



# The Latin American Map of Axial Spondyloarthritis

**Exploring the patient perspective and economic burden**

# Acknowledgements

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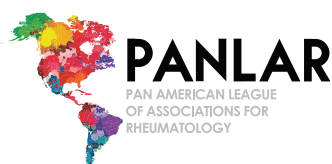
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# Foreword



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It is a privilege to introduce this unique report about axial spondyloarthritis (axSpA) in Latin America. It is published by the Axial Spondyloarthritis International Federation (ASIF), working alongside local rheumatology experts in axSpA.

This report is a summary of an analysis of data from the International Map of Axial Spondyloarthritis (IMAS). It provides much-needed evidence about the day-to-day burden of living with axSpA, along with evidence about the social and economic costs of the disease. We welcome this opportunity to collaborate with ASIF in showing the reality of living with axSpA in Latin America.

Over recent years, our region has seen meaningful progress, driven by the collective effort of the PANLAR community. Clinicians, researchers, and patients have come together in a shared mission: to improve the quality of life of those living with rheumatic diseases. In so doing, we have transformed our commitment into measurable achievements.

A defining feature of PANLAR's recent work has been the strengthening of regional collaboration in the field of axSpA. The organisation's strength lies in its ability to unite national societies, institutions, experts and patients across Latin America. The establishment of the Axial Spondyloarthritis Registry of Latin America (ESPALDA) represents a landmark in this collaborative journey. Conceived and developed by regional experts, ESPALDA provides a platform to capture comprehensive real-world data, generating insights that will

enhance both research and clinical practice across the continent.

Equally significant has been the release of the new PANLAR Regional Guidelines for Axial Spondyloarthritis, which have been developed through the collaborative efforts of specialists from multiple member countries. These 13 recommendations provide an evidence-based, regionally adapted framework that promotes consistency and quality in clinical decision-making.

While we take pride in these accomplishments, we also recognise the work that remains ahead. Latin America is a diverse region with varied ethnic compositions, distinct genetic backgrounds, and an expansive range of socioeconomic profiles. This heterogeneity needs locally generated evidence to better understand the patients we serve and develop appropriate strategies for axSpA management.

This LAMAS report supports PANLAR's work by providing local evidence, helping us to better understand the daily burden of axSpA patients and their unmet needs, to address disparities in access to care and to influence treatment approaches.

Our vision of unity also extends beyond our region. PANLAR looks forward to strengthening collaboration with ASIF and other international organisations that share our objectives. Such partnerships will amplify Latin America's contribution to global research and advocacy, ensuring that our perspectives and experiences deepen the worldwide effort to improve the lives of those living with axSpA.

# Executive summary

There are up to **6 million** people living with **axSpA** in Latin America<sup>4</sup>



**Axial spondyloarthritis (axSpA)** is a chronic inflammatory disease that primarily affects the spine and the sacroiliac joints (which connect the lower spine to the pelvis). This results in pain and stiffness in the lower back, hips and buttocks.

It can also affect other joints in the body, as well as tendons and ligaments. People with axSpA often experience chronic pain, impairments to their mobility and severe fatigue. They may also have inflammation of their eyes, skin or digestive system.

The onset of axSpA typically occurs before the age of 45. In many cases, people start experiencing symptoms in their 20s, when they are of working age and at the beginning of their adult lives.

Worldwide, axSpA affects an estimated 50 million people. In Latin America, estimates range between 1,326,000 and 5,967,000 people out of a population of 663 million.<sup>4, 12</sup> Yet the condition is under-recognised and often poorly understood. The patient perspective is poorly characterised, with limited data capturing how people describe their symptoms and daily lives. That's why the International Map of Axial Spondyloarthritis (IMAS) was set up in 2017: to provide data about the experiences of people living with axSpA with which to inform health policy and clinical decision-making.

IMAS surveyed 5,557 people with axSpA, from 27 countries around the world, across five continents. They completed a detailed online survey which has provided new insights into the condition, its diagnosis and treatment.

Of those who completed the survey, 498 were from four countries in Latin America: Argentina (115 respondents), Brazil (159), Colombia (164) and Mexico (60). The Latin American survey respondents were made up of more women than men – 56% to 44% – and their average age was 43 years old, slightly lower than in all other regions except Asia.

The survey responses from Latin America have been analysed in detail<sup>9</sup> and most of the statistics in this report are derived from these findings. Data from other sources are referenced. This report lays bare the delays in diagnosis that worsen outcomes for people with axSpA, details the differences between and within the four countries and between them and the rest of the world, and highlights the personal, social and economic costs of the disease.

On the following page we make some strategic recommendations, aimed at policymakers and healthcare services in Latin America, that we believe will both reduce the costs of axSpA and improve the lives of those living with the condition, whether diagnosed or not.

**The estimated annual cost of axSpA in Latin America is between USD 12 billion and USD 54 billion**

# Strategic recommendations

- 1 Improve detection of axSpA in primary care** by implementing structured training programmes for general practitioners, physiotherapists and orthopaedists about inflammatory lower back pain and how to recognise the signs and symptoms of axSpA.
- 2 Prioritise early and accurate diagnosis** by developing referral pathways that ensure patients suspected of having axSpA can be referred promptly to a rheumatologist.
- 3 Improve specialist distribution and training** by promoting and delivering training in the axSpA sub-specialisation and incentivising rheumatologists to practise outside urban metropolitan areas.
- 4 Simplify treatment supply processes** to accelerate the approval of new treatments and to ensure that drugs are consistently available.
- 5 Promote multidisciplinary care** coordinated by an appropriate healthcare professional and supported by relevant clinical specialists.
- 6 Incorporate psychosocial support into treatment plans** by integrating psychological care, employment support and patient education programmes.
- 7 Promote patient participation in decision-making** through policy and professional development training. Encourage healthcare professionals to co-develop treatment plans with patients. Treatment plans should focus on quality of life.
- 8 Strengthen rehabilitation therapies** by guaranteeing access to physiotherapy and supervised exercise within public health plans.
- 9 Develop national and regional axSpA registries** that collect clinical, therapeutic and patient-reported outcome data, to be consolidated by region.
- 10 Develop a regional cooperation agenda** by establishing a Latin American axSpA network to harmonise guidelines and share data.

# The global picture

## How does Latin America compare to the rest of the world?



We conducted a **literature review** to find out what the existing research already tells us.



Here, we compare the results of that review with some of the results of the **global IMAS survey**.



And we also see how the existing research and the IMAS results compare with some of the key findings of the **LAMAS survey**.

### High levels of disease activity and functional impairment



Disease activity in people with axSpA is measured by the **Bath Ankylosing Spondyloarthritis Index (BASDAI)**, which ranges from 0 to 10, with 0 being the best outcome and 10 the worst. A BASDAI score of 4 or more indicates that a person's disease is not well-controlled. The higher a person's BASDAI score, the more likely they are to have functional impairment.<sup>9</sup>



One study found that people living with axSpA in Latin America have levels of both disease activity and functional impairment that are higher than in any other region.<sup>10</sup> Other studies found that both disease activity and functional impairment in Latin America were on a par with the rest of the world.<sup>3, 11</sup>



**LAMAS participants had an average BASDAI score of 5.7,** the second highest of all IMAS regions.

# The global picture

## Genetic factors have a distinctly different profile in Latin America than elsewhere



There is a strong correlation between testing positive for a **genetic marker known as HLA-B27** and having axSpA,<sup>5</sup> though not everyone with axSpA has HLA-B27 and not everyone with HLA-B27 has axSpA. Blood tests for HLA-B27 are one of a number of tests often carried out during the diagnostic process.<sup>18</sup>



**Other research** has consistently found the prevalence of HLA-B27 among people with axSpA in Latin America to be lower than in other regions, at between 40%<sup>6</sup> and 70%.<sup>2</sup> By comparison, **the prevalence in Europe is 83%.**<sup>2</sup> HLA-B27 is rare among indigenous populations in Latin America.<sup>7</sup> Genetic heterogeneity – influenced by the multiethnic composition of the population and by non-B27 HLA variants such as HLA-B15 – likely contributes to the distinct axSpA phenotype described in the region.<sup>3, 8</sup>



HLA-B27 prevalence among **LAMAS respondents was 65%.**

## Greater reliance on conventional therapies and limited access to the most advanced therapies



Conventional therapies for axSpA include NSAIDs (non-steroidal anti-inflammatory drugs), corticosteroids and disease-modifying anti-rheumatic drugs (DMARDs) such as methotrexate and sulfasalazine. The most advanced and effective drug treatments are known as 'biologics'.



**One study** found greater use of NSAIDs (89% vs. 75%), corticosteroids (19% vs. 8%), methotrexate (34% vs. 10%), and sulfasalazine (32% vs. 19%) in Latin America compared with Europe.<sup>2</sup>



**In the overall IMAS cohort,** 79% used NSAIDs and 49% biologics.



**Of the LAMAS cohort,** 89.5% reported use of NSAIDs but only 28.1% used biologics.

## Higher frequency of peripheral and extra-musculoskeletal manifestations



As well as back and hip pain, many people with axSpA experience arthritis in other, peripheral parts of their bodies, such as their hands, wrists and ankles. Other conditions, not related to the joints (extra-musculoskeletal), such as eye, skin and bowel problems, are also common.



**One study** found that in Latin America 60% of people with axSpA had peripheral arthritis, 52% had enthesitis (inflammation of the tendons and ligaments), 19% had psoriasis (an inflammatory skin condition) and 12% had dactylitis (severely swollen fingers or toes).<sup>10</sup> These are higher rates than those found anywhere else. Another study reported more peripheral arthritis and enthesitis in Latin American versus European axSpA patients.<sup>2</sup> The first comprehensive multinational effort in the region found rates of psoriasis at up to 19%, and of uveitis (an inflammatory eye condition) and inflammatory bowel disease both at approximately 6%.<sup>3</sup>



**Of those in the LAMAS cohort** who reported an extra-musculoskeletal manifestation of their axSpA, more than a quarter (26.8%) reported having uveitis, 21.9% had psoriasis and 12.3% Crohn's disease (an inflammatory bowel condition).

## Diagnostic waiting times are long but on a par with the rest of the world



The longer the delay between the onset of symptoms and the diagnosis (and therefore treatment) of axSpA, the worse the outcomes.<sup>1</sup>



**Previous studies** estimate average diagnostic delays in Latin America to be in the range of **7 to 9 years**<sup>2,3</sup>, though one study did find delays as high as 14 years.<sup>4</sup>



**The IMAS survey** found the average global diagnostic delay to be **7.4 years**.



**The LAMAS survey** found the average diagnostic delay to be **6.5 years**, the second shortest of all IMAS regions.

# Regional and country profiles



## Latin America

The population of Latin America is approximately 663 million,<sup>12</sup> which means that roughly one in twelve of the world's population are Latin American. The LAMAS countries, Argentina, Brazil, Colombia and Mexico, have a combined population of 437 million, representing around two thirds of the population of Latin America.

The populations of all four countries are largely concentrated in urban areas. Outside those urban areas, population density is low and access to healthcare is very limited.

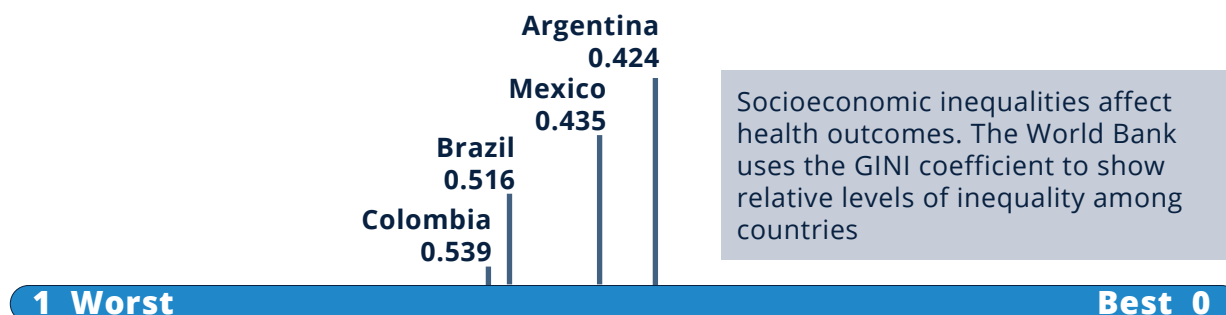
Argentina, Brazil, Colombia and Mexico are the four wealthiest countries in Latin America, as measured by gross domestic product (GDP). They are classified by the World Bank as being upper-middle income level countries. Their **Human Development Index (HDI)** score is

high or very high, meaning high levels of education, longevity and well-being. People in these four countries have a life expectancy in excess of 75 years, well above the global average.

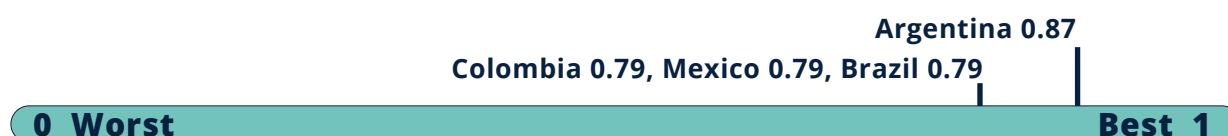
Inequality of wealth and income is high in global terms. The World Bank uses a measure of inequality known as the **GINI coefficient** (named after the Italian statistician Corrado Gini).<sup>13</sup> GINI values range from 0 to 1, with 0 meaning complete equality. Two of the LAMAS countries, Colombia and Brazil, are among the top ten most unequal countries in the world. The other two come in at 28th most unequal (Mexico) and 33rd (Argentina).

Spending on health as a proportion of GDP varies across the four countries, from 6.55% (Colombia) to 3.05% (Mexico).<sup>14</sup>

## GINI coefficient of inequality



## HDI Human development index



## Healthcare professionals in the LAMAS countries

The number of healthcare professionals per capita varies significantly from country to country and within each country. Most healthcare professionals are based in the major metropolitan urban areas, with relatively few in rural areas.

### Rheumatologists per 1,000,000 people

Argentina **15**      Colombia **9.3**



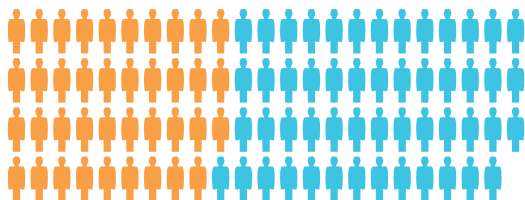
Brazil **6.3**      Mexico **5.8**



### Primary care physicians (PCPs) and nurses per 10,000 people

 PCPs       Nurses

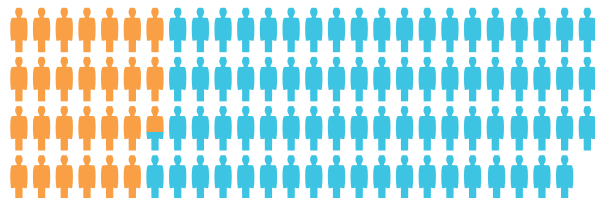
Argentina      **38.8 PCPs**      **52.1 Nurses**



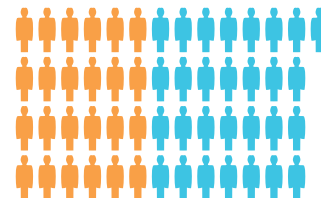
Colombia      **15 PCPs**      **13 Nurses**



Brazil      **26.5 PCPs**      **76.4 Nurses**



Mexico      **24 PCPs**      **29 Nurses**



# Argentina



## REPÚBLICA ARGENTINA

Population	46 million	HDI (human development)	0.865 (very high)
GDP per capita	USD 14,362	GINI (inequality)	0.424 (high)

**Estimated average annual cost of axSpA per patient:**

**USD 12,161**

**Argentina** is the second largest country in Latin America by area and third largest by population. It is the wealthiest of the four LAMAS countries and the fourth most economically unequal.

There are wide variations in physical and mental health across the country. In the less populated, rural areas, people with axSpA have fewer annual visits to rheumatologists and physiotherapists than those in areas with a high population.

### Healthcare

The private sector in Argentina has a much larger role in providing healthcare than in the other three countries, accounting for 62% of all health spending. Health spending, at USD 1,371 per head of population, is the highest in LAMAS.

### Access to rheumatology

There are approximately 1,000 rheumatologists distributed across 60 rheumatology units, the majority (60%) of whom work in the private sector. Only 20% have specific training in axSpA. Between six and seven rheumatologists are members of the international expert group, the Assessment of SpondyloArthritis international Society (ASAS). Specialists are concentrated in Buenos Aires, Córdoba, Mendoza and Tucumán, creating marked regional inequities.

### Waiting times and access to treatments

Patients typically wait between one and two months for a rheumatology appointment. Initiation of biological therapy may take up to six months in the public sector and around one month in the private sector. The full spectrum of drug therapies, including biologics, is available in both the public and private systems. Delays depend more on administrative procedures than on availability.

Physiotherapy and rehabilitation are available free of charge in the public sector but with lengthy waiting lists. Access is faster in the private sector, although out-of-pocket costs may be a barrier.

**Argentina spends more on health per capita than any other LAMAS country**



# Brazil

## REPÚBLICA FEDERATIVA DO BRASIL

Population	211.7 million	HDI (human development)	0.788 (high)
GDP per capita	USD 10,294	GINI (inequality)	0.516 (very high)

**Estimated average annual cost of axSpA per patient**

**USD 12,563**

**Brazil** is by far the largest country in Latin America, by area and by population. It is the third wealthiest country among our four, as measured by GDP per head of population. But inequality is very high, with a GINI score of 0.516, the sixth highest in the world.

There are wide variations in outcomes for people with axSpA across the country. In the less populated areas, people with axSpA have less access to certain diagnostic tests, such as magnetic resonance imaging (MRI).

### Healthcare

The public healthcare system (Sistema Único de Saúde or SUS) provides universal coverage and accounts for 72% of all health expenditure, while the private sector covers approximately 25% to 30% of the population.

### Access to rheumatology

There are an estimated 1,800 to 2,000 certified rheumatologists in Brazil, most of whom are concentrated in the southern and southeastern regions of the country. Fewer than 50 clinicians specialise exclusively in axSpA.

### Waiting times and access to treatments

Access to rheumatology care is highly uneven. In major metropolitan areas, diagnosis tends to be relatively swift, whereas in rural regions or the northern part of the country, patients may need to travel several hundred kilometres to reach a specialist. Within the state health system, waiting times range from one to 12 months for a rheumatology appointment and from one to three months for approval of biologic treatments.

In the public system, some biologics (anti-TNF agents and some IL-17 inhibitors) are funded, but others (JAK inhibitors) are not. In the private sector, all pharmacological classes are available; however, JAK inhibitors must be requested outside the standard procedures, which can delay access. Once approved, biologics are provided at no cost through the Specialised Pharmaceutical Services Component (CEAF) high-cost medication programme.

Access to physiotherapy and rehabilitation within the public system is limited (less than 50% coverage), and complementary therapies are not funded.

**Brazil has the 6th highest level of inequality in the world**

# Colombia



## REPÚBLICA DE COLOMBIA

Population	52.9 million	HDI (human development)	0.788 (high)
GDP per capita	USD 6,947	GINI (inequality)	0.539 (very high)

**Estimated average annual cost of axSpA per patient:**

**USD 4,966**

**Colombia** is the smallest of the LAMAS countries by area and the third largest by population. The least wealthy country among our four, as measured by GDP per head of population. But inequality is the highest in LAMAS and the fifth highest in the world. In the past decade, differences in the HDI of the country's regions have widened and the World Bank estimates that more than 16 million Colombians live in poverty.<sup>15</sup>

There are wide variations in patient outcomes between the regions. In areas with a higher population, people with axSpA report more MRI scans than those in other parts of the country.

### Healthcare

The public sector plays the largest role in providing healthcare of all the LAMAS countries, accounting for 95% of health expenditure. Colombia has the lowest per capita expenditure on health, at USD 557.54, but near-universal health coverage (between 98% and 99% of the population).

### Access to rheumatology

Colombia has an estimated 400 to 500 rheumatologists, of whom only two are ASAS members. Most rheumatologists are located in six to eight major cities.

No more than 25% have sufficient expertise and clinical capacity to effectively diagnose non-radiographic axSpA.

### Waiting times and access to treatments

Waiting times for rheumatology range from two to four months, with similar delays reported for MRI and HLA-B27 testing. Diagnostic tests and biologics are covered by the state benefits plan, but administrative and logistical hurdles frequently delay access. Although the system formally covers all therapeutic drug classes (NSAIDs, csDMARDs, anti-TNF, IL-17, JAK inhibitors), authorisation procedures and pharmacy shortages reduce real-world equity.

Universal healthcare coverage does not translate into equitable access. Access depends upon geographic location and the economic capacity to purchase supplemental insurance ("prepaid medicine") to reduce waiting times and increase treatment continuity.

Rehabilitation and physiotherapy services are covered by the state health system but are limited outside large urban centres.

**Colombia has the lowest per capita expenditure on health of all the LAMAS countries**



# Mexico

## ESTADOS UNIDOS MEXICANOS

Population	126 million	HDI (human development)	0.789 (high)
GDP per capita	USD 13,790	GINI (inequality)	0.435 (high)

**Estimated average annual cost of axSpA per patient:**

**USD 5,080**

**Mexico** is the third largest of the LAMAS countries by area and the second largest by population. Mexico is the only one of the LAMAS countries to lie in North America. The second wealthiest country of the four, as measured by GDP per capita, Mexico also has the third highest GINI score.

As with all the LAMAS countries, there are wide variations in patient outcomes across Mexico. In areas with a higher population, people with axSpA have more annual visits to a physiotherapist than those in other parts of the country.

### Healthcare

The public sector accounts for the majority (71%) of health expenditure and Mexico has the third highest per capita expenditure on health, at USD 650.97. More than 65 million people lack social security coverage, relying on private or basic public services. System fragmentation produces significant institutional and territorial inequities.

### Access to rheumatology

Mexico has 1,300 rheumatologists, the lowest per capita of all four LAMAS countries. Most are based in Mexico City, Guadalajara and Monterrey. Only seven centres provide structured training in axSpA.

The General Hospital of Mexico is one of the few centres with a specific focus on axSpA.

### Waiting times and access to treatments

In the public sector, rheumatology appointments may occur only once every 12 months.

Social security institutions provide broad coverage for biologics. However, shortages of biologics and restrictions on who may prescribe them severely limit practical access. In the private sector, treatments are usually available but only 2% of the population has private insurance with full biologic coverage.

Rehabilitation services vary widely and are often insufficient. Many patients rely on informal providers, such as 'hueseros' ('traditional', often indigenous, bone healers) and chiropractors. Territorial inequity is profound, exacerbated by issues of insecurity that reduce specialist presence in certain areas.

**Mexico has the fewest rheumatologists per capita of all four LAMAS countries**

# Regional conclusions



<b>Availability and equity</b>	Resources exist, but distribution and access are highly uneven. Large cities concentrate specialists and diagnostic capacity.
<b>Diagnostic delay</b>	Delays of up to 10 years persist across the region, driven by low primary-care awareness, insufficient specialist availability and slow imaging or laboratory processes.
<b>Administrative and structural barriers</b>	Complex bureaucratic procedures and fragmented systems hinder timely access – particularly in public healthcare.
<b>Insufficient non-pharmacological provision</b>	Rehabilitation and therapeutic exercise programmes are inconsistently available, representing an opportunity for policy improvement.
<b>Spatial and socioeconomic inequity</b>	Rural areas and low-income populations face the greatest barriers to timely and continuous care.
<b>Clinical and social challenges</b>	Fatigue, functional impairment, anxiety, depression, and economic hardship significantly impact patient well-being and adherence.
<b>Emerging strengths</b>	Telemedicine expansion, growing interest among young rheumatologists, and national high-cost drug programmes (such as in Brazil or universal coverage mechanisms in Argentina).

# The burden of axSpA

## The diagnostic delay

The burden of axSpA is most keenly felt and profoundly expressed by those who live with the condition. Throughout this report, we have included short quotes from respondents to the LAMAS survey to illustrate different aspects of that burden. Here we also introduce two stories that add more detail to the picture. They begin by showing how difficult it can be to get a diagnosis of axSpA.



### RAFAEL'S STORY

"The first signs of pain and stiffness in my spine began in my late thirties, worsening after a period of stress, intestinal problems, dizziness, and gallbladder surgery. The situation only got worse over time.

"Like many others, I visited several doctors and attended multiple physiotherapy sessions without any progress, until I finally met a rheumatologist. This new doctor listened attentively and ordered both an MRI and blood test. The results revealed that I had ankylosing spondylitis, even though I was HLA-B27 negative."



### MARTÍN'S STORY

"Ten years ago, I started experiencing symptoms I had never had before: inflammation in my left eye, which led me to see an ophthalmologist. I was told it was uveitis — another new word for me. It got better with corticosteroid treatment, but the doctor's words still echo: 'You should follow up, because it could happen again and may be related to other diseases.'

"That episode passed, and I thought it was all behind me. A year later, I had uveitis again, this time with several days of disability due to its severity. I remembered the doctor's advice — reluctantly — I repeated the corticosteroid treatment and began seeing an internal medicine specialist. Little by little, after many tests, I was referred to a rheumatologist, where the diagnosis was finally confirmed: ankylosing spondylitis."

Over time, if untreated, axSpA can lead to irreversible damage to joints. That's why it is important to diagnose the condition and begin treatment as soon as possible.

The greater the diagnostic delay, the worse the outcome. In the LAMAS cohort, people who waited up to four-and-a-half years for diagnosis had no spinal stiffness. People who had severe stiffness had average diagnostic delays of over nine years.

The average diagnostic delay across all four LAMAS countries was 6.5 years,

the second lowest, after Asia, of all the IMAS regions. But there were big variations between countries. Brazil had the highest average delay of 8.6 years, followed by Argentina (6.6), Colombia (5.7) and Mexico (2.9).

#### Healthcare professionals

On average, 81.5% of LAMAS respondents were diagnosed by a rheumatologist. The proportion was highest, at 92.2%, in Argentina and lowest in Mexico at 41.7%.

Most people saw other healthcare professionals before being diagnosed.

# The burden of axSpA

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## The diagnostic delay

Over two-thirds saw their primary care doctor or an orthopaedist first. That's in line with other studies and other parts of the world. Many health systems require primary care doctors to make referrals to specialists such as rheumatologists. Nevertheless, speeding up referral to specialists can help cut the diagnostic delay. A programme known as Rheuma-check, developed in Argentina, has been shown to lead to earlier diagnosis for people with axSpA.<sup>16</sup>

### HLA-B27 positivity

In the Latin American countries included in the study, most participants tested positive for HLA-B27, with a regional average of 65.1%. The highest proportion of positive cases was observed in Mexico (77.8%), followed by Colombia (69.0%) and Argentina (68.5%), while Brazil showed the lowest rate (57.5%). These findings are consistent with the well-established association between this genetic marker and axSpA. It's important to note that HLA-B27 positivity does not by itself constitute a definitive diagnosis of axSpA, while HLA-B27 negativity does not definitively rule it out.

### Testing for diagnosis

In the LAMAS survey, the tests used to diagnose axSpA varied between countries. Diagnosis typically involves a combination of different tests and an assessment of the patient's history. Overall, across Latin America, HLA-B27 blood testing (75%) and MRI scans (37.9%) were the most commonly reported diagnostic tools. HLA-B27 testing can be helpful when someone already has symptoms suggestive of axSpA and may speed up referrals and further testing.

In Colombia and Mexico, MRI scans and X-rays were used most often, while Argentina relied heavily on HLA-B27 (80.2%). Compared with other regions, Latin America used HLA-B27 tests more and MRI less than in Europe, North America and Asia. These tests are important for identifying axSpA early, especially in people with back pain but no visible changes on X-rays. Using HLA-B27 testing and MRI together, along with assessing symptoms, helps doctors make a faster and more accurate diagnosis.

***“The length of time it took to reach a diagnosis was extremely frustrating, painful and expensive”***

*LAMAS respondent*

# The burden of axSpA

## Physical health

**“The fatigue and pain are brutal”**

*LAMAS respondent*

Living with axSpA imposes a tremendous physical burden upon the affected person. It is a fluctuating condition that can flare up, leading to a worsening of symptoms. It is also unpredictable – you might feel quite well today and make plans for tomorrow only to feel suddenly worse when morning comes.

Common symptoms include pain in the lower back, hips and buttocks; morning stiffness, often so severe that getting out of bed is near-impossible; mobility difficulties; pain and swelling in other parts of the body, including the fingers, toes and ribs; and severe fatigue. People with axSpA may also develop uveitis, a serious eye condition that can damage eyesight if not treated; psoriasis, an inflammatory skin condition, and inflammatory bowel disease, such as ulcerative colitis and Crohn’s disease.

The aim of axSpA treatment is to reduce disease activity in order to minimise symptoms and limit the impact and damage caused by the condition.<sup>17</sup>

### The BASDAI scale

The BASDAI scale is commonly used to evaluate disease activity in axSpA. BASDAI scores range between 0 and 10, with 0 indicating no disease activity and 10 the maximum disease activity. A BASDAI score of 4 or more means that the disease is not well controlled.

Disease activity in Latin America, with an average BASDAI score of 5.7, was the

highest of all IMAS regions, except South Africa (6.0). The highest average BASDAI score was seen in Brazil, at 7.1, with Argentina showing the lowest, at 4.8.

In the LAMAS study, higher disease activity was often linked to greater stiffness, more difficulty with daily tasks, and more comorbidities (other health conditions), especially in Colombia. For example, BASDAI scores there were strongly associated with functional limitations and the number of comorbidities. Spinal stiffness also showed strong links to functional difficulties and the number of affected body parts.

### Spinal Stiffness Index

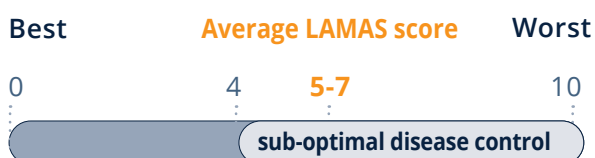
We measured spinal stiffness using the Spinal Stiffness Index (SSI), which was developed for use in the overall IMAS project. It assesses the degree of stiffness experienced by patients in the spinal column, distinguishing between the cervical, dorsal, and lumbar areas. Possible responses range from the least to the most severe: 1, without stiffness; 2, mild stiffness; 3, moderate stiffness; and 4, severe stiffness. Total scores are obtained by adding together the responses in each of the areas of the spine without weighting resulting in a scale ranging from 3 to 12.

Longer diagnostic delays were associated with higher SSI scores. Across the LAMAS cohort, severe spinal stiffness was experienced by people with an average diagnostic delay of 9.3 years. Whereas those with no stiffness waited on average 4.5 years for a diagnosis.

### Comorbidities

Higher disease activity scores correlate with increased numbers of other health conditions (comorbidities) experienced by our LAMAS survey respondents. Overall, those with higher disease activity (BASDAI greater than or equal to 4) had an average

### The BASDAI scale



# The burden of axSpA

## Physical health

of 3.5 comorbidities, while those with a BASDAI of less than 4 had only 1.3. Over a third were obese or overweight and more than a quarter had high blood pressure (hypertension), severe infections requiring treatment with antibiotics or uveitis.

### Weight and axSpA

People who kept their weight down generally had better axSpA outcomes.

Overweight or obese people had average BASDAI scores of 6.0 and 6.7 respectively compared to 4.8 for those with normal weight or underweight.

Spinal Stiffness Index (SSI) scores were higher for people who were obese (7.3) and overweight (7.2) than for others of normal weight or those underweight (6.3).

### Functional Limitation Index

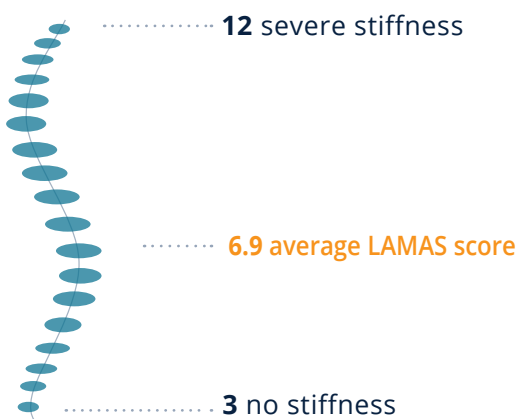
We used the Functional Limitation Index (FLI) to assess the degree of limitation in 18 activities from daily life, such as doing housework, using public transport and showering. Each of these activities

was assigned as 0 for no limitation, 1 low limitation, 2 medium limitation and 3 high limitations, resulting in values between 0 and 54. A total score from 0 to 18 was considered low limitation; between 18 and 36, medium limitation; and between 36 and 54, high limitation.

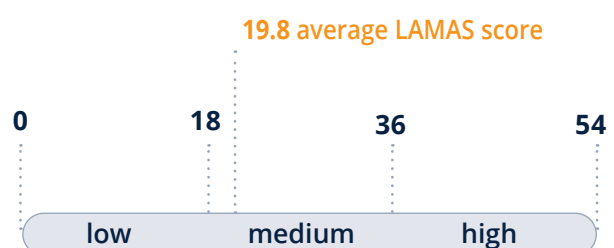
We saw the same impact of obesity and excess weight on daily activities as on disease activity and spinal stiffness. Overweight people had an average FLI score of 20.2 and obese people 22.4, compared to a score of 17.6 for others of normal weight or those underweight.

Higher levels of disease activity were generally seen amongst women and people with low educational levels or with lower incomes. Women had an average BASDAI of 6.1 compared to 5.2 for men. People with no schooling had an average BASDAI of 7.3 compared to 5.0 for those with a university education.

### Spinal Stiffness Index (SSI)



### Functional Limitation Index (FLI)



# The burden of axSpA

## Mental health

Mental distress is common in people with axSpA, with 43% of LAMAS participants having depression. Across all four of our study countries, more than half of people surveyed reported anxiety and sleep disorders.

### Measuring mental health

Psychological distress can be assessed by using the general health questionnaire (GHQ). The most commonly used version, GHQ-12, gives a score between 0 and 12. A GHQ-12 score of three or more indicates that the patient is at risk of psychological distress.

The average GHQ-12 across the LAMAS countries is 5.2, higher than all other regions except South Africa, which was marginally worse with a score of 5.3. Brazilian patients with axSpA had the highest GHQ-12 scores (7.9), Argentinian patients the lowest (3.2).

### Disease activity and mental distress

LAMAS patients with GHQ-12 scores of 3 or more tended to have more active disease, greater spinal stiffness and more difficulty with daily tasks. In Brazil, BASDAI scores rose from 5.6 among those with a GHQ-12 score of less than 3 to 7.3 among those scoring 3 or more. Functional limitation scores increased from 17.6 to 22.3 among those with higher distress. Spinal stiffness was also worse in those experiencing more psychological distress.

### Mental health support

People with more active disease need more mental health support. In the 12 months preceding the LAMAS survey, those whose BASDAI score was 4 or more, indicating poorly controlled disease, made an average of 4.4 visits to a psychologist or psychiatrist. But those with a BASDAI score of less than 4, made half as many visits (2.1) on average.

***“Pain and fatigue took away the joy of living. I am very unhappy”***

*LAMAS respondent*

## The 12-Item General Health Questionnaire (GHQ-12)



# The burden of axSpA

## Daily living



### MARTÍN'S STORY

"Facing the disease has not been easy. I remember the best advice anyone ever gave me: one afternoon, I received a call from a former boss, also a rheumatology patient, who told me, 'What you have to do is follow the doctor's recommendations to the letter', and that's what I did.

"That means taking on many things: medical check-ups, medications, healthy eating, rest, exercise – which I still struggle with – and emotional management. AxSpA requires a comprehensive approach, because it affects all areas of life: family, work, and relationships."

Using the FLI or Functional Limitation Index (see page 20), we found that higher FLI scores were strongly associated with high levels of disease activity across the LAMAS countries.

AxSpA restricts daily activities, such as housework, washing and doing physical exercise. **Across the LAMAS countries, only 25% of respondents reported being able to exercise without restriction** – more than half said they found exercise very difficult. Housework was only possible without restriction by 30% and just over 50% had difficulties with washing themselves.

**Getting in and out of bed** was problematic for 69% of LAMAS respondents.

**People with axSpA often need help with daily activities.** Over half said they

sometimes or frequently needed help with getting dressed, shopping, going up and down stairs, tying their shoelaces or using public transport.

**People with axSpA face difficulties with intimate relationships.** Almost 60% of those surveyed by LAMAS reported that they experienced limitations on their intimate relationships – and more than half of those rated their restrictions as high.

**Less than half (48%) of LAMAS patients are currently employed.**

All temporary sick leave and most permanent sick leave or early retirement (92.3%) taken by people with axSpA in the LAMAS countries is because of their disease.

Four out of ten patients in LAMAS are influenced in their work choice by axSpA.



### RAFAEL'S STORY

"Much of my day is currently spent managing both axSpA and its related conditions, which leaves less time for work, family, leisure and other activities. About a year ago, following my psychologist's suggestion, I started playing bass guitar. Focusing on this instrument strengthened my hand and forearm muscles, and as a result, the pain in my fingers decreased significantly – now, discomfort only arises around the time I am due to have my immunotherapy sessions.

"I also have to cover expenses for medications, physiotherapy, muscle strengthening and psychiatric care."

# The burden of axSpA

## Healthcare utilisation

The better a person's axSpA is controlled, the fewer healthcare visits they will have to make.

### **Greater utilisation of healthcare services is associated with higher disease activity.**

Across the LAMAS countries, in the 12 months before they responded to the survey, those with high disease activity (a BASDAI score of 4 or more) saw a rheumatologist on average 5.1 times, a primary care physician (PCP) 3.7 times and a physiotherapist 6.9 times.

For those with lower disease activity (BASDAI less than 4), the comparable number of annual visits were 3.3 (rheumatologist), 1.2 (PCP) and 2.5 (physiotherapist) respectively.

### **Supervision by rheumatologists**

Most LAMAS patients (91.6% across the four countries) are managed by a rheumatologist, but there is some variation.

In Argentina, all patients are managed by a rheumatologist. In Brazil and Colombia, 95% and 96.3% are, but only 53.3% are in Mexico. Apart from Mexico, the LAMAS countries had the highest global levels of rheumatologist supervision.

Compared to other regions, Latin America had relatively high rheumatologist visit rates (4.6 appointments on average in the year preceding the LAMAS survey), but fewer physiotherapy visits than Europe.

### **Emergency departments and hospitalisation**

One in eight (12%) LAMAS patients is hospitalised due to their axSpA more than once a year.

Usage of hospital emergency departments was higher in Latin America than other regions. In the 12 months preceding the LAMAS survey, patients made an average of 4.6 visits to hospital emergency departments. This compares to 2.8 in Europe, 2.6 in North America, 2.5 in Asia and 1.3 in South Africa.<sup>1</sup>

### **Alternative therapies**

Overall, 39.4% of Latin American participants with axSpA used alternative therapies, comparable to the usage in Europe (38%) but lower than in Asia (51%) and North America (47%). Acupuncture and homoeopathy were the most used alternative therapies.

***“Access to healthcare and specialists is a big problem”***

*LAMAS respondent*

# The costs of axSpA

If the physical and psychological burden of living with axSpA is heavy, so, too, are its economic costs – for the individual, their families and for society at large.

## Direct healthcare costs (DHC)

These include healthcare appointments, diagnostic and monitoring tests, such as blood tests, MRI scans and X-rays, medications and emergency care. Using official national sources, verified by expert rheumatologists in each country, we calculated the direct healthcare costs alongside other elements of healthcare provision.

### Diagnostic costs

Across LAMAS, the average cost of diagnosing axSpA was **USD 589 per person**.

#### Diagnostic tests were the largest component (70%) of all diagnostic costs.

MRI scans represented the largest category of expenditure (22%), followed by X-rays and HLA-B27 testing. Brazil recorded the highest mean diagnostic test costs, largely driven by expensive procedures such as radionuclide imaging and CT scans.

Mexico had the lowest diagnostic test costs, reflecting reduced MRI usage and relatively modest expenditure across all test types

#### Diagnostic healthcare appointments cost an average of USD 160 across LAMAS.

Argentina had the lowest costs in this category, reflecting a lower number of appointments, while Mexico had the highest.



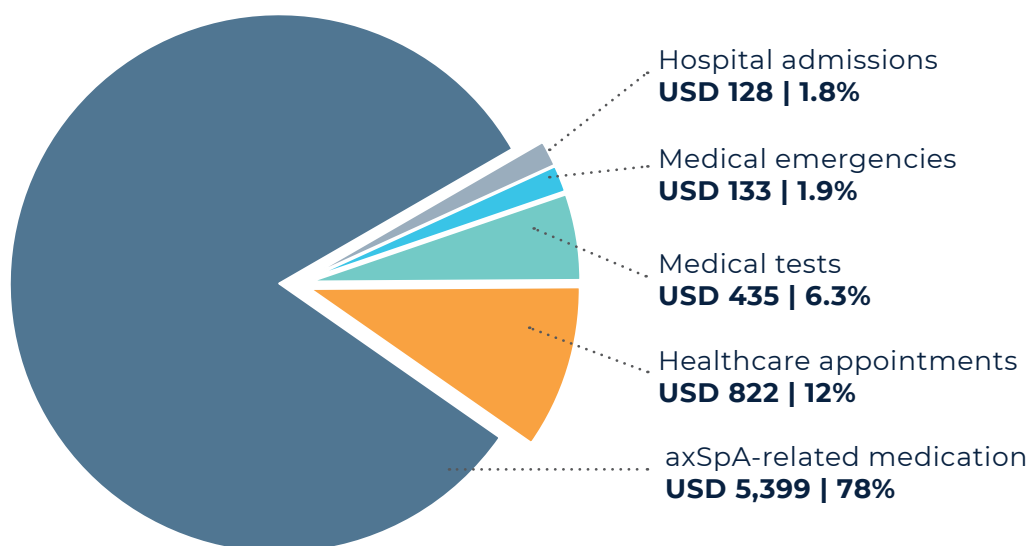
### How Argentina keeps diagnostic costs down

Diagnostic costs are the least overall in Argentina despite having the highest use of MRI. The lower number of visits to healthcare professionals in Argentina suggests a more streamlined diagnostic pathway than in the other countries. The use of MRI as an early diagnostic tool is a key reason for this. Argentina's example shows that targeted incorporation of advanced imaging techniques such as MRI can optimise resource usage and reduce overall diagnostic expenditures by shortening the time to an accurate diagnosis.

### Post-diagnosis costs

Average post-diagnosis direct healthcare costs per person per year were **USD 6,917**.

After diagnosis with axSpA, people will have regular follow-up and therapeutic appointments with, for example, their rheumatologist, a physiotherapist and a psychiatrist or psychologist. They will also likely start taking medication and will have regular monitoring tests, including MRI scans, X-rays, and blood and urine tests. They may also require hospitalisation at times and may experience medical emergencies that require immediate treatment.



**Across LAMAS, the average cost of diagnosing axSpA was USD 589 per person**

# The costs of axSpA

## Direct non-healthcare costs (DNHC)

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**Average direct non-healthcare costs per person per year were USD 267.**

This category of costs covers out-of-pocket expenses reported by LAMAS respondents.

- **Alternative treatments** cost each patient an average of **USD 22** per year.
- **Rehabilitation therapies and physical exercise** cost an average of **USD 245** per person per year.

## Indirect costs (IC)

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**The average indirect costs of axSpA per patient per year were USD 1,880.**

This category of costs measures the mean annual labour productivity cost per patient. It includes productivity losses related to employment, temporary and permanent sick leave, early retirement and unemployment.

- There was high variability between countries and between individuals. Brazil had the highest overall mean productivity loss per person (USD 4,908), followed by Colombia (USD 605); Argentina (USD 403); and Mexico (USD 165).
- Among employed people with axSpA, mean productivity loss per person was relatively low across all four countries at USD 23.
- Permanent sick leave, reported only in Brazil and Colombia, represented the largest average loss per person, at USD 9,781. Temporary sick leave, early retirement and unemployment were also substantial contributors to overall indirect costs at well over USD 7,000.

## Total cost (TC)

For LAMAS as a whole, **the average annual total cost per patient was USD 9,064.**

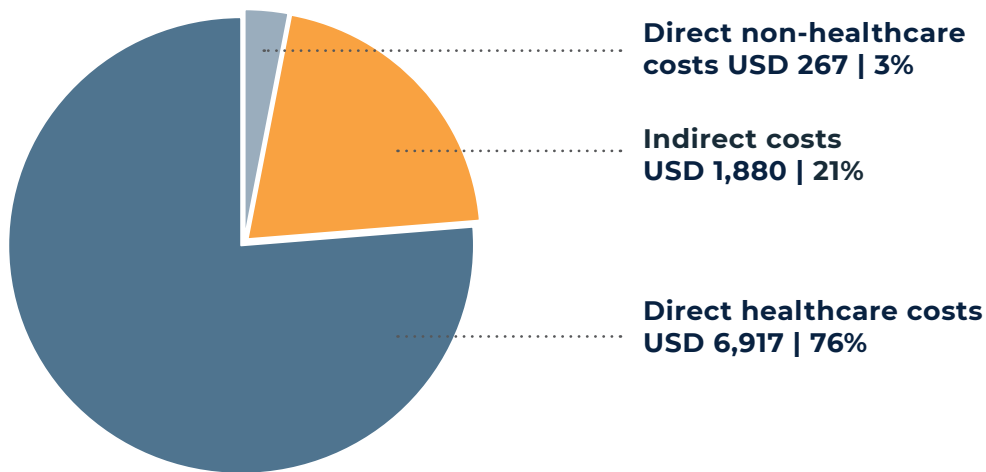
After diagnosis, the total mean annual cost per patient of axSpA is the sum of DHC (less the one-off cost of diagnosis), DHNC and IC.

Brazil had the highest total costs per patient per year at USD 12,563. Argentina came next at USD 12,161, then Colombia at

USD 9,473, with Mexico having the lowest costs at USD 5,080.

DHC made up more than 90% of total costs in both Argentina and Colombia. But the proportion was lower in Mexico (82%) and Brazil (59%).

Indirect costs as a proportion of total costs were by far the highest in Brazil (39%). Colombia was next at 6% while Argentina and Mexico were joint lowest at 3%.



## Costs, diagnostic delay and health

Across the whole LAMAS cohort, longer diagnostic delays contributed to a greater overall economic burden:

- Longer diagnostic delays were associated with slightly higher expenditures on diagnostic procedures and a greater number of tests.
- Longer diagnostic delays were associated with greater productivity-related losses.
- Higher total costs were also associated with longer diagnostic delays.

Higher disease activity was associated with a higher economic burden, mainly through productivity loss and work impairment:

- Higher indirect costs were associated with higher BASDAI scores across the LAMAS cohort, as were higher total costs.

Across LAMAS, higher indirect costs and total costs were associated with poorer mental health, indicating that patients with higher psychological distress tend to incur greater productivity losses and overall economic burden.

- In Argentina and Colombia, increased direct healthcare costs were associated with higher GHQ-12 scores, suggesting that poorer mental health may lead to increased usage of medical services.
- In Brazil, Colombia and Mexico, higher indirect costs were associated with higher GHQ-12 scores, suggesting a link between poor mental health and productivity loss.

**Across LAMAS, the average annual cost of axSpA per person is USD 9,064**

## The regional economic burden of axSpA

**Across the LAMAS countries, the average annual cost of axSpA per person is USD 9,064. With estimates for the prevalence of axSpA in Latin America ranging from 0.2% to 0.9% of the total population of 663 million, the total annual cost of the condition is between USD 12.02 billion and USD 54.16 billion.**

- **Argentina** shows the smallest estimated axSpA population due to its very low reported prevalence, resulting in a comparatively modest budget impact, despite relatively high per-patient costs.
- **Brazil**, despite the wide range of reported prevalence estimates, has a potentially large axSpA patient population due to its large population size, resulting in a substantial and highly variable estimated annual cost.

- **Colombia**, with a moderate prevalence, has a sizeable estimate for its patient population and a correspondingly high annual cost.
- **Mexico**, combining a prevalence similar to Colombia with a much larger population, has the highest estimated number of patients and therefore the largest overall budget impact among the individual countries.



# Concluding comments

The significant physical, psychological and socioeconomic impacts of axSpA in Latin America are clearly demonstrated in the data provided by LAMAS participants.

Nearly every aspect of an individual's life can be affected by axSpA, with a clear link demonstrated between delayed diagnosis, poorly managed disease and worse health outcomes.

Those with greater physical health complications were more likely to suffer from poorer psychological health, with data suggesting this is a two-way relationship.

Addressing these challenges requires coordinated regional action to reduce diagnostic delay, strengthen specialist care, ensure equitable access to effective treatments, integrate mental health into clinical practice, and promote multidisciplinary care models.

Improving axSpA care is not only a clinical priority but also a matter of public health, social equity and long-term health system sustainability.

We hope that this report will prove to be a useful tool for:

- Increasing awareness of axSpA among healthcare professionals, policymakers, patient organisations and the general public;
- Helping patient organisations to support people with axSpA more effectively;
- Increasing the understanding among healthcare professionals and policymakers of the burden that axSpA places on individuals, families and society as a whole.

Reflecting on the high levels of unmet need reported by LAMAS participants, it is imperative that:

- axSpA is recognised as a healthcare priority;
- the strategic recommendations set out in this report are adopted at a country level by policymakers and healthcare professionals.

Doing so will put the patient perspective at the heart of axSpA care planning, reducing the overall impact of the disease on healthcare systems and supporting the millions of people affected by axSpA across Latin America to control their illness with minimal impact on their happiness and quality of life.

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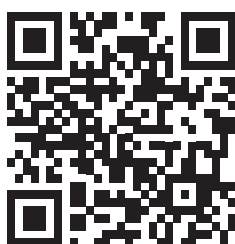
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## The IMAS global report

**The Burden of Axial Spondyloarthritis: A global patient perspective** is a report that summarises the findings of the IMAS survey.

You can find it at <https://asif.info/imas-global-report> or by scanning the QR code.



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## Glossary

**axSpA** or **Axial Spondyloarthritis** is an inflammatory disease that mainly affects the spine and sacroiliac joints (which attach the spine to the pelvis), causing chronic back pain, fatigue, morning stiffness and reduced mobility. AxSpA is an umbrella term that includes two forms: **radiographic axSpA** – which used to be known as ankylosing spondylitis (AS) or Morbus Bechterew – and **non-radiographic axSpA** (nr-axSpA), in which symptoms are present, but damage is not visible on X-rays. AxSpA can also affect other parts of the body, including peripheral joints, and may be associated with inflammation of the eyes, skin and digestive system.

**BASDAI** or the **Bath Axial Spondyloarthritis Disease Activity Index** is a system for measuring the degree of disease activity in axSpA. Its scores range from 0 (no disease activity) to 10 (maximum disease activity). BASDAI scores of 4 or more indicate that the disease is not well controlled.

**FLI** or the **Functional Limitation Index** was developed specifically for this study and assesses the degree of limitation in 18 activities of daily life. A total score from 0 and 18 was considered low limitation, between 18 and 36 medium limitation, and between 36 and 54 high limitation.

**GHQ-12** or the **12-point General Health Questionnaire** is used to assess a person's mental health. Scores greater than 3 indicate that a person is at risk of developing psychiatric disorders.

**GINI** is an index that measures a country's degree of economic inequality.

**HDI** or the **Human Development Index** assesses a country's levels of education, longevity and well-being.

**HLA-B27** or **Human Leukocyte Antigen B27** is a gene that plays a role in helping the body's immune system distinguish between the body's own tissues and harmful invaders, such as viruses and bacteria. Most, though not all, people with axSpA test positive for HLA-B27, but most people with HLA-B27 do not have AxSpA.

**IMAS** is the International Map of Axial Spondyloarthritis.

**LAMAS** is the Latin American Map of Axial Spondyloarthritis. Part of IMAS.

**SSI** or the **Spinal Stiffness Index** was developed specifically for IMAS. It assesses the degree of stiffness experienced by patients in the spinal column, distinguishing between the cervical, dorsal, and lumbar areas. Total scores are obtained by adding together the responses in each of the areas of the spine without weighting resulting in a scale ranging from 3 (no stiffness) to 12 (severe stiffness).

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## Organisations

**ASIF** | <https://asif.info>

The Axial Spondyloarthritis International Federation is a membership organisation representing 60 patient organisations in 48 countries around the globe that support people living with axSpA. ASIF is the publisher of this report and the accompanying statistical analysis and the owner of IMAS.

**ASAS** | [www.asas-group.org](http://www.asas-group.org)

The Assessment of SpondyloArthritis international Society is an international group of experts in the field of spondyloarthritis.

**PANLAR** | [www.panlar.org](http://www.panlar.org)

The Pan-American League of Associations for Rheumatology (PANLAR), founded in 1944, integrates rheumatology scientific societies, health professionals related to rheumatic conditions and groups of rheumatic patients from all the countries of America.

**Universidad de Sevilla (University of Seville)** | [www.us.es](http://www.us.es)

The University has played a key role in developing the foundational Spanish Atlas of axSpA, EMAS and IMAS projects and continues to collaborate closely with ASIF in advancing IMAS.

