
Conference:**Analysing how to reduce the Access Barriers to Health Care for People with Chronic Diseases in Europe**

Challenges, good practices and policy options for people with rheumatic and musculoskeletal diseases

European Parliament & Thon Hotel EU, 16 October 2014

Conference Report**Background, scope and objectives**

Access to quality health care is a major concern for people with rheumatic and musculoskeletal diseases (RMDs) and other chronic conditions. They often have to cope with a number of access barriers such as the lack of specialists and specialised health care facilities, the late referral to specialists, long waiting lists, the high cost of therapies, the absence of science-based standards of care and the need for further focused research, the lack or sufficient and adequate information for patients, and alike. The pressure of the financial crisis on health care systems is expected to make those barriers more evident, while deepening inequalities between better-off and worse-off groups of the population as well as between more affluent and less affluent EU Member States.

In order to analyse the situation of access to health care in Europe and discuss possible solutions, the European League Against Rheumatism (EULAR) organised the conference *“Analysing how to reduce the Access Barriers to Health Care for People with Chronic Diseases in Europe. Challenges, good practices and policy options for people with rheumatic and musculoskeletal diseases”*. The event took place in Brussels on 16 October 2014, and was hosted by MEP Takis Hadjigeorgiou and chaired by Maurizio Cutolo, President of EULAR.

The aim of the Conference was to identify and discuss possible policy developments for optimising access to health care and management of chronicity for people with RMDs and other chronic conditions.

The event, part of which was held in the European Parliament in Brussels, brought together around 150 participants, including Members of the European Parliament, high level representatives of the European Commission, the European Economic and Social Committee, Member States, the World Health Organisation (WHO), and a number of key scientific societies, patient organisations and health professional associations from across Europe.

Summary of discussions

Health care for chronic diseases in Europe - evidence for RMDs and beyond

One of the purposes of the event was to analyse the current situation of access to health care for people with chronic conditions, particularly with rheumatic and musculoskeletal diseases (RMDs).

Speakers pointed out that access to health care is being challenged by two main factors that have to some extent threatened the sustainability of health system. First, a significant rise in the prevalence of chronic diseases (CDs) such as RMDs is increasing the demand of health care services. Second, the financial crisis that has severely hit European economies in the last years, have put the supply of health care services in several countries under particularly pressure.

The increase in the burden of CDs is partly explained by the rise of life expectancy as well as by life style factors such as insufficient physical activity, tobacco consumption, and alike. Although traditional public health approaches have usually prioritised conditions with high mortality rates, the sustainability of health care systems is nonetheless being increasingly affected by conditions that are chronic in nature although not necessarily lethal (e.g. RMDs or mental health disorders). Thus, in order to make an efficient and effective use of health care services, policy makers should establish priorities based on the analysis of the economic and social impact of different chronic diseases rather than on mortality rate statistics, as pointed out by Dr Roberto Bertollini (WHO) and Prof. Anthony Woolf (The Bone & Joint Decade).

In order to support this assertion, Prof Woolf presented recent evidence of the burden of RMDs and other chronic conditions. Being the number one cause of disability in Europe (explaining about 33% of all disabled people) and being one of the most prevalent chronic conditions affecting more than 120 million persons in the EU, RMDs is a good example of the growing socioeconomic impact of some chronic conditions. RMDs demand a very intensive and increasing use of health care services (e.g. they rank third in GP consultation in the UK, with 20% of all primary care visits), and represent a big proportion of all illness costs (e.g. in Germany, RMDs rank 4rd with 11,2% of the total illness costs, cardiovascular diseases being the first with 14,5%). Furthermore, given its impairing effects, RMDs are a major cause of work and productivity loss, representing an enormous burden for the social security system.

On the supply side, speakers highlighted the heterogeneous situation of health care provision across EU Member States and regions, and consequently the different levels of access barriers faced by people with CDs. As Dr Antoni Dedeu (Chair of European Regional and Local Health Authorities, EUREGHA) pointed out, there are significant differences in health care access across Europe. Inequalities exist between more affluent and less affluent countries and regions, between urban and rural or isolated areas, and between higher and lower socioeconomic groups of the population. In addition, particular groups are more likely to face access barriers, such as elderly people, immigrants and people with rare diseases.

The financial crisis has particularly affected the provision of health care services in several Member States. Based on different indicators such as the average health expenditure growth, the annual change in public spending on health per person, and the changes in unmet needs due to cost, Willy Palm (European Observatory on Health Systems and Policies) provided evidence of the impact of the financial crisis on the provision of health care services in some countries (particularly in Eastern and Southern Europe). Among others, the financial crisis and the austerity measures that followed have

resulted in a number of negative effects on health care systems such as the reduction of the population covered by health services; the reduction of the basket of services; the increase in waiting times for essential services; the implementation of user charges for essential services; or the attrition of health workers caused by reductions in salaries.

Beyond the macro-level approach, the Conference aimed to bring in the patients' experiences with regard to health care in Europe. Focusing on RMDs, Diana Skingle (Chairperson of the Standing Committee of EULAR PARE, People with Arthritis/Rheumatism in Europe) presented the results of a survey to EULAR member organisations in different countries. The survey aimed at assessing the accessibility to therapy and treatments measures, the referral times for appointment and diagnosis and the RMD related challenges. Answers to the survey depicted the difficult situation that people with RMDs (particularly in some countries) face in access to health care. Among others it is worth mentioning the lack of specialists or the lack of national guidelines for minimum treatments, the excessive waiting times, the insufficient awareness in primary care (and therefore the failure in early diagnosis and referral), the lack of sufficient information and patient education, the difficulties in getting medications (in particular, biologics), and the limited medicine reimbursement and lack of financial resources in health systems.

Finding solutions – Innovations in health care

Based on the experience and contributions of the RMD community, the Conference also aimed at providing examples of innovative approaches to reduce access barriers and facilitate the prevention and management of chronic conditions. Innovative approaches were provided in three main areas: clinical practice and research, management of health care services and patient empowerment.

Speakers stressed that the progression of RMDs and other chronic diseases is to a large extent preventable or able to be controlled. From a clinical point of view, it was pointed out that treatments should aim to prevent the “chronicity” of possible acute inflammatory conditions, which could eventually result in chronic organ insufficiency and invalidity or even in the development of cancer. In this sense, Prof. Maurizio Cutolo (EULAR President & ILAR Chair) suggested that research and innovation should aim to identify or optimise the use of advanced biomarkers in order to (a) detect the resolution of acute inflammatory conditions; and (b) detect and prevent the progression of chronic inflammation to cancer. As a matter of fact, chronic inflammation is a common pathway in almost all chronic diseases.

Therefore, early intervention (including early diagnosis and early referral to specialists) was identified as key elements in facilitating the care and treatment of musculoskeletal conditions and hence the treatment outcomes. In presenting the results of a study, Prof. Juan Jover (Hospital Clínico Madrid & Fit For Work Europe) pointed out that the early intervention initiative undertaken in Madrid (which included measures such as patient education and self management) was able to significantly reduce both temporary and permanent work disability (39% and 50% respectively). In addition, the benefits of the experience were also perceived in the increased satisfaction of patients as well as in the reduction of both direct and indirect costs associated to the RMDs conditions.

The analysis of care trajectories (the analysis of care options depending on the stage of a disease) was presented as a possible innovative approach to improve the management of health care services and hence the disease prognosis. Prof. Bruno Fautrel (Université Pierre et Marie Curie Paris)

presented a 5-steps model for the care of rheumatoid arthritis (RA), emphasising the importance of early referral and hence the need to train GP in identifying the symptoms of RA, among others. In doing so, he pointed out that the education of both health professionals and the population, as well as the facilitation of care seeking, are important elements for optimising access to health care.

Empowering patients was said to be crucial in improving access to health care and health care outcomes. In this sense, Ailsa Bosworth (National Rheumatoid Arthritis Society /NRAS, UK) presented the “patient activation” approach used by the NRAS. Among others, she described the NRAS approach as focusing on: (a) the provision of a comprehensive range of services to empower patients, their families and carers (including information, training on self management, etc.); (b) the implementation of campaigns at national, regional and local levels; (c) the support to academic and clinical research and the undertaking of research on quality of life.

Tackling access barriers to health care – Policy options and recommendations

One of the main purposes of the Conference was to develop policy recommendations on how to reduce access barriers to health care. To this end, four breakout sessions were organised, each focusing on a specific barrier or issue:

- Health systems responses to financial constraints
- Patient empowerment, health literacy & Information to patients
- Health professionals: availability/composition, roles, training, mobility, accreditation
- Access to treatments and medicines: availability, pricing and reimbursement

In order to bring in a broader approach to these subjects, each of the workshops was co-organised together with a well known stakeholder organisation: the European Public Health Alliance (EPHA), the European Patients’ Forum (EPF), the Standing Committee of European Doctors (CPME) and the European Hospital and Healthcare Federation (HOPE) respectively.

The workshops aimed to identify the most important issues or barriers in each of these topics, as well as policy recommendations to tackle or reduce those barriers.

A summary of the workshop discussions is presented in the Appendix.

The results of the workshops were further discussed in a panel debate that brought together representatives of the European Commission, the European Economic and Social Committee (EESC), the European Social Observatory, the RMD community, and the European Forum for Primary Care. The aim of the panel was to discuss the role of the EU, Member States, regions and stakeholders in reducing access barriers to health care.

Overall, panellists agreed that the establishment of the new European Commission could be an opportunity to reinforce the role of the EU in supporting Member States to strengthen their health care systems. However, this would not imply a transfer of competences.

Participants expressed their concern about the impact of the financial crisis on access to health care and equity. Marios Kouloumas (EULAR Vice-President representing People with Arthritis/Rheumatism in Europe) pointed out that it is difficult to reconcile austerity measures with the right of EU citizens to quality health care.

While it was pointed out that it is very unlikely that spending on health care will be increased in the years to come due to the austerity measures, some panellists stressed that there is nonetheless room for improving the care of people with chronic conditions. According to Andrzej Rys (European Commission, DG SANCO) and Ingrid Kössler (Member of the European Economic and Social Committee, EESC), the EU has a key role to play in improving access to care, for instance in promoting the sharing of good practices and the exchange of knowledge. This notably includes the further development and implementation of standards of care, as the ones already developed by the eusmusc.net project (a project initiated by EULAR, which was implemented with the support of the European Commission).

Furthermore, strengthening the monitoring activities at the EU level would be important to support Member States to bring cost effectiveness and access to care on par against the backdrop of budget oversight and austerity measures. Dr Rys emphasized that the cross border directive already serves as a good example for cooperation across the different member states, which could be seen in a range of successful projects that followed the implementation of the Directive, in areas like eHealth, Health Technology Assessment and the European reference network. Ms Kössler pointed out that, as it happened with the Cross-Border Directive, it is important that the EU uses the principles of the internal market to further EU health policy initiatives.

Asked about what the new Commission should do in the field of RMDs, panellists proposed the following initiatives:

- Development of increased investments on research and of better standards of care
- Furthering the share of good practice and the exchange of knowledge in the field of RMDs
- Furthering initiatives on prevention and rehabilitation
- Development of a set of indicators of access to care
- Acknowledge of RMDs as one of the major chronic diseases and policy initiatives proportional to the burden of RMDs

Final remarks

The Conference proved the relevance of health care access issues not only for patients and health professionals but also for policy makers and for the overall health community. As Takis Hadjigeorgiou (MEP) pointed out, the basic requirement of equal access to quality care for people with chronic diseases in Europe is not yet met.

As participants agreed, overcoming access barriers to health care requires the strong commitment of policy makers and stakeholders not only at national and/or regional levels, but also at the EU level.

Investments in dedicated research may help to reach the targets. MEP Hadjigeorgiou pointed out that in the case of a major disease such as RMDs, initiatives to tackle access barriers should be framed in a set of coherent and consistent measures in order to provide an effective response to the enormous burden of these conditions. To this end, he called for the adoption of a EU Strategy on RMDs, similar to EU frameworks on other major chronic diseases.

Such a strategy, and more in particular the measures to reduce access barriers, also require the commitment of stakeholders. To this end, Prof. Cutolo and Mr. Kouloumas stressed that EULAR is ready to provide support and engage in the design and implementation of policy initiatives, as it has been doing in recent years.

Appendix 1: Workshops conclusions

Workshop 1: Health systems responses to financial constraints

Main Barriers/issues	Policy recommendations	
<p>Access to specialist care:</p> <ul style="list-style-type: none"> • Training in primary care • Electronic information not integrated: data in different places collected, but not interrelated (e.g. privately, workplace, etc.) • Austerity affecting disadvantaged parts of population disproportionately 		
<p>Access to good outcomes:</p> <ul style="list-style-type: none"> • Inadequate emphasis on prevention of disability • Inefficient models of care • Costs of interventions 		

Workshop 2: Patient empowerment, health literacy & Information to patients

Main Barriers/issues	Policy recommendations	
Lack of time between patients and healthcare professionals	Member States / Regions	<ul style="list-style-type: none"> ➤ Collecting data in advance of consultations ➤ Transfer tasks between health professionals; ➤ Promoting eHealth ➤ Promoting self-management
Lack of involvement in healthcare policy planning and improvement.	EU institutions Member States / Regions Stakeholders	<ul style="list-style-type: none"> ➤ Gathering and sharing best practices ➤ Patient involvement in guideline development and standards of care – example from cancer care ➤ Training of patient representatives ➤ Partnership between patient and professional organisations
Division of cultures and power imbalance between patients and professionals	Member States / Regions	<ul style="list-style-type: none"> ➤ Education and continuous training of young health professionals ➤ Facilitating the provision of financing for information, training and support of patients
	Stakeholders	<ul style="list-style-type: none"> ➤ Developing educational programmes for patients and patient representatives
Insufficient access to healthcare professionals as intermediaries (nurses, etc.) to act as a catalyst between patients and professionals (translate knowledge)		

Workshop 3: Health professionals: availability/composition, roles, training, mobility, accreditation

Main Barriers/issues	Policy recommendations	
Lack of public awareness / negative attitudes / lack of motivation	EU institutions	<ul style="list-style-type: none"> ➤ Information in different languages on health professionals role in MDT ➤ Funding of research on implementation of evidence on health professionals interventions
	Member States / Regions	<ul style="list-style-type: none"> ➤ Funding of multidisciplinary team as an incentive
	Stakeholders	<ul style="list-style-type: none"> ➤ Organization of joint meetings; more visibility; ➤ Strengthening collaboration between different professional organisations
Differences in definition / training / legal framework / scope of practice	EU institutions	<ul style="list-style-type: none"> ➤ Understand variation; definition of health professionals ➤ Defining specialists & postgraduate competencies
	Member States / Regions	<ul style="list-style-type: none"> ➤ Define scope of practice; legal framework ➤ Defining basic competencies
	Stakeholders	<ul style="list-style-type: none"> ➤ Involvement of patients ➤ Professional specific approach ➤ Engage legislative organizations and professional bodies ➤ Look at practices of other professionals (e.g. GPs)
Lack of care pathways / care strategies	EU institutions	<ul style="list-style-type: none"> ➤ Creating networks ➤ Workforce training and collaboration
	Member States / Regions	<ul style="list-style-type: none"> ➤ Professional societies encouraging networks ➤ Encouraging interdisciplinary teams ➤ Stepped care approaches
	Stakeholders	<ul style="list-style-type: none"> ➤ Professional organisations encouraging networks

Workshop 4: Access to treatments and medicines: availability, pricing and reimbursement

Main Barriers/issues	Policy recommendations	
Insufficient patient involvement (including for orientation of research and development)	EU institutions	<ul style="list-style-type: none"> ➤ To gather knowledge and good practices on patient involvement (EUPATI) ➤ Recommendations
	Member States / Regions	<ul style="list-style-type: none"> ➤ Implement recommendations in-full ➤ Include specific training for patients at state costs
	Stakeholders	<ul style="list-style-type: none"> ➤ Societies, pharma, universities: To support research on the area
Delay in the marketing authorisation and pricing and reimbursement processes	EU institutions	<ul style="list-style-type: none"> ➤ Review and Revise the processes ➤ Justification of the delay in the marketing authorization
	Member States / Regions	<ul style="list-style-type: none"> ➤ Review and Revise the processes ➤ Increase transparency ➤ Using patent extension rights for negotiations
Unequal access due to different eligibility criteria and variation between guidelines and protocols	EU institutions	<ul style="list-style-type: none"> ➤ Increasing research ➤ Collate and disseminate best practice ➤ Include societal costs ➤ More guidance from EMA
	Member States / Regions	<ul style="list-style-type: none"> ➤ Dissemination of EULAR recommendations with translation in country language
	Stakeholders	<ul style="list-style-type: none"> ➤ Patient and clinicians together lobby organizations that control market access
Silos between health systems budgets and welfare social systems	EU institutions	<ul style="list-style-type: none"> ➤ Promotion of the approach of health in all policies
	Member States / Regions	<ul style="list-style-type: none"> ➤ Cross departmental policies ➤ To include work as an outcome
	Stakeholders	<ul style="list-style-type: none"> ➤ To include work as an outcome ➤ Campaign the financial ministers