

# Content analysis of Twitter in relation to biological treatments for chronic inflammatory arthropathies: an exploratory study

Noemí Martínez-López De Castro,<sup>1,2</sup> Marisol Samartín- Ucha,<sup>1,2</sup> Alicia Martín-Vila,<sup>1</sup> Miriam Álvarez-Payero,<sup>1,2</sup> Guadalupe Piñeiro-Corrales,<sup>1</sup> José M Pego-Reigosa<sup>2,3</sup>

<sup>1</sup>Department of Pharmacy, EOXI, Vigo, Spain

<sup>2</sup>Group of Investigation in Rheumatology and Immune-Mediated Diseases, Instituto de Investigación Sanitaria Galicia Sur, EOXI, Vigo, Spain

<sup>3</sup>Rheumatology, Department of Rheumatology, EOXI, Vigo, Spain

## Correspondence to

Noemí Martínez-López De Castro, Department of Pharmacy EOXI, Vigo, Spain; noemi.martinez.lopezdecastro@sergas.es

Received 13 September 2017

Revised 30 November 2017

Accepted 12 December 2017

Published Online First

24 January 2018

EHPH Statement 4: Clinical Pharmacy Services.

## ABSTRACT

**Objective** To analyse the volume and content of tweets in relation to biological treatments for chronic inflammatory arthropathies.

**Methods** A Twitter analysis was carried out during one month using the following keywords: 'rheumatoid arthritis', 'ankylosing spondylitis', 'psoriatic arthritis' and their biological therapies: 'abatacept', 'adalimumab', 'certolizumab', 'etanercept', 'golimumab', 'infliximab' and 'tocilizumab'. Tweets were hand-coded and filtered for content.

**Results** 25 441 tweets contained at least one of the keywords. After filtering, 2480 tweets were included in the analysis. Regarding the 983 tweets about therapies, the most frequently mentioned biologics were 'adalimumab' (n=359), 'infliximab' (n= 278) and 'etanercept' (n= 205). In the 1497 tweets about diseases, the term 'rheumatoid arthritis' (n= 1109) was used more frequently than 'psoriatic arthritis' (n= 233) and 'ankylosing spondylitis' (n= 155). The most commonly addressed subjects in the tweets in relation to biological therapies were related to safety/adverse events (136 of 983 (13.8%)) and to administration, particularly drug infusion (60 of 983 (6.1%)) and self-administration (57 of 983 (5.8%)). Regarding diseases, the most commonly addressed subjects were non-pharmacological recommendations such as alternative therapies (145 of 1497 (9.7%)), nutrition (128 of 1497 (8.5%)) and exercise (91 of 1497 (6.1%)).

**Conclusions** Twitter is widely used to search for information about biological treatments for chronic arthropathies. Learning more about the subjects dealt with in the tweets will enable us to improve our understanding of the areas of greater interest and concern among patients. This could help hospital pharmacists establish patient-focused strategies addressing the needs of the patients.

## INTRODUCTION

The internet is being increasingly used as a source of information on health. About 35% of US adults reported going online at some time with the idea of diagnosing a condition for themselves or someone they knew, and 72% of US internet users reported looking online for information about health within the previous year.<sup>1</sup> A study based on computer-assisted telephone interviews was carried out in seven European countries, showing that 70% of internet users make health-related searches.<sup>2</sup> About 58% of internet users all over the world are also users of social networks.<sup>3</sup> However, this attitude is not always

welcome in clinical settings, particularly when relational aspects such as mutual trust, uncertainty and vulnerability are affected because of conflicting information and views that can be found on the internet.<sup>4</sup>

Rheumatoid arthritis (RA), ankylosing spondylitis (AS) and psoriatic arthritis (PA) are rheumatic diseases that globally affect as many as one in 100 people.<sup>5</sup> Many people with these conditions experience symptoms that worsen their quality of life. They must cope with these symptoms and also with other aspects related to these diseases or their treatments. Frequently, these patients with chronic inflammatory arthropathies have different difficulties and unmet needs so they have to seek help and use online social networks to get information and support. The analysis of the social media phenomenon leads to a better understanding of patients' perceptions, as pointed out in a number of non-rheumatic studies.<sup>6–8</sup>

There are no data about the information that internet users share on Twitter with respect to rheumatic disorders and their treatments. To our knowledge, our current study is the first attempt to carry out a detailed content analysis of Twitter in relation to treatments for chronic inflammatory arthropathies. The aim of our study is to provide insights into how Twitter users share information about the biological treatments for RA, AS and PA, and to analyse that information so we can learn more about their main perceptions and areas of interest. Our findings may be useful in establishing patient-focused strategies to improve the pharmaceutical care for these patients.

## MATERIALS AND METHODS

This is an exploratory study of Twitter data associated with biological treatments for chronic inflammatory arthropathies.

Twitter, Inc. provides an online social networking and microblogging service that allows the user to send and read comments (tweets) about any topic within a 140-character limit. The set of streaming application programming interfaces (APIs) offered by Twitter gives developers access to Twitter's global stream of Tweet data, that include the tweet text along with metadata, such as the time, the geographical coordinates associated with the tweet (if GPS is enabled) and information about the user profile such as the name and location. Access to public tweets is limited by the APIs to a random 1% sample and to those posted during the previous week.



**To cite:** Martínez-López De Castro N, Samartín- Ucha M, Martín-Vila A, et al. *Eur J Hosp Pharm* 2019;**26**:124–128.

The Twitter analysis was performed from 25 May 2015 to 25 June 2015. Tweets were searched in Spanish and English. Brand names were used as we thought this would be more likely to reflect patient searches. All tweets that contained the keywords 'rheumatoid arthritis', 'ankylosing spondylitis', 'psoriatic arthritis' and their biological therapies: 'Abatacept', 'Orencia', 'Adalimumab', 'Humira', 'Certolizumab', 'Cimzia', 'Etanercept', 'Enbrel', 'Golimumab', 'Simponi', 'Infliximab', 'Remicade' and 'Tocilizumab'-'Roactemra' were downloaded. All these tweets were transferred to QDA Miner Lite to create the dataset for analysis.

All of the tweets were read one by one by two investigators (NMLC and JMPR) and, after filtering, those which had presumably been written by patients or carers were selected.

Filtering was aimed at excluding tweets related to scientific content, company share prices/stock market news or other diseases. In order to avoid duplicate information, all retweets were removed.

Criteria for tweet exclusion were as follows:

1. Tweets related to manufacturing companies or containing their names.
2. Tweets that contained news published by universities, scientific societies, magazines or scientific articles and spams.
3. Tweets with contents suggestive of coming from doctors and other health professionals.
4. Tweets about other diseases: those containing a biological therapy keyword together with the words 'hidradenitis', 'inflammatory bowel disease', 'Crohn's', 'ulcerative colitis', 'psoriasis', 'gastrointestinal', 'juvenile idiopathic arthritis'.

To describe the content of the tweets, two investigators (NMLC and JMPR) used QDA Miner Lite to code one by one all the tweets for each biological treatment and disease. Then, the coding categories were discussed with the rest of the research team for their refinement.

In the searches connected with 'golimumab', the combined search with 'Simponi' was not carried out as that is the word that many people use to search some musical albums, which could lead to misinterpretation of the data.

In addition to the thematic analysis, tweets were classified according to the nature of the content in five categories: personal stories, information sharing, questions about therapies or diseases, fundraising or need for support.

Word frequency analysis in tweets was carried out by using QDA Miner Lite. All the data were compiled in an Excel table, which was used to calculate basic descriptive statistics.

## RESULTS

From an initial sample of 25 441 tweets containing words related to the above-mentioned therapies and diseases, a total of 7366 retweets were removed. A total of 929 tweets were excluded because they included names of pharmaceutical companies. A total of 12 002 were withdrawn because they were spams or contained names of scientific associations or universities, or references to scientific papers or included contents suggestive of coming from doctors and other health professionals. Another 2664 tweets were removed because they contained information about other diseases.

Finally, 2480 tweets were selected for the analysis, 171 of them in Spanish.

### Analysis of twitter messages

The most tweeted therapy was adalimumab, both in Spanish and English, with etanercept being the second one. Table 1 shows the number of tweets by treatment and disease after filtering.

**Table 1** Number of tweets about treatments and diseases after filtering

	n(%)
<b>Tweets about therapies</b>	
Adalimumab (Humira)	359 (36.52)
Infliximab (Remicade)	278 (28.28)
Etanercept (Enbrel)	205 (20.85)
Abatacept (Orencia)	60 (6.10)
Certolizumab (Cimzia)	60 (6.10)
Tocilizumab (Roactemra)	12 (1.22)
Golimumab*	9 (0.92)
<b>Total number of tweets about therapies</b>	<b>983 (100)</b>
<b>Tweets about diseases</b>	
Rheumatoid arthritis	990 (66.18)
Psoriatic arthritis	219 (14.64)
Ankylosing spondylitis	139 (9.22)
Artritis reumatoide†	119 (7.95)
Espondilitis anquilosante‡	16 (1.07)
Artritis psoriásica§	14 (0.94)
<b>Total number of tweets about diseases</b>	<b>1497 (100)</b>

\*The combined search with 'Simponi' was not carried out as that is the word that many people use to search some musical albums, which could lead to misinterpretation of the data.

†Spanish term for rheumatoid arthritis.

‡Spanish term for ankylosing spondylitis.

§Spanish term for psoriatic arthritis.

Most of the tweets in our analysis were used to express awareness or to tell personal stories (1944 tweets: 78.41%). Two hundred and eight tweets (8.39%) were posted to share information in blogs, internet videos or YouTube. Sixty-one tweets (2.46%) were used to ask questions about the diseases and 140 tweets (5.64%) to ask questions about the therapies. Eighty-seven tweets (3.51%) were about the need for support or problems about authorisation or availability of the treatments and 39 tweets (1.57%) were about fundraising.

### Tweet content

Tweet content varied across and within therapies and diseases. The most widely coded terms in relation to therapies dealt with safety aspects such as adverse events related to drug administration, infections or general adverse effects. Comments about drug infusion or self-administration of the therapies were also common. All the information gathered can be seen in table 2 (semantic contents of tweets about therapies) and table 3 (semantic contents of tweets about diseases).

## DISCUSSION

People share and search for information online about treatments and diseases. To the best of our knowledge, this is the first analysis of Twitter seeking to discover the areas of interest raised online regarding biological therapies for chronic inflammatory arthropathies. Similar studies have been conducted for other diseases such as cancer,<sup>6</sup> multiple sclerosis,<sup>7</sup> glaucoma<sup>9</sup> and cardiovascular diseases.<sup>10</sup>

In our study, RA appeared more frequently in tweets than PA and AS, in all likelihood due to its higher prevalence.<sup>11</sup>

In our analysis, safety of the therapies was mentioned in a high number of tweets, particularly adverse events related to drug administration. Most of them were mild adverse effects such as pain related to administration or post-administration hangover symptoms, more than serious adverse

Table 2 Semantic content of tweets about therapies

	ABA n=60	ADA n=359	CER n=60	ETA n=205	GOL n=9	INF n=278	TOC n=12	Total n=983
Safety aspects								
Adverse events related to the administration*, n	4	51	18	35		28		136
General adverse effects, n		16	2	11		7		36
Infections, n	6	9	3	1		5		24
Skin reactions, n		12		11				23
Allergic reaction, n		2	4	4	1	10		21
Immunosuppression, n		7		3		1		11
Neurologic problems therapy-related, n		5				6		11
Gastrointestinal side effects, n		3		1	1	2		6
Lupus therapy induced, n		1	2			3		6
Fatigue, n		1		2		2		5
Headache, n					1	3		4
Pulmonary toxicity therapy-related, n		2			2			4
Onco-haematologic diseases therapy-related, n		3				1		4
Death therapy-related, n		3						3
Hair loss, n				1		2		3
Liver damage therapy-related, n		3						3
Cardiovascular side effect, n				2				2
Genitourinary toxicity therapy-related, n				1		1		2
Total tweets safety, n (% of total tweets of each therapy)	10 (16.67)	118 (32.86)	29 (48.33)	71 (34.63)	5 (55.56)	71 (25.54)	0	304 (30.93)
Posology and administration								
Drug infusion, n	3					57		60
Autoadministration, n	1	35	3	18				57
Posology, n		1		2				3
Total tweets posology, n (% of total tweets of each therapy)	4 (6.67)	36 (10.03)	3 (5.00)	20 (9.76)		57 (20.50)		120 (12.21)
General aspects about therapies								
Cost of therapies, n	1	19		7		9	1	37
Biosimilar, n		8		3		5		16
Surgery and delay in biological administration, n	2		4	1				12
Antibody test, n		3				8		11
Infection and delay in biological administration, n		1		3		6		10
Adherence, n		5				3		8
Vaccines and interaction with biological therapies, n		2		2		1		5
Pregnancy, n		2	1	1				4
Conservation, n		3						3
Total tweets general comments, n (% of total tweets of each therapy)	3 (5.00)	43 (11.97)	5 (8.33)	17 (8.29)		37 (13.31)	1 (8.33)	106 (10.78)
Effectiveness aspects								
Treatment failure, n		12		14		14		40
Insufficient treatment, n		7		1		6		14
Persistence, n		2		2		1		5
Total tweets effectiveness, n (% of total tweets of each therapy)		21 (5.85)		17 (8.29)		21 (7.56)		59 (6.00)

\*45,60% pain and 21,60% hangover.

ABA: Abatecept/Orencia, ADA: Adalimumab/Humira, CER: Certolizumab/Humira, ETA: Etanercept/Enbrel, GOL: Golimumab, 4 INF: Infliximab/Remicade, TOC: Tocilizumab/Roactema.

**Table 3** Semantic content of tweets about diseases

	AR n=119	EA n=16	AP n=14	RA n=990	AS n=139	PA n=219	total n=1497
<b>General aspects of the diseases</b>							
Alternatives therapies, n	13	3		112	6	11	145
Nutrition, n	15			102	4	7	128
Diagnosis, n	3	1	2	64	17	19	106
Exercise, n	10	1		58	7	15	91
Risk factors for disease, n	5	1	1	22	1	16	46
Cause of disease, n	3			29		2	34
Heredity, n	3			6	4	5	18
Vaccine for RA, n	7			10			17
Pregnancy, n	1			7		8	16
Cure, n	1	2		5		2	10
Cardiovascular risk, n				6	2		8
Meteorology, n				8			8
Prevention, n	2			6			8
Remission, n				2	1	3	6
Vacation, n				5			5
Dental health, n				3		1	4
Stem cell transplantation, n				3	1		4
Prevalence, n	1			1		1	3
Total tweets general aspects, n (% of total tweets of each disease)	64 (4.28)	8 (0.53)	37 (0.20)	449 (30.01)	43 (2.87)	90 (6.02)	657 (43.92)
<b>Quality of life aspects</b>							
Pain, n	9			64	13	17	103
Disability, n	6			33	2	6	47
Employment, n	1	2		15		5	23
Emotional effects, n	1		1	10			12
Sexual relation, n				4	5	2	11
Sleep problems, n				2	3	2	7
Marriage relation, n				3		2	5
Stress, n				1		2	3
Total tweets related to quality of life, n (% of total tweets of each disease)	17 (14.28)	2 (12.50)	1 (7.14)	132 (13.33)	23 (16.67)	36 (16.44)	211 (14.10)
<b>Disease-related symptoms</b>							
General management of symptoms, n	2		1	17		3	23
Joint inflammation, n				17	1	2	20
Flare-up, n				12	1	3	16
Tired, n				10		1	11
Feet symptoms, n				8		2	10
Stiffness, n				5		2	7
Nails' changes, n						6	6
Lung problems, n				3			3
Itching, n						1	1
Total tweets about symptoms, n (% of total tweets of each disease)	2 (1.68)		1 (7.14)	72 (7.27)	2 (1.45)	20 (9.13)	97 (6.48)

Sixty-five tweets about therapies (6.61%) cited another concomitant treatment in addition to biological therapy (52 tweets of disease-modifying antirheumatic drugs, seven of steroids, five of antihistaminics and one of nonsteroidal anti-inflammatory drugs).

AR, artritis reumatoide (Spanish term for rheumatoid arthritis), AP: artritis psoriásica (Spanish term for psoriatic arthritis) AS: ankylosing spondylitis EA: espondilitis anquilosante (Spanish term for ankylosing spondylitis), RA: rheumatoid arthritis, PA: psoriatic arthritis.

effects like death or cancer, which were barely cited. These findings are relevant because these events are frequently the reason why patients discontinue the therapies. Bolge et al<sup>12</sup> examined the reasons why RA patients discontinued their subcutaneous biological treatments in an attempt to understand the patient perspective. Lack of effectiveness and injection experience were the most frequent reasons for discontinuation. Another study, based on data collected by the US Psoriasis Foundation via biannual surveys in patients with psoriasis and PA, concluded that the main reasons for discontinuation of the biological treatments were adverse effects, inefficacy, drug conflict or impossibility to afford the treatments.<sup>13</sup>

As to tweets related to drug administration, patients often shared experiences about their visits to day hospital

to receive infliximab. In their tweets they frequently talked about how they were treated by health professionals, the duration of drug infusion and their tolerance to the drugs. The subcutaneous self-administration (particularly of adalimumab or etanercept) was often cited. Patients provided different recommendations to facilitate the administration of these therapies and reduce the risk of local reactions.

Another subject that was often discussed was the cost of the biological therapies. Most of the tweets contained comments about how much the treatments cost and how patients could sometimes barely afford them.

We found that other important areas of interest were those connected with non-pharmacological recommendations such as alternative therapies, nutrition and exercise. We have not found any references in the literature reporting the importance of such

recommendations although they are commonly brought up by patients in daily clinical practice.

Twitter is an informal social setting in which people exchange their everyday thoughts and feelings. Patients and carers often search for information, seek support and also find social networks to be an important emotional outlet. A thorough analysis of social media should give us a good idea of their main perceptions and concerns in relation to therapies, and also enable us to identify possible areas of misinformation. Consequently, any information gathered from social media could prove invaluable when devising patient-centred improvement strategies aimed at addressing the patients' needs.

### Limitations

Our study must be interpreted in the light of the following limitations. First, the tools available for extracting information from Twitter only do a partial extraction of the information. Second, searches were conducted in only two languages, which can limit the results obtained, and although English and Spanish are widely spoken languages all over the world, they do not represent all people and all cultures. Third, it is also clear that not all of the tweets analysed came from patients diagnosed with chronic inflammatory arthropathies. However, we did carry out an exhaustive coding and filtering process and that enables us to reasonably assume that most of the tweets analysed were posted by patients, relatives or people close to them. It is also true, on the other hand, that some patients' tweets may have been lost during filtering. Fourth, the keywords Inflectra and Remsima (infliximab biosimilars) were not included in the search. It would have been of interest since the European Medicine Agency (EMA) approved both infliximab biosimilars Inflectra and Remsima in 2013. However, in the case of Inflectra, it was authorised by the Food and Drug Administration (FDA) in May 2016 and Remsima is still not authorised at the moment in the United States. Their inclusion would have entered a bias in the results. Despite not collecting these trade names, the term 'biosimilar' is reflected in the results. Finally, although we eliminated the re-tweets, we did

not search for multiple tweets by the same author, so it could be a bias in our results.

Further work is needed to understand the patient perspective on treatments for rheumatic diseases but our findings offer new insights into patients' areas of interest or concern. Future studies should validate the data obtained from Twitter information through surveys to patients. Furthermore, social media contains information of importance to patients and provides an emotional outlet where they can voice their thoughts. Hospital pharmacists could use the information on social media platforms to learn more about the concerns of patients in relation to biological treatments. Strategies could then be developed truly addressing all of the needs of patients with RA, AS and PA.

**Contributors** NM-L: concept and design (25%), data collection (25%), data interpretation (25%), writing of manuscript (50%) and revision of manuscript (0%). MS-U: concept and design (25%), data collection (25%), data interpretation (0%), writing of manuscript (25%) and revision of manuscript (0%). AM-V: concept and design (0%), data collection (25%), data interpretation (25%), writing of manuscript (25%) and revision of manuscript (0%). MÀ-P: concept and design (0%), data collection (25%), data interpretation (50%), writing of manuscript (0%) and revision of manuscript (0%). GP-C: concept and design (25%), data collection (0%), data interpretation (0%), writing of manuscript (0%) and revision of manuscript (25%). Jose MP-R: concept and design (25%), data collection (0%), data interpretation (0%), writing of manuscript (0%) and revision of manuscript (75%).

**Funding** Pfizer.

**Competing interests** None declared.

**Ethics approval** This study was certified as exempt from review by the Ethics Committee on Human Research of the University Hospital of Vigo (Spain).

**Provenance and peer review** Not commissioned; externally peer reviewed.

© European Association of Hospital Pharmacists (unless otherwise stated in the text of the article) 2019. All rights reserved. No commercial use is permitted unless otherwise expressly granted.

### REFERENCES

- 1 Pew Research Center Health Online. 2013. <http://pewinternet.org/Reports/2013/Health-online.aspx> (accessed 16 Mar 2015).
- 2 Andreassen HK, Bujnowska-Fedak MM, Chronaki CE, *et al.* European citizens' use of E-health services: a study of seven countries. *BMC Public Health* 2007;7:53.
- 3 Statistic Brain. Social Networking Statistics. <http://www.statisticbrain.com/social-networking-statistics> (accessed 16 Jun 2015).
- 4 Townsend A, Leese J, Adam P, *et al.* eHealth, participatory medicine, and ethical care: a focus group study of patients' and health care providers' use of health-related Internet Information. *J Med Internet Res* 2015;17:e155.
- 5 Gabriel SE, Michaud K. Epidemiological studies in incidence, prevalence, mortality, and comorbidity of the rheumatic diseases. *Arthritis Res Ther* 2009;11:229.
- 6 Tsuya A, Sugawara Y, Tanaka A, *et al.* Do cancer patients tweet? Examining the twitter use of cancer patients in Japan. *J Med Internet Res* 2014;16:e137.
- 7 Ramagopalan S, Wasiak R, Cox AP. Using Twitter to investigate opinions about multiple sclerosis treatments: a descriptive, exploratory study. *F1000Res* 2014;3:216.
- 8 Carbonell P, Mayer MA, Bravo À. Exploring brand-name drug mentions on Twitter for pharmacovigilance. *Stud Health Technol Inform* 2015;210:55–9.
- 9 McGregor F, Somner JE, Bourne RR, *et al.* Social media use by patients with glaucoma: what can we learn? *Ophthalmic Physiol Opt* 2014;34:46–52.
- 10 Sinnenberg L, DiSilvestro CL, Mancheno C, *et al.* Twitter as a potential data source for cardiovascular disease research. *JAMA Cardiol* 2016;1:1032–6.
- 11 Sangha O. Epidemiology of rheumatic diseases. *Rheumatology* 2000;39:3–12.
- 12 Bolge SC, Goren A, Tandon N. Reasons for discontinuation of subcutaneous biologic therapy in the treatment of rheumatoid arthritis: a patient perspective. *Patient Prefer Adherence* 2015;9:121–31.
- 13 Armstrong AW, Robertson AD, Wu J, *et al.* Undertreatment, treatment trends, and treatment dissatisfaction among patients with psoriasis and psoriatic arthritis in the United States: findings from the National Psoriasis Foundation surveys, 2003–2011. *JAMA Dermatol* 2013;149:1180–5.

### What this paper adds

#### What is already known on this subject

- ▶ People share and search for information online about treatments and diseases.
- ▶ Patients with chronic inflammatory arthropathies have different difficulties and unmet needs so they have to get information and support.

#### What this study adds

- ▶ The analysis of social networks allows learning more about the concerns and areas of interest of the patients with chronic inflammatory arthropathies in relation to biological treatments.
- ▶ Non-pharmacological recommendations such as alternative therapies, nutrition and exercise are important areas of interest for patients with chronic inflammatory arthropathies.