STUDY REVEALS SIGNIFICANT GAPS IN ESSENTIAL RHEUMATOID ARTHRITIS CARE ACROSS EUROPE AND BETWEEN EUROPEAN COUNTRIES

Over half of patients and rheumatologists report diagnosis within six weeks as the most problematic standard of care.

Madrid, Spain, 14 June 2019: The results of a large pan-European survey presented today at the Annual European Congress of Rheumatology (EULAR 2019) investigated significant gaps in rheumatoid arthritis care across 16 patient-centred Standards of Care (SoC) in rheumatoid arthritis.

Results reveal ‘diagnosis within six weeks’ as the most concerning SoC, with 52% (weighted means across countries) of patients and 59% of rheumatologists reporting problematic gaps. The next highest were; information about patient organisations (40% and 38%), training on aids, devices and ergonomic principles (39% and 34%), vaccination-related information (38% and 27%), receiving a schedule of regular assessment (33% and 23%), information on adequate physical exercise (35% and 20%), and availability of treatment plan (35% and 18%). The least frequent problematic SoC for both patients (8%) and rheumatologists (3%) was adequate disease-modifying anti-rheumatic drug received.

“It is concerning to see so many problematic gaps reported across many essential aspects of rheumatoid arthritis care,” said Rachelle Meisters, PhD, Care and Public Health Research Institute (CAPHRI), Maastricht University, The Netherlands. “We hope these results act as a loud wake up call to services across Europe.”

Analysis of the data reveals patients with higher education and lower self-reported health report problematic gaps more frequently. Among rheumatologists, patterns in determinants across SoCs were less consistent.

Country disparities by GDP

However, for about half of the SoCs, rheumatologists from lower gross domestic product (GDP) countries identified problematic gaps more often than those from medium or high GDP countries. Additionally, large variation remained across countries for patient analyses, and most rheumatologist analyses, despite adjustment for individual characteristics.

“At EULAR, our aim is to reduce the burden of rheumatic diseases on the individual and society and to improve the treatment, prevention and rehabilitation of musculoskeletal diseases within and across countries,” said Professor Thomas Dörner, Chairperson of the Scientific Programme Committee, EULAR. “These results highlight how far there is to go to translate
the advantages elucidated through scientific study into the daily care of people suffering these diseases.”

The survey included 1,422 patients from 27 European countries, and 1,044 rheumatologists from 33 European countries. The mean age was 57.2 and 47.7 for patients and rheumatologists respectively, with 74% and 53% being female. The 16 SoCs were those developed by Eumusc.net, a EULAR and EU supported initiative to raise and harmonise quality of care for patients across Europe. Participants were asked to rate each SoC on the level of care standard that was achieved (1-10), and on level of importance (1-10). The distance of level of care from the maximum was multiplied by the level of importance and was defined as problematic when this score was greater than 30 and the importance score was six or more.1

An additional study presented today at EULAR 2019 analysed the quality of care of patients with systemic lupus erythematosus in Germany. They also revealed significant gaps as on average only 61% of relevant care aspects were fulfilled. In a second step, the study analysed whether the quality of care was associated with disease outcomes.2

Results showed that fulfilling more quality measures in 2013 was predictive for high disease-related quality of life (p=0.004), low progress in disease-related damage (p=0.048) and low disease activity (p=0.046) in the subsequent years.2

“Our results show that consistent consideration of these care parameters, recommended in several management guidelines, yield a positive effect on outcome,” said Dr. Med. Anna Kernder, Policlinic of Rheumatology & Hiller-Research Unit, Heinrich-Heine-University Düsseldorf, Germany.

Data derived from the LuLa study, collecting annual data from a representative cohort of patients with SLE in Germany. In 2013 they additionally inquired about clinical care as a main topic. From 21 clinical care parameters, 10 were evaluated in univariate analysis. The fulfillment varied between 22.8% having fat metabolism counseling to 97.6% receiving osteoporosis protection with a glucocorticoid. The others were antimalarials, vaccination, blood pressure, yearly testing of urine and blood, treatment of fat metabolism disorder, osteoporosis, and hypertension. Linear regression was used to examine the relationship between quality measures calculated in 2013 and outcome parameters in subsequent years adjusted for age, disease duration and gender.2

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NOTES TO EDITORS
For further information on this study, or to request an interview with the study lead, please do not hesitate to contact the EULAR Press Office:

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About Rheumatic and Musculoskeletal Diseases
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, muscle 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.\(^3\)

About ‘Don’t Delay, Connect Today!’
‘Don’t Delay, Connect Today!’ is a EULAR initiative that unites the voices of its three pillars, patient (PARE) organisations, scientific member societies and health professional associations - as well as its international network - with the goal of highlighting the importance of early diagnosis and access to treatment. In the European Union alone, over 120 million people are currently living with a rheumatic disease (RMD), with many cases undetected.\(^4\) The ‘Don’t Delay, Connect Today!’ campaign aims to highlight that early diagnosis of RMDs and access to treatment can prevent further damage, and also reduce the burden on individual life and society as a whole.

About EULAR
The European League against Rheumatism (EULAR) is the European umbrella organisation representing scientific societies, health professional associations and organisations for people with RMDs. EULAR aims to reduce the burden of RMDs on individuals and society and to improve the treatment, prevention and rehabilitation of RMDs. 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 RMDs by the EU institutions through advocacy action.

To find out more about the activities of EULAR, visit: [www.eular.org](http://www.eolar.org)

References
3 van der Heijde D, Daikh DI, Betteridge N, et al. 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). Ann Rheum Dis. 2018 Jun;77(6):829-832.
4 EULAR. 10 things you should know about rheumatic diseases fact sheet. Available at: [https://www.eular.org/myUploadData/files/10%20things%20on%20RD.pdf](https://www.eular.org/myUploadData/files/10%20things%20on%20RD.pdf) [Last accessed May 2019].