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 on the External Advisory Board. Three patient organisations support the project: GRAPPA-EU (Group for Research and Assessment of Psoriasis and Psoriatic Arthritis) and EUAR-PARE (People with Arthritis/Rheumatism in Europe) as consortium partners, and EUROPSO (European Federation of Psoriasis Patients’ Associations). EUAR 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 PsA 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.

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

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GREAT 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) offers psychosocial support to its member, patients with RMDs, their families and everyone else that is 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 ELEANAs 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.

Method: 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 81,25% 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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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 diettian 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 diettian 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.

Conclusion: The 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 diettian. 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 relationships.

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 diettian is crucial for further engagement.

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9. None declared
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