

# Global patient survey reveals gaps in axial spondyloarthritis management

May 10, 2021

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- Launched in June 2019 by the Axial Spondyloarthritis International Federation (ASIF) in partnership with Novartis, the International Map of Axial Spondyloarthritis (IMAS) survey included 2,846 people diagnosed with axSpA from 13 countries in Europe.
- The IMAS survey is currently being expanded to more countries, including the Philippines.

**May 10, 2021** – A global research initiative assessing the impact and burden of axial spondyloarthritis (axSpA) from the patient's perspective has revealed gaps in diagnosis, treatment and work support for people living with the debilitating disease.<sup>1</sup>

Launched in June 2019 by the Axial Spondyloarthritis International Federation (ASIF) in partnership with Novartis, the International Map of Axial Spondyloarthritis (IMAS) survey included 2,846 people diagnosed with axSpA from 13 countries in Europe. Key findings of the IMAS survey include:<sup>1</sup>

- Despite improvements, diagnostic delay is still too long: people living with axSpA suffer a delay in diagnosis of over 7 years
- Active disease limits professional opportunities: 74% of people surveyed living with axSpA reported difficulties finding a job due to the condition, 56% were forced to take sick leave and 45% had difficulties in fulfilling their working hours
- Symptoms appear during prime of life: on average, people surveyed living with axSpA began experiencing disruptive and debilitating symptoms at around the age of 26
- Despite fear of losing mobility, pain and disease progression: 1 in 3 people surveyed living with axSpA had never discussed their treatment goals with their doctor
- Co-creating solutions with all stakeholders will improve quality of life and standard of care for people living with axSpA

axSpA is a chronic inflammatory disease that primarily affects the spine and sacroiliac joints that connect the spine to the pelvis.<sup>2</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. 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</sup>

“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,” according to ASIF. “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.”<sup>3</sup>

ASIF is an international membership organization representing patient associations around the globe specializing in the support of patients with axSpA.<sup>1</sup> It has 51 patient organization members from 42 countries around the world.<sup>4</sup> ASIF leads the annual celebration of World Axial Spondyloarthritis Day, which this year falls on May 8, 2021. World Axial Spondyloarthritis Day aims to raise the profile of this disease and increase awareness of the effect it has on people's lives as it impacts not only physical but mental health as well.<sup>4</sup>

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. As well as the European countries, the survey has also now closed in Canada, Taiwan and South Korea – with responses from a further 800 patients. The survey is currently open in Turkey and four Latin American countries; Mexico, Colombia, Argentina and Costa Rica. IMAS is expanding further into six new countries: USA, Philippines, India, South Africa, Algeria and Lithuania.<sup>5</sup>

“Novartis is privileged to support the ASIF in conducting IMAS to better understand the axSpA patient experience and address gaps in disease management. Locally, we are working with the Axial Spondyloarthritis Association of the Philippines (ASAP) and Philippine Rheumatology Association (PRA) in supporting Filipinos living with axSpA,” said Mr. Jugo Tsumura, President and Managing Director, Novartis Healthcare Philippines, Inc.

In celebration of World Axial Spondyloarthritis Day, ASAP in partnership with Novartis, held the Rheum for Knowledge webinar on “Early AS Possible: Avoid Diagnostic Delay” last May 8, 2021 to understand barriers and discuss recommendations for timely diagnosis of axSpA. The resource speakers were ASAP president Engr. Clark Ferrer and Dr. Heizel D. Manapat-Reyes, consultant rheumatologist at the Philippine General Hospital.

An app is now available to help individuals suffering from chronic low back pain, which is one of the symptoms of axSpA. Clarrio allows users to identify whether their chronic low back pain is inflammatory or mechanical through a 5-item questionnaire. The app has a link to the website of the Philippine Rheumatology Association (PRA), which provides a list of more than 200 rheumatologists categorized based on area of practice. Clarrio provides science-based tools to help users monitor and manage pain. The app is available for free in App Store and Google Play.

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### References:

1. <https://asif.info/emas/>
2. [https://asif.info/about/#:~:text=Axial%20Spondyloarthritis%20\(axSpA\)%20is%20a,Bechterew%20in%20some%20European%20countries.](https://asif.info/about/#:~:text=Axial%20Spondyloarthritis%20(axSpA)%20is%20a,Bechterew%20in%20some%20European%20countries.)
3. [https://asif.info/wp-content/uploads/2018/04/190320-IMAS-backgrounder\\_Final.pdf](https://asif.info/wp-content/uploads/2018/04/190320-IMAS-backgrounder_Final.pdf)
4. <https://asif.info/worldasday/#:~:text=ASIF%20has%2051%20Patient%20Organisation,on%20Saturday%208th%20May%202021.>
5. <https://asif.info/imas-is-expanding-news-update/>

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