

## Building patient led organisations

PARE0005

### REFRESHING THE SOCIAL MEDIA STRATEGY OF FIBROMYALGIA ACTION UK: RESULTS OF A NATIONAL PATIENT ORGANISATION SURVEY

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**Background:** Patient organisations have traditionally provided support for patients. However, the method by which people seek support is increasingly desired across social media, particularly among certain populations within the fibromyalgia community who rely on social media as a key form of communication. In addition, the activity of patient organisations on social media is evolving to encompass greater advocacy and awareness activities with a growing target population of different stakeholders. To address this growing demand, Fibromyalgia Action UK conducted an online survey to inform the organisation's future social media strategy.

**Objectives:** The aim of the survey was to understand the preferences of people interacting with Fibromyalgia Action UK's social media platforms, in order to inform the organisation's evolving social media and wider communications strategy.

**Methods:** An online survey was disseminated via Facebook, Twitter and a post on Fibromyalgia Action UK's website over a one-month period, between October and November 2018. Questions focused on general demographics, social media branding, style and content.

**Results:** A total of 301 people responded to the survey, 89% of whom had been diagnosed with fibromyalgia and 5% of whom were a friend or relative. More than half of respondents (60%) were aged between 45 and 64 years, with only 13% of respondents aged under the age of 35 years. 91% of respondents felt happy with the organisation's current branding, with 78% rating the organisation's social media sites as 'Good' or 'Excellent'. While 92% of respondents were happy with the organisation's current social media content, around half (51%) suggested an increase in the amount of visual posts (such as infographics), and two thirds (66%) suggested an increase in news articles and patient/carer stories.

**Conclusion:** The survey highlights the need for more visual, engaging content to inform and educate people about fibromyalgia and related activities. Respondent demographics also highlighted a limited interaction on social media with younger people under the age of 35 years. Together, these findings have prompted the organisation to launch of a new campaign, titled #BecomeFibroAware, using visual content to inform, educate and empower the community, as well as an increased focus on engaging younger people with fibromyalgia.

#### REFERENCE

[1] Armstrong, S. Social networking for patients. *BMJ* 2016; 354 :i4201.

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### LIVING WITH A RHEUMATIC DISEASE: A RESEARCH ABOUT QUALITY OF LIFE AND WORK CONDITIONS

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**Background:** There are 5 million people who suffer from rheumatic diseases in Italy with an annual expenditure of the health system, estimated for the chronic forms, around 4 billion euros. During the World Arthritis Day 2018 the Association of Persons with Rheumatic and Rare Diseases - Apmar Onlus presented the results of the survey "Living with a rheumatic disease" with the aim of raising public awareness by disseminating

data useful to understand the quality of lives of people living with one of the 150 rheumatic diseases.

**Objectives:** The research investigated:

- The quality of life of people with a rheumatic disease
- The work problems and conditions experienced by people suffering from a rheumatic disease.

**Methods:** The survey was both qualitative and quantitative. The qualitative phase was held in Milan and was preparatory to the development of the questionnaire distributed at national level. In this first phase two groups of five people were interviewed for two hours. The people interviewed in the focus groups were women and men, age 25-55 years (50% 25-40; 50% 41-55) with at least one rheumatic disease, currently workers/laborers at least part-time.

In the quantitative phase, a questionnaire was administered throughout the national territory to a sample of 1,020 people, women and men, age 18-75 years with at least one rheumatic disease, currently workers/laborers at least part-time or who worked for a period following the diagnosis of the rheumatic disease. The used methodology of on-line investigation was the Cawi (Computer Aided Web Interview).

**Results:**

- 89,1% of separated and/or divorced interviewed reported that the disease caused problems in the sexual relationship with the partner as to cause their divorce/separation;
- 61% of the sample had to reduce working activities significantly, in many cases abandoning the job completely;
- 26.3% of the sample stated that he prefers not to speak about his illness either with his work colleagues or with his boss and/or superiors.

**Conclusion: Rheumatic diseases affect relationships and social life negatively.** The research shows how the rheumatic disease can have a particularly critical effect in the relationship with the partner. The problems arising in the relationship of the couple are so meaningful, and cause of misunderstandings and psychological suffering to be considered among the main causes of divorce and separations.

**Rheumatic diseases heavily affect the working life.** From the research emerges that people with rheumatic diseases that have managed to preserve their work despite the disease, are often reluctant to talk about their health conditions at work. The main reason is the fear of worsening and/or compromising their relations with colleagues and superiors with consequent negative effects on work tasks and the risk of losing their workplace.

People suffering from rheumatic diseases in Italy declare that their condition of difficulty due to the pain, is often underestimated, this leads them to take a closing attitude for the fear of not being understood. The respondents also expressed the fear that in the highly competitive society we live in, there is no place for people to express their pain: they are afraid of being considered weak and in a certain way "to be put aside" and so they must therefore "show themselves strong".

#### REFERENCE

[1] A. Celano, President - APMAR Onlus; S. Mingolla, Journalist - APMAR Onlus, Matteo Santopietro - Managing Director - WeResearch - ricerche di marketing.

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### RHEUMATISM CHALLENGE 2018 – "RHEUMATISM IN MOTION" WE ARE GOING IN THAT TOGETHER!

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**Background:** Czech League Against Rheumatism plays an important role in promoting rheumatic patients in the Czech Republic. Its activity is aimed at:

- raising awareness about RA for early diagnosis and RA treatment
- improve an attitude of the Czech patients to the modern treatment, including the biological treatment
- co-operate on the change together with the professional community, regulatory authorities and Health Insurance Companies.
- striving to qualify the people with so called "moderate activity" of the disease for the biological treatment