

EULAR Position Paper on Access to health care for people with rheumatic and musculoskeletal diseases (RMDs)

"[...] whilst ensuring equitable access to high quality health care services in circumstances of scarce economic and other resources has always been a key question, at present it is the scale and urgency of the situation that is changing and, if unaddressed, it could become a crucial factor in the future economic and social landscape of the EU"

Council of the European Union, 2011

1. INTRODUCTION

Access to quality health care is one of the main concerns for people with rheumatic and musculoskeletal diseases (RMDs) and other chronic conditions in European countries. Despite the principle implied in EU law and most national legislations that health services should be accessible to all, European citizens still have to cope with a number of access barriers. The pressure of the financial crisis, particularly on some health care systems, is making those barriers more evident, while deepening inequalities between better and worse-off groups of the population as well as between more affluent and less affluent EU Member States.

Access barriers are not only a problem for individuals in need of medical care. When it comes to major chronic diseases such as RMDs, tackling access barriers to quality care is vital to reducing the enormous burden of these conditions on the productivity of our economies as well as on the sustainability of our health care and social security systems. The number of people with chronic conditions (particularly major chronic diseases such as RMDs) and hence the number of people seeking health care, have significantly increased in recent years, to a large extent due to the ageing of the population and unhealthy lifestyles.¹ This demands specific public health and chronic condition strategies if we are to optimise health outcomes and reduce the burden of these diseases.

RMDs are in fact one of the most burdensome chronic conditions affecting European societies, a problem that is substantially increasing with an overall ageing of the population. RMDs comprise of more than 200 different diseases and include all painful conditions of the musculoskeletal system.² These affect the joints, tendons, ligaments, bones and muscles, while some of these disorders also involve internal organs. Among others, low back pain, osteoarthritis, rheumatoid arthritis,

¹ For instance, the demand in some countries for hip and knee replacement surgery continue to rise as a result of the growing elderly populations but also as a result of the challenges faced in tackling obesity and the lack of physical exercise.

² In some countries, the term "arthritis" is more frequently used than RMDs. Arthritis simply defined means 'joint pain'. However, this term has caused confusion and in many cases failure for people to seek urgent medical advice believing there is 'nothing that can be done for their condition'. It is for this reason that the term RMDs is used within the European Rheumatology community.

osteoporosis, ankylosing spondylitis are the most frequent and burdensome musculoskeletal conditions.

RMDs affect more than 120 million people in the EU (1 out of 4 persons) and are the number one cause of disability in Europe. Due to their disabling consequences, RMDs are one of the main causes of absenteeism, work loss and early retirement, the main occupational disease, while also explaining a large proportion of unemployment.³⁻⁴ In addition, RMDs are one of the most costly conditions, placing a yearly economic burden of more than € 240 billion on public budgets in Europe and accounting for a large proportion of national health care costs.⁵

Bringing down barriers to health care for people with RMDs (and other chronic conditions) is not an option, but a necessity. It is an investment that will ease the burden of RMDs on individuals and member states' coffers. It is an opportunity to not only enhance citizens' health and socio-economic inclusion, but also increase productivity and reduce the strain on public health systems and social security systems.

The aim of this paper is to present some of the main access barriers faced by people with RMDs and other chronic conditions in the EU⁶ (including access to cross-border care) and call EU institutions, national and regional authorities and stakeholders to implement a number of policy actions to tackle those barriers.

This position paper recognises the different circumstances in each country and that recommendations will be different on a country-by-country basis. The recommendations should therefore neither be seen as finite nor as all-encompassing. They are calls to action at EU level, national & regional level as well as for stakeholders that can be adapted for each country.

Most of the barriers identified in this paper as well as the set of recommendations are based on the results achieved during two Pan-European Conferences EULAR organised in 2014 and 2015 respectively: *"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"* (Brussels, October 2014); and *"Towards more integrated health care in Europe: Strengthening patients' access to cross-border care and enhancing health professionals' mobility"* (October 2015). The two events were hosted by MEP Takis Hadjigeorgiou and were organised with the support of key stakeholder organisations.⁷

For the development of this position paper, EULAR got the support of its member organisations at national level, who revised the first draft and provided evidence of the access barriers identified in the document.

³ For instance, the percentage of sick leave days attributed to RMDs ranges from 19% in Slovenia (2006) to 40% in Belgium (2008) [Musculoskeletal Health in Europe, eumusc.net Report].

⁴ According to experts of the Academic Network of European Disability (ANED), unemployment is –on average- twice as high for people with disabilities (ANED: Targeting and mainstreaming disability in the context of EU2020 and the 2012 Annual Growth Survey, Synthesis report, 2012.)

⁵ In Germany, for example, RMDs is the fourth most costly illness (11,2% of the total illness cost), only slightly below mental disorders (11,3%) [Source: Cost of illness accounts, Federal Statistical Office 2011; cited in eumusc.net report: Musculoskeletal Health in Europe].

⁶ There are important differences between Member States with regard to access to health care issues.

⁷ The European Public Health Alliance (EPHA), the European Patients' Forum (EPF), the European Hospital and Healthcare Federation (HOPE), and the Standing Committee of European Doctors (CPME) collaborated in the development of workshops during the EULAR Conference in 2014. EPF, the European Health Telematics Association (EHTEL), and CPME collaborated in the development of workshops during the EULAR Conference in 2015.

2. MAIN ACCESS BARRIERS FOR PEOPLE WITH RMDs AND OTHER CHRONIC CONDITIONS

People with RMDs (and other diseases) experience various types of barriers, whose determinants can be grouped in 5 main clusters:

- a. Health systems coverage and management (in terms of the proportion of the population covered as well as the depth of the coverage)
- b. Performance and organisation of health care services
- c. Relationship of patients with health professionals⁸, health systems and treatments
- d. Availability and affordability of medicines and treatments
- e. Provision of cross-border health care in the EU

The main barriers within each cluster are briefly described in this section. Not all access barriers are mentioned, rather focusing on those that represent a major concern for people with RMDs. Following on from this, key policy recommendations are set out for European and national/regional decision-makers, as well as stakeholders.

a. Health systems coverage & management

The size, extent of coverage, and principles of health systems ultimately establishes a bigger or smaller group of the population whose health care needs will be unmet, either by limiting the entitlements of citizens or by limiting the resources available. For people with RMDs and other chronic diseases, barriers of this kind are mostly related to the insufficient coverage and supply of health care services as well as with the narrow approach of health systems, which almost exclusively focus on access to medical treatments.

Insufficient supply and coverage

While the tendency towards full, universal and inclusive coverage prevailed for a long time in most EU Member States, the tendency has reverted in recent years in many, to a large extent as a consequence of the financial crisis. The insufficiency of supply⁹ and coverage is the result of two interrelated trends. First, an increase in the demand of health care services, particularly amongst the more vulnerable groups of the population. Second, the reduction in public expenditure on health care.¹⁰ This has also resulted in a lack of modern technical equipment in many of the crisis-struck countries, something people with RMDs have strongly noticed. The impact of the crisis on national budgets has particularly struck health systems such as those of Greece, Portugal, or Spain, among others. These have seen a decrease not only in spending but also in coverage.

⁸ “Health professionals” refers to all professionals participating in the provision of care and rehabilitation and not only to physicians: e.g. nurses, physiotherapists, etc.

⁹ Latvia, for instance, employs a system that limits the amount of joint replacements that are covered with patients having to wait up to 2 years for surgery. Patients who can afford to pay for joint replacement themselves receive surgery quicker, leading to inequality of access.

¹⁰ Karanikolos et al (2013): Financial crisis, austerity, and health in Europe; The Lancet Journal.

Many countries also report a shortage of health professionals specialised in RMDs, leading to an overall lack of knowledge and specialised care for people with RMDs.¹¹

Narrow approach of health care - Silos between health systems and social welfare systems

For people with RMDs, access to health care goes beyond access to medical facilities, doctors, health professionals, treatments and medicines. The primary, secondary and tertiary prevention and the management of many RMDs often require, for instance, adequate or special working conditions or the provision of social care. However, the narrow approach towards health care and the tendency of policy areas and departments to work in silos and not in a coordinated or cooperative manner, often result in the underestimation of non-medical treatments, the absence of integral and coherent health (and social) care, loss of part of the effectiveness of medical treatments, or even in contradictory effects of medical and non-medical practices. For example, while remaining at work or returning to work as soon as possible is strongly recommended to slow down or stop the progression of several RMDs, the working conditions and pension systems often discourage or prevent people with these conditions to retain an active working life. This narrow approach also leads to unwanted outcomes of budgetary decisions, as the impact of funding cuts to social care and welfare on the health of people with RMDs and other chronic conditions is not sufficiently taken into account. Cross-departmental policies could significantly improve the provision and outcomes of integrated care. Evidence from Sweden and other countries, for instance, showed that joint governance structures and budgets can lead to considerable systematic improvements.¹²

b. Performance and organisation of health care services

While the size, coverage and approach of health systems determine who will be covered and what type of coverage will be provided, a large number of barriers are found in the way health care services are organised as well as in the performance of health care services. Although linked to the size and coverage of health systems, these types of barriers prevent people with RMDs and other chronic conditions from getting adequate treatments, even if they are entitled to them.

Delay in timely access to diagnosis and treatment

Early diagnosis and treatment are important for many chronic diseases, and they are vital for RMDs. If not treated timely, many RMDs could be irreversible and lead to disability. Lack of access to early diagnosis and treatment is one of the main access barriers faced by people with RMDs.¹³ There are three main factors that explain these delays: late visits to doctors, lack of timely referral to a RMD specialist, and lack or insufficient number of specialists and specialised care centres. Late visits to doctors are often due to a lack of knowledge and awareness about RMDs as well as a misconception

¹¹ In Portugal, for instance, there is a lack of rheumatology department at a major hospital in some referral areas for more than 300,000 inhabitants.

¹² McQueen D et al (Eds) (2009): "Intersectoral governance for health in all policies. Structures, actions and experiences"; WHO Europe & European Observatory, http://www.euro.who.int/_data/assets/pdf_file/0005/171707/Intersectoral-governance-for-health-in-all-policies.pdf.

¹³ Rheumatoid Arthritis (RA) is an example where a disease can lead to disability if not treated timely. RA can only be appropriately treated if diagnosed within 6 weeks of the onset of symptoms. However, currently a third of RA sufferers in the UK have to wait 6 months to obtain referral for specialist care, with nearly one quarter having to wait over a year (National Audit Office. 2009. Services for People with Rheumatoid Arthritis. NAO London. http://www.nao.org.uk/publications/0809/services_for_people_with_rheum.aspx).

that sees RMDs as a natural consequence of ageing. Late referrals are often the result of insufficient training of GPs and primary care professionals, who often fail in identifying a musculoskeletal condition that could be treated by specialists. Finally, the lack of (an adequate amount of) specialists, specialised care centres and rehabilitation institutions is an important barrier in many places, which can result in long waiting times¹⁴ or the need for patients to find treatment elsewhere. A contributing factor to the often insufficient number of RMD specialists, is the underrepresentation of RMDs in the curriculum of many medical schools.

Lack of care pathways & standards of care

Health care trajectories and standards of care are crucial in ensuring effective treatment and promote the efficient use of health care facilities and resources. However, the provision of health care for people with RMDs often lacks such pathways and standards and too often focuses on emergency short-term treatment. These factors create a barrier to effective long term treatment of RMDs. Furthermore, there is a lack of recognition of the importance of educating patients to understand their care pathway and to encourage more self-management approaches that should be built into any care pathway. This results in a considerable variability in the provision of care, while preventing improvements in access to quality health care.¹⁵ Furthermore, the lack of coordination and collaboration between health professionals or the absence of effective interdisciplinary teams, also contribute to a reduction in the effectiveness of treatments.

Care pathways and standards of care are also increasingly defined by periods in different countries. A mismatch between availability and competences of the health workforce on the one side and patients' requirements and expectations on the other is visible across Europe. This is particularly manifest in the overall low levels of awareness of RMD treatment at primary stage, lack of standards for various health professional groups, an incompatibility of competences and patients' pathways and a general unawareness of treatment opportunities for RMDs. Many of these issues are particularly relevant in cross-border health care where disparities between countries can have a major impact on patients' access to quality care.

Lack of integration of electronic information and use of eHealth technology

Information technology has helped to innovate many sectors, but more needs to be done in health care. For genuine high quality care all necessary information needs to be available to practitioners and patients, be it information from the workplace, personal or from other health professionals. However, the relevant electronic information is not integrated, hence preventing more effective and coordinated health care.

eHealth also has the potential to improve the treatment of RMDs and other chronic diseases, while acting as a tool for patient empowerment and self-management. The potential for scale effects and reduced need of geographical proximity to health professionals can act as a catalyst for overall

¹⁴ Examples of waiting times for RMD in some EU countries: In Latvia, waiting time for rheumatology consultation is approximately 3 to 4 months. In Ireland, waiting time for (non-urgent) rheumatology services stands at 18 months. In Italy, waiting times for RMD specialists are reported to have reached more than 6 months. In Hungary, average waiting time for knee orthopaedic surgery stands at 530 days. In Germany, average waiting time for Rheumatoid Arthritis (from appointment to diagnosis) is more than 18 months.

¹⁵ The UK's National Institute for Health and Care Excellence (NICE) has developed such a pathway for RA with clear guidelines on execution. This paper acknowledges the existing work done through projects such as the Innovation Partnership on Active and Healthy Ageing (EIP on AHA), but sees the need to increase the usage of these (Rheumatoid Arthritis: National clinical guideline for management and treatment in adults, NICE, published by Royal College of Physicians, (2009).

improvements in access to quality health care. However, there are still barriers for these new technologies in reaching the patient. Often, they disproportionately focus on organisational improvements and cost efficiencies for health care providers rather than offering tangible treatment benefits for patients. EU-wide access to these new technologies is also impeded by an absence of common technical language and different legal frameworks across Europe.

c. Interaction between patients and health professionals, health systems and treatments

Although linked to other barriers mentioned above, there are special types of barriers that occur in the interaction of patients with health systems, services, providers and health professionals. In particular, these barriers concern the time available for patients during medical visits, the power imbalance between patients and medical doctors, and the insufficient access to other health professionals.

Insufficient time between patients and health professionals

Due to the increasing demand of health care, the shortage of resources and the pressure to make the most efficient use of health professionals and other resources, the time patients spend with health professionals (particularly doctors) is generally reduced to the minimum. This has a severe negative impact on the quality of care that patients receive. Among others, this affects the possibility of effective communication where, for instance, doctors could explain different treatment options to patients.¹⁶ Furthermore, the insufficient time physicians allocate to each patient is not compensated by other health professionals (like specialised nurses, for instance), partly due to the fact that health professionals other than medical doctors do not act as intermediaries between doctors and patients (see below).

Cultural differences and power imbalance between patients and health professionals

With the increase of multicultural and multilingual societies, both health professionals and patients often have to cope with linguistic and cultural differences. Such differences often impose communication barriers that affect proper access of patients to quality health care. In addition, there still exists an imbalance of power between physicians and patients, where doctors are seen as “beyond questioning” and patients are uncomfortable providing feedback or asking questions. Although this traditional relationship is changing, the still widespread power imbalance affects the communication between health professionals and patients.

Insufficient access to other health professionals (nurses, etc.)

Health professionals other than physicians (e.g. nurses, physiotherapists, etc.) could make a significant contribution to improving access to health care by acting as catalyst between patients and doctors. Such a role would be particularly important in times of limited resources, lack of an adequate amount of medical doctors (particularly specialists), reduced consultation time between physicians and

¹⁶ In the UK, for instance, doctors openly confirm that deciding what can safely be omitted for each patient as the consultation is truncated from an hour to 10 minutes and what must be included is a matter at great art and skill (<http://www.patient.co.uk/doctor/history-and-physical-examination>).

patients, and long waiting times. There are also cases where rheumatologists are replaced by other doctors and put in charge of RMD management even though they are not sufficiently trained in RMDs. Furthermore, there is a need for access to more specialist nurses¹⁷ and other health professionals who can supplement doctors' interventions with more details and follow up with support for information and guidance – such as telephone advice line support. However, people with RMDs and other chronic conditions do not have sufficient access to these health professionals either.

In addition there is also a lack of cooperation and communication between different health professionals. This has two unwelcome consequences: lack of confidence when referring patients to other health professionals and lack of cooperation when patients require treatment by different specialists (e.g. detrimental for well-organised comorbidity treatment).

d. Access to medicines and treatments

Barriers of this kind are particularly related to the availability and affordability of medicines and treatments. There are substantial inequalities between EU Member States when it comes to access to medicines and treatments, especially as some studies have suggested that access to expensive drugs is directly related to a country's GDP.

Unequal eligibility rules for treatments and medicines

Eligibility criteria for accessing treatments and medicines differ between Member States. Thus, people with RMDs are not equally entitled to receive and be reimbursed for specific treatments (the cases of biosimilars and off-label drugs being examples of this in Germany). To some extent, this is the result of different policy goals and regulatory frameworks, but also the result of variations between protocols and guidelines.

Delay in the marketing authorisation, pricing and reimbursement processes

Delays of this kind often pose a significant burden on people with RMDs in different Member States. As early treatment is crucial for slowing down or stopping the progression of RMDs, as well as preventing the disabling consequences of many of them, unnecessary delays in marketing authorisation, pricing and reimbursement may have a severe impact on health and wellbeing of people with these conditions.¹⁸ To a large extent, these delays are the result of inadequate procedures and the absence of effective controls and oversight.

Insufficient patient involvement in the development of new therapies

The participation of patients in research and in the development of new therapies is beneficial for improving research outcomes and the overall development of new treatments. Patients are experts in living with their diseases and thus have a unique experiential knowledge that could be used at different stages of the development of new therapies (e.g. in designing the methodology, in clinical

¹⁷ In Spain, for example, only 37.5% of patients have access to rheumatology nursing care.

¹⁸ For example, for those new medicines that doctors can prescribe under the national health care provisions, average time elapsing between the date of EU market authorisation and the "accessibility" date (i.e. date of completion of pricing / reimbursement procedures) will vary from 116 to 550 days (source: EFPIA).

trials, in the evaluation of results, etc.). However, patient involvement is still insufficient, partly due to the lack of training of patients, as well as researchers and developers.

e. Cross-border access to high-quality treatment

For people with RMDs and other chronic diseases being able to receive treatment, not just in their home country but across the EU by recognised specialists is essential. The cross-border health care Directive, adopted in 2011, expanded this possibility and patients are now supposed to be able to receive treatment in another Member State and be reimbursed¹⁹. This new mechanism has the potential to improve access, quality and timeliness of health care and is widely welcomed by people with RMDs and other chronic diseases.

However, this new instrument has not yet lived up to its transformative and access-improving potential despite Member States having had to transpose the Directive by October 2013. The implementation and effectiveness gap was recognised by the European Commission in its report on the operation of the Directive.²⁰ To the disappointment of people with RMDs and other chronic diseases, there are still substantial barriers for patients exercising their right to cross-border health care, both as a result of deficiencies in the legislation itself and its insufficient implementation in different Member States.

Without a doubt, the major shortcoming can be found in the implementation at Member State level, many of which show a pronounced lack of ambition. The Directive established National Contact Points (NCP) within the Member States in order to assist patients in seeking treatment abroad. Many of the barriers could be eliminated through better operation and coordination of the NCPs, as well as more ambition by the Member States.

Lack of awareness and access to information

The most fundamental prerequisite for the successful implementation and operation of any policy is awareness by the intended target group, an area where the Directive is particularly underperforming. As a survey of EULAR's patient organisations, as well as a special 2015 Eurobarometer showed, patients lack awareness and knowledge of their rights to cross-border health care²¹.

There are two fundamental reasons explaining this lack of awareness, one being delayed transposition and implementation of the Directive by some Member States, and the other the reluctance by governments and health care systems to inform patients about their rights. In addition, patients who are aware of the mechanism feel incapable of understanding the jargon and complex language of the available information. All these factors prevent patients from accessing quality health care across Europe, which they are clearly entitled to.²²

Financial barriers and reimbursement

Financial constraints for patients wishing to exercise their right to cross-border health care are particularly worrying. People with RMDs, already facing substantial health care expenses, often do not

¹⁹ Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare

²⁰ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, available under http://ec.europa.eu/health/cross_border_care/docs/2015_operation_report_dir201124eu_en.pdf

²¹ Special Eurobarometer 425: Patients' rights in cross-border healthcare in the European Union

²² It has to be said that this reluctance does vary between the Member States, with some serving as positive examples.

have the necessary resources to cover the upfront payments required by many Member States and also experience delays in reimbursement.

Furthermore, the choice of whether travel costs and accommodation for patients and their accompanying family members are reimbursed is at the discretion of the Member States and therefore not consistent across the EU. Often patients have to cover these costs and when faced with additional financial barriers, choose not to pursue cross-border health care in spite of possible better treatment options. Overall, patients lack an overview of the total cost of treatment abroad, which would help them make a qualified decision. Complexity is also widespread in the reimbursement procedure, where patients are unsure about the timeframe and practicalities.

Communication difficulties and continuity of care

The underpinning of informed consent, the key behind appropriate health care choices, is seamless communication between patient and health professional. Unsurprisingly, this is at times problematic in cross-border health care, where language problems can lead to potentially dangerous misunderstandings. There is a lack of understanding and absence of solutions to alleviate this growing problem.

Importantly, quality health care can only be ensured when all information is available to patients and health professionals at all times and across borders. Too often, communication ends at countries' borders, with a lack of formal and informal communication channels and insufficient data-exchange between them. Continuity of care is also a crucial concern for patients, who need to be assured that the next steps in their treatment are available in their home country. People with RMDs and other chronic diseases at times lack the guarantee of access to after-care, medicines and rehabilitation in their home country.

3. RECOMMENDATIONS

Having considered the barriers that people with RMDs face, the following section will provide key policy recommendations for EU and national policy makers on each barrier. In order to support policy makers' efforts it is also necessary for other stakeholders to take action. Implementation of these recommendations will help to achieve the crucial aim of improving access to quality health care for patients with RMDs.

a. Health systems coverage & management

Barrier: Insufficient supply and coverage		
Policy goals: To ensure adequate provision of financial and technical resources to ensure access to quality and timely care for people with RMDs and other chronic conditions		
EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> • To set up, together with MS, a monitoring system to periodically assess the state of access to health care • To assess the impact of austerity measures on access to health care • In implementing financial support packages to MS, to exclude austerity measures when they significantly affect the provision of health care services • To promote innovative practices in ensuring quality and timely access to care following budget cuts in health care expenditures • To research and develop EU-wide recommendations on the necessary number of specialised RMD health professionals for a certain population size 	<ul style="list-style-type: none"> • To monitor and examine access to health care, in coordination with the EU • To make access to health care a priority goal, particularly in times of financial restrictions • To promote research and innovation in health care to face challenges in the provision and access to health services • To ensure that patients and health care professionals organisations in the RMD and other chronic diseases fields are involved and heard in the policy making process on health care policies 	<ul style="list-style-type: none"> • To raise awareness about access barriers to health care • To actively participate in the policy-making process, providing advice and opinions on policy measures, participating in assessments of health care services, and advocating for adequate supply and coverage of health systems, among others

Barrier: Narrow approach of health care - Silos between health systems and social welfare systems		
Policy goals: To promote access to integral care of RMDs, including actions in areas other than medical care		
EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> • To promote best practices and encourage MS to follow an inter-sectoral and cooperative approach towards health care, including health in all policies • To support research on the impact of working conditions on health recovery 	<ul style="list-style-type: none"> • To develop cross-departmental policies aiming to improve access to health care in a broad sense, including employment under certain conditions as an integral part of the treatment • To make sure that possible funding cuts in social care and welfare do not adversely impact on the health of people with RMDs 	<ul style="list-style-type: none"> • To raise awareness on the need for a broader, integrative approach to health care • To advocate for integral solutions to care, including the coordination of different policy areas

b. Performance and organisation of health care services

Barrier: Delay in timely access to diagnosis and treatment		
Policy goals: To ensure that people with RMDs have access to early diagnosis and treatment		
EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> • To promote best practices in reducing waiting times • To promote the development and implementation of standards of care for RMDs • To promote wide standards of education that ensures primary care professionals are able to identify RMDs or have adequate access to specialist health professionals or medical support • To promote the participation of patients and health professionals in the development of policies to reduce delays in diagnosis and treatment 	<ul style="list-style-type: none"> • To implement improvements in RMD recognition training for health professionals at primary care level • To monitor delays in diagnosis and treatment and take action where necessary (through measures such as waiting time guarantees) • To develop and implement standards of care for RMDs, in coordination with other MS • To ensure the availability of specialist health professionals in RMDs (e.g. through support for more university-level training for RMDs) • To implement campaigns that raise awareness of RMDs, as well as the consequences of late diagnosis and treatment 	<ul style="list-style-type: none"> • To advocate for and participate in the development of standards of care • To raise awareness of RMDs, as well as on the consequences of late diagnosis and treatment

	<ul style="list-style-type: none"> To ensure that patients and health care professionals organisations in the RMD and other chronic diseases fields are involved and heard in the policy making process 	
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Barrier: Lack of care pathways & Standards of care

Policy goals: To promote the development and implementation of care pathways & standards of care, health professionals' development, as well as the development of networks and interdisciplinary teams

EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> To support the development and implementation of standards of care for people with RMDs across Europe and collect comparable evidence To promote best practices in care pathways, integrated care and multidisciplinary teams To promote networks of health professionals at the EU level To develop professional standards (medical and non-medical) To support research in innovative health care organisation 	<ul style="list-style-type: none"> To develop and implement standards of care & care pathways for people with RMDs, in collaboration with other MS and stakeholders To require the collection of standards of care and health quality indicators To encourage interdisciplinary teams and the use of the stepped care model To establish a health workforce able to deal with all stages of the patient pathway (training, education, continuous professional development, incentives for medical students) To develop a reimbursement system that provides for all services along the patient pathway 	<ul style="list-style-type: none"> To encourage the development of health professionals' networks To advocate for and participate in the development of standards of care and care trajectories To produce, disseminate and implement best practice recommendations for high-quality RMD care

Barrier: Lack of integration of electronic information and use of eHealth technology

Policy goals: To further develop regulatory, technological and organisational procedures aiming to facilitate the integration of electronic information, and encouraging the development and uptake of patient-centred eHealth technology

EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> To promote best practices in the integration of electronic information 	<ul style="list-style-type: none"> To promote the development of common regulatory, technological and 	<ul style="list-style-type: none"> Advocating for and enabling patients' and clinicians'

<ul style="list-style-type: none"> • To further support research and innovation in eHealth issues • Develop common legal framework and communication standards for eHealth • Aligning policies across different diseases with the active involvement of stakeholders 	<p>organisational procedures aiming to facilitate the integration and use of electronic information in health care</p> <ul style="list-style-type: none"> • To ensure that the opinions of patients organisations are taken into account in the development and implementation of eHealth regulations and technologies • Aligning eHealth technology with vision of moving care from hospital to home 	<p>involvement in defining system needs</p> <ul style="list-style-type: none"> • Advocating for patient-centred approach (rather than institutional/managerial focus)
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c. Interaction between patients and health professionals, health systems and treatments

Barrier: Insufficient time between patients and health professionals		
Policy goals: To ensure that limited time between medical doctors and patients is compensated by other means, in order to guarantee fluent and adequate information and enhance patient engagement with self-management approaches		
EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> • To further develop and promote the use of eHealth technologies in health care 	<ul style="list-style-type: none"> • To promote the collection of data in advance of consultations • To promote the transfer tasks between health professionals • To further develop and implement the use of eHealth technologies in health care • To promote self-management 	<ul style="list-style-type: none"> • To promote self-management among patients • To advocate for and participate in the development and implementation of eHealth technologies

Barrier: Cultural differences and power imbalance between patients and health professionals		
Policy goals: To reduce the impact of cultural differences on health care outcomes. To reduce the power imbalance between patients and health professionals and promote more horizontal, collaborative models of shared decision-making		
EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> • To promote best practices in the management of risks associated 	<ul style="list-style-type: none"> • To train health professionals in dealing with cultural differences 	<ul style="list-style-type: none"> • To provide information, training and education for patients in

<p>with cultural differences in health care</p> <ul style="list-style-type: none"> • To promote patient-centred care and also enable active participation and ownership of health and well-being by individuals with chronic conditions 	<ul style="list-style-type: none"> • To train health professionals in empowering patients and building patient-centred approaches to care • To facilitate the provision of financing for information, training and support of patients in dealing with cultural differences and power imbalances 	<p>managing cultural differences and power imbalances with health professionals</p>
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Barrier: Insufficient access to other health professionals (nurses, etc.)		
Policy goals: To promote the role of other health professionals as intermediaries between patients and medical doctors		
EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> • To support research and good practices in the use of other health professionals as intermediaries 	<ul style="list-style-type: none"> • To promote access to other health professionals in health care services • To promote collaboration and a multi-disciplinary approach among health professionals (e.g. through creation of liaison health professional) 	<ul style="list-style-type: none"> • To support legislative frameworks and policy initiatives that encourage greater specialist expertise and support offered by nurses and other health professionals

d. Access to medicines and treatments

Barrier: Unequal access to treatments and medicines		
Policy goals: To promote equal access to treatment and medicines by harmonising protocols, guidelines and standards of care		
EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> • To further support research in access to treatments and medicines in Europe • To collate and disseminate best practice in access to treatments and medicines • To further develop guidance from the European Medicines Agency 	<ul style="list-style-type: none"> • To disseminate EULAR recommendations with translation in country language • To increasingly include representatives from different stakeholders in the development of new guidelines (Health professionals, patients, etc.) 	<ul style="list-style-type: none"> • To encourage patients and clinicians to jointly lobby organisations that control market access • To regularly disseminate internationally recognised guidelines and recommendations to national organisations

Barrier: Delay in the marketing authorisation, pricing and reimbursement		
Policy goals: To improve the marketing authorisation, pricing and reimbursement procedures in order to reduce delays		
EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> To review and revise the processes of authorisation and pricing To include the justification of the delay in the marketing authorisation 	<ul style="list-style-type: none"> To review and revise the processes of authorisation, pricing and reimbursement To increase transparency To use patent extension rights for negotiations 	

Barrier: Insufficient involvement of patients in the development of new therapies		
Policy goals: To promote the participation of patients and patient organisations in the development and evaluation of new therapies		
EU	Member States/Regions	Stakeholders
<ul style="list-style-type: none"> To gather knowledge and good practices on patient involvement (EUPATI) To promote the involvement of patients in research and in the development of new therapies 	<ul style="list-style-type: none"> To implement recommendations in full To include specific training for patients through public funding 	<ul style="list-style-type: none"> Societies, pharmaceutical companies and universities: To support research in the area of patient involvement in the development of new therapies

e. Cross-border access to high-quality treatment

Barrier: Lack of awareness and access to information		
Policy goals: To ensure that Member States fully implement the Directive and patients are aware and understand their right to cross-border health care		
EU	Member States/Regions & NCPs	Stakeholders
<ul style="list-style-type: none"> To ensure that all MS fully and adequately implement the Directive and launch further infringement procedures against MS if necessary To raise awareness through EU-wide information campaign To offer education programmes for all actors involved regarding the functioning of the Directive 	<ul style="list-style-type: none"> To refrain from discouraging patients in exercising their rights to cross-border health care To actively encourage use of health care in another MS when it offers better treatment opportunities To consistently use lay language in all communication on the mechanism and facilitate 	<ul style="list-style-type: none"> To make members aware of their right to cross-border care To encourage and participate in the development of networks that seek to implement the Directive (e.g. health professionals, patients, health insurances)

(HoNCAB project as a positive pilot project)	information access (e.g. through mobile apps)	
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Barrier: Financial barrier and reimbursement

Policy goals: To make sure that patients are not discouraged from seeking the best possible health care across the EU as a result of financial barriers

EU	Member States/Regions & NCPs	Stakeholders
<ul style="list-style-type: none"> • To aim for the adoption of the direct payment systems by all MS • To ensure that MS' reimbursement mechanisms work without delay and complexity for the patient • To provide clear timeframes for reimbursement and benchmark MS on duration of reimbursement 	<ul style="list-style-type: none"> • To adopt the direct payment system, which should at least cover advance payments for people facing financial hardship • To provide for travel and accommodation for an appropriate number of accompanying persons (especially parents) • To provide comparable information on full costs of health care in another country (e.g. financial overview and timeline) 	<ul style="list-style-type: none"> • To advocate for a quicker and less complex reimbursement procedure, as well as adoption of the direct payment system

Barrier: Communication difficulties and continuity of care

Policy goals: To improve communication between everyone involved in the provision of health care and ensure continuity of care is upheld across borders

EU	Member States/Regions & NCPs	Stakeholders
<ul style="list-style-type: none"> • To establish a training/education programme for medical linguistic facilitators • To support patient and health professionals organisations assisting their members in cross-border care • To explore the development of a "smart card" that includes all relevant medical records for treatment across the EU • To develop best-practice guidelines for the transfer of patient data at EU level 	<ul style="list-style-type: none"> • To provide translation of medical documents and prepare health professionals for incoming patients from other countries • To provide information on language capacities of medical specialists • To facilitate the transfer and access to electronic health records across borders 	<ul style="list-style-type: none"> • To advocate for continuity of care as a key consideration in cross-border care • To actively build formal and informal networks between health professionals in order to ensure continuity of treatment • To assist patients in accessing cross-border health care (e.g. translation assistance, travel guides)