European League Against Rheumatism (EULAR)

Position paper

Horizon 2020 Framework Programme
EULAR's position and recommendations

Introduction

The aim of this document is to provide EULAR's position and recommendations regarding the current debate on the Horizon 2020 proposal.

EULAR, the European League Against Rheumatism, is the umbrella organisation representing scientists, health professionals and patients from the rheumatic and musculoskeletal diseases (RMDs) communities of more than 30 European countries. RMDs comprise more than 200 diseases and conditions, being **osteoarthritis, rheumatoid arthritis, osteoporosis, low back pain, ankylosing spondylitis** and **Gout** the most prevalent and disabling ones**. Many RMDs particularly affect older people, for which the burden of this diseases is dramatically increasing with the ageing of the population.**

The document emphasises the need to prioritise research and innovation (R&I) in health areas and disciplines with a high burden on individuals and societies (such as RMDs). It also summarises evidence on the social and economic burden of RMDs, and provides details on some of those aspects of R&I in RMDs that need further funding support.

Horizon 2020. New approach and focus on Societal Challenges

The new EU approach to research and innovation (R&I) is expected to play a key role in achieving the main goals of the Europe 2020 Strategy: to foster productivity and sustainable growth, while ensuring social inclusion.

One of the distinctive characteristics of the new approach is that **"societal challenges",** and not the logic of different scientific disciplines, will be the main criteria for shaping EU research efforts. Focusing on innovative, collaborative solutions to specific "societal challenges" would aim to reduce existing fragmentation of disciplines and duplication of research efforts, while providing clear criteria for setting priorities.

In the health domain, the European Commission's proposal for the upcoming Horizon 2020 Framework Programme, defines the **increasing burden of "disease, disability and reduced functionality" resulting from the ageing of the population** as one of the main challenges to be addressed in the coming years.

The focus on these societal challenges implies that priorities should be given to those disease areas where research activities can be expected to have a higher impact in **tackling the physical barriers that prevent people to remain healthy and active for longer years**.

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Limiting the mobility and therefore the independence of millions of citizens in Europe (particularly the elderly), rheumatic and musculoskeletal diseases are a clear example of how furthering R&I in a strategic area could have a major positive impact in reducing the individual, societal and economic burden of chronic diseases.

The European Commission has in previous Framework Programmes denied RMDs the status of "major chronic disease" despite the solid and unequivocal evidence showing that **RMDs are among the most prevalent, disabling and costly chronic conditions** (see below). Notwithstanding the reluctance of the Commission to discuss on specific diseases in the Horizon 2020 and its arguments in favour of a more generic and more bottom-up approach compared to the 7th Research Framework Programme, other disease areas are mentioned in the Horizon 2020 proposal, even though RMDs are equally or, in some instances, even more important in terms of prevalence, disabling consequences and impact on public health systems.

Therefore, in order to be concise and coherent with the "societal challenges" approach to R&I, the **EU should align the criteria for prioritising disciplines and diseases with the overall goal of tackling specific societal challenges and grant RMDs a major disease status and thus mention them specifically in all documents related to Horizon 2020**. This is a more than justified request, given that more than 120 million of European citizens suffer from RMDs and major advances in these diseases have already been accomplished especially in Europe in the past and promise to further be achieved in the future.

Rheumatic and Musculoskeletal Diseases at the core of the main "societal challenges" in the health area

The claim for **RMDs to be prioritised and fairly recognised in the Horizon 2020 Framework Programme**, together with other major chronic conditions, is based on scientific evidence that proves that RMDs represent an enormous burden to our societies in terms of the number of people affected (particularly among the elderly), the impact of RMD-related absenteeism and early retirement on the productivity of our economies, and the financial and operational sustainability of our health care and social security systems.

Recent findings from the EUMUSC.NET project (an initiative co-financed by the European Commission and EULAR, www.eumusc.net), have confirmed that **RMDs are among the most prevalent, disabling and costly chronic conditions** affecting the European population.

Among others, it is worth mentioning the following evidence:

- RMDs affect around **25% of the overall EU population** (around 120 Million people);
- The prevalence of **RMDs will increase dramatically in conjunction with the ageing of the European population;**
- RMDs are the **largest single cause of work loss** in Europe an d their effect on worker participation gives rise to **substantial work productivity costs**;
- 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**;
- 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);
- **RMDs are in the top 5 diagnostic groups in Europe in terms of health care costs**;

Moreover, European research in RMDs has been recognized to be world-leading compared with the research efforts on other continents and especially compared with other disease areas where generally centres outside Europe are spearheading, and this leadership should not be jeopardized.

Tackling "societal challenges" in health: Furthering research in RMDs in the Horizon 2020 Framework Programme

The EU has a key role in providing financial and strategic support to research and innovation. For research and innovation in RMDs to have a high impact in tackling the societal challenges the Commission has identified, EU efforts in the Horizon 2020 should aim to:

- *Facilitate the integration of EU research and innovation of research efforts at European and International level*

  European research and innovation in chronic diseases is mostly highly fragmented. In the RMDs area, however, the integration of basic, translational and clinical research as well as epidemiology has not only been developed to various degrees at the national level, but also already been integrated on a pan-European level to foster European research. Nonetheless, more integrated research at the European level is needed to accomplish the tasks in adult and paediatric rheumatology as regards translational research, epidemiological research focusing on the complex aetiology and the burden of illness, as well as evaluative health care research.

  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;
  - Expansion of already existing European research networks in the field of degenerative and inflammatory rheumatic and musculoskeletal diseases;
  - Integration of basic, clinical and health care (including outcomes) research for a fast translation of new concepts;
  - Integration of competence in developmental and molecular biology, genetics, immunology and systems biology;
  - 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.

- *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'.
    - Focus on most promising targets
    - Define patients at risk and develop biomarkers
    - Diseases in focus could, among others, be osteoarthritis, rheumatoid arthritis, osteoporosis and orphan diseases, such as connective tissue diseases, as well as ageing problems, such as frailty

- **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
    - Disease in focus should be particularly the inflammatory rheumatic diseases, such as spondyloarthritis, rheumatoid arthritis and connective tissue diseases
- **Healthcare, disease treatment & management:** clinical outcome measures, genomics, proteomics, immunological research, pathogenesis, personalised medicine
    - Diseases in focus should be the degenerative rheumatic diseases, especially osteoarthritis of the peripheral joints and the spine, inflammatory rheumatic diseases, such as psoriatic arthritis and rheumatoid arthritis, and ageing disorders of the musculoskeletal system

Further, priorities in research and innovative therapies in RMDs should focus on:

- Mechanisms leading to degenerative joint disease, such as **osteoarthritis** of the hands and the large joints
- Mechanisms of inflammatory bone and joint destruction
- Vaccines for adults and children with autoimmune rheumatic diseases
- Connectivity of chronic inflammation with autoimmunity as well as degenerative changes of cells and matrix
- Epidemiologic research and innovative biometric approaches

➢ *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

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May 2012