist of a large part of the publications in both entities. In FEDER, concerning the degree of intermediation, unlike with EURORDIS and NORD, the proximity of the International Day of RD did not reach the same relevance, nor did the other two organizations appear in the first positions. In the Spanish case, the presence of Sanofi Spain should be highlighted, a company that is part of Genzyme Corporation, the third-largest biotechnology company in the world.

If we consider the network in terms of authority, the best-connected accounts in the network that involved the three studied profiles were almost the same ones that obtained a greater degree of closeness. This indicates that there were no major differences in the centrality of the network when the degree of prestige was measured.

In this specific study, by mapping the network of the three RD federations, besides identifying the Twitter users who were the most influential, the visualization showed how users in different groups had specific conversations in which they talked about different topics. The software allowed to represent through an image how the words were interrelated and demonstrated that these associations

used social networks to sensitize, educate, and inform about RD and their problems. In NORD the most connected terms were related to the publicity of the International Day of RD and in EURORDIS it was with a symposium about access to therapies to combat RD. Finally, in FEDER the main words included the promotion of the race for the hope of the RD, where one of the most relevant actors were the singer Alejandro Sanz and his foundation.

Finally, it is hoped that this work will serve as a valuable resource for future researchers who can use the SNA technique to obtain information on how users talk about certain topics and study how networks are structured. It should be mentioned that this work has focused on NodeXL, but that other tools can be used for the analysis of social networks such as DMITCAT (Felt, 2016) or Gephi (Mochon, 2016), among many others.