Rheumatic and Musculoskeletal Diseases: Lessons for innovative policy making in the prevention and management of chronic diseases

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Rheumatic and Musculoskeletal Diseases: Lessons for innovative policy making in the prevention and management of chronic diseases

Rheumatic diseases:
- All painful conditions of the musculoskeletal system
- 200 different disorders
- Joints, tendons, ligaments, bones and muscles affected
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120,000,000 EU citizens affected by MSKD (~1/4 of total population)

Individuals’ well-being affected

Productivity and economic losses

Burden on social and health systems

Genetic and biological determinants

Socio-economic determinants

Lifestyle determinants

Absence / withdrawal from work
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Determinants of MSKD:

- Genetic and biological determinants
- Socio-economic determinants
- Lifestyle determinants

120,000,000 EU citizens affected by MSKD (~1/4 of total population)

- Age
- Gender
- Occupational risks (e.g. heavy work, repetitive work)
  *MSKD account for 50% of all work-related health problems, and 60% of permanent work incapacity in the EU*
- Obesity
- Reduced physical activity
- Smoking
- Excess of alcohol
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120,000,000 EU citizens affected by MSKD (~1/4 of total population)

The impact of MSKD on individuals’s well-being:

Absence / withdrawal from work

- Coping with symptoms (pain, fatigue, etc)
- Depression
- Work loss
- Focusing life on treatments

Individuals’ well-being affected
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120,000,000 EU citizens affected by MSKD (~1/4 of total population)

Absence / withdrawal from work

⚠️ Productivity and economic losses

- 40,000,000 workers with MSKD in the EU
- €240 billion cost for the EU economies per year
- Direct costs of around 2% of GDP

40,000,000 workers with MSKD in the EU

€240 billion cost for the EU economies per year

Direct costs of around 2% of GDP
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- 120,000,000 EU citizens affected by MSKD (~1/4 of total population)

Absence / withdrawal from work

- Increasing need of carers
- Billions of Euros annually spent in medical costs and drugs across Europe

Burden on social and health systems
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(Foundations: 1947)

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Scientific associations

Health Professionals associations

Patients organisations
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EULAR mission:

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

EULAR activity areas:

- Education & Research
- Translation into daily care
- Advocacy for MSKD community
Promoting the optimal quality of life for people with musculoskeletal diseases

- Fostering excellence in education and research
  - Disseminating knowledge through annual congresses and publications

- Promoting the translation of research advances into daily care
  - Developing recommendations on diagnosis and treatment standards
  - Contributing to intelligent and comprehensive prevention strategies

- Advocating concrete improvements for people with musculoskeletal conditions
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Recent initiatives at EU level on MSKD:

- 2005: EP Written Declaration 41/2005 on rheumatic diseases
- 2008: EP Written Declaration 08/2008 on rheumatic diseases
- 2009-2014: European Parliament Interest Group on rheumatic and musculoskeletal diseases
- 2010: Funding by European Commission of European musculoskeletal surveillance network project
- 2010: Belgian EU Presidency Ministerial Conference on Chronic Illness & Conference on MSKD
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EU Presidency Conference on MSKD

Key facts:

- 150 Delegates (representatives of Member States, EU institutions, health professionals, people with rheumatic diseases, scientists and other stakeholders)
- Outcome oriented event
## EU Presidency Conference on MSKD

### Structure

<table>
<thead>
<tr>
<th>Time</th>
<th>Session/Workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning</td>
<td>Opening Session</td>
</tr>
<tr>
<td></td>
<td>Plenary Session 1</td>
</tr>
<tr>
<td></td>
<td>Plenary Session 2</td>
</tr>
<tr>
<td>Afternoon</td>
<td>Workshop #1: Prevention: Improving health</td>
</tr>
<tr>
<td></td>
<td>Workshop #2: Prevention: Patient involvement</td>
</tr>
<tr>
<td></td>
<td>Workshop #3: Disease management and patient-centred partnerships</td>
</tr>
<tr>
<td></td>
<td>Workshop #4: Chronic diseases and health systems</td>
</tr>
<tr>
<td></td>
<td>Plenary Session. Presentation of results</td>
</tr>
<tr>
<td></td>
<td>Closing Session</td>
</tr>
</tbody>
</table>

### Title

Rheumatic and Musculoskeletal Diseases: Lessons for innovative policy making in the prevention and management of chronic diseases
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EU Presidency Conference on MSKD

Main goals:

- To develop recommendations to both Member States and EU institutions for improving the prevention and management of MSKD;
- To identify best practices in the prevention and management of MSKD, as examples for the prevention and management of other chronic diseases
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Recognition of the socio-economic importance of MSKD

- Medical costs (diagnosis, treatment, hospitalisation, complications)
- Work incapacity
- Impaired quality of life
- Continuous care
- Functional loss
- Need for carers
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Lessons for innovative policy making in the
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Recognition of full rights of people with MSKD

Barriers to inclusion for people with MSKD

- Environmental (buildings, transport)
- Social (stigma, social attitudes)
- Institutional (policies, law)
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Recognition of full rights of people with MSKD

Reduce personal impact: Absence / Withdrawal from work

- Focus on capacity, not incapacity
- Incapacity is never absolute
- (Good) work is good for health
- Flexibility, environmental adaptation, jobs demands adjusted
- Main goal: retention!
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Prevention

1. Practical Issues
   - What is prevention?
   - How to improve prevention?

- Early diagnosis
- Early referral
- Early treatment

Addressing health determinants of MSKD

Primary prevention

Secondary prevention

- Tackling health determinants
- Education / Awareness raising
- Patients’ involvement
- Research
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Prevention

2 Addressing determinants of MSKD

- Lifestyle determinants (physical inactivity, nutrition, etc.)
- Focus on addressing socio-economic and working determinants (education, working conditions, working environment, etc.)
- Focus on addressing genetic/biological determinants
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Prevention

3 Education and awareness raising for:

- General practitioners (early referral)
- Specialists (early diagnosis + treatment; control)
- Health professionals
- Patients (information)
- Patients’ organisations
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Disease management / treatment

- Health care management:

  Diagnosis / Treatments
  Organisation of health care services

- How to improve disease management?

  - Recognition of rights of patients to appropriate care
  - Implementation of standards of care
  - Patients' involvement
  - Research
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Disease management / treatment

Principles

- Guaranteeing patients’ rights to appropriate and timely care
  - Education and training of general practitioners and specialists
  - Specialised centres
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Disease management / treatment

Standards of care

- Treatments should be based on scientific evidence
  - Evidence-based as consensus of professionals experienced in the treatment of patients with a given condition
- Recommended treatment should be applicable irrespectively of financial constraints
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Disease Management and health care systems

What is still needed?

- Standard of care infrastructure
- Standard of care training
- Implementation of standard of care throughout Europe
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Patient involvement

<table>
<thead>
<tr>
<th>The old world</th>
<th>The new world</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Passive role</td>
<td>▪ Active role</td>
</tr>
<tr>
<td>▪ Paternalism</td>
<td>▪ Equal partners</td>
</tr>
<tr>
<td>▪ Patients as service users</td>
<td>▪ Patients as consumers of services</td>
</tr>
<tr>
<td>▪ Limited rights / Limited responsibilities</td>
<td>▪ “Responsible patient”</td>
</tr>
</tbody>
</table>

(Courtesy of Neil Betteridge)
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Patient involvement

Why should patients be empowered?

- Functionality and self-sufficiency are the ultimate goals
- Self-management should be prioritized
- Patients can give information on their needs regarding the delivery of health care services
- They can help in setting priorities in disease management goals, research, etc.
- Can give input on relevant outcomes in clinical care and research
- It would benefit the patient and the healthcare system, in terms of efficacy and cost savings
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Patient involvement

What is still needed?

- More recognition of the “expertise” of people with MSKD by medical doctors
- Validated tools to support Shared Decision Making and to measure patient experience
- More research addressing the involvement of patients
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Research needed

- **Primary prevention**: on ‘pathogenesis’, ‘genetics’ and ‘environmental factors’. Use:
  - Specific therapeutic targets
  - Risk patients
  - Type of therapeutic ‘action’

- **Secondary prevention**: on prevention of further disease progression; prevention of new ‘events’; prevention of further functional loss; prevention of further loss of quality of life

- **Disease treatment and management**: on ‘clinical outcome measures’, ‘genomics’, ‘immunological research’, ‘pathogenesis’
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Conference recommendations

1. The European Union and its Member States should recognise the socio-economic importance of rheumatic and musculoskeletal diseases of all ages and assign them appropriate priority

2. There is an urgent need to prioritise basic and clinical research regarding the causes, predictors, management and impact of these chronic diseases
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Conference recommendations

3. The European Union and Member States should ensure that people with disabilities related to rheumatic and musculoskeletal diseases have the right to full inclusion in society; this encompasses optimisation of environmental and life-style factors, the availability of self-management tools, and respect for the right to a flexible education and work environment.

4. People with rheumatic and musculoskeletal diseases should receive prompt access to high quality care, ideally in specialised centres, thus maximising long-term quality of life.
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Lessons for innovative policy making in the prevention and management of chronic diseases

Conference recommendations

5. Management of rheumatic and musculoskeletal diseases should be in accordance with evidence-based recommendations in every European Union Member State.

6. People with rheumatic and musculoskeletal diseases are experts in living with their condition and should be involved in the design, delivery and evaluation of their services.
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Follow-up EU and Member States

1. A European Union Strategy to fight musculoskeletal disorders
   - covering: public health and employment best practices, disability/anti-discrimination legislation, research

2. National Action Plans to allow for holistic and integrated measures covering:
   - Access to treatment/care, specialised centres, training, workplace regulation, disability aspects, research support, etc.