Patient information and education

PARE0003 ESTABLISHING A PATIENT TRAINING CENTER OF RHEUMATOLOGY

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Background: Patient education is considered of pivotal importance for the Organization. Patients should be informed, educated and well trained to acquire the necessary skills needed to deal with the challenges of living with a chronic disease. Equally important is the need of patients to acquire certain skills, necessary for advocating for their rights and representing their Organizations, both at the National but also at the European level. Realizing the above issues, the National Organization decided to create this training centre at its own premises, as it was noted that there was a lack of expertise in the above area, and that patients needed to be empowered to be equal partners in health decisions, but also effective Self managers of their condition.

Objectives: One main objective is to educate individual patients to Self manage their disease by accepting the new situation in their life, but also by learning how to effectively communicate with HPs, to be adherent to treatment, to cope with family work and social environments, and to regain self –confidence. The other objective is to train expert patients, enhance their knowledge and empower them for representing the Organization on all relevant Health committees and participate on all stages of the decision making process.

Methods: First step was to create a Brand name and acquire the relevant certificate of the establishment of the training centre. After the certification process had been finished, two volunteers from the Organization were trained by the National Authority of Human Resources and after successfully passing the 8-hour examination, they became certified trainers. A committee, under the two coordinators is now in the process of revising the modules of the first 5 courses which are offered initially, by restating the aims and objectives of each course as well as the training procedure, teaching techniques, methods and evaluation process. The courses are: The self-management (running), the expert patient (running) Self Diagnosis (running), Training for parents of Children with Rheumatic diseases (Coming before the end of Year), "Rebuilding the story of our life" –Systemic Sculpture method (Running from October 2019- April 2019)

The plans for the next steps include the creation of training course on building patient advocacy skills (Participation in Health committees, HTA, Advisory committees etc) and one on recruiting and training of volunteers.

Results: The experience from the implementation at the initial stage of the three training courses (Self-management, expert patient and self-diagnosis) shows that patients are happy to join, to share experiences and feelings and they successfully attempt to use the skills acquired in their everyday life. Some of the Organization's members have now become members on National Health committees. These include the Committee for Pricing of Medical products, National Health Insurance, ad hoc for updating the rights of patients, rare diseases, for digital Health etc. Success of the existing modules has led the Organization to decide on building an online portal for digital learning.

Conclusion: The creation of a rheumatology training centre for patients, although at its initial stage, has shown positive results for patients, by enhancing their ability to deal in an effective way with the chronic disease but also in improving their skills and knowledge to strive for effective advocacy and for being part of all in decisions that affect their rights in health.

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Best practice campaigning

PARE0004 EASY TO OPEN/EASY TO USE: ACCESSIBILITY FOR PEOPLE WITH REDUCED HAND FUNCTION

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Background: One fifth of Sweden's population, more than 1.5 million people, has reduced hand function.^[1] For the European population, it would equal well over 60 million people.

People with reduced hand function, for example due to illness or age, are often unable to handle products or packaging without additional daily living aids. In addition to the 20 percent of the population with reduced hand function, often due to rheumatic disease, women on average have 40 percent lower hand strength than men. In other words, the market for inclusive design is huge and concerns a large portion of all consumers.

The Swedish Rheumatism Association, SRA, has for many years fought for accessibility of products and services for our members. The SRA has a history spanning over 15 years of activism for inclusive design. The highlight being the launch of the universal standard *SS-ISO 17480:2015 Packaging - Accessible design - Ease of opening*, of which the SRA was a big contributor. However, the aim for this abstract is not to put emphasis on previous successes but to describe current attempts to make the packaging industry adapt a more inclusive design for the many people with reduced hand function.

Every third year thousands of delegates visit Scanpack, Northern Europe's biggest packaging fair. Last year was the first time the SRA attended as an exhibitor, making the SRA the only non-profit organisation working for people with rheumatic diseases, to participate. 463 exhibitors from around 30 countries attended, with 16,500 delegates in total, of which 12,900 were visitors. The fair took place on October 23-26, 2018 in Gothenburg, Sweden.

Objectives: "Products that are functional and easy-to-use for people with reduced hand function, are suitable for everyone". This tagline defined our work for inclusive design. We focused on three objectives in order to make more visitors at the fair aware of the benefits with inclusive design on packages and products. We addressed the packaging industry, the pharmaceutical industry and those who produce products for the public environment. These were the objectives:

- Everyone should know that it is possible to measure manageability.
- Everyone should know that help is available. Tests apply to all types of products and packaging.
- Everyone should know that there is an "Easy to use" and "Easy to open" seal of approval available for packages.

Methods: At the fair, the SRA showed and told visitors how tests on manageability were done, and offered companies to do our small-scale tests of their products. We showed examples of packages that were approved with our certification method. The visitors were also encouraged to participate in our questionnaire.

The questions they had to answer were:

1. How many percent suffer from reduced hand function in Europe? 52 percent of the survey responses were correct. Correct answer: about 20 percent.
2. Women have weaker hand strength, compared to men. How much weaker? 56 percent of the survey responses were correct. Correct answer: 40 percent.

328 people participated in the survey.

Results: Representatives from leading packaging companies and visitors at Northern Europe's biggest packaging fair lack insight in the extent of reduced hand function in Sweden.

Half of the participants who visited the SRA's exhibition responded correctly to our questionnaire regarding reduced hand function, suggesting there is room for improvement in the packaging industry to adapt a more inclusive approach towards design that benefits people with rheumatic diseases.

Conclusion: Half of the participants who visited the SRA's exhibition responded correctly to our questionnaire regarding reduced hand function, suggesting there is room for improvement in the packaging industry to adapt a more inclusive approach towards design that benefits people with rheumatic diseases.

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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.

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PARE0006

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 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".

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

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PARE0007

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