

EULAR position on Horizon Europe

INTRODUCTION

The European League Against Rheumatism (EULAR) welcomes the European Commission's proposal on Horizon Europe and supports the Commission's efforts in strengthening the social and economic impact of EU's investment in research and innovation.

Nonetheless, EULAR is concerned about several aspects of the proposal that may undermine or jeopardise EU's efforts in this area and proposes areas where this can be improved-

From a budgetary point of view, and despite the increase in the budget with regard to Horizon 2020, we believe that the proposed investment (particularly in the area of health research) is far away from the efforts required to put Europe at the forefront of research and innovation, showing a lack of ambition to boost growth and employment, and address the growing challenges to the health of the population. Moreover, the overall approach (e.g. emphasis on market oriented investments to the detriment of basic research, or the emphasis on the UN Sustainable Development Goals) raise some questions on the priorities of the new programme, which in EULAR's views may not properly address the real challenges faced by European societies. Finally, there is a need to better clarify how decisions on priorities will be taken, in particular to ensure that experts and key stakeholders (e.g. patients and scientists) are at the core of the decision-making process.

In the following pages, EULAR's views and recommendations on the following aspects of the proposal are described:

1. Horizon Europe's budget
2. Global challenges: allocation of EU funds for health cluster
3. Missions
4. Balance between basic & clinical research and innovation
5. United Nations Sustainable Development Goals
6. Health - Areas of intervention
7. Strategic planning - Ensure full participation of scientific societies, health professionals and patients

At the end of the document, brief references to EULAR and the substantial burden of rheumatic and musculoskeletal diseases (RMDs) are provided, including specific references to research and innovation challenges in the field of RMDs.

1. Horizon Europe's budget

The Commission's proposals foresee a budget of around € 100 bn for Horizon Europe for the period 2021-2027, which represent an increase with respect to Horizon 2020. However, such an increase is

not sufficient to address the needs of European economies and societies, and it does not reach the 3% of GDP target for investment in research and innovation. In some areas, including health research, the proposed budget puts the main goal at risk, namely to boost growth and employment of European economies and address key societal challenges.

Furthermore, whereas the quality of many submissions to the current framework programme is recognised, the dramatically low success rates due to budget limits create enormous frustration in the scientific community. It should be ensured that excellent researchers do not refrain from participating as a result of low chance of success.

EULAR proposal:

- *EULAR calls on the Council and the European Parliament to be ambitious in fostering EU research and innovation, by prioritising research and innovation in the EU's long-term budgets and by doubling the budget allocated to Horizon Europe in the next Multiannual Financial Framework, as recommended by the Independent High Level Group on maximising the impact of EU Research & Innovation Programmes (Lamy Report).¹ As a minimum, the allocation for research and innovation must be at the level of 120 bn for the period 2021-2027, as proposed by the European Parliament Rapporteur.*

2. Global challenges: allocation of EU funds for health cluster

Improving health is one of the main responsibilities for European societies, and one of the main priorities for EU citizens.² The ageing of societies and the increasing prevalence and burden of major chronic conditions such as rheumatic and musculoskeletal diseases (RMDs) prevent a large proportion of the population from participating in the labour market, severely affect the productivity of economies, and place a substantial financial strain on health and social security systems.

Investing in health research and innovation is not only expected to address one of the main societal challenges, but is also expected to boost growth and employment in one of the largest and most dynamic economic sectors. In Europe, health care represents around 10% of the EU GDP and 10% of Europe's workforce³, and is expected to grow further due to the ageing of the population. As the example of RMDs shows, investment into research creates significant long-term economic value. A recent economic study showed that every Euro invested in research on RMDs delivers a return equivalent to around 25 cents every year, for ever⁴.

¹ http://ec.europa.eu/research/evaluations/pdf/archive/other_reports_studies_and_documents/hlg_2017_report.pdf

² According to the Eurobarometer (May 2017), 70% of EU citizens believe that health should be prioritised in EU policies.

³ EUROSTAT

⁴ See the study undertaken by the King's College London and Brunel University: <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-017-0276-7>

While the European biomedical research community has been successful in furthering basic research, Europe lags behind in terms of translational research and medical innovation. This represents an enormous loss for European economies, as innovative industries are increasingly located outside the EU and new start-ups and innovators often leave the EU to scale up in other countries. Ambitious political decisions are therefore required and should be reflected in the budget allocated to biomedical research and innovation.

The EU support to health research and innovation (R&I) is crucial to address complex challenges that can no longer be addressed by Member States individually. However, the European Commission's Horizon Europe proposal foresees only € 7.7 bn for the Health Cluster, just a slight increase compared to Horizon 2020, corresponding to inflation adjustment. The amount proposed does not reflect the challenges that societies increasingly face in providing access to healthcare, nor takes into account the economic opportunities and impact of investing in research throughout the health care sector and the high return on investment associated with biomedical research.

EULAR proposal:

- *EULAR urges EU decision makers to prioritise health research and innovation and allocate 10% of Horizon Europe's budget to this R&I in health. It is particularly important to significantly increase the budget of health R&I under Pillar 2.*

3. Missions

The introduction of R&I missions in Horizon Europe aims at increasing the impact and added value of R&I investments. It is expected to do so by better aligning and coordinating R&I activities with well-defined, targeted, measurable and time-bound missions, which should be co-designed with end-users and citizens. While missions could be an interesting approach to better orient and target R&I investment efforts, the concept raises a number of questions: (a) The concept of the missions in a European context has not demonstrated its value so far. The examples from the US usually given present a number of particularities which may make successful translation to the European R&I landscape more than uncertain; (b) The missions will cost a lot of money which will be taken away from well-established research and innovation approaches which have proven their value and potential; (c) It is not sure the missions will achieve societal relevance and adequately take into account the views and priorities of EU citizens.

EULAR proposal

- *EULAR calls on the EU institutions to further develop the concept of missions, better specifying their scope and articulation with the rest of the programme, as well as its financial sources.*

- *Should missions materialise in the future, EULAR urges the Commission to ensure that missions achieve societal relevance and prioritise EU citizens' needs and views. In this sense, health related R&I missions should in particular contribute to the achievement of the EU's "major priorities", the first one being economic growth and employment. Reducing disabling conditions and impairment and facilitating independent living should therefore be at the core of health related missions to be adopted in the future.⁵*
- *Missions in the field of health R&I must include at least one focusing on health at the work place, creating a bridge between health and social policies. Hardly any other area is so closely connected with the concerns of a wide majority of EU citizens.*

4. Balance between basic & clinical research and innovation

Although the Commission's proposal states that there will be a balance between basic research and innovation in the prioritisation of topics as well as in the allocation of funds, the overall approach of Horizon Europe seems to prioritise the development of market oriented solutions to the detriment of basic and clinical research. EULAR considers an adequate balance between basic, clinical and translational research as crucial to ensure that priorities in basic research are supported.

EU support to basic research is crucial not only for developing new, innovative therapies but also for furthering the understanding of a number of diseases, as well as scientific excellence. In the field of RMDs, EU support is critical to achieve this excellence. With over 200 different diseases, many of them can only achieve excellence when a critical mass is brought together at European level – This is especially the case for the many RMDs that are considered rare diseases. However, there is little incentive from the private sector to invest in blue-sky research as it is "considered high-risk without immediate economic impact, despite its significant long-term potential".⁶

Similarly, EU support is crucial for undertaking high-quality, industry-independent, patient-centred clinical research, which is unlikely to get support from industry.

EULAR proposal

- *EULAR calls on the EU institutions to keep an appropriate balance between basic, clinical and translational research when deciding on Horizon Europe's priorities.*
- *In addition, EULAR urges the EU institutions to prioritise patients' needs and the need to invest in furthering our understanding of major chronic diseases in order to better prevent the onset and development of these conditions.*

⁵ Reducing disability to facilitate employability of EU citizens is one of the missions EULAR proposed for the European Commission's consultation on missions. The other 3 focused on a) increasing early diagnosis, b) reducing rare diseases; and c) reducing the burden of RMDs.

⁶ Recommendations of the Alliance of Biomedical Research in Europe for the EU's ninth Framework Programme for Research and Innovation (FP9).

- *European Reference Networks are a very useful tool to link research to the organisation of healthcare. They deserve to be supported even more strongly under the new MFF.*

5. United Nations Sustainable Development Goals (SDGs)

The Horizon Europe proposal for health R&I aims to contribute to the achievement of the goals of other international organisations, in particular two of the UN Sustainable Development Goals (SDGs): SDG 3 ([Good Health and Well-Being for People](#)) and SDG 13 ([Climate Action](#)). Although EULAR agrees with the need to contribute to the achievement of the UN SDGs, prioritising these goals might be misleading and not properly represent the real health R&I needs of European societies. SDGs and their corresponding targets were particularly developed with a view to developing countries and less to the specific needs and priorities of European societies.⁷ While Health SDG targets to a large extent focus on the need to reduce mortality rates of communicable and non-communicable diseases, these rates are relatively low in Europe and have significantly decreased in the last 25 years. Nonetheless, Health SDG targets do not include any specific goal related to reducing disability and impairment, one of the main problems affecting European societies and the main health-related barriers to economic growth and employment. Major disabling conditions like RMDs and mental disorders are the only chronic conditions (together with diabetes) whose relative burden has increased in Europe in the last decades⁸, to a large extent due to the ageing of the population and the reduction of mortality rates among major chronic diseases. Finally, health SDG and its targets cannot be dissociated from other SDGs, particularly those related to social affairs and employment.

EULAR proposal

- *EULAR calls on the European Commission to better specify how UN SDGs will be used to define priorities in Horizon Europe, particularly to address health challenges. It also calls on the EU to take into account the goals established by other international bodies that better address the needs of European societies (e.g. the current WHO action plan for the European region)*
- *EULAR urges the EU to prioritise the fight against disability and loss of physical capacity in Horizon Europe, a problem that severely affect the ability of dozens of millions of EU citizens to participate in the labour market and has enormous consequences on the productivity of our economies and the sustainability of our health and social care systems*
- *Calls on decision makers to break down silos and define priorities and strategies across the traditional boundaries of policy sectors. In terms of the UN SDGs, this would imply*

⁷ Commission Communication COM(2016)739, for instance, specifies that “The Commission will help Member States to reach the SDG targets, in particular reducing chronic diseases’ mortality, ensuring quality healthcare, strengthening capacity to prevent and manage global health threats (including antimicrobial resistance), ending HIV/AIDS and Tuberculosis (and reducing Hepatitis), and implementing the Framework Convention on Tobacco Control.”

⁸ Global Burden of Disease

a comprehensive approach including not only Health and Climate SDGs, but also others such as SDG 8 (Promote sustained inclusive and sustainable economic growth, full and productive employment and decent work for all)

6. Areas of intervention in Health

While the areas of intervention proposed by the European Commission tend to cover some of the main health challenges, the content and priorities of each of the areas of intervention should clearly take into account the needs and priorities of European societies, as well as the European Commission's overall priority goals. Furthermore, an adequate balance between basic, clinical and translational R&I efforts should be ensured.

EULAR proposal

Health throughout the life course

- *Disability and independent living for disabled and elderly people should be among the priorities of this area of intervention, given the burden of disability and the ageing of the population on individuals and societies.*
- *However, although addressing the “consequences” of disability is important, priority should be given to R&I investment in furthering our understanding of the aetiology of disabling conditions as well as in furthering therapeutic capacities to prevent, control or even revert disabling and impairing conditions.*

Environmental and social health determinants

- *In the area of social health determinants, explicit attention should be given to the prevention of work-related health conditions. This includes not only primary prevention, but also secondary and tertiary prevention. R&I efforts should focus on the impact of working conditions on the set up and worsening of occupational diseases, as well as on possible organisational and therapeutic solutions.*
- *Cross-cutting R&I efforts should also address the potential health and economic benefits of the adaptation of workplaces and working conditions to facilitate the retention of people with disabilities at work.*

Non-communicable and rare diseases

- *In this area and despite the cross-cutting approach of Horizon Europe, priorities should be given to R&I on diseases or medical issues with a higher return on investment⁹, in order to increase the impact of EU R&I efforts.*
- *Diagnosis is possible in most inflammatory and non-inflammatory RMDs, although early diagnosis is often not possible. Efforts should focus on improving early diagnosis for major chronic conditions such as RMDs.*
- *Despite significant advances in the understanding of the biological process of many RMDs¹⁰, the causes of these diseases remain unknown, which makes prevention difficult or impossible. In this sense, efforts should focus on basic research to understand the aetiology of conditions such as RMDs.*
- *In addition, priority should be given to investment in R&I in rare diseases, a large proportion of which are related to the musculoskeletal system. As a result of the few number of cases for each rare diseases, a single country would often not permit the undertaking of effective R&I activities at national level. The EU however provides adequate scale for these types of research and should therefore promote and prioritise R&I in rare diseases.*

Tools, Technologies and Digital solutions for Health and Care

- *In this area, priorities should be given to further large scale cross-border big data exploitation; the use of artificial intelligence in health; personalised/stratified medicine; and genomics. Moreover, it should also prioritise new disease detection methods, the use of big data for follow-up, the provision of more data on drug adherence, and on drug toxicity.*

Health care systems

- *In addition to the topics identified in this working line, other aspects should be included. In particular, R&I in this area should promote research and innovation on the coordination and synergies between policy departments to address health issues. In the field of RMDs, for instance, it is crucial to develop better models of coordination between public health and social affairs departments, usually responsible for health and safety and work and disability issues.*

⁹ See Grant, J. et al (2018): Estimating the returns to United Kingdom publicly funded musculoskeletal disease research in terms of net value of improved health outcomes (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5761203/>)

¹⁰ For details of R&I needs in the area of RMDs, see [RheumaMap](#) (the Roadmap for research and innovation in RMDs).

7. Strategic planning - Ensure full participation of scientific societies, health professionals and patients

Horizon Europe foresees to implement a strategic planning cycle that would not only involve key decision makers at EU and national levels, but would also include the consultation of key stakeholders. In this sense, EULAR believes that work programmes' priorities should be driven by the needs of patients and societies, taking also into account the return of investment of different alternatives (According to a recent study undertaken in the UK, every Euro invested in medical research delivers a return equivalent to around 25 Cents every year, for ever).

EULAR proposal

- *EULAR calls on the European Commission to make sure that the views and recommendations of patients, scientific societies and health professionals are effectively taken into account when discussing priorities and possible investments under Horizon Europe.*

ABOUT EULAR AND RHEUMATIC AND MUSCULOSKELETAL DISEASES (RMDs)

EULAR (the European League Against Rheumatism) is the European umbrella organisation representing scientific societies, health professional's associations and patient's organisations in the field of rheumatic and musculoskeletal diseases (RMDs).

RMDs cover a wide range of painful medical conditions, affecting joints, bones, cartilage, tendons, ligaments and muscles. RMDs are typified by pain and a consequent reduction in the range of motion and function in one or more areas of the musculoskeletal system. Typical examples of RMDs are rheumatoid arthritis, osteoarthritis, osteoporosis, low-back and neck pain, fibromyalgia and systemic autoimmune diseases such as systemic lupus erythematosus.

RMDs pose a further significant risk to the population by virtue of accelerating a number of **co-morbidities** including increased rates of some cancers, cardiovascular disease, gastrointestinal disease, diabetes and increased rates of mental health disorders. RMDs represent a major part of the rapidly increasing **multi-morbidities**.

RMDs are one of the more burdensome chronic conditions affecting European societies. The high prevalence of RMDs as well as their disabling consequences impose an enormous burden not only on individuals and families, but also on our societies as a whole, particularly in terms of work and productivity loss and costs of the health care and social security systems.

- RMDs affect around **25% of the overall EU population** (that is more than 120 million citizens) and a third of all people will be affected at some point during their lifetime.
- **RMDs are the number one cause of disability in Europe.** According to the Global Burden of Disease Study, RMDs are responsible for almost 30% of the Years Lived with Disabilities (YLDs) in Europe.
- RMDs are the main health issues at work, representing up to 60% of all health issues. As such, it is the main cause of productivity loss¹¹, either due to presenteeism (lost productivity while at work due to **diminished capacity**), **absenteeism** (time off work due to sick leave), work **disability** (permanent partial or complete disablement for work purposes), **early retirement**, **premature death** (income loss and reduced taxation revenue) as well as **compensation for household work performed by others**.
- As one of the top Five diagnostic groups in Europe in terms of healthcare costs, RMDs also represent one of the most important risks to the sustainability of health care and social

¹¹ European Agency for Health and Safety at Work (EU-OSHA) (2010): *OSH in figures: Work-related musculoskeletal disorders in the EU - Facts and figures*, Luxembourg: Publications Office of the European Union.

security systems. For instance, RMDs rank second as most common reason for consulting a doctor and for most countries they correspond to 10-20% of primary care consultations, disability pensions and allowances granted to people with RMDs are the most important ones.¹²

As the greatest cause of disability in Europe, and given their high rate of co-morbidity with other major chronic conditions, research and innovation in RMDs has the potential to significantly contribute to reducing the burden of chronic, disabling conditions. As mentioned above, a study recently undertaken in the UK showed that the return on investment was approximately 25% (25p for each Pound invested every), which supports substantial investment in this area.

European research has been successful in advancing the understanding of RMDs. However, a number of important challenges still remain, as stated in RheumaMap¹³:

- In the last decade there has been remarkable progress in understanding the biological processes that lead to several RMDs. Critically, however, the causes of RMDs are not yet known. As such, prevention is currently challenging or impossible.
- The foregoing biological discoveries have yielded new therapies that have brought significant improvements in some RMDs. However, many unmet clinical needs remain, and no cures exist. The costs of ongoing treatment are significant and rising for both the individual and society, and are unsustainable.

Addressing RMDs will also require substantial efforts in implementing innovative approaches in research and health care. The development and use of innovative solutions such as eHealth tools, big data analytics, or artificial intelligence are expected to further our capacity to prevent, diagnose, treat and manage RMDs. In the next few years, important advances could be made, as for instance big data informing patient treatment, Artificial Intelligence analysing images, or even accurate patient self-diagnosis, which could have a positive impact on the health of the population, as well as on the sustainability of health care systems.

¹² eumusc.net (2010)

¹³ https://www.eular.org/public_affairs_rheumamap.cfm?fromSearch=rheumamap. RheumaMap was launched in 2017 and provides recommendations on priority areas requiring further investments. It will be periodically updated to keep