

THE EUROPEAN MAP OF AXIAL SPONDYLOARTHRITIS (EMAS) – LIVING WITH THE CONDITION

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Aim. The European Map of Axial Spondyloarthritis (EMAS) aims to describe how patients diagnosed with axSpA experience the disease from a physical, psychological, and everyday life perspective and how they are managed within the healthcare systems.

Methods. EMAS employed a cross-sectional survey adapted from the Spanish Atlas of Axial Spondyloarthritis 2017, and containing 120 items on socio-demographics, diagnosis, comorbidities, psychological distress (General Health Questionnaire- GHQ-12), healthcare utilization, pharmacological treatments, disease activity (BASDAI), physical activity and limitations, productivity loss, and patient perspective. Patients from Austria, Belgium, France, Germany, Italy, Netherlands, Norway, Russia, Slovenia, Sweden, Switzerland and UK were included. Data from Spain was retrospectively added. A scientific steering committee, formed by 9 leading axSpA experts was selected to validate the results.

Results. 2,846 axSpA patients participated in the survey: mean age was 44 years, 61.3% were female, 67.9% were married and 79.2% were HLA-B27 positive. Almost half were university educated (48.1%), working (51.5%) and members of a patient support group (38.9%). Participants reported a diagnostic delay of 7.2 years with a disease duration of 16.8 years. Active disease (BASDAI ≥ 4) was detected in 70.9%, while 33.5% had received biological therapy. High GHQ-12 (≥ 3) was observed in 57.1%, and patients reported diagnosed anxiety (37.2%) or depression (33.3%).

Conclusion. In this sample of non-selected patients, long diagnostic delay and high patient burden, including self-reported active disease and psychological distress, indicate important unmet needs in axSpA. As the first snapshot of issues relevant to European axSpA patients and disease management, EMAS results may contribute to increasing disease awareness and improving the standard of care.