The Burden of Axial Spondyloarthritis: A global patient perspective

Exploring the results from the International Map of Axial Spondyloarthritis (IMAS)

January 2024

ASIF
AXIAL SPONDYLOARTHRITIS
INTERNATIONAL FEDERATION

IMAS International Map of Axial Spondyloarthritis

Acknowledgements

We would like to thank the thousands of individuals across the world who gave up their time to respond to the IMAS survey, without which these findings would not be possible. We are also grateful to the expert contributors who shaped this report and analysed the data that informed it. Particular recognition goes to the members of the IMAS Global Report Development Steering Group (listed below), whose counsel and feedback was an invaluable part of the development process.

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This report has been developed as part of a collaboration between Novartis Pharma AG and Axial Spondyloarthritis International Federation.

Writing support has been provided by M+F Health.

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Novartis MLR ID: 315692 | Date of Preparation: 2 January 2024

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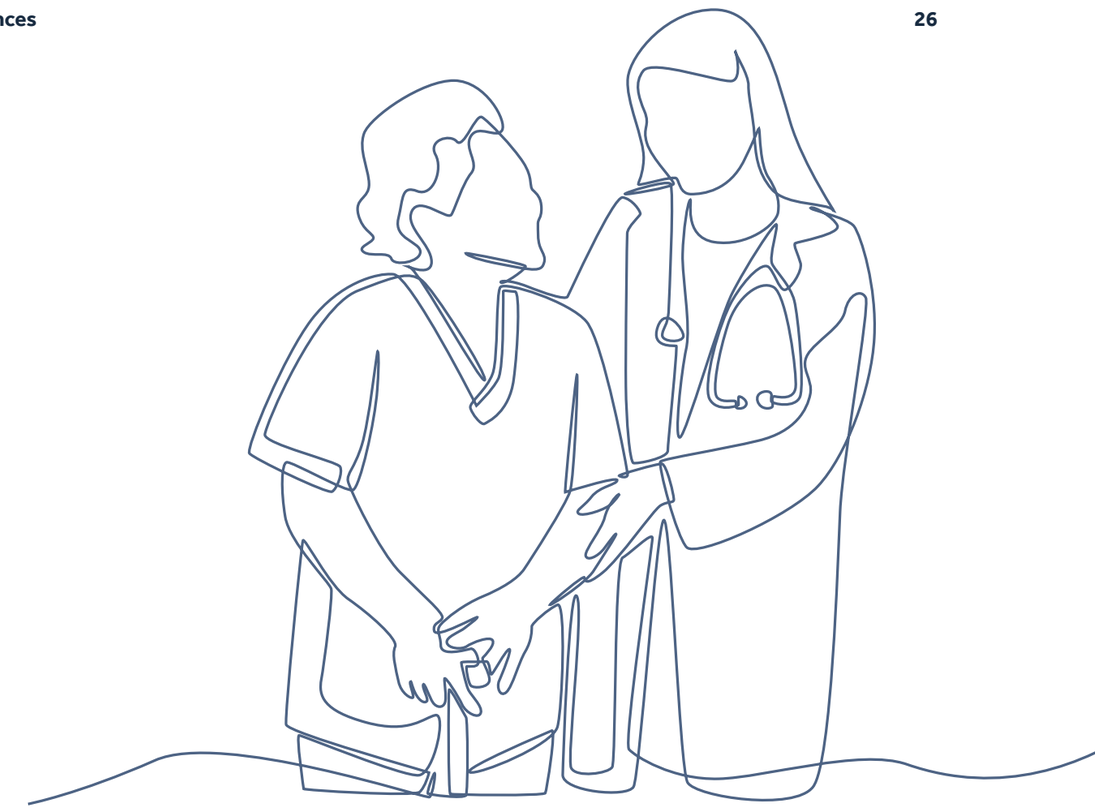


Foreword

It is both a pleasure and a privilege to be able to introduce the latest chapter of the International Map of Axial Spondyloarthritis (IMAS) research project. Since its inception in 2017, IMAS has grown in scale and scope, and has now assembled the views of over 5,500 respondents from 27 countries across five continents.

Each participant has their own personal story and axSpA journey to share, and their responses provide invaluable insights into the realities of how people across the world are affected by axSpA on a day-to-day basis. Tellingly, they remind us that there is almost no area of a person's life that is not impacted by the disease, particularly when it is diagnosed late or poorly managed. This reinforces the critical need that best practices in axSpA management are embedded within healthcare systems, including prioritising early diagnosis, providing multidisciplinary care and adopting shared decision-making when considering treatment goals.

When these components are not in place, IMAS demonstrates just how damaging the consequences can be. Individuals are likely to experience poorer physical and psychological health, while suffering greater socioeconomic harms. Healthcare systems are also likely to be put under more strain, as people typically need greater levels of care to manage the complex and multifaceted symptoms and comorbidities associated with sub-optimally controlled axSpA.

IMAS contributes to the growing body of knowledge demonstrating the impact of axSpA, and corresponding advances in treatment and service delivery provide hope for better patient outcomes. Policymakers and healthcare practitioners should take the compelling evidence from IMAS and reflect on the ethical and economic reasons to take forward the calls to action this report sets out. Doing so, alongside implementing the ASAS-EULAR recommendations for the management of axSpA, can transform the lives of millions, both now and in the future, in a disease area that has for too long been overlooked and misunderstood.

Dr Xenofon Baraliakos - Professor for Internal Medicine and Rheumatology, Ruhr-University Bochum and President of the Assessment of SpondyloArthritis International Society (ASAS)

Executive Summary

Axial spondyloarthritis (axSpA) remains a deeply misunderstood and under-recognised disease, despite affecting up to 1 in 150 of the global population – equivalent to over 50 million people. This painful, progressive and chronic inflammatory rheumatic disease has a huge impact on those that live with it.

The *International Map of Axial Spondyloarthritis* (IMAS) was designed to improve understanding of axSpA through generating and disseminating evidence about how people experience their disease physically, psychologically and socioeconomically. IMAS is the largest ever global axSpA patient survey, with responses gathered from 5,557 individuals, across 27 countries.

1in150

OF THE GLOBAL POPULATION – EQUIVALENT TO OVER 50 MILLION PEOPLE.

IMAS participants waited on average 7.4 years to receive an axSpA diagnosis, with women waiting on average 2 years longer than men. During this time, the disease can progress significantly and, in some cases, lead to irreversible disability. Longer delays are strongly associated with higher levels of disease activity, more severe functional limitation and greater spinal stiffness.

Three-quarters of respondents considered their disease sub-optimally controlled, leading to significantly increased levels of pain, fatigue and stiffness, while also increasing the risk of comorbidities. Poorly controlled disease was particularly common amongst female participants, who fared worse in almost every IMAS metric.

Findings also reinforce the close relationship between the physical and psychological aspects of axSpA. 60% of respondents indicated they were affected by psychological distress, with poorer mental health reported by those with higher levels of disease activity. Despite the high psychological burdens of axSpA, two-thirds said they had not visited a psychologist or psychiatrist in the last 12 months.

People living with axSpA are also likely to experience a wide range of socioeconomic difficulties. Half of all respondents were restricted in carrying out everyday household activities. Almost half of respondents highlighted that axSpA had influenced their job choice, with nearly three-quarters saying the disease had caused difficulties in finding a job.

Those with higher disease activity generally reported greater use of the healthcare system. Compared to those with well-managed axSpA, respondents with sub-optimally controlled disease made on average nearly double (92%) the number of visits to their primary care physician, 71% more visits to a physiotherapist and 58% more visits to a psychologist or psychiatrist. Half of IMAS respondents have never used classes of treatment that are most associated with slowing disease progression or achieving optimally controlled disease.

When looking to the future, respondents told us of their hopes around preventing disease progression, reducing pain and improving overall quality of life. These go hand in hand with an individual's treatment goals, meaning these factors should be a crucial part of the conversation between patients and healthcare professionals.

The IMAS findings demonstrate the urgency of addressing unmet needs for those living with axSpA, and the importance of taking a multidisciplinary and person-centred approach to care.

Calls to Action

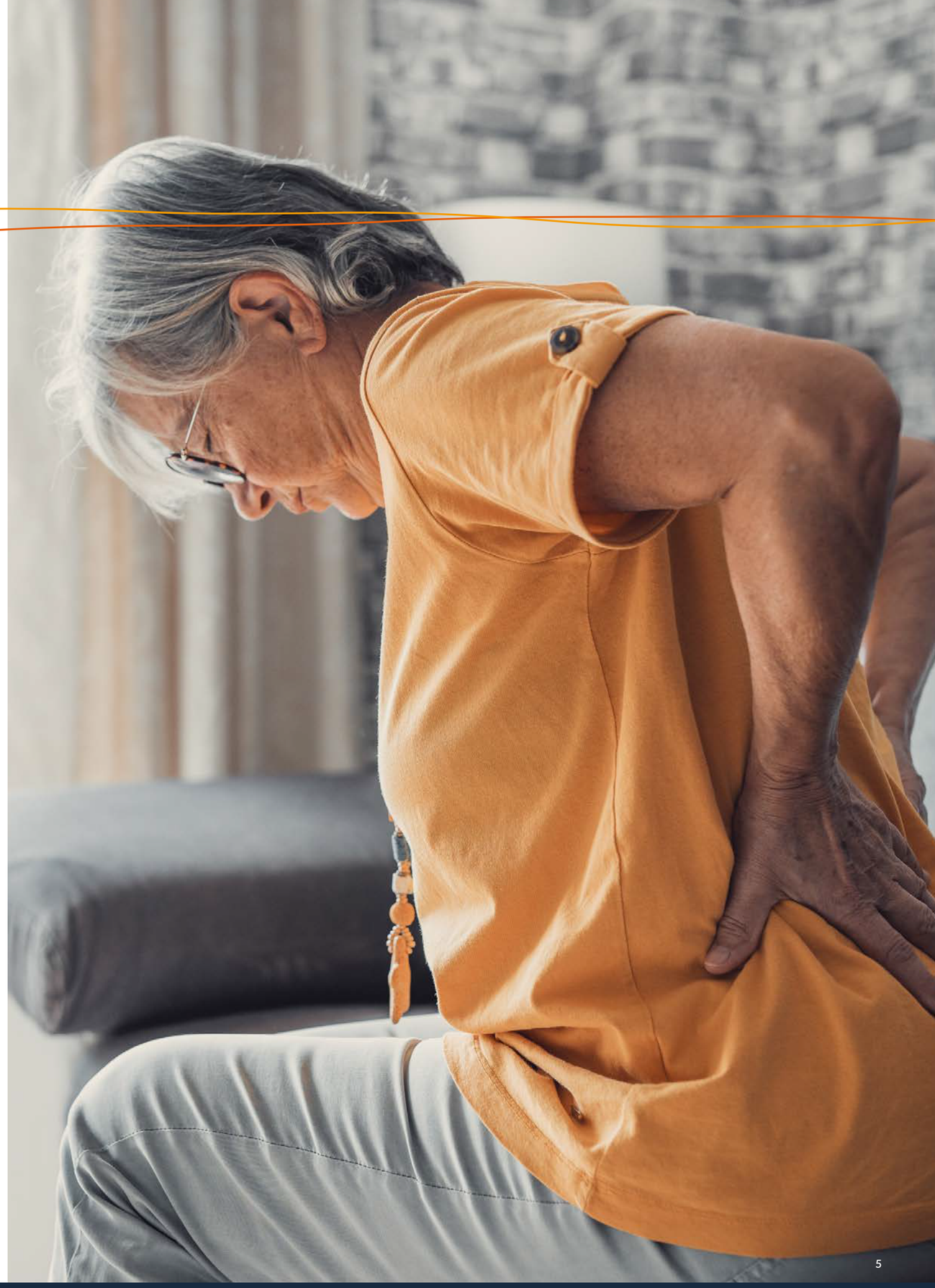
These nine calls to action urge policymakers and healthcare professionals to make improvements in the care of those living with axSpA. The calls to action have been developed in response to the overwhelming evidence gathered through IMAS. They complement ASAS-EULAR international axSpA management guidelines, which set out principles and recommendations to support best possible care and disease outcomes.[1] Significant improvements in the care, outcomes and overall quality of life of people with axSpA are needed. These improvements are not only good for individuals, but will likely produce benefits for wider society, through enabling individuals to contribute more to the workplace economy and by reducing the need for healthcare system utilisation.

Calls to action for policymakers

1. Undertake a country-level assessment, working with patient groups and clinical experts, using IMAS data to better understand the needs of people with axSpA. Drawing on the outputs of the assessment, identify measurable actions to address key challenges, and regularly review progress.
2. Prioritise early and accurate axSpA diagnosis through reliable referral systems that promptly transition patients from primary care to an appropriate specialist (ideally a rheumatologist), with the aim of avoiding delays in diagnosis that often contribute to poorer long term health outcomes and higher social and healthcare system costs.
3. Actively promote multidisciplinary care coordinated by an appropriate specialist and supported by relevant physical and mental health specialists, with a focus on ensuring optimal treatment and outcomes.
4. Work with employers' and patients' groups to define solutions that enable people with axSpA to access and remain part of the workforce.

Calls to action for healthcare professionals

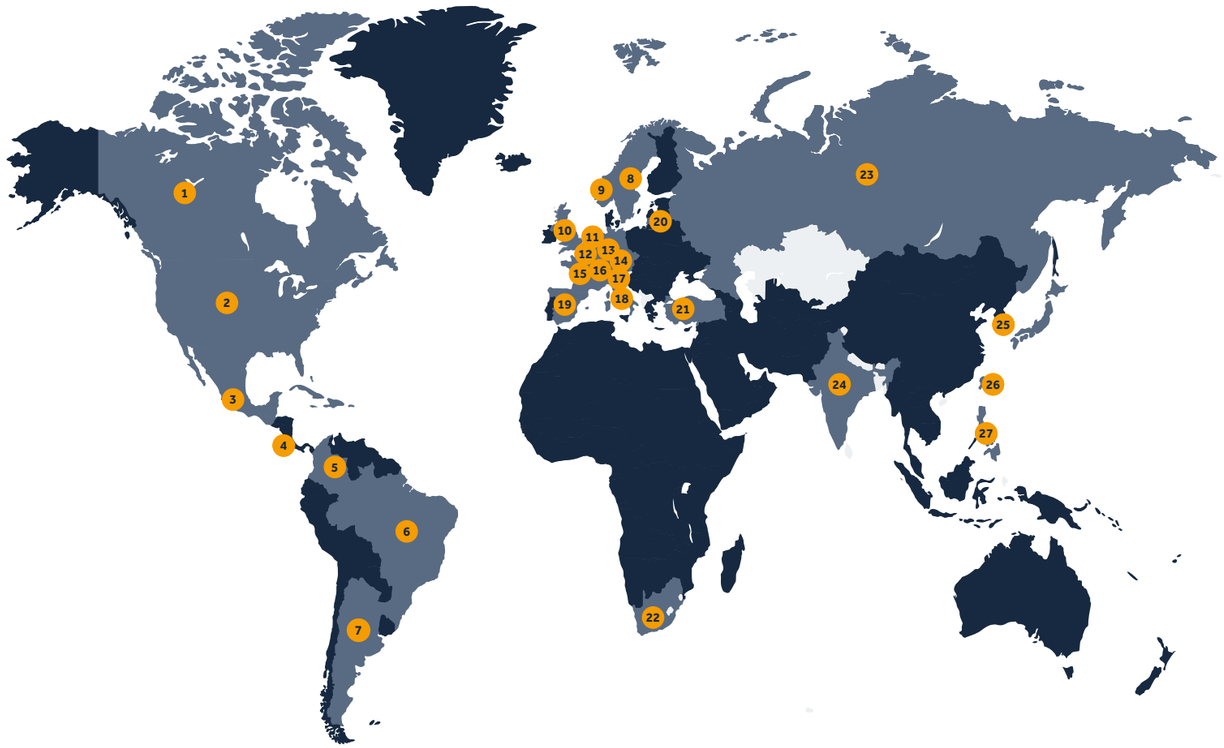
5. Educate primary care health professionals to recognise signs and symptoms of axSpA and to facilitate appropriate and timely referral to an appropriate specialist (ideally a rheumatologist).
6. Increase awareness and recognition of the signs and symptoms of axSpA amongst all healthcare professionals that may see undiagnosed people with symptoms. This includes physiotherapists, orthopaedic doctors and any specialists that treat associated manifestations of axSpA, such as ophthalmologists, dermatologists and gastroenterologists.
7. Ensure that people with axSpA have co-developed, individually tailored and regularly reviewed care plans in place – coordinated by an appropriate specialist.
8. Tailor individual care plans to maximise long-term quality of life, recognising an individual's treatment goals and their physical, psychological, and socioeconomic needs.
9. Deliver education and training initiatives that help to identify patients requiring specific mental health support and ensure access to appropriate care is available when needed.



Chapter 1: axSpA and the IMAS research project

5,557

People diagnosed with axSpA who completed the IMAS survey were from 27 countries across five continents



1. Canada
2. United States
3. Mexico
4. Costa Rica
5. Columbia
6. Brazil
7. Argentina
8. Norway
9. Sweden
10. United Kingdom
11. Netherlands
12. Belgium
13. Germany
14. Austria
15. France
16. Switzerland
17. Slovenia
18. Italy
19. Spain
20. Lithuania
21. Turkey
22. South Africa
23. Russia
24. India
25. South Korea
26. Taiwan
27. Philippines

Key Messages

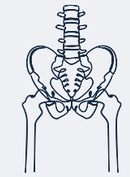
Axial spondyloarthritis (axSpA) is a chronic and painful inflammatory disease that has multiple impacts on people's lives. Despite affecting up to 1 in 150 of the global population, axSpA is often poorly understood, with signs and symptoms of the disease typically not recognised, contributing to diagnostic delays and sub-optimal management. The International Map of Axial Spondyloarthritis (IMAS) aims to address these issues by providing extensive global data on the lived experiences and the needs of people with axSpA, which can be integrated into health policy and clinical decision-making.

Axial spondyloarthritis (axSpA) is an under-recognised chronic, painful inflammatory condition predominantly affecting the spine and sacroiliac joints.[2,3] The disease, which can also affect other joints, tendons and ligaments, typically presents earlier in life, with symptoms most commonly emerging in a person's twenties.[3] It is a painful and progressive condition characterised by flares where symptoms can temporarily worsen, and often places a considerable burden on those living with axSpA through a wide range of physical, psychological and socioeconomic impacts. Despite a low general awareness and understanding of axSpA, it is not a rare disease, with up to 1 in 150 people affected by it.[4] This suggests that there could be over 50 million people living with axSpA across the globe.

To improve awareness of axSpA and incorporate the patient perspective into health policy and clinical care, there is a pressing need to better understand the real-life impact and burdens of the disease. The International Map of Axial Spondyloarthritis (IMAS) is a comprehensive survey that assesses the burden of the disease on those living with it.

The 5,557 people diagnosed with axSpA who completed the IMAS survey were from 27 countries across five continents. It is the largest ever global project gathering evidence of the lived experiences of people with axSpA. The programme brings together patients, patient organisations, clinicians and researchers from around the world to address the questions that matter most to those with the disease. By generating and disseminating evidence about how people with axSpA experience their disease physically, psychologically and socioeconomically, IMAS aims to raise the voice of the axSpA community.

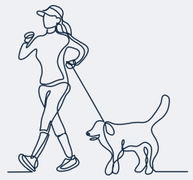
Key signs and symptoms of axSpA



Gradual onset of pain and stiffness in the lower back, buttocks and hips

20s

Onset of symptoms before the age of 40, but typically in a person's 20s



Pain and stiffness, that often gets better with movement and worse with rest

Fatigue

Chapter 2: axSpA diagnosis

Key Messages

Early diagnosis of axSpA is crucial and one of the best predictors of how severely the disease will impact an individual. There is currently an unacceptable average global diagnostic delay of 7.4 years, during which time the disease, and a person's corresponding prognosis, can worsen significantly. IMAS data suggests that those with longer diagnostic delays are at increased risk of having higher disease activity and experiencing more comorbidities, with negative consequences for almost every aspect of day-to-day life. IMAS also shows that diagnostic delays are associated with increased healthcare utilisation, generating additional demands and costs for healthcare systems. It is crucial therefore that healthcare policy prioritises early axSpA diagnosis, with effective referral pathways and education initiatives put in place to achieve this.

AxSpA is a progressive disease, with early diagnosis and effective treatment closely associated with better outcomes. Without timely diagnosis, individuals are much more likely to experience physical and psychological distress, including the possibility of permanent disability - whilst also jeopardising socioeconomic prospects.[7]

Findings from IMAS data show that there is an average 7.4 year wait to diagnosis following first onset of symptoms. Table 1 shows the regional differences.

Participant Region	Average diagnostic delay (years)
Europe	7.7
Asia	4.2
North America	9.0
Latin America	5.9
South Africa	10.8

***Table 1.** Average axSpA diagnostic delay, broken down by IMAS participant region[5]*

The importance of early axSpA diagnosis is demonstrated by the close association between diagnostic delay and health outcomes. IMAS respondents who experienced longer delays were more likely to suffer from higher levels of disease activity, greater spinal stiffness and more severe functional limitation (see Table 2). Not only do these factors lead to significant pain and distress for individuals, making everday activities difficult, they can also generate additional costs for healthcare systems (see Chapter 6 on healthcare utilisation).

> **"It took almost 30 years to get a diagnosis. I was treated like my symptoms were in my head and dismissed by many doctors.**

Misdiagnosis is one of the key contributors to the delay in obtaining an accurate diagnosis of axSpA. Due to the nature of some symptoms, most notably lower back pain, healthcare professionals at the first point of contact are likely to overlook the possibility of axSpA. Initial misdiagnosis was reported by nearly three-quarters of IMAS participants from India, and around two-thirds of respondents from the United Kingdom and the United States. IMAS data shows that healthcare professionals were likely to mistake axSpA for mechanical back pain, rheumatoid arthritis and even anxiety or depression.

Women were particularly likely to experience challenges in achieving diagnosis, with IMAS data showing that they waited on average an additional two years compared to men. This disparity could reflect a persistent misconception that axSpA is a predominantly 'male condition'. Recent improvements in understanding of the disease and the different ways it can present mean we now know however that axSpA prevalence is broadly equivalent in both men and women.

		Average diagnostic delay (years)
Disease Activity	Low disease activity[i]	6.6
	Sub-optimally controlled disease	7.7
Spinal Stiffness Index	No restriction	3.7
	Mild	5.4
	Moderate	7.5
	Severe	9.1
Functional Limitation Index	Low	6.2
	Medium	8.2
	High	9.5

***Table 2.** Correlation between measures of physical health and diagnostic delay[6]*

The IMAS data reinforces the importance of individuals with signs and symptoms of axSpA being referred promptly to an appropriate specialist (ideally a rheuamtologist), as recommended by ASAS-EULAR guidelines[8]Early referral to a rheumatologist is recommended by international axSpA management guidelines and is one of the best predictors of prompt diagnosis.[1] IMAS respondents largely corroborated this, with the overall majority of individuals – despite some notable regional differences – reporting that a rheumatologist diagnosed their axSpA (see Table 3).

The IMAS data make the clear case that healthcare policy needs to prioritise early diagnosis. Early recognition of the signs and symptoms, as well as reliable referrals to an appropriate specialist, are crucial in reducing and eventually eliminating diagnostic delay. By avoiding delays in diagnosis, we can improve health outcomes for individuals and reduce social and healthcare system costs.

> **"The belief that women simply do not get an inflammatory arthritis, such as axSpA is something I have unfortunately experienced first-hand..... It ultimately took years of suffering and the progression of my disease before I was taken seriously.**

Participant region	Rheumatologist	Primary Care Physician	Orthopaedic Specialist	Physiotherapist	Other
Europe	76.5%	12.6%	5.7%	1.1%	4.0%
Asia	53.9%	8.0%	33.9%	1.8%	2.3%
North America	66.4%	19.6%	5.1%	2.6%	6.4%
Latin America	74.3%	14.2%	7.7%	0.5%	3.3%
South Africa	70.8%	12.5%	7.6%	0.0%	9.0%

Diagnosing specialty

***Table 3.** Healthcare professional providing a confirmed axSpA diagnosis, broken down by IMAS participant region[6]*

i For ease of review, 'low disease activity' and 'sub-optimally controlled disease' is used interchangeably in this table with respective BASDAI participant scores of < 4 and ≥4/10. More information on the BASDAI scale is available in the following chapter.

Chapter 3: Physical health impacts of axSpA

Key Messages

People with axSpA often suffer with considerable physical health impacts, significant pain and can experience irreversible disability. There is also a wide range of debilitating associated conditions, including uveitis, inflammatory bowel disease and psoriasis. Three-quarters of IMAS respondents reported a 'BASDAI' score – a commonly used, validated axSpA disease activity measurement index – that indicated their disease was sub-optimally controlled, leading to significantly increased levels of pain, fatigue, stiffness and difficulty carrying out routine tasks. Higher disease activity is also associated with the increased risk of comorbidities. It is essential that everyone living with axSpA is able to access multidisciplinary care to support effective management of all aspects of the disease. Care plans should be co-developed and regularly reviewed.

As a chronic and long-term condition, axSpA can place significant physical health burdens on those living with the disease. One of the key validated axSpA assessment tools is the 'BASDAI' scale,[ii] an index developed to specifically measure severity of the disease. The index comprises six separate categories of disease activity measurement, with each category assessed on a 0-10 scale. An overall score of ≥4/10 is the threshold at which the disease is considered to be sub-optimally controlled. This is a particularly significant threshold considering that sub-optimal management of axSpA is strongly associated with increased prevalence of physical and psychological comorbidities and worse socioeconomic impacts.

Worryingly, 75% of IMAS respondents reported a BASDAI score of equal to or greater than 4, with a mean respondent score of 5.4. The majority of respondents are therefore living with sub-optimally controlled disease, leaving them at increased risk of additional health complications and significant challenges in their daily life. Every participating IMAS region reported a mean participant BASDAI score above 4 (see Table 4).

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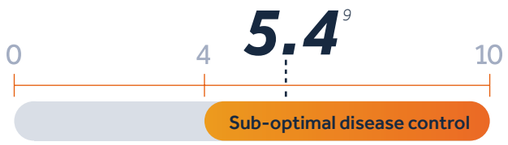
Participant Region	Average BASDAI score
Europe	5.4
Asia	4.9
North America	5.5
Latin America	5.6
South Africa	6.0

***Table 4.** Average BASDAI score by region, as reported by IMAS participants[9]*

Average participant BASDAI score:



> **"It's frustrating having to carry on with daily activities (caring for children, managing household and working full time) while suppressing the pain and fatigue.**

Levels of disease activity were high across each of the six BASDAI categories. Mean reported disease activity scores were highest in the 'fatigue' and 'neck, back and hip pain' categories, but were ultimately above the ≥4/10 threshold in every area. Women were especially likely to report higher levels of disease severity, with more than 80% of female respondents reporting an overall BASDAI score of ≥4/10 and a mean score of 5.7, 13% higher than the mean score reported by men.[10]

BASDAI Category	Average BASDAI score
Level of fatigue	5.9
Neck, back and hip pain	5.7
Morning stiffness severity	5.3
Discomfort	4.8
Pain other than neck, back and hip	4.6
Morning stiffness duration	4.2

***Table 5.** Recorded BASDAI scores across the 6 key disease activity areas, as reported by IMAS participants[6]*

In addition to the pain, stiffness and discomfort, symptomatic of axSpA, the disease is also associated with a range of other debilitating conditions. At least one of over 25 different physical health conditions and diseases were experienced by 4,382 IMAS respondents. These included extra-musculoskeletal manifestations such as uveitis, psoriatic arthritis and inflammatory bowel disease, as well as comorbidities such as obesity and hypertension.[iii]

Significantly, there was a direct correlation between an individual reporting a higher BASDAI score, and the likelihood of being affected by an increased number of comorbidities. Respondents with sub-optimally controlled disease reported a mean average number of 2.4 comorbidities, compared to 1.4 reported by those with low disease activity. It is crucial to note that this correlation between increased risk of comorbidities and higher disease activity is just one of the many factors associated with having more active disease. It is important to recognise that sub-optimally controlled disease also indicates an increased likelihood of worse psychological health, a longer delay to diagnosis and increased use of the healthcare system.

> **"With having fibromyalgia too and many other problems of chronic long-term pain it's degrading when the medical profession don't take you seriously and say that you just need to get on with it.**

ii The Bath Ankylosing Spondylitis Disease Activity Index

iii Extra-musculoskeletal manifestations (EMMs) are co-morbidities that occur outside of the musculoskeletal system in patients with axial spondyloarthritis (axSpA). These peripheral manifestations vary in symptom severity, are often associated with the underlying inflammatory process and can have a significant impact on disease activity, an individual's activity, and treatment effectiveness in axSpA patients.

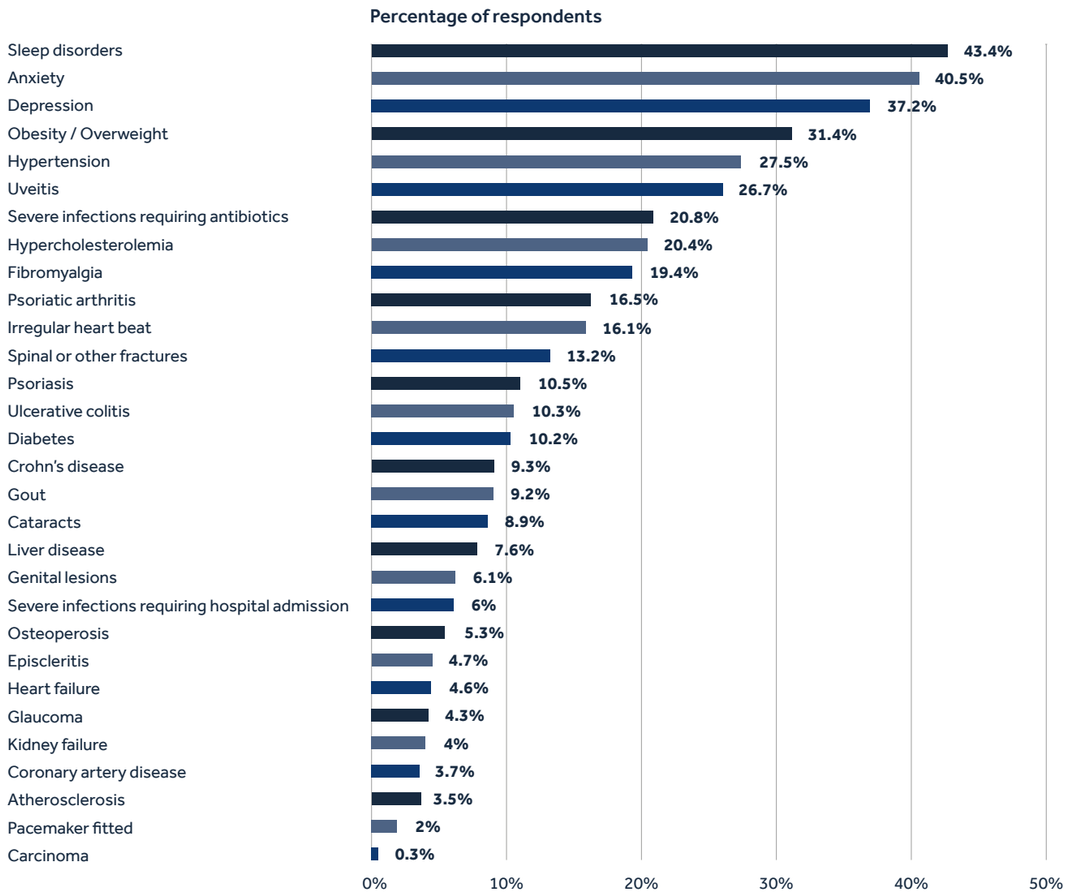


***Table 6.** Comorbidities reported by IMAS participants [n = 4,382]*[6]

Comorbidities place significant burdens on individuals and they generate extensive additional utilisation of, and associated costs for, healthcare systems, as described in Chapter 6. Ensuring axSpA is optimally managed and that an individual's symptoms are under control should be a clear moral, health management and economic priority. This can be achieved through ensuring individuals are able to access joined-up, multidisciplinary care, underpinned by tailored care plans. Plans should be developed through decision-making shared by the clinician and patient and should consider individual needs and treatment goals.

Fears, hopes and treatment goals: Physical Health

IMAS responses showed that:

56% feared disease progression

54% hoped to eliminate pain

43% cited 'improved mobility' as a key treatment goal

Chapter 4: Mental health impacts of axSpA

Key Messages

In addition to the significant physical health impacts of axSpA, people living with the disease are much more likely to experience psychological comorbidities such as depression, compared to the wider population. 60% of IMAS respondents indicated they were affected by some form of psychological distress, and mental health impacts were more common amongst those with higher levels of physical disease activity. Evidence also suggests a bidirectional relationship, with mental distress influencing disease activity. It is essential that healthcare services improve the recognition of mental health needs amongst people living with axSpA, and that appropriate support to address these needs is readily available.

AxSpA can place a significant psychological toll on those living with the disease. Data shows a strong correlation between axSpA disease progression and poorer mental health outcomes, with up to two-thirds of those affected by the condition experiencing depression during their lifetime, a proportion several times higher than the general population.[11,12,13]

> **Live with guilt for passing it on to my children. Sick and tired of being sick and tired. Pain levels get so unbearable and that has caused me severe depression and anxiety. I am no longer me.**

IMAS participants were asked to complete a General Health Questionnaire (GHQ-12) to assess current mental health challenges and pressures they are experiencing.[iv] Responses are scored on a range from 0 to 12, with a higher score indicating poorer levels of mental health. Almost 60% of IMAS respondents reported a GHQ-12 of higher than 3, which is considered the threshold level indicating the presence of psychological distress. The following table shows the regional differences, but notably all regions average a score of 3 or more.

Participant Region	Average GHQ-12 score
Europe	4.0
Asia	3.0
North America	3.0
Latin America	4.0
South Africa	5.0

***Table 7.** Average GHQ-12 score of IMAS respondents, broken down by participant region[6]*

In addition to GHQ-12 scores consistent with general psychological distress, IMAS respondents also reported high levels of psychological comorbidities. Over 40% said they were living with sleep disorders or anxiety, with over a third affected by depression.

Psychological comorbidities

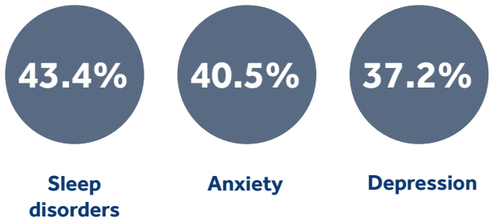


***Figure 1.** Proportion of IMAS respondents reporting psychological comorbidities[6]*

Number of visits to psychologist or psychiatrist in the last 12 months

NONE	ONE	TWO	THREE	FOUR	FIVE	SIX OR MORE
66.1%	7.6%	5.3%	2.9%	3.7%	2.3%	12.1%

***Figure 2.** Breakdown of visits to psychologist or psychiatrist in the past 12 months[6]*

Despite these psychological comorbidities and almost 60% of respondents being at risk of psychological distress, over two thirds had not visited a psychologist or psychiatrist in the previous year, demonstrating a significant gap between those in need of treatment and those accessing it. This potentially leaves many at risk of not having the care and support that is needed to manage the multifaceted nature of axSpA. .

Significantly, the data also demonstrates a clear link between individuals with higher disease activity and poorer levels of mental health.[14] IMAS respondents who did not report psychological distress were more likely to be living with better controlled disease (an average BASDAI score of 4.4). Meanwhile, individuals affected by psychological distress reported an average BASDAI score of 6.1. IMAS data also suggests a correlation between poorer mental health and increased spinal stiffness, functional limitation and diagnostic delay.

The results indicate that certain groups and individual circumstances were particularly prone to poorer mental health outcomes. Respondents who were younger, female, had a comparatively low level of education or were separated or divorced, were all more likely to report higher average GHQ-12 scores and therefore be at greater risk of mental ill health. This suggests that healthcare teams managing those with axSpA should be particularly mindful of potential mental health needs amongst individuals who have higher-risk characteristics.

While a third of IMAS respondents are regularly accessing some form of psychological support, there is a clear need to support healthcare professionals to improve the recognition and identification of the psychological burden of axSpA. People with axSpA should have co-developed and tailored care plans that specifically recognise their psychological needs to improve disease management.

Fears, hopes and treatment goals: Mental Health

IMAS responses showed that:

17% feared future anxiety or sadness

18% hoped to improve their mood

40% Approximately 40% cited 'improved quality of life' as a key treatment goal

iv The 12-item General Health Questionnaire has been adopted by the World Health Organization for use as a screening tool to assess the presence of poor mental health or psychological distress in non-clinical settings. It is considered to be a 'gold standard' validated tool for assessing mental health comorbidities.

Chapter 5: Socioeconomic impacts of axSpA

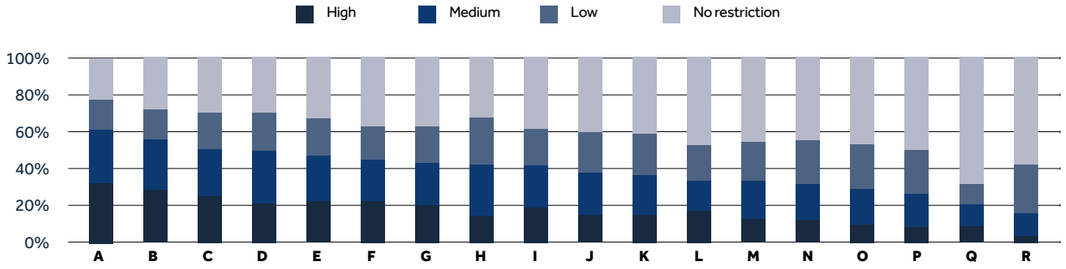
Key Messages

People with axSpA are likely to experience a wide range of socioeconomic difficulties. They are up to three times more likely to withdraw from work compared to the general population, while a significant proportion report routinely needing help with everyday activities, such as personal care or shopping. Those with more active and poorly managed axSpA are particularly likely to suffer poorer socioeconomic outcomes. It is crucial that healthcare and workforce policy implements changes that can help people with axSpA remain in employment, and that an individual's socioeconomic needs are factored into care plans.

IMAS findings paint a clear picture of the wider socioeconomic difficulties experienced by people living with axSpA. Participants were asked how the impacts of axSpA affected their ability to carry out everyday activities, including whether they routinely needed to ask for help. As demonstrated in Table 8, respondents reported high levels of restriction across many of the 18 activities that were assessed.

Half of respondents reported experiencing 'high' or 'medium' levels of restriction when attempting to carry out housework, walking down the stairs or getting up from bed. Over a third reported that driving or using public transportation resulted in high or medium levels of restriction, while around 3 out of 10 considered washing or going to the toilet to be restricted to a high or medium degree.

> "
>
> **Losing my ability to skate and exercise as I once used to. And the frustration of knowing that none of my close friends or family truly understand the pain.**



A Doing physical exercise
B Housework
C Down the stairs
D Getting up from bed
E Tying shoe laces
F Shopping
G Engaging in intimate relations
H Dressing / undressing
I Walking (street)
J Walking (house)
K Driving
L Using public transportation
M Cooking
N Taking a bath
O Washing
P Going to the toilet
Q Going to the doctor
R Eating

***Table 8.** Restricted daily activities reported by IMAS participants[6]*

Activities where respondents felt they were most highly restricted were also the ones in which they most often needed help. Almost 70% of respondents 'frequently' or 'sometimes' needed help to complete housework, while over 60% highlighted frequently or sometimes needing support with shopping. Over half of respondents needed help on a regular or semi-regular basis to get out of bed, tie their shoelaces, dress or cook. Around 1 in 4 respondents said they regularly needed help to go to the toilet.

The results show the considerable impact that axSpA can have on almost every facet of a person's life. It appears that these impacts also extend to a person's relationships. Almost a third of respondents (31.3%) said their relationship with their spouse or partner was 'worse' or 'much worse' than before their disease onset, with a similar proportion reporting a deterioration in relationships with their friends. A worsening in relationships with colleagues was even more apparent, with around 45% of respondents indicating these had become poorer following onset of the disease.

Relationships	Worse or much worse that before (%)
Work colleagues	45.1
Friends	35.1
Spouse / partner	31.3
Family	23.2
Neighbours	19.3

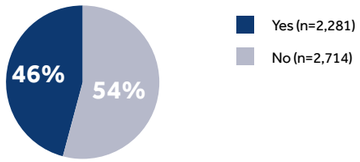
***Table 9.** Impact of axSpA on participants' relationships following disease onset*[6]

The impact of axSpA on an individual's employment is particularly significant. Almost half (45.7%) of respondents highlighted that axSpA had influenced their job choice, with nearly three-quarters (71.4%) revealing that the disease had caused challenges in finding suitable employment.

Not only does axSpA present a formidable barrier to finding a job, but it can also have a persistent impact on an individual's ability to carry it out, as demonstrated by the high levels of sickness absence reported by IMAS participants. 12% of respondents reported being on temporary sick leave at the time of the survey, with 8% on permanent sick leave. The vast majority of these cases (around 9 in 10 for both temporary and permanent sick leave) were directly attributed to axSpA. 32.7% of respondents also found it difficult to fulfil their working hours with 25.3% ultimately having to reduce them. These trends reinforce existing data from a UK-led study, which suggested that people with axSpA can be three times more likely to withdraw from work compared to the general population.[15]

These findings demonstrate the considerable real-world burdens that axSpA can place on individuals. Taken together, these difficulties reinforce the urgency to define solutions that enable those with axSpA to access and, remain part of, the workforce. Healthcare professionals should also ensure that an individual's social and economic needs are incorporated in their care plans, and that these are regularly reviewed to ensure they reflect changing circumstances.

Job choice influenced by axSpA



Participants who experienced difficulties finding a job due to axSpA

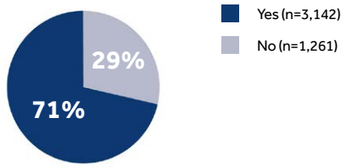


***Figure 3.** Impact of axSpA on finding a job*[6]

Fears, hopes and treatment goals: Socioeconomic

IMAS responses showed that:

22% feared being a burden to their family

37% hoped to be able to live without constraints

27% cited 'to be able to work' as a key treatment goal

Chapter 6: Healthcare system utilisation and treatment

Key Messages

IMAS data shows a clear link between higher levels of axSpA disease activity and greater healthcare system utilisation. As higher levels of axSpA disease activity are most closely associated with delayed diagnosis and sub-optimal disease management, taking steps to improve early diagnosis and increase the provision of multidisciplinary care can lead to benefits for the wider healthcare system. Ensuring that everyone with axSpA has access to effective treatment should be a priority, considering that pharmacological intervention can be key in supporting the best possible disease outcomes.

As highlighted in previous chapters, the impacts of sub-optimally controlled axSpA are considerable. Due to the progressive nature of axSpA, the longer it takes to provide access to effective treatment, the greater the disease burden faced by individuals is likely to be. IMAS data makes clear that earlier intervention, which is associated with better outcomes for individuals, can also reduce likely healthcare utilisation needs.

IMAS shows that individuals with sub-optimally controlled disease (BASDAI score of 4 or greater) generally had a considerably higher number of visits to every healthcare specialty assessed. Those with sub-optimally controlled disease made on average nearly double the number of visits to their primary care physician, 71% more visits to a physiotherapist and 58% more visits to a psychologist or psychiatrist (see Table 10).

Type of professional	Average number of visits	
	BASDAI < 4	BASDAI ≥ 4
Physiotherapist	8.0	13.7
Primary care physician	2.7	5.2
Rheumatologist	3.0	3.7
Psychologist/Psychiatrist	1.9	3.0
Clinical nurse	1.7	2.9
Chiropractor	1.2	2.1
Other	1.6	2.1
Orthopaedic specialist	1.2	1.7
Ophthalmologist/optician	1.2	1.5
Gastroenterologist	0.5	0.9
Cardiologist	0.6	0.7
Pulmonologist	0.5	0.6

Table 10. Average number of axSpA-related healthcare appointments in the prior 12 months per participant, assessed against disease activity[6]

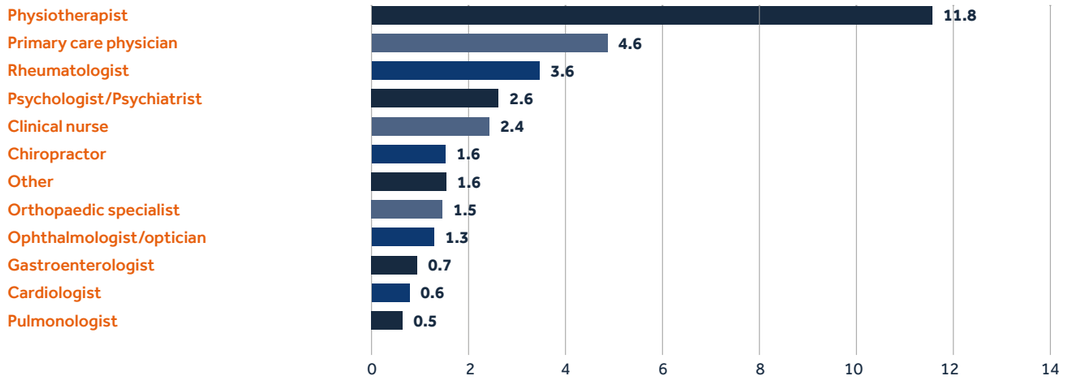


Table 11. *Average number of axSpA-related healthcare appointments in the prior 12 months, per respondent*[6]

IMAS respondents generally reported high usage levels of a range of healthcare services. As set out in Table 11, the average respondent made multiple visits per year to physiotherapists, primary care physicians, rheumatologists and mental health practitioners. Regional differences were observed within these responses. Respondents from Europe were, for instance, more likely to visit physiotherapists, those from Asia reported an increased number of orthopaedic visits, and those from North America and South Africa were more likely to visit a chiropractor.

Female respondents were more likely to report an increased level of service utilisation compared to men. This was likely driven by a range of factors including higher levels of disease activity and more debilitating symptoms and comorbidities. Female respondents on average made double the number of visits to a physiotherapist and a psychologist or psychiatrist, and around 40% more consultations with their primary care physician (see Table 12).

Type of professional	Average number of visits	
	Male	Female
Physiotherapist	7.2	14.9
Primary care physician	3.7	5.2
Rheumatologist	3.4	3.7
Psychologist/Psychiatrist	1.6	3.4
Clinical nurse	1.7	3.0
Chiropractor	0.8	2.2
Other	0.8	2.3
Orthopaedic specialist	1.6	1.3
Ophthalmologist/Optician	1.2	1.4
Gastroenterologist	0.5	0.8
Cardiologist	0.6	0.7
Pulmonologist	0.5	0.6

Table 12. Average number of axSpA-related healthcare appointments in the prior 12 months per participant by gender[6]

One key factor in managing axSpA well is receiving specialist care – most typically this would be a rheumatologist – so that effective assessment and treatment are provided. Responses from IMAS participants however suggest there is widespread variation. While four-fifths of respondents reported that their condition was being managed by a rheumatologist, the remainder said that their main point of healthcare contact came from a different specialty. This suggests these patients may not be receiving care from healthcare teams with appropriate knowledge and training in axSpA. Access to a rheumatologist was highest amongst respondents from Europe, with those from Asia most likely to be receiving care elsewhere.

Participant Region	Rheumatologist	Other
Europe	85.9%	14.1%
Asia	61.5%	38.5%
North America	72.3%	27.7%
Latin America	83.4%	16.6%
South Africa	79.5%	20.5%

Table 13. Specialist responsible for managing condition, broken down by IMAS respondent region[6]

In terms of treatment access, most respondents (79%) said they had taken non-steroidal anti-inflammatory drugs (NSAIDs), which is typically the first stage of axSpA pharmacological management. Although NSAIDs can provide significant symptomatic relief, especially for joint pain and stiffness, their role in slowing disease progression and lowering disease activity is less clear.[16] It is notable therefore that less than half of IMAS respondents said they had ever taken disease-modifying antirheumatic drugs, which are typically used when symptoms are not well controlled. 49% had taken biologic or targeted synthetic disease-modifying antirheumatic drugs (b/tsDMARDs) and 44% had ever taken conventional synthetic disease-modifying antirheumatic drugs (csDMARDs).[9]

Participant Region	NSAIDs	b/tsDMARDs	csDMARDs
Europe	75.4%	45.0%	36.9%
Asia	74.7%	37.0%	52.3%
North America	82.6%	61.8%	40.2%
Latin America	90.1%	65.5%	65.4%
South Africa	94.4%	42.5%	79.3%

Table 14. Use of treatment reported by IMAS respondents, by region[9]

Responses also indicated variation between different regions in typical use of treatment types. The greatest use of NSAIDs was in South Africa and Central and South America, with b/tsDMARDs being most used across the Americas, while csDMARDs were most commonly used in South Africa. Use of csDMARDs was higher amongst younger respondents, while females also reported having taken a higher proportion of all three treatment types compared to male participants.[6,10]

AxSpA and the Commitment to Universal Health Coverage

Universal health coverage (UHC) means that all people have access to the full range of quality health services they need, when and where they need them, without financial hardship. It covers the full life course and includes diagnosis, treatment and rehabilitation, which makes it highly relevant to axSpA.

UHC is one of the three core priorities of the World Health Organization (WHO)[v] and every member of the United Nations has committed to achieving UHC in their countries. UHC recognises that less developed countries need to focus on core services and expand healthcare provision over time as more **resources become available.**[vi]

UHC focuses on a country's health systems, especially primary care, more than on individual health conditions. It can therefore highlight if a country does not have the healthcare services needed by people with axSpA and is not meeting its obligations under UHC. The axSpA community can work with stakeholders in other conditions, for example other rheumatic and musculoskeletal diseases, to assess healthcare provision across related conditions.

While not every country has embedded the concept of UHC in their health economy, it is prominent in all major international health fora. Universal health coverage is also included in the United Nations' Sustainable Development Goals which aim, by 2030, to achieve "access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all".

The data and patient experiences provided by IMAS demonstrate the multiple impacts of axSpA on people's lives. When read in the context of universal health coverage, IMAS provides a person-centred approach for highlighting the improvements countries have committed to make which would advance the diagnosis, care and support of people with axSpA.

v https://www.who.int/europe/about-us/our-work/core-priorities
vi https://cms.ifpa-pso.com/tools/UHC-Toolkit.pdf

Concluding Comments

The significant physical, psychological and socioeconomic impacts of axSpA are clearly demonstrated in the data provided by IMAS 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 a bidirectional relationship between the two.

Reflecting on the high levels of unmet need reported by IMAS participants, it is imperative that axSpA is recognised as a healthcare priority, and that the calls to action 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 the globe to control their illness with minimal impact on their happiness and quality of life.

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About ASIF

Axial Spondyloarthritis International Federation (ASIF) is a global umbrella organisation established to increase awareness of axial Spondyloarthritis (axSpA) and related conditions. It aims to disseminate knowledge of the disease around the world to key stakeholders including patients, rheumatologists and other healthcare professionals, researchers, pharmaceutical organisations, policy makers and the general public. It also aims to improve the quality of life for people living with the disease.

AxSpA is a form of inflammatory arthritis primarily affecting the spine and sacroiliac joints, but can also affect other areas of the body. It can lead to chronic pain and to fusion of the spine.

ASIF is member-led and continues to grow, with over 50 Patient Organisation members in more than 40 countries. We aim to share the most up-to-date information regarding developments in axSpA with our members around the world and we encourage the sharing of information and collaboration between them.

ASIF coordinates World AS Day, which falls annually on the first Saturday after 1 May.

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