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Axial Spondyloarthritis: Overcoming the Barriers to Early Diagnosis—an Early Inflammatory Back Pain Service

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Abstract

Purpose of Review To discuss the challenges to early diagnosis of axial spondyloarthritis (axSpA) and present the impact an early inflammatory back pain service (EIBPS) had on diagnostic delay in the UK.

Recent Findings Diagnostic delay in axSpA varies greatly worldwide, and has continued in the UK at an average of 8.5 years. Education, public awareness, and accessibility to inflammatory back pain (IBP) pathways are some of the key barriers to achieving a prompt diagnosis. A recent national inquiry has highlighted insufficiencies in the availability of specialist axSpA services and limited provision of education and training to first contact practitioners and allied healthcare providers.

Summary We demonstrate diagnostic delay in axSpA can be successfully reduced to 3 years when an early inflammatory back pain service is embedded within a rheumatology department alongside a local educational and awareness campaign. Sharing these experiences and outcomes will enable other departments to engage in best practice and achieve similar results, facilitating a timely and accurate diagnosis.

Keywords Axial spondyloarthritis · Diagnostic delay · Education · Inflammatory back pain · Barriers

Introduction

Axial spondyloarthritis (axSpA) is an inflammatory condition causing chronic back pain with a prevalence that varies greatly across the world ranging between 0.2 to 1.6% [1], and an average symptom onset between the ages of 24 to 27 years [2]. A recent systematic review outlined the burden of delayed diagnosis, with higher disease activity, worse physical function, and more progressive structural damage [3]. Additionally, diagnostic delays are associated with worsening quality of life, depression, work disability, and higher healthcare costs [3]. Delay in diagnosis remains a fundamental challenge with many patients being incorrectly diagnosed with mechanical back pain and therefore enduring lengthy delays in diagnosis, treatment, and support. With newer highly effective therapies, it is crucial to establish a model of early and accurate diagnosis. In the UK, the time between symptom onset and diagnosis has shown no signs of improving over the past decade, with an unacceptable average of 8.5 years [4]. The median is suggested to be a more informative way of recording diagnostic delay due to the non-normality of data typically collected [4]. The last recording in the UK demonstrated a median of 5 years remained unchanged between 1999 and 2013 [4]. A systematic review recently published demonstrates great variability internationally, reporting median durations between < 1 and 8 years [5]. 48.7% of patients in the UK are recorded to have been diagnosed beyond 6 years of symptom onset [4].

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Barriers

Understanding why these lengthy delays exist is vital to overcoming the barriers and enabling health systems to provide the high standard of care axSpA patients deserve.

Education

Despite the high prevalence rate in specialist clinics, awareness of axSpA among non-rheumatologists remains low [6, 7]. Commonly, patients are misdiagnosed with mechanical back

pain which is significantly associated with delayed diagnosis [5]. With an average 75% of axSpA patients experiencing IBP as their first symptom [8], education and awareness of these features remains central to shorten the delayed diagnosis. In 2019, a national inquiry in the UK revealed only 15% of clinical commissioning groups (CCGs) were found to have specific programs in place to raise awareness of axSpA, highlighting the need for public health initiatives to address this [9]. Targeted education of primary care doctors has been shown to markedly improve the recognition and referral of patients with suspected axSpA to specialist rheumatologists [10]. Reductions in diagnostic delays have also been reported when first contact practitioner education is incorporated within an early inflammatory back pain service [11]. It is acknowledged that randomized controlled trials are needed to evaluate the effectiveness of educational interventions and their direct impact on diagnostic delay [12].

Pathways

Recent analysis in 2019 into the provision of services for axSpA in the UK highlights the main concerns. Only 21% of CCGs had a specified inflammatory back pain (IBP) pathway in place to refer suspected axSpA patients [9]. IBP pathways, providing access to the "right specialist at the right time," promote timely and appropriate access to care [9]. This has also received support from the patients' perspective. The experience of obstacles from symptom onset to referral throughout their endeavors to reach a diagnosis is common preventing timely diagnosis [13]. The aim to establish specialist axSpA clinics with written pathways between referrers and specialists should be the goal. Local implementation and application of referral strategies allows for prompt screening of suspected axSpA, limiting a lengthy diagnostic experience for the patient.

In recent years, extended practitioner roles have been established in rheumatology. In the field of axSpA, physiotherapists with specialized training in inflammatory arthritis are seen working alongside rheumatologists, providing MSK expertise in the assessment of patients with inflammatory back pain and an important role in supporting patients with long-term health conditions. Additionally, a recent study demonstrated clinical impressions of extended role practitioners were comparative with rheumatologists in the assessment of axSpA [14]. Models of care that include extended role practitioners may be valuable in providing holistic care to axSpA patients.

Many referral strategies have been published in attempts to provide the most suitable screening tool for patients with suspected axSpA to a specialist. In 2017, Abawi and colleagues compared 13 referral models with 261 patients referred to a rheumatologist and concluded that despite most performing well, all had their disadvantages [15]. Assessment of Spondyloarthritis International Society (ASAS) referral criteria was found to be the most sensitive, performing the best if the goal was that no patient should be missed. However, knowledge of the wide range of SpA features is necessary when being able to determine the presence or absence of them which may provide problematic with non-specialist clinicians [15]. Furthermore, choosing a very sensitive, yet low specificity strategy, IBP services may need to see many patients in order to diagnose one [15] and many patients will need to undergo unnecessary diagnostic investigations. Recent National Institute for Clinical Excellence (NICE) guidance for axSpA has been published outlining referral criteria first contact practitioners should be adhering to when assessing a patient with back pain [12]. This referral criteria was not included in Abawi and colleagues article when comparing the performance of referral strategies; however, it does provide an evidence-based selection from published literature on the performance of individual and combinations of factors associated with axSpA [16, 17]. A two-step referral strategy, similar to the screening guidance proposed by NICE, was recently evaluated, prospectively screening patients < 45 years of age with chronic back pain with SpA features in primary care and providing an option to request HLA B27 status before onward referral to the rheumatologist [18]. The strategy had a sensitivity of 87% and specificity of 56.8%. Combining specific SpA features, "early morning stiffness > 30min," "positive response to NSAIDs," and an "elevated C-reactive protein" in screening performed the best with 91% sensitivity and 67% specificity providing an alternative model for use in primary care. Combining education of first contact practitioners with these sensitive parameters should provide a successful strategy.

Diagnostic pathways should also include procedures that ensure the accurate interpretation of imaging findings, fundamental to driving the diagnosis times down. It is widely known heterogeneity exists surrounding MRI protocols and image interpretation in the UK, contributing to inconsistent diagnosis [19]. Guidance on diagnostic MRI protocols now exists to support clinicians incorporate these recommendations into their pathways [20].

Awareness

Over recent years, there has been promising work campaigning to raise awareness of axSpA among the public and primary/secondary care. UK national guidance for spondyloarthritis has been published [12] along with quality standards [21] in encouraging steps to set out criteria we should be working towards to provide high quality of care to people with suspected or confirmed axSpA. More recently, five recommendations to drive improvements in National Health Service (NHS) care for axSpA have been published by a newly formed All-Parliamentary Party Group (APPG) [9]. The APPG provides a platform to raise awareness of axSpA and encourage facilitation of high-quality care standards at a national level. Awareness campaigns at a national level can provide the necessary exposure to lesser known conditions. The formation of local groups linking

together with the common theme to deliver a national message of awareness can provide the essential networks required to raise the profile of axSpA among the public, healthcare professionals, and policy makers.

The continued support and drive of public awareness campaigns in axSpA is essential and undoubtedly the most efficient and effective means to deliver information to the public. To date, limited published data exists demonstrating the impact of awareness interventions on referrals to rheumatology services and diagnosis rates. A successful national public awareness campaign was demonstrated in New Zealand, running over 3 months, resulting in a significant increase in the number of patients with suspected axSpA referred to rheumatology and an increase in the number of patients diagnosed [22]. Limited real-world data is published to demonstrate the effect of combining an axSpA awareness program with a specialist IBP service on diagnosis delay. Adshead and colleagues revealed a significant reduction between symptom onset and diagnosis to a median of 3.1 years, over a 3-year period [11]. Similar improvements were demonstrated in Canada with the implementation of primary and secondary care screening for patients presenting with back pain [23]. Longer studies are required to assess the prolonged effect of these services and campaigns.

Our objective was to assess the combined effectiveness of an educational campaign, raising awareness of axSpA to primary and secondary care colleagues, allied health practitioners (AHP's), and the public whilst providing a specialist IBP service in rheumatology. The service was set up to establish whether diagnosis delay and initiation of biologic therapy could be shortened over a sustained period of time.

Reducing the Delay—Early Inflammatory Back Pain Service

The following real-world experience demonstrates the practical implementation of NICE's quality standards and how this can translate to reducing the diagnosis delay in axSpA.

In 2010, local primary care colleagues and musculoskeletal community services were contacted and asked to refer patients with suspected inflammatory back pain to an early inflammatory back pain service for triage and screening. A referral proforma pack with posters outlining the features of IBP and guidance on locating the service via their online referral system was included.

Awareness Campaign

Concomitantly, primary care practitioners within the local area were routinely invited to attend frequently hosted educational meetings detailing the differences between mechanical and inflammatory back pain, in addition to the associated features of axSpA. Meetings were extended geographically to cover larger areas of London. Local physiotherapists were invited to attend interactive half-day courses on the "Essentials of Rheumatology for Physiotherapists." This was run by specialist axSpA physiotherapists and rheumatologists. In-house training was provided for allied health practitioners (AHPs), hospital doctors, and consultants of other specialties.

A community "Back on Track" campaign supported by the National Association of Axial Spondyloarthritis (NASS) to raise public awareness of the features of IBP was set up in local gyms and hospitals. Back on Track provided sufferers of back pain the opportunity to discuss their symptoms with axSpA rheumatologists and a physiotherapist offering advice.

Pathway

A screening pathway was developed and endorsed by NASS as outlined in Fig. 1. Suspected IBP patients were referred into the EIBPS. Referrals are initially triaged by rheumatologists for their suitability for the service. The first appointment consists of a thorough screening of back pain and the presence or absence of extra-articular features, by a specialist physiotherapist in axial spondyloarthritis or specialist rheumatologist.

Diagnostic screening encompasses X-rays of the sacroiliac joints, whole spinal including coronal/oblique sacroiliac joints (STIR), and laboratory tests including HLA-B27.

Radiographic axial spondyloarthritis is diagnosed in patients with bilateral grades 2–4 or unilateral grade 3 sacroiliitis based on modified New York criteria [24]. If plain film X-ray does not show sacroiliitis, ASAS classification criteria for non-radiographic axSpA (clinical or imaging arm) alongside clinical judgment were used to assist a diagnosis of non-radiographic axSpA. Patients' imaging is reviewed within a radiology multidisciplinary meeting with consultant radiologists and rheumatologists present to discuss imaging findings and clinical features and discuss diagnosis. Where patients are found to be HLA B27 positive with IBP and no other features, repeat imaging 6–12 months later is provided and the patient followed up. All new patients receive advice and exercise guidance from the specialist physiotherapist. Those patients requiring further support are referred for a course of physiotherapy.

Diagnosis

Support

Patients are followed up by the specialist axSpA physiotherapist to discuss investigations and diagnosis. All

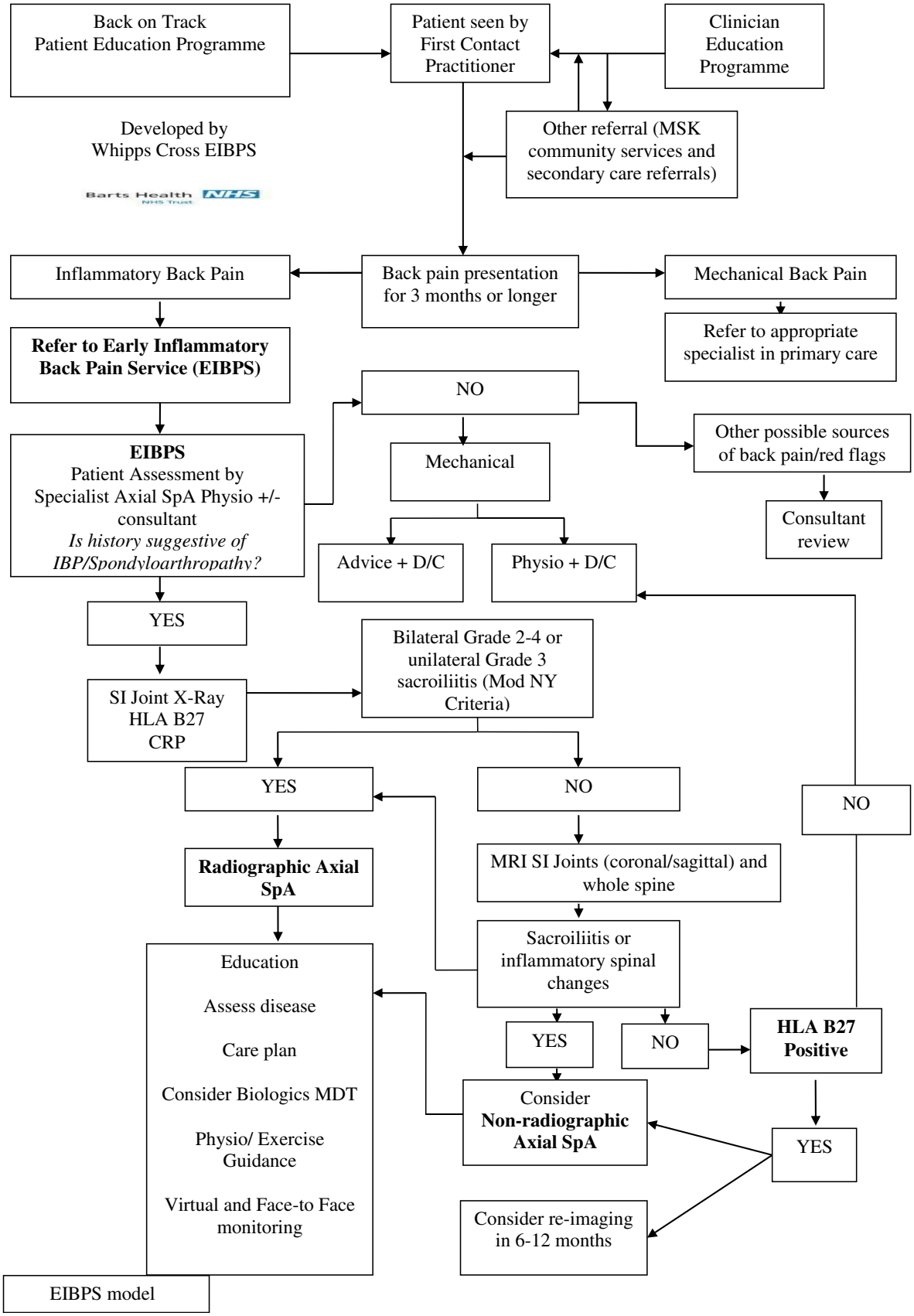

Fig. 1 EIBPS model

patients with a new diagnosis of axSpA are provided with face to face education about their condition within the consultation in addition to discussing their management care plan with the specialist axSpA consultant. Patients are invited to attend an educational afternoon with the opportunity to learn about management strategies and meet other patients. Exercise tips and guidance are provided in addition to details about joining their local NASS group which provides weekly exercise classes and hydrotherapy as well as contact information for the department. Helpful strategies are discussed with a clinical psychologist to facilitate patients managing long-term conditions. Patients are asked to register with MySpA, an educational app available to download worldwide, designed for patients to access information about axSpA, exercise examples, and assessments to remotely support them in between appointments. Availability of a hot clinic for AS flares is highlighted.

Monitoring

Following on from diagnosis, a care plan is discussed with the patient in clinic. Patients who fulfill NICE criteria for biologic therapy are discussed within an MDT for suitability and safety for treatment, supported by rheumatology consultants, specialist axSpA physiotherapist, rheumatology, and research nurse specialists and a pharmacist. Patients are assessed jointly by a rheumatologist and specialist axSpA physiotherapist annually within the specialist clinic, providing a joint approach to management. In addition, patients on either immunosuppressant treatment, flaring, or with underlying comorbidities are offered the option of further follow-up with the specialist physiotherapist at a later date via video consultation or face to face. Patients are encouraged to use MySpA in between appointments to record their disease activity (BASDAI), in addition to other functional and quality of life measures, within the assessment section of MySpA, sharing their completed assessments with their rheumatology team. For those patients requiring a shared care approach across other specialities, joint clinics with dermatology, respiratory and gastroenterology were provided. Blood test monitoring can be undertaken within community phlebotomy departments. Patients flaring can contact the department via email or telephone and have access to flare-up appointment slots and are seen promptly by a specialist clinician.

Service Outcomes

Between 2010 and 2018, 599 patients received an initial assessment within the early inflammatory back pain service (EIBPS). The mean age was 39.6 years, with 52% (312) female (Tables 1 and 2).

Table 1 Referred patients diagnosis

	Patients
Patients seen in EIBPS	599
Inflammatory back pain/axSpA suspected	413
AxSpA diagnosis (total)	238
Pre-existing axSpA diagnosis	59
New non-radiographic axSpA diagnosis	51
New radiographic axSpA diagnosis	128

Cost Analysis

The added cost of the service to the rheumatology department was a funded, 0.5 part-time senior physiotherapist who was trained in SpA by attending consultant–led axSpA clinics and mentored whilst establishing the EIBPS and axSpA pathway. Patients with axSpA were gradually transferred from general rheumatology clinics to the specialist axSpA clinics and new patients were assessed within clinic following triage of referral by the rheumatologist.

Conclusions

Diagnostic delays in axSpA exist worldwide, and thus far the UK has proven no exception [4]. Patients are suffering a number of years before diagnosis and support is provided and far too many are consulting multiple medical and HCP opinions before receiving an accurate diagnosis [13, 25]. The physical, psychological, and social impact this has on the individual as well as their families during formative years can be devastating and permanent.

Following a recent survey evaluating axSpA services in the UK followed up by an inquiry led by UK Government and the National Axial Spondyloarthritis Society (NASS), it is clear that patients with axSpA are being provided differing levels of care and expertise dependent upon their geographical location [9, 26]. A framework for service providers and commissioners in the UK has recently been published to support clinicians in addressing key areas leading to lengthy diagnostic delays [12, 21]. Delays in diagnosis in axSpA are best overcome with a

Table 2 Diagnostic delay and treatment commencement durations

	Duration (median)
Onset of back pain to axSpA diagnosis (diagnosis delay) ($n = 179$)	3 years (0.3–30 years)
Diagnosis delay in patients with symptom onset age < 40 years ($n = 162$)	3 years (0.3–30 years)
Initiation of biologic therapy from initial EIBPS appointment*	5.6 months (mean)

*Patients suitable of biologic therapy and fulfilling NICE criteria

holistic approach. As such, services addressing education and awareness of axSpA in the local community and healthcare sectors alongside the development of a care pathway are essential.

This review article provides a real-world example of how to address and overcome the challenges to diagnosis with promising results. The overall service yield for diagnosing axSpA with the referral pathway and combined local education and awareness campaign is high, with almost 1 in every 3rd person referred into the service newly diagnosed with axSpA. The algorithm and referral strategy developed by Rudwaleit and colleagues [27] in 2004 to help early diagnosis of axSpA provided the first steps in the development of referral models based on probabilities of clinical features. Their groundwork has led to several other models proposed to tackle the primary aim of reducing delays in diagnosis. It can be challenging when deciding between multiple referral strategies that exist, and each needs to be considered in the context of daily clinical practice and service availability. It is essential to implement referral strategies that can identify as many patients with axSpA as possible, as early as possible in primary care to avoid delays in diagnosis. Ease of use and time efficiency with a limited number of referral parameters are all vital factors that should be considered before implementing strategies [15, 28]. Using imaging within primary care would be costly and places responsibility in non-specialist hands of interpreting results which, as discussed, can still be challenging in secondary care among specialist clinicians [19]. UK guidance now exists providing direction on referral criteria which suggests clinicians should refer patients if they have low back pain starting < 45 years of age for longer than 3 months with a combination of 4 or more IBP symptoms/SpA features; additionally, they recommend that HLA B27 is performed if only 3 features are present [12]. The authors acknowledge the limitations of using IBP criteria alone within the referral pathway to EIBPS. IBP is the principle symptom of axSpA [8]; however, since 20–30% of patients do not experience this symptom, a proportion may be missed. Additionally, it has been suggested that using a non-specific referral criteria can create a possible overload in outpatient clinics [15]. In the twice weekly EIBPS clinics, over two thirds of patients referred warranted further investigation following initial assessment. It was felt the referral strategy chosen performed well for the catchment area and alongside training provided.

Many years have passed since the development of the first axSpA referral strategy [27] and despite updates in classification criteria to include early non-radiographic disease and advances in imaging, many countries including the UK have still not improved their average delay in diagnosis times. A contributing factor may be the limited application and uptake of these referral strategies into individual rheumatology pathways resulting in the continuous circulation of patients within primary care. With several referral strategies published demonstrating similar sensitivity and specificity values, clinicians should decide based on their individual service provisions, healthcare structure, and prevalence of referral parameters such as HLA B27 which strategy they should implement. Formulating good connections with first contact practitioners is essential to promote and reinforce new pathways.

Using the ideal referral strategy, however, is only a piece of the puzzle, with education featuring prominently in the goal to shorten diagnostic delay. Training first contact practitioners and allied healthcare practitioners to differentiate between mechanical and inflammatory symptoms of back pain is essential and unfortunately a key area shown to be lacking in many local commissioning groups in the UK [9]. It is time-consuming for individual rheumatology departments to undertake the challenging task of FCP and AHP training. Furthermore, ensuring this training in ongoing as new doctors and clinicians qualify would be required. Therefore, opportunities to provide axSpA education within protected Continued Professional Development (CPD) training sessions and utilizing e-learning training modules would assist in the dissemination of information to larger groups of clinicians. Encouraging the application of supplementary questionnaires or online screening tools to assist with identifying IBP in primary care may also prove useful when teaching clinicians to differentiate between IBP and MBP.

The early inflammatory back pain service demonstrated a low median delay in diagnosis of 3 years over 8 years of data collection. This real-world data is the shortest recorded in the UK, including many other countries, over such a prolonged period of time. It is presumed the combined approach of continued education and public awareness facilitated the effectiveness of the service in reducing the time to diagnosis and is therefore a recommended model for specialist teams. Early diagnosis is crucial in the goal to optimal management of axSpA. An average of 5.6 months from the patient's first attendance in the EIBPS to the start of a biologic for those patients meeting the requirements to commence on treatment is relatively short. The timely commencement of biologics is essential for the optimum treatment response and prevention of spinal damage [29].

The pursuit to reduce patient suffering and long-term disability associated with axial spondyloarthritis can only be achieved if we raise awareness in the community and educate our first contact practitioners, secondary care colleagues, and healthcare practitioners and provide an accessible IBP pathway to specialist axSpA services. This can be realized by sharing successful experiences such as the EIBPS and facilitating rheumatology departments to consider restructuring or achieve commissioning to replicate services such as this, thereby reliably reducing average time a patient has to wait

for an accurate diagnosis, in every single location in the UK and ideally globally. It's time for a new standard.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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