- Should we speak about our disease (and when, how?), or not speak about our disease at work?

- What means « disablement », « being disabled » for you as a person affected by a rheumatic disease?

- What have you been able to do to get a paid position, or keep your job, that you could quote as an advice for other people in the same situation?

- If you had been given, or were given now a magic wand to make it easier to get or keep a job, or get/keep the job you dreamed of, what would you change?

At the end, videos will deliver further advice, tools and resources taken from the booklet, such as a model of decisional scale, or reference institutional website addresses.

Results: AFLAR wishes to contribute actively to rheumatic patients', and especially young people's information on the topic thanks to these more innovative and interactive tools.

Conclusion: Furthermore, wishes, solutions and ideas of witness patients and users will be gathered for advocacy towards employers, institutions and decision makers.

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SATURDAY, 06 JUNE 2020

Campaigning

PARE0012 AWARENESS CAMPAING "LUPUS.GR 2020"

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Background: LUPUS GR 2020

Objectives: To sensitize and educate the wide public about lupus
To contribute to the process of de-stigmatization as the rigid problem of prejudice and stigma prevails.

Methods: The campaign "LUPUS GR 2020" consists of photographs, each of which has a different message for Lupus and 2 TV spots. The well know artists participated did not take any fee.

The campaign consists of
Press Announcements in digital and off digital media, in Social Media (Instagram - Twitter - Facebook), in Eleana Site and in YouTube
Post of the artists in their personal social media pages
Press Conference

Direct mail in international NGOs e.g. Lupus Europe, PAIN ALLIANCE EUROPE, AGORA PLATFORM, etc.

Results: We announced the campaign on January 24, 2020. Until end of January, we have 36 press clipping, 3 TV interviews, more than 35.000 views of the post in our fb and increase of telephone calls in our help line about lupus

Conclusion: The campaign has a high impact in the wide public as well as in all the stakeholders.

Figure:

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SATURDAY, 06 JUNE 2020

Patient information and education

PARE0013 'FIND A NUDGE' AND OTHER TIPS TO MAINTAIN YOUR LEVEL OF PHYSICAL ACTIVITY FOR A LONGER TIME

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Background: Pain, fatigue, physical disability, reduced well-being and sleep problems are common consequences of Rheumatic and Musculoskeletal Diseases (RMDs). Paradoxically, these consequences may all lead to a reduction of physical activity, while physical activity actually is an antidote against these consequences. This is acknowledged by experts that included physical activity and exercise into recommendations for management of RMDs [1-3]. Indeed, after programs aimed at a gradual build-up of exercise, many people with a RMD showed an increase of physical activity. However, it is hard to maintain a higher level of physical activity for years as part of daily routine [4-5].

Objectives: To identify and present tips, applications and illustrations that support people with an RMD to maintain their level of physical activity for a longer time.

Methods: Theoretical considerations and empirical findings guided the identification of tips. Care was taken that the tips and illustrations were translated into layman language and fitted in daily life of common people.

Results: Ten tips were found:

- 1) break the habit,
- 2) make sure you can do the exercise activity,
- 3) use aids if needed,
- 4) believe in a good outcome,
- 5) choose a physical activity that fulfils personal goals,
- 6) find a physical activity that you enjoy,
- 7) stop moving while it's still fun,
- 8) find a buddy,
- 9) make an action plan, and
- 10) find a nudge.

A "nudge" is a little push in the right direction that makes a person unconsciously perform physical activities. Examples are an outdoor photography hobby, a dog that comes to you with a dog leash in his mouth, or grandchildren that persuade you to go with them to the playground nearby. If a person with a RMD manages to find a nudge that stimulates instinctive moving without feeling the effort, then physical activity may be maintained. People differ a lot and must discover for themselves which tips help them to maintain physical activity. They must be aware that it may take up to two months for changed habits to stick.

Conclusion: The presented tips will help to maintain your level of physical activity. Nevertheless, be aware that effort and perseverance are needed to keep on moving. A challenge for the future is to get more knowledge of natural and pleasurable physical activities. Peers with successful experiences and

behavior change experts can help. For the time being, a main advice to maintain a higher level of physical activity with less effort is to find your own nudges.

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PARE0014

CANNABIS – HOW TO NAVIGATE BETWEEN PRESSURE FROM PATIENTS, LEGISLATION AND NEED FOR EVIDENCE

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Background: Around the world, focus on cannabis has been increasing immensely the last couple of years. Patients with RMD very often experience pain and many of these patients do not get adequate relieve from ordinary painkillers. Therefore, the pressure from patients wanting to try cannabis in order to ease their pain, is very understandable but also a difficult field to navigate in for a rheumatism association. Mainly because there are so many different interests in cannabis from many sides.

Objectives: The Danish Rheumatism Association has taken a very active role in unfolding knowledge of the positive and negative effects of cannabis to patients with RMD. We want to show, that we are aware of our patients needs and interests and we wish to give independent information to patients with RMD about suitable pain relief also when this involves the use of cannabis.

Methods: In order to get more knowledge about the need of the patients, the Danish Rheumatism Association has registered every inquiry from patients to our professional helpline in 2018 regarding cannabis. This information has been used in our political work with the Danish Ministry of Health and has given us a deeper understanding of the RMD-patients background and motivation for using cannabis. The Danish Rheumatism Association has supported cannabis research financially, and we have taken part in the public debate with editorials. On our website, we have fact sheets regarding cannabis along with a theme about cannabis in our magazine. The Danish Rheumatism Association has been very active politically in order to get RMD-patients to be part of a national project with medical cannabis to different groups of patients. We have an ongoing contact with the Danish Ministry of Health regarding RMD-patients experience in using cannabis and we pass on RMD-patients difficulties in even getting cannabis legally. In addition, to continuously gain knowledge about RMD-patients' experience with cannabis, we have also conducted questionnaires and surveys both in collaboration with other patient organizations and through our own channels.

Results: We have made it clear that we take an active role in the public debate regarding the use of cannabis and that we understand the desire from patients to have as many options as possible to choose from when it comes to relieve their pain. However, we also acknowledge the fact, that we need more evidence when it comes to the use of cannabis as an actual option for patients with RMD-related pain. We are a reliable partner that politicians and other stakeholders take very seriously.

Unfortunately, patients with RMD did not get to be part of the national project in Denmark with medical cannabis, but nevertheless many of these patients are using cannabis and most of the patients buy it illegally.

Conclusion: The use of cannabis is still a very "hot topic" in many countries and the legislation can vary a lot from country to country. It is important that the rheumatism associations across Europe have knowledge about cannabis so that they can advise patients with RMD in a serious, objective and evidence-based manner.

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PARE0015

UNDERSTANDING THE NEEDS OF PATIENTS WITH OSTEOARTHRITIS TO INFLUENCE THE DEVELOPMENT OF RELEVANT PATIENT-CENTERED PRODUCTS & TREATMENTS

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Background: Osteoarthritis (OA) is the most common form of arthritis and affects over 30 million adults in the United States of America.¹ There is no cure for osteoarthritis, and unlike other forms of arthritis where great treatment advances have been made in recent years, progress has been much slower in osteoarthritis.² However, there is increasing interest in removing barriers to treatment development, and the U.S. Food & Drug Administration has adopted and implemented new patient-focused drug development meetings to ensure the patient voice is informing new treatments.³

Objectives: To gain a robust understanding of the barriers, needs and hopes of patients with OA to influence the development of relevant patient-centered products and treatments.

Methods: A 34-question web-based survey was distributed between November 1 - 10, 2019. Survey invitations were sent via e-newsletters and e-mails to patients engaged with the Arthritis Foundation. The first survey question screened out patients who had not been diagnosed with OA.

Results: 2,437 patients diagnosed with OA completed the survey. There are 5 key findings:

1. Patients would like pain (90%) addressed more than any other symptom. Other symptoms such as fatigue (50%), sleep (39%), ability to walk (35%), stiffness (32%), ability to stand (16%), and ability to go up & down the stairs (14%) were ranked significantly below pain.

2. Patients use a variety of techniques to manage their OA and related symptoms. Physical activity (62%) and heat & cold interventions (62%) are the most prevalent. Approximately half of the patients use topical cream (53%), supplements & vitamins (51%), NSAIDs (50%), and/or acetaminophen (48%). Approximately one-third of patients utilize diet/nutrition (39%), assistive devices (38%), cortisone injections (36%), and/or physical therapy (34%). Other methods, including surgery (26%), were utilized less frequently.

3. 41% of respondents reported they were "very interested" in participating in OA clinical trials; 40% reported "somewhat interested." Only 19% reported they were "not interested." The top 2 reasons patients were not interested included fear of possible risks/unknown effects (48%) and potential impact on other health problems (44%).

4. Primary care physicians are diagnosing (44%) and treating (48%) OA patients more than any other health care provider.

5. Many daily living tasks are difficult, and patients are interested in tools/equipment to help. Yard work (66%), opening jars (64%), and cleaning the house (63%) are the most difficult. Over half of patients reported that physical activity (57%) and getting up and down from a chair (54%) are difficult. Patients would like tools/equipment to help them clean the house (54%) and help with physical activity (50%).

Conclusion: OA patients use a variety of management techniques yet are still in pain and have difficulty doing everyday tasks. These findings, along with other patient data, will be used to influence product developers to create easier to use products, to inspire researchers to focus on addressing patients' most pressing needs, and to encourage government agencies to remove barriers and facilitate new patient-centered treatments.

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