

BELGIAN EU PRESIDENCY CONFERENCE ON RHEUMATIC AND MUSCULOSKELETAL DISEASES (RMD)

Brussels, 19 October 2010

Summary Report

Background and Objectives of the conference

The Conference on Rheumatic and Musculoskeletal Diseases, organised in collaboration with EULAR, the European League against Rheumatism, was part of the Belgian EU Presidency's initiative addressing chronic illnesses.

The growing burden of these conditions in the European Union and the common challenges faced by Member States in this regard elicited the special attention of the Belgian EU Presidency to this issue. The Belgian EU Presidency thus addressed the necessity for Member States to share knowledge and best practices in the prevention and treatment of chronic diseases, and that the EU institutions should play a subsidiary but relevant role in supporting Member States' initiatives.

Prior to the Ministerial Conference "Innovative Approaches for Chronic Illnesses in Public Health and Healthcare Systems", held in Brussels on 20 October, the Belgian EU Presidency organised two supportive conferences on major chronic disorders affecting European citizens: (a) Rheumatic and Musculoskeletal Diseases (RMD) and (b) Respiratory Diseases (RD). The pre-conferences on RMD and RD were thought to serve as pivotal examples for other chronic diseases. They aimed at feeding into the Ministerial Conference by providing conclusions and specific recommendations for further action on the prevention and management of these disorders. The resulting conclusions and recommendations of the three events will feed in the Employment, Social Policy, Health and Consumer Affairs Council (EPSCO Council) in December 2010.

Conference's goals

The purpose of the Conference on Rheumatic and Musculoskeletal Diseases (RMD) was to discuss current challenges in RMD prevention and treatment and to exchange ideas and best practices on how to improve the health of citizens affected by these disorders.

The Conference on RMD pursued three main objectives:

- To present and discuss innovative approaches in the management of RMD, particularly on prevention, disease management, patient involvement, training of health professionals and equal access to care;
- To raise awareness at European and national levels about how life style and environmental factors impact on the development of RMD and what can be done to improve the health as well as the quality of life of people living with a RMD;
- To develop recommendations on initiatives that could be taken on board by the European Union and the Member States to improve prevention and management of RMD across EU countries, particularly on those initiatives that could be transferred to other chronic disease areas.

Structure of the conference

The conference aimed at producing concrete results and recommendations to both the EU and Member States for the improvement of the prevention and management of chronic diseases, particularly RMD.

In this sense, the event combined both plenary and workshop sessions. During the two plenary sessions, experts presented on the challenges and needs in the field of rheumatic and musculoskeletal diseases. Plenary sessions were co-chaired by Prof. Paul Emery (EULAR President) and Ms. Leen Meulenbergs (Federal Public Service Health, Food Chain Safety and Development, Belgian Health Ministry).

The four parallel workshops focused on key issues in prevention and management of these conditions:

Workshop #1: Prevention: Improving health now and in the future (education, environmental issues, early diagnosis, laboratory tests, early referral, etc.)

Workshop #2: Prevention: Innovative approaches and best practices in patient involvement

Workshop #3: Disease management and patient-centred partnerships

Workshop #4: Chronic diseases as a challenge for health care systems and innovative models of health care delivery

During the workshops, policy recommendations to EU institutions and Member States were discussed and further developed by participants. These recommendations were presented at the Ministerial Conference on “Innovative Approaches for Chronic Illnesses in Public Health and Healthcare Systems” on the following day.

High representatives from the Belgian Presidency, the European Commission and the World Health Organisation were involved in both the opening and the closing plenary sessions.

Participation

Representatives from EU institutions, Member States, patients and physicians organisations, academic institutions and other stakeholders participated in the event.

While Brussels based institutions were of course strongly represented, conference participants came from all over Europe.

Registrations by country

Country	Participants	Country	Participants
Austria	2	Italy	2
Belgium	45	Latvia	2
Croatia	1	Malta	4
Cyprus	2	Netherlands	8
Czech Republic	2	Norway	4
Denmark	5	Poland	1
Estonia	2	Romania	2
Finland	1	Slovakia	1
France	4	Spain	3
Germany	4	Sweden	6
Greece	3	Switzerland	10
Hungary	4	United Kingdom	20
Iceland	1	USA	1
Ireland	3		
		Total	143

Summary of discussions

Presentations and workshop discussions mainly focused on six issues: the recognition of the burden of RMD to both individuals and society; the recognition of the rights of people with RMD to full inclusion in society; the need to increase efforts in improving primary and secondary prevention of these disorders; the need to find innovative approaches in the management of RMD; the new roles of both patients and health professionals; and the necessity to further research on different aspects of rheumatic and musculoskeletal diseases.

The burden of rheumatic and musculoskeletal diseases

The recognition of the socioeconomic importance of musculoskeletal diseases for both individuals and society was one of the main concerns for participants and speakers. It was pointed out that the

development and implementation of effective strategies to reduce the burden of RMD is only possible if policy makers and stakeholders do recognise the problem.

Recognising the importance of RMD means that policy makers and stakeholders at both EU and Member States levels are aware of the burden of these diseases on the lives of dozens of millions of citizens, but also the burden on the sustainability of healthcare and social security systems and on the productivity of the overall economy. It also means acknowledging that the problem is expected to increase dramatically in the coming decades as a result of the ageing of the population, if no further actions are taken now.

Therefore, positioning RMD as a priority on the policy agendas of Member States and EU institutions was mentioned as a prerequisite for an effective and coordinated action against rheumatic and musculoskeletal conditions.

The rights of people with rheumatic and musculoskeletal diseases

Delegates and speakers also discussed on the need to recognise and guarantee the rights of people with RMD to full inclusion in society. People affected by these disorders face unsuitable urban and working environments that limit even more their mobility. Moreover, our societies still tend to stigmatise or even discriminate people with disabilities, and our legal systems and our policies are not yet sufficiently developed to avoid these situations. The aim must be to guarantee that everyone can enjoy full participation in social and economic life.

As it was stated several times, these environmental, social and institutional restrictions have severe consequences for the capacity of people with these conditions to remain and actively participate in the labour market.

The improvement of the working environment, the introduction of flexible working conditions and the fight against stigmatisation were pointed out to be essential to allow people with RMD to remain in the labour market. Allowing people to remain at work not only avoids negative economic consequences; it has been proved to be also beneficial for their health and therefore, for the sustainability of health and social systems.

In order to make significant improvements in the environmental, social and institutional areas, delegates pointed out that legislation needs to be reinforced and that all relevant policy areas should take into account musculoskeletal disorders.

Primary and secondary prevention

The improvement of primary and secondary prevention of rheumatic and musculoskeletal diseases was discussed in detail throughout the event. The debate embraced two main issues¹:

- the necessity for further actions addressing the determinants of musculoskeletal disorders in order to avoid, postpone or slow down the development of these diseases; and
- the need to raise awareness and improve education and training.

Delegates agreed on the need to reinforce actions tackling the determinants of RMD. This is particularly important with regard to some of the lifestyle determinants such as obesity, lack of physical activity, smoking or excess of alcohol. Some of these determinants are also key risk factors of other chronic diseases. Therefore, combined efforts with other stakeholders would result in more effective and efficient outcomes.

Tackling other socioeconomic and working determinants is also crucial. As mentioned above, working conditions and working environments are key determinants of RMD. Addressing these factors is necessary to avoid the outbreak of these disorders among healthy people as well as the aggravation of these conditions among people who have already developed them. It was also pointed out that it should be convenient to work together with key players in other areas, such as social security, employment authorities, business and alike, in order to be more effective in tackling these determinants.

Delegates of the conference also concluded that education and awareness raising should play a key role in the prevention of these disorders. Health professionals -particularly general practitioners and specialists- must be able to detect potential symptoms of these disorders at an early stage, and refer patients to specialists for diagnosis and, eventually, for treatment as soon as those symptoms are detected.

Policy makers and stakeholders should also receive enough and updated information on best and innovative practices in prevention and management of these diseases in order to better design and implement policy initiatives. Furthermore, they should be aware of the need for leadership in this area as well as on the consequences of not doing enough to reduce the burden of RMD.

Patients, and the overall population, should also receive information and should be aware of those factors that harm their musculoskeletal systems. Moreover, patients should have knowledge and apply self-management preventive techniques in order to avoid or slow down the development of their diseases.

¹ The need to reinforce the **involvement of patients** as well as the need for furthering **research** was also discussed from the prevention perspective. Nonetheless, as they were also discussed as key elements in the management of RMD, the results of these discussions are presented under separate headings.

Disease management

Together with prevention, the management of RMD also received significant attention from delegates. Two main topics were discussed:

- The right of patients to receive care from well-trained physicians; and
- the implementation of standards of care.

One of the important desiderata in the management of rheumatic and musculoskeletal disorders is to guarantee the right of patients to receive appropriate and timely care from well-trained physicians. The underestimation of patients' musculoskeletal problems by physicians in the EU healthcare systems is partly the result of inadequate education at undergraduate and postgraduate levels. The little attention of these issues in the curricula of undergraduate and postgraduate programmes contrasts with the fact that musculoskeletal complaints are the second most common reason for consultation, exceeded only by disorders of the respiratory system.

The importance of having specialised centres where people with musculoskeletal conditions receive specialised care and treatment was clearly demonstrated during the debates.

The need for better training of physicians, and better treatment of patients in specialised centres, were two of the main conclusion in this regard.

Nonetheless, it was pointed out that it is not enough to have well-trained general practitioners and specialists: healthcare systems also need to guarantee that specialists are trained in, and apply, the most effective evidence-based treatments, which should be the results of a consensus among experienced professionals.

The development and implementation of standards of care throughout Europe would be a milestone in the use of treatments based on scientific evidence. It would specify a set of established, defined norms, procedures or practices to use in the diagnosis and treatment of patients with musculoskeletal disorders. Moreover, it would be useful for guiding physicians in the selection and use of treatments as well as in general aspects concerning the organisation of patient care. The further development and implementation of these standards was stated to be still a pending task though.

Patients' involvement

Delegates strongly agreed on the need to reinforce the involvement of patients in both prevention and management of RMD. This not only means assuming more responsibilities in their own treatment; it also means that their involvement would be beneficial for the design, implementation

and evaluation of healthcare services, as well as for the design and implementation of policy initiatives.

The traditional role of patients, as passive receivers of treatments with no voice and limited rights and responsibilities, is no longer functional for their own treatments and might be eventually harmful. In the treatment of these diseases, patients' strong commitment and responsibility are needed in defining what is best for them, in partnership with medical doctors. Speakers and delegates stressed the need of a new relationship between health professionals and patients, which should focus on structured self-management as a means of complementing support provided by health professionals: a move from the 'expert patient' to the 'responsible patient'. Greater self-determination provided more control, more confidence and higher levels of independence

However, structured self-management is not the only area where their involvement is required. Given their experience in dealing with their diseases and with different treatments, their input is important for improving the delivery of healthcare services.

From discussions among delegates, three things stood out regarding patient empowerment. First, it is necessary that health professionals, and particularly physicians, recognise that patients are experts in living with their conditions. Second, it is necessary to validate tools to support common decision-making between patients and doctors. This would guarantee that decisions are taken on the basis of shared and sufficient information concerning the characteristics of alternative treatments and their potential consequences. Finally, more research is needed to estimate the real impact of patient involvement in the treatment of musculoskeletal disorders. The results of this research would be beneficial to design innovative partnerships between doctors and patients, as well as to draft better self-management practices.

Research

Fostering research was one of the main demands of participants.

Further investigation on the causes of all rheumatic and musculoskeletal diseases should be a priority for funding bodies and researchers. A better understanding of these elements would significantly contribute to the improvement of diagnostic techniques, for which further research is also needed. Altogether, the results of this research would considerably reduce the development of musculoskeletal conditions in the population.

Funding bodies and researchers should also further support research on disease management, particularly on the development of innovative therapies and treatments. So far, medical sciences and healthcare institutions can only offer limited help or relief to the millions of people affected by these disorders. Developing better therapies and treatments would considerably reduce the impact of these diseases on individuals' lives as well as on healthcare and social security systems.

Beyond fostering research on prevention and treatment, other managerial and organisational aspects should also need further investigation, as for example the involvement of patients in prevention and management and the improvement of the working environments.

Participants pointed out that more funding is certainly needed for research on these diseases. Nonetheless, they also underlined the importance of setting appropriate research agendas as well as better coordinate and integrate research activities.

In spite of the progress made in recent decades in research, delegates agreed that efforts are still insufficient. Without a strong commitment of Member States, the EU and private actors this work is not possible.

Conclusions and recommendations

As a result of these debates, participants further developed a set of recommendations and proposed a number of specific initiatives for their implementation. The final recommendations agreed by delegates are as follows:

1. The European Union and its Member States should recognise the socioeconomic 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
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
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

Participants also proposed specific initiatives for the implementation of each of the recommendations at both the EU and Member States levels. The proposed initiatives are mentioned below.

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

Member States level	European Union level
<ul style="list-style-type: none"> • Member States including regions to develop frameworks for RMD / national strategies tackling RMDs • Ministers of Health/Social Affairs to create national clinical direction of RMDs and appoint a director • Patients Groups, rheumatologists, orthopaedics, health professionals, governments to include RMDs in top 5 list of major diseases in every member state⁽¹⁾ 	<ul style="list-style-type: none"> • European Commission to develop a European Strategy on RMDs • European Commission to mainstream/standardise data format for Member States to allow for data comparison, underline issues and measure impact of RMDs • European Commission to gather more socio economic data at EU level • EU Council to include specific recommendations in Council Conclusions e.g. European Strategy

⁽¹⁾ Example of Ireland. Other countries have a similar position for cancer.

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

Member States level	European Union level
<ul style="list-style-type: none"> • EULAR to co-ordinate visits to national key stakeholders including ministers for research and briefing – so that these key decision makers can exercise their influence in the Research Council • Ministries, funding bodies, public health institutes, patients' organisations, universities and research institutes to <ul style="list-style-type: none"> ➤ further fund research on RMDs ➤ set appropriate research agendas ➤ better coordinate and integrate research 	<ul style="list-style-type: none"> • European Commission to further define research agenda, including RMDs as a priority • European Commission to further fund research on RMDs • European Commission to equally fund research on RMDs and research on other chronic diseases as for example cardiovascular or neurologic diseases • European Commission to provide financial incentives, e.g. funding streams • European Commission (DG Research) to include RMDs in more FP7 calls

<ul style="list-style-type: none"> ➤ promote innovation ➤ liaise with funding bodies about the inclusion of RMDs • Member States to further fund and researchers and patients organisations to further research on: <ul style="list-style-type: none"> ➤ Care ➤ Early childhood ➤ Causes of RMD ➤ Clinical issues ➤ Health care systems • Health professionals and patients' organisations to inform patients on ongoing research issues in a user friendly way • Public health institutes, patients' organisations and physicians to further collect information on RMD • Ministries, patients' organisations, scientific organisations to make relevant information available • Member States and national stakeholders to advocate for inclusion of RMDs in FP7 calls and other funding opportunities • Member States and national stakeholders to lobby for the inclusion of RMDs in FP8 • Insurance companies to pay for research and prevention programmes • All stakeholders to emphasize burden (awareness-raising, appropriate communication, dissemination of information) 	<ul style="list-style-type: none"> • European Commission (DG Research) to include RMDs as a major disease area on its own and significantly increase the amount of funding in FP8 • European Commission to promote country collaboration/set up of network and partnership on RMDs • European Commission to develop multidisciplinary legal framework for all member states needed for primary and secondary prevention • European Commission, WHO to further collect information and data on RMDs • European Commission, WHO to make relevant information available
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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.

Member States level	European Union level
<ul style="list-style-type: none"> • Health Services and patients' organisations to provide self-management tools • Governments to legislate on accessibility • Member States to implement Work Charter • Employers, trade unions to guarantee and promote sustainable enterprising • Media to promote positive messages and attitudes • Member States to translate EC recommendations into national law 	<ul style="list-style-type: none"> • European Union to develop and adopt legislation and other initiatives for the promotion of social inclusion of people with chronic conditions • European Union to enhance accessibility for funding and knowledge • European Union to fund dissemination of information across Europe • European Commission to enhance NGO and government coordination

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.

Member States level	European Union level
<ul style="list-style-type: none"> • Member States to promote the use of best practices and benchmarking • Member States and umbrella organisations to promote continuous learning • Member States, insurers, medical associations etc. to disseminate information • All stakeholders to raise awareness and to inform the general public 	<ul style="list-style-type: none"> • European medical associations with the support of the European Union to develop standards of care • Industry with the support of the EU and medical associations to develop eHealth tools • All stakeholders to promote the use of new media (technology), e.g., self-diagnosis

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

Member States level	European Union level
<ul style="list-style-type: none"> • Member States to define needs (profession-specific, region-specific etc.) • Member States and their health authorities to promote multidisciplinary treatment • Member States and their health authorities to guarantee access to information • Member States to promote audits • Member States to promote continuous improvement of evidence-based recommendations • Member States to promote research for all groups • Member States and their health authorities as well as medical associations to promote sharing of information between GP and specialists 	<ul style="list-style-type: none"> • European Union bodies to promote research for all groups • European Commission to support pilot projects on sharing of information between GPs and specialists

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.

Member States level	European Union level
<ul style="list-style-type: none"> • Politicians, service providers and researchers to consult patients' organisations • Insurance companies, media and pharmaceutical companies to support and encourage patients' organisations • Governments to set up an agenda to consult patients' organisations • Health services, ministries and patients' organisations to develop national strategic plans for users' involvement • Research funding bodies to initiate research on users' involvement • Health care systems to make information available • Health care systems to guarantee accessibility to services • All stakeholders to promote multidisciplinary, integrated approaches • All stakeholders to initiate user groups • National governments to fund national and regional patient organisations • National governments and insurers to promote access to self-management on local level • National governments and insurers to facilitate self-management programmes • National governments and insurers to enhance practical support for carers 	<ul style="list-style-type: none"> • European Commission to provide information on patients organisations and involvement • European Union to take initiatives to ensure patients' involvement • EULAR to consult and bring together patients' organisations • European Union and medical associations such as EULAR to promote the involvement of patients in research • European Union and medical associations such as EULAR to promote the involvement of patients in decision making processes • European Union and stakeholder organisations to promote education of EU citizens on RMDs • European Union and stakeholder organisations to promote multidisciplinary, integrated approaches • European Union and stakeholder organisations to develop an expert patient partners platform • European Union to fund European patient organisations