EULAR World Arthritis Day Conference 2018
Bringing chronic diseases to the forefront of health innovation:
From the lab to individualised health care
Thon EU Hotel (Brussels), 9 October 2018

Report

Background and objectives

Fostering health innovation is crucial for reducing the burden of chronic diseases on individuals, and hence ensuring the sustainability of European health and social care systems. Innovative approaches and developments in both research and health care (such as those based on eHealth solutions, big data and artificial intelligence) are expected to enhance our understanding of the causes and characteristics of chronic diseases as well as improve their prevention, diagnosis, treatment and management.

Fostering research and health care innovation still faces a number of financial, technical and organisational challenges though, for which adequate policies at both the EU and national levels are required. Ongoing and future EU policy initiatives (such as Horizon Europe and policies aiming to promote the implementation of eHealth solutions), will play a key role in strengthening health innovation in Europe.

In order to contribute to the debate on the future of health innovation, the European League Against Rheumatism (EULAR) organised its World Arthritis Day Conference 2018 on the topic of ‘Bringing chronic diseases to the forefront of health innovation: From the lab to individualised health care’. The aim of the conference was to bring together EU, national and regional decision makers, scientists, health professionals and patients, as well as representatives of key stakeholder organisations to discuss main challenges and possible solutions in furthering health innovation in Europe. In particular, the conference aimed at developing policy recommendations on relevant issues, which were discussed in four parallel workshops:

- Can citizens have a leading role in health care innovation?
- Organisational and human challenges in the introduction of digital solutions in health care services
- Policy issues in the use of big data in health care and research
- How to foster innovation through Horizon Europe (FP9)?

1 The outcomes of the workshops can be found in the annex to this report.
develop recommendations to EU and national policy makers on how to address key challenges in fostering health care innovation in order to better help reducing the burden of chronic diseases in Europe.

Around 150 participants attended the event in Brussels, while more than 6000 did it online from a number of European countries.

Opening Session

Prof. Johannes W. J. Bijlsma (EULAR President) opened the conference and highlighted EULAR’s long-standing and successful engagement at EU level where the annual conferences represent a fundamental tool in drawing attention to key policy issues. He highlighted the importance of fostering innovative health solutions to reduce the enormous burden of rheumatic and musculoskeletal diseases (RMDs) and other chronic conditions, for which he welcomed the upcoming 9th European research and innovation framework programme and other policy initiatives in health innovation.

Lieve Wierinck (Member of the European Parliament and shadow rapporteur for Horizon Europe) stressed the Horizon Europe is crucial in strengthening Europe’s research and innovation landscape and in delivering a fruitful base for market uptakes and business innovation. It should draw on Horizon 2020, its success stories and learned lessons. With regard to research and innovation in the field of health, Ms Wierinck highlighted the social and political relevance of health research and innovation, for which she called for a budget increase and simultaneously further enabling citizens’ involvement. Ms Wierinck pointed out that health research and innovation under Horizon Europe should target citizens’ priorities and needs, for instance by reducing the enormous burden of chronic diseases, such as RMDs.

Pierre Meulien (Executive Director, Innovative Medicines Initiative) presented the Innovative Medicines Initiative (IMI) as a good example of long-lasting health innovation supported by the public and private sector as it brings together several stakeholders with the common aim of speeding up innovation for patients. Meulien stressed the importance of developing innovative research for the purpose of triggering ground-breaking health technology. Furthermore, research and innovation programmes in the field of health should focus their efforts on further promoting health prevention. With regard to current social and political challenges in the field of health, education and training play a crucial role and the EU needs to invest in creating a safe and interoperable framework for health data collection and management. Dr Meulien shared his personal views on investment priorities in health innovation, as for instance prevention, education of people and bringing more innovative health economics into mainstream thinking.
Keynote speeches

Prof. Stephen Hanney (Researcher and member of the Health Economics Research Group, Brunel University) presented the findings of recent studies on return on investment (ROI) of health research and innovation. According to investigations carried out by partnering institutions, investment in health research creates a yearly economic return varying between 15 and 18%. As an example of these studies, Prof. Hanney described the approach used in assessing ROI for research and innovation in RMDs and showed the results of the study. The results of their study in the case of RMDs, research brings a yearly economic return of 25% showing the value of furthering investing in research and innovation in RMDs.

In his keynote speech, Prof. Timothy R.D.J. Radstake (Utrecht University) address innovation in science, underlining the importance of research and innovation in the field of health prevention. He showed how big data and data-driven medicine are triggering the development of personalised medicines and molecular networks, while further developing the role of artificial intelligence. According to Prof. Radstake, these are crucial steps for the transformation of health care systems where patients need to play a central role and should be involved in the process.

Barbara Kerstiëns (Head of Unit, Non-communicable diseases and the challenge of healthy ageing, DG Research and Innovation, European Commission) highlighted that RMDs have been a priority of the EU’s research framework programs. Within Horizon 2020, several projects were focusing on these diseases which will be continued under Horizon Europe. She furthermore presented the European Commission’s proposal for Horizon Europe. The missions that are being developed in the field of health research and innovation will also support a patient-oriented approach.

During the Q&A session, Virginia Enache (Research and innovation Attaché, Permanent Representation of Romania) highlighted the need for a substantial budget increase in EU funds for health research and innovation. Health has high social, political and economic relevance and it therefore represents an area on which Europe should invest substantially and should increase the budget within Horizon Europe. Furthermore, Enache highlighted the supportive role of private financing and partnerships in further developing research and innovation projects in the field of health.

Panel Debate: How to foster European innovation to tackle chronic diseases?

The panel debate, moderated by Kathy Smith, aimed to discuss challenges and policy initiatives to promote health innovation in Europe. To this end, panellists represented the views of the European Commission, the scientific community, patients and industry.

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The discussion brought together different positions and highlighted several aspects currently influencing the development of health innovations solutions for RMDs. Participants to the panel identified challenges and health policy initiatives to foster European innovation to tackle chronic diseases in Europe. In particular the discussion focused on:

1. Patient engagement
2. Patient inclusion
3. Transformation of health care systems
4. The need for adequate funding for health research and innovation

With regard to the first point, all participants to the panel highlighted that patient’s engagement remains a crucial element for fostering European innovation solutions with regard to chronic diseases. The patient should get involved at the stage of prevention, prediction and treatment of diseases. The development of home care and personalised medicine solutions should aim at ensuring the patient's empowerment and participation in their well-being. Gerlinde Bendzuck (Deutsche Rheuma-Liga Bundesverband e.V.) highlighted that patients’ engagement increases the efficiency and sustainability of health innovative solutions while fostering at the same time citizens and patients’ knowledge and trust in innovation.

Patient engagement initiatives need to go hand in hand with patient inclusion: innovative health solutions should aim at enabling people affected by RMDs to participate in economic and social life. Especially with regard to new health technologies, these should offer patients the opportunity to break down diseases’ implied boundaries and ensure as much as possible the inclusion in society and work. Prof Rik Lories (EULAR & K.U. Leuven) pointed out that despite progress in recent years, there is still much room for improvement to increase patient engagement and inclusion.

To be efficient and sustainable, innovative health solutions need to be embedded in modernised health care systems. These need to be equipped with the best innovative solutions to guarantee high levels of health care quality and safety. As an example, Carolina Rubio Miner (Savana Medica) mentioned that health care providers need to be equipped with innovative solutions to better collect, evaluate and manage health care data.

With regard to the funding of health research and innovation, it was pointed out that health innovation needs to be a top priority on the European policy Agenda and be adequately funded. Cross-stakeholder cooperation is key to bring further RMDs patients’ main concerns on this issue and to call for competitive and farsighted innovative health solutions in Europe. In this regard, Barbara Kerstiēns, mentioned EULAR’s three pillar model that includes scientists, health professionals and people with RMDS as an example of good cross-stakeholder engagement practice.

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Promoting innovation in health care

Valentina Laurenzia Ancona (Senior Manager Government Affairs, MedTech Europe) presented the views of the medical devices industry on the trends and challenges in health care innovation. Acknowledging that RMDs represent the most common cause of disability and present a major impact on people’s quality of life, Ms Ancona stated that medical innovation technologies delivers valuable support to patients, health care professionals and health care systems by accelerating new ways of healthcare delivery. However, health care systems need to integrate these innovative technologies, by ensuring interoperability and providing legal and ethical guarantees.

William Dixon (Manchester University) delivered an overview on how technology, and especially electronic health care records, might revolutionise healthcare. The collection, evaluation and management of data through technological devices, such as smartphones and wearables or innovative applications such as social media or digital traces, will transform our healthcare systems by increasing its quality.

Pascal Garel (CEO European Hospital and Healthcare Federation — HOPE) explained how innovation technologies, such as artificial intelligence, big data, robot technology, internet, apps, wearables & sensors and precision medicines might pose several challenges to hospitals and health care systems in terms of transformation, leadership, and interoperability. However, Garel also highlighted that the introduction of innovative technologies creates relevant opportunities for overcoming the issues that health care systems are facing. These include ageing populations, decrease in caregivers, increase in chronic diseases, financial sustainability, climate change and other socio-economic factors.

With regard to the digital transformation of health and care, in April 2018 the European Commission published its Communication on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society. As highlighted by Andrzej Rys (Director for Health systems, medical products and innovation, DG SANTE, European Commission), the Communications sets out a roadmap for the EU to take further action on a) citizens’ secure access to and sharing of health data across borders, b) better data to advance research, disease prevention and personalised health and care, and c) digital tools for citizen empowerment and person-centred health care.

digital-single-market-empowering

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Innovative solutions in RMDs presented at the conference

Three innovative solutions in health research and health care were presented during the conference.

**Inertial Movement Sensors (IMUs) - Philip V. Gardiner**
- Integration of patient-generated health data into clinical consultation.

**MedXcell Science SAS - Prof. Christian Jorgensen**
- Develop Adipose derived Stem (ASC) based cell therapy in osteoarthritis & DDD, based on data obtained ADIPOA and RESPINE.

**REMORA - Prof. William Dixon**
- Smartphone app to collect daily symptoms in patients with Rheumatoid Arthritis.

Closing session

**Dieter Wiek** (EULAR Vice-President representing PARE) highlighted the speed at which innovative technologies are developing, as well as the digitalization process of health care systems and the collection, evaluation and management of big data. He welcomed efforts in further promoting innovation and research in this field but underlined that policy makers, researchers and health professionals need to make sure that patients, that is to say citizens are equally involved in this process and that these transformations do not lead to increasing inequalities. Research and innovation in the field of health need to be supported by strong awareness-raising and patient empowerment initiatives, which enable citizens to be actively and knowingly part of the societal, political and economic transformations.

**Prof. Johannes W. J. Bijlsma** took the opportunity to thank participants, speakers and organisers and highlighted that EULAR and its activities are effectively and positively bringing forward one of the main aims of peoples affected by RMDs, which is the promotion of research and innovation in the field of health. This can lead to a reduction of the enormous burden of chronic diseases, such as RMDs. On behalf of EULAR, he strongly welcomed the European Commission’s proposal for Horizon Europe but added that there is still room for improvement and that RMDs need to be a top priority.

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Annex: Workshop outcomes

The development of recommendations on key policy issues was one of the main goals of the conference. Participants discussed and developed recommendations in parallel workshops. The results of those debates are presented below.

**Workshop 1: Can citizens have a leading role in health care innovation?**

Chairs: Dieter Wiek (EULAR Vice-President representing PARE) and Elsa Mateus (Portuguese League Against Rheumatic Diseases & EULAR)

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<thead>
<tr>
<th>Issues/challenges</th>
<th>Recommendations</th>
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<tbody>
<tr>
<td>Lack of education of researchers to include patients</td>
<td>• Mandatory involvement of patients from the beginning (design of projects)</td>
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<td>Lack of basic/common understanding, lack of communication skills</td>
<td>• Measures to overcome language barriers</td>
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<td>Lack of incentive for research</td>
<td>• Better communication of research results</td>
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<td>Hindrances for patients: time; accessibility, competences</td>
<td>• Training of patients (e.g. through patient academies)</td>
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<td></td>
<td>• Training of scientists</td>
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<td>• Recognition of the role of expert patients</td>
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<td>Patient’s/Consumer’s organisations</td>
<td>• European umbrella organisations defining own projects and priorities</td>
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<td>• European umbrella organisations providing support to national organisations</td>
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<td>through capacity building</td>
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Workshop 2: Organisational and human challenges in the introduction of digital solutions in healthcare services

Chairs: Prof. Laure Gossec (EULAR & Université Pierre et Marie Curie) & Pascal Garel (European Hospital and Healthcare Federation — HOPE)

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<tr>
<th>Issues/challenges</th>
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| 1. Interoperability/integration (lack of standardisation) | **EU**
| 2. Costs and cost-benefit evidence | • Targeted and increased investment (common priority-setting with Member States)
| 3. Variability (practical application) | • Recognition of best practices at EU level (e.g. through targeted awards)
| 4. Patient and healthcare provider behaviour | • Understanding of best digital solutions in Europe (evidence-based), incl. stamp of approval at EU level that also considers data privacy
| 5. Data privacy | • Bottom-up development of standards for interoperability
| 6. Accessibility barriers (e.g. language, digital infrastructure, digital literacy) | • Data sharing agreements (EU-wide templates)
| | • Patient engagement projects and inclusion in panels
| | **Member States / Regions**
| | • Targeted investment
| | • Incentives (financial or other)
| | • Taking on European guidelines and best practice solutions
| | • Developing standards for electronic health records
| | • Awareness and education
| | **Health care providers**
| | • Defining core sets of outcomes/data
| | • Increased collaboration
| | **Other stakeholders**
| | • Researchers: understanding of best digital solutions (evidence-based, incl. economic benefits)
| | • Codes of conduct/quality standards developed by all stakeholders (incl. patient organisations)
| | • Development of sustainable business models
| | • Patient engagement in product development
| | • EULAR recognition of good projects
**Workshop 3: Policy issues in the use of big data in health care and research**

**Chairs:** Prof. Loreto Carmona (EULAR) & Carolina Rubio Miner (Savana Médica)

### Issues/challenges

1. **Fear of risk due to lack of regulation and knowledge on possible uses of personal health data**
2. **Fragmentation due to missing interoperability of national and local health care systems and unstructured collection of data**
3. **Lack of trust due to ethical issues, as well as ownership and privacy of personal health care data**

### Recommendations

**EU**
- Regulations to guarantee safe and secure collection and use of health data
- Information and awareness-raising on the benefits of big data and new technologies
- Reconciliation between GDPR and research

**Member States / Regions**
- Implementation and information on rules and regulations that safeguard data ownership and privacy
- Improve interoperability of national and local health systems

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**Workshop 4: How to foster innovation through Horizon Europe (FP9)?**

**Chairs:** Prof. Xenofon Baraliakos (EULAR) & Prof. George Griffin (FEAM)

### Issues/challenges

1. Participation of scientific societies, health professionals and patients in strategic programming
2. Balance between basic & clinical research and innovation
3. Reduce the entrepreneurship gap between Europe and the rest of the world

### Recommendations

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<th>Challenge</th>
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| **Challenge A)** | • Inter-societal education and communication, involved from the very start  
• To define and enhance endpoints/aims  
• Involvement of patient research partners |
| **Challenge B)** | • Maintain appropriate good balance between areas  
• Support moon shot projects with potential breakthrough  
• Encourage training and education |
| **Challenge C)** | • Identify reasons for the gap  
• Use the information to be included in dedicated future calls |

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