

Common language description of the term rheumatic and musculoskeletal diseases (RMDs) for use in communication with the lay public, healthcare providers and other stakeholders endorsed by the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR)

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ABSTRACT

A European League Against Rheumatism-American College of Rheumatology working group consisting of practising and academic rheumatologists, a rheumatology researcher and a patient representative created a succinct general statement describing rheumatic and musculoskeletal diseases (RMDs) in adults and children in language that can be used in conversations with the lay public, media, healthcare providers and other stakeholders. Based on the literature review, several elements were deemed important for inclusion in the description of RMDs. First, RMDs encompass many different diseases that can affect individuals at any age, including children. Second, there are various pathophysiological pathways underlying different RMDs. Third, the impact of RMDs on individuals and society should be emphasised. The working group agreed that the language should be comprehensible to the lay public. Thus, the following description of RMDs has been developed: 'Rheumatic and musculoskeletal diseases (RMDs) are a diverse group of diseases that commonly affect the joints, but can affect any organ of the body. There are more than 200 different RMDs, affecting both children and adults. They are usually caused by problems of the immune system, inflammation, infections or gradual deterioration of joints, muscles and bones. Many of these diseases are long term and worsen over time. They are typically painful and limit function. In severe cases, RMDs can result in significant disability, having a major impact on both quality of life and life expectancy.' This description can be used by rheumatology groups, researchers and those who work in advocacy and education related to RMDs.

The field of rheumatology encompasses a wide range of medical conditions that affect many organ systems. These conditions reflect diverse pathogenic mechanisms and result in functional limitations, diminished quality of life and increased patient mortality. In addition, although rheumatic conditions in total are among the most common of all medical problems, many of the individual diseases are uncommon or even rare. This situation results in an ever-present dilemma for the field. Most of the public and policymakers around the world do

not know about many of the rheumatic and musculoskeletal diseases (RMDs) and even if they have heard of them, there is broad lack of awareness about the complexity and enormous importance of this area of medicine.

To further public awareness and support policies directed towards lessening the impact of these diseases on patients and society, a working group from the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR), consisting of practising and academic rheumatologists, a patient representative and a rheumatology health professional, has developed a formal description of these conditions. The goal of this effort was to create a succinct general statement describing RMDs in adults and children in language that can be used in conversations with the general population with and without RMDs; media; healthcare providers; policymakers at local, national and international levels; health insurance companies; charities; employers and other stakeholders.

Several elements were deemed important for inclusion in the description of RMDs by the group. First, it should be emphasised that RMDs encompass many different diseases that can affect persons at any age, including children. Second, it should be clear that there are various pathophysiological causes of RMDs. Third, the impact of RMDs on individuals and society should be emphasised. Finally, the language should be easily understood by the lay public. Here we will discuss various aspects that provide relevant background information, which can be used during the discussion about the importance of RMDs with the relevant stakeholders.

METHODOLOGY

The participants of the working group were selected based on their position in the respective organisations. For EULAR this was the president, the chair of the EULAR standing committee of clinical affairs, the EULAR liaison to the ACR and a patient representative. For the ACR, the president and president-elect of the ACR, the president of the Association of Rheumatology Health Professionals and the president of the Rheumatology Research



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Foundation were included. The group met once in person, had one teleconference (TC) and all other exchanges were conducted by email. There was a scoping review of the literature with emphasis on grey literature such as reports from the European Union (EU).

RMDS ENCOMPASS MANY DIFFERENT DISEASES THAT CAN AFFECT PERSONS AT ANY AGE, INCLUDING CHILDREN

Data suggest that there are over 200 RMDs; some conditions are very common, while others are rare. Lists of RMDs have been compiled in a number of publications and survey results. For example, the ACR website features a detailed list as does the EULAR website.¹² The latter is considered the official list as applied by the European Union of Medical Specialists (EUMS) (see online supplementary appendix 1). In addition, the Arthritis Foundation, a patient organisation in the USA, and the ACR maintain patient-oriented lists of RMDs.^{3,4}

Well-known and prevalent examples of RMDs are rheumatoid arthritis (RA), osteoarthritis (OA) and gout. According to a conservative estimate of the United Nations, symptomatic OA, or degenerative joint disease, affects 15% of people worldwide, and it is estimated that by 2050, over 130 million people will suffer from OA worldwide and 40 million will be severely disabled.⁵

RA is the most common autoimmune inflammatory form of arthritis and affects approximately 1 in 100 persons worldwide, with women affected twice as commonly as men.⁶

Gout is the most common cause of inflammatory arthritis in men and has a prevalence in the USA and Europe of about 4%.^{7,8}

Many other RMDs are less common, but cause significant morbidity and mortality. For example, systemic lupus erythematosus, which affects women approximately nine times more frequently than men, is a systemic autoimmune disease that frequently causes arthritis and dysfunction of connective tissues among many other systemic manifestations.^{9,10} The overall lifetime risk for developing an inflammatory RMD including RA, gout, lupus and others for an adult in the USA has been calculated as 1 in 12 for women and 1 in 20 for men.¹¹ Many RMDs are uncommon or rare, which contributes to the lack of familiarity and/or experience with many RMDs on the part of general practitioners. RMDs frequently affect joints resulting in arthritis, and also frequently involve other internal organs and the skin. Although arthritis is commonly considered as a disease of ageing, many RMDs—including many that cause disabling arthritis—occur in children. Lack of awareness of these conditions in both children and adults can lead to excessive and unnecessary damage and disability.^{12–15}

THERE ARE VARIOUS PATHOPHYSIOLOGICAL PATHWAYS OF RMDS

Review of these many diseases and conditions indicates that they develop through a diverse range of pathogenic pathways, most of which are not completely understood. Many result from dysregulation and activation of immune mechanisms that lead to inflammation and tissue damage. Some of these are classified as autoimmune diseases. Other RMDs result from acute or chronic damage to musculoskeletal structures including bone, cartilage, muscle, tendon, ligament and blood vessels. Other primary metabolic, endocrine, neurologic and infectious diseases can lead to secondary dysfunction and damage of musculoskeletal tissue. For example, prolonged hyperglycaemia in diabetes can result in changes in the structure of tendons and other soft tissues resulting in impaired mobility and joint function. The metabolic changes of the iron-storage disease haemochromatosis can result

in degenerative arthritis in the hands. In addition, an increasing number of genetic variations and mutations are associated with the development of RMDs.

RMDS RESULT IN A MAJOR BURDEN FOR BOTH THE INDIVIDUAL AND THE SOCIETY

Many of the diseases are chronic and as they can start as early as during childhood (eg, juvenile idiopathic arthritis) or young adulthood (eg, spondyloarthritis), patients suffer with their disease for decades. Moreover, most RMDs worsen over time with increasing impact on both the physical and psychological conditions of the patient. Some patients die prematurely as a result of the condition or comorbidities, although if appropriately treated, mortality is relatively low in most of these conditions.

Large population studies emphasise that RMDs are highly prevalent worldwide. The eumusc.net project is a collaboration of 22 organisations in 17 member states of the EU investigating musculoskeletal health in Europe.¹⁶ Their report summarises the epidemiology of major RMDs, impact on the individual and society, and management and health services utilisation. They concluded that musculoskeletal problems are the most common cause of severe long-term pain and disability in the EU and lead to significant healthcare and social support costs. Moreover, RMDs are a major cause of loss of work productivity resulting in significant economic costs and may have serious impact on quality of life, affecting those with the conditions and their relatives.

Musculoskeletal pain is prevalent in the EU with just over one-fifth (22%) of the population reporting current or long-term muscle, bone and joint problems in a survey performed by the EU in 2007.¹⁷ Exactly a quarter of all EU respondents say that at some point in their life they have experienced chronic (lasting for at least 3 months) restrictive pain affecting muscles, joints, neck or back which affected their ability to carry out activities of daily living. Such pain is reported more by women than by men (28% vs 22%). Musculoskeletal pain is the second most common complaint underlying long-term treatment contributing to major healthcare costs.¹⁷ Twenty-four per cent of the respondents to the survey received long-term treatment for RMDs (second after hypertension with 36% of respondents). It is likely that the overall burden of arthritis is underestimated in virtually every population. A recent study from the USA using national data from a health interview survey and doctor-diagnosed arthritis and symptoms revealed that arthritis affected 91.2 million (36.8%) of the adult population, including about 29% of men and 55% of women between the ages of 18 and 65.¹⁸

RMDs were the most frequent reason among non-infectious diseases to consult the primary care physician in the UK in 2003, and this was increasing with age and higher in female patients in all age categories.¹⁶ In Germany, 11.2% of the total cost of illness in 2008 was spent on musculoskeletal and connective tissue diseases.¹⁶ These numbers appear to be rapidly increasing. For example, a recent report provides data on doctor-diagnosed OA in the USA between 2013 and 2015.¹⁹ A total of 54.4 million Americans (22.7%) had doctor-diagnosed OA and this percentage was even higher among adults with heart disease (49.3%), diabetes (47.1%) and obesity (30.6%). In 2012, 54% of people in the USA over age 18 reported suffering a musculoskeletal problem and the prevalence approached 75% for those aged 65 and older (Burden of Musculoskeletal Diseases in the United States).²⁰ Several factors have an impact on the prevalence of RMDs, including sex, age, body mass index and physical

activity. As the population is ageing this has a major impact on the prevalence of RMDs. For example, the EU will have 58 million more people aged 65 and over in 2050 in comparison to 2004.¹⁶ Similarly, obesity is increasing, which again will lead to a higher prevalence of RMDs.¹⁶

RMDs have led to significant reduction in function and quality of life as well as increased disability. Among those with OA, 43.5% of the adults experienced limitations in activity attributable to OA, and there was a significant increase of 20% in the proportion of adults reporting these limitations since 2002. The disability-adjusted life year (DALY) is a measure to compare impact of various diseases on disability and can be interpreted as the loss of 1 year of healthy life. The WHO listed OA as the eighth leading cause of impact measured by DALYs in their report on global burden of disease.²¹ Another way of assessing the impact on disability is the years lived with disability (YLD). The WHO listed musculoskeletal diseases as the third cause for disability among non-communicable diseases assessed by YLDs. And among musculoskeletal diseases, OA was the most common disease followed by RA, 'other musculoskeletal diseases' and gout.²² As common and impactful as musculoskeletal diseases are, such surveys do not always include the entire range of RMDs. This further underscores the high prevalence and cost of these conditions and emphasises the need for a unifying definition of RMD. An example of defining the global burden of 'other musculoskeletal disorders' was presented in a large study in 2010.^{23 24}

The International Quality of Life Assessment project examined the effect of multiple chronic conditions on populations in Denmark, France, Germany, Italy, Japan, the Netherlands, Norway and the USA using the 36-item Short Form Health Survey (SF-36). This showed that arthritis, chronic lung disease and congestive heart failure were the conditions with the highest impact on SF-36 physical component summary score. RA had a significant negative effect on the SF-36 mental component summary score. Arthritis had the highest impact on health-related quality of life (HRQoL) in the general population.²⁵ A large survey study in the Netherlands which compared HRQoL (using SF-36 or SF-24) across a wide range of long-term conditions showed that people with musculoskeletal conditions (included are back impairments, RA, OA/other joint complaints) reported the lowest levels of physical functioning, role functioning and pain.²⁶

A Spanish study showed that rheumatic diseases are among the diseases that produce the largest impairment in HRQoL and daily functioning.²⁷ When the definition of the burden of disease includes a measure of function and of HRQoL that is weighted by the prevalence of disease, RMDs, as a group, may be considered on a par with other major diseases such as neurologic, cardiac or pulmonary diseases.¹⁶

For many of the RMDs, it is important to recognise the disease early to have the best option to start treatment early and prevent or limit long-term consequences. To achieve this, EULAR has started the awareness campaign 'Don't delay, connect today'. The best example is RA. Early diagnosis, improved treatment options and applying treatment to target principles have improved the percentage of patients in (sustained) remission, and improved the quality of life and work productivity.^{28 29} Even overall excess mortality in patients with RA in comparison to the general population, which was apparent in previous decades, is lower and even no longer present when RA is diagnosed and treated early and intensively.^{30 31}

Cause-specific morbidities, such as cardiovascular disease, are greater in many of the RMDs, and may also be declining with improved disease management.³²

WORKFORCE TAKING CARE OF PATIENTS WITH RMDS

A range of practitioners manage musculoskeletal problems. These include medical specialists, general practitioners, community pharmacists, physical therapists (physiotherapists, chiropractors), occupational therapists and behavioural therapists (counsellors, psychologists and social workers). Rheumatologists, including paediatric rheumatologists, are the specialists with the most broad and specific training for diagnosing and treating RMDs. Rheumatology specialty training standardised by EUMS across the EU and the Accreditation Council for Graduate Medical Education in the USA requires proficiency in general internal medicine followed by detailed training in the pathogenesis, diagnosis and management of the entire range of RMDs.^{1 2}

The number of practising rheumatologists varies widely. The average number of rheumatologists in EU is 1.7 per 100,000 inhabitants, ranging from 0.5 in Ireland to 4.2 in France.¹⁶ Similarly, in the USA, the number of rheumatologists ranges from greater than 2 per 100,000 in heavily populated regions to less than 1.5 per 1,000,000 in more rural regions.³⁰ However, due to a variety of factors affecting physician workforce, including the increasing prevalence of RMDs, these numbers are changing rapidly. For example, recent workforce projections in the USA estimate that by 2025 the average number of rheumatologists in the large majority of the country will be 0.5–1.0 per 100,000 inhabitants.³³ There is also a severe shortage of paediatric rheumatologists as substantiated by a survey in the USA.³⁴ Other specialists caring for patients with RMDs are orthopaedic surgeons, internists and rehabilitation specialists. There is also a wide variation in the workforce of allied health professionals. The number of physiotherapists varies enormously across EU countries from 34 per 100,000 inhabitants in Ireland to 234 per 100,000 in Finland.¹⁶ Similarly, the variation in occupational therapists ranges from 2 in Italy to 100 per 100,000 inhabitants in Sweden and Denmark.¹⁶ In contrast, in the USA, there were about 114,600 occupational therapy jobs listed in 2014 for a population of close to 318,500,000 (360 per 100,000).³⁵

Based on the above data and considerations, the following common language description of RMDs was endorsed by both EULAR and ACR.

RMDs are a diverse group of diseases that commonly affect the joints, but can affect any organ of the body. There are more than 200 different RMDs, affecting both children and adults. They are usually caused by problems of the immune system, inflammation, infections or gradual deterioration of joints, muscles and bones. Many of these diseases are long term and worsen over time. They are typically painful and limit function. In severe cases, RMDs can result in significant disability, having a major impact on both quality of life and life expectancy.

SUMMARY

The description of RMDs is a succinct statement in common language detailing many of the important aspects of these conditions. Given the prevalence and impact of RMDs as well as the availability of effective management options, it is important to be able to communicate clearly what RMDs are with the public and stakeholders. It is especially imperative to communicate the impact and importance of RMDs to healthcare policymakers.

The many unanswered questions about the causes of RMDs, the importance of improved diagnosis for RMDs and clear need for effective and safe treatments that are unavailable for many

of these diseases emphasise the importance of increased research on RMDs. At the same time, the fact that many recent advances have been made in developing new therapies for RMDs so that many people are now treated very effectively—with prevention of disability and comorbidity—emphasises how critical it is that patients have ready access to diagnosis and care for these conditions. We hope that the description of RMDs provided in this report will enable improved communication about and advocacy for these conditions and the patients who suffer from them.

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