

European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases

9th Meeting – 26 June 2012

The RMD community's perspective on pain

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Roles and interests of presenter

- Vice President, EULAR, representing People with Arthritis and Rheumatism in Europe (PARE)
- CEO of the patient group Arthritis Care for last 7 years
- Director of company providing patient perspective
- Vice Chair, Chronic Pain Policy Coalition (UK)
- Patient Representative on Dept. of Health Clinical Reference Group on Specialised Pain Services (England)
- Patient Adviser to NHS Improvement (England)

Overview from patient perspective

- Why is chronic pain important for EULAR?
- Why does chronic pain matter so much?
- Two case studies from national level
- What are the challenges?
- What are the solutions?
- Implications & key issues for EU policymakers

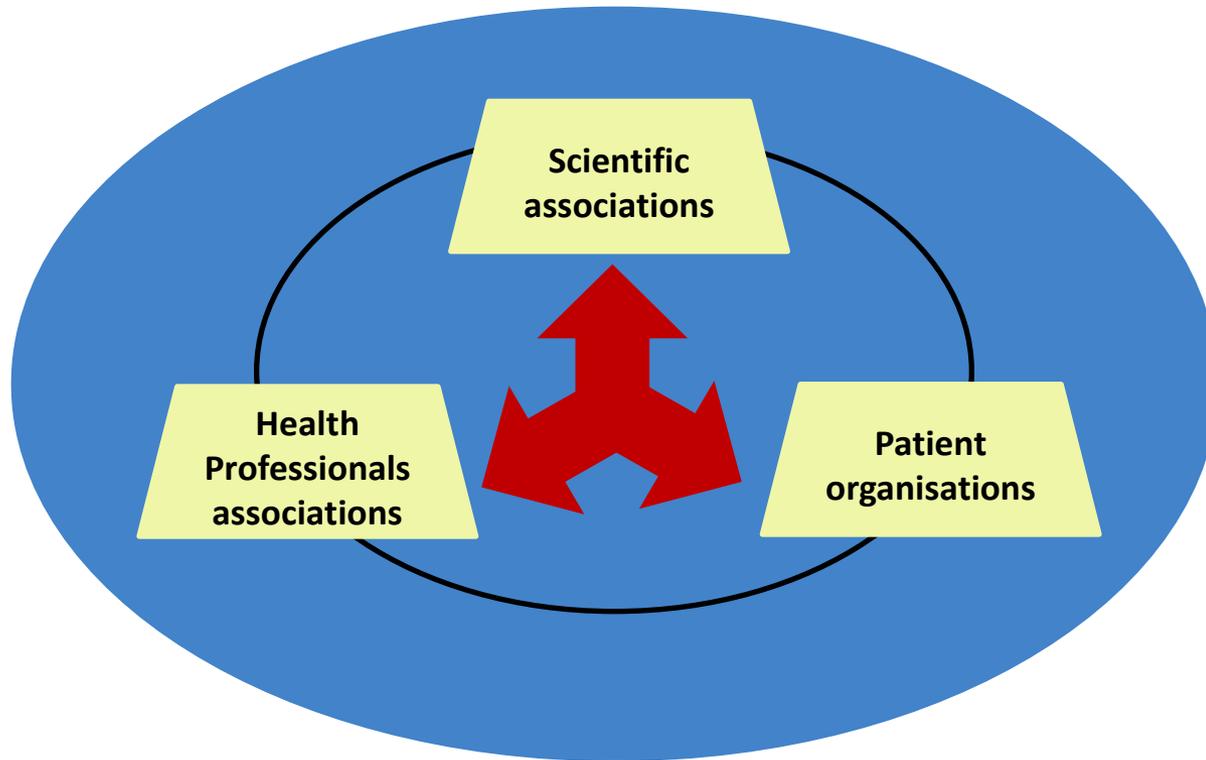
Who does EULAR represent?

- Composed of 3 main pillars:
 - Scientific and clinical
 - Health professional
 - People with RMDs in Europe / 'Patients'
- Close links with all key stakeholders, eg newly established alliance with orthopaedic body, EFORT: European Musculoskeletal Health Alliance (EMSA)

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**All aspects of RMDs
(rheumatic and musculoskeletal diseases)**

Foundation: 1947



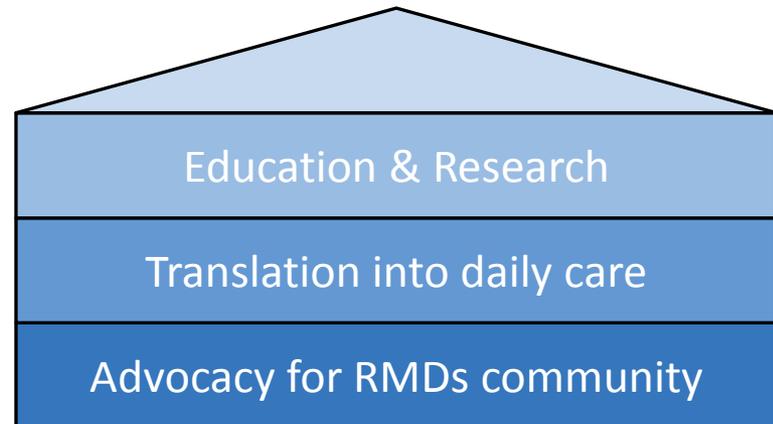
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About EULAR

EULAR mission:

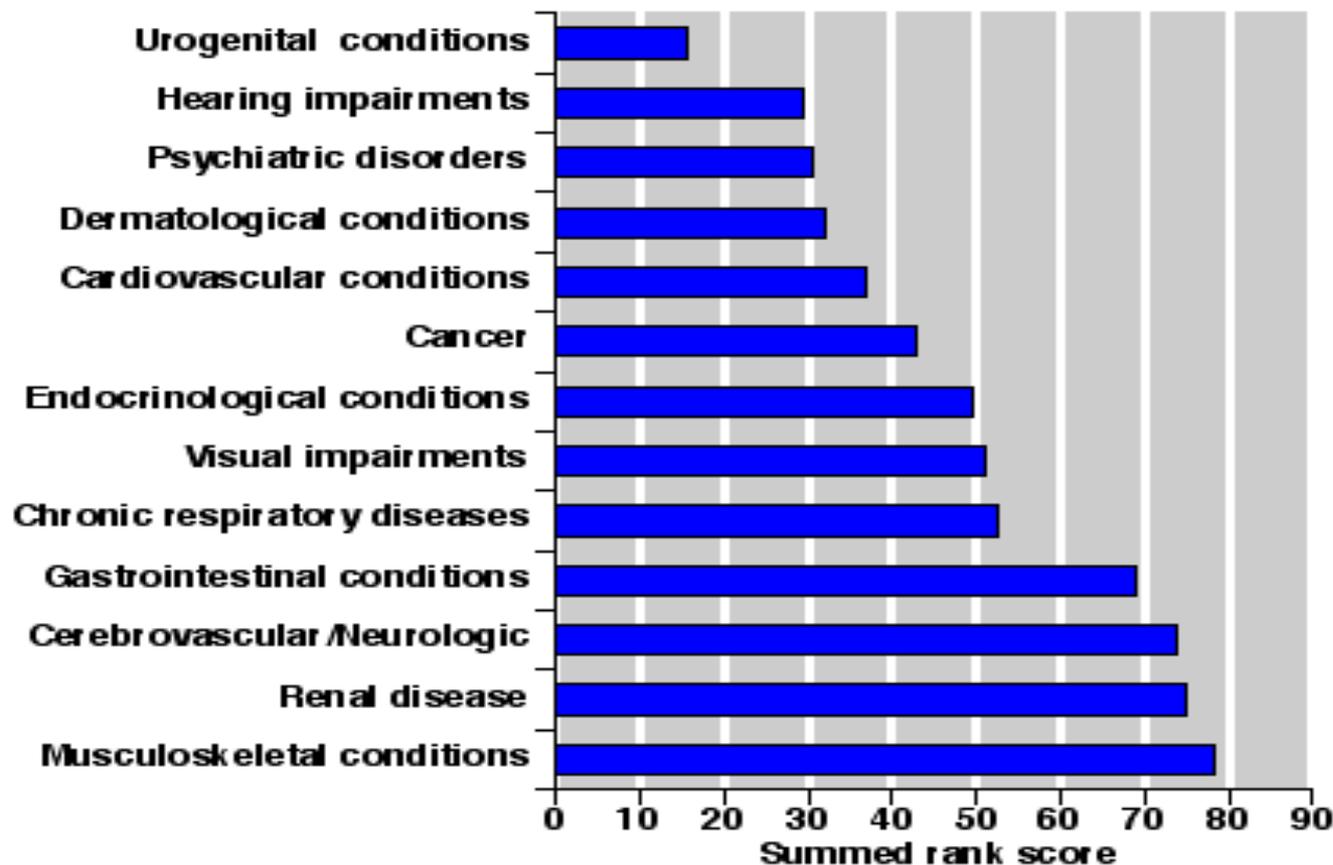
- to improve the treatment, prevention and rehabilitation of musculoskeletal diseases; and thereby
- To reduce the burden of rheumatic diseases on the individual and society

EULAR activity areas:



Disability & RMDs. Evidence

Impact on quality of life of chronic disease (Netherlands)



Source: Sprangers MA, de Regt EB, Andries F, van Agt HM, Bijl RV, de Boer JB et al. Which chronic conditions are associated with better or poorer quality of life? *J Clin Epidemiol* 2000; 53(9):895-907 as quoted in *European Action Towards Better Musculoskeletal Health BJD* 2005.

Why this matters: the economy (1)

Work loss: example from Portugal

- Indirect costs alone (work loss and absenteeism) of lower back & joint pain is 740m euro p.a.
- This is 0.5% of GDP and 7.53% of all health expenditure

Why this matters: the economy (2)

Back pain alone is enormously expensive:

- Recent study in UK showed back pain cost the country £12.3bn / 15.25m euro ⁽¹⁾
- In Australia, back pain was the subject of a major public health campaign: 'keep moving'

⁽¹⁾ *Maniadas N., Gray, A. (2000), 'The Economic Burden of Back Pain in the UK'*

Why this matters: labour market

Sub-optimal care and poor rehabilitation is wasteful:

- Denmark has removed subsidies so people with pain now receiving cheaper morphine derivatives
- In Germany, of all people off work with back pain, only 35% ever return.

Why this matters: health care

Huge, and increasing, demands on health systems:

- “Health in the EU”, the Euro-barometer from 2007, identified that one quarter of EU citizens experience pain lasting >3 months
- In primary care, RMDs represented 66% of all painful states presenting

Why this matters: people

One young woman describing her early experience of Rheumatoid Arthritis:

- 'I never want to feel pain like that again. My skin hurt. My joints all ached. I could have been overtaken by depression at any time. If it wasn't for my husband, I don't know what I would have done' (*Arthritis Foundation member*)
- 'My neck felt like it was made of rock salt' (*Arthritis Care member*)

National case study (1): the challenges

‘Arthritis Hurts’, UK survey of people living with RMDs on their experience of living with pain, Arthritis Care (2010):

- >90% of all respondents reported at least moderate pain every day
- 77% of respondents said their pain prevented them sleeping through the night
- 48% said it often prevented them from working
- 58% said they hid their pain from loved ones

‘Mustn’t grumble’ is our enemy....

National case study (1): solutions (1)

As a result of the survey, Arthritis Care called on:

- Governments in the UK to promote awareness that people should seek medical advice at the earliest possible moment
- Health professionals to offer patients early referral to secondary care and to direct them to accredited patient groups for self-management support

National case study (1): solutions (2)

Arthritis Care's '*Challenging Pain*' course offers structured self-management support - techniques to regain control of your life:

- 2 x 3 hour sessions over consecutive weeks
- Led by people living with chronic pain
- Practical e.g. relaxation techniques

National case study (1): solutions (3)

‘Challenging Pain’ includes:

- Training in breathing and diversion techniques
- ‘Pacing’ techniques to minimise pain & fatigue
- Awareness of the need to keep active
- Safe exercise techniques
- Support in setting longer term personal goals
- Problem solving skills

‘It gave me helpful steps to manage my pain’

National case study (2): challenges

The first England 'Pain Summit' was a high level event held in November 2011, co-ordinated by the *Chronic Pain Policy Coalition* (UK). It brought together all key stakeholders, e.g:

- British Pain Society
- Faculty of Pain Medicine
- Royal College of General Practitioners
- People with chronic pain & their representatives

National case study (2): challenges (2)

The purpose was to come together as a community to better address challenges such as:

- Prevalence, severity, costs – and yet neglect
- Poor HP training in pain management
- Lack of documentation of pain by HPs
- Long waits and inconsistent treatment standards

National case study (2): progress

The Pain Summit wants to build on recent developments e.g:

- National reports on chronic pain in Portugal, Scotland, Wales (and Australia, Canada, USA)
- 2010: International Pain Summit, Montreal - 'access to pain management a human right'
- Royal College of GPs, UK, declared pain a clinical priority 2011-'14 - appointed a Pain Champion

National case study (2): solutions (1)

- The report of the Pain Summit to be launched in UK Parliament on 4 July 2012 by health minister.
- Specific recommendations are embargoed but in broad terms will address four main areas, where urgent need has been identified for:
 - 1) Agreed standards of care
 - 2) Awareness campaign to educate public & HPs

National case study (2): solutions (2)

- Key recommendations of 'Pain Summit Report' continued:
 - 3) Agreed commissioning guidance to describe best value in treatment and management of chronic pain
 - 4) New national data strategy to better understand the epidemiology of chronic pain

Summary of EULAR's political actions (I)

European Parliament Written Declarations 2005/2008:

- Calling on the EU and Member States to strengthen disability legislation, improve access to care and enhance research funding

Brussels Declaration 2008:

- To improve the situation of people living with RMDs (e. g. by accessing public environment, having the right to work, being fully included in society etc.)

EULAR's political actions (II)

- **Council Conclusions 7 December 2010** (Innovative approaches for chronic diseases in public health and healthcare systems, including treatment and self-management of pain)
- **Hungarian EU Presidency Conference** „Burden of Rheumatic and Musculoskeletal Diseases: Challenges in Work Capacity and Prevention of Disability in the EU“
 - **Hungarian EU Presidency Declaration:** to remove barriers to work participation for people with RMDs, where effective pain management is essential to job retention

Conclusion (1)

- RMDs are not only the biggest cause of physical disability in the EU but:
 - *Are one of the most painful sort of chronic conditions*
- Prevention and Research are the most effective ways to reduce the prevalence of RMDs and with it the pain of daily living for tens of millions of EU citizens

Conclusion (2)

‘It is good to be better, but it is better to feel good’

***PASS study, involving EULAR President
Maxime Dougados***