EULAR Position Paper on Innovation in Healthcare

Innovation in healthcare has the potential to substantially reduce the burden of chronic diseases and ensure the sustainability of European health and social care systems. It can make a substantial difference to the 120 million people in Europe living with Rheumatic and Musculoskeletal Diseases (RMDs), which inflicts a GDP loss of up to 2% on national economies year-on-year.

Current innovation trends in the area of healthcare are highly promising and come in many forms: Artificial Intelligence, eHealth solutions, electronic health care records and use of big data. Many of these are successfully implemented for the benefit of people with RMDs and other chronic diseases, but cannot fulfil their full transformative potential due to barriers that policy-makers need to address.

With innovation developing ever more quickly, the implications for the health community and the relevant policy considerations are crucial. It is in these areas that the EULAR would like to provide its considerations for the development of future policy at EU, national and regional level. To have the desired effect on individuals, societies and economies, policies need to address the following issues:

1. Ensuring a leading role for people with chronic diseases in health care innovation

2. Overcoming organisational and human challenges in the introduction of innovation

3. Enhancing the use of big data in health care for the benefits of patients

The recommendations contained herein were developed at a high-level conference organised by EULAR on the occasion of World Arthritis Day 2018 on the topic of *Bringing chronic diseases to the forefront of health innovation: From the lab to individualised health care[1]*. It brought together EU, national and regional policy-makers, scientists, health professionals and patients, as well as other key stakeholders to discuss the main challenges and solutions in furthering health innovation in Europe[2].

1. Ensuring a leading role for people with chronic diseases in health care innovation

Key to the successful implementation of innovation in health services are its end-users, which in the case of health care are patients. There are however some challenges in this area, including an insufficient level of patient involvement in innovative projects, differences in understanding and communication between stakeholders and hindrances for patients in terms of time, accessibility and competences.

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[1] For the full conference report, please click here.

[2] The conference also discussed the issue of health research, which is omitted from this position paper as it is included in the separate position paper on Horizon Europe – click here.

Recommendations

EU-level	• Mandatory involvement of patients at an early stage (design of projects)
	• Measures to overcome language barriers
	• Better communication of innovation results
	• Patient engagement projects and inclusion in panels
Member States & Regions	• Training of patients (e.g. through patient academies)
	• Training of innovators and entrepreneurs
	• Recognition of the role of expert patients
Patient & consumer organisations	• European umbrella organisations defining own projects and priorities
	• European umbrella organisations providing support to national organisations through capacity building

2. Overcoming organisational and human challenges in the introduction of innovation

Besides the impact on end-users and the crucial need for their involvement, other actors and considerations of the health systems need to be taken into account. These include health professionals, hospitals and all other centres of healthcare delivery, as well as the physical and virtual infrastructures. The challenges in this area pertain to the lack of standardisation, high costs, missing cost-benefit evidence, variability in practical application of innovation, divergent behaviour of patients and health care providers, data privacy concerns and lack of accessibility (such as language, digital infrastructure and digital literacy).

Recommendations

EU-level	• Targeted and increased investment (common priority-setting with Member States)
	• Recognition of best practices at EU level (e.g. through targeted awards)
	• Understanding of best digital solutions in Europe (evidence-based), including stamp of approval at EU level that considers data privacy
	• Bottom-up development of standards for interoperability
	• Data-sharing agreements (EU-wide templates)

Member States & Regions	• Targeted investment at addressing challenges
	• Incentives for deployment of innovation (financial or other)
	• Implementation of European guidelines and best-practice solutions
	• Development of standards for electronic health records
	• Raising awareness and providing education
Health care providers	• Definition of core sets of outcomes/data
	• Increased collaboration
Other stakeholders	• 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

3. Enhancing the use of big data in health care for the benefit of patients

One of the key drivers for innovation with a potentially substantial positive impact on health outcomes will come from the use of big data, its analysis and deployment of the results. While the benefits are clear, it cannot be sufficiently used and there is a need to address the challenges that exist. These are the fear of risk due to lack of regulation and knowledge on possible uses of personal health data, fragmentation due to of lack of interoperability between national and regional health care systems, unstructured collection of data and a lack of trust due to ethical issues, as well as uncertainty around ownership and privacy of personal health care data.

Recommendations

EU-level	• 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 & innovation
Member States & Regions	• Implementation and information on rules and regulations that safeguard data ownership and privacy
	• Improving interoperability between national and local health systems

About EULAR

The European League Against Rheumatism (EULAR) is the organisation which represents the people with arthritis/rheumatism, health professionals (HPR) and scientific societies of rheumatology of all the European nations. The aims of EULAR are to reduce the burden of rheumatic diseases on the individual and society and to improve the treatment, prevention and rehabilitation of musculoskeletal diseases.

To this end, EULAR fosters excellence in education and research in the field of rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with musculoskeletal diseases by the governing bodies in Europe.

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