

## **EU Reflection on Chronic Disease**

### ***Contribution from the European League Against Rheumatism (EULAR)***

The aim of this paper is to respond to the European Commission consultation on the Reflection Process on Chronic Disease which was launched on 14 March 2012. Our answers aim to contribute to the overall analysis on chronic diseases as well as to the debates on how to better address chronic diseases at both EU and national levels. Nonetheless, our comments are based on the perspective, experience and needs of the Rheumatic and Musculoskeletal Diseases (RMD) community.

EULAR, the European League Against Rheumatism, is the umbrella organisation representing scientific societies, health professional and patient organisations from more than 30 European countries. The opinions presented in this paper represent the perspective of the overall RMDs community in Europe.

#### **WHAT IS THE CURRENT SITUATION ON CHRONIC DISEASES IN EUROPE?**

- 1. What further information and evidence should be taken into account by National Governments and the EU regarding the chronic disease situation?*

EULAR is convinced that counting on reliable and updated information on different aspects of chronic diseases is crucial for the development of accurate and effective policies. This not only implies promoting consistent and regular data collection but also, and foremost, it implies the definition of what type of information and evidence is required for the design and implementation of policy initiatives aiming to tackle medical, but also societal and economic challenges.

For many years, mortality rates have been the main criteria for deciding which diseases deserved most attention and visibility in public health policies. While mortality is, indeed, an important factor when deciding on the priorities of health initiatives, it is well established that thanks to the advances in medicine, mortality rates of the better recognised chronic diseases (such as cancer, or cardiovascular diseases) have been significantly reduced in the last decades.

As the European Commission rightly proposes for the Europe 2020 Strategy and for the Innovation Union flagship, public efforts should focus on addressing “societal challenges”, which – in terms of health issues - go much beyond mortality rates. Societal challenges also - and foremost - imply increasing the number of healthy years, reducing the disability consequences of various diseases, or ensuring the social and economic inclusion of the population affected by chronic diseases (and particularly the elderly). Societal challenges also imply improving the productivity of our economies as well promoting sustainable and healthy environment (including working environments) and the

sustainability of our public institutions (including our health and social care systems), among many others.

In this sense, **it is crucial that decisions on public health policies at both the EU and Member States' levels are based on reliable and updated information on the impact of chronic diseases on individuals and societies.**

In particular, it is important to promote regular, systematic and reliable collection of (comparable) data on:

#### **Health burden**

- Incidence & prevalence of different chronic diseases
- Co-morbidity

#### **Social and economic burden**

- Disability and reduced mobility
- Productivity loss
- Financial impact on healthcare and social security systems

So far, many decisions on chronic diseases initiatives are only based on estimates or on preconceived ideas of what is more relevant or less relevant. This needs to change if we want to accurately and efficiently address chronic diseases in order to obtain the highest possible impact on societal challenges.

The **EUMUSC.NET project**, co-funded by the European Commission and EULAR, is a good example of what type of information should be collected in order to appropriately inform the policy making processes. Despite being the first step in the monitoring of rheumatic and musculoskeletal diseases across Europe, the EUMUSC.NET project was able to provide scientific evidence of the aforementioned aspects of chronic diseases that could be used in the development of more accurate and effective policies.

This evidence has finally confirmed that **RMDs are among the most prevalent, disabling and costly chronic diseases affecting European citizens.** It is worth mentioning some of this evidence in order to illustrate the relevance of this type of information for decision-making process at different levels:

- **RMDs affect around 25% of the overall European population** (around 120 Million people)
- **RMDs are the largest single cause of work loss in Europe** and their effect on worker participation gives rise to substantial work productivity costs;
- **RMDs are one of the main causes of disability**, with a significant impact on the social security systems (for example, in Austria 35% of all new disability pensions in 2001 were due to RMDs; in Belgium, RMDs were the primary cause of disability among men in 2009, and the second among women, after mental disorders).

- **RMDs represent 39% of all occupational diseases;**
- **RMDs are the main cause of early retirement**, impeding a high proportion of European citizens to remain economically and socially active when becoming older (in Sweden, for example, up to 60% of persons on early retirement or long-term sick leave claim musculoskeletal problems as the reason);
- **RMDs also give rise to significant health resource utilisation with associated health and non-healthcare costs for society** (it is estimated that RMDs represent a burden of **EUR 240 billion every year**, while direct costs represent **2% of the European GDP**. Only in Germany, healthcare costs in RMDs represent 11% of the total illness costs, being the fourth most costly diseases in terms of healthcare expenditures);
- **RMDs are in the top 5 diagnostic groups in Europe in terms of health care costs.**

An important consequence of this new evidence is that EU institutions, Member States and international organisations such as WHO are starting to revise their priorities and include RMDs in the group of major chronic diseases.

## HEALTH PROMOTION AND DISEASE PREVENTION: WHAT MORE SHOULD BE DONE?

1. *What additional actions and developments are needed to address key risk factors to prevent chronic diseases?*

Policy initiatives usually focus on four main lifestyle factors of chronic diseases: tobacco, excess of alcohol, poor nutrition and insufficient physical activity. EULAR agrees with these initiatives, as they are also common risk factors of RMDs (for instance, overweight is more likely to cause osteoarthritis than cardiovascular diseases; smoking is an important determinant of rheumatoid arthritis, osteoporosis and ankylosing spondylitis).

Nonetheless, the prevention of chronic diseases also requires paying attention to two other types of determinants:

- Genetic/biological risk factors
- Socio-economic and work-related risk factors

**Genetic/biological risk factors:** In the RMDs field for example, inflammatory joint diseases, and osteoarthritis of the hands, are associated with such factors. Even more, ageing, as a biological

process, also explains some of the most common chronic diseases among the elderly, such as osteoporosis and osteoarthritis.

In this area further investment in RMD research is needed on pathogenetic, genetic and environmental factors by focusing on most promising targets, defining patients at risk and developing biomarkers. With regard to the links between RMDs and ageing these diseases should be included in main initiatives and actions of the European Innovation Partnership on Active and Healthy Ageing (EIP on AHA).

**Socio-economic and work-related risk factors:** The socio-economic situation of a person has a vital impact on its health. Several studies have shown that poverty and a low education level correlate with inflammatory diseases severity and developing comorbidities. Moreover, a substantial amount of rheumatic and musculoskeletal diseases (e.g. back pain, soft tissue rheumatism, etc.) are work-related. Work-related risk factors are particularly important for RMDs. Evidence shows that RMDs represent 39% of all occupational diseases. Even more important, work-related risk factors are highly preventable.

In the area of work-related risk factors the European Commission should unify and enforce its legislation on work-related musculoskeletal diseases. The upcoming proposal for a work-related musculoskeletal diseases directive should ensure that employers create appropriate working environments and flexible working conditions preventing employees from developing or deteriorating already existing RMDs.

Additional actions aiming to tackle lifestyle factors and work-related determinants should focus on the following aspects:

- Education / Awareness raising among health professionals and patients
- Patients' involvement

This will be further described below.

*2. How can existing actions on primary prevention be better focussed and become more effective?*

In order to be more effective in primary prevention, we think it should be necessary to focus on the following areas:

**Promotion of healthy lifestyles in key institutions.** Primary care practitioners, schools and employers can play a key role in promoting active and healthy lifestyles. For this, it is important to reinforce the role of these institutions in addressing chronic disease risk factors, to provide adequate and sufficient training to professionals in those institutions, as well as to provide incentives for those institutions to become involved in these activities.

**Education.** It is necessary to include or reinforce topics on risk factors (such as smoking and obesity) in the national education programmes at different levels of the education system.

**Awareness raising.** It is important to further raise awareness on risk factors. In particular, these campaigns should point out that common lifestyles factors are not associated with only one disease as it usually happens (e.g. obesity is known to be associated with cardiovascular diseases; smoking is known to be related to cancer or respiratory diseases). However, some of these (and especially the mentioned) risk factors are more likely to result in the development of rheumatic and musculoskeletal diseases, the occurrence of pain, etc., although this has not captured people's awareness.

**Data collection and analysis.** More information on the impact of risk factors on chronic diseases is necessary and should be disseminated in education programmes, mass media activities, etc. Likewise, decision makers should further support the generation of more prevalence and incidence data.

*3. What potential is there for broad based early detection action?*

Early detection is crucial in order to effectively manage and treat chronic diseases. For many chronic diseases early detection followed by early referral to a health specialist can significantly reduce the outbreak of the disease and help to keep the symptoms experienced at a lower level. From a cost perspective early detection is also important, since early and effective treatment can save significant costs spent at a later stage of disease management and treatment.

Concerning RMDs, especially in osteoarthritis, one of the main musculoskeletal diseases, there is a high potential for broad based early detection. However, evidence has still to be provided through further research into the benefits of early access to quality assured information and self-management support as prevention tools.

One of the main problems in early detection of RMDs lies in the **insufficient training on RMDs received by general practitioners**. In many cases, GPs cannot recognise the symptoms of RMDs and do not refer (or delay the referral) of patients to the specialists for appropriate treatment.

There is also a **wrong understanding (even among several GPs), that pain is a “normal aspect” of ageing** and that there is little or nothing one can do. For people suffering from pain, this may mean to postpone the visit to the doctor.

4. *In what areas is there a particular need for additional action at EU level?*

EULAR welcomes the importance the Commission is putting on health promotion and prevention since in this area there is a need for EU-wide actions addressing all Member States and EU citizens. Awareness raising in this regard can be best achieved when being coordinated at EU level.

Additionally, **EULAR believes that the EU should further invest in chronic diseases research**. Research in this area is crucial, since by tackling these diseases and providing innovative solutions for prevention (partly by better understanding of causes of RMDs), their burden on healthcare systems and economies would be significantly reduced.

In the area of occupational health the EU disposes of legislative competences which provide an opportunity for the EU to set high standards concerning working environments and conditions to be implemented by the Member States. Therefore the proposal for a work-related musculoskeletal directive should contain **clear provisions for employers at national level to adapt working environments and conditions to the needs of their employees**. This should be envisaged to prevent RMDs as well as to adapt to the needs of RMD patients at the workplace.

5. *In what areas is there a particular need for additional action at national level?*

Member States' actions should focus on their main areas of competence. Hence, they should play a major role in developing and including chronic diseases in national education programmes and in the promotion of these programmes respectively national health promotion and prevention campaigns. They also have a crucial role in **restructuring national healthcare systems** in order to provide better healthcare services to chronic disease patients as will be referred to in the next section. Furthermore, national actions are needed when **training healthcare practitioners**, but also provide **practical support to carers**. Here national training plans could be developed, providing clear guidelines and standards.

Once the EU has finalised the reflection process and has developed clear guidelines or recommendations for Member States, these should be adopted at the national level. Besides adopting EU initiatives, Member States should be encouraged to adapt national strategies such as promotion of early intervention, return to work services and the promotion of people with disabilities' participation in society in line with EU wide approaches.

*6. What will you/your organisation contribute to address this challenge?*

EULAR, as an umbrella organisation comprising scientific societies, health professionals and patient organisations, has vast experience in health promotion and disease prevention. EULAR plays a key role in furthering knowledge on RMDs via research activities and the scientific annual conference, as well as in educating and training health professionals, patients and health facilitators, among other actions.

In this sense, EULAR is very active in finding and developing medical solutions for most of RMDs, while it is actively involved in education, training and awareness raising regarding healthy lifestyle factors, patients empowerment, etc.

Moreover, EULAR is willing to collaborate with the EU, Member States and stakeholders to find better solutions in tackling risk factors. To this end, EULAR can bring in the expertise of scientists, health professionals and patients.

## HEALTHCARE

*1. What changes could be made to enable health care systems to respond better to the challenges of prevention, treatment and care of chronic diseases?*

EULAR believes that further changes towards a **more personalised care and support for people with chronic diseases** would make a positive difference to millions of EU citizens currently affected by these diseases. A patient-centred, holistic model of care and support, beginning with a form of joint needs assessment which takes account of lifestyle factors as well as medical needs, is the main way to ensure effective and cost effective support. Prevention results in large part from **keeping people active, independent and continuing to live as close to their 'normal' life as possible**. On the other hand, personalized care requires sufficient knowledge on how to personalize care which has to come from respective research activities.

EULAR also believes that in the area of RMDs, as indeed with chronic diseases more widely, greater emphasis needs to be placed on **lifestyle determinants** (e.g. physical inactivity, nutrition); on addressing **socio-economic and working determinants** (e.g. education, working conditions, working environment); on **addressing genetic/biological determinants**; and on strengthening the **rights of disabled people** (e.g. by being able to fully access the built environment, having the right to

education, training and work opportunities, being fully included in society etc.). Therefore EULAR strongly welcomes the approach by the Commission to initiate a chronic disease reflection process referring to these aspects.

2. *What changes could be important to better address the chronic disease challenge in areas such as: financing and planning; training of the health workforce; nature and location of health infrastructure; better management of the care across chronic diseases?*

An area where there is great scope for improvement in the area of prevention of chronic diseases generally but RMDs specifically is **early diagnosis**. One change which would bring major benefit would be better **training of primary care/general practitioners** to enable them to identify conditions such as inflammatory arthritis early and refer the patient for specialist care without delay. In conditions such as Rheumatoid Arthritis, diagnosis within the first twelve weeks of the onset of the disease means that by using newer, more effective therapies there is every chance that the disease will be well controlled, to the point in many cases of the disease going into remission. Given that RA usually strikes people of working age, the benefit to the European community of enabling tens of thousands of people per annum to work and pay taxes rather than need to claim disability benefits and become expensive users of health services for the rest of their lives is enormous.

The largest subset of people with chronic physical illness is that of people living with degenerative joint damage (e.g. osteoarthritis), which affects tens of millions of EU citizens at any one time. For these people in particular, who may not be receiving any ongoing specialist care, prevention has to be premised on the principles of **structured self-management**. The collective view of members of the EULAR PARE (People with Arthritis/Rheumatism in Europe) is that as people with RMDs, including osteoarthritis, spend just a tiny part of their time using health care services that the old model of acute-based support is inappropriate. Instead, managing life with the condition, rather than managing the condition per se, is for them the only effective way to prevent or minimise deterioration. To do this they require **high quality information**, ideally from complementary sources: medical information from their health care team; and wider, personal and social information from relevant user-led patient organisations, to empower them to self-manage as effectively as possible and thereby also minimise demands on primary care systems in particular.

With regard to the overall management of care in chronic diseases **clear quality indicators concerning care management process, structure and outcomes** have to be established, providing **standards of care to be implemented at national level**. This should also include management recommendations for RMDs which partly already have been established by EULAR (please also see healthcare questions 4 and 5).

*3. In what areas is there a particular need for additional action at EU level?*

Besides promoting primary prevention as outlined above, EULAR also sees a need for EU action regarding secondary prevention as briefly touched upon before. In this field it is especially important to educate and train general practitioners and patients. General practitioners have to be educated and trained in order to recognise the symptoms for RMDs as soon as possible to refer patients to a specialist at an early stage of the disease so that effective and efficient treatment is ensured from the beginning on. Although the competencies to carry out these actions mainly lie within the Member States, the EU can play a vital role in promoting best practice examples regarding early referral and treatment. Organisations comprising patient organisations, for example EULAR, should be regularly consulted and involved in these policy actions.

Besides, studies have shown that the levels of care highly differ within EU Member States which results in significant regional health inequities. Consequently it is important at EU level to develop and promote standardised levels of care through the quality indicators referred to above. These standards of care should ensure equal access to treatment and care at Member States' levels.

The EU has already made a first step forward by supporting the EUMUSC.NET project in its Community Action in the field of Health 2008-2013. This projects aims, inter alia, to establish standards of care for Rheumatoid Arthritis and osteoarthritis. However, similar projects are needed developing and promoting standards of care also in other musculoskeletal diseases. The EU should have a key role in supporting these projects and promoting its results within Europe.

*4. In what areas is there a particular need for additional action at national level?*

Member States should be facilitating a common assessment framework so that people's individual needs are more effectively met from a range of agencies e.g. health care professionals working with relevant user-led patient organisations; employers; social care providers and others whose occasional interventions can make the difference between independence rather than dependence for the person living with RMD and/or any other chronic condition. Once quality indicators have been established, they should be adequately implemented at national level.

Providing adequate and up-to-date information to patients is crucial for them being able to effectively self-manage their disease, as previously mentioned. Here health care providers and patients or patient organisations need to work together closely to ensure that patients are fully included in disease management processes from the beginning of their treatment. In relation to information on RMDs further research has to be carried out on the social and economic impact of RMDs providing aggregated data at EU level. Data to be collected should be standardised and fully comparable as will still be emphasised in the following responses.

*5. What will you/your organisation contribute to address this challenge?*

EULAR has within its structure, working collaboratively alongside its health care constituencies, a network of national organisations which are led by people living with RMDs themselves (PARE: People with Arthritis and Rheumatism in Europe). These ‘user-led’ patient organisations provide the sort of structured self-management support for their service users which complements the interventions those people receive from their health and social care systems. Keeping people longer by promoting awareness of public health issues and offering tailored support for the individual, including social support, is a unique contribution which patient organisations make, and has a net result of limiting the otherwise more expensive demands which are made on the health economy when people live unsupported and their condition deteriorates more quickly.

EULAR has also established different recommendations for management, covering various issues such as management of specific musculoskeletal diseases, for example rheumatoid arthritis, ankylosing spondylitis or knee osteoarthritis but also on the role of the health workforce in the management of RMDs.

At EU level EULAR is actively advocating for innovative healthcare systems, including a better trained workforce and a more patient-centred approach to healthcare. On 19 October EULAR organised a conference on “Rheumatic and Musculoskeletal Diseases: Lessons for Innovative Policy Making in the European Union” in the framework of the Belgian EU Presidency. As an outcome of this conference EULAR contributed to the Council Conclusions 7 December 2010 (Innovative approaches for chronic diseases in public health and healthcare systems), which officially call on Commission and Member States to initiate a chronic disease reflection process.

EULAR also contributed to the Hungarian EU Presidency Conference „Burden of Rheumatic and Musculoskeletal Diseases: Challenges in Work Capacity and Prevention of Disability in the EU“. This led directly to the Hungarian EU Presidency Declaration, of the need for the new EU Disability Strategy to promote action in the field of health and safety at work, in particular by improving working life for disabled persons, recognising that people with RMDs represent the largest subset of physically disabled people in the EU.

In autumn 2012 EULAR is planning to organise a conference on preventing chronic diseases, taking into account aspects such as primary and secondary prevention and giving input to EU policies in this regard.

## RESEARCH

*1. How should research priorities change to better meet the challenges of chronic diseases?*

EULAR is strongly convinced that research priorities should change in two different ways:

**1. Research areas.** As already established by the European Commission, research efforts should be defined (and prioritised) in terms of their contribution to tackling specific societal challenges identified in the Europe 2020 Strategy, the Innovation Union flagship and other initiatives and tools. Among others, these societal challenges comprise the effects of the ageing of the population (increasing numbers of unhealthy years in an ageing population, reduced mobility among the elderly, early retirement, dependency, social and economic exclusion, etc.); the loss of productivity due to disability but also due to short and long-term sick leave among the working population; the impact of chronic diseases on the sustainability of the healthcare and social security systems, etc. The focus on these societal challenges implies that priorities should be given to research in those disease areas that are expected to have a higher impact in tackling the physical barriers that prevent people to remain healthy and active for longer years.

Given the strong correlation between RMDs and some of the main societal challenges identified by the EU, RMDs is certainly one of those disease areas where further research and innovation would have an enormous beneficial impact.

**2. Integration.** European research and innovation in chronic diseases is highly fragmented. In the RMDs area, the integration of basic, translational and clinical research as well as epidemiology has been developed to various degrees at the national level. Nonetheless, integrated research at the European level is lagging behind. Similarly, the efforts of the rheumatology sector in adult and paediatric rheumatology as regards translational research, epidemiologic research focusing on the complex aetiology and the burden of illness, as well as evaluative health care research, are mainly done at the national level.

In this sense, research strategies on RMDs in Europe should in the coming years focus on:

- Integration of successful national research efforts into a pan-European research strategy,
- Integration of basic, clinical and health care (including outcomes) research for a fast translation of new concepts, and
- Integration of competence in developmental and molecular biology, genetics, immunology and systems biology.

In particular, integrated research efforts should focus on:

- Better understanding of the molecular and cellular basis of chronicity in rheumatic diseases for the development of curative and preventive strategies;

- Better understanding of the pathways leading to severe comorbid conditions and premature mortality in the course of RMDs, such as lymphoma and cardiovascular disorders;
- Evaluating the incidence and outcome of rheumatic diseases and the development of prevention strategies and also to evaluate different therapeutic strategies for adults and children;
- Developing basic strategies for cell therapies of rheumatic diseases, especially immune ablation of pathogenic cells, reinstallation of tolerance and regeneration of degenerated or inflamed tissues.
- Better understanding of the molecular and cellular pathology of osteoarthritis and osteoporosis.
- Accurate phenotyping of the connective tissue disease patients and Identification of imaging and serological biomarkers of disease activity to better define clinical response in Connective Tissue Diseases.
- Developing markers that are useful for personalized care approaches
- Comparative effectiveness research to obtain evidence based information on best therapies independent of pharmaceutical industry activities

2. *In what areas is there a particular need for additional action at EU level?*

The EU has a key role in providing financial support to research and innovation in different domains, including chronic diseases. Nonetheless, further efforts are needed at the EU level to ensure that European research and innovation have a high impact in tackling the societal challenges the Commission has identified.

Among others, it is worth mentioning the following additional actions:

- **Further define the agenda for research and innovation in chronic diseases.** The EU should define, together with Member States and key stakeholders, a long-term research and innovation agenda. As mentioned above, this agenda should prioritise research and innovation in those disease areas that could better help tackle societal challenges (disability, reduced mobility, healthy ageing, sustainability of the healthcare and social security systems, etc.);
- **Facilitate the integration of EU research and innovation of research efforts at European and International level.** This particularly means:
  - Integration of successful research efforts into a pan-European research strategy
  - Integration of basic, clinical and health care research into new concepts

- Integration of competence in developmental and molecular biology, genetics, immunology and systems biology into innovative therapies
- **Support research and innovation in the prevention and management of diseases.** In the RMDs field, this implies focusing on the following aspects:
  - **Primary prevention:** on ‘pathogenesis’, ‘genetics’ and ‘environmental factors’. Use:
    - Focus on most promising targets
    - Define patients at risk and develop biomarkers
  - **Secondary prevention:** on prevention of further disease progression; prevention of new ‘events’ and comorbidities; prevention of further functional loss; prevention of further loss of quality of life
  - **Healthcare, disease treatment & management:** clinical outcome measures, genomics, proteomics, immunological research, pathogenesis, personalized medicine
- **Further support research on the social and economic impact of chronic diseases.** In the RMDs area, this would imply:
  - Prevalence and morbidity of RMDs
  - Impact on the well-being of patients and their families
  - Impact on productivity
  - Impact on health and social care systems
  - Effectiveness of policy initiatives aiming to reduce the burden of RMDs

3. *In what areas is there a particular need for additional action at national level?*

Member States play a key role in funding research in chronic diseases. Nonetheless, they can further support research activities in.

**Health research priorities.** In line with the EU research and innovation initiatives, Member States should prioritise and further support research and innovation in disease areas that have a higher impact on the aforementioned societal challenges.

In coordination with EU efforts and also other Member States, **prioritise and provide support to research and innovation in prevention and management of rheumatic and musculoskeletal diseases** (see above)

*4. What will you/your organisation contribute to address this challenge?*

EULAR has an excellent reputation in research and innovation in the RMDs field, being its Annual Conference one of the best attended events in the medical sector in Europe. Moreover, it participates in a number of scientific associations and forums.

As it has been doing in the last years, EULAR is willing to provide its expertise and network to further develop EU strategies for research and innovation in the chronic diseases field.

**INFORMATION, AND INFORMATION TECHNOLOGY**

*1. What more needs to be done on the development of information and data on chronic diseases?*

EU and Member States are clearly lacking consistent, up-to-date and comparable data on chronic diseases. Many of the data available at the moment are outdated or estimated figures based on self-report. Thus, further research is necessary. On the one hand this research should be conducted on general aspects such as incidence and prevalence as outlined before. On the other hand disease-specific research is needed, providing evidence on the particularities of single diseases to develop personalised models of treatment and care.

*2. In what areas is there a particular need for additional action at EU level?*

The EU should, via the EUROSTAT Eurobarometer and the health surveys mentioned in the consultation document, conduct further studies on aspects such as prevalence and morbidity of chronic diseases and gather more socio-economic data at EU level. Additionally, the EU should standardise data formats for Member States to allow for data comparison at EU level. For RMDs a first attempt has already been made by launching the EUMUSC.NET project referred to above. However, further projects or a follow-up of this project should be envisaged since EUMUSC.NET does not provide overall data on RMDs but only on specific forms of these diseases.

Furthermore, EUROSTAT has recently decided to exclude a number of questions about musculoskeletal conditions from the European Health Information Survey (EHIS). This decision

should be reconsidered, as there is a need to monitor different aspects of RMDs as one of the most prevalent chronic diseases (in a 2007 EU survey it was found that 22% of the population currently had, or had experienced long-term muscle, bone and joint problems such as rheumatism and arthritis).

*3. In what areas is there a particular need for additional action at national level?*

At national level the collection of adequate data should be enforced, especially concerning prevalence and morbidity as stressed above but also social and economic costs of RMDs. These data should be collected according to standardised indicators, guaranteeing the comparability throughout Europe. Many of the national data available at the moment are based on self-reported data. These data tend to be rather inaccurate. Hence, it should be ensured that there are clear standards of data collection as underlined.

In addition, national research plans on different musculoskeletal diseases such as osteoarthritis or inflammatory joint diseases, some of the most prevalent RMDs, could be developed, as could plans for implementation of standards of care at the national level.

*4. What will you/your organisation contribute to address this challenge?*

EULAR strongly supports the EUMUSC.NET project whose idea was actually developed at a EULAR workshop in Brussels in 2008. The project will be finished by end of this year and EULAR is planning, in collaboration with EUMUSC.NET to organise a conference at the beginning of 2013, presenting the final results. It is also envisaged to work on policy implications following the presented data. EULAR is currently in the planning phase for this conference.

Moreover, EULAR has and will continue to support systematic literature research activities in various areas of RMDs to obtain information on existing and missing evidence and develop respective research agendas.

## ROLES OF MEMBER STATES, THE EU AND STAKEHOLDERS

- 1. What additional activities on chronic diseases beyond the four areas described above should be considered at EU level?*

Chronic diseases do not only have an impact on the health of patients but also on their entire living conditions. Therefore they should also play a major role in other EU policies and the European Commission Directorate General (DG) for Health and Consumers should work directly together with other DGs such as DG Employment, Social Affairs and Inclusion. Regarding RMDs we already mentioned that they are today's main cause for disability in the EU. Consequently, EULAR is strongly urging for RMDs to be fully recognised in the EU disability policy, starting with the EU Accessibility Act to be launched by the end of this year. With regard to work disability the EU should engage Member States to create flexible working environments and conditions as stressed above. EULAR would appreciate sharing documents including guidelines for employers as the Work Charter with the Commission and to provide best practice examples from the Member States.

- 2. How can the EU engage stakeholders more effectively in addressing chronic diseases?*

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.

First of all, the EU should consult and bring together patients' organisations to be fully informed about patients' needs and interests. The EU should then take initiatives to ensure patients' involvement such as promoting the involvement of patients in research or policy decision making processes. It should also promote multidisciplinary, integrated approaches with patient organisations such as developing an expert patient partners' platform or by funding European patient organisations and patient-related projects.

Within EULAR patients are, through PARE, strongly represented in all policy fields, from education and research to EU affairs. Hence, EULAR is representing an estimate of 120 million RMD patients within the EU which amounts to one quarter of the EU population. We would appreciate working closer together with the EU and to become an institutionalised partner of the Commission.

*3. How can EU Member States engage stakeholders more effectively in addressing chronic diseases?*

At Member States' level patients' organisations should also be consulted by politicians, service providers and researchers concerning relevant policy and decision making procedures. Governments should set up agendas to consult patients' organisations and health services, ministries and patients' organisations should develop national strategic plans for users' involvement.

Besides, national governments and insurers should fund national and regional patients' organisations, promote access to self-management at local level and facilitate those programmes. With regard to the carers' side, national governments and insurers should enhance practical support for carers because they carry a significant burden.

In general, national healthcare systems should make information to patients more available and guarantee accessibility to services since many patients do not feel sufficiently informed and may experience barriers to treatment.