

IFPA

GLOBAL LEADER IN FIGHTING
PSORIATIC DISEASE

eular²⁵

EUROPEAN
CONGRESS OF
RHEUMATOLOGY

BARCELONA
11-14 JUNE

IFPA at EULAR

conference report

Summary of Activities

IFPA once again attended the EULAR (European Alliance of Associations for Rheumatology) conference. This year, the conference was held in Barcelona, Spain, between the 11-14th of June. The IFPA board president Ingvar Ingvarsson and the secretariat's Scientific Project Leader Raquel Vaz attended the conference.

The conference served as an opportunity to attend relevant lectures and engage with key stakeholders and collaborators. This year we had a special assignment to connect with EULAR PARE and discuss opportunities for future collaboration. Leading to the conference, we were invited to participate in the PARE assembly, held on Wednesday the 11th at 6pm, and we booked a meeting with Simon Stones, at the time vice-Chair of PARE.

Summary of activities with PARE summarized in another document (IFPA at EULAR – PARE report).

The IFPA delegation also met with our industry partner to present our initiatives and projects on psoriatic arthritis, the next IFPA conference, and WPD.

Lastly, Ingvar and Raquel also attended the conference dinner, where they had another opportunity to network.

IFPA Presence at EULAR 2025

This year, IFPA did not have a booth, therefore the plan of activities was different from 2024. With that, the delegation was able to attend more conference sessions and find key people of interest to meet.



Day 1

The first day at EULAR started with the Opening Plenary, led by **Prof. Daniel Aletaha**, the EULAR President.

Following an overview of EULAR activities and the presentation of the myEULAR platform with available resources, networking opportunities and knowledge sharing, we celebrated the recipients of the annual awards given to those who, in different ways, have been doing an outstanding work in the rheumatic and musculoskeletal disease (RMDs).

Still at the opening plenary, we heard about two patient, Caroline Kirsten and Corinna Elling-Audersch, sharing their experience on the importance to have access to evidence-based information and how EULAR supports them and other people living with RMDs to better understand and manage the disease. This is, largely, due to the establishment of the EULAR recommendations for care. Another important source of information and support, the national patient organization, was also highlighted as crucial for those living with RMDs. Thereafter, a panel discussion with **Professor Laure Gossec** and **Dr. Elsa Mateus** offered insights on the efforts continuously made by EULAR to be a reliable source of information for people living with RMDs. The new EULAR journal was also mentioned, as well as the importance of having patients as collaborative partners, or PRPs (Patient Research Partners), to review and improve methodology and outcomes, and bringing the patient voice and input in research.

Lastly, awards for scientific achievements were given to those who had submitted outstanding abstracts from basic to clinical research. All leading institutions working on RMDs were also highlighted.


After the plenary, a few different sessions interesting for us at IFPA and our members were scheduled. The highlights from each are below.

Transforming Healthcare: Navigating New Technologies

This session focused on highlighting challenges and solutions in developing information for patients using digital technologies and discussing how are the healthcare (HC) sector and its users dealing with digital health innovation.



Professor Frances Mair gave a good insight on HC response type. To date, it is mostly reactive, somewhat inflexible and disease focused, while in the future, with the emergence and use of technologies both at home and elsewhere, there is a potential for HC to become more proactive, flexible and predictive. With the current HC limitations and shortages, for example of HC professionals, AI can be of help. One way of leveraging AI in HC is by using it to support with disease monitoring, for example of glucose levels, blood pressure, and others, which has the potential to have a smaller impact to the user or patient. People living with RMDs often live with multiple comorbidities, that results in a burden to patients and care, also called burden of treatment. It is important to stress that the burden of treatment (workload of self-management) is different to different people. While AI and technology can be valuable, it needs to be tailored for the person it is meant to use it. One size fits all approach does not work for everybody, therefore it is essential to work with patients or people living with disease to find and design the solutions, instead of involving patients only on the testing phase.



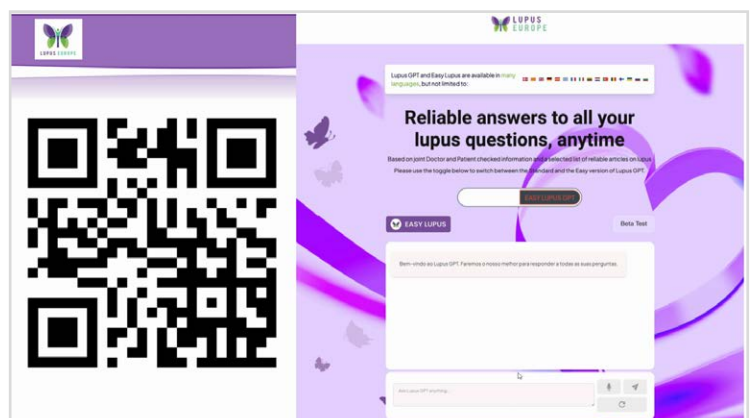
Health Systems Need to Change

Our focus should be on developing approaches that are better **tailored** to patients' needs based on their **capacity** factors as well as their **personal goals**.

A one size fits all approach to healthcare is unlikely to work.....

Digital health has potential **IF** it makes healthcare simpler, kinder and less hard work.

Jeanette Andersen, a person living with Lupus, presented a ChatGPT-based platform called Lupus100 (Lupus100.com), that is a depository of information checked by doctors and patients in collaboration. This platform gives trustworthy information about the disease. Since the platform is closed to outside sources of information, it guarantees that those who ask questions receive the correct information and when the platform is not able to find answers to specific questions, the creators of the platform receive that information and get the input from both HC and patient representatives to create content related to the topic. Moreover, Lupus100 is translated into many languages and has a simplified version with voice accessibility for those with, for example, visual impairments or living with dyslexia. This initiative shows the value of having a locked source of information, that does not use non-validated content to answer questions from the users. It is also open access and free.



Dr. Ioana Andreica, a rheumatologist from Germany, presented the results of a study aimed to identify where to people with RMDs search and find information about their disease in their daily life. Most people living with disease search for information online, especially following the appointments with their doctors. Most of the information searched for is related to symptoms, treatment options and effectiveness of the therapies. These findings clearly show that people living with RMDs are still left with questions, especially after seeing their specialist. There is a risk that looking up information online may raise more questions or even wrongly inform people about their disease or treatment.

Searched internet-based information	% (percent of total pat.)
Symptoms of RMD	60.9%
Treatment options for own RMD	84.8%
The effectiveness of therapies	58.4%
Side-effects of therapies	55.3%
Diet for own RMD	61.8%
Physical therapies to improve mobility or reduce pain	57%
Needed lifestyle changes for own RMD	47.1%
The prognosis of own RMD	44.4%
Self-help groups for own RMD	19.7%
Patient's organisations in RMD	22.7%
Health policy decisions affecting rheumatism	24.0%
Social law topics e.g.: rheumatism and pension or rheumatism and degree of disability	44.7%

Nele Caeyers, presented RheumaNet, an information map for people with a recent RMD diagnosis, emphasising how important it is to have truthful information accessible to those who need it. Twelve different maps in leaflet forms were also created, specific for Psoriatic Arthritis, Rheumatoid Arthritis, Fibromyalgia, and other RMDs.

Objectives

- To offer quality, tailor-made and up-to-date information and guidance to (new) RMD patients in order to empower them.
- To offer rheumatologists and HP's a qualitative information tool that can be adapted to the patient's needs.
- To make patient support groups and help lines known to (new) RMD patients.

REUMA NET

EULAR 2025 - Barcelona

5

Clinical Abstract Sessions: Shaping the Future of Psoriatic Arthritis Treatment

In this session we heard some of the latest news in PsA treatment.

Professor Laura Coates presented results from a study showing that an early intensive therapy approach with combination csDMARD (conventional Disease-Modifying Antirheumatic Drugs) can improve the outcomes for people whose disease has poor prognosis, such as involvement of more than 5 joints, erosive disease and difficulties with daily activities. The results showed that an initial intensive therapy is superior to standard step-up care for rapid control of disease. The intensive approach was also associated with a higher patient treatment satisfaction, even though it is associated with a small increase in non-serious medication side effects.

Inclusion criteria

MONITOR

- ✓ Age ≥ 18 years
- ✓ Active PsA with ≥1 tender/swollen joint or enthesitis

X


- Current or previous treatment of arthritis with DMARD therapy
- Recent use of investigational therapies

SPEED

- ✓ Consented to MONITOR and potential studies
- ✓ Presence of ≥ 1 poor prognostic factor
 - Polyarthritis (≥5 active joints), HAQ ≥1, CRP ≥5, erosive disease
- ✓ Acceptable baseline safety bloods

X

- Safety issues preventing use of DMARDs
 - Renal or hepatic impairment, hepatitis, HIV, active TB, cancer in last 5 years
- Female patient who is pregnant, breastfeeding or planning pregnancy



Laura C. Coates

Early intensive therapy with combination csDMARDs or TNF inhibitors are superior to standard step up care for the treatment of moderate to severe psoriatic arthritis: the 3-arm parallel group SPEED RCT.

Dr. Andre Lucas Ribeiro showed that, despite the large availability of compounds, only about 30% of patients experience sustained remission using LDA (Low Disease Activity) scores. The goal of the study presented was to characterize the profile and treatment outcomes of PsA patients receiving five different treatment combinations, targeting IL-17, IL-23 or TNF in combination with TYK2 or JAK inhibitors. Even though the study has a small sample size and no control group, there was some short-term effectiveness in the combination approach. Further research is needed to validate the results.

Combination of Biological and Targeted Synthetic Disease-Modifying Antirheumatic Drugs in Psoriatic Arthritis

Andre Ribeiro, MD, MSc

Co-authors: Virginia Carrizo Abarza, Jensen Yeung, Khalad Maliyar, Siddhartha Sood, Ahmed Bagit, Muskaan Sachdeva, Sahil Koppikar, Dafna Gladman, Vinod Chandran, Lihi Eder



Andre Lucas Ribeiro

Combination of Biological and Targeted Synthetic Disease-Modifying Antirheumatic Drugs in Psoriatic Arthritis






Iain B. McInnes shared the preliminary insights into his project ideas. Following a review of previous studies, it is fairly consistent that people previously treated with TNF-inhibitors are less likely to respond positively to biologics (bDMARDs) than people who are naïve for TNF-inhibitor therapy (not have received such treatment before). Is there some biological compensatory mechanism? Some preliminary analyses suggest that there may be a negative correlation between circulating TH17 cell numbers and the responsiveness to TNF-inhibitors. Future studies are necessary to confirm this hypothesis.

Markers of IL-17 Signalling in the Blood of Patients with Psoriatic Arthritis with Inadequate Response to Tumour Necrosis Factor Inhibitors

Iain B. McInnes,^{1,*} Ioana Cutcutache,^{2,*} Leon Eyrich Jessen,³ Magnus Petersen,⁴ Melanie Randahl Nielsen,³ Marie Skougaard,^{4,5} Victoria Svinti MacLeod,² Andrew Skelton,² Adam R. Prickett,² Stevan Shaw²


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*Iain B. McInnes and Ioana Cutcutache jointly contributed to this study



To access the presentation, scan the QR code

Link expiration: 12 September 2025




Iain B. McInnes

MARKERS OF IL-17 SIGNALLING IN THE BLOOD OF PATIENTS WITH PSORIATIC ARTHRITIS WITH INADEQUATE RESPONSE TO TUMOUR NECROSIS FACTOR INHIBITORS


EULAR 2025 | Barcelona, Spain | 11–14 June 2025
Presentation number: OP0091


Gonul Hazal Koc, similarly to Laura Coates, also presented the results of a study with an intensive Treat-to-Target approach compared to standard of care approach. Early intensive approach has better clinical outcomes at early time-points of treatment (3-months), but this difference is not seen at 6-months of treatment. The findings support that the intensive approach may be beneficial for rapid improvement of symptoms.

CONCLUSION



- Primary endpoint not met but still...
- Both T2T strategies are effective at the end of the study
- **Early intensive treatment** in T2T design demonstrated faster clinical response within 3 months.
 - Robust efficacy across all PsA domains, including joint, skin, and enthesitis
 - Higher initial treatment retention rates
 - Fewer treatment escalations and switches
- Future Implications...






Gonul Hazal Koc

Using an Intensive Treat-to-Target Strategy to Improve Outcomes In Early PsA: 1 Year Results From the STAMP Study

EULAR 2025 | Barcelona, Spain | 11–14 June 2025
Presentation number: OP0091


Raphael Hurtubise shared the results of a study aimed at determining the effectiveness of combination DMARD therapy in psoriatic arthritis (PsA), as few studies have been done on this topic. The results support that combination DMARD is a valid treatment option and resulted in a reduction of the number of patients that further require biologics. Importantly, both groups presented with similar disease activity at 48 and 96 weeks of treatment, showing that the no-biologic group was not undertreated.




Effectiveness of Combination csDMARD Therapy in Psoriatic Arthritis Using Data from the MONITOR-PsA Cohort.

R. Hurtubise, JG Letarouilly, E Saeedi, L. James, N Gullick, A Francis, W Tillett, Y Sinomati, L Tucker, N Mian, M.S. Massa, L.C Coates.



Raphaël Hurtubise
Effectiveness of Combination csDMARD Therapy in Psoriatic Arthritis Using Data from the MONITOR-PsA Cohort.

Professor Philip J. Mease presented the results of a multicenter phase-3 study of a TYK-2 inhibitor. The results show that it has the potential to be a good option for treating PsA, when approved.

Presented at the EULAR 2025 European Congress of Rheumatology; June 11-14, 2025; Barcelona, Spain

Efficacy and safety of deucravacitinib up to week 52 from POETIK PsA-2: a multicenter, randomized, double-blind, placebo-controlled, phase 3 study in patients with psoriatic arthritis

Philip J. Mease,¹ Vinod Chandran,² April W. Armstrong,³ Ricardo Blanco,⁴ Alexis Ogdie,⁵ Evan Siegel,⁶ Alice B. Gottlieb,⁷ Xiaofeng Zeng,⁸ Diamant Thaçi,⁹ Mitsumasa Kishimoto,¹⁰ Hendrik Schulze-Koops,¹¹ Alan Kivitz,¹² Eva Dokoupilová,¹³ Akimichi Morita,¹⁴ Eric M. Ruderman,¹⁵ Michael Plewinski,¹⁶ Kejia Wang,¹⁶ Caroline Sardinas,¹⁶ James Thielke,¹⁶ Eleni Vritzali,¹⁷ John Vaile,¹⁶ Atul Deodhar¹⁸

¹Providence Swedish Medical Center and University of Washington, Seattle, WA, USA; ²Division of Rheumatology, Departments of Medicine and Laboratory Medicine and Pathobiology, University of Toronto, and Krembil Research Institute, University Health Network, Toronto, ON, Canada; ³University of California, Los Angeles, Los Angeles, CA, USA; ⁴Department of Rheumatology, Hospital Universitario Marqués de Valdecilla and Immunopathology Group, IDIVAL, Santander, Spain; ⁵Hospital of the University of Pennsylvania, Philadelphia, PA, USA; ⁶Arthritis and Rheumatism Associates, Rockville, MD, USA; ⁷Department of Dermatology, The University of Texas Southwestern Medical Center, Dallas, TX, USA; ⁸Department of Rheumatology and Immunology, Peking Union Medical College Hospital, Beijing, China; ⁹Institute and Comprehensive Center for Inflammation Medicine, University of Lübeck, Lübeck, Germany; ¹⁰Department of Nephrology and Rheumatology, Kyorin University School of Medicine, Tokyo, Japan; ¹¹Division of Rheumatology and Clinical Immunology, Department of Internal Medicine IV, Ludwig-Maximilians-University of Munich, Munich, Germany; ¹²Altoona Center for Clinical Research, Altoona, PA, USA; ¹³Medical Plus, s.r.o., Uherské Hradiště, Czech Republic, and Department of Pharmaceutical Technology, Masaryk University, Brno, Czech Republic; ¹⁴Department of Geriatric and Environmental Dermatology, Graduate School of Medical Sciences, Nagoya City University, Nagoya, Japan; ¹⁵Department of Medicine, Division of Rheumatology, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA; ¹⁶Bristol Myers Squibb, Princeton, NJ, USA; ¹⁷Bristol Myers Squibb, Boudry, Switzerland; ¹⁸Oregon Health & Science University, Portland, OR, USA

Presentation number: OP0095



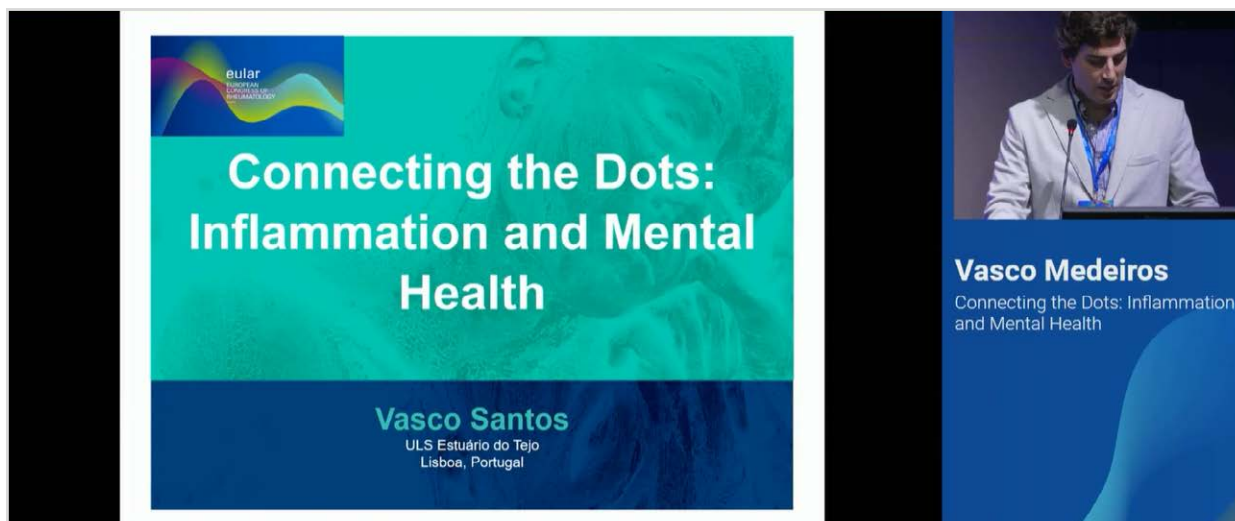
Philip J. Mease
Efficacy and safety of deucravacitinib up to week 52 from POETIK PsA-2: a multicenter, randomized, double-blind, placebo-controlled, phase 3 study in patients with psoriatic arthritis

Day 2

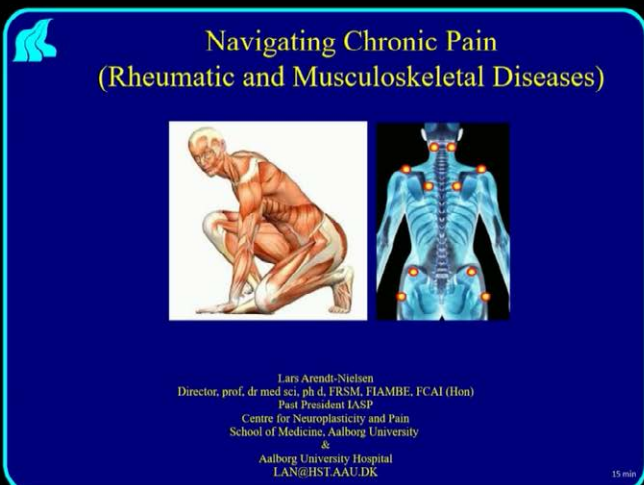
On this day, Ingvar and Raquel attended highly relevant sessions on the patient perspective of RMDs.

Breaking the silence on mental health and inflammation

Vasco Medeiros, a psychiatrist, kicked off the session with a fantastic presentation on the link between psychiatric disease, RMD and inflammation. The first description of a potential link between mental health and disease was proposed several decades ago by Franz Alexander, who established the Holy Seven: seven diseases believed to be influenced by the mental state, including rheumatoid arthritis. The World Health Organization (WHO) estimates that the prevalence of depression and anxiety disorders are 4.4 and 3.6%, respectively, which means that around 322 million people live with depression. Studies have shown that there is an increased burden of psychiatric disorders in rheumatoid arthritis, high prevalence of depression, between 9-22%, and suicidal ideation, as high as 39.2%, in people living with psoriatic disease. The question is what is the link between the two? Stress seems to be the answer, but the etiology (the trigger) seems to be related to inflammation. Several findings seem to support this hypothesis, such as the increase of depression in inflammatory comorbidities such as cardiovascular disease, type 2 diabetes, cancer, and autoimmune diseases. Stress is also involved in inflammation, as studies have shown that the fight or flight response results in an increase in inflammatory molecules in the body. Some studies have also suggested that certain genetic units (larger areas of the genome) correlate with depression. Vasco also shared an interesting theory that links stress and inflammation but mentioned that more research is needed.




Professor Lars Arendt-Nielsen presented a project on navigating chronic pain. Lars described how pain is not only a sensory but also emotional experience, can be associated with tissue damage and it's impact has been more and more accepted in the context of disease. Chronic pain can occur from a combination of biological, social and psychosocial factors. RMDs are the most common cause of chronic pain and physical disability. In fact, a study from Norway showed that people living with rheumatoid arthritis report that the top symptoms they would like to see an improvement with treatment are pain followed by those related to function, such as hand and finger function, walking and bending, household tasks, mobility, etc. Nevertheless, pain is still underestimated, also because there is not a straightforward connection between RMD severity and pain and it is challenging to quantify. Lars also described how, over time, local pain can expand to the entire body. He also explained the negative spiral on how stigma from the lack of recognition and understanding of chronic RMD pain created both a mental and physical barrier to health management, further impacting the quality of life and increasing the marginalization of people living with RMDs.



**Navigating Chronic Pain
(Rheumatic and Musculoskeletal Diseases)**

Lars Arendt-Nielsen
Director, prof. dr med sci, ph d, FRSM, FIAMBE, FCAI (Hon)
Past President IASP
Centre for Neuroplasticity and Pain
School of Medicine, Aalborg University
&
Aalborg University Hospital
LAN@HST.AAU.DK

15 min



Lars Arendt-Nielsen
Navigating Chronic Pain: Insights into Brain Impact and Coping Strategies

Franklin Hiagbe, member of the IPARE, presented the tRi Ghana, a non-profit organization committed to improving the lives of people living with rheumatic disease in the country and across Africa. tRi Ghana has 3 pillars: education, advocacy, and research. The organization regularly organizes workshops, webinars and educational sessions; raises awareness on the impact of disease via campaigns on TV, radio and social media, visits schools and churches, and facilitates the creation of support groups, so important for fighting isolation, providing a sense of belonging and empowering people to better understand and manage the disease. The group also collaborates with HC, including psychologists and counselors.



Patient Support Group

- RHEUSOLUTE – The General Support Group.
- Global Lupus Outstanding Warriors (GLOW) – Subgroup for only people with Lupus.
- Global Rheumatoid Arthritis Support and Platforms (GRASP) – Subgroup for only people with Rheumatoid Arthritis.
- Global Empowered Myositis and MCTD Survivors (GEMMS) – Subgroup for those with all other autoimmune rheumatic diseases.

www.trighana.org



Franklin Hiagbe
GRASP and tRi: support to the RMD community in Ghana

Corinna Elling-Audersch, the vice president of the German Rheumatism-League, presented their initiatives on fighting loneliness. Some facts about loneliness were presented: it affects all age groups, women more than men, there is no difference if the person lives in the city or in the country, and it can be experienced as a result of mental and physical diseases. Loneliness is often associated with fear or rejection and isolation, therefore it is essential to promote activities that bring people together, for example volunteering.



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EUROPEAN SOCIETY OF RHEUMATOLOGY
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Fighting loneliness with a rheumatic disease

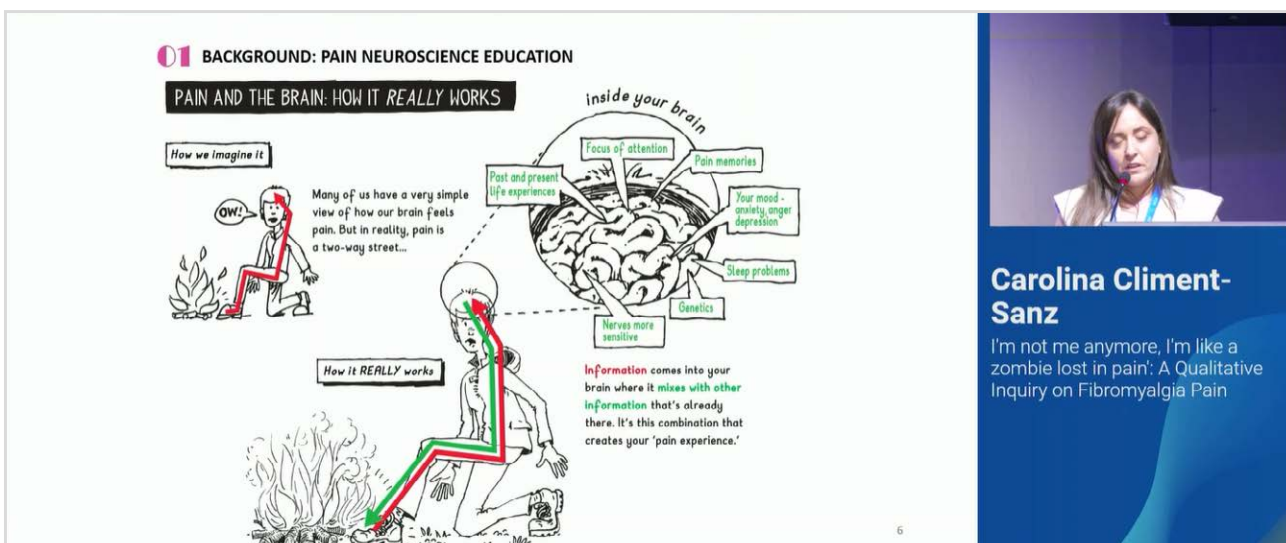
A major project for our German Rheumatism-League

Corinna Elling-Audersch, Vice President
Deutsche Rheuma-Liga Bundesverband e.V.
www.rheuma-liga.de

Deutsche RHEUMA-LIGA
• GEMEINSAM WIRT KRAEFTER •

Corinna Elling-Audersch
Fighting loneliness with a rheumatic disease

Dr. Carolina Climent-Sanz presented a qualitative survey on fibromyalgia pain, with good insights into what it really means to live with pain. A qualitative study was presented and showed the real extent of the experience of pain, refers to as "a monster" and the feelings of self-blame many participants described. There is a clear benefit in practicing mindfulness and other stress and pain reducing activities, as well as group-setting activities. Carolina also emphasized the need to have a personalized approach to pain management.



01 BACKGROUND: PAIN NEUROSCIENCE EDUCATION

PAIN AND THE BRAIN: HOW IT REALLY WORKS

How we imagine it

OW!

Many of us have a very simple view of how our brain feels pain. But in reality, pain is a two-way street...

How it REALLY works

inside your brain

- Focus of attention
- Pain memories
- Your mood - anxiety, anger, depression
- Sleep problems
- Genetics
- Nerves more sensitive
- Past and present life experiences

Information comes into your brain where it mixes with other information that's already there. It's this combination that creates your "pain experience."


Carolina Climent-Sanz
I'm not me anymore, I'm like a zombie lost in pain: A Qualitative Inquiry on Fibromyalgia Pain


Let's talk about relationships – conception to birth

Jose Negron presented Rheumasutra, a set of short educational videos to help people with RMDs to navigate sexuality. This project was also expanded to a documentary on the topic. From the start, ten participants were recruited, several of them living with RMDs, some were HCP or patient advocates. Following the qualitative analysis of the interviews, 4 main areas of impact were identified: structural violence and microaggressions against women; lack of education on DEI within the medical community; the transformations of a new identity after the diagnosis; women's bodies as factories for producing life. The question left is: Are there better ways to talk about these topics?

Understanding Sexuality in Rheumatic and Musculoskeletal Diseases: Expanding the **Reumasutra Project** to the General Population

— José B. Negrón, Jaime J. De la Guardia, Reu +





José Bernardo (J.B.) Negrón
Understanding Sexuality in Rheumatic and Musculoskeletal Diseases: Expanding the Reumasutra Project to the General Population


Dr. Luis Perez presented his project on RA and intimacy, from a men's perspective. Following a survey, when men were asked "Have you ever discussed intimacy with your rheumatologist?", most did not, but wished they had. From the HCPs perspective, most responded that they discussed it, but probably there is a biased sampling, as it is likely that those responding to the survey are already more aware of the topic and ask questions. The study also found that male sexual dysfunction high in men with RMD. But the impact of the disease encompasses several spheres of male sexual health, including impact on manhood, self-esteem, shame, etc. RMDs are found to impact intimacy, e.g. emotional withdrawal, fear of being a burden, changes in relationships; impact on passion (lower libido, erectile dysfunction, body image issues), impact on commitment for fear of abandonment and uncertainty about the future, financial stress. RMDs affect all aspects of the love triangle: intimacy, passion and commitment. Still today men's concerns often remain unspoken, even though deeply felt. It is important to create space for conversations on this topic. We were left with a call for action: for HCPs to start the conversation, for patients and partners to know that their experiences matter and they deserve the right care, and for researchers and policymakers to recognize intimacy is a key dimension of the quality of life in RMDs.

Embracing Intimacy: Men's Perspective on Living with RMDs

Luis Fernando Perez, MD PhD

Department of Rheumatology – Reproductive Rheumatology
Erasmus University Medical Center
Rotterdam, the Netherlands





Luis Fernando Perez
Embracing Intimacy: Men's Perspective on Living with RMDs

Louise Moore explained the need for a multidisciplinary team for care provision and medication management in reproductive health. Pregnancy and child rearing are often important life goals for many women, and they need to get the support and care they need. Several studies have already advocated multidisciplinary care as best practice. But what is multidisciplinary care? There should be involvement of partners and family or friends, patient support groups, and a wide range of health care professionals, from midwives to nurses, rheumatologists and other specialties. Ideally, women are followed up before pregnancy, so that disease can be well managed before pregnancy occurs. Despite guidelines being in place for several years, there is generally no shared care among rheumatologists and obstetricians, including a lack of opportunity to discuss concerns and pregnancy planning. Moreover, even if women are being monitored, they still feel there is not enough guidance. This is particularly relevant after birth, where many women with RMDs experience flares. In this talk, it was reiterated that we need to have appropriate care and monitoring before, during, and after pregnancy.

Who is the multidisciplinary team?

- Partner, family/friends
- Patient support groups



Gorman A, Moore L, O'Brien C, Soldati B, Veale DJ, McAuliffe FM. Management of rheumatic diseases in the preconception, antenatal and postnatal periods. National Women and Infants Health Programme and The Institute of Obstetricians and Gynaecologists. October 2023.




Louise Moore
Medical Treatment and Psychology during Pregnancy



Day 3

This day was marked by a very busy schedule of meetings with industry partners, EULAR members, and attending sessions. Two sessions were relevant for people with RMDs.


From abstract to concrete – perspectives, preferences and expectations in RMDs

We first heard from **Yvonne Balvers**, recipient of the Edgar Stene Prize 2025, talking about her experience living with JIA (Juvenile Idiopathic Arthritis). Yvonne, now 63 years old, wrote an essay on her growing up and how her disease affected her life. Her hands are particularly affected by the arthritis, a part of her body that made her self-conscious and on her everyday life she usually hid them away, either in pockets or behind her back when getting her photograph taken, for example. She decided to embrace her limitation and getting inspired by a book from childhood, Yvonne decided to start painting with watercolour, namely giraffes, representing her disability and the struggles of anyone living with physically disabling diseases. Even though her physical limitation is still very present in her life, she has found a way to express her feelings and use it in a powerful way.



Sladana Rumpil Tunjić presented a very interesting study assessing if Patient Research Partners and Researchers share the same perspective on collaborative research. Assessing implementation of the EULAR recommendations for PRP involvement in the STRATA-FIT Consortium. There were several objectives in this project, focusing on the develop innovative decision aid to stratify difficult to treat rheumatoid arthritis patients and provide personalised treatment advice and demonstrate the improvement of care using this strategy, and establish the approach and infrastructure that can be used as a blueprint for other chronic conditions. The patient involvement was very strong, with a patient advisory panel participating in all steps of the project. The evaluation survey showed that there was still a need to improve communication: the number of emails and calls sometimes got overwhelming, and the concepts and language used were complex and difficult to understand. From the researchers' perspective, this was not a problem. Patient representatives reported being interested in having more training on best practices and understanding the scientific procedures and findings. The researchers agree with the need to have more online workshops with the consortia on PRP. Everyone agreed that the patients' perspective was taken in. For the future, more feedback on each side's participation is needed. Even though the participation in the project was time consuming, the benefit was felt by everyone. Finally, the final survey showed that it was very positive to have a strong involvement of PRPs in the project. From the 10 recommendations of EULAR PRPs, six have been fully implemented, and 4 have been partially implemented, with the expectation that by the end of the project, in 2029, they will all be fully implemented. Feedback from the researchers involved in the project highlighted the value of having PRPs voice, for example in helping shift the discussions into different directions, that otherwise would have been overlooked or dismissed.


EULAR PRP recommendations in STRATA-FIT



Analysis of implementation of EULAR recommendations for the involvement of PRPs in rheumatology research: 2023 update


1. **Type of research** - PRPs should be involved in all types of research, including basic, translational and clinical research.
2. **Phase** - Researchers should involve PRPs from the inception of a research project and throughout all its stages.
3. **Number** - A minimum of two patient research partners should be involved in each project.
4. **Recruitment** - Recruitment of PRPs should be based on a clear and agreed-upon description of mutual roles and responsibilities, and should aim for diversity and inclusivity.
5. **Support** - The research team must provide a supportive environment and facilitate the contribution of PRPs to research.
6. **Coordinator** - A designated coordinator should support the collaboration of researchers and PRPs.
7. **Training** - Researchers should have access to training and support, to achieve effective communication and collaboration with PRPs as equal partners.
8. **Training** - PRPs should have access to training relevant to their roles.
9. **Evaluation** - Researchers and PRPs should regularly evaluate their collaboration and adjust their way of working when needed.
10. **Acknowledgment** - The contribution of PRPs must be appropriately recognised, including co-authorship when eligible; financial compensation should be considered.

6 recommendations have been fully implemented, while
4 recommendations are partially implemented



Sladana Rumpil
Tunjić

Do Patient Research Partners and Researchers share the same perspective on collaborative research. Assessing implementation of the EULAR recommendations for PRP involvement in the STRATA-FIT Consortium.



Coralie Bouillot showed the results a project aimed to combining perspective and expectations of patients and physicians while assessing treatments in clinical trials in Sjögren's Disease: the necessity project. The diagnosis is still very difficult, and no treatment has been approved to date. The necessity project's working group comprised of 38 HCPs and 2 PRPs that prepared a DELPHI panel of clinicians, scientists and patients. Of note, patient participants had the same input as clinicians or researchers when defining the different domains used to measure outcomes. The differences on the set of outcomes chosen by the different groups of participants were quite different, with patients highlighting the need for assessing fatigue, pain, and quality of life, while fatigue was only defined as important in about 50% of clinicians and researchers. This shows the importance of having patient representation in this type of project. The STAR responder score was defined, where the patient-reported symptoms have more weight, comparing to the other score used for clinical trial outcomes in Sjögren's syndrome, CRESS.

CONCLUSION

S. ARENDS ET AL.

Coralie Bouillot
How to combine the perspectives and expectations of patients and physicians while assessing treatments in clinical trials. The example of STAR

Ailsa Bosworth presented a patient initiated follow up initiative, or PIFU. Since the national guidelines in the UK are aimed to reduce the follow-up appointments with the clinical team, it is important to make sure that when flare ups occur, such as inflammation of the joints, these are not missed. Therefore, the NRAS (National Rheumatoid Arthritis Society) got involved in an initiative, called TAILOR, to address if PIFU is comparable to the standard care follow-up. In this project, resources and a handbook for clinicians and materials were made to provide support and educate patients to ensure the best outcomes.

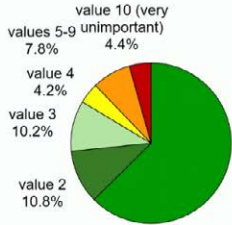
Patient Initiated Follow Up Pathways - Resources for Patients with Inflammatory Arthritis and HCPs in the UK

Ailsa Bosworth, National Patient Champion
National Rheumatoid Arthritis Society, UK

Ailsa Bosworth
Patient Initiated Follow Up Pathways - Resources for Patients and HCPs with Inflammatory Arthritis in the UK

Gerlinde Bendzuck talked about the expectations and fears of people living with RMDs and the implementation of digital tools in healthcare. Similar to other projects presented in the conference, those who participated in the survey think that personal contact with their doctor is still very important. Participants are generally satisfied with having E-prescriptions, for example, as they are practical and a convenient way to renew prescriptions, but problems with the delays in their availability are still strong negative factors that affect people's experience. As more digital tools are used in healthcare, it is important to make sure they are user-friendly, and that the users are educated on how to use them.

With digitalisation in healthcare, personal contact with the doctor is still considered as very important by the majority of patients with RMDs




Value	Percentage
value 1 (very important)	62.6%
value 2	10.8%
value 3	10.2%
value 4	4.2%
values 5-9 (unimportant)	7.8%
value 10 (very unimportant)	4.4%

Text of question: Digitalisation in the healthcare sector is unstoppable and is changing medical care. How important is personal contact with your doctor to you?

n = 835
 $\sigma = 2.27$

Deutsche RHEUMA LIGA
• GEMEINSAM WIRTSCHAFTEN •



Gerlinde Bendzuck
 Digital dawn: Here comes the sun
 The RMD Patients perspective.

Marcos Seneca Garcia Rodriguez presented the RheumaCuida project, that focuses on raising awareness the dual burden faced by women with RMDs who also have the role of caregivers, providing support and education, and a community where women can share their experiences. RheumaCuida is also a peer-mentoring program with 3 phases, from baseline assessment of the background and personal goals, one-to-one peer mentoring and group and emotional empowerment. This 6-month program resulted in a very positive impact in different areas, from self-esteem and emotional well-being, family transformation by re-structuring the family roles and others.

Why ReumaCuida?

- Women represent 80% of people living with rheumatic diseases (RMDs).
- Many of them also care for children, partners, or elderly relatives — often without support.
- Traditional family roles expect women to “care for others” even when they need care themselves.
- This leads to exhaustion, lack of self-care, and worsening of their health.
- ReumaCuida addresses this problem by combining peer mentoring, feminist education, and emotional empowerment to support women caregivers with RMDs.





Marcos Séneca García Rodríguez
 ReumaCuida: Empowering Women with RMDs in Caregiving Roles

06/13/2025

ReumaCuida

Abstract N° 159



The Sleep Struggle: Navigating Fatigue in RMDs

Professor Teresa Paiva is the first to present her work on sleep: Understanding the Importance of Restorative Sleep on Health and Wellbeing. Teresa is a neurologist living with an RMD. We heard about how sleep has a very important restorative function, as it allows for muscle repair, tissue growth and is important for brain function. Fatigue is a consequence of non-restorative sleep, found in about 20% of the general population, but is much more prevalent in people living with RMDs, up to 82% in fibromyalgia, and 57% in psoriatic arthritis. During sleep, very important molecules and hormones are produced. Sleep is also important for reducing pain, as “pain off neurons” are activated during sleep. As already mentioned, sleep is essential for brain function: from cognitive ability and learning, emotional regulation, creativity, well-being, longevity, survival, etc. People living with RMDs often have reduced or disturbed sleep, and sleep disorders are often associated with the RMD. Several strategies to improve sleep quality were presented by Teresa.

SLEEP HYGIENE

- Give Sleep a good chance
- Regular Sleep Schedules
- Regular meals
- Prevent excessive drinking at evening/night
- No Heavy dinner
- Low or No alcohol at dinner
- Take care with Medication
- Exercise 4h per week
- Get sunlight
- Be outside
- Pause before sleep
- At bedtime
 - None/ few screens
 - No work
 - Keep Worries away
 - No bad TV News

TO SLEEP WELL

MENTAL HYGIENE

- ❖ Be optimistic
- ❖ Be thankful
- ❖ Relativization
- ❖ No catastrophizing
- ❖ Keep work-family balance
- ❖ Keep time for yourself

FAMILY HYGIENE


- ❖ Do not do too much
- ❖ Rules: not too much, not too less
- ❖ Share work and responsibilities
- ❖ Adapt to new habits
- ❖ Children centric off
- ❖ Enjoy ...

WORK HYGIENE

- ❖ Do not work excessively
- ❖ Prevent multitasking
- ❖ Prevent interruptions
- ❖ Pause regularly
- ❖ Relativise conflicts
- ❖ Relativise timelines
- ❖ Do not mix work /home

YOUR OWN HYGIENE

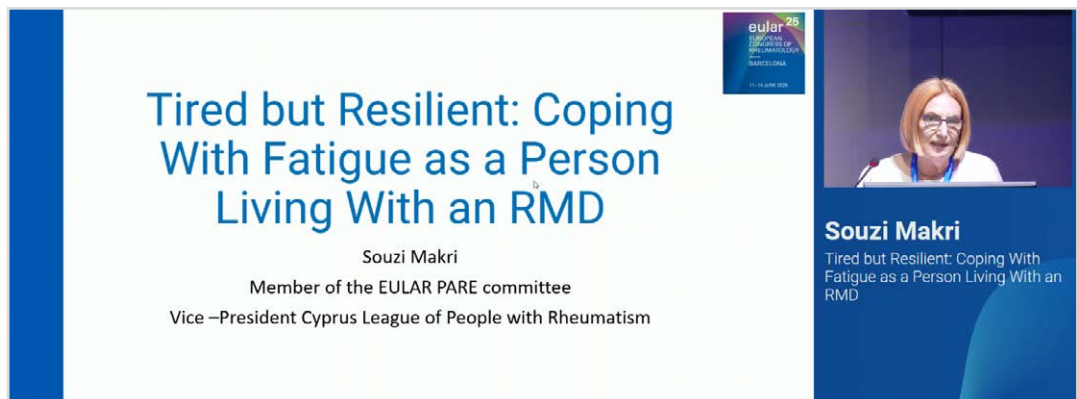
- ❖ Perfectionism OUT
- ❖ Worries OUT
- ❖ Green and Blue
- ❖ Hobbies
- ❖ Amusements
- ❖ Keep your dreams/ Sleep Well



Teresa Paiva
 Sleep Hygiene 101: Understanding the Importance of Restorative Sleep on Health and Wellbeing



Next, **Souzi Makri** talked about fatigue, which is a persistent lack of energy that interferes with daily activities and is one of the most debilitating symptoms for people living with RMDs. Fatigue can be physical and mental, and is related to sleep issues, with impact on physical, emotional, and social well-being. Souzi presented some strategies to manage and cope with fatigue: prioritize rest and sleep by establishing a regular sleep routine and taking short naps to recharge when possible; conserve energy by breaking tasks into smaller steps, using tools and equipment to make the tasks easier, and planning and pacing the activities throughout the day; exercise and keep active, by engaging in gentle and low impact exercises like walking and swimming and perform stretching and strengthening exercises that may help reduce fatigue over time; have a balanced diet to ensure the proper nutrition to support energy levels; seek mental health support by seeking counselling or support groups for emotional well-being and practice stress-reducing activities such as medication, mindfulness or deep-breathing exercises. Souzi also emphasized that healthcare providers have an important role in disease management, as they prescribe medication to reduce inflammation, pain or improve sleep, provide guidance on physical therapy and do regular monitoring, tracking for example fatigue levels and disease symptoms. People living with RMDs can also make lifestyle adjustments, such as having a positive mindset, adjust daily routines and take breaks and asking for help when needed, and make adjustments in the workplace when possible, such as having flexible and remote working hours.



Tired but Resilient: Coping With Fatigue as a Person Living With an RMD

Souzi Makri
Member of the EULAR PARE committee
Vice –President Cyprus League of People with Rheumatism

Souzi Makri
Tired but Resilient: Coping With Fatigue as a Person Living With an RMD

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Professor Jose Antonio da Silva also emphasized the significance of fatigue in RMDs, from a clinical perspective. He also mentioned the several spheres impacted by fatigue in people living with RMDs. Even though there are 26 scores to evaluate fatigue, it is still very challenging to evaluate it since it is unclear what are the causes and mechanisms associated with fatigue. Disease activity, comorbidities, genetics, the nervous system, and psycho-social factors are a few causes for fatigue. There is still much left to understand about the topic to be able to address them properly and use the relevant instruments of measuring fatigue. Jose calls for a creation of a EULAR working group to specifically address this topic.



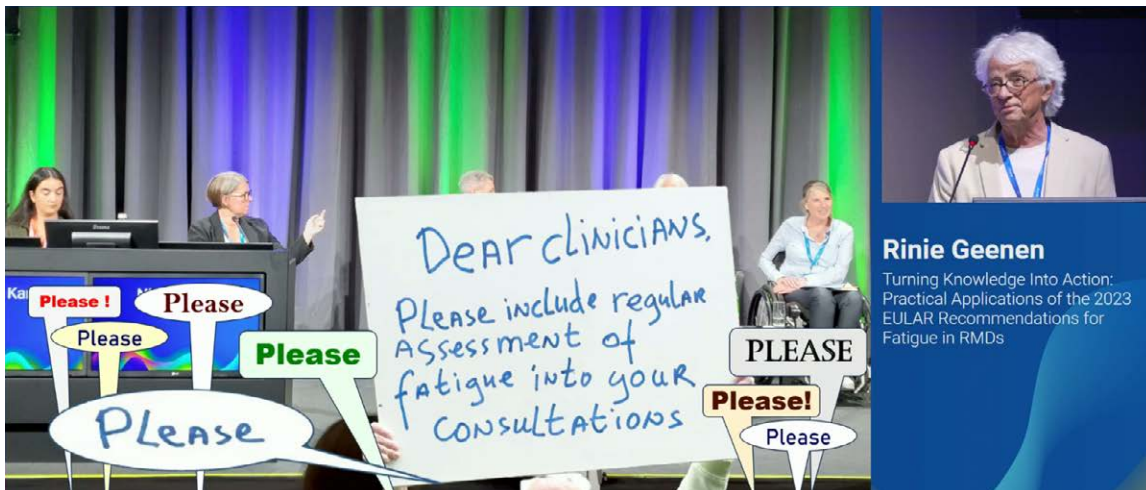
**Beyond pain:
Understanding the clinical significance of fatigue in RMDs**

José António P. Da Silva
University of Coimbra, Portugal.

José Antonio P. da Silva
Beyond Pain: Understanding the Clinical Significance of Fatigue in RMDs

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Professor Rinie Geened presented Practical Applications of the 2023 EULAR Recommendations for Fatigue in RMDs. He emphasised how fatigue is multimodal, as for some people it can be associated with pain, disease activity or sleep, for others it can be related to pain, physical activity and obesity, or even stress, and coping strategies. He presented some of the critical challenges in turning knowledge into action. Even though it is highly prevalent, only 50% of patients felt that their physicians directed insufficient attention to this symptom; often fatigue is not considered as a core symptom, with only 23% of professionals thinking that fatigue is an important outcome to address, versus 67% of people living with osteoarthritis. Several studies show that pharmacological interventions can reduce fatigue, showing the importance of aiming for good disease management that will improve these other symptoms as well. Psychoeducation and physical activity are important and have shown to be beneficial for those living with RMDs and reduce fatigue. However, the individual differences can make it quite difficult to tailor, and some feel even more fatigued after exercising. Even though it comes with challenges for HC and how to set guidelines and routines, a tailored and graded physical activity plan is needed to achieve the best outcomes.



Day 4

On the last day of EULAR, we listened to several interesting sessions from PARE.

AI in Medicine: Your future doctor and researcher

Professor Norelee Kennedy was the first presenter of the session, giving a great presentation on the innovations and pitfalls of AI in RMDs. AI can be used in RMDs in different ways: diagnosis, biomarker discovery, digital health technologies and wearables and prediction. Deep learning can be used to improve diagnosis, for example. AI can improve precision and use large datasets to make decisions, that is beyond the capacity of humans. Even though patients or people living with disease are generally open to the use of prediction models in decision-making, they still wish for the involvement of the clinician, education to understand the details of the technology, and most importantly, they want to be involved in the creation of such tools, so that they consider the patient needs. One major setback for clinicians is the implementation in the clinical setting are the issues with data protection and security. Trust in data storage and use and AI is essential, and it is important to have clear regulations on data availability and ethical concerns, for example, and make sure that these tools do not create wider gaps in equitability and access to care. AI tools should complement but not replace the clinicians' knowledge. And empowerment of patients is necessary for an ethical AI in healthcare. Developers also need to be accountable for the automated decisions provided by the tools they develop.

Innovations and Pitfalls: The Landscape of AI in RMDs

Prof Norelee Kennedy
University of Limerick
Ireland
www.ul.ie

UNIVERSITY OF LIMERICK
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Norelee Kennedy
Innovations and Pitfalls: The Landscape of AI in RMDs

Dr. Paul Studenic also shared his insights on AI in flares, from a researcher's perspective. Several challenges are presented in healthcare and disease management: inter-patient differences, drug choices, unresponsive patients, optimal management support, integration of technology, and time and workforce. E-health can be of help to some of these challenges, from the use of electronic health records, wearables, mobile health apps and remote monitoring, with AI to do the integration of all these. Other challenges to the use of technology in healthcare include people living with RMDs not having a device that supports such tools and many do not really monitor health status, especially for those with low disease activity. On the one hand, some of the limitations of model predictors include the limited amount of clinical data and concerns that the physicians may rely too heavily on the model predictions while ignoring other patient data. The advantages, on the other hand, are the ability to support decision-making, giving feedback to individual risk of patients, being able to integrate much more data in the decision-making process, and giving a clear overview over the patient's history of therapies and disease activity. In summary, technology can make an impactful contribution to the remote monitoring paired with self-management and can help with diagnosis, forecast and decision-making.



Barcelona, 14.06.2025
EULAR 2025

AI for IA patients in flares – the researcher's perspective

Paul Studenic MD, PhD
Department of Internal Medicine 3, Division of Rheumatology, Medical University of Vienna
Department of Medicine (Solna), Division of Rheumatology, Karolinska Institutet

Paul Studenic
AI for IA patients in flares – the researcher's perspective

MEDIZINISCHE UNIVERSITÄT WIEN

Marieke Voshaar brought the patient perspective to the discussion. In her talk, she presented some of the challenges in inflammatory arthritis, such as delayed diagnosis that can result in irreversible damage of the joints, treatment inefficacies, as treatments do not work similarly to all patients, and difficulties in monitoring disease progression. As mentioned earlier, digital technologies with deep learning can support doctors, but not replace them, help solve problems or make decisions, predict disease flare ups and even help choose the right medication for each patient. For patients, it is important that AI is safe and there is still human oversight, that everyone is trained appropriately to use these tools and it does not affect the ability to listen to the patient's choice, that it doesn't deepen the inequalities, and that data is safe and that is secured against cyber attacks or blackouts.



Is AI always right?
Can I trust it?
Who is accountable?

Marieke Voshaar
AI for IA patients in flares – the patient's perspective

How to involve patients in your research

Ana Vieira presented the updated EULAR recommendations on PRPs involvement in research. In brief, PRPs are essential to research as they bring the lived experiences to share relevant and impactful research, they ensure that the research addresses real patient needs and priorities, and that there is transparency and trust in the findings. PRPs help identify and prioritise ideas and topics, design protocols and materials, participate in data collections and analysis, disseminate and implement findings, as well as evaluate impact. With time and increase in their involvement in research, PRPs are more than just tokens in the projects, they are increasingly involved in co-developing and giving feedback to projects. Previous studies showed that up to 85% of research, particularly in the medical field, may be wasted because the studies are not well designed or they fail to advance the scientific understanding. PRPs can be a great resource in addressing research waste.



The slide features a green background with the EULAR logo in the top right. The main title is "The updated EULAR recommendations on Patient Research Partners' involvement in research". Below the title, it lists Ana Vieira as a Patient Research Partner and Sjögren Europe Co-founder & Board member, with her ORCID ID (0000-0003-1299-3137). The slide also mentions the EULAR 2025 European Congress of Rheumatology on 14 June 2025 in Barcelona. A small image of a diverse group of people is shown at the bottom center. On the right side, there is a video inset of Ana Vieira speaking, with her name and a brief description of her presentation below it.

Paul Studenic talked about how to motivate and involve PRPs in research projects. A study from 2023 showed that translational studies have virtually no PRP participation, and only a small percentage of randomized control trials involved PRPs. It is important that the recruitment of PRPs should be based on a clear and agreed-upon description of mutual roles and responsibilities. It is important to communicate the purpose clearly, emphasize the unique expertise, offer training and onboarding, value time and contribution, create a safe and inclusive environment and celebrate together.



The slide has a teal background with the title "Collaborative Research" in large, white, reflective letters. Below the title is an illustration of two hands shaking, symbolizing collaboration. At the bottom left, the logo of the Medizinische Universität Wien is visible. On the right side, there is a video inset of Paul Studenic speaking, with his name and a brief description of his presentation below it.

I Can't Afford to Have a Rheumatic and Musculoskeletal Disease

Stine Wasenius Dahl presented the work of the Norwegian Rheumatology Association on the cost related to RMDs in comparison to cancer. Norway's spending in health is amongst the highest in EU, and just slightly under the European average when calculated according with the GDP (Gross Domestic Product). In Norway, cancer is one of the diseases that takes most of the resources. But given the nature of RMDs, that are chronic and debilitating and more prevalent than cancer, these result in a heavy burden for the healthcare system. RMDs are the leading cause of long-term sick leave and, therefore, lack of productivity. Adding the access of expensive medication, in the country, RMDs have a large economic impact for the country. Still, the fact that RMDs are not as high-profile as cancer, RMDs patients feel under-prioritized and neglected. Given the geography of the country, many have very limited access to rheumatologists and rehabilitation facilities, resulting in an added burden to those living with RMDs.

Per-Patient vs Total Burden



Cancer: High cost per patient (intensive treatment)



RMDs: Lower cost per patient, but many more patients



RMDs have a higher total societal cost

 NORSK REVMATIKERFORBUND



Grainne O'Leary presented the project of Arthritis Ireland on evaluating the personal costs of arthritis. These are any personal costs usually not considered in health economic evaluations and health technology assessments, such as healthcare provision (appointment visits), medications costs, help at home or home adaptations. The study consisted of a survey including several topics, such as financial support for healthcare time spent on healthcare and transport, employment status, sleep quality and general health status, medical expenses, mobility and assistance, etc. Over 1600 people completed the questionnaire. Some interesting findings included that 70% have private insurance, showing the need for further support than the one given by the public system. The mean cost of use of healthcare services was approximately €2000 per year. Women, older people, lower educated people and those with longer disease duration and poorer health experience higher costs. On personal expenses, the average yearly cost was over €3500, on medication was almost €1000 and in assistance related to arthritis and help at home were approximately €500 and €100, respectively. The impact on employment is also very significant, creating loss of income (70% of respondents) or being unable to work due to health (31%). This research shows the impact of the disease and how important it is to do more to support the people living with disease.

Counting the Cost of Arthritis

Gráinne O'Leary









Grainne O Leary
Individual Cost of Arthritis

Main findings: Personal expenses

Average personal 12-month cost:	• €3538
Healthcare services:	• €1980
Medication and related medical products:	• €975
Assistance related to arthritis:	• €478
Help at home:	• €105




Counting the Cost of Arthritis

Living with arthritis imposes an average cost of €3,538 per person each year



Arthritis Ireland



Grainne O Leary
Individual Cost of Arthritis

Natasha Trehan presented the unmet needs of young people living with RMDs. Areas such as mental health, social support, healthcare, medication access and costs were mentioned as needing more support. In fact, 2 out of 3 participants of the survey find it difficult to access school accommodations, 64% feel worried about attending school because of their disease and 30% do not feel supported by their school. Natasha also listed recommendations so that young people living with RMDs feel more accepted and included.

MAKE RHEUM FOR YOUTH - RECOMMENDATIONS

- Work, School and Health**
 - Discuss **accommodations for school and work**
 - HCPs can **educate patients about their options for accommodations in school or work.**
 - Offering a **template letter that explains the nature of rheumatic conditions and the need for accommodations can streamline the process for patients.**
 - **Assisting patients in understanding the support systems built into the education system**, such as student loans, bursaries, and financial aid, can be beneficial.
- Dedicated Platform with Relevant Resources**
 - Create a **digital space** with reliable and easily accessible information for many to access
 - Include **resources** such as mental health, work, medication costs, school, and **more**
 - **Listen to people** to gain further insights and areas
- Work and Health**
 - Create resources with **all the steps of getting a job**
 - Consider **regions specific** resources, such as federal and provincial employment laws
 - Include a space with **reliable external resources**
- School and Health**
 - Create resources that help students **advocate and ask for accommodations** in a school environment
 - A community of individuals **sharing experiences**
 - Resources on **financial aid** for schooling (disabilities)
 - Resource list on **different accommodations** to try
- Stigma and Public Knowledge**
 - Raise **awareness** about rheumatic diseases
 - **Teach self-advocacy** for individuals to break barriers
 - Utilize **different forms of media**
 - Target some resources at individuals who **want to learn** about rheumatic diseases



Natasha Trehan
Beyond the Doctor's Office: The School and Workplace Needs of Young People Living with Rheumatic Disease





Key Takeaways from EULAR:

- Most people living with RMDs look for information online and AI search tools. Many organizations are creating platforms that are hubs of trustworthy information, with contribution of HC professionals and patient representatives.
- RMDs are associated with a strong impact on mental health, pain, and loneliness. Encouraging people living with RMDs to engage with support groups such as local patient organizations can help fight some of these symptoms.
- Some studies showed the large burden of living with RMDs, from difficult to evaluate symptoms such as sleep disruption and fatigue, and the real cost of living with a chronic and debilitating disease, including health care complementation and costs associated with appointment visits, home adaptation and complementary medications. The cost is staggering and it showed the need to provide more support for people living with RMDs.
- There is a large number of treatments available for people living with RMD. Despite efforts to take in the patient perspective and what is important to them, there is still much to do in engaging physicians on what the patient needs are.
- Giving a voice to PRPs (patient research partners) early on project planning is invaluable, providing important feedback and insight from the research question, methodologies and protocols, patient recruitment and analysis of results.

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11-14 JUNE



www.ifpa-pso.com

Report by Science Team
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