

and used them directly in our political campaigning and communicative work – without the time waster of making fancy reports.

Results: It turned out to be more difficult to establish a representative user panel than we thought. The barriers were various, but we succeeded in the end. The knowledge gained from the user panel has focused and strengthened our political work. This obtained influence would have been very difficult or even impossible to achieve without the experiences of the users. In our presentation we will go into details about the barriers of the establishing phase, share how we use the panel, give examples of how the answers are an added value and show how it helped us gain more political impact.

Conclusions: After overcoming several barriers it will possible to establish a digital user panel which can help organisations to improve their political campaigning.

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THURSDAY, 15 JUNE TO SATURDAY, 17 JUNE 2017

Patient information and education

PARE0012 EDUCATING YOUNG CHILDREN, PARENTS AND DOCTORS THROUGH THE MEDIUM OF AN ILLUSTRATED CHILDREN'S BOOK

T. Egert¹, Y. Egert², R. Vitman¹, W. Costello³, ¹4682, Efrat, Israel; ²Netzach Yerushalayim 8, 4682, Efrat, Israel; ³4682, Dublin, Ireland

Background: Chronic illness in a child is a complex reality for all involved. *The child* often feels confused and afraid. He doesn't understand why he is sick and in pain, he worries about the doctor and hospital visits, as well as the medications and shots to which he is subjected. *Parents* are unsure how the illness will affect their child, and how to best prepare him for future challenges. Both parent and child are not always sure how to communicate to the *Doctor* their needs and concerns. Communication, however, between parent, doctor, child and health professional is critical for the effective treatment of the disease.

Objectives: This book attempts to open lines of communication between parent and child, to educate, give coping tools, and a voice to the young patient in a fun and optimistic manner. The book targets many of the children's challenges through identifying with Kipo, the young monkey who also has JIA.

The objectives: 1. To give the child strength and tools to deal with his illness. 2. Improve compliance through a better understanding of treatment.

Methods: A list of challenges young children with JIA face was compiled through meetings with parents, doctors and children. Next, a list of coping strategies was produced based on discussions with parents and health professionals. The story addresses the challenges and methods of dealing with them in a fun and optimistic manner through young Kipo's routine. Included are also messages addressed to the parent and doctor. To keep the child an active part of the story, thus allowing him to voice his concerns and discover coping skills, the story line requires active participation through "reading the pictures" which accompany the text. (The book includes a "how to read" guide). The back page includes a brief description of the illness, as well as other useful web addresses: parents associations, PRINTO, etc'.

Results: Working jointly with the illustrator an illustrated children's book in 3 different languages (Hebrew, English and Arabic) was published. The book addresses the challenges and difficulties of a young child with JIA through the story of Kipo the monkey who is also ill. Included are a visit to the doctor, getting an injection, going to the physiotherapist, etc. The book is distributed free of charge through the paediatric rheumatologists to the families, and is received very enthusiastically by parents, children and doctors. The children read and reread the book sharing it with family, friends and kindergarten classrooms. They use the terminology introduced in the book to describe their own physical and emotional feelings, and adopt coping strategies used by Kipo.

Conclusions: The success of the book motivated us to allow for a more international distribution. The illustrations and the text are available allowing it to be used by any national group.

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PARE0013 BEHIND THE SMILE - RA AWARENESS VIDEOS - RAISING AWARENESS OF THE HIDDEN IMPACT OF RHEUMATOID ARTHRITIS

C.B. Jacklin, D. Saunders. *External Affairs, National Rheumatoid Arthritis Society, Maidenhead, United Kingdom*

Background: NRAS was approached by Lilly Pharmaceuticals to contribute to the design and production of a series of videos to raise awareness of the hidden impact of rheumatoid arthritis. As this clearly met the charity's own objectives of raising awareness to a variety of audiences NRAS gladly collaborated on this project.

Objectives: The key aim of developing these resources to be utilised in European countries was to raise awareness of the impact of RA on daily life to 1) the general public, 2) clinicians, 3) payers, 4) industry and 5) people living with RA and their

families. The challenge was to capture, in a two minute video, key messages that would resonate with all these stakeholders.

Methods: NRAS worked with a PR agency to develop an appropriate script for the main Behind the Smile resource. The main character, Jane, who lives with RA, was to be in her mid 30s – to represent that RA is not associated with ageing; a school teacher – to represent that working is more than just a job for her and that she is a valued contributor to society; and a daughter, wife and mother – to represent how many other people depend on her and that she has commitments to.

We filmed with the support of Donna Saunders, NRAS Member & Volunteer, on hand to comment and ensure authenticity of how the actress moved and dealt with every day activities. The final scene shows the character of Jane attending her clinic appointment with her rheumatologist and even then putting on a brave face and hiding behind the smile of the typical response "I'm fine".

In addition, Donna who lives with RA, was filmed giving her personal comments on the awareness film and insights into her personal struggles. Finally, Prof. Iain McInnes, was filmed giving the clinicians perspective and offering advice as to how health care professionals need to keep at the forefront of their minds that patients are people and to be truly effective as physicians they should always make the time to open the dialogue on how the individual is truly "feeling"

Results: The films were released on World Arthritis Day 2016 via Lilly and NRAS social media channels in the UK. To date the "Jane" clip has been viewed in access of 200,000 times. The feedback from patients has been overwhelmingly that it has truly captured their "story". Physicians and industry staff have been left speechless and moved by the emotive film. NRAS and Lilly continue to utilise the films at health care professional training, staff and patient events.

Conclusions: Plans for 2017 is to develop more similar awareness raising videos as it is evident that using social media with video has impact and reach.

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PARE0014 EXPLORING THE ADDED VALUE OF A BOOSTER SESSION AFTER COMPLETING THE DUTCH SELF-MANAGEMENT TRAINING "CHALLENGING ARTHRITIS"

M. Vos¹, R. Van den Brink², S. de Jong², J. Ammerlaan³, ¹Expert Patient/Psychologist, Purmerend; ²Dutch Arthritis Foundation, Amsterdam; ³Rheumatology & Clinical Immunology, University Medical Centre Utrecht, Utrecht, Netherlands

Background: In the Netherlands, the peer-guided self-management training "Challenging Arthritis" exists for over 15 years and is being organized by the Dutch Arthritis Foundation and the University Medical Center Utrecht. The training is based on the "Arthritis Self-Management Program" but has recently gone through several updates, improvements and extensions². The goal of the training is to improve self-management skills of patients and thereby improving their physical and emotional health and quality of life. Evaluations show that participants highly appreciate the training, but some of them have suggested that they would like to have an extra moment of training, (i.e., a booster session) after the ending of the regular program. Research shows that self-management programs are effective but mostly in the short term³. The effects of "Challenging Arthritis" may be enhanced and prolonged by organizing booster sessions.

Objectives: Aim of this research is to make recommendations about organizing booster sessions based on 1) a literature search and 2) a needs assessment among former participants and peer trainers.

Methods: A literature search was performed in databases like Google Scholar, PubMed and Science Direct, focusing on articles about the use of boosters in self-management interventions, limited to the years 2000–2016. Next to that, a needs assessment was conducted among participants and trainers on needs and preferences, using two separate online surveys. The survey for the participants, who followed a live training between 2012 and 2015, included items on the need for a booster and on preferences regarding its form, content and frequency. The survey for peer trainers addressed the perceived usefulness and the trainers' willingness to provide booster sessions. The resulting data were analyzed using SPSS and thematic analysis.

Results: The literature search yielded 27 articles describing health interventions with aspects of self-management, including one or more booster sessions. From a theoretical perspective, boosters are a way to maintain new behavior over an extended period of time. As of yet, there is little evidence that the use of boosters lead to better outcomes in terms of health or health behavior, but it has been suggested that tailoring may lead to better results^{4,5}. Regarding the needs assessment, 124 participants and 34 trainers completed the survey. Results showed that almost half of the participants (47.5%) expressed a need for a booster, while the other half (52.5%) expressed little or no need. Participants who prefer a booster want to share experiences, learn how to stay active with self-management and how to cope with setbacks. Trainers think boosters are very useful for the participants to stay active with self-management and maintain behavior and they are unanimously willing to provide booster sessions.

Conclusions: Boosters may contribute to the maintenance of newly acquired health behavior, although more research is needed on this subject. A substantial

part of the participants expresses the need for a booster and trainers are highly motivated to provide it. Therefore, we think it's worthwhile to start experimenting with organizing booster sessions on a small scale and, depending on the outcomes, consider further implementation.

References:

[1] References can be obtained from the first author.

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PARE0015 THE IMPORTANCE OF FACE-TO-FACE NETWORKS: FINDINGS FROM THE 2ND EULAR YOUNG PARE CONFERENCE, "CHANGE THE FUTURE"

J. Andersen^{1,2}, P. Balazova^{3,4}, W. Olsder⁵, S. Ostuzzi⁶, D. Papastavrou^{4,7}, S. Stones^{8,9}, T. Wilhelmer¹⁰, P. Boyd¹¹ on behalf of EULAR Young PARE.
¹Sle/Lupus Ung Dk, Gigtforeningen, Gentofte, Denmark, Gentofte, Denmark;
²Lupus Europe, Essex, United Kingdom, Essex, United Kingdom; ³Slovak League Against Rheumatism, Piestany, Slovakia, Piestany, Slovakia; ⁴EULAR Standing Committee of PARE, Zurich, Switzerland, Zurich, Switzerland;
⁵Youth-R-Well.com, Lisse, The Netherlands, Lisse, Netherlands; ⁶ANMAR Young, Rome, Italy, Rome, Italy; ⁷ELEANA Hellenic League Against Rheumatism, Athens, Greece, Athens, Greece; ⁸School of Healthcare, University of Leeds, Leeds, United Kingdom, Leeds; ⁹Fibromyalgia Action UK, Paisley, Renfrewshire, United Kingdom, Paisley, United Kingdom; ¹⁰Österreichische Rheumaliga, Salzburg, Austria, Salzburg, Austria; ¹¹Arthritis Ireland, Dublin, Ireland, Dublin, Ireland

Background: EULAR Young PARE's strategy for 2020 is to establish and strengthen groups for young people with rheumatic and musculoskeletal diseases (RMDs) across Europe, by developing a collaborative network. We aim to empower youth leaders to ensure the voice of young people with RMDs is heard. To facilitate this, the 2nd EULAR Young PARE Conference was held in Retie, Belgium in October 2016.

Objectives: To empower and educate EULAR Young PARE youth liaisons, focusing on developing academic and interpersonal skills to best support young people across Europe living with RMDs. This was achieved through a series of practical, skills-based workshops and plenary sessions.

Methods: The EULAR Young PARE working group reflected on the conference during a debrief meeting. A post-conference evaluation was completed by liaisons. A five-point Likert scale (1= very bad, 5= very good) was used alongside open questions. In addition, there was an informal meeting to generate discussions and receive input from participants regarding the future direction and focus of EULAR Young PARE in 2017 and 2018.

Results: The conference was attended by 22 youth liaisons from 20 organisations. The programme was well received with the face-to-face interactions favoured to establish and grow collaborative networks. Through a series of digital poster presentations, each liaison had the opportunity to share recent work in their national organisations. This session was evaluated positively and encouraged liaisons to identify opportunities for collaboration and new national activities, using the VKC as a platform for the sharing of best practices. Workshops were delivered in collaboration with EMEUNET and a EULAR member organisation representative and we piloted a series of six walk-in workshops. While these workshops were evaluated positively, a lack of structure and the need for time constraints was a consistent finding.

Conclusions: The "Change the Future" conference was a successful meeting of youth liaisons from across Europe, who were highly satisfied with the programme and mechanism of delivery. Meeting in person facilitated the growth and continued involvement within the EULAR Young PARE network. The activities of EULAR, and specifically the Standing Committee of PARE, were shared with liaisons, encouraging liaisons to become involved in a wider number of EULAR activities. Theoretical and practical skills were developed, while best practices and experiences were shared and highly valued. Furthermore, in future conferences, bitesize workshops will replace walk-in workshops for structure and clarity. Despite living in a digitally connected world, face-to-face interactions cannot be replaced. Learning can be enhanced and actions implemented when motivated individuals are physically united, demonstrating the need for the use of multiple meeting methods to drive innovation. Following the conference, everyone felt inspired, empowered and motivated to implement concrete and tangible steps to inform ongoing and future work. Together, we can change the future for young people living with RMDs.

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PARE0016 KEEP CALM AND TELL ME YOUR STORY!: A NARRATIVE MEDICINE PILOT PROJECT FOR ITALIAN YOUNG PEOPLE LIVING WITH RHEUMATIC AND MUSCULOSKELETAL DISEASES

U.G. Viora¹, S. Ostuzzi^{2,3} on behalf of ANMAR Italia - ANMAR Young. ¹Anmar Italia, Torino; ²Anmar Young, Anmar Italia, Rome, Italy; ³Eular Young Pare, Zurich, Switzerland

Background: The 7th point of EULAR Young PARE's Youth Strategy states that "By 2020, every European country has an active national youth group

for young people with rheumatic and musculoskeletal diseases (RMDs)". On this basis, ANMAR – Italian national association for people with RMDs – has engaged in the creation of a youth group dedicated to Italian young people (aged 18–35) living with RMDs: ANMAR Young was born in 2015, through EULAR's Knowledge Transfer Programme. During its first year of activities, ANMAR Young has launched the pilot project of a narrative medicine campaign called *Keep Calm and Tell Me Your Story!*

Objectives: *Keep Calm and Tell Me Your Story!* was designed to make sure that the voice of young Italian people living with RMDs is heard, spread, and listened to. In its pilot phase, the project aimed to consult, engage, involve young rheumatic patients while building an Italian network. A major pilot phase's objective was, as well, the launch of a booklet presenting the collected stories on World Arthritis Day 2016.

Methods: The ANMAR Young task force has drafted the four different writing traces to compose the campaign, investigating some crucial issues, such as: the impact of RMDs on young people's personal life, working life and education; the experience of transitioning from pediatric to adult rheumatology care services; young rheumatic patients' unmet needs and priorities. The criteria for inclusion of participants were deliberately simple: every Italian person living with any RMDs and aged from 18 to 35 could take part in the campaign. Texts have been collected anonymously exclusively through an online form, promoted and disseminated mostly through social media. The pilot project campaign has lasted one month, from the end of July 2016 until the end of August 2016.

Results: From the end of July 2016 to the end of August 2016 21 stories have been submitted by 20 female respondents and 1 male respondent coming from 11 different Italian regions, suffering from different RMDs (among which the condition reported more often is Juvenile Idiopathic Arthritis). The collection has become the subject of a booklet, published in an edition of about 5,000 copies and officially launched in October 2016 in Rome, on World Arthritis Day. The campaign spread online, allowing ANMAR Young to gather different experiences, expand its network, contribute in the process of empowerment and engagement of Italian young rheumatic patients.

Conclusions: The campaign *Keep Calm and Tell Me Your Story!* has proved to be a valuable, peer-to-peer, economically sustainable, easily manageable and repeatable (also abroad) engaging tool for raising awareness about the impact of RMDs on the quality of life of young people. We intend to further develop this narrative medicine experience by keeping collecting new stories, by sharing them weekly through social media, by promoting our printed booklet. We intend to further analyze in detail the collected texts, in order to read them not only as personal experiences but also as a qualitative mapping of Italian young people with RMDs' unmet needs and priorities.

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PARE0017 EMPOWERING PATIENTS WITH OSTEOARTHRITIS WITH NON-PHARMACOLOGICAL MEASURES

J. Vergés¹, J. Monfort², M. Bibas¹, M.T. Vergés¹. ¹Osteoarthritis Foundation International; ²Hospital del Mar, Barcelona, Spain

Background: Osteoarthritis (OA) and other joint pains are generally seen as ailments that affect people with age. With the increase in life expectancy over recent decades, the prevalence of people with OA is drastically growing. Estimates suggest that there are 242M people with OA in the world¹; 30M live in Europe². The most commonly affected joint at the present time is the knee, followed by hips and shoulders³.

Objectives: To run an educational program that will provide elderly people with tools to tackle their problems of joints so that they can improve their quality of life by adopting non-pharmacological measures. A well-informed patient knows how to address their disease. Thus, they can improve their quality of life.

Methods: The method is based on the capacity of a motivated patient to positively influence others also worried by their health situation by sharing their experiences and awareness of the disease.

Stage I. Preparatory actions:

1. Elaboration of contents: An expert team (psychologist, nurse, rheumatologist, family doctor, physiotherapist and rehabilitator) elaborates the content: Knowledge, Weight control, Doing the right exercise, Dealing with the disease
2. Engagement of the target group: "La Caixa" Banking Foundation is supporting this study by giving access to its 63 senior centers in Catalonia (Spain)
3. Selection of senior centers: The educational program is planned to be run in 6 centers. Currently, 20 centers are conducting initial presentations to evaluate interest and ensure the selection of 6 final centers
4. Enrollment of smart seniors: 12 people will be selected (2 per center), called hereafter, "smart patients", through a survey so we can assess interest of enrolling and quality of the presentation

Stage II. Training and implementation:

5. Training of smart patients: Train selected smart patients during 9 sessions, 90 minutes each
6. Training groups of patients: Every smart patient will train 2 groups of 10 people also interested in joint health. A nurse will be in every session, giving support only if necessary
7. Evaluation and follow-up: Improvement of participants in the course will be assessed (anticipated sample size 240 people) by surveying level of satisfaction