



#EULAR2018: The Annual European Congress of Rheumatology—a Twitter hashtag analysis

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Abstract

The objective of this study was to explore the hashtag #EULAR2018 on Twitter during the period of the European League Against Rheumatism (EULAR) Annual European Congress to better comprehend the implications and patterns of social media (SM) data and their possible impact on users interested in rheumatic and musculoskeletal diseases. A mixed methods study combining SM performance data with qualitative content analysis of tweets was conducted. All the tweets publicly posted with #EULAR2018 were tracked using Symplur™ and Keyhole. Parameters such as number of users, engagement, reach, impressions, gender, source used to tweet, type of post, countries, trending topics, and main themes were analyzed. A total of 10,431 tweets using #EULAR2018 were tracked. Most of them were original and reached by > 2,950,000 users. Some of the retweets came from non-attendees to the congress. Males tweeted more than females; however, this gender disparity was not notable among the influential users. “Patients” were identified as the key topic. Sharing knowledge from the in situ congress, marketing or advertising, and sharing experiences or thoughts were identified as the main themes. Some dissonances between EULAR discourse and behavior that require further attention were identified. The EULAR congress is a staggering source of information with the potential of generating debate and promoting new practices in the rheumatology field, regardless of the place of origin of the users exposed to it, or whether or not the users attended the congress. EULAR should recognize the value and power of these data and incorporate them in the benchmarking of challenges and opportunities for the organization.

Keywords EULAR · Social media research · Twitter · Qualitative research · Rheumatology

Introduction

The European League Against Rheumatism (EULAR) is a pan-European organization fostering a wealth of activities in areas of research, patient care, and education [1].

Since 2000, EULAR celebrates the annual European Congress of Rheumatology which has become the primary platform, worldwide, for the exchange of scientific and clinical information on rheumatic and musculoskeletal diseases (RMDs) facilitating the interaction between medical doctors, scientists, people with arthritis/rheumatism, health professionals and representatives of the pharmaceutical industry [2].

In the last 2 decades, social media (SM) have been gaining presence and acceptance in society. SM are web-based platforms that allow individuals, communities, and organizations to collaborate, connect, interact, and build a community by enabling them to create, co-create, modify, share, and engage with user-generated content that is easily accessible [3, 4].

Many institutions hold accounts in SM platforms, and EULAR is not the exception. Among all, it is on Twitter, a microblogging SM that focus on short updates that are released publicly, where EULAR is more active. Since 2010, the annual congress has been documented on SM by the incorporation of the hashtag—a word or phrase preceded by a hash sign (#), used to identify messages on a specific topic—EULAR preceding the year of the congress, e.g., #EULAR2018 [5]. In addition, since 2015 and a month before the annual congress, the Emerging EULAR NETWORK (EMEUNET) Social Media Subgroup celebrates the “10 Days of Twitter Course #EMEUN10DoT” aimed at

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people who wish to learn the basics of using Twitter and explore its relevance and potential in the context of education and networking. This year the EULAR Twitter official account (@eular_org) encouraged users to use the hashtag #EULAR2018 during the annual congress. However, the participants had to follow and respect the rules and regulations of the social networks developed for it (http://congress2018.eular.org/myUploadData/files/EULAR_2018_Social_Media_Rules_and_Regulations_final.pdf). The congress was held in Amsterdam from June 13 to June 16 with an approximate attendance of 14,000 participants from 130 countries and a scientific program with 176 sessions, 560 speakers and, 32 industry-supported scientific symposia [2].

Despite having started documenting the annual congress activity on Twitter, no formal in-depth analysis has been performed and published with this SM data, in contrast with other medical congresses [6–14]. For that reason, the objective was to explore and analyze the hashtag #EULAR2018 during the period of the annual congress to better comprehend the implications and patterns of SM data, and their possible impact on users with interest in RMDs.

Methods

Study design

A mixed methods study combining SM performance data with qualitative content analysis of tweets was conducted. All the tweets publicly posted with the congress official hashtag #EULAR2018 during the EULAR Annual European Congress of Rheumatology were tracked with Symplur™ (<http://www.symplur.com>) and Keyhole (<http://www.keyhole.co>). The hashtag was monitored from June 13 (9:00 a.m.) to June 16 (4:00 p.m.) with an initial analysis focused on tweet statistics during the congress. The following parameters were measured and are defined in Table 1: number of users, engagement, reach and impressions. It is important to highlight that, despite similar definitions, reach and impressions are not the same. Reach is the number of people who have seen the tweet, while impressions are the number of times the tweet was seen. The same concept exists in other scenarios, such as web analytics, where a metric shows how

many times a webpage was viewed (pageviews) vs. how many people viewed it (visitors). In fact, visitors are to reach as pageviews are to impressions [15, 16]. In addition, usage statistics such as gender of the users, source used to tweet, type of post, and country were obtained.

Another important feature in the SM is influence. Studying influence patterns can help to better understand why certain trends or innovations are adopted faster than others and how we could help advertisers and marketers design more effective campaigns [17]. Traditional communication theory states that a minority of users, called influentials, excel in persuading others [18]. This theory predicts that by targeting these influentials in the network, one may achieve a large-scale chain-reaction of influence driven by word-of-mouth, with a very small marketing cost [17–19]. Influential users during the congress were identified using the following measures: engagement, klout, and frequency; which are defined in Table 2.

SM data inherently create specific challenges presented as the 6Vs: (1) volume—the sheer amount of data being produced on SM platforms, (2) variety—the multimodal nature of the data including text, videos, geospatial check ins, and audio, (3) velocity—the speed at which SM data are generated and how quickly users respond to real-world events, (4) veracity—primarily concerned with the accuracy, reliability and quality of the data, (5) virtue—ethics and (6) value—an assessment of how SM data increase our understanding of the social world by opening hitherto unavailable avenues of research and/or augmenting existing work through access to new data [3, 20]. For this reason, all the numbers regarding tweet statistics presented in this work should be taken as approximations of the real values and not as the real values.

Regarding the qualitative content analysis, transcriptions of the tweets were obtained by triangulation of data sources using Symplur™, Keyhole, and ATLAS.ti (GmbH, Berlin, v.8) software [21]. Transcriptions were merged and debugged reducing the total number of tweets. An analysis of trending topics with subtopics was performed.

In addition, for a more in-depth content analysis and to allow the inclusion of tweets disregarding the day of the congress, tweets were assigned a number from 1 to 10,425. RANDOM.ORG (<https://www.random.org/>) was used to randomly generate 1000 numbers which were then

Table 1 Statistics of the tweets using #EULAR2018

Measure	Definition	Total
Users	The number of users who have posted with the tracked hashtag	> 1233
Engagement	The number of times someone intentionally interacts with a post with the tracked hashtag (likes, comments and/or shares)	> 2686
Reach	The number of unique users who have seen posts containing the tracked hashtag	> 2,950,000
Impressions	The numbers of times that users have seen posts containing the tracked hashtag	> 14,270,000

Table 2 Top five influential users by different measures

Measure of influence	User	Brief description
Engagement—determined by the number of likes and shares they have earned for posts containing the tracked hashtag	@genentech	Official Twitter site for Genentech. Pharmaceutical company in the US
	@jcnietogon	Male Spaniard rheumatologist interested in ultrasound and pediatric rheumatology
	@etrujillomartin	Female Spaniard rheumatologist
	@psufka	Male US rheumatologist and startup advisor. Interested in healthcare technology
	@creakyjoints	Community of people with rheumatic diseases in the US
Klout—determined by Klout score, which is a ranking algorithm ranging from 0 to 100 that quantifies social influence	@thelancet	Official Twitter site for The Lancet. General medical journal
	@ucb_news	Official Twitter feed of UCB, a global biopharmaceutical company
	@genentech	Official Twitter site for Genentech. Pharmaceutical company in the US
	@boehringer	Global Twitter channel for Boehringer Ingelheim. Pharmaceutical company in Germany
	@conarthritis	Spaniard national arthritis coordinator
Frequency—determined by the number of times they have posted within a set time period	@lillyrheumeu	Official Twitter site for Eli Lilly and Company. Pharmaceutical company in the UK
	@carmona_loreto	Female Spaniard rheumatologist, epidemiologist and researcher
	@creakyjoints	Community of people with rheumatic diseases in the US
	@chriswincup	Male clinical researcher and rheumatologist from the UK
	@emeunet	Official Twitter site for EMEUNET, a EULAR working group of young clinicians and researchers in rheumatology

paired with their corresponding tweets and included for a more in-depth analysis—this helps to reduce the possibility of mistakenly achieving data saturation. Tweets were analyzed with ATLAS.ti, for which the author is a certified trainer.

Data codification was divided into first and second cycles of coding methods. The first cycle enclosed in vivo coding, initial coding, and/or values coding which are often recommended as a method of attuning to the participants language and perspectives. In the second cycle, data coded in the previous cycle were reorganized, recoded and analyzed with pattern coding and focused coding to identify emerging themes or explanations [22]. The codification cycles finished when data saturation was achieved—in-depth analysis of 790 tweets randomly selected—and no new themes emerged.

Ethical approval was not needed because all the tweets studied were published by users with public accounts in the public domain.

Results

A total of 10,431 tweets using #EULAR2018 were tracked. Figure 1 shows a summary of the daily distributions.

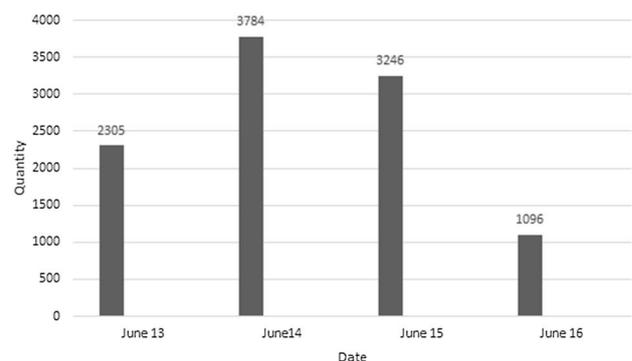


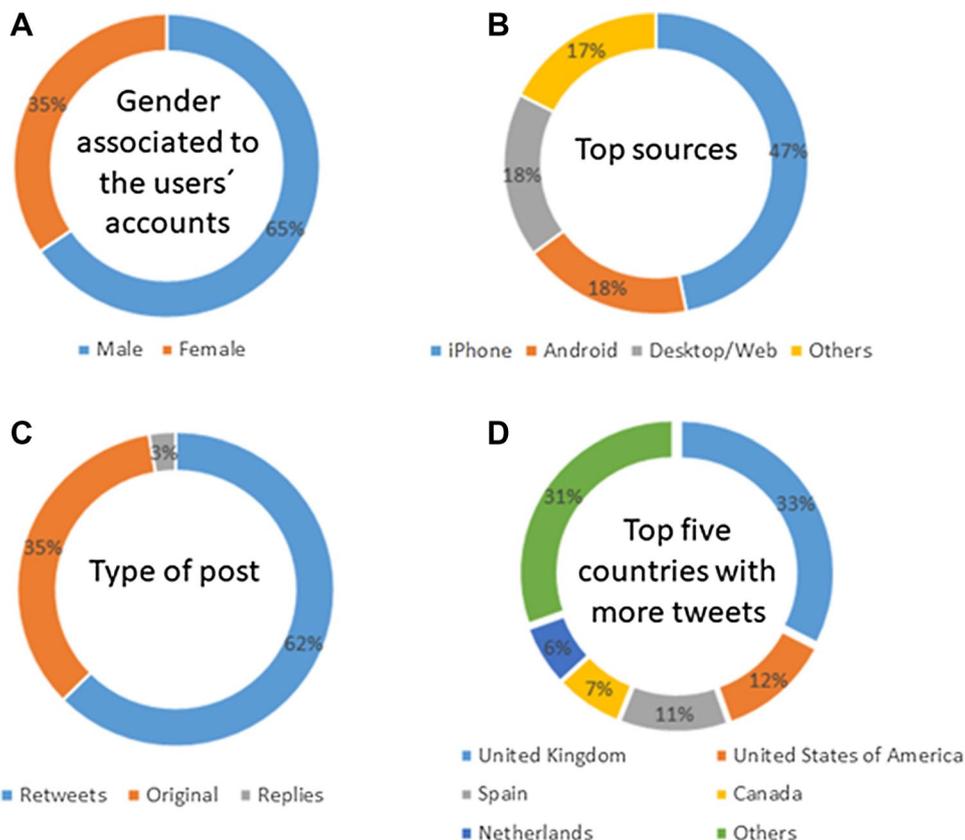
Fig. 1 Daily distributions of tweets using #EULAR2018 during the EULAR Annual European Congress of Rheumatology

#EULAR2018 statistics

Table 1 shows the basic statistics of the tweets tracked using #EULAR2018.

In addition, Fig. 2 shows the usage statistics of the tweets using #EULAR2018. Most tweets were posted by males and iPhones were the preferred device to tweet. Original tweets were more frequent than retweets and replies. Interestingly, some of the retweets and replies came from people who identified themselves as non-attendees to the congress. However, in-depth data of

Fig. 2 Usage statistics of the tweets using #EULAR2018



non-attendees involvement is missing. Users from the United Kingdom (UK), United States of America (US), and Spain were responsible of 56% of all tweets.

Table 2 shows the top five influential users by different measures.

#EULAR2018 content analysis

After merging transcriptions and filtering by noise, e.g., Amsterdam, EULAR, combinations of the top three trending topics with subtopics were identified (see Fig. 3).

In addition, in a more in-depth analysis, three main themes were identified: (1) sharing knowledge from the in situ congress—encompasses any post that shared information from the oral presentations or poster sessions of the congress, (2) marketing or advertising—encompasses any post that promoted any brand or any type of intervention (pharmacological and nonpharmacological), and (3) sharing experiences or thoughts—encompasses any post referring to experiences or thoughts related to the congress. All tweets can be categorized into one or more of the previously mentioned themes, which means that in some cases a theme can co-appear with another. Misinformation and trolling, common practices in SM, were not recognized in the data.

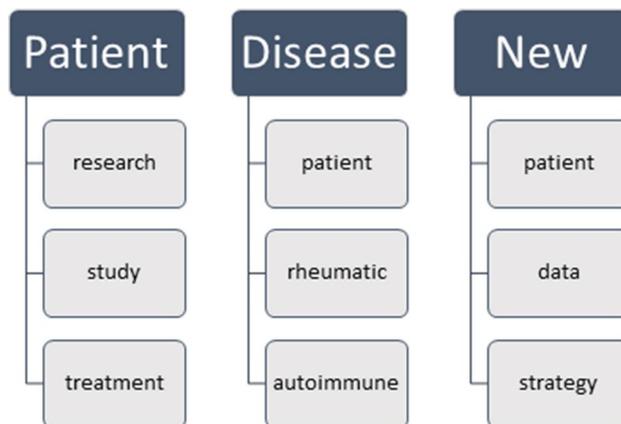


Fig. 3 Combinations of the top three trending topics with subtopics

Discussion

A total of 10,431 tweets were tracked using #EULAR2018. In comparison with similar studies, this is the highest amount of tweets registered for a medical congress [6–14]. #EULAR2018 generated a 63% SM original public content that was reached by millions of users. This amount of content and participation can contribute to change the

perception of rheumatology from a black box to something more accessible to young physicians, people with RMDs, other health professionals, and the general public [23]. Mobile phones were the preferred devices to post content with more than half of the tweets posted by iPhone or Android users. This reflects our social reality where wearable technology devices are becoming an essential part of our daily lives. To maximize the creation of original content, EULAR should encourage a mobile-friendly user environment in which the free exchange of information is allowed. Confusion for attendees may arise if speakers request not to take pictures, but at the same time, they are continuously encouraged to tweet. Ambiguous information may cause attendees to desist from sharing information on the SM to avoid potential conflicts. EULAR should be clearer on this matter to ensure a fruitful information exchange.

A greater part of the tweets came from five countries and were posted in English and in Spanish. A curious case was observed in the tweets from Spain where three scenarios emerge: some of the users posted directly the original information in English; others posted twice the same information, first in English and then a translated version in Spanish; others posted directly a translated version in Spanish. Translating the original information can be useful or useless, depending on the skills of the translator. This should be taken carefully because a good translation may help to break the language barrier, but a poor translation can lead to misinformation.

Regarding gender, males tweeted more than females. There is no logical explanation for this gender imbalance, but in SM the importance does not rely on how much a person of a determined gender tweeted, but in the number of users that interact with or react to those tweets. The influencers or influential users can enhance those interactions. The top five influential users by different measures were identified. These were rheumatologist of both genders, associations of people with RMDs, an association of clinicians and researchers, pharmaceutical companies and a scientific journal. It is important to highlight that influence is not gained spontaneously or accidentally but through concerted effort, such as limiting tweets to a single topic [17]. To magnify the reach of the information shared in the SM, EULAR should create formal collaborations with those influential users.

In addition, misinformation, deception and trolling were not recognized in the data. Similar studies on information dissemination during medical conferences showed that Twitter was used to discuss medical education themes related to the conference more often than for any other purposes [7, 24, 25].

From the qualitative content analysis, three trending topics—Patient, Disease, New—with their respective subtopics were identified. However, the Patient topic (Patient

research, Patient study, Patient treatment) called the attention because it was the only topic also paired as subtopic—Disease patient, New patient. This highlights the central role of the patients in EULAR. This was not a surprise because a unique feature of EULAR is being held on three pillars: medical doctors/scientists, health professionals, and people with RMDs, representing a broad audience and ensuring that voices from all relevant stakeholders are heard [1, 2, 26].

Nevertheless, there is a dissonance between the vocabulary proposed by EULAR and the vocabulary used in the congress. EULAR has increased the awareness of the importance of using the term “people with RMDs” instead of “patients”, but the data show that this practice is not well expanded despite the directly expressed desire of the people with RMDs of not being labeled as “patients”. Language is about daily interactions in the social construction of reality and labeling people in this way and against their will is the most common way in which the healthcare institutions dehumanize those they are supposed to care for [27, 28]. As social reality is changed and forced to be reconstructed, the language which accompanies it also changes [27, 29, 30]. The data suggest that we must make a conscious effort to extinguish the language that establishes distance by turning people into objects. The term “patient/patients” should be replaced by “people with RMDs/person with RMD”. To reduce the negative connotations, a similar effort was taken in the medical community with the term “compliance” which has evolved into “concordance”, and more recently into “adherence” [31]. As other researchers have pointed out, language both reflects and shapes our thinking and thus our behavior and discourtesy cannot be the basis on which a healing relationship is built [28, 32, 33].

From a more in-depth analysis, three main themes were identified: sharing knowledge from the in situ congress, marketing or advertising, and sharing experiences or thoughts. There was a large virtual participation in the multiple conferences of the congress. Using direct citations of the oral presentations and posters was the most frequent method to share the in situ conference knowledge. In some cases, pictures of graphics and tables were also posted to provide a clearer context and promote debate. Pharmaceutical companies lead the effort in the advertising, sharing information about their medications and latest research. However, there was also nonpharmacological advertising in the form of information, e.g., benefits of being part of an association, promotion of psychological care, or of exercise-based interventions. In addition, attendees shared extensive information and experiences. Twitter users provided an environment for public debate and critical thinking, allowing an opportunity for knowledge exchange and learning. There was a great amount of discussion in which non-attendees actively participated and exchanged information with attendees. Prior works have shown a high participation of non-attendees, indicating that

clinical information relevant to the practice might be useful beyond the confines of the conference [6, 8, 9, 14, 25]. Data have shown that modern web-based communication technologies have the potential to add another dimension to the conference experience for speakers, delegates and others who are not able to attend in person; they also give the attendees the opportunity to access information from parallel sessions that would otherwise have been missed [14]. The large amount of shared information pushes EULAR to rethink their role in the SM and to move forward to a more organized index that would allow an easier retrieval of SM data. In this sense, EULAR should adopt the usage of secondary hashtags for each of the topics or sessions; this will not only allow a more complex SM data categorization but will also work as a content filter. For example, this year, OMERACT started documenting the conference activity on Twitter with the hashtag #OMERACT2018 but, for the oral presentation of the Polymyalgia Rheumatica (PMR) Special Interest Group, the activity was registered as #OMERACT2018 #PMRSigSummary. Predetermined official secondary hashtags coexisting with the primary hashtag provide context to SM data which is essential for an insightful analysis.

The behavior of SM users can be studied through two different ways: asking the users to self-report their behavior or by looking directly at their behavior. In rheumatology, the first one has been studied, but this work is the first study assessing directly their behavior during the EULAR annual congress [34]. The study limitations are all those related to the 6Vs. However, the SM platforms are in constant development and the emergence of new technologies in the upcoming years might be able to reduce some of the challenges of the 6Vs. Despite the potential challenges, SM are inevitably claiming a role in modern rheumatology [35]. Future studies should triangulate data by a combination of self-report behavior by the users and direct observation of their behavior; this might provide a more complete picture and a better understanding.

Some SM researchers have claimed that SM and the phenomena that emerge within it are closely interlinked to other spheres of life [36, 37]. Moreover, SM data serve as a mirror which gave the institutions the opportunity to see themselves with external eyes or what is known as “bird’s eye view” which means looking at something with distance to have a wider perspective. This broad view helps to bring to consciousness the existing dissonances in the institutions and gave them the opportunity to adopt new practices and models to reduce them.

In summary, the EULAR congress is a staggering source of information with the potential of generating debate and promoting new practices in the rheumatology field, regardless of the place of origin of the users exposed to it, or whether or not the users attended the congress. EULAR

should recognize the value and power of these data and incorporate them in the benchmarking of challenges and opportunities for the organization.

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Author contributions JB: conceived, planned, and conducted the study. He was also in charge of the data analysis, the interpretation of the results, the writing of the manuscript, and its revision.

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Compliance with ethical standards

Conflict of interest Dr. Negrón reports personal fees and Grants from the European League Against Rheumatism outside the submitted work.

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