
EULAR Conference 2017

The future of health research and innovation after Horizon 2020. Do we need a novel approach?

Report

Background and objectives

Research and innovation is key to reducing the enormous burden of chronic diseases, such as rheumatic and musculoskeletal diseases (RMDs) on individuals, societies and economies. Across Europe, 120 million citizens are still affected by these diseases. The EU's research framework programmes and in particular the current Horizon 2020 have been crucial for health research over the past decades. RMDs are among the disease areas that have seen successful research being translated into concrete improvements for patients and been a step towards decreasing their burden.

For the EU as a whole, research and innovations rightly remains a crucial topic. The European Commission is evaluating Horizon 2020 and beginning to develop the 9th research framework programme (FP9). In light of this development, the European League Against Rheumatism (EULAR) organised its annual Brussels conference around World Arthritis Day on the topic of *"The future of health research and innovation after Horizon 2020. Do we need a novel approach?"* held in Brussels on 17th October 2017.

It brought together the European Commission, the upcoming Bulgarian EU presidency and Members of the European Parliament, other key policy-makers, international organisations, stakeholders, the scientific community, people with RMDs and health professionals. Together participants explored some of the key areas in implementing successful research and innovation policies that are required to successfully ease the burden of RMDs and other chronic diseases. Among the topics that were prominently discussed, including in dedicated workshops with key stakeholder organisations¹ were:

- Engagement of patients in research and innovation
- Public Private Partnership in research and innovation
- Lessons from Horizon 2020 for the next research framework programme
- Challenges in the transfer of research and innovation results into clinical practice

¹ Alliance for Biomedical Research in Europe (BioMed Alliance), European Specialist Nurses Organisations (ESNO), European Patients' Academy (EUPATI) and the Innovative Medicines Initiative (IMI).

Opening session

Prof. Johannes W. J. Bijlsma (EULAR President) opened the conference and highlighted EULAR's long-standing and successful work at EU level where the annual conferences around World Arthritis Day have played a crucial role in drawing attention to key policy issues. He summarised the key aims of the conference, which are identification and discussions of key challenges in health research and innovation and develop policy recommendations. He also presented EULAR's 2017/2018 campaign "*Don't delay, connect today*". The campaign aims to raise awareness of the importance of early diagnosis in preventing further damage to those living with RMDs, and to encourage timely access to evidence-based treatment².

In his introductory statement, **Prof. Colm O'Morain** (President of the Alliance of Biomedical Research in Europe) pointed to an urgent need to advocate for clinical and health research in Europe in view of the development of FP9. He called for increased support for collaborative multi-disciplinary translational biomedical research, continuity in funding for successful networks established in previous framework programmes and the creation of a European Council for Health Research that will support biomedical and clinical research in Europe.

Luminata Hayes (Senior Adviser, WHO) reminded the audience that RMDs have recently been recognised as one of priority areas of the WHO Action Plan for non-communicable diseases (NCDs).³ This inclusion demonstrates the urgent need to implement policies in the coming years across Europe that include strong and concerted action. She highlighted that good RMD health is a precursor for an active and healthy life. **Merja Kyllönen** (Member of the European Parliament) emphasised the strong support in the European Parliament for research and innovation, as well as the different levels of investment into research and innovation at national level, which ranges from 0,2 to 3% of GDPs. However, the European Parliament will be a strong advocate for an increase in health research funding, which is key to achieving equal access to medicines and treatments and reducing the impact on daily life for those affected.

Dieter Wiek (EULAR Vice-President representing PARE) outlined the importance of research for patients, where diseases with a high prevalence have a huge impact, but are still lacking treatments for patients. He likewise emphasised the need to increase research funding for rare diseases. For people with RMDs and other chronic diseases, it is clear that the EU needs to take the lead and prioritise research and innovation in healthcare in order to reduce the enormous burden on citizens. He also highlighted the need for inclusive research that that involves patients in the development of priorities, as well as engages them during the research process.

² For more on the campaign, please click [here](#).

³ Action plan for the prevention and control of noncommunicable diseases in the WHO European Region, 2016 – click [here](#) for the full document.

Keynote speeches

Prof. Timothy R.D.J. Radstake (Utrecht University) provided an insight into success stories of research and innovation in the past years, focussing on the aspects that will define the next decade of research for RMDs and other chronic diseases. He highlighted the need for radical systematic change in order to get new and innovative treatments to patients, the transformational potential of big data, issues around molecular re-classification and the importance of cross-sector collaboration between different disciplines and the deployment of best-practices from different areas. He also echoed previous statements about the importance of patient engagement relevance to achieve successful outcomes.

Prof. Dr. Andreas Radbruch (German Rheumatism Research Centre Berlin, DRFZ) presented his perspective on the challenges in health research and innovation in the next decade and the process of establishing research priorities. According to his organisation's work, a number of key challenges are clear. Among them are the use of immune cells as biosensors, early intervention, the possibilities of immunoreset, precision medicine and the use of big data. He called on policy-makers to take up the social and political responsibility to fund research and innovation in healthcare and develop priority areas that take these challenges into account.

Medical research under Horizon 2020 and beyond: Lessons, achievements and future developments

Manfred Huber (Coordinator Healthy Ageing, Long-term Care, Disability and Rehabilitation, WHO Europe) presented the role of research in WHO's strategies and the newly developed NCD action plan. For the WHO there is a clear link between the role of research and occupational health and work incapacities. It has become clear that RMDs are the key risk factors for sickness and disability benefits, which makes it imperative to tackle through appropriate policy.

Following this, **Cornelius Schmaltz** (Head of the Strategy Unit, European Commission DG Research & Innovation) presented the process of developing of FP9 where a proposal is expected to be published in the second half of 2018. He highlighted the importance of the financial perspective of research funding and that at this point it seems likely that the level of research funding will be maintained in FP9, which the European Parliament also strongly supports. He also presented the outcome of the interim evaluation of Horizon 2020, which according to the Commission has been broadly successful regarding the societal challenge health and well-being. Key areas that were analysed included coherence, effectiveness, efficiency, relevance and EU added value. The European Commission however recognised that it is crucial to improve applicants' success rates, support market-creating innovations and increase outreach to civil society.

Prof. Tanja Stamm (Head of Section for Outcomes Research Center, Medical University of Vienna) provided the health professionals' perspective for innovation in the treatment of RMDs. The work of health professional is key for early intervention and workplace health and safety. She emphasised the crucial connection to research and innovation, which is urgently required for these and other areas and involves the development and deployment of precision medicine and large-scale research

projects involving health professionals. The future of research and innovation in RMDs and the RheumaMap was presented by **Prof. Johannes W. J. Bijlsma**. He pointed to the increasing prevalence of RMDs and their burden on individuals and the economy, as well as a lack of coordination and support for research and innovation in RMDs as key reasons for developing the RheumaMap⁴. It defines priority areas for research and innovation, based on the impact of different RMDs and identifies current unmet needs for selected diseases and research focus areas to address these.

The key focus areas for the RheumaMap are prevention of RMDs and optimisation of care for people with RMDs. He emphasised that EU funding should concentrate on the costliest diseases that exhibit a high economic and social impact. He also underlined the importance of EU support to achieving excellence in RMDs as with over 200 different diseases, many of which only can be effectively tackled through a critical mass at European level. **Nele Cayers** (Chair of the Standing Committee of PARE EULAR) laid out the patients' perspective on research and innovation. Evidence has shown clearly that successful research and innovation requires effective patient engagement as it improves methodologies, research outcomes, credibility of results and finally also the translation into clinical practice. In order to provide feedback 'from the ground', patient organisations within EULAR provided input on the topic. It showed that despite the positive potential of patient engagement there is still low involvement in all stages of health research across Europe and many hurdles remain for patient involvement to be consistent and effective. Key areas of improvement that patient organisations highlighted were lack of funding, overall unawareness of patient involvement opportunities, bureaucracy, lack of an advisory board of patients at the Ministry of Health and missing EU-wide coordination.

Workshops

Four parallel workshops were organised, each of them addressing a different issue.

- ◆ Horizon 2020: Lessons for the next research framework programme
(Co-chaired by EULAR and the BioMedical Research Alliance)
- ◆ Challenges in transferring research findings and innovations into clinical practice
(Co-chaired by EULAR and the European Specialist Nurses Organisation)
- ◆ Engagement of patients in research and innovation
(Co-chaired by EULAR and European Patients' Academy -EUPATI-)
- ◆ Public Private Partnership in research and innovation
(Co-chaired by EULAR and Innovative Medicines Initiative -IMI-)

The aim of the workshops was to develop policy recommendations to EU and national policy makers, as well as to stakeholder organisations.

A summary of the recommendations is included in the Appendix.

⁴ Research Roadmap to transform the lives of people with Rheumatic and Musculoskeletal Diseases, in full on the [EULAR website](#).

Panel debate: The role of EU and Member States in fostering medical research and innovation to reduce the burden of major chronic diseases

The panel discussion was moderated by **Tamsin Rose** (Director, Progress Works). It discussed the role of the EU and Member States in promoting medical research and innovation to reduce the burden of chronic diseases such as RMDs. Key discussion points were the importance of a multi-disciplinary approach and multi-stakeholder involvement. This was highlighted by **Bonnie Wolff-Boenisch** (Head of Research Affairs, Science Europe) with regard to the importance research to have a meaningful impact and **Valentina Strammiello** (Programme Officer, European Patients' Forum) mentioned the access of patients to quality health care as paramount besides involving patients in setting up the research agenda for the future. Although the challenges of patient involvement are clear, the panel agreed on its necessity as it contributes to better results for patients. This was underlined by **Cornelius Schmaltz**, who emphasised that the final goal is ultimately improving the lives of patients.

In the discussion, he also pointed out that the European Commission recognised the problems related to Horizon 2020 and will narrow down topics, as well as introduce a two-stage-approach. According to him, the biggest problem however remains the limited budget. Another key area within the wider research agenda is disease prevention, where **Valentina Strammiello** stressed the fact that prevention is a societal issue and responsibility should not solely be placed on patients and citizens. **Pierre Meulien** (Executive Director, Innovative Medicines Initiative) likewise highlighted the importance of prevention and early intervention.

Prof. Johannes Bijlsma emphasised that the effective implementation of research outcomes into clinical practice as important in that regard. The issue of data sharing was also addressed as a crucial topic, including the protection and potential misuse thereof. While patients are in general acceptant of data sharing, the question of the necessity of further regulation in this area was discussed. It is the view of the European Commission that sharing of best practices and use existing legislative tools is sufficient at this point. The key demands of the panel for the further development of research and innovation were improving outcomes of clinical trials, extension of successful public-private-partnerships, more meaningful patients' involvement at all stages and cooperation of scientists with entrepreneurs to drive innovation.

Closing session

Karina Angelieva (Head of Sector 'Education and Research', Permanent Representation of Bulgaria to the EU) presented the key priorities of the upcoming Bulgarian EU presidency in the area of research and innovation. Key in this regard are the creation of synergies between different EU funding tools, improving the low participation in the research programmes from specific regions across Europe. She underlined that the health sector in the newer EU Member States, for instance, has some of the lowest participation rates in research programmes. In addition, it will be key to find ways to accelerate the distribution of knowledge and maximisation of research results. Research infrastructures will play an important role for the Bulgarian EU presidency, in particular big data and the role of universities.

To conclude the conference, **Takis Hadjigeorgiou** (Member of the European Parliament and Vice-Chair of the Interest Group on RMDs) provided the perspective of the European Parliament on the topic of research and innovation. He highlighted that health research is the area that is the closest to citizens' concerns, which is shown clearly in the number of people affected by chronic diseases such as RMDs.

This makes it a political priority for the coming months and years that will receive attention by policy-makers. He called on the European Commission to be proactive and tackle the key challenges that the health community faces and aim to increase rather than decrease funding for research and innovation in healthcare and tackle the low success rates of applicants through more focussed calls. He particularly called for a focus on disease areas that exhibit a particularly high impact on society. Factors that need to be taken into account are the cost of disability, work absenteeism and the loss of productivity linked to chronic conditions. He wrapped up his speech by arguing that EU citizens expect the EU and Member States not to look towards decreasing funding for research and innovation in health, but ensure the best possible access to innovative treatments that are urgently required across the EU.

Appendix

WORKSHOP 1: Horizon 2020: Lessons for the next research framework programme

Chairs: Prof. Rik Lories (University Hospitals Leuven & EULAR)

Prof. Colm O'Morain (Alliance for Biomedical Research in Europe)

Issues/challenges to be addressed in next Research Framework Programme

Issues / Challenges
1. Interdisciplinary & innovative
2. Representing the entire RMD/EULAR community; integrated care
3. Personalised medicines/strategic CTs
4. Prediction, prevention, early intervention

Recommendations for the next Research Framework Programme

	Recommendations
Collaborative research	<ul style="list-style-type: none"> • Collaborative research should have a strong role also in FP9 • Project design should facilitate interdisciplinary research and allow to integrate new partners (e.g. technology providers) • There are merits both for more generic and more narrow call topics; balance to be found
Links to public health	<ul style="list-style-type: none"> • Sufficient space to be foreseen for scientific approaches to research implementation; use of research outcomes for health sector organisation • Non-pharmacological interventions should not be neglected
'Research workforce'	<ul style="list-style-type: none"> • There is a lack of translational scientists • EU programmes should contribute to make research-oriented careers more attractive
Research led by health professionals	<ul style="list-style-type: none"> • Developing fast over recent years • Needs more funding opportunities
Evaluations	<ul style="list-style-type: none"> • Excellence principle should also apply to evaluation • Transparency to be strengthened • Identification of appropriate evaluators = joint responsibility of EU Commission and research institutions
Administrative burden	<ul style="list-style-type: none"> • Effort should be made to limit administrative burden to strict minimum • Success rates for stage 2 should be increased

WORKSHOP 2: Challenges in transferring research findings and innovations into clinical practice

Chairs: Nina Østerås (Diakonhjemmet Hospital Oslo & EULAR)

Yvonne van Eijk – Hustings (ESNO & EULAR)

Main barriers for implementation

Barriers

1. Access to unbiased and high-quality research publications, as well as availability in easy to understand languages
2. Funding for implementation of new drugs and further innovations such as care models

Main facilitators for implementation

Facilitators

1. Standardization and quality of education
2. Bringing together relevant stakeholder
3. Champions

Recommendations to policy makers and stakeholders to facilitate the transfer of results findings and innovations into clinical practice

	Recommendations
EU institutions	<ul style="list-style-type: none"> • Funding of Phase 4 trials for chronic diseases which represent different European regions • Inclusion of patients' evaluation of funding applications • Promotion of studies results that can be generalized
Member States / Regions	<ul style="list-style-type: none"> • Inclusion of patients' evaluation of funding applications • Focusing on economic and other consequences of not implementing recommendations
Health care services	<ul style="list-style-type: none"> • Reporting outcomes to monitor implementation
Other stakeholders	<ul style="list-style-type: none"> • Accreditation and education that can increase motivation

WORKSHOP 3: Engagement of patients in research and innovation

Chairs: Elsa Mateus (Portuguese League Against Rheumatic Diseases & EULAR)
David Haerry (EUPATI)

Challenges / barriers for the engagement of patients in research and innovation

Challenges / Barriers

1. Matching expectations, understanding the language
2. Missing legislation – European and national level
3. Clear assignment, equal treatment hierarchies
4. Governance infrastructure, stakeholders involvement criteria

Recommendations to policy makers and stakeholders to further engage patients in research and innovation

	Recommendations
EU institutions	<ul style="list-style-type: none"> • Finance education for patients in a long run (forming umbrellas and clusters) • Develop a compulsory framework for the same standards on the cooperation with the public and all stakeholders • Better legislation on all levels • Special structural funds for patient engagement
Member States / Regions	<ul style="list-style-type: none"> • National policies to reflect European standards • Unless provided smaller funding on national level • Involvement of patient consultants for national authorities • Public money only with patient involvement
Patients' organisations	<ul style="list-style-type: none"> • Organize educational courses for patients and researchers • Create national network of PRPs • Create databases of clinical trials • Develop capacities for engaging research and promote it • Attract public funding
Other stakeholders	<ul style="list-style-type: none"> • Adapt university curricula to engage patients as experts and acknowledge their input • Best practice sharing and provide multi-stakeholder education on patient involvement • Accept patients as full partners

WORKSHOP 4: Public Private Partnership in research and innovation

Chairs: Prof. Francis Berenbaum (Pierre & Marie Curie University & EULAR)
Pierre Meulien (Innovative Medicines Initiative)

Challenges in the development of Public-Private Partnerships

Challenges
1. Mutual understanding between partners
2. Communication between stakeholders and general public
3. Datasets/open data (private and non-private bodies, patient organisations)
4. Involvement/inclusion of patient throughout the process
5. Choice of the topic

Recommendations to policy makers and stakeholders to address main challenges in the development of PPP

	Recommendations
EU institutions	<ul style="list-style-type: none"> • Increased patient involvement policies • Increased funding for research and innovation, esp. health research • Continued IMI funding under FP9 • Regulation supporting sharing of data
Member States / Regions	<ul style="list-style-type: none"> • Support strong EU role and funding for research and innovation • Regulation supporting sharing of data
Universities / Research centres	<ul style="list-style-type: none"> • Development of clear research focus • Awareness building of nature of IMI • Better communication of research results
Industry	<ul style="list-style-type: none"> • Development of clear research focus • Awareness building of nature of IMI
Patients' organisations	<ul style="list-style-type: none"> • Better communication of research results • Encouragement of strong role in research and innovation
Other stakeholders	<ul style="list-style-type: none"> • Involvement of new stakeholders; such as digital, food and nutrition sectors