

## About the International Map of Axial Spondyloarthritis (IMAS)

### INTRODUCTION

The International Map of Axial Spondyloarthritis (IMAS) is a research initiative assessing the impact and burden of axial spondyloarthritis (axSpA) from the patient's perspective. The European data from the IMAS survey included 2,846 people diagnosed with axSpA from 13 countries<sup>1</sup>. Developed by patients, for patients, the aim of this national and international collaboration is to generate insights into the real-life experiences of people living with axSpA. Ultimately, these insights will provide a better understanding of the challenges faced by patients, with the aim of shaping discussions towards improving patients' quality of life. The IMAS survey is currently being expanded, the next phase will include results from additional countries in Europe, North America, Latin America and Asia Pacific later this year.

### WHAT IS AXIAL SPONDYLOARTHRITIS?

The axSpA patient experience is poorly understood, with symptoms and flares varying every day causing uncertainty for patients and worry for their future. It places a huge physical impact and psychological stress on patients, which can disrupt every aspect of their life and its quality including mobility, sleep, work, and relationships<sup>1</sup>. Symptoms typically manifest as chronic inflammatory back pain, stiffness and, fatigue of the pelvis and lower back – although all regions of the body can be affected<sup>2</sup>. AxSpA occurs in approximately 1% of the general population and can affect both men and women, with patients typically being in their twenties when they first develop symptoms<sup>3,4</sup>.

### THE IMAS STORY

IMAS started in Spain through a pilot initiative led by a Spanish axSpA patient working as a researcher at the Health and Territory Research (HTR) group of the University of Seville, supported by the Spanish Coordinator of Spondyloarthritis Associations (CEADE), medical experts, and Novartis Spain. The survey was originally created to explore and shed light on how this devastating disease affects Spanish patients' relationships, work, daily activities and their mental health, whilst also highlighting long diagnosis delays and suboptimal management of axSpA.

IMAS was created by patients, for patients, thus giving them the unique ability to address the questions that matter most to patients about their disease, the disruptive impact on their lives and the management of their disease

The survey was then expanded to 12 European countries together with a pan-European steering committee made up of patient representatives from Ankylosing Spondylitis International Federation (ASIF), Agora, the Spanish Coordinator of Spondyloarthritis Associations (CEADE) and nine axSpA experts, including rheumatologists and psychologists. IMAS is also supported by multiple stakeholders at a national level, with patient groups and medical experts working together to utilize the insights for local impact. The survey is now being further expanded, with the next phase to include results from additional countries in Europe, North America, Latin America and Asia Pacific later this year.

This multi-stakeholder collaboration and the insights generated by the survey are the starting point to bringing the patient's perspective on the impact of axSpA to the forefront of discussions on policy and disease management.

## METHODOLOGY

The European survey data was collected via a 30-minute online questionnaire fielded in 12 countries (Austria, Belgium, France, Germany, Italy, Norway, the Netherlands, Russia, Slovenia, Sweden, Switzerland and the UK) between July 2017 and March 2018, with data from the Spanish pilot added retrospectively<sup>1</sup>. Participants were recruited through patient organizations or via online panels and were aged 18 or older with a self-reported diagnosis of axSpA and under the care of a physician<sup>1</sup>.

The survey questions covered the demographic, social, working life, physical and psychological impact of the disease and participants' experiences of diagnosis and care. The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) was used to measure the severity of respondents' axSpA and Goldberg's General Health Questionnaire (GHQ-12) was used to assess their risk of psychological distress<sup>1</sup>. Validation of the results was provided by a pan-European steering committee made up of patient representatives from Ankylosing Spondylitis International Federation (ASIF), Agora, The Spanish Coordinator of Spondyloarthritis Associations (CEADE) and nine axSpA experts, including rheumatologists and psychologists<sup>1</sup>.

## NEXT STEPS

The next phase will include results from additional countries in Europe, North America, Latin America and Asia Pacific later this year.

By generating patient-based evidence of the true impact of axSpA around the world, IMAS will help raise awareness of this chronic disease and the burden it places on patients. Furthermore, its insights will enable stakeholders nationally, regionally and globally to discuss ways to improve the diagnosis, disease management, treatment and, ultimately, the quality of life of people living with axSpA, grounded in the patient's perspective.

## References

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