

of all topics relevant to understand and manage fatigue in patients with rheumatoid arthritis (RA), spondyloarthritis (SpA, including psoriatic arthritis (PsA)), osteoarthritis (OA) and fibromyalgia (FM).

Objectives: To scope published reviews on aspects of fatigue identified by patients in a preceding initiative as relevant for care and mapped to the following research areas: 1) definitions for fatigue, 2) measurement instruments for fatigue, 3) determinants of fatigue, 4) impact of fatigue, and 5) effect of interventions on fatigue in patients with RMDs of interest.

Methods: A methodological framework for scoping reviews was followed¹. A systematic literature search was performed in five bibliographical databases. Data selection followed by data extraction was done by two independent researchers.

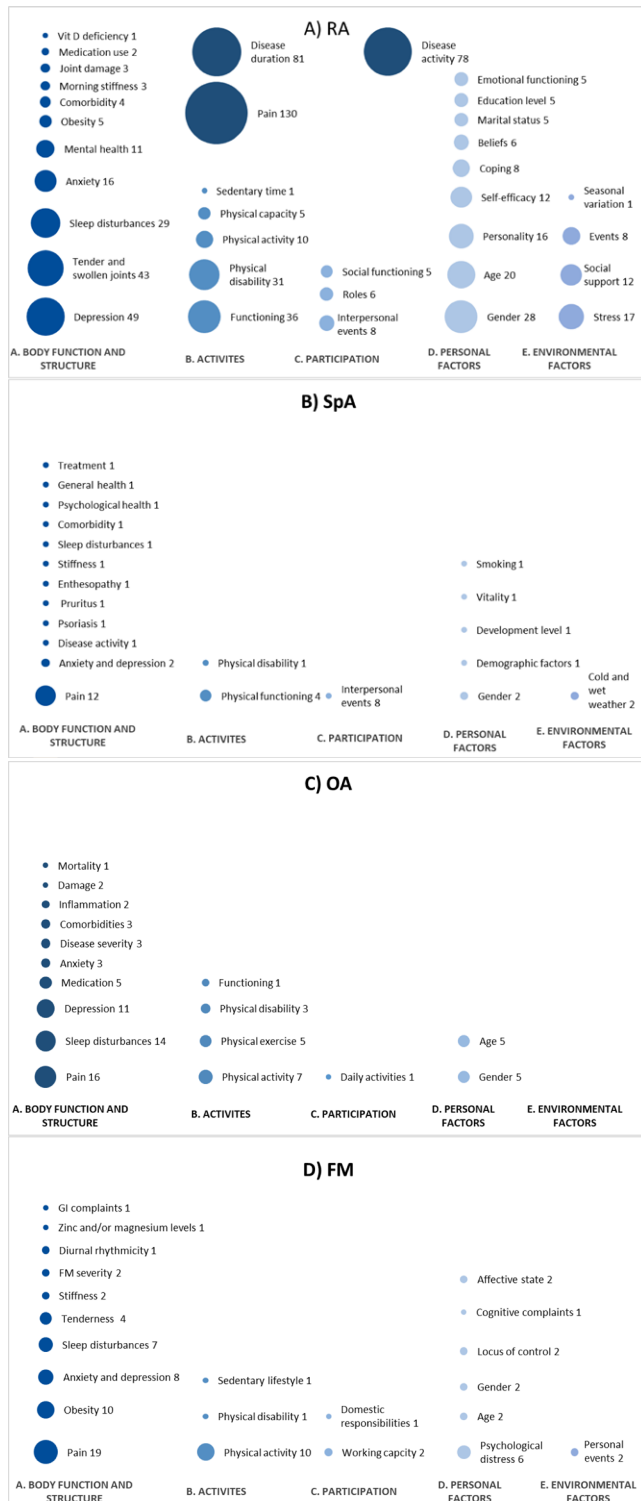


Figure 1. Determinants of fatigue and the related minimal number of underlying studies within reviews

Included reviews were categorized in Cochrane reviews (CRs), non-Cochrane systematic reviews (SRs) or narrative reviews (NRs). Data extraction was performed hierarchal based on review type (CRs followed by SRs and NRs) and year of publication. SRs and NRs were excluded if there was overlap in the underlying studies within the reviews. Data synthesis accounted for hierarchy in level of evidence by review type (CRs were considered as best evidence followed by SRs and NRs). For each research area and stratified per type of RMD, a narrative synthesis was performed. Two meetings were organized with a patient panel to discuss the results from a patient perspective.

Results: The scoping review included 144 reviews (18 CRs, 42 SRs and 84 NRs). RA was addressed most frequently (60/144 (42%)). Fatigue was a secondary outcome in the majority of these reviews.

No agreed upon definition for fatigue in any of the RMDs was found. Across reviews, there was agreement that fatigue is a complex multifactorial and highly subjective symptom, including various subtypes with specific characteristics.

Reviews discussed 23 generic and 3 disease-specific self-reported outcome instruments to measure fatigue in RA, SpA and FM, but no reviews on outcome instruments for OA were found. Four of these 23 (17.4%) instruments included validated cut-off values to diagnose or classify excessive fatigue.

Numerous factors were associated with fatigue (Figure 1), but the study design (often cross-sectional) hindered studying causality. Across RMDs, pain, physical function, and depressive symptoms were the most frequently studied disease related factors; gender and stress the most frequent contextual factors related to fatigue. The strength of association was small or moderate, but mostly not reported. Work disability was one of the most frequently studied consequences of fatigue in RMDs, followed by impact on pain, physical activity and stress. Strength of these associations was not reported.

Finally, both pharmacological and non-pharmacological interventions, including physical activity-based and psychological interventions, generally had a small positive effect on fatigue in RMDs. No reviews described the effect of pharmacological interventions on fatigue in OA.

All results were relatable for the patient panel and some missing aspects were pointed out. The patient panel advised to develop a research agenda to specifically diagnose and treat excessive fatigue in RMDs, as continuing the current path is likely to increase publications about fatigue, but unlikely to change patients' lives.

Conclusion: This scoping review emphasizes the complexity of fatigue. Only a minority of the reviews had a primary focus in fatigue, whereas to patients this prominent symptom deserves specific attention.

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OP0204-PARE MEANINGFUL PATIENT INVOLVEMENT IS CRITICAL TO SUCCESSFUL INTERNATIONAL GRANT APPLICATIONS: THE CASE OF THE HIPPOCRATES CONSORTIUM

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Background: HIPPOCRATES is a large, international research project addressing the unmet needs of people with psoriatic arthritis (PsA). It aims to improve early identification of PsA in people with psoriasis, as well as therapeutic options and outcomes for people living with PsA. The project will run for five years with a budget of € 21 million provided by the Innovative Medicines Initiative (IMI) – a joint undertaking of the European Union and the European Federation of Pharmaceutical Industries and Associations (EFPIA). During the evaluation of the HIPPOCRATES grant application, the patient involvement was highly praised: "A strength of this proposal is that patient representative organisations seem highly integrated in the proposal and will be important avenues for dissemination."

Objectives: To explore the components of an effective strategy for incorporating the patient perspective in an international research consortium.

Methods: The experiences of the first six months of patient involvement in HIPPOCRATES were examined. We organized a survey and an online workshop with all participating patient research partners (PRPs) to gather data on the experiences of participation in the different working groups of the project, as well as to discuss common challenges and solutions.

Results: Patient involvement was visible and reported from the very beginning of the project, including participation of PRPs in the first consortium meeting for study design. The chosen strategy is characterized by an integrated approach containing multiple layers of patient involvement [Figure 1], with the consortium following the EULAR recommendations for the inclusion of patient representatives in scientific projects.

The active participation of 13 PRPs with well-defined roles and responsibilities ensures the preservation of the patient perspective during the entire duration of the project. Together they form the HIPPOCRATES Patient Advisory Council (PAC). PRPs are represented in the project's management team, in all work packages and in the External Advisory Board. Three patient organisations support the project: GRAPPA-EU (Group for Research and Assessment of Psoriasis and Psoriatic Arthritis) and EULAR PARE (People with Arthritis/Rheumatism in Europe) as consortium partners, and EUOPSO (European Federation of Psoriasis Patients' Associations). EULAR is co-leading the work package focusing on Communication, Dissemination, Exploitation and Sustainability, and especially those activities targeting patients, PRPs (regular educational sessions), patient organisations and the general public. Finally, people with PsO will be recruited for a large European cohort study (HIPPOCRATES Prospective Observational Study, HPOS) which aims to identify clinical and molecular risk factors for developing PsA. Results from the PRP survey were positive. Almost all PRPs have been invited to their work package meetings and included in email exchanges, and all feel well-included in their assigned groups and roles. Nevertheless, it was reported that some PRPs may be reluctant to raise their voice or to be involved in discussions at virtual meetings. This was one of the topics addressed during the online workshop, together with discussions on ethics and recruitment strategies for HPOS.

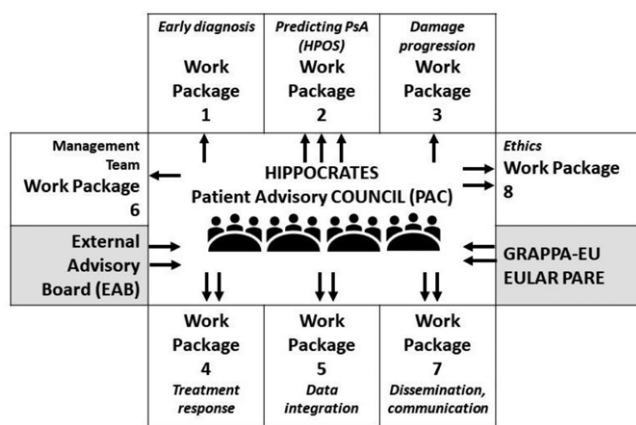


Figure 1 Multiple layers of patient involvement in HIPPOCRATES

Conclusion: It has been central to the HIPPOCRATES ethos that highly experienced PRPs were involved from its initial conception. PRPs with leading responsibilities in patient organisations or representing relevant academic backgrounds have contributed substantially to the definition of research priorities and will have active on-going engagement in the interpretation and implementation of future results. By demonstrating the pervasive benefit of the patient voice throughout the project, HIPPOCRATES will be an example for future projects in RMD and health research.

Acknowledgements: Meaningful patient involvement is critical to successful international grant applications: the case of the HIPPOCRATES consortium ["Health initiatives in Psoriasis and Psoriatic arthritis Consortium European States"]

Lars Werner on behalf of the HIPPOCRATES Patient Advisory Council (PAC)

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OP0205-PARE **GREEK RMDs PATIENTS' NEED FOR SELF-MANAGEMENT AND THE USE OF NEW TECHNOLOGIES: THE CASE STUDY OF THE HELLENIC LEAGUE'S AGAINST RHEUMATISM SUPPORT LINE**

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Background: The Hellenic League Against Rheumatism (ELEANA/HELAR) offer psychosocial support to its member, patients with RMDs, their families and everyone else that's interested in RMDs. More than 5000 members from all over Greece, with local ELEANA/HELAR groups in major cities such as Athens, Patras, Karditsa, Trikala, Thessaloniki and others. The helpline has been receiving incoming calls from patients with RMDs, members of ELEANA, their relatives and others that are interested in RMDs or are requesting information.

Objectives: This case study aimed at outlining that self-management is the main reason for incoming calls to ELEANA's helpline and secondly that during the

pandemic and even after lockdown measures being lifted patients still use the online support offered thus making it apparent that digitalization is not a trend anymore but a necessity.

Methods: Empirical data from the helpline were gathered through the day-to-day helpline registry. This is a detailed registry containing basic info on demographics of the callers, reasons for calling and outcome of communication. Descriptive statistics as well as qualitative data have been used such as observations of the trained staff of the helpline.

Results: From 543 incoming calls, 49,91% were about self-management and the rest 50,09% were calls requesting information. 52,40% of self-management calls were about psychological issues (anxiety, depressive symptoms) and the rest were about treatment (adherence), such as the use of medication, alternative treatments, medical issues and questions on RMDs. 40,96% of patients with RMDs called again the helpline to follow up and 61,25% used online tools to communicate with the helpline both times. Psychologists receiving calls observed that patients needed counseling regarding their self-management, especially during the pandemic and that even though lockdown is lifted they keep on requesting online communication instead of face-to-face meetings.

Conclusion: The above findings show that digitalization is not a trend rather than a necessity in the self-management of RMDs. Patients seem to find it easier receiving support online and the requests for online support for their anxiety, depressive symptoms, difficulties in managing their medication makes it clear that more emphasis needs to be put on self-management programs.

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OP0206-PARE **FOOD COMMUNITIES**

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Background: In recent years the focus on healthy food and lifestyle has become a more important part of everyday life for many – with or without RMD. Many NGO-initiatives engaging citizens cooking and eating together has seen the light of day; people meet to talk, laugh and have a good time while making a healthy meal.

The kitchen is an often discussed topic among the volunteers and members of The Danish Rheumatism Association. "Simple" tasks as opening a can of beans or cutting bread can be complicated for people with RMDs. The fundamentals of cooking are different for this group of people; hence the idea of communities around "arthritis friendly" food unfolded during fall 2019.

Objectives: The main objective is to create "food communities" for people with RMDs, helping them to get a better understanding of how to make "arthritis friendly food", dispel the myth that it is expensive and hard, and to give them inspiration to better working positions with assistive devices - resulting in a healthier lifestyle which is important to keep the inflammation low and the quality of life high.

Methods: To obtain these objectives, a dietitian is facilitating 6 three hour "courses" guiding the participants through healthy cooking – each course with a different theme/subject which is introduced through a short presentation. Two volunteers are responsible for booking kitchen facilities (often school kitchens which is free of charge), coordination with the dietitian and making sure everything runs smoothly and that the atmosphere is top-notch. An occupational therapist is joining the group one time to ensure optimal working positions and introducing and demonstrating assistive devices.

One of our main goals is to create sustainable and longer lasting (more than 6 facilitated courses) communities, which is why an important part of the volunteer's responsibility is to initiate a talk about the opportunity of meeting without a dietitian. The 6 facilitated courses aim to give the group the ability to find recipes (provided by DRA) and being comfortable cooking with ingredients that the average Dane might not use very often. Furthermore, our assumption is that the group creates social bonds and therefore an interest in keeping these relations.

Results: About twenty groups all around Denmark has been a part of the course so far. The feedback from the participants is extremely good – they feel they are learning in an inspiring environment while having a great time with their new acquaintances. Unfortunately, only one of the groups has become a community that exists after the facilitated courses. One of the reasons is, without a doubt, that most of the groups have been affected by different Covid-19 restrictions which has had an impact on the level of social bonding and feeling of ownership. But most participants feel that the dietitian is crucial for further engagement.

Conclusion: The concept has been very successful in terms of creating a course that imparts useful knowledge about "arthritis friendly" food and lifestyle for people with RMD's. It seems we need to make corrections to create the basis for sustainable communities; small changes that helps the group visualizing how to overcome the challenge of the absence of a dietitian, the logistics of grocery shopping for a group etc. We plan to leave out the dietitian from the fifth of the six courses to prepare the group to establish their own "food community" with lots of healthy food, learning experiences and high spirit.

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