

EULAR 2026 Report

Executive Summary

The European Alliance of Associations for Rheumatology (EULAR) Congress 2026, held in London from 3–6 June, brought together clinicians, researchers, healthcare professionals and patient organisations from around the world to share the latest developments in rheumatology research, clinical practice and patient care. ASIF was represented throughout the congress by members of the team and trustees, who attended a range of scientific and patient-focused sessions, presented and chaired sessions and poster presentations, and met with key stakeholders from patient organisations, academia, healthcare and industry.

This report highlights a selection of sessions that were particularly relevant to our members' work and priorities. The topics covered include improving access to rheumatology care, reducing health inequalities, supporting young people and older adults living with rheumatic diseases, the role of artificial intelligence in patient education, and the importance of patient-centred approaches to remission and disease management. The report includes summaries of poster presentations featuring ASIF members and partners, demonstrating the growing contribution of patient organisations to research, advocacy and innovation.

A recurring theme throughout the congress was the importance of listening to and involving patients in every aspect of care and research. Sessions emphasised the need for equitable access to services, improved health literacy, earlier intervention, holistic care and stronger partnerships between healthcare professionals and patient organisations. The role of exercise, confidence in movement, digital innovation and tailored support featured prominently, highlighting opportunities to improve outcomes and quality of life for people living with rheumatic conditions.

This report captures key learning points from the sessions attended by the ASIF team and aims to share practical insights that can inform ASIF's future work, support member organisations and strengthen advocacy for people living with axial spondyloarthritis and related rheumatic diseases.

ASIF Trustee, Geraldine Bonites has prepared a report on her first experience attending EULAR and on the sessions she attended. Read it here.

POSTER Sessions

Act on AxSpA: identifying gaps in care and improving patient awareness

Dale Webb, National Axial Spondyloarthritis Society (NASS)



Watch Dale talk about his session

This poster session presented work from the Act on AxSpA initiative**,** focusing on identifying gaps in care and improving patient awareness, using data-driven and patient-focused approaches.

One key area highlighted was a Danish study examining geographic inequalities in access to evidence-based rehabilitation services. The study mapped variation in rehabilitation provision across different regions, using visual tools such as maps to clearly demonstrate disparities. The findings have been used beyond research, including by media and policymakers, to support advocacy and raise awareness of unequal access.

The project uses a longitudinal approach, with surveys repeated every two years to build a dataset over time. This allows changes in access and provision to be tracked and supports sustained advocacy efforts. The methodology was noted to be adaptable and could be applied to other areas of the healthcare system where inequalities exist.



The project also explored patient awareness and perception of cardiovascular disease risk, which remains under-recognised, particularly in women. A survey was developed in English and translated into nine languages to ensure accessibility. It was distributed through social media, patient organisations, and related platforms, reaching 951 respondents across 43 countries.

Findings showed that a majority of respondents considered themselves not well informed about cardiovascular risk. This highlights a significant gap in communication and understanding and underlines the need for clearer explanations and improved patient education around comorbidities in rheumatic conditions.

The session demonstrated how digital communication tools and campaigns can be used to engage patients and share information more effectively, reinforcing the role of patient organisations in raising awareness and supporting informed decision-making.

Key takeaway
The work presented shows that both inequalities in service provision and gaps in patient knowledge must be addressed together. Combining robust data, accessible communication, and sustained advocacy can help drive more equitable care and better-informed patients.

Leveraging AI to empower people with axSpA in India

Prachee Bholse, ASWS, India (and ASIF Trustee)



Watch Prachee talk about her session

This poster presented a multilingual, patient-led advocacy initiative exploring how artificial intelligence (AI) can be used to empower people living with axial spondyloarthritis (axSpA) in India. The initiative focuses on improving digital inclusion, health literacy, and patient confidence through accessible AI tools.

Many people face a combination of language barriers, difficulties understanding complex medical terminology, and limited access to reliable information, which can affect family understanding and support. The project uses multilingual AI tools to help patients engage with health information in ways that are more accessible and relevant to their context.

Patients are supported to use AI tools safely and effectively, including guidance on protecting personal information when uploading data and understanding that AI should be used for information only. Clear guardrails were emphasised, including the need to verify sources and recognise that healthcare professionals remain the primary authority in treatment decisions.

In practice, patients can upload key health information and use AI tools to translate and explain this information in simpler language, making it easier to understand their condition and communicate with family members. This approach was reported to improve both disease understanding and family awareness, which can contribute to better support and improved adherence to medication.

The initiative highlighted broader benefits of AI adoption. These include increased digital confidence, improved communication, and opportunities for skill-building, such as using AI to support CV development or identify suitable work opportunities, particularly for individuals with physical limitations.

The project emphasised that multilingual AI can help address cultural and language differences, supporting more inclusive communication across diverse populations.

Key takeaway
This work demonstrates that **patient-led use of AI**, when supported by clear guidance and safeguards, can improve health literacy, strengthen support networks, and reduce barriers linked to language and access.



From Global Insights to Local Impact: Unveiling South Africa's Axial Spondyloarthritis Needs Through the Patient-Led SFAS Survey

Maranda van Dam, ASASA, South Africa

Watch Maranda talk about her poster.



Watch Lillann Wermskog talk about the importance of patient organisations submitting posters to EULAR



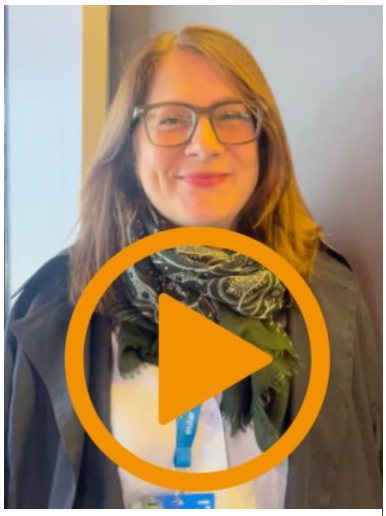
Watch Jill Hamilton talk about her thoughts on EULAR.

From Pain to Progress: Encouraging Exercise and Healthy Living in AxSpA

Chairs Lillann Wermskog & Simone Battista

One of the most thought-provoking sessions at EULAR 2026 explored the relationship between pain, movement and exercise in people living with axSpA. The presentations combined clinical evidence with practical experiences, reinforcing the importance of helping people move with confidence rather than fear.

Denis Orlinov, a member of ASIF's Executive Advisory Council, opened the session by discussing kinesiophobia – the fear of movement. He explained how pain can lead to fear, causing people to avoid movement, which in turn can prolong pain, reduce physical function and contribute to ongoing problems. He described how pain interpreted as threatening can lead to catastrophising, avoidance behaviours and deconditioning, creating a cycle that amplifies pain. His key message was that movement and pain are not inherently inseparable: movement is medicine, but fear can become a significant barrier. He concluded that movement should feel safe and be tailored to each individual rather than following a "one size fits all" approach.



Watch Nadia talk the role of managing pain.

Nadia Malliou focused on the complexity of pain in AxSpA. She highlighted that many people continue to experience pain despite successful treatment of inflammation, with residual pain often reflecting neuropathic or nociplastic mechanisms. She presented evidence that exercise therapy can improve pain, physical function, spinal mobility and overall disease activity, although responses vary between individuals. Nadia discussed findings showing that people with spondyloarthritis report higher levels of kinesiophobia than healthy controls, with greater fear of movement associated with poorer quality of life, increased depressive symptoms and reduced physical function. Her presentation emphasised that understanding pain mechanisms, pacing activity, reducing fear of flares and rebuilding trust in the body can help people regain confidence in movement.

The patient perspective came from Andri Phoka, President of the Cyprus League of People with Rheumatism (CYPLAR), who shared practical experience of how annual walking events can encourage people to become more active and stay engaged over time.

The session concluded with an important reminder: the best exercise programme is often the one that people with AxSpA can sustain over the long term, supported by education, confidence and approaches that meet individual needs.

AI as a Partner in Care: Empowering the RMD Community with Information

Zoe Karakikla Mitsakou, Lupus Europe

Purpose

LupusGPT is a multilingual AI information tool designed to provide validated, patient-friendly lupus information when people need it most. It addresses a key information gap where patients often search using their own words, often when they are worried or looking for reassurance, and risk encountering misleading or unreliable information online.

Key Features

- Built on a curated library of validated lupus documents
- Available in 19 languages (covering ~87% of Europe's population)
- Free, open access with no login required



Watch Jo talk about the session

- Designed with patient-friendly language
- Explicitly states when it cannot answer (no hallucinations – when AI generates incorrect, fabricated, or nonsensical information that is not grounded in reality - or speculation)

What Makes It Different

- Not a medical device or replacement for healthcare professionals
- Not a general AI chatbot
- Only provides answers based on approved information and does not answer outside its knowledge base Designed with low creativity to prioritise accuracy and safety

Core Design Principle: Safety

AI safety is a human decision. It requires clear rules, regular oversight and ongoing testing. It is important guardrails are put in place.

Safety is achieved through:

- Restricting answers to approved documents only
- Clearly explaining when information is unavailable
- The system clearly stating what it is designed to do to avoid misinterpretation
- Continuous testing across languages
- Ongoing updates to content, prompts, and governance

An important feature of LupusGPT is its ability to say "I don't know that" when reliable information is not available, rather than providing a potentially incorrect answer (hallucinating or finding information from an unverified source). This helps to:

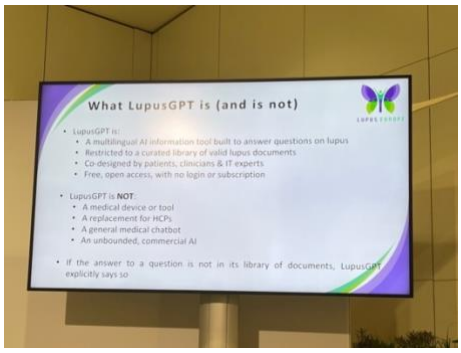
- Maintain trust
- Highlight areas for improvement
- A core part of the system's ethics

Collaborative Model

The tool is co-designed and maintained by:

- Patients – define needs, boundaries, tone and accessibility
- Clinicians – ensure medical accuracy and validation
- AI specialists – build and contain the system technically

Broader community includes translators, researchers, national groups, and underserved populations.



Learning & Iteration

LupusGPT evolves through real-world use:

- Early issues included missing information, language variability, and ensuring answers were delivered in an appropriate way,Some answers were factually correct but emotionally distressing
- Gaps only became visible through real user questions

The team recognised it was vital to learn from this. Information needed to be accurate but also phrased in a way that felt supportive and sensitive to the concerns of people living with lupus.

These lessons continue to inform improvements to the tool and were seen as part of a learning loop rather than failure.

Accessibility Focus

The project actively addresses who is "quietly left behind," including those with:

- Low literacy or health literacy
- Language barriers
- Brain fog, fatigue, or difficulty typing

EasyLupus

- Simplified version using the same validated content
- Shorter sentences and simpler vocabulary
- Includes a spoken beta version (voice interaction)
- Extensively tested to avoid loss of accuracy

Impact to Date

- 65,000+ questions answered
- Users in 189 countries
- Use in 39 low- and middle-income countries

Identifying knowledge gaps

- Enabling clinicians to provide information where none existed locally

Future Direction

The next phase of development is highly collaborative and will focus on:

- Experience & access: voice, interface, accessibility tools
- Content expansion: turning "no answer" into new resources
- Collaboration & reach: linking with clinicians and patient organisations
- Security & resilience: strengthening governance and testing

Key Message

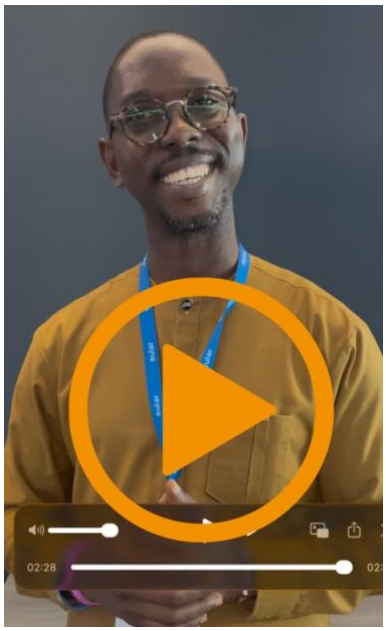
LupusGPT is:

- Built together
- Kept safe together
- Improved together

The strength of the tool lies not only in the technology, but in the community around it. Lupus Europe are happy to share knowledge and experience with other patient organisations who are considering creating something similar to Lupus GPT for their patients in different disease areas.

Bridging the Gap – Expanding Rheumatology Access for Underserved Communities

Chairs: Franklin Hiagbe & Mrinalini Dey



Watch Franklin talk about the session

No Exceptions: Building Universal Access to Rheumatology Services

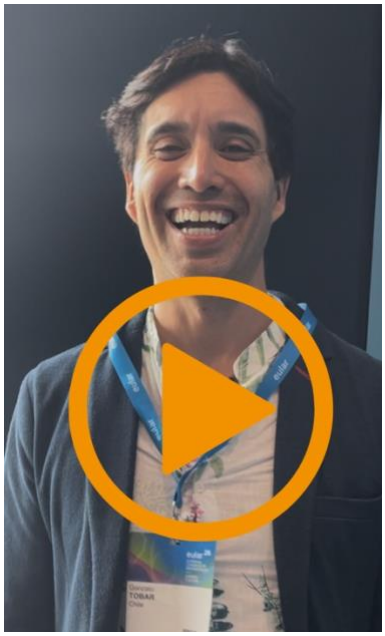
Gonzalo Tobar

This session highlighted the real-world barriers many people face in accessing rheumatology care and explored practical solutions, with a strong focus on Chile as a case study. The key message was clear: access is not just about healthcare systems, but also about inequality, geography, costs and patient involvement.

Why access remains difficult

Chile provides an example of how a centralised healthcare systems can leave many patients behind. Although the country has around 20 million inhabitants, nearly 40% live in the capital, Santiago, where most specialist services are located. Patients in regional

or rural areas face poorer services, lower investment and fewer opportunities to access care.



Watch Gonzalo talk about the session

There is also a significant shortage of rheumatologists, around one specialist per 84,000 people, with only about 200 nationwide and very limited paediatric care in some regions. These shortages can lead to delays in diagnosis and treatment, potentially leading to poorer health outcomes.

Access is further shaped by deep social and economic inequality. Chile has high levels of income inequality, with clear divides between public and private healthcare. These inequalities contribute to barriers such as high costs, long travel distances and uneven quality of care.

Financial barriers and health policies

Many patients in Chile face high out-of-pocket costs (around 30–35% of health spending), particularly for innovative treatments, although generic medicines are more affordable.

Two key national policies aim to improve access:

- **GES (Explicit Health Guarantees)** ensures access, maximum waiting times, financial protection and quality standards for a limited list of conditions (currently around 85). It helps standardise care, but does not cover all diseases or treatments.
- **Ricarte Soto Law**, introduced following strong patient / public-led protests, provides financial protection (no co-payment) for high-cost treatments over a set threshold. It has enabled access to some biologic therapies for conditions such as RA, PsA and SLE.

However, both systems are limited. Only certain conditions and treatments are covered, and no new conditions have been added to the Ricarte Soto Law since 2019, largely due to financial constraints.



Current challenges

The healthcare system is under pressure. Budget reductions and competing priorities, such as cancer care, mean fewer resources are available for rheumatic diseases. This reflects a broader issue: rheumatology is often not seen as a policy priority, despite its major impact on patients' lives.

Patient experience and unmet needs
Patient described the day-to-day reality of living with rheumatic diseases, which often involves managing multiple, overlapping challenges, including fatigue, isolation, financial strain, mental health issues and difficulties accessing transport and care. Health literacy is also an issue - not just understanding information, but understanding what care involves beyond medication.

Opportunities and the role of patient organisations
Encouragingly, there are strong opportunities for progress:

- Growing collaboration between the Chilean Society of Rheumatology and patient organisations
- Development of national patient networks (since 2019)
- Increased patient education and data collection to inform policy
- Promoting the role of rheumatology nurses and use of biosimilars to reduce costs
- Greater involvement of patients in public discussion and decision-making

Key takeaway
Moving towards universal access is challenging and slow. However, one message stood out strongly: **empowered patients and active patient organisations are essential to driving change**. By strengthening patient voices,
building partnerships and identifying unmet needs, there is real potential to improve access and equity in rheumatology care.

Portuguese patient panel pilot Rheumatology Care

Zoe Karakikla Mitsakou

This session explored new ways of reaching people living with rheumatic diseases who may not currently be accessing support, information or patient organisations.

Rethinking how we reach patients
Patient panels are a well-established way to understand patient experience and needs. However, the traditional model is often centralised at European level and requires travel, time, English language skills, and connection to a patient organisation (PO). As a result, it may only include those patients who are already engaged, risking a partial picture of the patient voice.

Lupus Europe therefore explored whether a more localised model could help reach people who are often missed.



A local model: the Portuguese pilot

A pilot patient panel was held in Portugal (November 2024) in a non-metropolitan hospital setting, with 11 participants. The session was:

- Run entirely in Portuguese
- Supported by local volunteers from a lupus patient organisation
- Designed to be short (one day) and accessible
- Built around interactive discussion, exercises and shared reflection

A key feature was the role of the doctor. Participants were invited through their doctor, who opened the session before stepping back to allow a patient-led discussion. This helped create trust and encouraged people to share their experiences openly.

What patients shared

The discussion revealed that patients' experiences are often complex and interconnected, rather than single issues:

- **Isolation** was both social and self-imposed
- **Fatigue** was described as sudden and overwhelming
- **Loss of independence** could feel humiliating
- **Family support** was important but not always available
- **Transport, access to care, medication and costs** all compounded each other

Participants described managing multiple pressures at once, including health, finances, family responsibilities and mental health.

Going beyond expected questions

While organisers expected discussions about treatment and disease, patients instead spoke about:

- Daily functioning and dependence
- Financial pressures and practical support
- Mental health and fatigue
- Trust in community advice and self-medication
- Concerns about family and children
- Uncertainty about where to turn next

This discussion highlighted that access is not only about seeing a doctor, but about the wider context of living with a condition. Many patients described layered barriers, rather than a single obstacle.

Health literacy: a broader challenge

The pilot showed that understanding health information (health literacy) involves much more than simply being able to read it. It includes understanding key concepts:

- What "treatment" actually means (beyond medication)

- How care fits into daily life
- How to navigate the health system

Even commonly used healthcare terms sometimes required explanation, showing the need for clear, accessible communication.

What this approach can achieve
The local model demonstrated several important benefits:

- Helps POs reach beyond already engaged patients
- Shows that trusted healthcare professionals can open doors without dominating discussions
- Provides a clearer understanding of what patients truly need, rather than what is assumed
- Supports better signposting, guidance and accessible information
- Is low-cost, adaptable, and suitable for different settings

The pilot demonstrated the value of learning from patients before expanding the approach to other settings.

Key takeaway
The Portuguese pilot showed that. local, patient-led approaches can help reach people whose experiences are often missing from traditional engagement activities, it showed the importance of inclusive programmes grounded in real-life experiences. Working together, clinicians and patient organisations, can create safe and accessible opportunities for people to share their experiences and help shape future support and services.

Equity is Not Equality: Tackling Ethnic Disparities in Rheumatology Access

Arumugam Moorthy

This session highlighted the importance of addressing ethnic disparities in access to rheumatology care, emphasising that achieving fairness in healthcare requires different approaches for different groups.



Understanding equity in healthcare
A key message was that equity is not the same as equality. Providing the same services to everyone does not always result in equal outcomes. Equity means recognising that people face different barriers and may therefore need different levels and types of support to achieve the same opportunities and outcomes.

In practice, this includes:

- Allocating resources based on need rather than uniform provision
- Providing translated information and culturally tailored education
- Developing community outreach and prioritised access pathways for underrepresented groups

Why disparities exist

The session highlighted a combination of patient, social and healthcare system factors that contribute to unequal access.

Patient-related factors include:

- Differences in health literacy
- Language barriers
- Cultural beliefs about illness and medicines
- Concerns about taking long-term medication and following treatment plans

These factors can influence how and when people seek care, and how they engage with treatment.

A real-life example was discussed of a patient who travelled abroad to seek traditional medicine, resulting in significant disease progression due to lack of appropriate treatment. This example showed how cultural beliefs and access to healthcare can all influence treatment decisions and health outcomes.

Barriers within healthcare systems

Healthcare systems themselves can unintentionally create barriers, including:

- Lack of culturally tailored education materials
- Limited involvement of people from diverse ethnic backgrounds in patient engagement activities
- Insufficient interpreter support
- Under-representation of minority groups in research and service design

In addition, patients may face difficulties such as navigating referral pathways and communication, and socioeconomic barriers, including arranging transport, balancing work commitments or caring responsibilities.

In some communities, lower awareness of inflammatory arthritis symptoms, combined with reduced trust in healthcare systems, can contribute to delays in seeking care and receiving a diagnosis.

Impact on access and outcomes

These barriers are often interconnected. For example, language difficulties can affect understanding of symptoms, delay presentation, and reduce confidence in navigating healthcare systems. Cultural beliefs and concerns about medicines may influence treatment decisions and adherence.

Moving towards solutions
The session outlined practical approaches to improve equity:

- Providing information in multiple languages
- Developing culturally adapted education programmes
- Strengthening community engagement and outreach
- Supporting shared decision-making, recognising cultural beliefs and patient preferences
- Improving data collection on ethnicity to better understand and address disparities

Clear communication in a person's preferred language was identified as one of the most important ways to improve access, understanding and trust.

Key takeaway
The session reinforced that people do not all face the same barriers to accessing rheumatology care. Improving access requires healthcare providers and POs to understand the needs of different communities, and the barriers they face, and tailor support and access accordingly. Clear communication, culturally appropriate information and meaningful community engagement all have an important role to play.

Making Rheum for Youth: Identifying Barriers to medication Access and Healthcare for Young People with Rheumatic Diseases

Natasha Trehan

This session explored the challenges faced by young people living with rheumatic diseases, highlighting how access to medication and healthcare becomes more complex during transition to adulthood.

Transition: a critical point for access
A key theme was the transition from paediatric to adult care. Young people face multiple simultaneous changes:

- Moving from paediatric to adult healthcare services
- Shifting from parent-supported insurance to independent coverage
- Transitioning from school into the workforce

These changes create uncertainty around medication access and affordability, even where effective treatments are available.

Many young people rely on temporary systems during adolescence, including:

- Parents' employer-sponsored insurance
- Student health plans
- Pharmaceutical patient support programmes

However, these sources of support often end as young people become adults, leaving them to navigate complex healthcare and insurance systems on their own, including private insurance, public drug plans, reimbursement processes, prior authorisations and co-payments.

Barriers identified by young people

Survey findings from the *Make Rheum for Youth* initiative revealed that many young people feel unprepared for the practical challenges of managing their healthcare independently:

- **49% of participants did not know how they would pay for medications after graduating**
- **60%** did not know how to navigate drug insurance plans
- Only **42%** felt confident navigating the healthcare system
- Just **38%** reported that the transition to adult care went well

These results underline that access barriers are not only financial. Many also need more support to understand healthcare systems, insurance and medication access.

What young people need

Participants consistently emphasised the need for clear, practical and accessible information. Priorities included:

- Understanding insurance systems and drug coverage
- Navigating the healthcare system
- Developing self-advocacy skills
- Learning how to cope with living with a rheumatic disease

Many young people are actively seeking information, but want it to be relevant, easy to understand and help them deal with real-life situations.

They highlighted the importance of:

- Resources explaining reimbursement and medication access options
- Information on public and private drug plans
- Medication-specific guidance
- Dedicated platforms offering accessible and reliable information



The role of different stakeholders

Improving medication access requires action from multiple groups, including healthcare professionals, patient organisations and industry.

Healthcare providers should:

- Start conversations about insurance and medication access early, before transition
- Integrate coverage planning into transition care

- Refer patients to support services such as social workers or patient navigators
- Recognise how financial pressures can affect whether young people are able to access and continue treatment

Patient organisations can:

- Develop youth-friendly resources tailored to different healthcare systems
- Provide practical guides to help young people prepare for adult healthcare services
- Offer peer support and mentorship programmes
- Advocate for policies that improve access to care and medications

Pharmaceutical companies should:

- Simplify patient support and reimbursement processes
- Increase awareness of financial assistance programmes
- Provide education materials tailored to young people
- Work in partnership with patient organisations

Recommendations for improving access

The *Make Rheum for Youth* initiative outlined practical next steps:

- Develop resources showing different payment options to support future planning
- Create information on commonly prescribed medications
- Build a dedicated digital platform with reliable, accessible information, including topics such as mental health, work, school and treatment costs
- Raise awareness and reduce stigma, including through different forms of media
- Support self-advocacy and empower young people to manage their own care

Key takeaway

The transition to adulthood can be a particularly difficult time for young people with rheumatic diseases. Alongside managing their health, many are learning how to navigate healthcare systems, understand insurance and take greater responsibility for their care.

Better information, earlier planning and stronger collaboration between healthcare providers, patient organisations, policymakers and industry can help young people feel more prepared and confident during this transition. By focusing on the real-world needs of young people, there is an opportunity to improve both access to treatment and long-term outcomes.

Rethinking care for brighter outcomes in older adults with RMDs

Chairs: José Antonio P da Silva & Anne-Katrin Rausch

Why would it make sense to adapt our disease management to older people

Marta Novella-Navarro



This session explored how care for older adults with rheumatic and musculoskeletal diseases (RMDs) needs to be adapted to reflect the realities of ageing.

A key distinction was made between *young-onset* and *elderly-onset* disease. People diagnosed earlier in life often experience long-term disease progression with treatment adjusted over time, while those diagnosed later may face challenges around diagnosis and initial treatment decisions. As people are living longer, , the session emphasised that RMD care must respond to the changing needs of an ageing population.

Multimorbidity and polypharmacy

Older adults with RMDs frequently live with **multimorbidity** (two or more co-existing conditions) and **polypharmacy** (use of multiple medications, often five or more). As the number of comorbidities increase, so does the number of medications required, leading to:

- Higher risk of drug interactions
- Increased likelihood of medication errors
- Greater risk of serious adverse events
- Increased treatment-related toxicity

Changes that occur naturally with age, including reduced kidney and liver function and changes in body composition, further increase these risks. The concept of a “prescribing cascade” was highlighted, where medications prescribed for side effects can lead to additional treatments and complications.

Treatment: efficacy, safety and limitations

Evidence for treatment effectiveness in older adults remains limited, as they are often underrepresented in clinical trials. Research findings are mixed, with some studies favouring younger patients and others showing no clear differences.

Safety is an important consideration when treating older adults.. Treatment-related risks include:

- **Infections**, with higher risk linked to age, comorbidities, disease activity, and immunosuppressive therapies

- **Cardiovascular events**, with increased risk due to both ageing and inflammatory disease
- **Cancer**, with higher baseline risk in older adults

Preventive strategies such as vaccination, screening, and regular monitoring were highlighted as essential. Some treatments may carry additional risks, making careful discussion between patients and healthcare professionals particularly important.

Common treatments may present additional challenges in older patients. Non-steroidal anti-inflammatory drugs (NSAIDs), glucocorticoids and Disease-Modifying Antirheumatic Drugs (DMARDs) must be used cautiously, with attention to dosing, monitoring, and risk–benefit balance.

Moving towards holistic, patient-centred care

The session highlighted that managing the disease itself is only one part of caring for older adults. Maintaining independence, mobility and quality of life are also a priority.

Important considerations include:

- Supporting strength and balance
- Planning activity to reduce risk of flares
- Identifying frailty early
- Measuring outcomes in simple but meaningful ways
- Identifying triggers for deterioration

Integrated, multimodal care was highlighted as more effective than focusing on disease control alone. Coordinated support across services, alongside involvement of families and caregivers, can help prevent crises and improve outcomes.

Key take-home messages

- Care for older adults should be individualised
- Comprehensive geriatric assessment should be considered
- Clinicians should actively look for comorbidities and concurrent treatments
- Effective treatment should aim to control disease activity and prevent complications
- Inappropriate prescribing should be avoided, maximising benefits while minimising risks

Summary

Older adults with RMDs have complex and distinct needs, including potentially managing multiple health conditions and medications., The session highlighted the importance of careful, individualised decision-making. Improving outcomes for this population will depend on a more holistic, coordinated approach to care that balances disease control with safety, function, and quality of life.

Understanding Frailty: From Identification to Identification

Luise Lindgren



This session focused on frailty in older adults with rheumatic and musculoskeletal diseases (RMDs), highlighting why it matters, how it can be recognised, and how it can be managed through practical, patient-centred approaches.

What is frailty?

Frailty was defined as a clinical state of reduced physiological reserve and increased vulnerability to stressors, resulting from age-related decline across multiple systems. Changes associated with ageing, such as loss of muscle mass (sarcopenia), immune and hormonal changes, reduced cardio-respiratory reserve, worsening balance and reaction time, nutritional challenges, polypharmacy, and reduced cognitive reserve, all contribute to increased vulnerability.

Frailty means that even relatively minor events, such as an acute illness, can lead to greater loss of function and longer recovery times.

Frailty and RMDs

The presence of an RMD can further increase the risk of frailty. Symptoms such as Inflammation, pain, fatigue and reduced physical activity can make it more difficult to maintain strength and independence over time. Medication use, including polypharmacy and treatment side effects, also contributes.

Frailty is common across rheumatic conditions. For example, it was reported in:

- 55% of people with rheumatoid arthritis
- 45–85% in systemic lupus erythematosus
- Around 45–50% in conditions such as ankylosing spondylitis and systemic sclerosis
- 47% in psoriatic arthritis
- 35% in osteoarthritis

This compares with around 10% of people over 65 years in the general population, rising with age. Many people experience ”pre-frailty”, where early signs are present. Recognising these signs are an important opportunity for early intervention.

Recognising and measuring frailty

Frailty can be identified using a range of approaches:

- **Physical measures** (e.g. weight loss, exhaustion, weak grip strength, slow walking speed, low activity)
- **Clinical assessment tools**, such as the Clinical Frailty Scale (CFS), which provides a quick overall assessment based on function and independence

- **Frailty indices**, which consider a broader range of factors including disease, cognition, nutrition and social issues

In practice, simple and pragmatic tools are useful for routine care, particularly when combined with clinical judgement.

Typical signs of frailty include:

- Weakness
- Slow walking
- Exhaustion
- Low levels of physical activity
- Weight loss or undernutrition

A clinical example illustrated how frailty may present in practice, including reduced adherence to treatment, poor nutrition, inactivity, social isolation, increasing pain and fatigue, and loss of independence in daily routines.

Frailty is dynamic and potentially reversible

An important message was frailty is not a fixed state. Individuals may move between stages, from robust to vulnerable (pre-frail) to frail, depending on health events and support. Importantly, there is potential for **recovery and improvement**, particularly when frailty is identified early.

Interventions: a multimodal approach

The session highlighted that addressing frailty requires a **combination of approaches**, rather than focusing on disease control alone. Key elements include:

- **Medication review**: simplifying treatment and minimising side effects
- **Nutrition support**: ensuring adequate protein intake, vitamin D, and hydration
- **Physical activity**: strength and balance exercises,tailored to the individual
- **Prevention strategies**: falls prevention, vaccination, and flare planning
- **Psychosocial support**: Supporting mental wellbeing, sleep, isolation, and involving carers where needed

Evidence from intervention studies showed that combined approaches, including exercise, nutrition, and lifestyle interventions, can improve strength, function and quality of life.

A clinical example demonstrated how practical actions, such as reviewing medication, supporting nutrition, encouraging activity, and addressing social needs, can reduce vulnerability in a short period of time.

Key take-home messages

- Frailty should be considered early, as small changes may signal increased vulnerability

- It should be measured simply but thoughtfully, using practical tools
- RMD-related factors such as pain, inflammation and fatigue should be recognised as triggers
- Integrated, multimodal care is more effective than disease control alone
- Supporting patients and families together helps prevent crises and maintain independence

Summary

Frailty is common in older adults with RMDs and often develops earlier than expected. However, it is a dynamic and potentially reversible condition. Early identification and coordinated, holistic care, including physical, nutritional, medical and psychosocial support, can help maintain function, improve quality of life, and support people to live as independently as possible.

Voices of experience: What older adults with RMDs and their families need most

Dieter Wiek



Voices of experience: what older adults with RMDs and their families need most

This session shared patient perspectives on the needs of older adults living with rheumatic and musculoskeletal diseases (RMDs), based on questionnaire responses, interviews, and discussions with patients, patient organisations, and care providers.

Understanding patient experiences

The perspective was illustrated through people aged 70+, including individuals living long-term with conditions such as rheumatoid arthritis (RA), axial spondyloarthritis (axSpA), osteoarthritis (OA), psoriatic arthritis (PsA), and systemic sclerosis. Many participants had lived with their condition for decades and described the significant impact it continued to have on their daily lives. The questionnaire explored people's experiences of diagnoses, comorbidities, treatments, access to care, self-management, patient concerns, and satisfaction with healthcare professionals.

More than 30 people responded, with most aged between 70 and 79. The findings were complemented by discussions with patient group leaders, healthcare professionals, and representatives of care facilities.

Common challenges in older age

Across participants aged 70+, several common issues were identified:

- Many people reported multiple comorbidities and long histories of treatment, including surgeries

- Most required several medications, often for both RMDs and other conditions
- About half had a formal medication plan
- Most received physiotherapy and participated in exercise (e.g. hydrotherapy or gym-based activity)
- Many paid out of pocket for services, such as podiatry

Access to specialist care was one of the major concerns raised. Patients highlighted:

- A lack of rheumatologists
- Difficulty finding specialists who accept new patients
- Long waiting times and long travel distances

Data presented showed that a significant proportion of patients travel more than 20 km to reach a rheumatology clinic.

Some felt consultations were too short, leaving little opportunity to ask questions or discuss concerns fully.

Everyday impact of RMDs
When asked about the biggest problems caused by their condition, participants most frequently reported:

- **Functional disability**
- **Pain**
- **Fatigue**
- **Sleep problems**

Real-life examples illustrated how older adults may live with:

- High levels of disability
- Multiple health conditions (e.g. COPD, cardiovascular conditions)
- Long-term medication use
- Ongoing need for physiotherapy and physical activity

Life circumstances play an important role. For example, loss of a partner or caring responsibilities can significantly affect daily functioning and independence.

Concerns about care and ageing
A key concern expressed by patients was the possibility of losing independence. In particular many people reported a strong fear of:

- **Needing full-time residential care**
- The **costs associated with nursing homes**

Data showed that most people requiring long-term care receive **care at home**, often provided by relatives, while a smaller proportion are in full-time residential care.

However, the high costs for residential care was a major concern, especially with the significant out-of-pocket contributions required depending on level of need.

What patients say they need most

The session highlighted several priorities identified by patients:

- Access to specialist rheumatology care, including for those living in nursing homes
- Better non-pharmacological care, particularly for those in long-term care settings or receiving care at home
- More focus on the needs of older people with RMDs, especially those who are housebound or living in care facilities
- Greater support from patient organisations, including advocacy for those who cannot actively participate in patient group activities
- More research to better understand the needs and challenges of this population

Family support was also highlighted as essential, particularly as people become more dependent on others in later life.

Summary

The experiences shared in this session showed that many older adults with RMDs are managing not only their condition, but also multiple health and practical challenges and concerns about future care. Many wish to maintain independence and avoid residential care but face practical and financial barriers.

The findings underline the importance of improving access to both medical and non-pharmacological care, strengthening support systems, and ensuring that the needs of older and more vulnerable patients are not overlooked.

Global Remission Coalition: advancing patient-centred remission in inflammatory conditions

Neil Betteridge & Tony Wolf

This session introduced the work of the Global Remission Coalition (GRC), a global network of 77 patient advocacy organisations across five continents representing people living with chronic inflammatory conditions. The coalition is member-driven, with a steering committee defining priorities and a medical advisory council supporting its work.



The pursuit of remission

A central focus of the GRC is the “pursuit of remission”, recognising that while remission may be difficult to achieve in some conditions, it remains an important goal.

Early intervention is critical, offering opportunities to improve patients’ ability to achieve remission, reduce disability, and enhance quality of life. Progress requires coordinated efforts across health systems, policymakers, healthcare professionals, patient organisations, and communities.

Key priorities include improving awareness, strengthening primary care, supporting equitable care, expanding patient support networks, and ensuring patient-centred outcomes remain central.

Expanding the definition of remission

Clinical definitions of remission often focus on disease activity but do not always reflect what matters most to patients. Through collaboration with OMERACT, the GRC is working to include patient perspectives.

Key patient priorities include pain, fatigue, and independence. These are interconnected and equally important, with pain often being the most immediate concern. Mental health and wellbeing are closely linked.

Additional important areas include sleep quality, social participation, and financial and treatment burden. What independence means can vary from person to person depending on life stage, access to care, and support systems.

Advocacy priorities and stakeholder engagement

Advocacy priorities include early access to care, adherence to guidelines, patient information, public health campaigns, improved referrals, and person-centred care.

Key stakeholders include patients, patient organisations, healthcare professionals, and policymakers. Broader consultation through surveys, workshops, and discussions is planned.

Next steps

- Explore how remission reflects patient experience
- Identify actions across stakeholders
- Prioritise focus areas
- Shape future coalition support

Summary

The session highlighted the need for a more patient-centred understanding of remission. Combining clinical measures with outcomes such as pain, fatigue, independence and quality of life will support better policy and care. Collaboration across stakeholders is essential.

EULAR 2027

In 2027, EULAR will take place in Berlin, Germany, from 9–12 June. We look forward to another fantastic congress next year!