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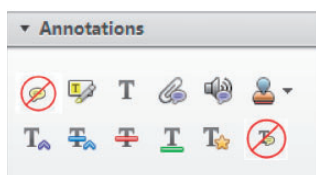
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## PAPER

# Characteristics and information searched for by French patients with systemic lupus erythematosus: A web-community data-driven online survey

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**Introduction:** To provide information about the needs of patients with systemic lupus erythematosus (SLE) using Carenity, the first European online platform for patients with chronic diseases. **Methods:** At one year after its creation, all posts from the Carenity SLE community were collected and analysed. A focused cross-sectional online survey was performed. **Results:** The SLE community included 521 people (93% females; mean age: 39.8 years). Among a total of 6702 posts, 2232 were classified according to disease-related topics. The 10 most common topics were 'lupus and ...' either 'treatment', 'fatigue', 'entourage', 'sun exposure', 'diagnosis', 'autoimmune diseases', 'pregnancy', 'contraception', 'symptoms' or 'sexuality'. 112 SLE patients participated in the online survey. At the time of diagnosis, only 17 (15%) patients had heard of SLE and 84 (75%) expressed a need for more information on outcomes (27%), treatments (27%), daily life (14%), patients' associations (11%), symptoms (8%), the disease (8%) and psychosocial aspects (7%). When treatment was initiated, 48 patients (43%) would have liked more information about side effects (46%), long-term effects (21%), treatment duration/cessation (12.5%) and type (10%) and mechanism of action (8%) of treatments. All participants except one had used the internet to find information about SLE. Sources of information included healthcare providers (51%/61%/67%), journals/magazines (7%/12%/6%), lupus Websites (51%/77%/40%), web forums/blogs (34%/53%/19%), patients' associations (11%/23%/9%) accessed at 'just before diagnosis', 'just after diagnosis' and 'before treatment initiation'. **Conclusions:** Online patient communities provide original unbiased information that can help improve provision of information to SLE patients. *Lupus* (2015) 0, 1–6.

**Key words:** Systemic lupus erythematosus; access to information; internet; information services; survey

## Introduction

Systemic lupus erythematosus (SLE) is a rare autoimmune disease.<sup>1</sup> Given the chronicity and uncertainty of SLE, patients and their family members face physical, financial, social and emotional challenges that can be overwhelming. As for other rare diseases, SLE comes with numerous unmet needs for patients.<sup>2</sup> Indeed, SLE patients often

report difficulties in obtaining information they feel may help them cope with the disease. Some patients still consider that physicians should make more effort to explain the disease and provide all sorts of relevant disease-related information. Consequently, and especially during the last decade, there have been many initiatives to improve the quantity and quality of sources of information. Patients' associations have done a lot to improve information sharing, and use multiple media sources (paper newsletters, websites, meetings with physicians, etc.). Unfortunately, these interventions have inherent limitations, one being the difficulty of reaching all SLE patients, as patients that belong to a patients' association represent only

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a relatively small proportion of the whole SLE population. Also, because knowledge is constantly evolving, some sources become rapidly outdated or incorrect. Lastly, but not least, it seems that physicians sometimes lack information about the real needs of patients and proxies in terms of what is important when living with this disease.

In recent studies, participants stated that information and support provided at diagnosis were inadequate.<sup>3</sup> Importantly, some available data from surveys performed amongst SLE patients from academic referent centres and/or patients' associations have representative biases because of the selection of, respectively, more severely-ill and/or more informed patients.<sup>4</sup>

At the same time, the internet has become widely used by people living in high-income countries. As a result, it is now one of the main tools used by people searching for information, including on health-related topics. Some authors report that patients with rheumatic diseases (including SLE) go to the internet to find information before their medical appointment.<sup>3</sup> Participation in internet forums and patients' online communities have also increased, and remain an understudied resource to understand aspects of living with SLE. Indeed, knowledge of the information that SLE patients are searching for and sharing with others, as well as a patient's behaviour on the web, is an opportunity to better understand the complex health needs of patients with this rare disease, and to set-up appropriate health communication strategies. Created on the model of 'Patients like me',<sup>5</sup> Carenity is the first French online platform to conduct peer-to-peer exchanges (posts) for patients with a chronic disease to share their experiences using specific-disease communities. It is also a website in which patients can find general information about health and specific information about their disease, and can monitor the activity of their disease and any treatments. Carenity is also used by healthcare professionals as a vector to spread online surveys. A SLE community was created in March 2012.

The aims of this study were to describe the characteristics of SLE community members and to better identify the needs and information that people living with SLE require.

## Methods

### *Study's design and the patients*

The use of the Carenity platform is anonymous and free. When people create their profile, they agree

that personal data may be used for scientific research ([www.carenity.co.uk/terms-of-consent](http://www.carenity.co.uk/terms-of-consent); see also [www.carenity.co.uk/terms-of-use](http://www.carenity.co.uk/terms-of-use), section 10 on 'personal data'). There is no financial support from any pharmaceutical company. The study was composed of two parts. First, at one year after creation of the SLE community on Carenity (<http://www.carenity.com/maladie/lupus>), all posts in forums dedicated to SLE were collected and analysed by physicians specialized in the management of SLE. Then, a focused cross-sectional survey was set-up and spread to members of the SLE community over a two-month period.

### *SLE community data collection and classification*

The following characteristics of the SLE community members at the time of the study were collected: age, gender, geographical location and personal status (patients or proxies). All the posts corresponding to the SLE community members between March 2012 and March 2013 were collected. The posts considered non-SLE-related (presentations, welcome messages, holidays, etc.) and posts from foreign countries were excluded. All the remaining posts were classified by quantitative and qualitative content analysis. All relevant threads (group of messages that were posted by at least ten different community members in response to a message) that focused on a SLE-related topic were identified by two investigators (BM and LC), and classified according the total number of posts to identify the most popular disease-related topics. Topics were determined both a priori from a recent survey conducted with French SLE patients to identify their needs,<sup>4</sup> as well as adding progressively as many topics as needed during posts analysis. Then, the remaining posts (out of any such threads) were reviewed and coded by the same investigators, assigning relevant codes only once to each post (regardless of how many times the same topic was expressed in that post, and choosing the dominant topic if more than one was expressed in the same post), in order to identify additional key topics that had at least ten corresponding posts. Translation from French posts for publication purposes were conducted by investigators with the help of native community managers from the UK Carenity platform ([www.carenity.co.uk/](http://www.carenity.co.uk/)).

### *Online survey*

The survey was conducted using a standardized questionnaire published online on the Carenity platform. During the study period (1 April–31 May 2013),

all SLE patients from the community were invited to anonymously complete the survey every time they logged on to the Carenity site, and an email was sent monthly as a reminder. The questionnaire included closed and open questions about socio-demographic data, clinical information, internet use, and habits of participants in terms of information research (sources of information and information needs) at different stages of the disease (just before diagnosis of SLE, just after diagnosis of SLE and before initiation of a treatment). An additional part of the questionnaire focused on the precise sources of information obtained on the web. The last section of the questionnaire was dedicated to the collected opinions of participants regarding the nature of potential additional web services they would like to access.

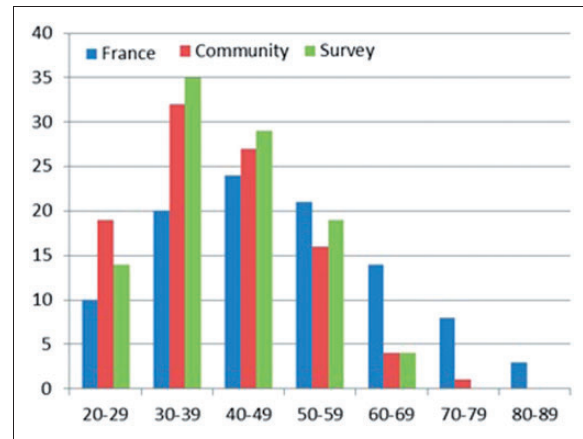
#### Statistical analyses

Data on the age distribution of the French SLE population were retrieved from a recent publication on the number of patients enrolled in all French national administrative databases.<sup>1</sup> The age distributions between those from all French national data on SLE, those in the Carenity community and those from survey respondents were compared using the  $\chi^2$  test. Logistic regressions, fitted with generalized estimated equations, were used to compare the sources of information according to the stage of disease, while taking into consideration the non-independent nature of the data structure (three measures for each patient). The same model was used to test the effect of age and a recent diagnosis on the sources of information searched for. Analyses were performed with IBM SPSS Statistics 20.0 (IBM Inc., New York, USA).

## Results

### Characteristics of the SLE community members

At one year after its creation, the SLE community included 521 members, of which 93% were female (versus 88% in the whole French SLE population). Among them, 473 (91%) were patients and 48 (9%) were relatives. Mean age was 38.9 years (Figure 1). All age categories were represented in the study population although differences in age distribution were observed compared to the whole French SLE population (Figure 1). SLE community members were geographically distributed homogeneously throughout France (Paris area: 18%; other French regions: 82%) (Figure S1).



**Figure 1** Age distribution of SLE patients among the whole French SLE population (in blue, from a 2010 nationwide population-based study), the SLE community (in red,  $n=521$ ) and participants in the survey (in green,  $n=112$ ). There was no difference between the whole community and the participants in the survey, but age distribution (%) among online patients was different from the whole SLE population, especially for patients aged >60 years ( $p<0.001$ ).

### Analyses of posts and identified key topics

The global activity of the SLE community at one year corresponded to a total of 6702 posts, of which 2232 were retained for further analyses according to pre-defined criteria (Table 1). From the analyses of threads, the ten most common topics, corresponding to a total of 836 posts, were ‘lupus and...’ either ‘treatment’, ‘fatigue’, ‘entourage’, ‘sun exposure’, ‘diagnosis’, ‘autoimmune diseases’, ‘pregnancy’, ‘contraception’, ‘symptoms’ or ‘sexuality’. Analysis of the other posts ( $n=1396$ ) identified additional topics of interest (i.e. out of previously identified threads and with at least ten posts each) such as ‘lupus and...’ ‘nutrition’, ‘physical activity’, ‘work’, ‘weight’, ‘psychological impact’, ‘toxicities’, ‘vaccines’, ‘fibromyalgia’, ‘global management’, ‘outcomes’ and ‘paraclinical investigations’.

### Characteristics of the participants in the online survey

A total of 112 patients completed the online survey, of which 95.5% were female. Mean age was 40 years (Figure 1) and their ages ( $p=0.54$ ) and geographical distributions were similar over the whole community (17% from the Paris area and 83% from other regions in France,  $p=0.76$ ). Thirty-eight responders (34%) were members of a lupus patients’ association. One-hundred and seven patients (95.5%) said they had already searched

**Table 1** Key topics of interest to the SLE-community members ( $n = 521$ ) identified by content analysis of their posts during a one-year period

Topic	Posts (n)
Global community activity	6702
SLE-related posts <sup>a</sup>	2232
Most popular threads <sup>b</sup>	836
SLE treatments	220
Fatigue	112
Entourage	106
Sun exposure	97
SLE diagnosis	58
Autoimmune diseases	55
Pregnancy	55
Contraception	49
SLE symptoms	49
Sexuality	35
Additional key topics <sup>c</sup>	1396
Nutrition	57
Physical activity	37
Work	29
Weight	37
Psychological impact	26
Toxicities	25
Vaccines	25
Fibromyalgia	24
SLE global management	23
SLE outcomes	17
SLE paraclinical investigations	16

<sup>a</sup>Posts considered non-SLE-related (presentations, welcome messages, holidays, etc.) or from foreign countries were excluded.

<sup>b</sup>All relevant threads (group of messages that were posted by at least ten different community members in response to a message) focusing on a SLE-related topic were classified by the total number of posts.

<sup>c</sup>Additional key topics with at least ten corresponding posts were identified from the remaining posts.

for information about lupus before the survey. Median duration of lupus at the time of the survey was five years (0; 45).

#### *Unmet needs for information according to the SLE patients*

At the time of diagnosis, only 17 (15%) patients had already heard of SLE. Eighty-four (75%) patients would have liked more information about outcomes (27%), treatments (27%), coping with daily life (14%), patients' associations (11%), symptoms (8%), the disease (8%) and psychosocial aspects (7%). At the time that treatment was initiated, 48 (43%) patients would have liked more information about side effects (46%), long-term effects (21%), duration/cessation of treatments (12.5%) and types (10%) and mechanisms of action (8%) of treatments. Only 16 (14%)

**Table 2** Sources of information of SLE patients participating in the online survey ( $n = 112$ ) according to the stage of their disease

Source	Before diagnosis	After diagnosis	Before initiating treatment	p-value
Conventional				
Healthcare providers	51%	61%	67%	0.002
Patients' associations	11%	23%	9%	<0.001
Newspapers and magazines	7%	12%	6%	0.017
Web-based				
Lupus websites	51%	77%	40%	<0.001
Forum and blogs	34%	53%	19%	<0.001

participants reported that the information they had found had an impact on treatment choice.

#### *Sources of information used by SLE patients*

Sources of information that patients reported using varied according to the stage of the disease (Table 2). Before being diagnosed with SLE, sources were, in descending order, healthcare providers, lupus websites, web forums/blogs, patients' associations and journals/magazines. Just after SLE was diagnosed, the main sources were lupus websites, healthcare providers, web forums/blogs, patients' associations and journals/magazines. At the time before treatment initiation, the sources were healthcare providers, lupus websites, web forums/blogs, patients' associations and journals/magazines. Overall, SLE patients aged  $\leq 45$  years ( $p = 0.003$ ) or who had SLE for at least two years ( $p = 0.008$ ) used significantly more web-based sources of information (lupus website and/or web forums/blog). Those with SLE for less than two years more frequently used healthcare providers ( $p = 0.014$ ), independently of age, which had no significant affect in this survey ( $p = 0.364$ ).

Concerning the methods used to search for information, all responders except one reported using the internet to look for information about SLE. Patients used search engines (74%), health portals (55%), forums (46%), patients' associations' websites (46%), French patients' blogs (31%) or Facebook© (21%).

#### *Web services expected by SLE patients*

Concerning possible additional online services, participants in the survey were interested in, in descending order, obtaining information on/via ongoing clinical investigations (46%), platforms

to query healthcare providers (43%), medical information about SLE (41%), therapeutic education programmes (33%), advice about administrative procedures (32%), advice about treatment management (29%), measurement and monitoring of treatment tools (21%), platforms to query non-healthcare providers, such as jurists (21%) and self-notification of side effects (16%).

## Discussion

The patients' web forums provided a unique opportunity for patients to spontaneously post their experiences and thoughts about this disease and its treatments.<sup>5</sup> Data generated through these platforms allowed unbiased knowledge of patients' real needs. Also, knowing how individuals who are affected by a specific disease search for health information on the internet may help healthcare professionals to provide information through the most-used sources. Herein, we provide the results from a first study that used information obtained from patients on web-based platforms to obtain more information about SLE.

A first finding was the high number of French patients using the Carenity platform to join the SLE community within the first year of its creation. SLE is a rare autoimmune disease, with a prevalence recently evaluated at around 30,000 in France.<sup>1</sup> Interestingly, the number of members in the SLE community was recently estimated at around 1300, confirming the importance of such online communities in the context of rare diseases.<sup>6–8</sup> Importantly, the characteristics of patients belonging to the online community were relatively well representative of the whole SLE French population in terms of gender and age distribution.<sup>1</sup>

A second finding was that members of the SLE community were very active in terms of exchanges, and that analysis of the posts gave indications of the most frequent issues that interested SLE patients in everyday life.<sup>9</sup> As an example, it was noticeable that sexuality was one of the ten most popular threads, a topic that is rarely addressed by SLE patients with their healthcare providers. In France, a survey was conducted of members of SLE patients' associations to evaluate the main topics of interest to be included in a therapeutic programme dedicated to SLE in a national reference centre.<sup>4</sup> Even though some of the proposed topics were voted for by patients, some of the most popular key topics identified in our study were not proposed, confirming the importance of

building a programme's content using direct input from affected patients.

A third finding was that patients used various media to obtain information, in general and according to the timing of their disease or its duration. 'New' (or web-based) media were used most often by the majority of patients, especially within the first years of the disease, whereas healthcare providers remained an important source of information in the context of obtaining information about treatments. Of note, very few websites provide exhaustive information on treatments dedicated to patients.<sup>10</sup> That recommendations on lupus treatments are poorly consensual, and because most SLE drugs are used off-label, may explain why the main source of information on treatments for this disease remains healthcare providers.

Finally, as in other studies, when asked, patients stated that the information and support currently provided at the time of diagnosis was inadequate.<sup>11,12</sup> They would like more detailed information, for example, about available treatments.

There are limitations to our study. First, there were too few male participants, although the proportion of females was exactly that expected for SLE. Also, the observed results could be biased because patients that participate in such web communities must have access to the internet. Moreover, respondents participated in the survey on a voluntary basis: thus, it is likely we selected patients with a higher interest in using the internet for health purposes. However, in France, as in other developed countries, most people have access to the internet, and the characteristics of patients and their geographical locations suggested that they were representative of the whole SLE population. Also, we feel that surveys that include patients from associations and that have been designed entirely by healthcare providers have other strong biases with regards to knowledge about specific groups of patients and the topics of interest chosen by physicians.

This study shows, for the first time, the feasibility of using data from a community of French patients to obtain insights into the needs and sources of information searched for in the context of a specific disease – SLE. This study confirms that patients with a rare disease (such as SLE) actively search the internet for information<sup>13</sup> and contribute to online communities, and that the data they obtain from online exchanges can provide useful information on subjects not biased or filtered by healthcare providers. This study provides original data on the needs and sources of information searched for by

SLE patients during different stages of the disease; this knowledge could be used to improve strategies and provide increased relevant and helpful information to these patients.

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## Conflict of Interest Statement

M. Chekroun is the founder of Carentity. All other authors have no conflicts of interest to declare.

## Authors' contributions

Study conception and design: LC, MC, NJ, FR; acquisition of data: BM, MC, NJ, LC; analysis and interpretation of data: BM, NJ, JM, FR, LC; all authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published.

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