CROHN'S & COLITIS UK

NASS
Axial SpA works silently. We don't.

Early recognition of axial spondyloarthritis (axial SpA) in patients with inflammatory bowel disease (IBD)

A UK survey of gastroenterologists and IBD nurses

Campaign fully funded by UCB.

ucb Inspired by patients. Driven by science.

NHS Royal United Hospitals Bath NHS Foundation Trust

NHS Norfolk and Norwich University Hospitals NHS Foundation Trust

act on Axial SpA

About the National Axial Spondyloarthritis Society

Our purpose:

To transform the diagnosis, treatment, and care of people with axial SpA so everyone can live well with it.

Our cause:

Axial SpA is an inflammatory condition of the spine and joints. It works silently, leaving people in increasing pain and exhaustion.

What we do:

We campaign to transform diagnosis and treatment.
We provide support to empower people living with the condition.

This report should be cited as follows:

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Our *Act on Axial SpA* campaign: A Gold Standard time to diagnosis

The current time to diagnosis of axial SpA in the UK averages approximately 8.5 years from symptom onset. This delay is unacceptable and has serious consequences for the patient. With our *Act on Axial SpA* campaign, we propose a roadmap for reducing the time from symptom onset to diagnosis to just one year.

Find out more by visiting:
www.actonaxialspa.com

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Acknowledgements

NASS wishes to express our sincere thanks to UCB for funding this programme, without which it would not have been possible to bring our plans to life.

Inspired by **patients.**
Driven by **science.**

We would like to thank Prof. Karl Gaffney, Norfolk & Norwich University Hospitals NHS Foundation Trust, and Prof. Raj Sengupta, Royal National Hospital for Rheumatic Diseases Bath, for being such committed and enthusiastic partners to the programme.

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We also want to also thank Dr Lesley Kay, Consultant Rheumatologist, Newcastle Hospitals NHS Foundation Trust, Executive Medical Director at Healthcare Safety Investigation Branch and National Clinical Lead for GIRFT Rheumatology, and Dr. Helena Marzo-Ortega, Chair of the Executive Committee British Society for Spondyloarthritis, Consultant Rheumatologist at Leeds Teaching Hospitals NHS Trust and honorary Clinical Associate Professor at the University of Leeds.

CROHN'S & COLITIS UK

Finally, we would like to thank Crohn's & Colitis UK and the British Society of Gastroenterology for collaborating with us on the creation of the survey and sharing it with their networks and clinicians.

Foreword Gastroenterology view

Patients living with IBD often have associated conditions outside the bowel. Inflammatory back pain (IBP), including axial SpA, is amongst the most common and serious extraintestinal manifestations (EIM) of IBD. Currently, it takes too long to correctly diagnose axial SpA and provide specialist treatment and support. This report has identified the key areas for improvement. We make recommendations for faster diagnosis and treatment to improve the quality of life of our patients.

Dr. Christian Selinger, MD MSc FRCP Edin

Chair of the British Society of Gastroenterology (BSG) IBD Committee and Consultant Gastroenterologist & Lead for IBD, Leeds Teaching Hospitals

Foreword Rheumatology view

We know from past research that there is a common link between axial SpA and IBD. It is also clear that there is a level of unmet need where patients with IBD are not referred to rheumatology if they experience persistent back pain.

The findings of this analysis show that there are some simple things that as rheumatologists we can do to support our colleagues in gastroenterology. These simple steps grounded in closer working, clearer communication and highlighting the key signs can help reduce this unmet need.

It is not just a one way need, as patients with axial SpA may also develop IBD as an extra musculoskeletal manifestation. So, as well as rheumatologists raising awareness with gastroenterology colleagues, closer working will lead to a reciprocal approach with earlier identification of IBD in axial SpA patients. This ultimately will ensure that patients are getting joined up optimal care to meet all their needs.

Commonality in treatment for both conditions means once patients receive appropriate treatment for IBD, it may also help their axial SpA symptoms. However, this could mask some of the musculoskeletal symptoms and make recognition by gastroenterology clinicians more challenging. There are simple tools, such as the NASS symptom checker, ASAS IBP criteria and SPADE tool, based on clinical history to identify likely inflammatory back pain and indicate referral to rheumatology.

Given the current pressures on NHS services, including rheumatology, it is crucial that we support gastroenterologists to know when to refer using these simple tools. If there is a high suspicion of IBP, then a swift referral to rheumatology is recommended.

Prof. Raj Sengupta

Consultant Rheumatologist, Royal National Hospital for Rheumatic Diseases Bath, Royal United Hospitals Bath, and NASS Medical Advisory Board member

Executive summary

Key findings

Positively, **72%** (n. 33) of the respondents had received some form of teaching on axial SpA during their training.

Only **28%** (n. 13) receive regular sessions on axial SpA in their current post.

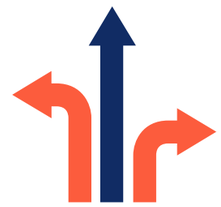
60% (n. 28) of respondents felt confident or somewhat confident in recognising axial SpA.

72% (n. 33) stated that they regularly discuss joint pain with IBD patients, with a further 22% (n. 10) indicating they sometimes discuss joint pain.

Only **4%** (n. 2) of respondents report that they have screening tools.

Just over half, **52%** (n. 24), were aware of local axial SpA services that they can refer to.

Only **21%** (n.10) of those who completed the survey regularly have some form of joint MDT or clinics with their rheumatology teams.



70% (n. 31) of respondents were able to identify that they have direct internal referral pathways to rheumatology.

89% (n. 41) of respondents were able to state they were confident to some degree of how to refer.

Recommendations

Gold Standard in gastroentetology ambition

All patients with a high suspicion of IBP, as identified by the NASS symptom checker or ASAS criteria, plus IBD are directly referred to rheumatology. Patients with back pain not identified as inflammatory are ideally offered musculoskeletal (MSK) physiotherapy, via a GP or primary care clinician if needed.

01

Gastroenterology and rheumatology should have an agreed two-way working practice that enables rapid communication and decision-making. As a minimum, each have named contacts in their corresponding units whom they can access for advice and guidance or directly refer patients.

02

Ongoing education is available for gastroenterologists and IBD nurses to raise awareness of axial SpA and inflammatory arthritis.

03

Patients with IBD should be able to access simple tools, such as the NASS symptom checker, to help them check their back pain symptoms and identify if it could be axial SpA.

04

Simple tools (such as the NASS symptom checker and poster and/or the SPADE tool) are available to gastroenterology for use in clinic, that act as a prompt or reminder of the symptoms of axial SpA and when to refer.

Introduction

Prevalence of axial SpA ranges from 0.5-1.5% in UK, but it can be as high as 5% in patients with IBD. Despite advances in technology and changes in classification to include early stages of the condition, there is still significant delay in diagnosis, which in the UK takes 8.5 years on average from symptom onset to diagnosis[1]. Diagnostic delays lead to significant functional disability, mental health issues, and financial detriment in patients and cost the UK economy £18.7 billion a year[2].

In 2021, NASS conducted a UK consultation with patients and the rheumatology community which led to the *Act on axial SpA* campaign to implement a Gold Standard time to diagnosis of one year. The implementation plan included a roadmap for delivery around the four main delays and four solutions[3].

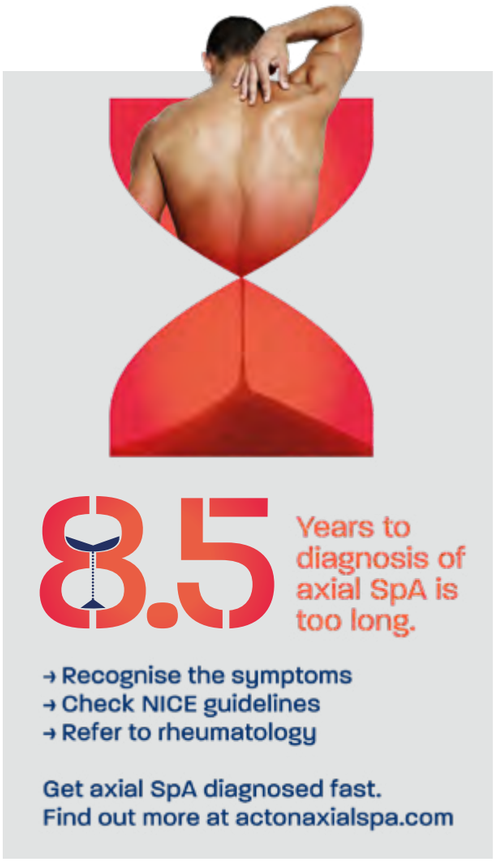
The consultation found that people with symptoms suggestive of axial SpA are not routinely referred to rheumatology. Act on Axial SpA aims to address delays in secondary care and has collaborated with the relevant professional bodes in gastroenterology, dermatology and ophthalmology. Our aim is to identify patients with suspected axial SpA at first presentation in secondary care, assess them for inflammatory indicators and urgently refer to rheumatology.

As part of this, NASS has commenced work in collaboration with the Royal Colleges or Professional Bodies within gastroenterology, dermatology, and ophthalmology. This initiative helps capture patients with suspected axial SpA who may present to a specialty other than rheumatology to help: identify patients with axial SpA at the first presentation of back pain; have them assessed for inflammatory indicators; and urgently refer to rheumatology. This requires the relevant secondary care services being aware of when the patient merits referral to rheumatology, how to assess, and how to make the referral.

[1]Sykes MP, Doll H, Sengupta R, Gaffney K. Delay to diagnosis in axial spondyloarthritis: are we improving in the UK? Rheumatology. 2015;54(12):2283-4.

[2]Howard Wilsher, S., Afolabi, O., Mishra, M., Xydopoulos, G., Zanghelini, F. and Fordham, R., 2022. The Economic Cost of Delayed Diagnosis of Axial Spondyloarthritis in the UK. London; The National Axial Spondyloarthritis Society.

[3]Webb D, Swingler L, Barnett R, Sengupta R, Marshall L, Hamilton J, Zhao S & Gaffney K. Act on axial SpA: A Gold Standard time for the diagnosis of axial SpA (2021). London: National Axial Spondyloarthritis Society



In a multicentre screening of patients with psoriasis, iritis, and colitis, 48% of patients who were younger than 45 years, and experienced undiagnosed back pain for more than three months were diagnosed with axial SpA when the three-stage evaluation approach (clinical evaluation, laboratory results [HLA-B27, CRP] and radiography, MRI) were used[4]; 69% were diagnosed with axial SpA after the clinical evaluation alone.[5] These figures suggest that many opportunities to identify, diagnose, and treat axial SpA are being missed.

Here, we present the data obtained from work undertaken by NASS, Crohn's & Colitis UK, and supported by the BSG IBD committee. It aimed to understand the drivers behind delays in diagnosis of axial SpA in patients who are under the care of gastroenterology. In particular, we looked to understand the barriers in recognising and referring patients with axial SpA amongst clinicians, and to identify any obstacles with the referral processes in secondary healthcare. A longer-term aim of the project is to develop resources to support clinicians with early diagnosis and referral.

What is clear from this study is the need to support clinicians with simple assessment tools. This is especially important in the context of the current NHS challenges and demand for services. These tools, coupled with a continuous effort to maintain regular communication with rheumatology and opportunities to refresh clinicians' knowledge of the signs of axial SpA, are imperative.

This report makes practical suggestions on how this can be achieved, and we continue to work with clinicians to identify and share best practice examples.

Dr. Dale Webb, FRSA, FRSPH
CEO, NASS

[4]Maksymowych WP, Carmona R, Yeung J, Chan J, Martin L, Aydin S,et al. Thu0393 performance of the ASAS classification criteria presenting with undiagnosed back pain? Data from the screening in axial spondyloarthritis in psoriasis, iritis, and colitis (SASPIC) cohort. Annals of the rheumatic diseases. 2019;78(suppl 2):482.

[5]Maksymowych WP, Carmona R, Yeung J, Chan J, Martin L, Avdin S, et al. Sat0339 What is the impact of imaging on diagnostic ascertainment of patients presenting with undiagnosed back pain and what is the impact of central evaluation? Data from the screening in axial spondyloarthritis in psoriasis, iritis, and colitis (SASPIC) cohort. Annals of the rheumatic diseases. 2019;78(suppl 2):1248-9.

Background

This report is part of the NASS *Act on Axial SpA* campaign to implement a Gold Standard Time to Diagnosis, which we launched in June 2021. It sits alongside other work in the campaign to highlight the impact of waiting, on average, 8.5 years for a diagnosis of axial SpA on individuals' life. Findings from this campaign's research are key to help us influence the thinking and behaviour of policy makers, system leaders and health care professionals (HCPs) that will translate into streamlined, improved, high quality care pathways and ultimately drive down diagnosis time, including identifying any areas where there is the greatest need for improvement.

What we did

NASS developed a 22-question survey in conjunction with key clinical advisors, Crohn's & Colitis UK and BSG. It was distributed amongst national gastroenterologists and IBD nurses via an electronic survey. The distribution was via newsletters, direct emails to hospitals / clinicians and through NASS, Crohn's & Colitis UK, and BSG social media channels. The data were collected between September and November 2023. The survey looked at several areas of practice:

- **Education: assessing the specialists' educational opportunities during training and their current posts, and the barriers they face in education.**
- **Axial SpA knowledge: the current level of knowledge and confidence in identifying axial SpA and what the barriers are.**
- **Ways of working: the relationships between gastroenterology and rheumatology, including access to and working with, specialist axial SpA services.**
- **Referral pathways: assessing the level of awareness around internal direct referrals and their use.**

We received responses from 46 clinicians from across the UK. This comprised 35 consultants, eight IBD nurses, and three registrars. The sample size was representative of a UK geographical spread, the types of units they are from, and their level of seniority. We recognise that it is a relatively low return and may not wholly represent the UK; the results may be more optimistic due to selection bias from more engaged clinicians.

NASS developed a 22-question survey in conjunction with key clinical advisors, Crohn's & Colitis UK and BSG.

Results, comment and analysis

Education and training

What we asked and why

Studies have shown that up to 5% of patients with IBD have axial SpA, but we know that once clinicians specialise in particular medical areas, they receive little formal education around conditions not within that profession directly. Given the association between axial SpA and IBD, we wanted to understand the level of education gastroenterology clinicians have and why a lack of education may exist. Therefore, we asked:

- **As part of your medical training did you receive any education on inflammatory arthritis / axial SpA or ankylosing spondylitis (AS)?**
- **Within your current role in gastroenterology do you receive any education on inflammatory arthritis / axial SpA or ankylosing spondylitis (AS)?**
- **What if any do you think are the educational barriers to understanding axial SpA and links to IBD?**

Results

Positively, 72% (n. 33) of the respondents had received some form of teaching on axial SpA during their training. This is as high as 91% for consultant gastroenterologists, but no IBD nurses have had axial SpA education.

Only 28% (n. 13) of respondents receive regular sessions on axial SpA in their current post. Half the IBD nurses responding have never received regular training, and 28% of consultants state not having ongoing education on the topic.

The feedback from the respondents cited various barriers to them receiving ongoing regular education with some strong consistent themes:

- **Limitations in time,**
- **Suboptimal integration between gastroenterology and rheumatology e.g., no joint education,**
- **Lots of extraintestinal manifestations in IBD, so it's difficult to cover them all.**

Our analysis

While there are clearly positive results with regard to education for those training to be consultants, there are concerns with the lack of education for IBD nurses and the low levels of ongoing training. It is critically important for clinicians to be able to access ongoing educational material to refresh their knowledge on axial SpA and inflammatory arthritis is critical. Given the barriers to this, it is clear that short and focused e-learning would help reduce the time constraints and enable rheumatologists, with specialist expertise in axial SpA, to deliver regular learning opportunities to their gastroenterology colleagues locally.

Axial SpA knowledge

What we asked and why

Given the prevalence of axial SpA in IBD, it is important for clinicians treating these patients to be aware of the gut-joint axis, be confident in what symptoms to look for, and what questions to ask their patients. To achieve our Gold Standard time to diagnosis, early identification and referral to rheumatology is needed. We wanted to assess the level of confidence that clinicians who manage IBD patients have with suspecting axial SpA. Therefore, we asked:

- **How often do patients have both IBD and inflammatory arthritis / axial SpA?**
- **What are the key signs or symptoms that would lead you to suspecting inflammatory arthritis or axial SpA?**
- **How confident are you in being able to recognise potential axial SpA patients in your care?**
- **Do you discuss joint pain with your IBD patients?**
- **What do you feel are some of the issues that impact your ability to recognise axial SpA?**

Results

60% (n. 28) of respondents felt either very confident, confident, or somewhat confident in recognising axial SpA, while 35% (n. 16) did not feel confident.

72% (n. 33) stated that they regularly discuss joint pain with IBD patients, with a further 21% (n. 10) indicating that they sometimes discuss joint pain.

Confidence is significantly higher amongst consultants compared to IBD nurses (74% to 17%), while both roles are reasonably similar with regard to regularly discussing joint pain (77% vs 83%).

Symptoms of axial SpA commonly identified by respondents were:

- **Persistent back pain over three months (85% identified),**
- **Morning stiffness (98% identified),**
- **Symptoms before the age of 40 (65% identified),**
- **Pain that improves with movement (65% identified).**

Additionally, all IBD nurses (100%) identified that patients wake during the night, which was not as strongly identified amongst clinicians (50%).

The feedback from the respondents cited various barriers to recognising axial SpA early within gastroenterology:

- **Limitations in time,**
- **Suboptimal integration between gastroenterology and rheumatology e.g., silo working,**
- **A perceived lack of need for educational sessions on axial SpA,**
- **A perceived lack of diagnostic criteria for axial SpA.**

Our analysis

There is a reasonable level of confidence, particularly amongst the consultant population, in recognising the signs of axial SpA and being able to identify the key symptoms that might raise suspicion of axial SpA. There is a lower level of confidence amongst the IBD nurse population, despite their increased awareness of the symptoms. Ongoing education should help to maintain these high levels of confidence. Simple tools highlighting the symptoms for clinicians to use in clinic can be a constant reminder whilst in high-demand clinical appointments, and act as a prompt for asking about back pain.

Ways of working

What we asked and why

Screening tools are commonly used within health services as part of assessment processes and give clinicians a common framework and objective measurement. They provide a consistent approach to testing for the presence of a disease or condition to help ensure patients receive effective treatment. For axial SpA, it would be beneficial to have screening tools available and utilised by specialties associated with extra-musculoskeletal manifestation (EMMs). We also have anecdotal evidence that closer working between rheumatology and other specialties results in a greater awareness and likelihood for increased knowledge. Therefore, we asked:

- **Do you use any specific screening tools for assessing potential axial SpA within gastroenterology?**
- **Do you have access to a local rheumatology service within your Trust?**
- **Do you have a local / regional axial SpA clinic / service that you can refer to?**
- **Do you have any formal or informal MDTs or joint clinics with your rheumatology or axial SpA service?**

Results

Only 4% (n. 2) of respondents identified that they have screening tools for axial SpA and neither shared an example with us.

Just over half, 52% (n. 24), responded that they were aware of local axial SpA services that they can refer to.

Only 22% (n.10) of those who completed the survey regularly have some form of joint MDT or clinics with their rheumatology teams. These ranged from regular joint clinics (monthly / quarterly), ad hoc virtual MDTs, to simply emailing a named consultant or rota mailbox.

Our analysis

We are concerned that there is little use of a common screening tool to aid referrals and triage once in rheumatology. There is a need to share best practice in how rheumatology and gastroenterology can work together in managing patients with IBD and axial SpA. This will allow for adoption locally to fit with the needs of their service. As a minimum, all gastroenterology teams should have a dedicated named rheumatology contact for referral and internal advice and guidance when needed. In services that have the sufficient scale to warrant a joint clinic this can aid the diagnostic process, but such working practices need to aid working and not be too onerous for both teams. To further support gastroenterology colleagues with assessing back pain to identify or confirm inflammatory signs, embedding the NASS symptom checker[6] within IBD clinics is recommended. The symptom checker is based on clinically validated criteria.

[6]Available at: https://www.actonaxialspa.com/symptoms-checker/

Referral pathways

What we asked and why

As we identified in our analysis of internal direct referral pathways, all UK Trusts and Health Boards allow direct referrals into rheumatology. They are often informal and reliant on consultant to consultant letters or phone calls. Once IBD patients are identified as potentially having axial SpA, IBP, or other inflammatory arthritis, a referral to rheumatology should be made. To ensure this is efficient for the patient, it should be done as quickly as possible. We wanted to assess if clinicians seeing IBD patients are confident in referring and how they refer. Therefore, we asked:

- **Are you aware of or do you have internal direct referral pathways to enable referral to rheumatology?**
- **If so, how do they work?**
- **How confident are you in being able to refer direct to rheumatology if you suspect axial SpA?**
- **What do you feel are some of the issues that impact your ability to refer to rheumatology?**

Results

70% (n. 31) of respondents were able to identify that they have direct internal referral pathways to rheumatology. The majority of those who identified the ability to refer stated this was done via consultant to consultant letters or sending to joint clinics where they exist.

89% (n. 41) of respondents stated they were confident to some degree of how to refer. Confidence level is much higher at 97% amongst consultant level clinicians.

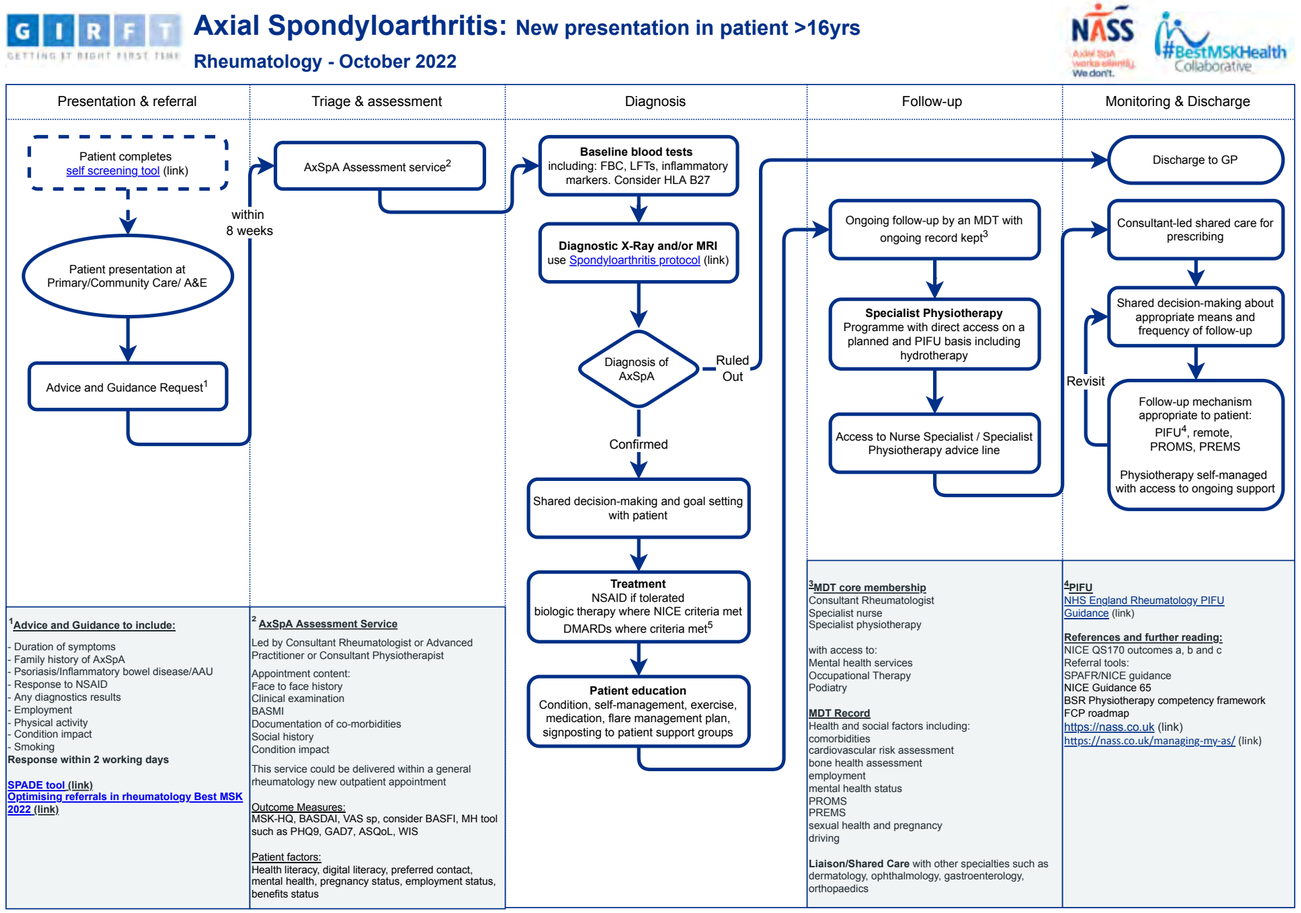
Reasons cited for delayed or lack of referrals included: NHS administrative backlog; the long rheumatology waiting times; concerns about over-referring; and a perception that internal referrals are not allowed or accepted.

Our analysis

These findings are in line with the results from our review of direct referrals[7], where internal referrals tend to be done on an informal consultant to consultant level via a call or letter, once again highlighting the lack of awareness that direct internal referrals are available. IBD physicians are more likely to refer patients suspected of axial SpA, which is encouraging. The new GIRFT pathway on axial SpA[8] aims to support clinicians in managing suspected and diagnosed axial SpA. Sharing this and other best practice with gastroenterology clinicians could help ensure that this confidence translates into swift and appropriate referrals to rheumatology. This process will also be helped by having named rheumatology contacts for advice and guidance, should a HCP suspect axial SpA or other inflammatory arthritis.

[7]Eddison J, Webb D, & Hamilton J; Review of direct referrals to Rheumatology for suspected axial SpA (2022) London: The National Axial Spondyloarthritis Society.

[8]Available at: https://gettingitrightfirsttime.co.uk/wp-content/uploads/2022/11/Rheumatology-Axial-Spondyloarthritis-Pathway.pdf



A recent study by Chong Seng et al (2022)[9] concluded that there is a significant hidden disease burden of axial SpA amongst patients with IBD. Appropriate identification and referral from gastroenterology is needed to shorten the delay in diagnosis and allow access to appropriate therapy. The study, which was based on sending a screening questionnaire to consecutive IBD patients in clinic at a university teaching hospital, identified that approximately 19% (91/470) of patients with IBD have self-reported chronic back pain and are under the age of 45. If all the patients with IBD who complained of chronic back pain were referred to rheumatology it would lead to a 20% increase in demand. However, the study goes on to further delineate, through medical review, physical examination, and patient reported outcomes, the true burden of undiagnosed axial SpA. It estimates a prevalence of undiagnosed axial SpA of 5% in patients attending IBD clinics who report chronic back pain. The study also identifies that mean symptom duration for these patients was 12 years. These findings support the need for gastroenterologists to differentiate between mechanical and inflammatory back pain and screen patients for appropriate referrals.

Advice from our rheumatology clinical advisors is that completion of a screening tool such as the NASS symptom checker will help identify those at increased risk of axial SpA and help aid an appropriate referrals process. Any patient scoring five or higher on the symptom checker should be referred, as there is a high likelihood of IBP which could be axial SpA. Patients who score four or less are unlikely to have IBP and should be referred to an MSK physiotherapy service to treat the symptoms. If a patient scores below five but the clinician has a high degree of suspicion for axial SpA, a request for advice and guidance from rheumatology can be made. NASS are working with a few rheumatology teams to estimate what the likely increase in referrals would be, and to validate the 5% and 19% identified by Chong Seng et al.

[9]Chong Seng Edwin Lim, Mark Tremelling, Louise Hamilton, Matthew Kim, Alexander Macgregor, Tom Turmezei, Karl Gaffney, Prevalence of undiagnosed axial spondyloarthritis in inflammatory bowel disease patients with chronic back pain: secondary care cross-sectional study, Rheumatology, Volume 62, Issue 4, April 2023, Pages 1511–1518, https://doi.org/10.1093/rheumatology/keac473

Conclusion

There are two major themes emerging from this analysis to help ensure swift recognition, identification, and referral of suspected axial SpA: education and joint working with rheumatology.

Despite there being positive detection of inflammatory symptoms and high confidence to refer, the survey highlights the need for regular educational sessions and resources on axial SpA that are accessible to all clinicians. Also, within secondary care, standardised screening tools and formal referral pathways could support clinicians in identification and onward referral.

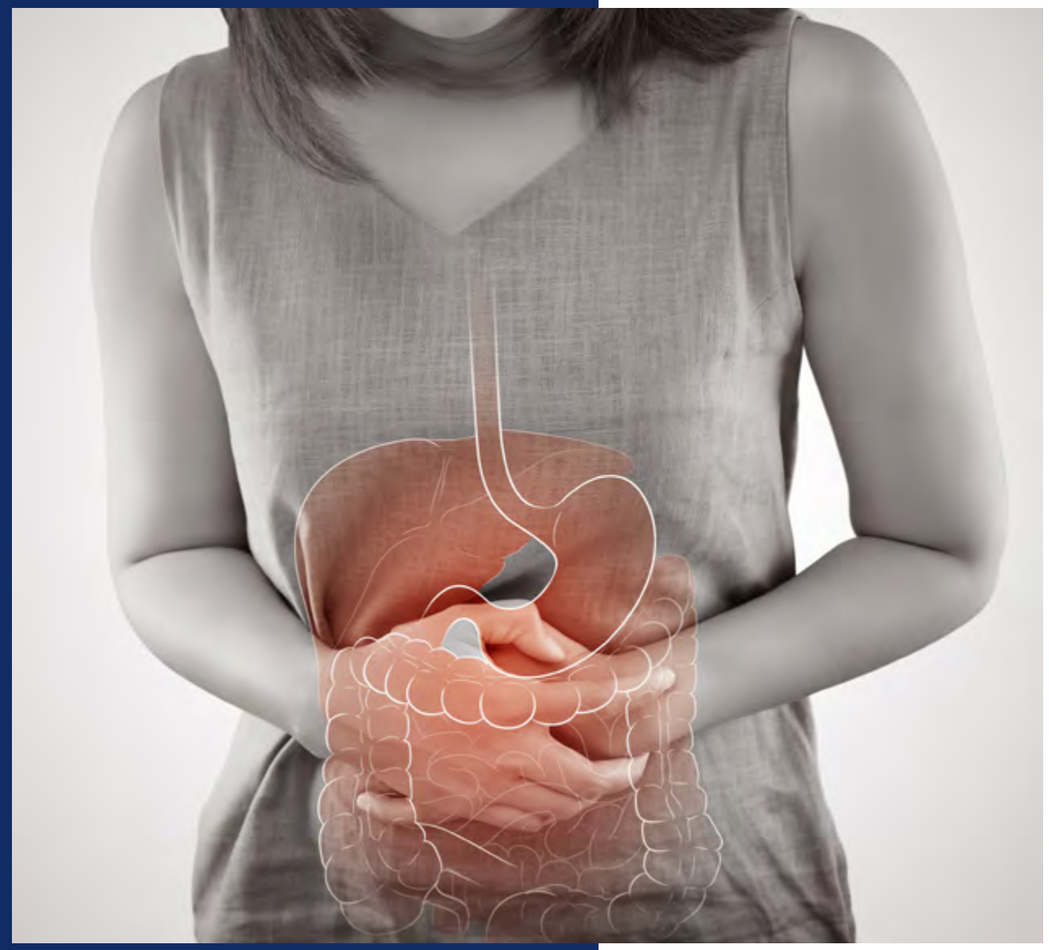
It is worth highlighting that NASS has been successful in influencing the development of a best practice axial SpA pathway to support clinicians by NHS England's GIRFT (Getting It Right First Time) and Best MSK collaborative initiatives[10]. Alongside this work, NASS utilised an FOI to explore the current ability of secondary care services including gastroenterology to make referrals to rheumatology[11]. The report recognised that all secondary care providers allow internal direct referrals but that this is reliant on clinical relationships. NASS recommended several improvements relating to internal referral pathways, standardised screening tools, tracking of internal referrals, and ongoing education and awareness of the clinical signs of axial SpA.

This survey of the barriers to education and service delivery in gastroenterology for managing IBD and axial SpA will be used in conjunction with other research in the *Act on axial SpA* campaign to drive improvements. To support the need to offer greater education, NASS will work to create tools and educational resources to support clinicians in conjunction with clinical advisors and professional bodies. The BSG IBD committee will also explore adapting the IBD curriculum to cover dedicated sessions on EIMs of IBD.

The analysis has also identified the need to offer clinicians access to best practice tools or resources they can use as appropriate, such as screening tools, successful MDT or joint clinic models, and experience of gastroenterologists and rheumatologists on how to work together effectively. We recognise the need for these measures to be on multiple solutions that are reflective of different needs of different units. It ranges from simply having a named rheumatology contact to full joint formal pathways and joint clinics.

We also know from our Gold Standard consultation that patient awareness is key to an efficient process. If a patient with IBD does not have awareness of the importance of other symptoms such as back pain, they are less likely to raise the concerns with the clinicians or push for review.

Helping patients with IBD who are experiencing back pain to recognise that it could be inflammatory, and potentially axial SpA, will improve the confidence to discuss the back pain with their gastroenterology team and trigger an assessment. Also, if patients have access to simple tools that help them check their symptoms, identify what this may mean, what they should do and where to get help and information, we are likely to see more patients comfortable with seeking the most appropriate help.



[10]Available at: https://gettingitrightfirsttime.co.uk/wp-content/uploads/2022/11/Rheumatology-Axial-Spondyloarthritis-Pathway.pdf

[11]Eddison J, Webb D, & Hamilton J; Review of direct referrals to Rheumatology for suspected axial SpA (2022) London: The National Axial Spondyloarthritis Society.

Recommendations

Gold Standard in gastroenterology ambition

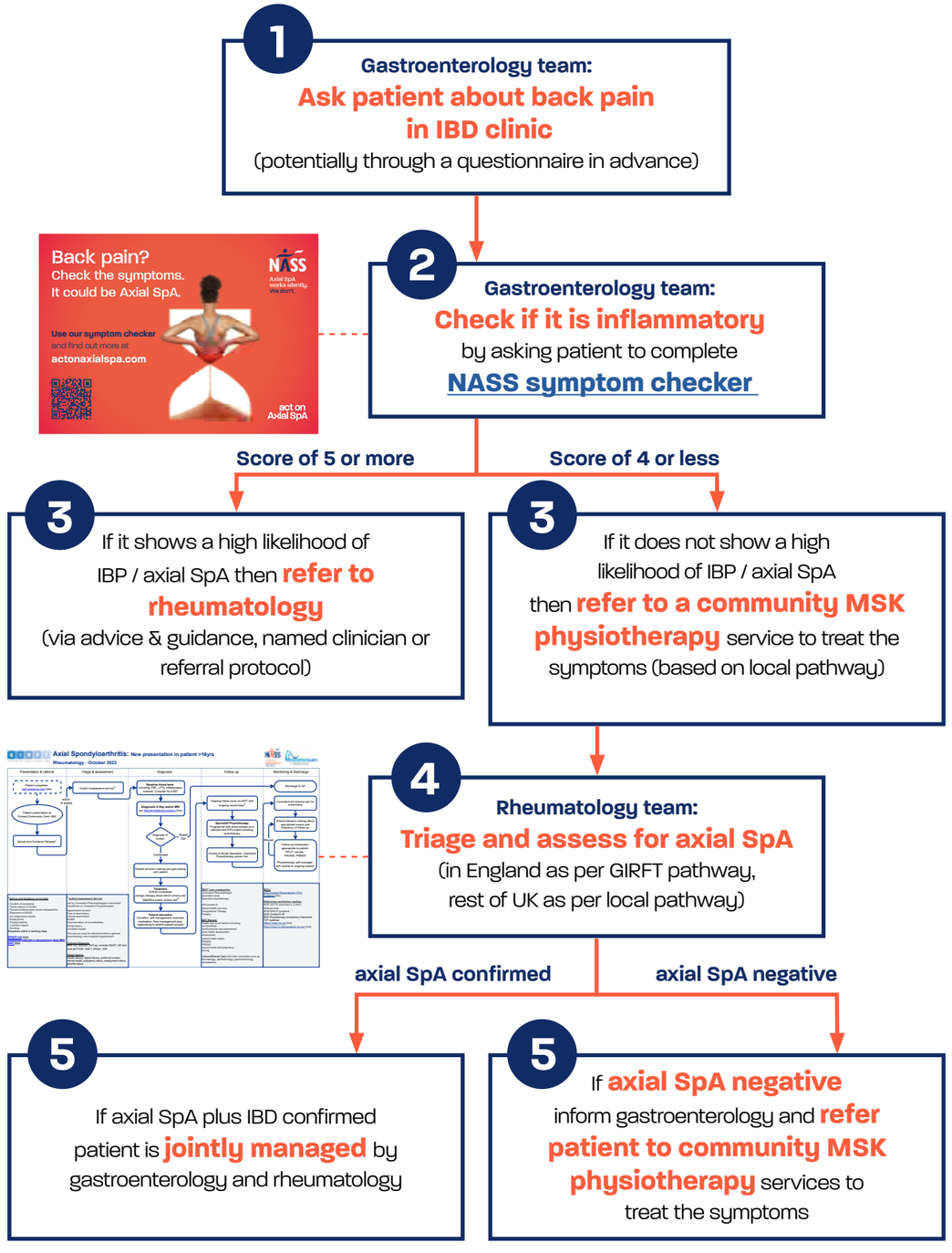
All patients with a high suspicion of IBP, as identified by the NASS symptom checker or ASAS criteria, plus IBD are directly referred to rheumatology. Patients with back pain not identified as inflammatory are ideally offered MSK physiotherapy, via a GP or primary care clinician if needed.

The NASS Gold Standard is focused on being ambitious in our drive to ensure all patients get the most optimal journey to diagnosis and treatment. In this context we feel that it should be the aim to ensure that patients with IBP plus another linked condition, such as IBD, get an immediate referral to rheumatology for assessment. As the ongoing care for IBD patients is within gastroenterology these clinicians play a crucial role in the initial assessment to differentiate mechanical back pain from inflammatory. It would not be possible to refer all patients with chronic back pain to rheumatology, so we need to support clinicians with the tools to assess and triage the back pain. NASS created a validated patient symptom checker that would be the easiest way to assess back pain for inflammatory signs and act as a regular reminder of the key signs.

In practice, not all secondary care services such as gastroenterology will have direct access to MSK physiotherapy, so for patients without inflammatory signs it may require advice back to their GP to refer to primary care physiotherapy services. In some areas patients will be able to self-refer to their local MSK physiotherapy service in the community.

We want to work towards a simple pathway as outlined across that has the symptom checker embedded and gives clinicians the confidence to refer the right patients.

Pathway



Recommendations

1

Gastroenterology and rheumatology should have an agreed two-way working practice that enables rapid communication and decision-making. As a minimum, each have named contacts in their corresponding units whom they can access for advice and guidance or directly refer patients.

Close working between rheumatology and gastroenterology increases the awareness of associated conditions and leads to a higher likelihood of swift appropriate referral. Each hospital Trust or Health Board should have mechanisms in place that allow a close working relationship. This should be via multiple solutions that can be adapted to fit the local care model and workforce model. NASS will share examples via our campaign website, **www.actonaxialspa.com**, of how this has worked across the UK for others to learn from.

By having an identified named contact in each of their corresponding units, both gastroenterology and rheumatology teams will have access to advice and guidance on patients. This will work both for IBD patients with back pain and axial SpA patients with gut issues to be jointly assessed. The named contact would then also be able to ensure the appropriate referral process based on local need is enacted. This can help not only with diagnosis of new conditions, but potential future joined up treatment.

2

Ongoing education is available for gastroenterologists and IBD nurses that raises awareness of axial SpA and inflammatory arthritis.

It is clear that more education is needed for those clinicians seeing patients with IBD so that they continue to maintain knowledge of EIMs associated with IBD, such as axial SpA. It may be beneficial for BSG to consider how to provide learning that covers the full spectrum of EIMs, of which axial SpA is part of. Some short simple educational content hosted on the NASS campaign site **www.actonaxialspa.com** and potentially through the BSG learning portal will be developed to help this. It would also be beneficial for axial SpA teams and rheumatologists to do some outreach education on the signs of axial SpA and when to refer.

3

Patients with IBD should be able to access simple tools, such as the NASS symptom checker, to help them check their back pain symptoms and identify if it could be axial SpA.

Public and patient awareness is the process of informing the public or a group of people to increase the levels of consciousness about a topic. Through raising awareness of health conditions, we can stimulate groups or individuals to seek help, information, and health services. Public awareness is a key component of our *Act on Axial SpA* campaign. We can make it easy for patients with IBD to understand the links to IBP and potentially axial SpA, by signposting from Crohn's & Colitis UK and IBD Relief information on joints to key NASS information and specifically the symptom checker. This will help them to know when to seek help for back pain, the symptoms of IBP and axial SpA, and how to discuss the issues with their healthcare team and gastroenterologists. We have seen from our symptom checker use so far that patients with a printout advising GPs on what to do leads to swifter referral into rheumatology that would otherwise not have been likely to happen.

4

Simple tools are available to gastroenterology for use in clinic that act as a prompt or reminder of the symptoms of axial SpA and when to refer.

Gastroenterology teams should be able to access simple tools such as posters or educational materials that show what they need to ask their patients, what signs to look out for, and when a referral should be made. This could be aided through the use of the symptom checker or the SPADE tool within clinic when patients identify they have back pain. To aid this, NASS is preparing to trial the use of the symptom checker on a cohort of IBD patients at two sites to assess the impact it could have.

What is NASS doing to support and drive change in this area?

As an organisation we have a key role in advocating for change and influencing those in the healthcare system to make these changes in the interest of improving patient care. We are already playing a pivotal role in this with specific focus on those recommendations above.

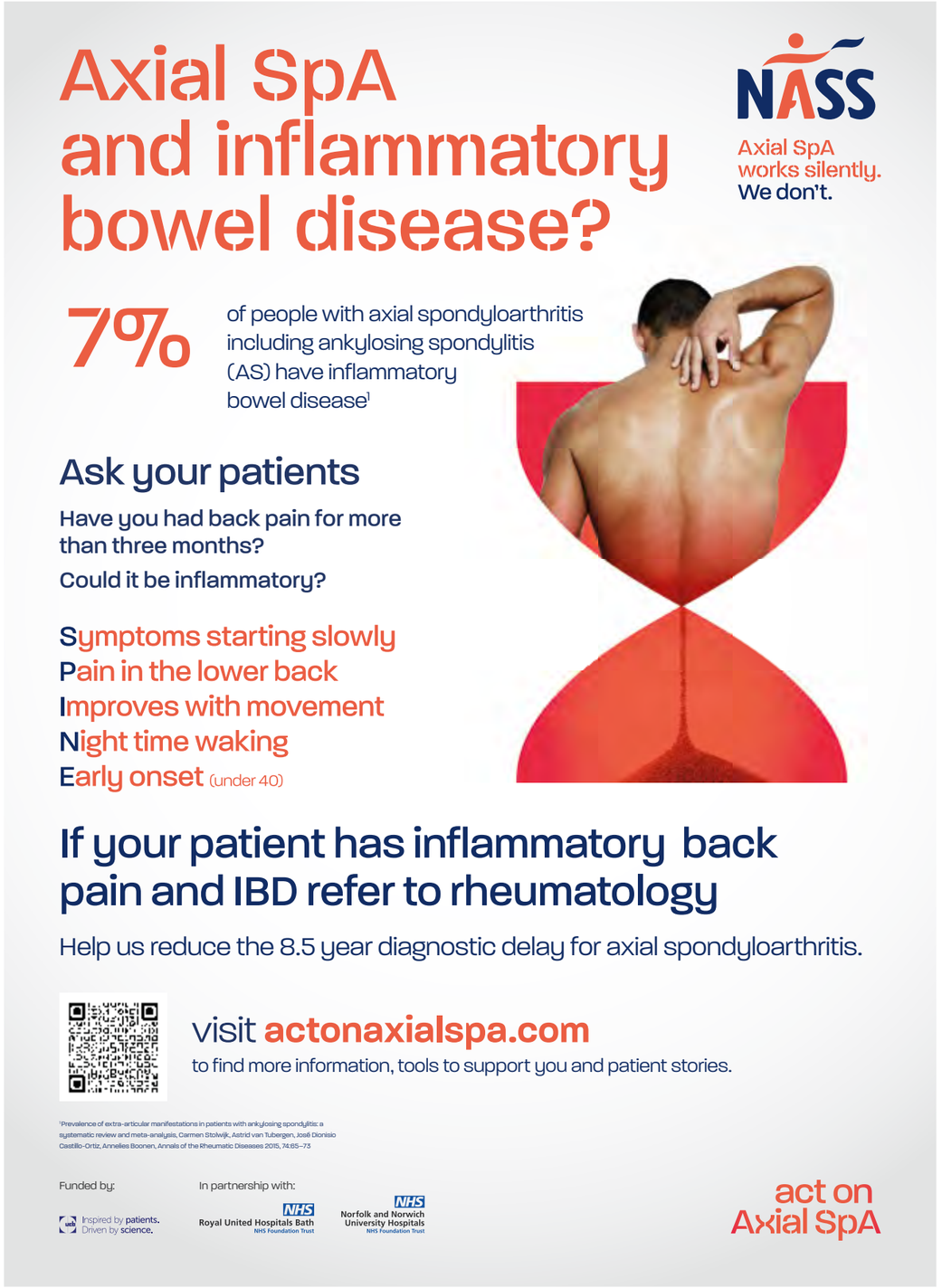
NASS is curating best practice examples from across the NHS and our *Aspiring to Excellence* programme that will support improved standardised direct referral processes. These are being shared via our campaign website **www.actonaxialspa.com** to enable HCPs to use them locally.

NASS is developing e-learning and educational materials that will be hosted on the dedicated campaign website and be available for clinicians to utilise to raise their awareness. NASS are also continuing to collaborate with the BSG to explore the merits of a continuous professional development (CPD) accredited learning package on EIMs of IBD, whilst also exploring opportunities with Health Education England for hosting e-learning on their platforms available to all clinicians in England. Similar discussions with bodies in devolved nations will be explored.

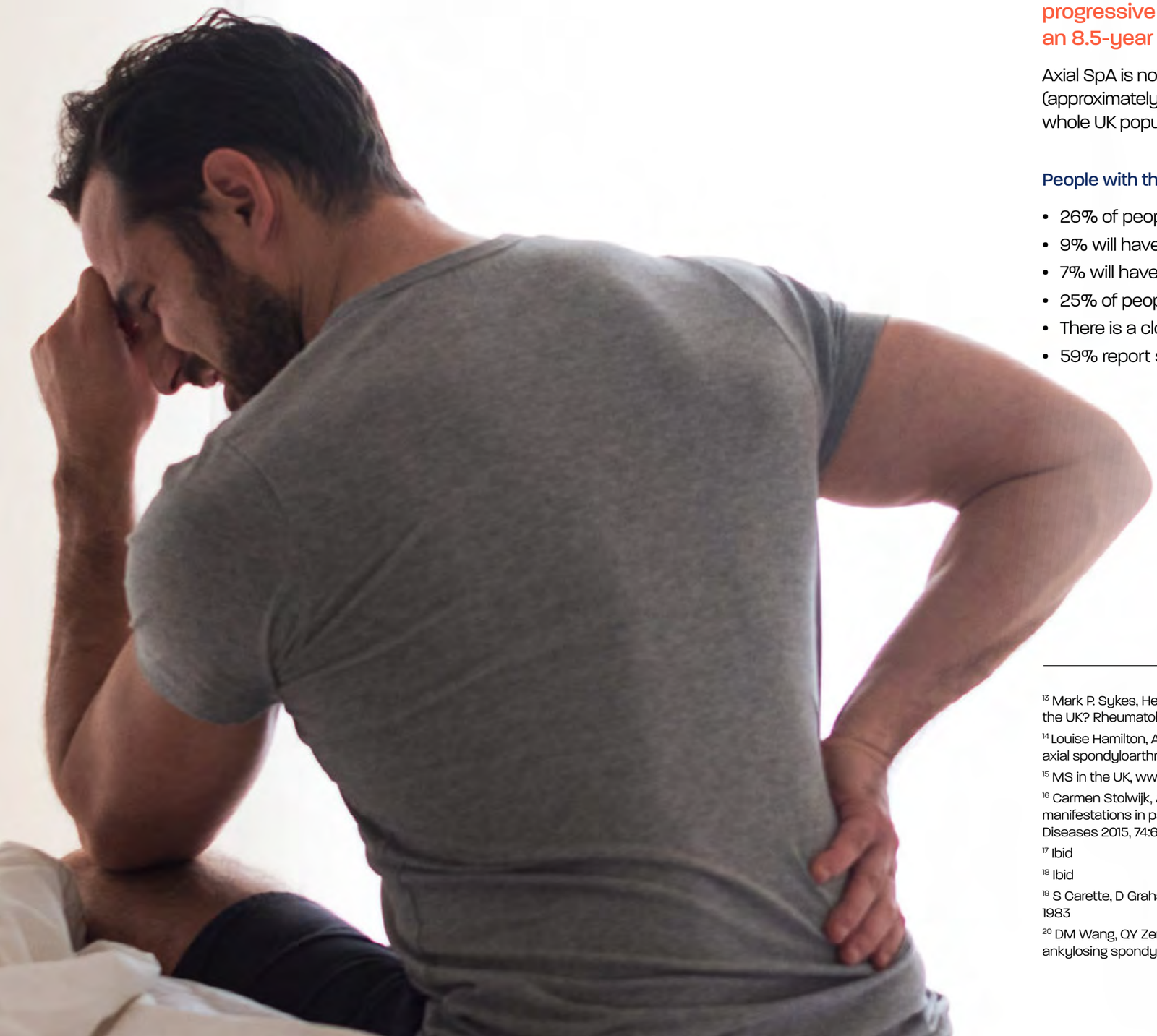
NASS has developed a simple poster for gastroenterology clinics on the signs of axial SpA in IBD patients, guidance on when to refer and how[12].

NASS will also continue to work with BSG to explore the potential for a consensus statement on when a referral should be made, such as a patient with IBD plus IBP should be referred to local rheumatology services.

NASS is exploring with Crohn's & Colitis UK and other patient bodies such as IBD Relief to raise awareness of the links to IBP and axial SpA for people living with IBD. This will also provide links to information and to the symptom checker, allowing patients to check their symptoms. NASS will also provide reciprocal links to Crohn's & Colitis UK's symptom checker for axial SpA patients with gut health issues to check if it could be IBD.



[12] Available at: https://www.actonaxialspa.com/news/poster-for-secondary-care-hcps/



Annex one – What is axial SpA?

Axial spondyloarthritis (axial SpA) is a form of inflammatory arthritis that most commonly affects the spine and sacroiliac joints. It is a painful and progressive long-term condition for which there is no cure. There is currently an 8.5-year average time to diagnosis[13].

Axial SpA is not rare and affects an estimated 1 in 200 of the adult population[14] in the UK (approximately 220,000), which is twice the prevalence of multiple sclerosis (MS) (1 in 600 of whole UK population or 107,000)[15]. The disease is characterised by painful flares and fatigue.

People with the condition can also have a range of complications and co-morbidities:

- 26% of people will have uveitis[16]
- 9% will have psoriasis[17]
- 7% will have inflammatory bowel disease[18]
- 25% of people will have irreversible spinal fusion[19]
- There is a close association with osteoporosis[20]
- 59% report suffering a mental health issue at some point.

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[14] Louise Hamilton, Alexander MacGregor, Andoni Toms, Victoria Warmington, Edward Pinch, Karl Gaffney, The prevalence of axial spondyloarthritis in the UK: a cross-sectional cohort study, Biomed Central Musculoskeletal Disorders, December 2015

[15] MS in the UK, www.mssociety.org.uk, January 2016

[16] Carmen Stolwijk, Astrid van Tubergen, José Dionisio Castillo-Ortiz, Annelies Boonen, Prevalence of extra-articular manifestations in patients with ankylosing spondylitis: a systematic review and meta-analysis,, Annals of the Rheumatic Diseases 2015, 74:65–73

[17] Ibid

[18] Ibid

[19] S Carette, D Graham, H Little, J Rubenstein, P Rosen, The natural disease course of ankylosing spondylitis, Arthritis Rehum, 1983

[20] DM Wang, QY Zeng, SB Chen, Y Gong, ZD Hou, ZY Xiao, Prevalence and risk factors of osteoporosis in patients with ankylosing spondylitis: a 5-year follow up study of 504 cases, Clinical and Experimental Rheumatology, July 2015

Annex two – Glossary of terms

Act on Axial SpA - NASS campaign to reduce the current 8.5-year average time to diagnosis in axial SpA to a Gold Standard time of one.

All Party Parliamentary Group - informal, cross-party groups formed by MPs and Members of the House of Lords who share a common interest in a particular policy area, region, or country.

Ankylosing spondylitis (AS) - ankylosing spondylitis is a form of axial SpA where changes to the sacroiliac joints or the spine can be seen on x-ray.

Aspiring to Excellence - *Aspiring to Excellence* is a strategic partnership between NASS, British Society for Spondyloarthritis, and NHS Transformation Unit, along with sponsoring companies AbbVie, Biogen, Lilly, Novartis, and UCB. It is an award programme designed to encourage and recognise service improvement in axial SpA care.

Axial spondyloarthritis (axial SpA) - axial SpA is a spectrum of disease whereby a person can have changes on an MRI but not x-ray (non-radiographic axial spondyloarthritis (nr-axial SpA)) to spinal fusion (ankylosing spondylitis (AS)).

Best MSK Health Collaborative - a new programme with the aim of sustaining the delivery of evidence-informed, personalised, high-quality integrated health care of value to all with an MSK condition.

British Society for Spondyloarthritis (BRITSpA) - a group of professionals working in the UK with a commitment to advancing knowledge and treatment of spondyloarthritis.

British Society of Gastroenterology (BSG) - a professional body focused on the promotion of gastroenterology and hepatology. It has over three and a half thousand members drawn from the ranks of physicians, surgeons, pathologists, radiologists, scientists, nurses, dietitians, and others interested in the conditions.

Community Care - community health services cover a wide range of services and provide care for people from birth to the end of their life. Services are mainly delivered in people's homes (this includes care homes) but also in community hospitals, intermediate care facilities, clinics, and schools.

Continuous Professional Development (CPD) - broadly defined as any type of learning you undertake which increases your knowledge, understanding and experiences of a subject area or role.

Crohn's & Colitis UK - the UK's leading charity for Crohn's and Colitis: lifelong conditions affecting over 500,000 people in the UK. The charity provides information and support for people affected by the conditions, funds research, campaigns for change, and works with healthcare professionals to improve diagnosis, treatment, and management of the conditions.

E-learning - learning that is conducted through electronic means.

Extraintestinal manifestations (EIM) - inflammatory bowel disease (IBD) can cause a variety of symptoms, both in the gut and out of the gut. When the disease affects other parts of the body, this is known as an EIM or complication. Between 25-40% of IBD patients experience EIMs, commonly in the joints, skin, bones, eyes, kidneys, and liver.

Extra-musculoskeletal manifestations (EMM) - co-existing conditions or presentations related to axial SpA.

Freedom of Information (FOI) - the Freedom of Information Act 2000 provides public access to information held by public authorities.

Gastroenterology - discipline which diagnoses, treats, and works to prevent gastrointestinal (stomach and intestines) and hepatological (liver, gallbladder, biliary tree, and pancreas) diseases.

Getting It Right First Time (GIRFT) - national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change.

Healthcare professionals (HCPs) - a health professional, healthcare professional, or healthcare worker is a provider of health care treatment and advice based on formal training and experience.

IBD Relief - a charity with the mission to improve the lives of people around the world affected by inflammatory bowel diseases like Crohn's disease and colitis.

Inflammatory back pain (IBP) - condition of pain localised to the axial spine and sacroiliac joints that is chronic and is differentiated from mechanical back pain by a key set of diagnostic features.

Inflammatory bowel disease (IBD) - a term mainly used to describe two long-term conditions that involve inflammation of the gut: ulcerative colitis and Crohn's disease.

National Axial Spondyloarthritis Society (NASS) - the only charity in the UK solely focused on supporting people with axial spondyloarthritis including ankylosing spondylitis. Formerly known as the National Ankylosing Spondylitis Society.

NHS Trust - provides goods and services for the purposes of the health service. This, for the purpose of this report, includes the terms of Health Board, Health & Social Care Trust, and all secondary care providers across the UK.

MDT - multidisciplinary team.

Primary Care - the day-to-day healthcare given by a health care provider. Typically, this provider acts as the first contact and principal point of continuing care for patients within a healthcare system and coordinates other specialist care that the patient may need.

Rheumatology - discipline specialising in immune-mediated disorders of the musculoskeletal system, soft tissues, autoimmune diseases, vasculitides, and inherited connective tissue disorders.

Secondary Care - medical care that is provided by a specialist or facility upon referral by a primary care physician and that requires more specialised knowledge, skill, or equipment than the primary care clinician can provide.

NASS

Axial SpA
works silently.
We don't.

National Axial Spondyloarthritis Society

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NASS is a registered charity in England and Wales (1183175) and Scotland (SC049746)