differences in life quality between people who have a diagnosis and people who do not have a PsA diagnosis or who have not yet received one:

1. Many are without diagnosis and treatment

High proportion of undiagnosed patients have symptoms indicating PsA. Many have suffered a long time from joint related pain and sought out treatment from a number of doctors.

3 out of 4 with joint pain have negative or very negative experiences of healthcare related to their joint pain. The survey participants indicated that they suffer from waiting a long time for healthcare.

2. Major differences in perception of care and treatment

Statistics on overall satisfaction with healthcare show remarkable differences that can be linked to getting a diagnosis. People with joint pain but without a PsA diagnosis indicate a great dissatisfaction with the care they receive. People who have been diagnosed with PsA are overall quite satisfied with the care and treatment they receive after getting a diagnosis.

3. High use of opiate remedies for pain

The use of pain reliever opiate drugs is remarkably high in the group with joint pain but without the diagnosis of PsA. Also very high use of non-steroidal anti-inflammatory drugs, NSAIDs.

Conclusions: Given that the prevalence for psoriasis arthritis in Sweden is between 10 000 -30 000 people, it is likely that the awareness campaign reached a considerable number of people with the diagnosis or with symptoms similar to it. The longer the patient goes without adequate healthcare the worse the disease gets. If untreated it could lead to permanent joint damage. Early diagnosis and treatment are important to slow down the disease.

References: www.HarDupsoarthritisarthritis.se

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.4448

PARE0009 CANADIAN ARTHRITIS PATIENT ALLIANCE: UNDERSTANDING MEMBER PROFILES AND NEEDS

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Background: Established in 2002, the Canadian Arthritis Patient Alliance (CAPA) is a grass-roots, patient-driven, independent, national organization with members across Canada. CAPA believes the first expert on arthritis is the individual who has the disease. We assist members to become advocates not only for themselves but all people with arthritis. CAPA works with other organizations, representatives from all levels of government, and researchers to ensure the patient voice is both heard and present. We communicate the latest news on health policy developments, research, technology and emerging issues relevant to members through our newsletter, website, Facebook, Twitter and YouTube channels. CAPA welcomes all of those who support CAPA's goals, especially Canadians with arthritis, to become members.

Objectives: CAPA underwent a strategic renewal in 2013, re-establishing its focus and operations. Since that time, CAPA has produced an annual strategic plan, and reported on yearly achievements in relation to the plan. In 2017, CAPA decided to conduct a membership survey.

The survey was designed with three objectives in mind: (1) Understand our membership's profile and interests, (2) Understand member awareness and support for CAPA projects and strategic direction, and (3) Seek membership input on CAPA's website.

Methods: A survey was created using Survey Monkey (in both English and French, Canada's official languages) and sent to members. Results of the survey were sent to the members and made available on CAPA's website (http://www.arthritispatient.ca/files/5315/1128/7211/CAPA_Survey_-_Spring_2017.pdf). As an additional incentive, two C\$50 VISA gift cards were drawn from among Canadian respondents. The survey was open from May 1 to 21, 2017.

Results: The response rate to the survey was 23% (that is, 85 respondents out of a possible 369). Of those who responded, the majority were women, with over 75% aged 55 years of age or over. Respondents came from all across Canada. Members generally came to CAPA to find information and stay abreast of events in the arthritis community; only a small portion, 17%, joined to become more involved. Members supported CAPA's strategic direction, which aligned with their stated interests.

Members also provided feedback on the website. For the most part, members appreciated the information, providing some recommendations moving forward, including supporting a mobile friendly website (i.e., responsive design).

Conclusions: CAPA is using the information from this membership survey as confirmation of its strategic direction moving forward; continued focus will be on providing information, connecting with key stakeholders in the arthritis community (Canadian and abroad), and undertaking focused projects as they arise.

Member feedback has been critical in guiding the website redevelopment, which is currently underway. We expect it to be complete in early summer 2018.

Acknowledgements: CAPA would like to thank the organizations that collaborate with us as well as various pharmaceutical companies whose funding enables our operation.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.3003

PARE0010 NATURALLY HEALING THE CHRONIC PAIN AND HEALTH MAINTENANCE

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Background: Everyday life is not easy for people with RMDs. Chronic Pain is the "roommate" usually on patient's life. Patients usually try to find other ways of confronting their symptoms, beyond drugs or other classic options such as physiotherapy. One of these ways that often people with RMD's are discussing is the treatment with Natural Healing Sources based on water which is used in various cultures from ancient times. Cyprus League Against Rheumatism gives these opportunities to the members every year; by organizing excursions in Natural healing resorts at least two times per year.

Objectives: The aim of organizing therapeutic trips to therapeutic treatment centers – Natural Healing Resorts, was to give members the opportunity to get acquainted with and experience this mode of therapy, with team approached on rehabilitation treatments, for patients who cannot afford to visit as individuals because of the cost or to travel as individuals tourists and they need extra services and attention. In addition to therapeutic qualities, it would also give psycho-social affiliation to people who would participate, which CYPLAR gives a lot of insight into all of its programs

Methods: In 2012 CYPLAR approach the Ayioi Anaryiroti Natural Healing Resort & Spa which is situated in Miliou, a small village in Paphos area, and their thermal waters are from ancient times, organized the first trip to this healing Resort.

In 2014 CYPLAR approached a Cypriot travel agency, and asked for help to organize a trip in Sandanski, in Bulgaria, as after a research find that it is a very good and famous thermal water springs and not too far from Cyprus so was easy to access and not too expensive.

Results: The trip to Ayioi Anaryiroti Natural healing Resort & Spa was very successful so every year at least one time is organized a trip for a weekend. The difference for the people with RMDs participated in this trip instead of going alone, is that CYPLAR is having better rates for members for this special weekend, and also the therapeutic treatments during this weekend are targeted on RMD's. Another ad is that people are coming close to each other, bonding, and sharing their experiences. Every time around 20 people with RMD's are participating on these trips. CYPLAR members have all year around discount. Future Goal is to be organized twice times per year.

The trip to Sandanski is organized every year in July (3 times until now). It is a ten days program and includes examination, target treatments based on each participant and his/her needs, also include sightseeing tours in the area, entertainment dinners, and many other amenities. It is a very succeed therapeutic excursion that 40 people are participating and has a lot of good results. CYPLAR conducted a survey among the participant of the last trip in July 2017 and the results are very encouragingly to continue and have these excursions for more and more years. At the question "Do you want to go again in Sandanski with Cyplar?" The answer was **Yes** for the 95% of the participants. Results showed also the need for people with RMDs to have this kind of therapies in their life and the beneficial effects on their health status.

Conclusions: Patients with RMD's need these types of therapy for their body health but also for their psychosocial improvement. CYPLAR will continue to support the members with these two excursions but also is trying to find new resorts to enrich the program and give more opportunities for members.

References: Survey – Participants Sandanski 2017 -CYPLAR

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.2490

PARE0011 FUNKA UTAN SKAM TO FUNCTION WITHOUT SHAME

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Background: Introduction:

Kids, youngsters and adults with an immigrant background are more vulnerable in the new country of arrival. It is quite hard to learn a new language and the rules and regulation in the new country.

In several cultures, people with a visible or invisible disability can experience guilt and Shame because of their diagnoses. Due to the cultural background, most of the time the families are also feeling the same. This feeling could be conscious or unconscious due to the cultural background.

Therefor did the Swedish National Assyrian Organization (SNAO) take the initiative to start a knowledge-sharing project together with the Swedish Rheumatism Association and the Swedish Neuro-Association to inform and educate the kids and their parents with the Assyrian background.

Objectives: The aim of this project is to empower the persons and families suffering of an RMD or/and neurological disease among the immigrants from Syria and to break barriers within the immigran's society as well as saving on the national welfare system.

Results: To achieve such a project the SNAO applied for funds from the Swedish General Inheritance fund nad worked closely with the Swedish Rheumatism Association as well as the Swedish Neuro-Association.

The project included other stakeholders that could embrace the goal and use unconventional methods to mark the point and reach out to the target group.

- Organizing weekend seminars open for to the target group
- Working with *Läsa för integration* (Reading for integration) <http://www.lasaforintegration.se/index.html>
- Opratat is a theater group that lifts difficult subjects to the surface and make a pedagogic scen of the subject. <http://anhoriga.se/opratat/>
- The Swedish Disability Rights Federation: that enable the project to reach a broader target but also to reach the decision makers.

References: The project reach a great number of immigrant with an Assyrian background and could inform the attendees about their right and how the Swedish society works. This was of a great help to the families as well as the kids.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.7574

PARE0012 THE FRENCH PATIENT'S ASSOCIATION AFLAR: HAS GENERATED THE FRENCH NATIONAL ALLIANCE AGAINST OSTEOPOROSIS AND THE FIRST GENERAL CONVENTION FOR OSTEOPOROSIS, THAT IS A CAMPAIGN TO CREATE A NATIONAL PROMOTING TOOL TO IMPROVE THE MANAGEMENT OF OSTEOPOROSIS: 7 PRIORITIES TO BETTER TREAT PATIENTS I

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Background: Osteoporosis is a major public health issue with 5 million of French affected. Overall, she seriously underestimated, and costs are barely covered in France. Considering this situation, AFLAR were urged to create the so-called National Osteoporosis Alliance made up of 15 various stakeholders and patients.

Methods: National consultations on osteoporosis rely methodologically on 2 pillars: First the bottom-up reporting on patient needs and expectations. Second the conduct of coordination meetings with various osteoporosis key stakeholders and patients as part of regional panel-discussions. The aim is to provide an overview of real obstacles contributing to the lack of government subsidies for osteoporosis and write consensual proposals compiled into a white paper.

Results: An online survey along with a citizen's panel were key to provide feedbacks on difficulties, knowledges and believes but also patient needs. From November 2016 to June 2017, 10 days of dialogue and debate covering 5 various topics were convened in 10 different cities: Consultation and consolidation work regarding proposals made during various panel-discussions allowed synthesis around one call: the creation of a real public health plan against osteoporosis-related fractures relying on 7 key axis.

Conclusions: The human and medico-economic rational considering dramatic fallouts caused by osteoporosis has been illustrated many times over. The policy makers mobilization made by stakeholders through white paper release, a real manifesto for public health plan against osteoporosis-related fracture, remain a significant challenge to face.

Disclosure of Interest: L. Grange Grant/research support from: ucb Lilly Amgen expanscience Roche company, B. Cortet : None declared, T. Thomas : None declared, F. Srou : None declared, P. Guggenbuhl : None declared, C. Roux : None declared, P. Monod : None declared, J. M. Feron: None declared, F. Alliot-launois: None declared, F. Tremollières : None declared, G. Chalés : None declared, J. Giraud : None declared, E. Senbel: None declared, G. Thibaud: None declared, P. Niemczynski: None declared, D. R. Bertholon : None declared, C. F. Roques : None declared, D. Buchon: None declared, C. Bonnet : None declared, H. Blain : None declared, C. Rolland : None declared, D. Lafarge : None declared, L. Carton: None declared

DOI: 10.1136/annrheumdis-2018-eular.3922

PARE0013 SOURCES OF INFORMATION AND KNOWLEDGE ABOUT RHEUMATIC DISEASES AMONG PEOPLE WITH RHEUMATIC DISEASES IN POLAND AND IN OTHER EUROPEAN COUNTRIES

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Background: Knowledge on rheumatic and musculoskeletal diseases (RMDs) is an important factor in helping patients live independent lives as long as possible. The internet and easy access to all sorts of information make it seem that delivering appropriate information to patients is one of the key objectives of health promotion.

Objectives: The aim of this study was to evaluate patients' knowledge on RMDs and find out how and when they seek and retrieve relevant information. The results provide an opportunity to increase efforts in proper education of patients and health care professionals, reduce adverse effects of incorrect information and increase self-awareness as well as personal health responsibility among patients.

Methods: We used questionnaires for patients with RMDs and carried out focus group interviews. The Computer-Assisted Web Interview Questionnaire was divided into 2 sections: one describing characteristics of respondents and evaluating importance of various information and its sources and the latter which tested knowledge on RMDs. The respondents were asked to rate their own knowledge and information provided by their physician. All the data were collected in 2017. We used two language versions of the questionnaire – Polish and English for international patients. The results from both groups were compared.

Both versions were distributed with the help of patient organizations. The link to the English version was distributed with the kind support from EULAR.

Results: We received 207 on-line responses – 140 in Polish and 67 in English. Both language groups had similar characteristics, however the English-speaking