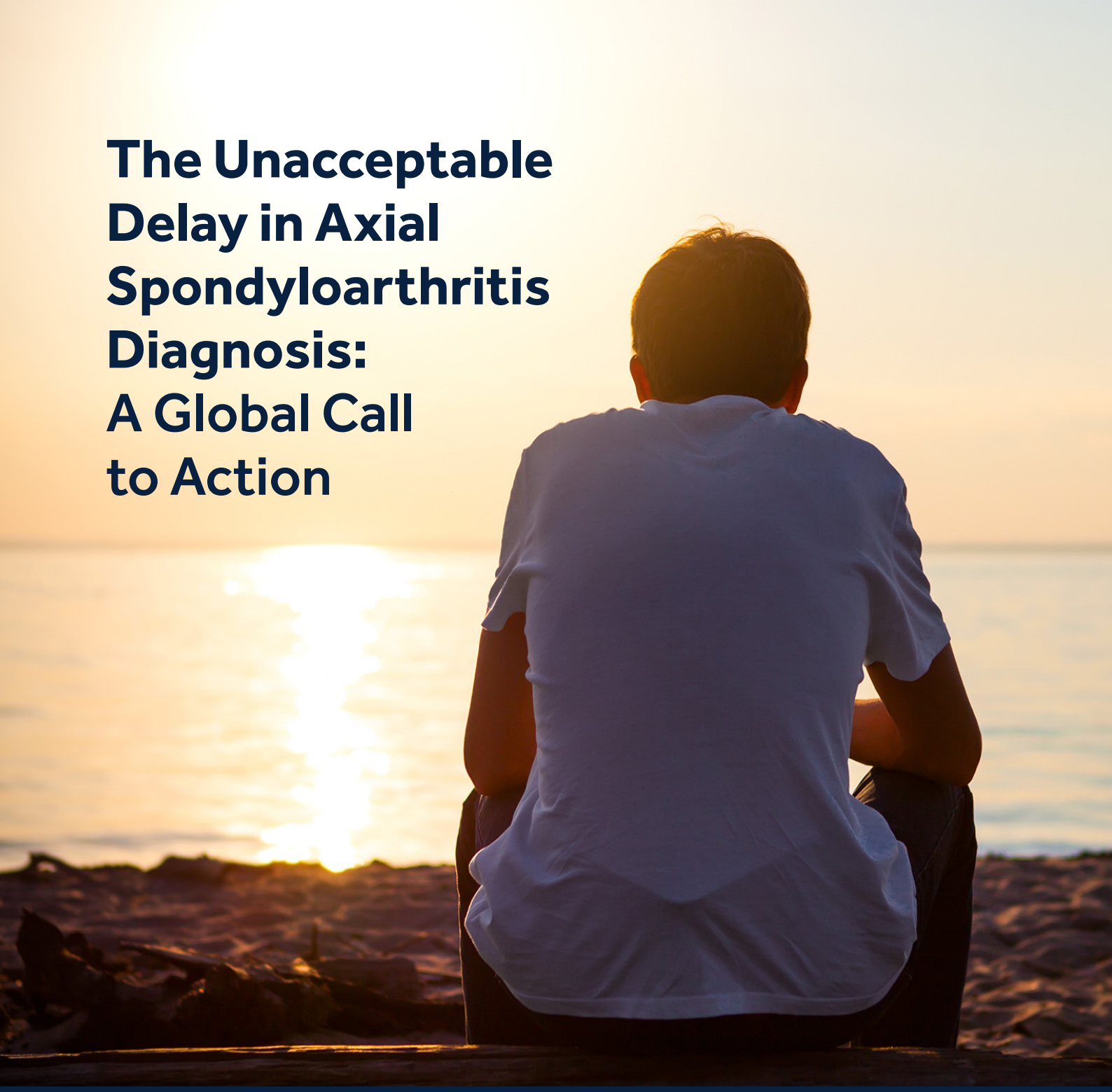
The Unacceptable Delay in Axial Spondyloarthritis Diagnosis: A Global Call to Action



A burden statement from the Axial Spondyloarthritis International Federation (ASIF)

THE TIME TO ACT IS NOW

Delay to Diagnosis

ASIF
AXIAL SPONDYLOARTHRITIS
INTERNATIONAL FEDERATION

JUNE 2021

Delay to Diagnosis

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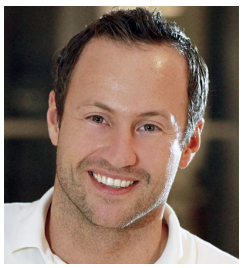
Foreword

It is a great privilege to help introduce this new burden statement from ASIF. Reducing the delay in axial spondyloarthritis (axSpA) diagnosis is a cause that all those affected by the condition care deeply about. Anyone who has seen or experienced the life-changing consequences of disease progression in axSpA will know that the current average global delay of more than seven years is quite simply not acceptable, particularly considering it typically first emerges in a person's twenties. It is also a delay that sadly unites each and every one of ASIF's member organisations. Across Europe, America, Asia, Africa or Oceania, each of our members has countless heart-wrenching stories of individuals who have been forced to wait unimaginable lengths of time for a diagnosis. Individuals who at the same time are also having to manage the crippling physical and mental pain that can go hand in hand with the disease.

Each delayed diagnosis is a life forever altered. Each delayed diagnosis represents an individual who has been failed by their healthcare system. It is because of this that ASIF has set out on its new *Delay to Diagnosis* project. The project seeks to highlight an area that has been consistently overlooked and under-recognised. Being involved in our *Global Forum* events, which brought together axSpA patients and experts from twenty-three countries, was one of the greatest honours of my ASIF presidency. It was both humbling and empowering to hear the stories of all those affected by axSpA diagnosis delay and the many barriers they faced to finally getting a diagnosis. We hope to tell these stories through the following pages, and demonstrate why now is the time to finally get serious about transforming how axSpA is diagnosed across the world. Thank you for being part of our journey.

Zhivko Yankov - President, ASIF and person living with axSpA (Bulgaria)



Axial spondyloarthritis has been the great passion of my career. It has been remarkable to see how far we have come in understanding the disease and how to treat it, even in the space of two decades. While there is currently no cure, we now have biologic medicines and other innovations in axSpA that can transform a patient's prognosis and fundamentally alter their life prospects. This can make the difference between someone feeling empowered to start a family or pursue their work aspirations, against an alternative of shattering physical pain, depression and social isolation.

The progressive nature of axSpA means that the longer it takes to provide access to this life-changing treatment and care, the greater the burden placed on individuals will be. The reality is that in the seven years it currently takes us on average to get to an axSpA diagnosis, the disease will have likely caused irreversible damage that makes its management even more difficult and costly. Great progress has been made in almost every area of axSpA, however it is in many ways the key area – reducing diagnosis delay – where progress has remained stubbornly out of reach. It is my great hope that this report, and the work of ASIF and all those who stand alongside them, can finally help to set in motion the progress that is so sorely needed.

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

Executive Summary

Axial spondyloarthritis (axSpA) encompasses a range of chronic, progressive inflammatory conditions that place a huge toll on the millions of people affected by the disease across the globe. Much of the burden comes from the considerable delay in achieving a confirmed diagnosis, which is currently around seven years on average from the first onset of symptoms.

Axial spondyloarthritis (axSpA) currently remains uncurable, however there has been considerable progress in recent decades in our understanding of the disease, and improvements in the tools we have available to treat it. Despite these advances, progress across the world has unfortunately been much more limited in achieving timely axSpA diagnosis. Ultimately, patients diagnosed in recent years experience very similar delays to those in the 1990s and 2000s.

ASIF and the axSpA stakeholder community believe that this is an unacceptable reality and one that must urgently be addressed. Achieving progress is particularly important because of the early onset of the disease - typically manifesting when someone is in their twenties - and its progressive nature. The longer it takes to achieve a diagnosis, the worse a patient's condition will likely become. Waiting seven years for a diagnosis can lead to irreversible damage and will often transform a young person's life into a period of intense physical and mental hardship.

Undiagnosed and poorly managed axSpA will not only limit an individual's ability to fully participate in society and maintain meaningful employment. It will also generate additional healthcare needs and costs, meaning that there is a clear moral as well as economic obligation to reduce diagnosis delay.

As set out in this report, diagnosing axSpA is not a straightforward process and there are a number of challenges that need to be overcome if the seven-year delay is to be reduced. Despite this, we have a better understanding of these barriers than ever before, and there are also encouraging signs of progress from across the world on how to address them. Our hope is that we can now build on this to help ensure all healthcare systems give axSpA the priority it deserves; and to create a future where no one living with the condition has to wait seven years for a diagnosis.

Achieving progress is particularly important because of the early onset of the disease - typically manifesting when someone is in their twenties - and its progressive nature.

Recommendations

As part of the development of this report, we heard examples of different local approaches that give a sense of the real opportunities that exist to transform the way axSpA is diagnosed. These examples have helped to inform the identification of the following five high-level recommendations that we believe can instigate much-needed change at a national-level.

1

Recommendation 1:
Country-level healthcare leaders and decision-makers should **commit to joining national conversations** about the current local state of axSpA diagnosis delay and recognise the importance of reducing this, through making it a health policy priority.

2

Recommendation 2:
Broader **awareness campaigns are needed** to increase axSpA knowledge and understanding amongst individuals and wider society as a whole.

3

Recommendation 3:
Opportunities should be sought to establish **collaborative-based approaches to addressing axSpA diagnosis challenges**, drawing on potential support from a range of local partners.

4

Recommendation 4:
AxSpA diagnosis is not straightforward, however there are increasing examples of best practice in achieving early diagnosis. **Healthcare leaders should raise awareness of these** across national rheumatology and general medicine networks and **support their implementation** in line with local circumstances.

5

Recommendation 5:
National or local-level axSpA delay initiatives should be **underpinned by robust data collection** to help assess their effectiveness and build a stronger evidence-base for others to draw on.

Introduction

ASIF's Virtual Global Forum Events: Providing a unique global perspective on axSpA Diagnosis Delay

2

VIRTUAL FORUM EVENTS

OVER

45

axSpA EXPERT DELEGATES AT EACH EVENT

23

COUNTRIES REPRESNTED

5

CONTINENTS ATTENDING

The contents of this report will help to build a clearer picture of what axial spondyloarthritis (axSpA) is and how its burdens manifest themselves. It will also set out the barriers that exist to achieving timely diagnosis, alongside examples of best practice from across the world in reducing diagnosis delay. These insights help to inform the key recommendations and the accompanying call to action for all stakeholders involved in the organisation, delivery and championing of axSpA care.

The report forms a key component of ASIF's *Delay to Diagnosis* campaign. The campaign seeks to deepen understanding at a global level of the factors that contribute to the current seven-year average delay in axSpA diagnosis, and the burdens that the delay places on individuals.

As part of the campaign, two virtual *Global Forum* events were held in Autumn 2020, bringing together patients, researchers, rheumatologists, physiotherapists and others involved in the management and championing of axSpA care from across the globe.

The *Global Forum* events provided a unique platform for experts from different healthcare systems and backgrounds to explore and share their respective experiences of axSpA diagnosis delay, their insights on the factors contributing to the delay and steps that could be taken to help reduce it.

Outputs from these discussions have helped to directly inform the findings of this report and we hope will continue to provide valuable insights for ASIF and the wider axSpA community beyond this.

Axial Spondyloarthritis Delay to Diagnosis Key Stats

What is Axial Spondyloarthritis?

Axial spondyloarthritis (axSpA) is a **painful chronic inflammatory disease** primarily affecting the spine and sacroiliac joints.[1]

AxSpA symptoms typically first emerge in the **third decade of life**.[2]

AxSpA is **characterised by 'flares'**, where symptoms can suddenly intensify for an undefined period of time.[3]

How common is Axial Spondyloarthritis?

BETWEEN 0.32–0.7%

Estimated global axSpA prevalence.[4]

24.6-53.9 MILLION

People estimated to be living with axSpA.[4,5]

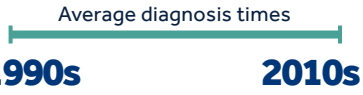
1in160 –1in300

Equates to around 1 in 160 to 1 in 300 **people living with axSpA globally**.[5]

How long does it take to diagnose Axial Spondyloarthritis?

7 YEARS AVERAGE DIAGNOSIS

The current average time for axSpA diagnosis, following symptom onset. **Irreversible and life-altering damage** can occur during this time.[6,7,8]



Average diagnosis times are largely the **same as they were 20 years ago**.[9]

2 YEARS LONGER FOR WOMEN

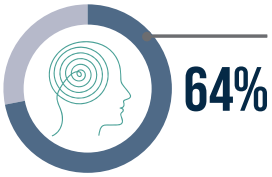
It can take **2 years longer to diagnose axSpA in women**, due to outdated beliefs that the disease primarily affects men.[10,11]

Early diagnosis and intervention is important to slow axSpA disease progression and support improved symptom management.[12]

Impact of living with axSpA

AxSpA is associated with a wide range of other clinical features, including:[13]

- cardiovascular disease
- diabetes
- renal disease
- inflammatory bowel disease
- enthesitis
- peripheral arthritis
- uveitis
- dactylitis
- osteoporosis



Up to 64% - **prevalence of depression** amongst people living with axSpA.[14]

75% of people living with axSpA have reported **difficulties finding a job** due to their condition.[7] They are also three-times more likely to withdraw from work.[15,16]

1. Sieper J, van der Heijde D. 2013. Arthritis Rheum; 65(3):543-51. **2.** Feldtkeller E, Khan MA, van der Heijde D et al. Age at disease onset and diagnosis delay in HLA-B27 negative vs. positive patients with ankylosing spondylitis. 2003. Rheumatol Int; 23:61–66. **3.** Jacquemin C, Maksymowych WP, Boonen A, et al. Patient-reported Flares in Ankylosing Spondylitis: A Cross-sectional Analysis of 234 Patients. 2017. J Rheumatol; 44(4):425-430. **4.** Stolwijk C, van Onna M, Boonen A, et al. Global Prevalence of Spondyloarthritis: A Systematic Review and Meta-Regression Analysis. 2016. Arthritis Care Res; 68(9):1320-31. **5.** United Nations. World Population Prospects 2019 Highlights. **6.** Redeker I, Callhoff J, Hoffmann F, et al. Determinants of diagnostic delay in axial spondyloarthritis: an analysis based on linked claims and patient-reported survey data. 2019. Rheumatology (Oxford); 58(9):1634- 1638. **7.** Garrido-Cumbrera, M., Poddubnyy, D., Gossec, L. et al. The European Map of Axial Spondyloarthritis: Capturing the Patient Perspective—an Analysis of 2846 Patients Across 13 Countries. 2019. Curr Rheumatol Rep. **8.** Zhao S, Pittam B, Harrison N et al. Diagnostic delay in axial spondyloarthritis: a systematic review and meta-analysis. 2021. Rheumatology. **9.** Seo MR, Baek HL, Yoon HH. Delayed diagnosis is linked to worse outcomes and unfavourable treatment responses in patients with axial spondyloarthritis. 2015. Clin Rheumatol; 34(8):1397-1405. **10.** Jovani, V., Blasco-Blasco, M., Ruiz-Cantero, M et al. Understanding How the Diagnostic Delay of Spondyloarthritis Differs Between Women and Men: A Systematic Review and Meta-analysis. 2017. The Journal of Rheumatology; 44, 174 - 183. **11.** Garrido-Cumbrera, M., Poddubnyy, D., Gossec, L. et al. Gender differences in patient journey to diagnosis and disease outcomes: results from the European Map of Axial Spondyloarthritis (EMAS). 2021. Clin Rheumatol. **12.** Wendling D, Claudepierre P, Prati C. Early diagnosis and management are crucial in spondyloarthritis. 2013. Joint Bone Spine; 80(6):582-585. **13.** Strand V, Singh J. Patient Burden of Axial Spondyloarthritis. 2017. Journal of Clinical Rheumatology; 23: 383-391. **14.** Zhao S, Thong, D, Miller N. et al. The prevalence of depression in axial spondyloarthritis and its association with disease activity: a systematic review and meta-analysis. 2018. Arthritis Res Ther; 20, 140. **15.** Martindale J, et al. The impact of ankylosing spondylitis/axial spondyloarthritis on work productivity. 2015. Best Practice & Research Clinical Rheumatology. **16.** Boonen A, Chorus A, Miedema H, et al. Withdrawal from labour force due to work disability in patients with ankylosing spondylitis. 2001. Ann Rheum Dis; 60(11):1033e9.

SECTION 1

What is axial spondyloarthritis and what impact does it have?

What is Axial Spondyloarthritis?

Axial spondyloarthritis (axSpA) is an umbrella term that encompasses a range of chronic inflammatory conditions affecting the spine, most notably non-radiographic and radiographic axial spondyloarthritis (also known as ankylosing spondylitis).[1,2] It is a disease characterised by an early age of onset, with symptoms typically first emerging in the third decade of life.[3] The disease is also characterised by 'flares', where symptoms and pain associated with the condition can suddenly intensify for an undefined period of time.[4]

How common is the disease?

Despite a low general awareness of these painful and progressive forms of inflammatory arthritis, axSpA is far from rare. Estimates suggest an axSpA prevalence of around 0.32% - 0.7% of the global population, with significant variation between geographic regions.[2,6] If this prevalence is applied to latest UN population estimates, it translates to an estimated global axSpA patient cohort of 24.6million to 53.9million, or around 1 in 160 to 1 in 300 people.[6] A key factor in the variation of axSpA prevalence is the presence of the gene most strongly associated with the condition, HLA-B27.[2,3]

How is axSpA currently prioritised and how does this impact upon diagnosis delay?

Axial spondyloarthritis (axSpA) has traditionally been under-prioritised within healthcare systems across the globe. Feedback from ASIF's country-level member organisations consistently highlights how knowledge and awareness of axSpA remains low, including amongst local decision-makers and politicians. This was a recurring theme from participants of ASIF's *Global Forum* meetings. There was a particular recognition that axSpA does not get the same airtime as other disease areas, even compared to those that also sit within the sphere of musculoskeletal health, a situation that seems at odds with the relative impact of axSpA.

This lack of prioritisation at national and supranational levels has likely been a factor in the slow progress made in reducing axSpA diagnosis delay. While there have been significant advances in the development of novel and effective therapy options for patients with a confirmed axSpA diagnosis, the speed of reaching diagnosis has changed little in recent decades. Data shows that axSpA patients diagnosed in the 2010s experience similar delays to those that were diagnosed in the 2000s and 1990s.[7]

To further highlight how diagnosis progress has stalled, country-level comparative data from 1996-2005 and 2006-2015 placed the mean axSpA diagnosis delay at 6.3 years and 7.4 years for those respective time-periods.[8] More recent data from the largescale 2017-18 *European Map of Axial Spondyloarthritis* (EMAS) survey revealed similar delays, with diagnosis taking on average 7.4 years according to its findings (albeit with slight improvements being made in some areas).[9] Other recent meta-analyses of axSpA diagnosis studies found comparably lengthy mean delays across the globe, although the data suggested that the delay was shorter in upper-middle and lower-middle income countries.[10,11]

Axial Spondyloarthritis classifications[1]

Axial spondyloarthritis is an umbrella term that incorporates the two below classifications:

Radiographic spondyloarthritis: where patients have already developed clear structural damage on the spine or in the sacroiliac joints, which are visible via X-ray *(this is also known as ankylosing spondylitis)*

Non-radiographic spondyloarthritis: where no structural damage is visible, diagnosis can be made from other clinical features and imaging

To put these figures into perspective, data from early arthritis clinics suggests that diagnosing psoriatic arthritis can take 4 years (around half the time of axSpA) and diagnosing rheumatoid arthritis can take 2 years (around 25% of the time of axSpA).[12]

Meta-analysis results of axSpA diagnostic delay figures, according to World Health Organization regions and World Bank economic class data[10]

	Number of studies	Mean Delay
World Health Organization Regions		
European	34	7.02
West Pacific	7	6.43
Eastern Mediterranean	7	6.62
Americas	4	5.76
South East Asia	3	6.38
World Bank Economic Category		
High	34	7.61
Upper-middle	16	5.38
Lower-middle	5	5.59

"

AxSpA diagnosis delay in Norway appears to be one of the longest in the world and the worst in Europe – 2011-2012 patient survey data showed an average diagnosis wait of 10-11 years for men, and 12 years for women. Disappointingly, almost exactly the same results were recorded in the 2018 International Map of Spondyloarthritis research. Clearly, our current practices are not working.

With that in mind, we have been making the case to policymakers in Norway about the need to address these shocking delays and do more to prioritise timely diagnosis. These efforts are very much ongoing, however, we are hopeful that they could eventually lead to the introduction of a 'target' time for axSpA diagnosis. While we would need to clarify exactly what time period any target should cover – for instance, a target for referral from primary care, or a target for diagnosis once seen by a rheumatologist – having such a target could make the condition more prominent in the minds of healthcare professionals and would also help to start addressing the absence of centrally collected axSpA data.

Lillann Wermskog - Leader, Spondylitis Association of Norway

Inequalities in axSpA diagnosis

Axial spondyloarthritis (axSpA) has traditionally been seen as a predominantly male condition, with prevalence of radiographic axSpA (also referred to as ankylosing spondylitis) reported as being 2 to 3-times higher in men than in women.[13,14] However, as our understanding of axSpA has improved in recent years, data now indicates that the overall prevalence and incidence of axSpA is very similar in men and women.[15] This is largely because of the recognition that axSpA classification should include earlier stages of the disease, before structural damage has necessarily occurred. Whereas radiographic axSpA remains more prevalent in men, non-radiographic axSpA appears to be more prevalent in women, with just over half to two-thirds of such cases recorded in women.[16,17]

There is a growing body of evidence demonstrating that axSpA affects equal numbers of men and women, however outdated perceptions of the disease unfortunately still prevail. These can unfortunately have a hugely detrimental impact on the recognition of symptoms in women, delaying the provision of impactful treatment and support. Recent multi-country studies and meta-analyses demonstrate that as a result of these disease misconceptions, women tend to experience significantly longer average delays in achieving axSpA diagnosis compared to men, adding as much as two years to an already unacceptable length of time. [18,19]

Perhaps unsurprisingly, the lived reality of women who have axSpA can therefore be considerably worse. Findings from the *European Map of Axial Spondyloarthritis* (EMAS) study demonstrated that women were more likely to experience greater levels of fatigue, pain and stiffness associated with axSpA.[20] Due to increased disease activity, something that is strongly linked to delayed diagnosis, women are also more likely to suffer from a range of mental challenges and depression.[20]

While there is less research on the area, there is also evidence to suggest that ethnic inequalities exist in axSpA diagnosis. Data shows that the gene associated with axSpA, HLA-B27, is more likely to be found in people of Caucasian ethnicity compared to those from Africa or Latin America for instance.[21] However, people who are HLA-B27 negative can still develop axSpA and those who are HLA-B27 negative are more likely to experience longer diagnosis delays.[3]

Conversely, Canadian data shows that the prevalence of axSpA is three times higher in First Nations people compared to other groups.[22] Unfortunately, anecdotal evidence indicates that barriers to achieving axSpA diagnosis are much higher for this group, reflecting the broader healthcare inequalities they experience.

It is difficult to reach conclusive judgements about the role of ethnicity in axSpA diagnosis due to the limited study sizes, but it is important that healthcare strategies acknowledge the possibility of bias, particularly as longer delays lead to poorer disease outcomes.

"

AxSpA has traditionally been believed to be more common in men, however we have now come to understand that this is not the case. In reality, the prevalence across men and women is very similar – the problem is that we are much better at diagnosing it in males. This is largely because diagnostic tests are not sensitive enough, in particular radiographs.

As axSpA progression is generally more prominent in males, this has put women at a distinct disadvantage in being considered as having a possible axSpA diagnosis. It also means that women are more likely to spend much more time going round different specialties before actually seeing a rheumatologist. We must raise awareness more widely that women suffer from axSpA just as much as men.

Dr Helena Marzo-Ortega - Rheumatologist and Chair of the British Society for SpondyloArthritis (UK)

The impact of axSpA diagnosis delay

A key theme from ASIF's *Global Forum* events was how a delay in axSpA diagnosis can lead to a range of physical, mental and socioeconomic harms for individuals. These are explored in further detail in the following section.

The Physical Impact of axSpA Diagnosis Delay

Axial spondyloarthritis (axSpA) is a progressive disease and achieving early diagnosis is fundamental to providing patients with access to the latest therapies. These therapies help to slow disease progression and support improved management of the debilitating symptoms associated with the disease.[7,23] Without early intervention, individuals can face irreversible and life-altering structural damage. In some instances this can lead to invasive surgery being needed, which can have a hugely negative impact on mobility and overall quality of life.[24]

> **The belief that women simply do not get an inflammatory arthritis such as axSpA is something I have unfortunately experienced first-hand. When my own symptoms first presented, doctors downplayed the severity of the pain I told them I was in and would not believe that I should be referred onwards for further investigation. It ultimately took many years of suffering and the progression of my disease before I was taken seriously and seen by a rheumatologist who was able to confirm the spondyloarthritis which was by this point clearly apparent. It is a tragedy that countless thousands of other women will have experienced similar fates.**
>
> **Souzi Makri - Chair-Elect of the EULAR PARE Committee, IMAS (Europe) Report Co-Author**

Without a confirmed diagnosis, patients are also less likely to receive support from appropriately trained healthcare professionals that can help to manage the range of symptoms associated with axSpA. This includes support for the management of the primary symptom of inflammatory back pain, as well as other manifestations of the disease, such as peripheral arthritis, uveitis, enthesitis, dactylitis, psoriasis, inflammatory bowel disease, cardiovascular disease, diabetes, renal disease, osteoporosis and depression.[26] *Global Forum* attendees described how these wider physical manifestations of axSpA can have a significantly detrimental impact on almost every aspect of an individual's quality of life.

The Psychological Impact of axSpA Diagnosis Delay

In addition to the significant physical impact that axSpA has on individuals, there is also a strong correlation between axSpA and poor mental health outcomes. Those with an axSpA diagnosis have a higher risk of reporting depressive symptoms compared to the general population, with prevalence of depression amongst individuals with axSpA ranging from 11% to 64%, depending on diagnostic criteria used.[26] Results from the EMAS study showed that 39% of axSpA patients reported feelings of heightened anxiety and half experienced sleep problems, further affecting their mental wellbeing.[9] Increased disease activity is a key risk factor for depression amongst axSpA patients, emphasising again the importance of earlier intervention to help reduce disease progression.[20,27]

Global Forum attendees also spoke about the poor mental health outcomes caused by diagnosis delays. Several attendees drew on first-hand experiences to describe how the uncertainty of not knowing what was causing their symptoms had a hugely damaging effect on their mental wellbeing. Some also explained how their symptoms were downplayed or challenged by healthcare professionals, further affecting their confidence. A recurring theme was the experience of having to 'fight' for a diagnosis, and how exhausting this was.

The Socioeconomic Impact of axSpA Diagnosis Delay

Considering the physical and psychological effects of delayed axSpA diagnosis, it is not surprising that delays can also affect employment and other socioeconomic aspects. There is a growing body of evidence demonstrating how damaging the condition can be for the employment prospects of those affected.

> **The results of recent national and pan-European patient research clearly demonstrate that the prevalence of mental disorders such as anxiety, depression and sleep disorders is disproportionally high among axSpA patients. Patients with more active disease, greater functional limitation and more comorbidities are particularly prone to suffer from poorer mental health. Diagnosis allows patients to improve their treatment by reducing the negative impact associated with the disease, improving their wellbeing and mental health. Such evidence should serve as a trigger to promote early diagnosis, as well as improvements in the management and treatment of those who have already been diagnosed.**
>
> **Professor Marco Garrido-Cumbrera - Health & Territory Research, The University of Seville; ASIF and CEADE Scientific Advisor (Spain)**

Data suggests that almost 75% of axSpA patients have reported difficulties finding a job due to their condition.[9] Half of those in employment have indicated that their job choice was influenced by having an axSpA diagnosis.[9] Those with axSpA are also up to three-times more likely to withdraw from work due to their condition, with the likelihood of this increasing with the more time that had elapsed since symptom onset.[28,29]

Global Forum attendees highlighted how the delay in receiving a diagnosis can effectively mean an individual's life is 'put on hold'. While peers forge ahead and can enjoy the semblance of a 'normal' life, the prospect of a rewarding career and a family can seem unobtainable for those waiting for a diagnosis. These experiences are supported by data, with studies showing that those with axSpA are more likely to be divorced or to have never married in the first place.[30] Women living with the condition are also less likely to have children compared to the general population.[31]

The case for earlier intervention

Due to the progressive nature of axSpA, the longer it takes to achieve diagnose, the worse a patient's condition will likely become. Untreated axSpA will lead to additional healthcare needs and costs, while at the same time limiting an individual's ability to fully participate in society and maintain meaningful employment.[7,9,31] This can be described as the cumulative disease burden (see *figure 1*), which is a theory that has been applied in other areas, such as chronic skin disease.[32]

Evidence also indicates that the effectiveness of available axSpA therapies is reduced the more the disease has already progressed, further strengthening the case for early intervention.[7]

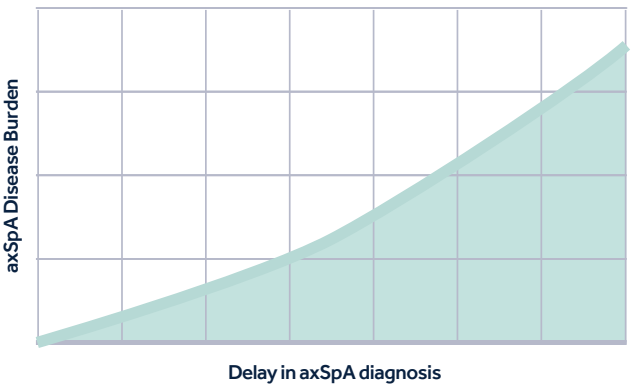


Figure 1: Model outlining theoretical cumulative disease burden in axSpA diagnosis delay

> **Those with axSpA are more likely to be divorced or to have never married in the first place. Women living with the condition are also less likely to have children compared to the general population.**

"

It took more than twenty years for my axSpA to be diagnosed, a delay which has undoubtedly impacted upon almost every aspect of my own life, as well as the lives of those closest to me. The delay in achieving diagnosis meant that my joint damage accelerated, and I experienced severe complications from the various non-steroidal anti-inflammatory medication I was prescribed for long periods, including gastro-oesophageal reflux disease and osteoporosis. A direct result of this was a curtailed ability to work, eventually forcing early retirement and a dependency on my partner's income. It also severely restricted my ability to participate in family life and social activities more generally, leading to a sense of isolation and at times, a much-reduced quality of life.

Annie McPherson - President, AS Victoria and person living with axSpA (Australia)

Patient Case Study 1

My own diagnosis journey spans 15 long and painstaking years – from the age of 9 when I had my first experiences of chronic and agonising back pain, it wasn't until I was 24 that I was finally diagnosed with the form of axSpA known as ankylosing spondylitis.

As a competitive dancer for much of my childhood, I was taught to always push through the pain and to never let it show, to continue even when you think you cannot. It was this mentality that drove my parents and I to pursue uncovering the reasons behind why I would spend nights of my childhood laid on my bedroom floor, clutching my knees to my chest and crying from the pain.

Time and time again, from family doctors, sports specialists, chiropractors, physiotherapists, naturopaths and all sorts of others, we were told that my back pain was mechanical. Or that I was suffering from growing pains, sports-related injuries or perhaps the most detrimental to my adolescent wellbeing, that it was "all in your head".

It was only in my final years of university that I was recommended to a rheumatologist – two more years of symptom-assessment, blood tests and imaging followed, but after that I finally heard the answer I had been searching so long for. I had axSpA.

Since my diagnosis, I have begun to experience far more symptoms than the chronic back pain that first characterised my disease, however having a diagnosis and the confirmation that this isn't "all in my head", helps give me the strength to keep continuing on. And if my story can help others achieve their axSpA diagnosis sooner than my own, that will help too.

Evelyn – 27-years-old (Canada)

Patient Case Study 2

I was 24 and working as a registered nurse when I first started noticing lower back pain. The doctor I saw diagnosed me with sciatica and accordingly prescribed anti-inflammatory medication. The medicine didn't really help and my continuing back pain resulted in the hospital where I was working providing me with occupational care, in the hope of improving the symptoms that were by now affecting my ability to work.

It was at this stage that it was first suggested that I wasn't simply suffering from a 'bad back', rather my pain was coming from the sacroiliac joint, the part which attaches the pelvis to my lower spine. I didn't know too much about this at the time, but I was prescribed more anti-inflammatories and also recommended to see a physiotherapist who could help teach me exercises to manage the pain.

The pain came and went but gradually was getting worse, leading to flares that were so intense they forced me to take time off work, and eventually, meant I could barely walk. I remember a period where it would take 15-minutes of agony to make it from my bedroom to my bathroom – and I lived in a small studio flat.

Over the course of the next 3 and a half years I eventually battled my way to an axSpA diagnosis, a battle that was complicated by the fact that I have a non-radiographic form of the condition, where the joint fusion typically associated with the disease isn't visible. Despite the real difficulties I went through to reach a diagnosis, I realise that my story is a lot better than many, many others living with axSpA.

This is because being diagnosed enabled me to start treatment with biologic medication, which had an immeasurably positive impact. Put simply, everything felt better. I was also able to start hydrotherapy, which helped alleviate my symptoms, as well as introduce me to others similarly living with axSpA.

I still have peaks and troughs and I'm aware that my condition is degenerative, as is everyone's with this disease, however I'm able to live life on my own terms and have also been able to give back to others living with axSpA, including through the establishment of the "Walk Your AS Off" walkathon.

Three and a half years is still a long time to wait for a diagnosis, however many people wait far, far longer, and I dread to think of where I would be now had this been my fate too.

Ricky White – 37-years-old, freelance developer, writer and stay-at-home-dad (USA)

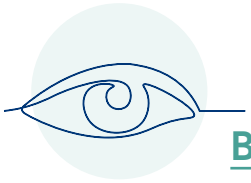
SECTION 2

Barriers to timely diagnosis

Identifying the barriers

There is a clear sense that achieving early and accurate axial spondyloarthritis (axSpA) diagnosis is not a straightforward process. A key priority of ASIF's *Global Forum* events was to therefore explore in more detail the factors contributing to the current long delays in diagnosis, with the aim of categorising these into distinct stages. Through setting these out, the hope is that it will help to support improved understanding of patients' typical diagnosis journeys, as well as the opportunities that exist to improve these.

Drawing on stakeholder input and available evidence, six distinct components contributing to the axSpA diagnosis delay have been identified.



Barrier 1:

Limited awareness of axSpA amongst those with symptoms

For many people, it will not be clear what the first signs and symptoms of axSpA actually are. In cases where there isn't already an existing axSpA diagnosis amongst a close friend or family member for instance, individuals are likely to attribute the early onset of the disease to general back pain or other common aches. This is particularly understandable considering that back pain is estimated to affect as many as 80-90% adults at some point in their life.[33,34]

Global Forum attendees explained that this situation is often exacerbated by the fact that the early stages of axSpA pain can be gradual as well as changing in intensity, with periods of days or weeks where the symptoms may be barely noticeable. This can create a sense that the symptoms will go away by themselves and do not require serious investigation. It is often only when the symptoms and pain worsen again, affecting the ability to engage in day-to-day life, that an individual may feel more compelled to seek out professional medical attention.

Barrier 2:

Lack of axSpA understanding amongst the general population

Limited axSpA awareness at an individual-level is fundamentally linked to a broader lack of knowledge and understanding of axSpA amongst the general population. Compared to many 'higher-profile' health areas, such as cardiovascular disease, cancers and neurodegenerative disorders, axSpA is very rarely talked about in public or featured within awareness campaigns.

While many people will have heard of and developed some conception of arthritis more broadly, the terms axial spondyloarthritis and ankylosing spondylitis (by which the disease used to be known) are largely unknown. Even their pronunciation and spelling are difficult for those who have not come across them before, creating a further barrier to awareness.

When axSpA is not in the public domain and not championed by higher-profile members of society, as many other conditions are, it is less likely that an individual with early axSpA symptoms will think that they are being caused by something more insidious than back pain.

> Most South Africans have never even heard of this disease, meaning that when a patient experiences back pain they would not likely think of it is axSpA.
>
> The reality is that South Africa faces significant challenges from infectious diseases such as HIV and hepatitis, and with the massive pressure on healthcare resources, axSpA does not in any way represent a current priority for the system. These problems in the system are further compounded by rheumatologists being in short supply - with only one for around every 650,000 patients.
>
> This means that unfortunately, up until very recently there has been little to no resource available to improve education around axSpA, let alone have support groups in place for patients with a confirmed axSpA diagnosis.
>
> **Maranda van Dam - Chairperson, Axial Spondyloarthritis Association of South Africa and person living with axSpA**

Barrier 3:

Incorrect/misdiagnosis at first point of healthcare system contact

One of the most commonly identified barriers to axSpA diagnosis is the likelihood that symptoms are not recognised at the first point of contact with the local healthcare system. When someone with axSpA initially seeks professional support, it is very likely that it will be a primary care or general practitioner who they see. Unfortunately, both anecdotal and published data consistently point to a low level of axSpA awareness amongst non-specialist healthcare professionals, significantly reducing the probability that an individual's symptoms are investigated for the possible presence of axSpA.[36,37]

Instead, it is much more likely that someone in the early stages of axSpA are treated for mechanical back pain, which may prompt advice to seek physical therapy or to modify exercise regimes in an effort to alleviate symptoms. Many *Global Forum* attendees provided first-hand accounts of repeated visits to primary care doctors where their symptoms were underplayed or even disbelieved. Sadly, this was a particularly common reality amongst women, reflecting outdated gender perceptions of the disease burden.

Irrespective of gender, a common theme from *Global Forum* attendees was having to fight for their symptoms to be recognised as something more than just a 'bad back'. Attendees also spoke of having to fight for further investigations and onward referrals to specialists, without which access to life-improving treatments would not be possible.

> Many *Global Forum* attendees provided first-hand accounts of repeated visits to primary care doctors where their symptoms were underplayed or even disbelieved.

> It seems common for people diagnosed with axSpA to use the benefit of hindsight of the many signs and symptoms that could have been connected sooner. Some of us that had incapacitating flares as children were told by the general practitioner that we had growing pains and we learned to not complain about something that we thought everyone went through. I often hear that people reported symptoms of axSpA that were diagnosed as an isolated issue such as enthesitis in the achilles tendon, even if there were other areas with enthesitis, immediate family members living with axSpA diseases and other red flags.
>
> Outdated information is still all too common. I'll never forget the person that travelled nearly three hours by bus to attend a SAA support group meeting. She not only wanted to meet others, she wanted to share that she was told how extremely rare it was for an African-American women to have ankylosing spondylitis (AS). She wondered if they were right and she was an isolated case. After meeting others, she wondered if her father had AS. The first thing he did everyday when he came home from work was to lay flat on the floor with his arms extended for 15 minutes because of his back pain. The healthcare system failed him and his family.
>
> **Richard A. Howard, MBA - Chief Mission Advancement Officer, Spondylitis Association of America and person living with axSpA (USA)**

Barrier 4:

Pathway and referral challenges

Even when an individual presenting to a doctor with signs and symptoms of axSpA is referred onwards for further investigation, in many cases it is to a non-rheumatologist or a specialty without appropriate knowledge or expertise.

Patients and healthcare practitioners spoke at our *Global Forum* events about how common it is for those with axSpA to be incorrectly referred onto and treated by a range of non-specialist medical disciplines and providers. These included chiropractors, orthopaedists, pain management clinics and even psychiatrists and alternative medicine practitioners. Non-rheumatologists however are less likely to have the knowledge or access to the diagnostic tools needed to distinguish the inflammatory nature of axSpA from mechanical forms of back pain. This is especially the case when the disease has not progressed to the point of appearing through radiographic investigation (such as with non-radiographic axial spondyloarthritis).[38,39]

It is also a common theme for individuals eventually diagnosed with axSpA to have first been referred from one part of the healthcare system to another, often without a clear rationale or medical grounding. *Global Forum* attendees explained that in some cases referral only took place after prolonged requests for further investigation, often adding weeks and months onto the time taken to achieve diagnosis.

> Patients and healthcare practitioners spoke at our *Global Forum* events about how common it is for those with axSpA to be incorrectly referred onto and treated by a range of non-specialist medical disciplines and providers.

"

Patients with suspected symptoms of axSpA often face considerable challenges with their diagnosis journey. Fragmentation of pathways is common, with many countries lacking a comprehensive approach to achieving timely referral to a rheumatologist. This means that even after the initial point of contact, a substantial number of patients are referred onto and assessed by other healthcare professionals not fully familiar with axSpA or how to reach effective diagnosis.

This ultimately contributes to the long delays we see in axSpA diagnosis, substantially increasing the burden of the disease not only for patients but also for healthcare systems as well. It is crucial that dedicated axSpA referral strategies are implemented across the globe.

Dr Wilson Bautista-Molano MD, PhD - Rheumatologist, ASAS member, GRAPPA member (Colombia)

"

There is great need for improved knowledge and awareness of axSpA at all levels of the health system. Although many health professionals would recognise the more typical and advanced forms of the disease, there can often be a lack of understanding and ability to recognise and suspect the earlier and milder presentation.

A particular challenge within physiotherapy is the difficulty in accessing further rheumatology training and education, which makes it much more difficult to remain up to date on the latest axSpA developments.

Similarly, rheumatology courses seldom receive physiotherapy input, meaning trainees will often graduate with limited appreciation of the importance of exercise and education within axSpA, thereby exacerbating fragmentation between the specialties.

Marg Lewington – Physiotherapist (Australia)

"

AxSpA diagnosis and referral is a real challenge in South Africa. Many of my physiotherapy colleagues know little about axSpA. There is a mismatch in the detail and emphasis of how it is taught to how it is experienced by axSpA patients.

Every medical professional knows the signs of angina or a heart attack, and how to respond appropriately. This is not the case for axSpA. Conventional medicine is designed to address acute and traumatic medical conditions—and we are really good at treating infection, fever, and broken limbs. But the singular focus on 'house-on-fire' emergencies is no match for the slow, persistent burn of inflammatory conditions such as axSpA.

When those with axSpA are seen by non-pain specialists, it often results in them being treated under the mistaken belief that they are suffering from the symptoms of mechanical, rather than inflammatory back pain. Needless to say, this does little to address the underlying cause of their pain and contributes to even longer delays in achieving diagnosis. Conversely, when the right support for patients is available, the effects can be transformative, helping someone get back to the person that they were before their symptoms deteriorated.

Lauren Angelli - Phsyiotherapist (South Africa)

Barrier 5:

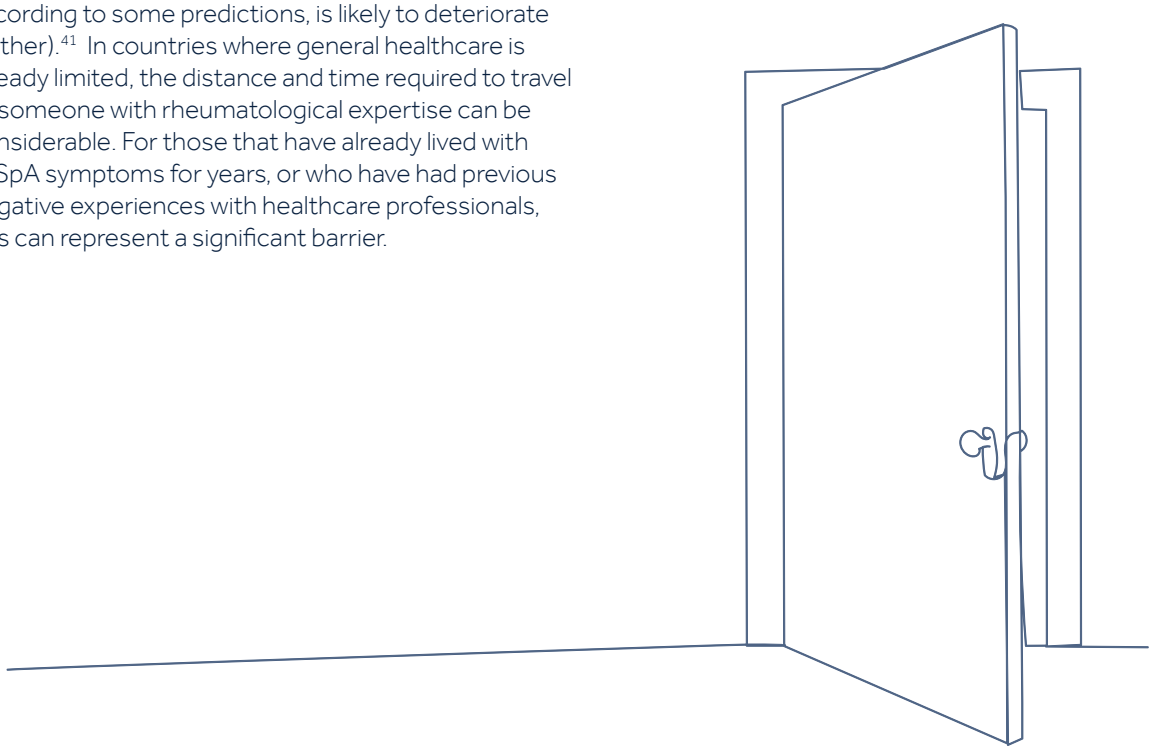
Challenges in accessing specialist care

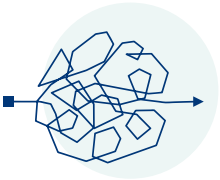
For many people across the globe, accessing the expert care required to achieve axSpA diagnosis can be an almost insurmountable barrier. In healthcare systems where access to care requires payment, those without some form of medical insurance will quite simply not be able to afford the costs associated with investigating the presence axSpA. This reflects the complex nature of axSpA and the multiple steps involved in accurately diagnosing it.

These were barriers highlighted by *Global Forum* attendees from a diverse range of healthcare systems, from South Africa to the Philippines, and from Russia to India. Recently published evidence exploring axSpA diagnosis barriers in North Africa and the Middle East further supports this viewpoint. Findings reveal how patients with fewer resources are more likely to limit their healthcare access to a pharmacist, with the aim of acquiring nonsteroidal anti-inflammatory drugs (NSAIDs) to help temporarily manage pain, rather than seek a longer-term solution.[40]

In addition to the monetary barrier of accessing specialist care, attendees also spoke of geographical barriers. These barriers were particularly challenging for those who lived in more rural parts of the world. Even amongst the best-resourced healthcare systems for instance, the availability and number of rheumatologists per head of population is low (and according to some predictions, is likely to deteriorate further).[41] In countries where general healthcare is already limited, the distance and time required to travel to someone with rheumatological expertise can be considerable. For those that have already lived with axSpA symptoms for years, or who have had previous negative experiences with healthcare professionals, this can represent a significant barrier.

> **It currently takes around 7 years on average to diagnose axSpA in India, however the delay is generally much worse in rural areas of the country. While the wait to achieve diagnosis in metropolitan areas can still be long, access to healthcare in cities is better and primary care practitioners working in these parts are more likely to be aware of axSpA and its symptoms.**
>
> **Outside of the main cities and towns in India almost nobody will have ever heard of axSpA, and knowledge of inflammatory back pain more broadly is also limited. Even when there is awareness of axSpA, the perception that it's not a 'life-threatening' disease means it's more often than not depriori-tised, with diagnosis and treatment coming only when all other approaches have failed.**
>
> **Jimit Thakkar - Member, StandForAS (India)**





Barrier 6:

Challenges within rheumatology

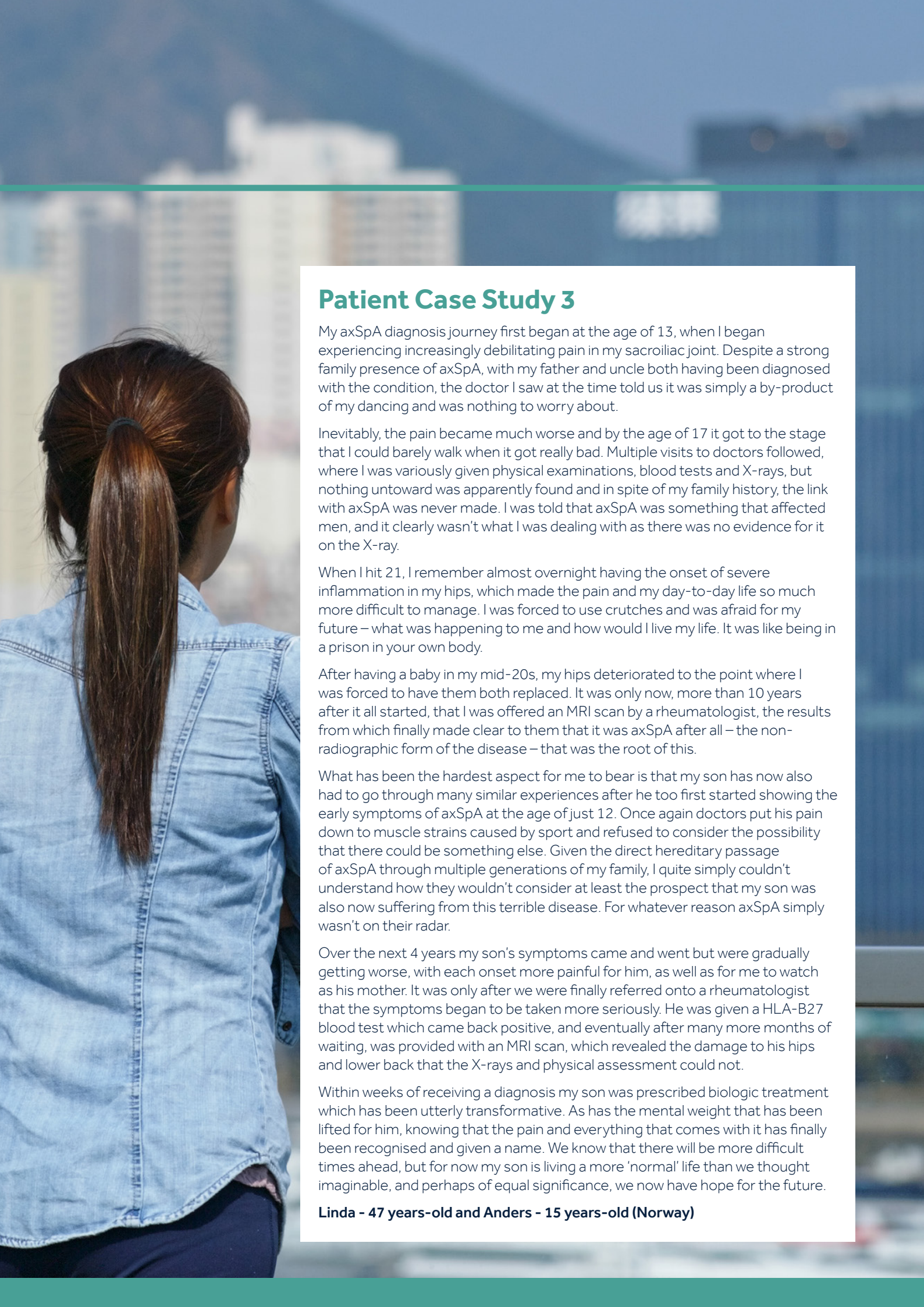
While early referral to a rheumatologist has been shown to significantly reduce axSpA diagnosis delays, being seen by a rheumatologist still does not guarantee swift diagnosis.[42]

This is largely due to the inherent complexity in diagnosing axSpA and the lack of a universally recognised assessment criteria. There is no single definitive test for the condition. Instead, diagnosis needs to be informed by a multitude of different criteria, including physical examination, blood tests (to look for inflammatory markers and the HLA-B27 gene associated with the condition), as well as X-rays and magnetic resonance imaging scans (MRIs), which are often in short supply in many parts of the world.[43]

> **Successfully diagnosing axSpA within rheumatology is not helped by the lack of effective, validated diagnostic criteria. While many classification criteria have been developed in axSpA, these have largely been for the purpose of clinical trials and have limited practicality in real-world settings. The modified New York Criteria for instance has poor sensitivity and shortcomings in identifying non-radiographic stages of the disease, whereas the ASAS classification criteria has good sensitivity, but can result in overdiagnosis of axSpA.**
>
> **Dr Tuncay Duruöz - Rheumatologist, Marmara University School of Medicine (Turkey)**

Data also suggests that rheumatologists themselves are liable to overlook the signs and symptoms of axSpA amongst patients already within their care.[44] *Global Forum* attendees highlighted how outside of a small cohort of axSpA specialists, broader awareness and understanding of the disease amongst rheumatological colleagues was often limited. This was a scenario common to many countries across the world.

> **Unfortunately, many rheumatologists have a limited or outdated understanding of axSpA. This means that when a patient presents with symptoms, the latest investigation and assessment techniques may not be used. The clinical area also suffers from a lack of definitive biomarkers, particularly when compared to other rheumatic conditions. HLA-B27 is the most commonly used blood test for axSpA, with the gene believed to be present in around 90% of people with axSpA. However, this also means that 10% of people with axSpA do not have the HLA-B27 gene, meaning that blood tests alone cannot be relied upon, but instead must be interpreted alongside the other clinical features that are being exhibited.**
>
> **The reality is that in many healthcare system across the globe, the availability of rheumatologists who are aware of these different factors and have the ability to reach an informed diagnosis of axSpA based on an individual's broad clinical presentation, is limited.**
>
> **Dr Shashank Akerkar - Rheumatologist, Mumbai Arthritis Clinic and Research Centre and Founder of StandForAS Foundation (India)**



Patient Case Study 3

My axSpA diagnosis journey first began at the age of 13, when I began experiencing increasingly debilitating pain in my sacroiliac joint. Despite a strong family presence of axSpA, with my father and uncle both having been diagnosed with the condition, the doctor I saw at the time told us it was simply a by-product of my dancing and was nothing to worry about.

Inevitably, the pain became much worse and by the age of 17 it got to the stage that I could barely walk when it got really bad. Multiple visits to doctors followed, where I was variously given physical examinations, blood tests and X-rays, but nothing untoward was apparently found and in spite of my family history, the link with axSpA was never made. I was told that axSpA was something that affected men, and it clearly wasn't what I was dealing with as there was no evidence for it on the X-ray.

When I hit 21, I remember almost overnight having the onset of severe inflammation in my hips, which made the pain and my day-to-day life so much more difficult to manage. I was forced to use crutches and was afraid for my future – what was happening to me and how would I live my life. It was like being in a prison in your own body.

After having a baby in my mid-20s, my hips deteriorated to the point where I was forced to have them both replaced. It was only now, more than 10 years after it all started, that I was offered an MRI scan by a rheumatologist, the results from which finally made clear to them that it was axSpA after all – the non-radiographic form of the disease – that was the root of this.

What has been the hardest aspect for me to bear is that my son has now also had to go through many similar experiences after he too first started showing the early symptoms of axSpA at the age of just 12. Once again doctors put his pain down to muscle strains caused by sport and refused to consider the possibility that there could be something else. Given the direct hereditary passage of axSpA through multiple generations of my family, I quite simply couldn't understand how they wouldn't consider at least the prospect that my son was also now suffering from this terrible disease. For whatever reason axSpA simply wasn't on their radar.

Over the next 4 years my son's symptoms came and went but were gradually getting worse, with each onset more painful for him, as well as for me to watch as his mother. It was only after we were finally referred onto a rheumatologist that the symptoms began to be taken more seriously. He was given a HLA-B27 blood test which came back positive, and eventually after many more months of waiting, was provided with an MRI scan, which revealed the damage to his hips and lower back that the X-rays and physical assessment could not.

Within weeks of receiving a diagnosis my son was prescribed biologic treatment which has been utterly transformative. As has the mental weight that has been lifted for him, knowing that the pain and everything that comes with it has finally been recognised and given a name. We know that there will be more difficult times ahead, but for now my son is living a more 'normal' life than we thought imaginable, and perhaps of equal significance, we now have hope for the future.

Linda - 47 years-old and Anders - 15 years-old (Norway)

Patient Case Study 4

The barriers I faced in eventually having my axSpA diagnosed are unfortunately typical for many living with the disease in the Philippines. My symptoms first emerged almost 10 years ago, manifesting initially as back pain. As I know now is common, my primary care doctor was my first port of call, however despite repeated visits I was only given over the counter pain medicine. As my symptoms gradually got worse, and the pain medication clearly wasn't helping, I was able through my workplace insurance to get access to an orthopaedic doctor. Exploratory tests were carried out over a number of sessions, however nothing specific was found and as the X-ray didn't show anything untoward, there was never any mention of the possibility of it being axSpA.

Several years after my symptoms first emerged, I was referred onwards to a rehabilitation physician, with whom I underwent multiple courses of therapy in the hope of finding an approach that worked. As with the orthopaedic doctor, none of this was successful and my symptoms were gradually deteriorating to the extent that nearly every aspect of my life was being impacted.

As the months and years went by, the pain in my lower joints got so bad that I went back to the rehabilitation doctor to see if there was anything else at all that could be done to help. Another scan was taken and it revealed that I had no synovial fluid whatsoever left in my hips, meaning I had no choice but to undergo full hip replacement surgery. Looking back, it was clear that this was a direct result of the repeated bouts of inflammation I had been suffering from because of my axSpA, and is therefore something that could almost certainly have been avoided had a diagnosis been made earlier.

The results from the scan did however trigger a referral onto a rheumatology specialist, who was ultimately able to conclude that axSpA was the cause of my years of suffering. Looking back there are many things that I wish could have happened differently in my diagnosis journey, however I was also extremely lucky to have had access to medical insurance through my workplace – many others in the Philippines do not have this and as a result quite simply cannot afford to see a specialist, let alone go through the years of consultations and tests that someone with axSpA typically faces. I therefore have no doubt that there are many thousands of people out there in the Philippines, and beyond, who are suffering from the symptoms of axSpA in silence and without the support they clearly need.

Kel Arceo - 35-years-old (Philippines)

Clinician Contribution

The importance of early diagnosis in axSpA

Achieving swift diagnosis of axSpA is far from straightforward, even for healthcare practitioners with strong experience in the area. The most common early symptoms of the disease - chronic back pain and stiffness - are nonspecific and easily mistaken for something else. A physician therefore who is not aware of the varied presentation of axSpA is likely to overlook the potential for diagnosis when a teenager or young adult describes their symptoms. This situation is exacerbated when some patients underrate their symptoms, perhaps having become used to living with the chronic pain instead of seeking treatment.

Despite growing understanding of how axSpA presents and manifests, we have yet to succeed in comprehensively reducing the delay across healthcare systems, meaning there is much more work still to do. Particularly for women, children and adolescents, who are more likely to experience longer delays compared to men and older patients. Those with axSpA who are HLA-B27-negative also wait longer for a diagnosis, demonstrating again that we must not use a single predictor in our clinical assessment.

The impact of the delay is clear for all those with direct or indirect experience of the disease. The longer it takes for someone to achieve diagnosis, the worse their functional outcomes are likely to be. There is also evidence to suggest that the growing range of treatments we have available are most effective when given early. It is vital therefore that we keep taking steps to increase the awareness of axSpA across as many healthcare disciplines as possible and promote the early referral strategies that demonstrate effectiveness.

Dr Muhammad Asim Khan – Rheumatologist and Professor of Medicine, Case Western Reserve University (USA)

Recognising the different axSpA diagnosis hurdles

The multiple symptoms of axSpA and the heterogeneous course of the disease make early diagnosis difficult. The treating physician may need to evaluate symptoms such as back and tendon pain, but also uveitis or intestinal inflammation, and have to assign these to a possible SpA. Differentiation of axial inflammation from nonspecific back pain by the physician is not an easy task and as another hurdle, they must also correctly judge imaging findings, especially MRI findings.

Bone marrow edema in the sacroiliac joints can be a manifestation of axSpA but also occurs in the general population, especially when mechanical stress factors may play a role. The extent and localization of the inflammatory areas differ between axSpA patients and healthy subjects, but ultimately a rheumatologist is necessary for differential diagnosis. In addition to clinic and imaging, laboratory parameters, especially HLA-B27 and CRP, play an important role in the diagnostic process. The low rate of CRP negative patients and also the different levels of local prevalence of HLA-B27 across the world represent additional hurdles that contribute towards a diagnostic delay. The evaluation of all these factors complicates the timely and correct diagnosis in patients with suspected axSpA.

Dr Uta Kiltz – Rheumatologist, ASAS, Elisabeth Gruppe and ASIF Scientific Advisor (Germany)

SECTION 3

Overcoming diagnosis barriers

Much of the initial focus of ASIF's *Delay to Diagnosis* project has been to highlight the extent of the axSpA diagnosis delay, exploring the reasons why it occurs and demonstrating the impact it has on millions of people around the world. However, we have also looked to highlight examples of best practice in reducing the delay from different healthcare systems, drawing on contributions from our *Global Forum* participants.

In this section we set out four case studies which help to illustrate a diverse range of approaches to reducing axSpA diagnosis delay. Each of these examples employs different methods, reflecting their unique local circumstance and challenges. These four examples provide a glimpse of ongoing efforts to reduce axSpA diagnosis times and give a sense of the real opportunities that exist to transform the way axSpA is diagnosed.

They also help to inform the five recommendations included in this report. Ultimately, learning from these examples and implementing the report recommendations will change the lives of millions of people affected by axSpA around the world for the better.[45,46,47]

Case Study 1 **United Kingdom:** A Gold Standard Approach to Diagnosis Time

The Approach

In the UK, the National Axial Spondyloarthritis Society (NASS) has embarked on an ambitious five-year programme to reduce the average time to diagnosis in the UK from 8.5 years to one year.

In July 2020, NASS - working with collaborators, and funded by UCB - published an analysis of the reasons for diagnostic delay.[i] It set out a proposal for a 'Gold Standard' time to diagnosis of one year and identified a series of solutions to address its four delays. NASS undertook a national consultation process and then developed a set of detailed proposals which were tested with stakeholder groups.

In June 2021, NASS published its final report which describes its proposals to achieve a Gold Standard of one year, under the campaign heading Act on Axial SpA. It also launched **www.actonaxialspa.com**, the most comprehensive online resource on time to diagnosis for axSpA anywhere in the world.

i https://nass.co.uk/get-involved/gold-standard

Findings

This process has helped to identify four visions that will help to fundamentally change the way axSpA is recognised and diagnosed in the UK.

- **Vision 1: General public awareness of axSpA and its symptoms is significantly improved**

  In June 2021 NASS launched the first in a series of public awareness campaigns with the theme 'a race against time'. It includes a new acronym – SPINE - to describe key symptoms:

  — **S**ymptoms slowly starting
  — **P**ain in the lower back
  — **I**mproves with movement
  — **N**ight-time waking
  — **E**arly onset (under 40)

The campaign raises awareness of axSpA and its symptoms and directs people to an online symptom checker and materials to help prepare for an appointment in primary care. It explains the referral pathway if the primary care professional suspects axSpA.

- **Vision 2: All patients who present to primary care with suspected axSpA are identified at the first presentation and urgently referred to rheumatology**

  In July 2021 NASS will launch an axSpA primary care clinical champions programme which will create and nurture a cadre of clinical champions who will work together in a national learning network to foster community-building, the exchange of ideas and good practice, and act as catalysts for change. They will lead local service improvement work and produce new resources to raise the profile of axSpA in primary care.

- **Vision 3: Patients with suspected axSpA who present at a range of services - including ophthalmology, gastroenterology, dermatology, orthopaedic - are identified at the first presentation and urgently referred to rheumatology**

  In early 2022 NASS will launch a national training programme for secondary care services. It will create learning tools to raise awareness of axSpA symptoms and to ensure it is on the checklist at first presentation of a new referral. A guide of screening questions to raise during the consultation will also be provided. In addition, NASS will create a toolkit to help rheumatology teams with the delivery of the educational package.

- **Vision 4: Every hospital in the UK seeing potential axSpA patients has an inflammatory spinal protocol MRI in place. Every rheumatologist in the UK is able to access an axSPA expert MSK radiologist in-house or via another specialist centre. All radiologists and rheumatologists are aware of and use the BRITSpA MRI guidelines.**

In 2022 NASS will undertake a national review of radiology training in axSpA and will audit all hospitals to assess if they are using an inflammatory spinal protocol MRI. It will develop an axSpA MRI training programme, co-developed with rheumatologists and experts from radiology. NASS will also assess the availability of regional tertiary referral services and the potential for additional tertiary capacity across the UK.

> **"The launch of NASS's Gold Standard represents a significant milestone for addressing the axSpA delay to diagnosis in the UK. Achieving the four visions contained within the programme will rely on close collaboration and engagement with all those involved in the path to successful diagnosis. We recognise that there is much work ahead of us to reduce the average time to diagnosis in the UK to 1 year, however we now also have the knowledge and tools available to help us get there. Transforming the lives of countless individuals who will go onto develop axSpA in years to come is within our grasp."**
>
> **Dr Dale Webb - CEO of the National Axial Spondyloarthritis Society (UK)**

Case Study 2

Argentina: Implementing a National axSpA 'Early Detection' Awareness Campaign

The Approach

One of the key barriers to timely axSpA diagnosis in Argentina is the very low level of awareness of the condition amongst the general population, as well as within much of the wider healthcare workforce. Despite there being good levels of capacity and axSpA expertise within the country's rheumatology departments, the challenge has traditionally been locating those with symptoms, as people with inflammatory back pain have tended to present to non-rheumatology specialties, such as orthopedics, ophthalmology and dermatology, where they often get stuck without being referred onwards.

In order to start addressing this, the first ever axSpA awareness-raising campaign was launched in two regions of the country in 2012 (Buenos Aires and Salta). Over a four-week period, a broad range of multimedia platforms were utilised to encourage those with potential axSpA symptoms in these areas to contact the pilot coordinators and be referred onwards to a participating rheumatology service, providing they met the inclusion criteria.

Funding was secured to run advertorials across newspapers, television, radio and the internet. Information leaflets were also distributed in different parts of the pilot regions, with all forms of the advertorials including contact details for a supporting call centre or email helpline.

Those that got in touch were filtered for suitability for onward referral according to an initial questionnaire designed to assess their back pain criteria. Patients who fulfilled the criteria were then interviewed and examined by a rheumatologist, with assessment including a physical exam, blood samples, X-rays and if necessary, HLA-B27 tests and an MRI.

Findings

Over the four-week period, 900 individuals responded to the promotional material and contacted the telephone or email helplines. Almost two-thirds (61.5%) of those who got in touch were recruited through TV advertising, with the remainder coming through newspaper, internet or other forms of advertising. After the first assessment questionnaire, 70% of the contacts from the call centre met the inclusion criteria for onward referral to a rheumatologist, while only 7.3% of those recruited via email did so.

A total of 157 rheumatology appointments were scheduled, with 80 patients eventually attending (the rest were lost to follow-up). Of those 80 appointments, half (42) were found to have definitively met the inclusion criteria and 9 patients were eventually diagnosed with axSpA. The frequency of axSpA in people with inflammatory back pain from the general population was 22.5% and axSpa was detected in 1.3% of this population who were unaware of their diagnosis.

"

This campaign represented the first time we had tried to increase awareness of axSpA on a larger-scale in Argentina. Not only were we able to reach hundreds of people who hadn't come across the disease before, and achieve new diagnoses in the process, but we were also able to use it as a means of building awareness of axSpA amongst other healthcare professions, where knowledge is much more limited. The results have helped to demonstrate the importance of getting axSpA higher on the healthcare agenda in Argentina and we are hopeful that we will be able to carry out further awareness-raising initiatives in the near-future.

Dr Fernando Somerfleck – Rheumatologist, coordinator of PANLAR SpA study group and Argentinian awareness campaign co-author (Argentina)

Case Study 3

Netherlands: Identifying Opportunities for Optimising axSpA Referral

The Approach

A number of suggested axSpA clinical referral strategies have emerged in recent years, however, there has been limited evidence about how they compare and whether any of these should be used more prominently than the others. The Leiden SPondyloArthritis Caught Early (SPACE) cohort study for the first time sought to address this by evaluating 13 of the most promising axSpA referral models, identified through a literature review (1).

Data from a research cohort of 261 patients was used for the study – in the cohort, patients aged ≥16 years and with chronic back pain (classified as almost daily, ≥3 months but ≤2 years, age of onset <45 years) were referred to the rheumatology outpatient clinics of five participating centres across Europe. Patients could be referred by general practitioners as well as other specialties, commonly including orthopaedic surgeons, ophthalmologists, gastroenterologists and rheumatologists from other centres.

Performance of referral strategies was evaluated against the final diagnosis of the local rheumatologist (reflecting the clinical setting in which the strategy would be applied), as well as against ASAS axSpA criteria as an external standard. A key goal was to establish which of the strategies offered the most promising balance between sensitivity (the ability of a test to correctly identify patients with the disease) and specificity (the ability of a test to correctly identify people without the disease).

Findings

Evaluation of the patient data and assessment criteria showed a wide range in performance across the different referral approaches. The study found the ASAS and Brandt I strategies to be the most sensitive (98%) but having a low specificity (18% and 11% respectively), resulting in high levels of over-referral.

RADAR 2/3 was the most specific strategy (82%), while the MASTER strategy had the most balanced sensitivity (64%) and specificity (76%), and therefore recorded the highest positive likelihood ratio.

The findings emphasised that there is no one single criteria that can be used to establish axSpA diagnosis – while screening for HLA-B27 for instance is appealing, its effectiveness is dependent on its prevalence amongst the general population, which varies considerably based on regional geography and ethnicity. Likewise, while inflammatory back pain is regarded as the leading axSpA clinical symptom, evidence suggests it is only present in around four-fifths of those with the disease, and it is difficult for non-specialists to accurately detect its presence.

In this sense, approaches like the Braun two-step strategy are promising as the assessed criteria are relatively untaxing for general doctors, non-invasive as they do not rely on imaging, and nor do they generate high costs.

"

Despite the differences in performance between the various approaches, our evaluation clearly showed that existing referral strategies can have a huge value in supporting timely diagnosis in axSpA. Alongside their comparative sensitivity and specificity, strategies must ultimately also be easily applicable in the respective local clinical setting and as inexpensive as possible, especially as chronic back pain is so common in primary care.

With this in mind, using imaging as a referral parameter is probably not feasible in most healthcare systems due to its high relative costs, although it should be considered in countries where it is more readily available. This suggests that optimal strategies will differ between countries, based on the relevant strengths and weaknesses of that healthcare system.

Most importantly, however, by including only patients with less than two years of chronic back pain, the SPACE project clearly demonstrates that early diagnosis of axSpA is feasible and has been shown to be very cost-effective in the Netherlands, despite the project having few restrictions concerning inclusion (2). Moreover, given that SPACE patients with axSpA had significantly better quality of life and work-related outcomes after two years of follow-up compared to those without axSpA, this supports the notion that timely diagnosis will generate huge value for individuals and the healthcare system (3,4). Best-practice must be rolled out more widely as a key healthcare priority.

Dr Floris van Gaalen - Rheumatologist, ASAS executive committee member and SPACE study co-author (Netherlands)

1 Abawi RMD Open. 2017 Apr 7;3(1):e000389
2 C. Webers. Ann Rheum Dis, volume 79, supplement 1, 2020, page 510
3 A Boel Ann Rheum Dis, volume 80, supplement 1, 2021, page 339
4 Boel Ann Rheum Dis, volume 80, supplement 1, 2021, page 741

Case Study 4

Russia: A Partnership-Based Approach to Online Advertising for AxSpA

The Approach

Achieving axSpA diagnosis in Russia takes on average 7 years, but there is significant variation between different regions. As with many other parts of the world, awareness of the condition is limited, particularly in non-urban regions of the country. When a patient does present with symptoms, they must first visit a general physician, with referral to a neurologist often being the next step.

In order to try and shorten this process and support increased awareness of axSpA and the importance of visiting a rheumatologist amongst hard-to-reach groups, an online advertising campaign was launched in October 2018 with the aim of reaching those with undiagnosed signs and symptoms of axSpA. The campaign was supported by a major online search network and was highly commended by experts from the President's Grant Fund of the Russian Federation.

Running for a total of 8 months, the campaign featured extensive contextual online advertising, targeted around search terms associated with axSpA, for instance 'joint / back pain' and 'inflammation'. Advertising ran on Google as well as a native Russian search engine. Those who engaged with the advertising were able to access an online test to help establish whether the back pain they are experiencing is inflammatory or mechanical in nature. For those meeting the criteria for inflammatory back pain, advice and information on visiting a rheumatologist was given, to help establish a potential axSpA diagnosis.

Findings

Over the course of the programme, more than 136,000 people engaged with the advertising. Of these, over 9,000 were tested for inflammatory back pain criteria, with 2,639 testing positive. Twice as many women took the test than men. If funding is secured, the next stage of the programme would involve coordinating appointments for those that tested positive at participating rheumatology centres across five regions in Russia – each patient would be given a number and a unique QR code, enabling them to be connected to a rheumatologist for further examination and to potentially reach a definitive diagnosis of axSpA.

> "
>
> In a relatively short space of time we were able to reach a very large amount of people suffering from inflammatory back pain and encourage them to think about whether axSpA is responsible for their symptoms. The ultimate aim of the project is to directly connect those with suspected axSpA with local rheumatologists, who can then use latest diagnostic testing to assess if the disease is actually present.
>
> While we are hopeful we will be able to carry out this second phase in the near future, the initial advertising has demonstrated the value that this kind of awareness-raising activity can have, and has also led to a sustained increase in the amount of people getting in touch with our patient support helpline, with lots of requests coming from people who had never heard of the disease before. It was particularly encouraging to see so many women engage with the campaign, considering that they are a group who have traditionally been under-recognised in this area.
>
> **Aleksei Sitalo - President of the Russian Ankylosing Spondylitis Association (Russia)**

Conclusion: It is Time for Action

In the process of developing this report, it has been overwhelmingly clear just how detrimental the impact of a delayed axSpA diagnosis can be. There is hardly any aspect of an individual's life that isn't negatively affected by the physical and mental pain that comes from repeated failures to correctly identify, manage and treat the progressive symptoms associated with the disease. As highlighted throughout the report, the disease also places huge burdens on families, caregivers and society as a whole.

Despite this, there is hope that we can do better. Progress in reducing the diagnosis delay is visible through a number of promising initiatives, and the onus now needs to be on scaling-up good practice where it exists. As we have heard from the wide range of experts and individuals living with the disease who have contributed to this report, there is both a clear moral and economic case for reducing the current seven-year global axSpA diagnosis delay.

1

Recommendation 1:
Country-level healthcare leaders and decision-makers should **commit to joining national conversations** about the current local state of axSpA diagnosis delay and recognise the importance of reducing this, through making it a health policy priority.

2

Recommendation 2:
Broader **awareness campaigns are needed** to increase axSpA knowledge and understanding amongst individuals and wider society as a whole.

3

Recommendation 3:
Opportunities should be sought to establish **collaborative-based approaches to addressing axSpA diagnosis challenges**, drawing on potential support from a range of local partners.

4

Recommendation 4:
AxSpA diagnosis is not straightforward, however there are increasing examples of best practice in achieving early diagnosis. **Healthcare leaders should raise awareness of these** across national rheumatology and general medicine networks and **support their implementation** in line with local circumstances.

5

Recommendation 5:
National or local-level axSpA delay initiatives should be **underpinned by robust data collection** to help assess their effectiveness and build a stronger evidence-base for others to draw on.

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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 (including Ankylosing Spondylitis, non-radiographic axial spondyloarthritis and psoriatic arthritis). 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 on the first Saturday after the 1 May.

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Contact information

For any further information on the content on this report or the work of ASIF, please contact **projectmanager@asif.info** or visit **www.asif.info**

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