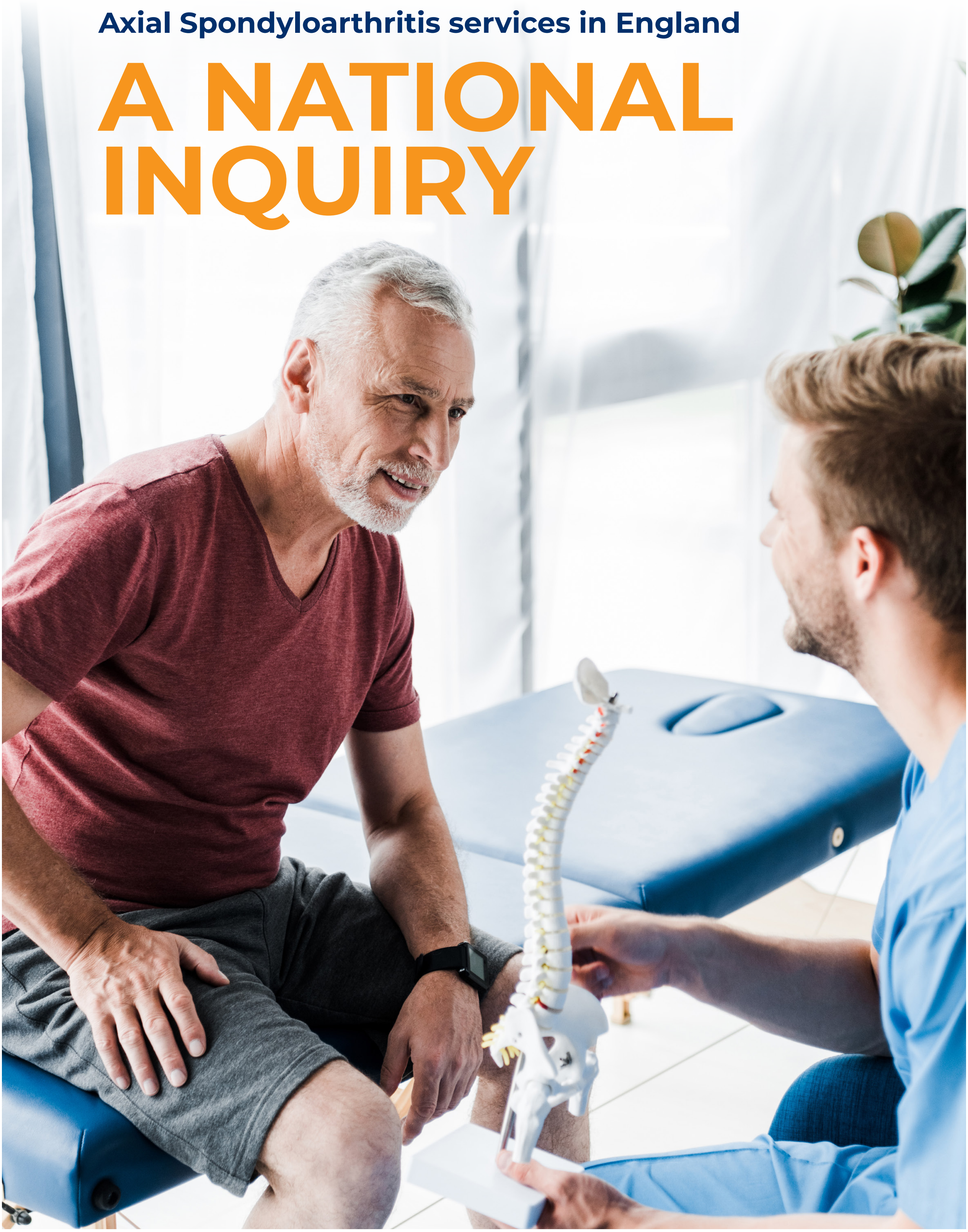
appg All-Party Parliamentary Group for
Axial Spondyloarthritis
Reducing the delay to diagnosis and improving services in axial SpA

NASS
FOR EVERYONE AFFECTED BY AXIAL SPONDYLOARTHRITIS

Axial Spondyloarthritis services in England

A NATIONAL INQUIRY



About NASS

For over 40 years we've been providing specialist support, advice and the most up-to-date information to empower everyone with axial SpA (AS) to manage their treatment and to stay in control of their lives.

We are driven to ensure that health professionals around the country deliver tailored and timely care to every patient, every time. If we are to reduce the current 8.5 year average delay to diagnosis in axial SpA (AS) and improve outcomes for people living with the condition, we must continue to work together as a community of patients, health professionals and parliamentarians. This is why NASS is proud to have worked with MPs and Peers to set up the first ever All-Party Parliamentary Group for Axial Spondyloarthritis, and to drive improvements in care with our Aspiring to Excellence programme, as well as continue with the ever important world-leading information and support that we have always provided.

Together, we will make a difference.

Dr Dale Webb, CEO

Contents

APPG Officers

Derek Thomas MP *(Chair)*

Lord Campbell-Savours *(Co-Chair)*

Dr Rupa Huq MP *(Vice Chair)*

Kerry McCarthy MP

Andy Slaughter MP

Ed Vaizey was an Officer during the time of this inquiry prior to the 2019 General Election.

Derek Thomas MP

Derek Thomas is the Conservative Member of Parliament for St Ives and a passionate advocate of achieving improved health outcomes in a range of disease areas. Since election to Parliament in 2015, Derek has spent a considerable portion of his time working to reduce barriers to early diagnosis and help support improved social mobility amongst those particularly at-risk of experiencing poorer standards of care. Derek is a member of the Work and Pensions Committee and the Environmental Audit Committee, as well as Chairing APPGs on Brain Tumours and Vascular & Venous Disease.

Lord Campbell-Savours

Lord Campbell-Savours is a Labour Peer, former Member of Parliament for Workington and a leading champion for Axial Spondyloarthritis. He spent 22 years as a Member of Parliament and was diagnosed with ankylosing spondylitis whilst on the party frontbenches, continuing to work with the condition and commute between the constituency and Westminster for a number of years. Since becoming a Peer, Lord Campbell-Savours has used his position to spearhead the creation of the first-ever APPG on Axial Spondyloarthritis and has also served on a number of Lords Committees, including the Liaison Committee, the House Committee and the Services Committee.

Acknowledgements

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This report was compiled by the National Axial Spondyloarthritis Society, which support the Secretariat to the All-Party Parliamentary Group on Axial Spondyloarthritis. M&F Health provides the Secretariat to the Group.

Throughout this report we will refer to axial spondyloarthritis (axial SpA) including ankylosing spondylitis (AS) to cover the full spectrum of disease (see Glossary of terms for full details).

Executive Summary

Key Findings

Only **21%** of Clinical Commissioning Groups (CCGs) have a specific inflammatory back pain pathway in place

15% of CCGs have specific programmes in place for educating Primary Care practitioners about axial SpA (AS)

17% of services do not routinely offer full spinal MRI

94% of services offer written information to newly diagnosed patients

37% of services organise face to face appointments for patients who are considering biologic treatment

One fifth of services do not have access to a specialist rheumatology physiotherapist

12% of services offered a personalised flare care plan

Less than half of the respondents offered a specialist axial SpA (AS) clinic

One quarter offer direct access to psychological services via secondary care to those who require it

Recommendations

RECOMMENDATION ONE:

All CCGs should have a clear and simple inflammatory back pain pathway to ensure swift referral directly to rheumatology following the NICE Guideline for Spondyloarthritis.

RECOMMENDATION TWO:

Continuous Professional Development (CPD) education about axial SpA should be available via CCG intranets as a minimum. Ideally, rheumatology departments should be running annual educational sessions with Primary Care Networks.

RECOMMENDATION THREE:

The importance of rheumatology physiotherapy including hydrotherapy should be promoted within NHS trusts, with all trusts providing access to a specialist rheumatology physiotherapist.

RECOMMENDATION FOUR:

All newly diagnosed patients should receive an individualised, structured exercise programme and, as a minimum, an annual appointment for key measurements to be taken.

RECOMMENDATION FIVE:

Providers should encourage multi-disciplinary working, including patients in any service development ensuring that secondary care clinicians are able to access direct referrals to mental health services

Joint foreword from the APPG's Chair, Derek Thomas MP, and Co-Chair, Lord Campbell-Savours

Derek Thomas MP

Lord Campbell-Savours

We are delighted to present this inaugural report from the All-Party Parliamentary Group on Axial Spondyloarthritis, which, for the first time, explores the commissioning and availability of axial SpA (AS) care in England. The findings from the report are significant, not least because they shine a spotlight on an area that has unfortunately been overlooked and under-prioritised for many years.

It is thought that 1 in 200 adults have axial SpA (AS), which equates to over 200,000 people living with the condition in the United Kingdom. That is more than the number of people with Parkinson's and multiple sclerosis combined, and it means that most people will either have a close friend or relative with axial SpA (AS) themselves, or will know someone with the condition by extension. Yet despite this, axial SpA (AS) currently seems to go under the radar.

Based on many of the candid and moving accounts provided during our APPG meetings by those living with axial SpA (AS), it is perhaps unsurprising that our inquiry has ultimately found that much more needs to be done to ensure that those with axial SpA (AS) receive the vital care and support they are entitled to.

Undoubtedly, recent years have seen tentative shoots of progress emerge, embodied at a national level by the introduction of the first ever NICE Guidelines and Quality Standard for Spondyloarthritis conditions, and at a local level by the implementation of best practice by forward-looking and progressive services, often driven by exceptional and passionate healthcare professionals whom we are lucky to have in this country. It is clear to us however that serious and concerning gaps remain.

The fact that only a fifth of Clinical Commissioning Groups have a specific inflammatory back pain pathway in place is hugely disappointing, considering that without one, swift referral to specialist care for those with signs and symptoms of axial SpA (AS) is unlikely. For a condition which already has an 8.5-year average delay to diagnosis, this quite simply must change.

There is also much work to be done when it comes to embedding awareness and understanding of axial SpA (AS) in primary care, which is likely to be the first port of call for those with symptoms. Whilst we are hugely conscious of the broad pressures placed on GPs, without a greater emphasis on axial SpA (AS) in this part of the pathway it will be difficult to address the longstanding challenge of delayed diagnosis.

For those who are 'lucky' enough to have received a diagnosis, our results suggest that they are still not certain to get the support they need in order to help them manage the often debilitating symptoms of axial SpA (AS) they're likely to face on a day to day basis. A fifth of areas in England do not offer specialist physiotherapy for those with the condition, despite the absolute necessity of these services in helping individuals manage flare-ups and the chronic stiffness and joint pain that is synonymous with the condition.

Living with axial SpA (AS) takes a real toll on an individual's mental wellbeing, with up to 60% of people with the condition experiencing depression. Despite this, only a quarter of those diagnosed appear to have direct access to psychological services via secondary care in their localities. If we are genuinely serious about achieving parity between physical and mental health, we should see this as unacceptable.

These findings have ultimately helped to shape the recommendations included in this report, the adoption of which by commissioners and providers across the country would have a marked impact on the speed of diagnosis and quality of care made available.

We are also heartened by the ongoing work of key individuals and groups in the area, including the National Axial Spondyloarthritis Society (NASS) and their newly announced *Aspiring to Excellence* programme. This initiative seeks to respond to the findings of the APPG's inquiry by working with local services and clinicians to raise awareness of axial SpA (AS) and spread best practice, some of which has been showcased within this report. We applaud NASS for their work and eagerly anticipate seeing the benefits come to fruition.

In a rapidly changing NHS environment, spearheaded by the emergence of Primary Care Networks and Integrated Care Systems, we have a tremendous opportunity ahead of us to inspire a fundamental shift in how axial SpA (AS) is prioritised and how services in the area are delivered. It is our sincere hope therefore that this report can help to instigate the conversations that are needed between all parts of the system to deliver meaningful and lasting change.

Introduction

Axial SpA (AS) is a painful, progressive form of inflammatory arthritis which most commonly affects the spine but can also impact upon other joints, tendons and ligaments. Those with the condition will typically experience a gradual onset of back pain and stiffness as a result of persistent inflammation at the site where ligaments or tendons attach to the bone. This can ultimately lead to excess bone formation and vertebrae within the backbone fusing together, potentially causing severe physical disability.[i] Where fusion occurs it is also known as ankylosing spondylitis.[i]
A range of other challenging comorbidities are more common in axial SpA (AS), including uveitis (which can cause blindness), psoriasis[ii], inflammatory bowel disease[ii], arthritis of other joints and enthesitis (inflammation of the tendons).

Approximately 1 in 200 of the adult population (around 220,000 people) in the United Kingdom have axial SpA (AS), which is twice as many as those with multiple sclerosis or Parkinson's. Significantly, the average age of onset is just 24 years, which means that most of those who are develop the condition will live with its symptoms for the majority of their adult life.

Despite the relatively high prevalence of axial SpA (AS) and the significant impact that it has on those living with axial SpA (AS), awareness of the condition remains low. Unfortunately, it has been under-prioritised and overlooked within health systems internationally. This is reflected in the current average delay of 8.5 years between the onset of axial SpA (AS) symptoms and diagnosis, during which time the condition can deteriorate considerably, and irreversible damage can occur.

Whilst there has been some encouraging progress in recent years in terms of recognising the need to provide more support for those with axial SpA (AS), most notably through the publication of the first ever NICE Spondyloarthritis Clinical Guidelines and Quality Standard, there is currently no system in place to ensure their effective uptake at a local level. Sadly, there remains a long way to go before those with axial SpA (AS) receive the level of care they are entitled to expect.

It is against this background that the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis was established in early 2019. The formation of the group provides a powerful platform to raise awareness of axial SpA (AS) and provide oversight to encourage effective national implementation of the recent NICE guidance.

Following the group's inaugural meeting in March 2019, it was agreed that as a first step, a formal inquiry should be taken forward on behalf of the APPG to explore the extent to which key areas of NICE guidance have currently been adopted across the country, and to get a better sense of the 'gaps' that need to be addressed.

The work of the APPG and the findings from this first group inquiry have assumed added importance in light of the Government's recognition of the need to move away from a health system that is predominantly focused on diagnosing and treating illnesses, towards one that is able to promote wellbeing and prevent ill-health in the first place. This approach is set out in the recently published Green Paper on Prevention, which recognises musculoskeletal (MSK) disorders as being the number one contributor to years lived with disability, and the need to prioritise support for those affected.

The Government's strategy in the area over the coming years will be informed by an MSK 'call to evidence' announced in the Green Paper on Prevention.

The APPG is committed to improving the support, care and outcomes for those affected by axial SpA (AS) in the UK. Driving down the 8.5-year average delay in diagnosis for those with axial SpA (AS) and improving the availability of accessible and high-quality axial SpA (AS) services will produce enormous benefits not just for individuals, but also for the health system and society as a whole.

What we did

Background

The recent NICE Guideline for Spondyloarthritis (2017) and the corresponding Quality Standard[viii] (2018) provide a framework for commissioning and providing services for people with axial SpA (AS).

In March 2019 we constituted a new All-Party Parliamentary Group (APPG) with a specific remit to provide national oversight of the implementation of the NICE Guideline and Quality Standard. Our first action was to undertake a baseline survey of the commissioning and service arrangements for axial SpA (AS) care in England.

We developed a ten-question quality framework, based largely on the NICE Guideline recommendations and Quality Standard, categorised under the following headings:

- Recognition and referral
- Diagnosis in specialist care settings
- Information and support
- Pharmacological management of axial SpA (AS)
- Non-pharmacological management of axial SpA (AS)
- Flare management
- Organisation of care
- Mental health and wellbeing

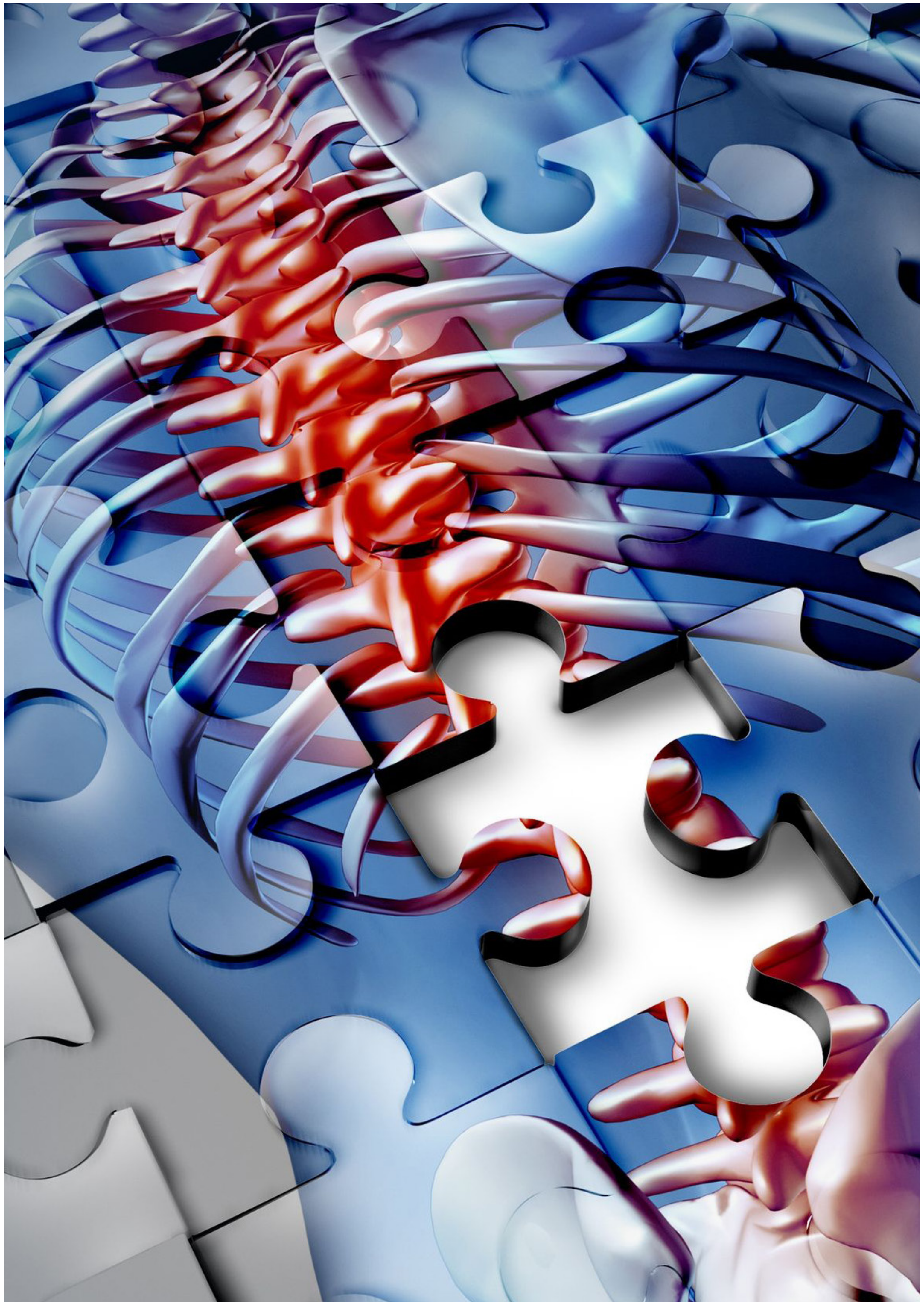
Commissioners and providers reviewed these questions to ensure that the information requests were reasonable. We sent the survey to all Clinical Commissioning Groups (CCGs) (commissioners) and NHS Trusts (providers) in England in the form of a Freedom of Information (FOI) request in order to get as high a response rate as possible.

We received responses from 178 CCGs (93%) and 75 provider Trusts (63%) within the statutory time frame. We analysed the data at national level which was presented to the APPG on 9 July by Dr Jon Packham, Consultant Rheumatologist at Haywood Hospital.

Following that meeting of the APPG, further responses were received from both Trusts and CCGs.

191/191 (100%) of CCGs (commissioners) responded. 99/114 (88%) of provider Trusts responded, with a further 2 refusing on grounds of cost and 13 not responding with the information requested. Eleven of the non-responders did acknowledge receipt of the request; reminders were sent to all non-responders following the APPG meeting.

The data were re-assessed to provide a more accurate picture.



Results, comment and analysis

Recognition and referral – Inflammatory back pain pathways

Why this matters

Patients wait on average 8.5 years for an accurate diagnosis of axial SpA (AS). This average wait has not reduced in the past 10 years[vii]. Numerous factors contribute to a delayed diagnosis including poor symptom recognition in primary care resulting in slow or non-referral to rheumatology.

Early diagnosis is crucial to achieving an optimal treatment response and is likely to contribute to preventing structural damage in the spine. It requires specialist assessment in rheumatology. NICE Quality Statement 1 says: 'Adults with suspected axial or peripheral arthritis are referred to a rheumatologist', whilst the NICE Guideline 1.1.5 states that 'If a person has low back pain that started before the age of 45 and has lasted for longer than 3 months, refer the person to a rheumatologist for a spondyloarthritis assessment' if they meet an additional set of criteria.

It is reasonable to expect therefore that each CCG has a specified pathway in place from primary to secondary care for inflammatory back pain.

What we asked

'Does your CCG have a specified pathway from primary care to secondary care for inflammatory back pain (IBP) in place?'

Only 21% of CCGs have a specified inflammatory back pain pathway in place with direct referral from primary care to rheumatology. Some had alternative arrangements including MSK triage, the use of NICE Guidelines for Low Back Pain and Sciatica, spinal back pain pathway and general back pain pathway.

Our analysis

We are concerned that only one in five CCGs have a specified IBP pathway in place. Where alternative arrangements are in place, this risks sub-standard care as the guidance is less specific and more relevant to mechanical (non-inflammatory) back pain. The use of MSK and spinal triage teams risks making the process much longer; NICE guidance recommends direct referral into rheumatology and avoiding the use of an interim group who may not refer on to rheumatology. Triage is only appropriate if the knowledge, training and resources are in place.

> “AS has affected my life by the impact it had over the last 28 years, 19 of which I didn't have a diagnosis and didn't know what was wrong with me. This I'm sure contributed to an ongoing battle with depression and anxiety.”

Recognition and referral – Raising awareness in primary care

Why this matters

Although 6-9% of people presenting to GPs will do so with back pain, only 7% - 15% of these will show symptoms of axial SpA (AS); axial SpA (AS) is therefore low on the clinical reasoning of an average GP. GPs are often unaware of the extra-articular features , and axial SpA (AS) has a slow disease progression making symptom recognition more difficult. Consequently, GPs may mis-diagnose axial SpA (AS) as mechanical back pain or ascribe psychosomatic or other reasons to it, which can lead to irreversible damage to the spine. Therefore, raising awareness of axial SpA (AS) amongst primary care professionals is key to ensuring timely referral to rheumatology; Quality Statement 1 asks for 'Evidence of local arrangements to raise awareness of signs, symptoms and risk factors of axial [and peripheral] spondyloarthritis in primary care'.

What we asked

'Please provide details of the pathway and arrangements in place to raise awareness in primary care of axial SpA in your local area.'

Only 85/191 (44%) of commissioners responded to this question. Of the total number of CCGs only 29/191 (15%) had specific programmes in place to raise awareness of axial SpA (AS) in primary care. These included training and events (11) and the use of Intranet and internal communications (18).

Only 7% of provider Trusts reported primary care awareness programmes in place.

Our analysis

It is concerning that so few commissioners have local arrangements in place to raise awareness of axial SpA (AS) in primary care settings. A greater knowledge of the signs and symptoms of axial SpA (AS) and the accompanying assessment would mean swifter referral into secondary care, reducing the number of visits to GPs and inappropriate treatment. There is an acknowledgement in the Quality Standard that there is a greater need for more awareness in primary care with the first quality measure 'Evidence of local arrangement to raise awareness of signs, symptoms and risk factor of axial spondyloarthritis'.

> “The biggest problem for me has been how difficult it has been to be referred to a rheumatology consultant for advice - once this happened the situation improved greatly.”

Diagnosis in specialist care settings – Time to diagnosis

Why this matters

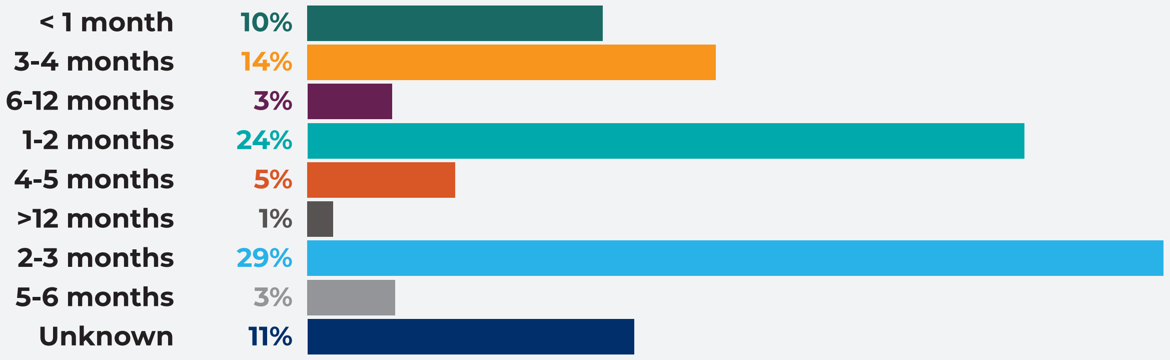
Axial SpA (AS) can lead to a lifetime of pain. However, a swift diagnosis can in the majority of cases means that symptoms can be managed and controlled quickly, reducing the impact on everyday life of those who have been diagnosed and their family and friends. Under the NHS Constitution, patients should be seen by a rheumatologist within 18 weeks of GP referral.

What we asked

'What is the average current waiting time to diagnosis for a patient referred with inflammatory back pain?'

Of the 168 CCGs that answered this question, 43 (23%) were able to give an exact figure, but 149 (77%) of commissioners did not hold the data and asked to refer to the provider (NHS Trust).

The results from the providers were as follows:



Over a **third (37%)** of patients received their diagnosis outside of the 3-month NHS Constitution window.

This information was submitted by the providers.

Our analysis

According to the data from providers who were able to answer the question, 63% of patients referred receive a diagnosis within three months, as per the NHS Constitution, leaving more than a third getting their diagnosis outside of this time frame.

However, it is worrying that 77% of commissioners are not holding their providers to account and are unaware if they are achieving their targets. There is a concern that CCGs may have misinterpreted the question as the 'waiting time to first appointment (which is routinely collected) rather than 'waiting time to diagnosis'. A diagnosis time of three months is still longer than other types of inflammatory arthritis, with referral to rheumatology for peripheral arthritis including rheumatoid arthritis currently standing at four to six weeks.

> “It took more than 30 years for my AS to be diagnosed, although I had been to hospital several times over the years suffering from back and hip pain. In the end I saw a rheumatologist privately.”

Diagnosis in specialist care settings – Imaging

Why this matters

Axial SpA (AS) is a spectrum of disease ranging from those people who have changes on an MRI but not X-ray (non-radiographic axial spondyloarthritis (nr axial SpA)) to those with spinal fusion (ankylosing spondylitis). Spinal fusion is less common in women; since the introduction of MRI as a diagnostic tool, there has been an increase in axial SpA (AS) diagnoses in women. Routine MRI scans do not generally include the sacroiliac joints or the sequences specific for detecting inflammation. Therefore, requesting an axial SpA (AS) specific sequence full spinal and sacroiliac joint MRI is important to ensuring accurate and timely diagnosis.

The NICE Guideline and Quality Standard however does not recommend MRI in the first instance but instead plain film X-ray unless the person is likely to have an immature skeleton. Guidance from both commissioners and providers however led us to believe that MRI is offered more commonly in the first instance and so the question was adjusted to reflect this.

What we asked

'Are patients with suspected axial SpA (AS) routinely referred for a full spinal MRI?'

YES 81% **NO** 17%

Those who gave further explanation of their local protocol made their decisions dependent on the individual patient following clinical assessment. Most only offerered a full spinal MRI when alternatives had been used. These alternatives most commonly included performing an MRI only when a negative result was produced on x-ray, and MRI of lumbar spine and sacroiliac joints only, unless deemed appropriate by the individual clinician.

This information was submitted by the providers.

Our analysis

It is very positive that such a large proportion of Trusts routinely offer MRI, although those that do not are adhering to the guidance and it is possible that the 17% who do not offer a full spinal MRI conduct an X-ray first with no perceived need for further imaging should the X-ray be positive.

It is a greater concern that there are those who routinely offer MRI but not on the whole spine. NICE Guidance states that a T1 inversion recovery (STIR) MRI be performed on the whole spine and sacroiliac joints should the X-ray be negative. It is possible to have a negative MRI, but a positive X-ray and so more complex cases will need fuller investigation, often using more than one type of imaging.

The gold standard in terms of imaging would be that all patients get a full MRI; these results suggest however that it is possible that 1 in 5 people are not getting this.

> “The humiliating disbelief before diagnosis with doctors accusing me of hypochondria, all proven wrong after the rheumatologist found my MRI and X-ray to be riddled with AS. If I'm honest it has ruined my entire existence.”

Information and support

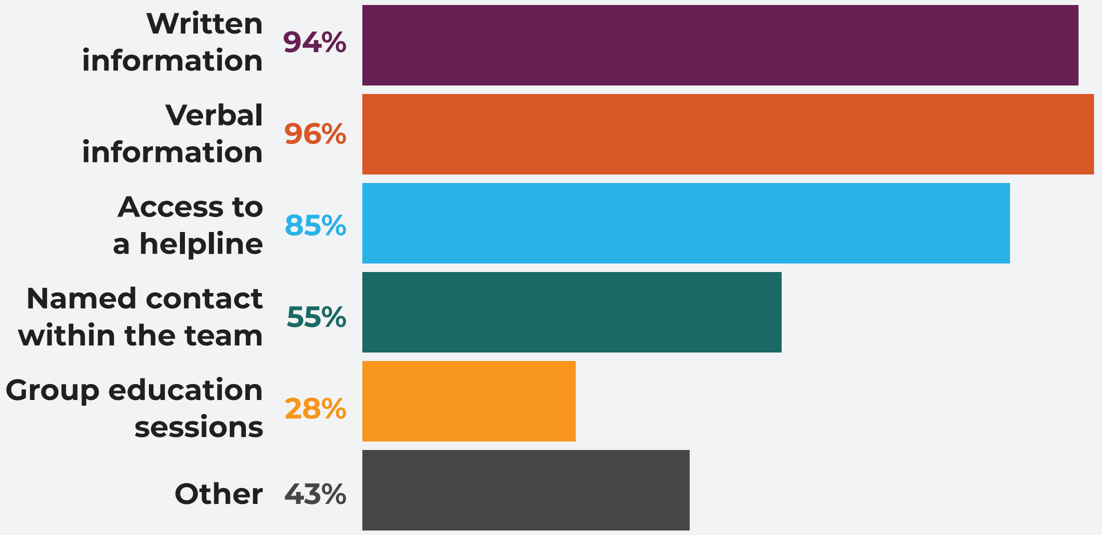
Why this matters

Getting a diagnosis of axial SpA (AS) can be worrying and confusing. During the period of diagnostic delay, patients may be feeling adrift and confused. Patients may well pay a 'psychological price'. It is important that patients have the information and support that they need to understand and manage their condition effectively.

NICE Quality Statement 4 says 'Adults with spondyloarthritis are given information about their condition, which healthcare professionals will be involved with their care, and how and when to get in touch with them'.

What we asked

'How do you ensure patients are given information and support following their diagnosis? Respondents were asked to tick all that apply.'



Of the 'other' information and support available, group exercise was the most popular with 13% directing patients to their local NASS branch and an additional three organising their own sessions, and one with a buddy system in place. Patients are also routinely signposted to the NASS website (www.nass.co.uk). One Trust was able to offer a two week rehabilitation course. Trusts also saw referral to specialist physiotherapy and the subsequent appointments as key to the information and support element of their service, with 39% citing this as a method of providing information and support.

This information was submitted by the providers.

Our analysis

It is encouraging to see such a high volume of services offering information and support to their patients, even more so to see that patients are referred to NASS branches and the NASS website.

A comparison with the patient perspective is relevant here; in 2016 NASS conducted a patient survey in which only 36% of patients considered that they had received all of the information they needed about their condition, with 52% looking for more information on fatigue and 46% on the long term prognosis,. The format of the information provided which only satisfies 36% is not known; it is possible that written information is not sufficient for most and more in-depth education sessions are preferred.

Quality Statement 4 requires that people 'have information on who to contact when they need extra advice and support.' Only 55% of units currently provide this.

It is also interesting to note the pivotal role that physiotherapists are seen to play in the overall care of people with axial SpA (AS) beyond physiotherapy and exercise advice. Details on the role of physiotherapists in this sense was offered voluntarily throughout this inquiry which emphasises how vital they are to a good service.

> “I was diagnosed by letter after a long list of diagnoses from him [Consultant Rheumatologist], never once was it mentioned in clinic until I became suicidal, when he then referred me to his nurse who finally helped me understand everything and did all she could to help me. Until then I had no clue what it was. Three years I had that diagnosis, and nothing was mentioned face to face.”

Pharmacological management of axial SpA (AS) – guidance when accessing biologic treatment

Why this matters

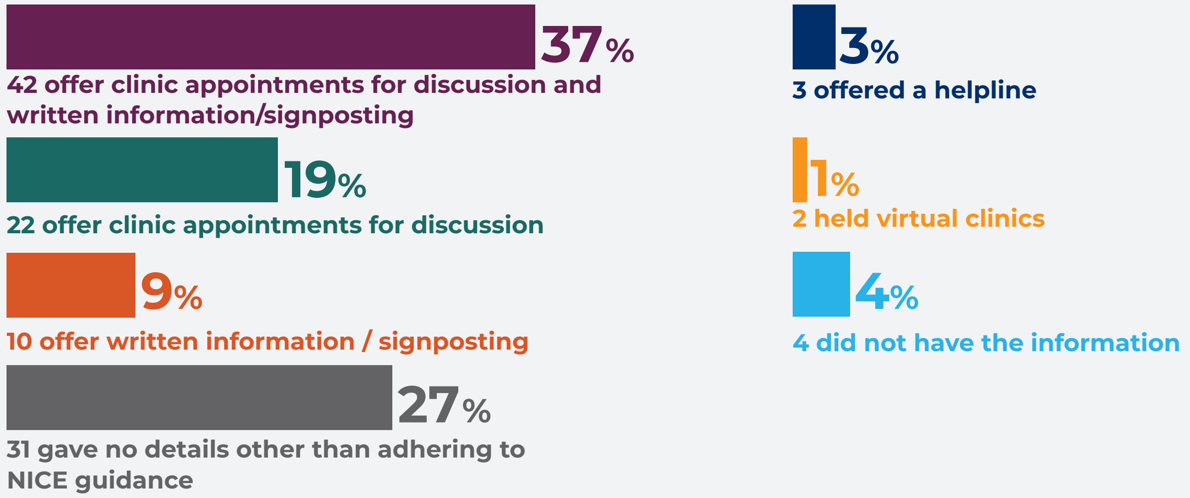
Most patients will try non-steroidal anti-inflammatory medication in the first instance. However, failure to respond to this medication often results in the offer of biologic medication. This is a type of medication that most people will be unfamiliar with and therefore need guidance on the benefits and risks are before making an informed choice.

The NICE Guideline states 'The choice of treatment should be made after discussion between the clinician and the patient about the advantages and disadvantages of the treatments available'.

What we asked

'What guidance are patients with axial SpA (AS) given when deciding whether to access biologic treatment?'

All Trusts offered some form of guidance prior to offering biologic treatment. Shared decision making was viewed as key as was the importance of individualised care. Most services offered an appointment with a biologics nurse or biologics clinic in a group setting. This was often combined with written information on the drugs, most commonly provided by NASS, drug manufacturers and Versus Arthritis, although some areas offered written information only.



177 commissioners did not answer this question or did not hold the data; this was also the case for six Trusts.

This information was received from the providers.

Our analysis

The results suggest that providers think that they are giving the support that patients need to make an informed decision. The role of rheumatology nurses was very much championed with their pivotal role in educating patients, particularly when considering starting biologic therapy.

However, NASS recently conducted a survey of patients who had been switched from an originator (adalimumab) to cheaper biosimilars. The survey opened in February 2019 and closed in December 2019. Only 41% said their consent was sought to switch and just 39% were informed via a face to face consultation with their consultant or biologics nurse. The apparent lack of shared decision making in this switching process suggests differing clinician and patient perspectives around treatment choice regarding biosimilars.

> "Is my condition worsening? When will remission occur, if ever? Is there anything I can do to reduce the fatigue that I suffer? Will taking anti-TNF cause the disease to slow down or reduce its activity, thereby prevent further joint and tissue damage or is it just a very good pain killer? This last question would allow the patient to assess the gains verses the risk of taking anti-TNF."

Pharmacological management of axial SpA (AS) – access to biologic drugs

Why this matters

In 2014, NICE produced guidance 'TNF-alpha inhibitors for ankylosing spondylitis and non-radiographic axial spondyloarthritis'. The draft did not recommend that patients should be able to try a second anti-TNF drug if efficacy wore off outside an initial 12-week period when the drug is first administered. NASS surveyed its members and 98% of people disagreed with this, offering insight into how being able to switch when the efficacy had worn off had impacted their lives, and more importantly how their lives would have been adversely affected had they not been allowed to switch.

This evidence was submitted to NICE and as a result the decision was reversed on appeal, allowing patients to try another anti-TNF when efficacy has worn off.

NASS operates a helpline which receives over 5,000 queries every year. Anecdotal information has been received through the helpline that some commissioners and/or providers are allowing patients who have failed one anti-TNF to only try one additional biologic drug, whereas they should be able to try an additional anti-TNF and then another biologic drug, currently IL17-a inhibitor secukinumab. This loose interpretation of the NICE Guidance for anti-TNF needs to be investigated and more robust evidence is needed to understand the scale of the issue, and how best to tackle it.

What we asked

'Bearing in mind the NICE anti-TNF guidance for ankylosing spondylitis (TA383) states that, 'Treatment with another anti-TNF is recommended for people who cannot tolerate, or whose disease has not responded to, treatment with the first TNF-alpha inhibitor, or whose disease has stopped responding after an initial response', after failure with one biologic, how many other biologics will your commissioners fund a patient with axial SpA (AS) to try, including IL 17As?'

None – 0%

One – 4%

Two – 20%

Three or more – 69%

Don't know / not applicable – 7%

This information was submitted by the providers.

Comment

The situation should be monitored closely, and further investigation conducted involving those who responded 'one'.

> "If my anti TNF was taken away and I was offered no alternative I don't know how I would cope. The thought of it actually keeps me awake at night sometimes."

Non-pharmacological management of axial SpA (AS)

Why this matters

The cornerstone of treatment for axial SpA (AS) is a combination of medication to reduce inflammation and exercise. In a condition that is characterised largely by pain and stiffness, exercise allows patients to maintain flexibility, range of movement and posture as well as helping to improve sleep and general health and wellbeing. Recent research published shows that exercise improves the symptoms of pain and stiffness associated with axial SpA (AS).

The NICE Guideline recommends: Refer people with axial spondyloarthritis to a specialist physiotherapist to start an individualised, structured exercise programme, as does Quality Statement 3 in the Quality Standard.

What we asked

'What proportion of adults with axial SpA (AS) are referred to a specialist physiotherapist for a structured exercise programme within your local area when first diagnosed?'

81% of providers had access to a specialist physiotherapist. Of those (n=92):

74% said that they referred 100% of their patients to a specialist physiotherapist. Of the other Trusts who had access to a specialist physiotherapist, 24% referred more than half, 2% referred less than half.

12% of reporting NHS Trusts said that they do not have access to a rheumatology specialist physiotherapist, and 7% did not have the information requested.

Nine Trusts were unable to answer the question, reportedly on cost grounds or lack of data.

This information was submitted by the providers.

Our analysis

As mentioned earlier, physiotherapists play a key role in the care of people with axial SpA (AS). We are concerned that one fifth of services are unable to offer specialist physiotherapy, instead referring on to more generic physiotherapy. This may be related to there being a relative paucity of rheumatology physiotherapists, but may also reflect provider Trusts not prioritising specialist physiotherapy as an integral part of rheumatology services.

With a fifth of Trusts not being able to offer the level of speciality required by the NICE Guideline and Quality Standard, and an apparent lack of rheumatology physiotherapists, it is a growing concern that patients are not being given the specialist advice that they need to self-manage their condition. Given the nature of axial SpA (AS), it is important that patients have an annual review; deterioration can be gradual and over a long period of time whereby a patient may not recognise that it has occurred. However, an annual review of measurements by a physiotherapist can monitor disease progression and ensure that the right treatment is in place.

In addition, the NICE Guideline also states that hydrotherapy should be considered as an adjunct therapy. However, the closure of several hydrotherapy pools around the country has highlighted the need to raise awareness of the benefits of hydrotherapy. A recent survey by members of AStretch, a group of special interest physiotherapists, showed that on average people rated hydrotherapy at 8.2 out of 10 for helping with stiffness and 8.0 out of 10 for helping with mobility and flexibility.

> “I need more regular hydrotherapy and physiotherapy on the NHS not just short bursts when desperate. Think of prevention not cure.”

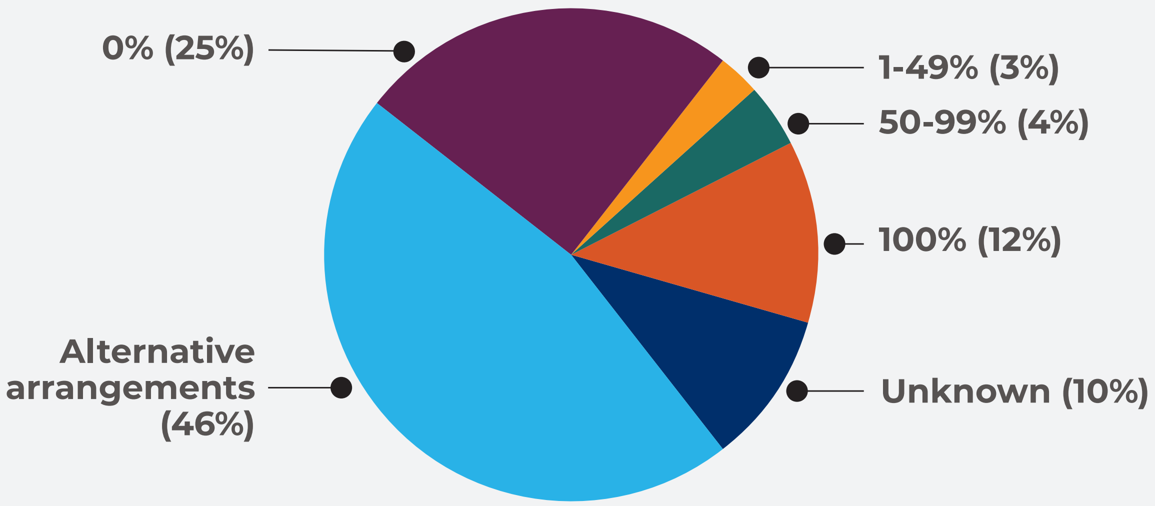
Flare management

Why this matters

Axial SpA (AS) characteristically has periods of severe flare in which pain and fatigue can be nearly unbearable, lasting days, weeks and even months. When experiencing a flare, it can be difficult to think clearly about how best to cope. The NICE Guideline 1.7.1 states 'Manage flares in either specialist care or primary care depending on the person's needs' indicating a need for personalised plans to cope when a flare occurs.

What we asked

'What percentage of patients with axial SpA (AS) have a written care plan to support them with a flare?'



Those offering alternative arrangements included a Helpline (40%), general care plans (4%), verbal information or information leaflets (52%) and specialist flare clinic (4%).

Most commonly, patients are given written information from NASS or Versus Arthritis or directed to online information.

This information was submitted by the providers.

Our analysis

It appears that specific care plans for flares are few and far between with only 12% of rheumatology centres offering these to all patients. It is also disappointing that 25% offer no care plan during a flare.

There are numerous clinical challenges to offering a personalised care plan for flares, not least the very nature of flares being that they can be different every time for each patient. Care plans for flares need to be kept general for this reason but should include a) a named individual as a contact in emergencies and b) sufficient clinical capacity to make urgent appointments where necessary. Although there is also a certain responsibility with the patient to self-manage, this needs to be with the support of health care professionals.

> "AS can be depressing as well as debilitating. It makes me feel about a hundred years old when it flares up. If I had it badly all the time, there would be no point in living anymore."

Organisation of care

Why this matters

Axial SpA (AS) is a complex condition, with a range of co-morbidities and extra-articular manifestations. A multi-disciplinary axial SpA (AS) clinic means that patients can see a range of health professionals in one visit, reducing the number of visits they need to make to the hospital and minimising the disruption to their everyday lives.

NICE Guideline 1.9.2 states 'Ensure that people with spondyloarthritis have access to specialist care in primary or secondary care settings throughout the disease course to ensure optimal long-term spondyloarthritis management', and 1.9.3 'Ensure that there is effective communication and co-ordination between all healthcare professionals involved in the person's care particularly if the person has comorbidities or extra-articular symptoms'.

What we asked

'Does the Trust have a dedicated axial SpA (AS) clinic?'

YES 44%   **NO** 42%

Where 'yes' or 'no' were not appropriate, respondents gave examples of alternative services offered. Two axial SpA (AS) clinics were currently in development whilst another was on hold as they did not have a rheumatologist specialising in axial SpA (AS) in post and one was in the process of setting up an annual review clinic. Another Trust did not have a multi-disciplinary clinic but offered a physiotherapy-led clinic which included one-to-one appointments, group education, a self-management programme and hydrotherapy, as well as patient-led sessions. One did not offer a specific axial SpA clinic but held an inflammatory arthritis clinic regularly, whilst another cited a large geographic area with a sparse population as a barrier to running a dedicated axial SpA (AS) clinic.

This information was submitted by the providers.

Our analysis

It is frustrating for a patient to attend several appointments and to give the same information time and again to different people. A dedicated clinic with a multi-disciplinary team is important to ensure well-coordinated care and a reduction in health inequalities.

Access to a rheumatologist, rheumatology nurse and physiotherapist would be sufficient although optimal service provision would involve a range of disciplines including but not limited to occupational therapist, podiatrist, psychologist, dermatologist, gastroenterologist and work adviser. In circumstances where access to all disciplines is not possible at the same time, communication across these disciplines is vital.

The definition of specialist care is not given explicitly in the NICE Guideline. However, it is the view of this group that specialist care cannot be delivered without a dedicated axial SpA (AS) clinic; general rheumatology does not in this case equate to specialist care. Population size and geographical spread may have an impact on the value of setting up a specialist clinic; it is worth noting however that the number of specialist clinics have seen little change since rheumatology unit surveys were conducted in 2011 and 2016.

> “I have been waiting for an occupational therapist appointment since I was diagnosed in five years ago. I know I can drop in for the eye hospital and they will see me. Dermatology is a long wait and needs a referral... I wish really that all the relevant people were somehow more connected to the rheumatology team, easier to access, perhaps involved on clinic days?”

Mental health and well being

Why this matters

Research indicates that up to 64% of people with axial SpA (AS) will have some form of mental health problem during their lifetime; compared with 25% of people with musculoskeletal conditions and 20% of the general population. This is a large burden of disease that is not being supported appropriately by healthcare professionals. Mental health is not specifically mentioned in the spondyloarthritis NICE Guideline; this is because it is already covered in a NICE guideline 'Depression in adults with a chronic physical health problem: recognition and management':

1.5.4.2 Collaborative care for patients with depression and a chronic physical health problem should normally include:

- *case management which is supervised and has support from a senior mental health professional*
- *close collaboration between primary and secondary physical health services and specialist mental health services*
- *a range of interventions consistent with those recommended in this guideline, including patient education, psychological and pharmacological interventions, and medication management*
- *long-term coordination of care and follow-up.*

What we asked

'Are axial SpA (AS) patients under the care of a rheumatologist offered access to psychological services?'

YES 24%

NO 57%

If neither of the above response options apply to you, please provide more information on your local arrangements below (19%)

Where no direct access was available via rheumatology, Trusts were aware of the ability to self-refer via Improving Accessing to Psychological Therapy (IAPT) services or that they can refer via GPs and signpost patients to services. One Trust aspired to provide such a service, funding permitting, whilst another was able to refer to a multi-disciplinary pain clinic and another to an occupational therapist with experience in cognitive behavioural therapy.

This information was submitted by the providers.

Our analysis

Given the reported high prevalence of depression and anxiety among people living with axial SpA we are concerned that only one quarter of rheumatology services have direct access to psychological services. As noted in a recent paper by the Arthritis and Musculoskeletal Alliance (ARMA), in health policy and NHS practice musculoskeletal and mental health are treated separately. However, the reality for patients is that the two are related and the delivery of integrated care is therefore crucial to improve outcomes and quality of life.

We support the recommendations of ARMA for policy makers which are as follows:

- Commissioners for musculoskeletal and mental health services should work together to integrate services, following the patient's actual disease and treatment pathway with all biopsychosocial aspects addressed.
- Commissioners should ensure MSK services are able to address the mental health needs of people with long-term conditions, and that these are available earlier in the treatment pathway.
- Integrated pain services should be commissioned that allow early access to support.
- All people with axial SpA should be made aware that they can directly refer themselves to IAPT.
- Enable close collaboration between rheumatologists and mental health specialists.

Training, skills and information for clinicians should be considered by educators and professional associations. MSK teams need people who are trained and skilled in mental health and mental health clinicians need an understanding of how pain and lack of mobility will impact on mental health. A reliance on patient self-referral and GPs is not enough and truly collaborative care should see direct links between rheumatology and psychology services.

> “Having no mental healthcare in place to help patients deal with the transition in life is beyond negligent”

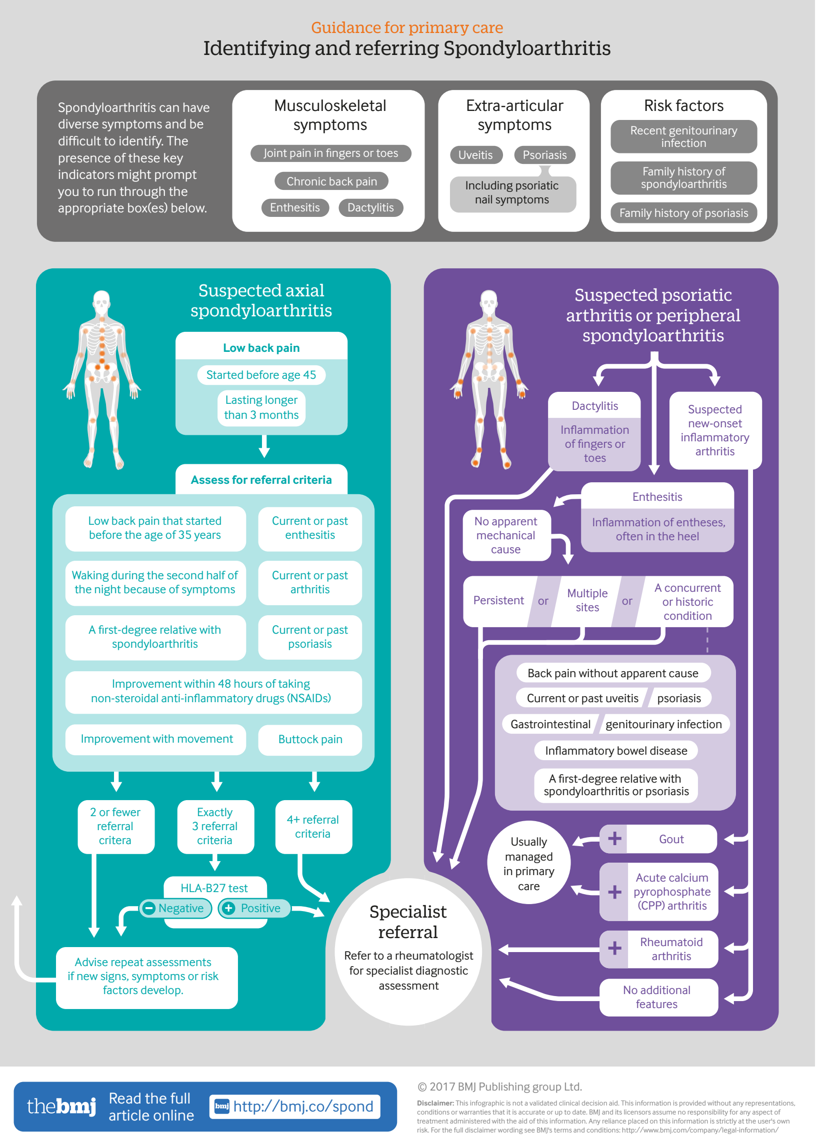
Recommendations

RECOMMENDATION ONE:

All CCGs should have a clear and simple inflammatory back pain pathway to ensure swift referral directly to rheumatology following the NICE Guideline for Spondyloarthritis.

The National Axial Spondyloarthritis Society worked with the British Medical Journal upon publication of the Guideline to produce a simple infographic showing when a patient should be referred into rheumatology for further investigation. Adherence to this pathway should ensure that swift and appropriate referrals are made. This infographic was sent via the BMJ to 70,000 hospital doctors and 28,000 GPs in 2017.

>>Example of best practice: the NICE Guideline for Spondyloarthritis infographic by the BMJ & NASS



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RECOMMENDATION TWO:

Continuous Professional Development (CPD) in primary care should be available via the CCG intranet as a minimum. Ideally, rheumatology should be running annual educational sessions in axial SpA (AS) with the newly formed Primary Care Networks.

There are already numerous CPD options available for GPs and other primary care practitioners. NASS worked with the Royal College of GPs (RCGP) along with Professor Karl Gaffney (Consultant Rheumatologist) and Dr Daniel Murphy (GP with a special interest in rheumatology) to produce two e-learning modules on diagnosis and treatment of axial spondyloarthritis. These modules remain available to members of the RCGP.

Dr Murphy also worked with the British Society for Rheumatology (BSR) and the RCGP to produce the 'Inflammatory Arthritis Toolkit' which is available for anyone to view on the RCGP website.

During the July 2019 Axial SpA APPG meeting it was suggested that clinical champions from rheumatology could be the key to ensuring that awareness was raised consistently in primary care. NASS is committed to investigating this as an option for future work in primary care, working with clinicians to deliver programmes such as those in the case study below.

>> Example of best practice: The Royal Berkshire Hospital NHS Trust

Dr Antoni Chan and his team at the Royal Berkshire Hospital in Reading began their work in reducing the delay to diagnosis in 2013 with the development of an inflammatory back pain (IBP) pathway which was co-produced with GPs and is available via internal systems. Since then the team have worked to deliver educational programmes and materials for primary care practitioners including:

- Introduction of the Inflammatory Back Pain Checker, designed to assist medical professionals define the probability of axial spondyloarthritis in a patient with chronic back pain, to community physiotherapists.
- Integrating services with the Integrated Pain Assessment and Spinal Service (IPASS) which provides musculoskeletal triage and treatment.
- An annual masterclass on axial SpA for GPs including education and training on the signs and symptoms of axial SpA.
- Twice yearly education and training sessions for community physiotherapists.
- Multidisciplinary case discussion with GPs and physiotherapists to aid decision making and onward referral.

As a result, the average local delay to diagnosis has reduced from 9.8 years in 2013 to 4.4 years in 2019.

RECOMMENDATION THREE:

The importance of rheumatology physiotherapy - including hydrotherapy - should be promoted within NHS Trusts, with all Trusts providing access to a specialist rheumatology physiotherapist.

Testimony from Roger Stevens, NASS Member

"Specialist rheumatology physiotherapists have been crucial in the successful management of my condition. They have identified and treated AS problems and flares, referring me to hydrotherapy as necessary. Exercising in warm water is extremely beneficial because it supported my body weight and enabled me to exercise in ways that increased mobility, relieved pain, and without having to resort to high levels of medication. Physiotherapists who have been trained in managing AS have helped me with posture and methods of exercising that directly related to my condition in ways that general MSK physios would not have been able to do."

RECOMMENDATION FOUR:

All newly diagnosed patients should receive an individualised, structured exercise programme and, as a minimum, an annual appointment for measurements to be taken.

The Bath Indices are a set of primary outcome measures that are mostly patient reported but the BASMI is measured by a clinician. They measure the patient's disease activity, their functional ability, how their axial SpA (AS) affects them overall and their range of movement. The use of the Bath indices, in particular the BASDAI, is a key feature in the NICE criteria for determining the need for Anti-TNF medication to be prescribed. The BASMI is usually undertaken by a physiotherapist and it assesses the person's posture and the flexibility of their spine which needs to be assessed on an annual basis. (See glossary for details of terms used.)

It was clear from the inquiry that physiotherapy-led services offer more than just exercise. As well as a structured programme and Bath Indices measurements, physiotherapy services also provide patients with education and support in self-management and are an integral part of the service. NASS also offers an additional resource, with weekly or fortnightly exercise and hydrotherapy physiotherapist-led sessions at 74 locations in England.

>>Example of best practice – Salford Royal NHS Foundation Trust

Salford Royal Hospital provides a physiotherapy-led service, headed up by Will Gregory.

"We have recently (two years) established an award-winning self-referral programme to physiotherapy "*Go2Physio*" which allows simple self-referral open to all Salford-resident rheumatology patients. In addition, all patients who have had previous physiotherapy input will have a lifelong open appointment they can re-access by calling into or phoning the department.

Most patients tend to have four or five appointments over a two to three-month period. Many go on to access our gym and hydrotherapy services, putting appointment numbers up to 12-15. The service runs a fortnightly axial SpA (AS) specific self-management gym and hydrotherapy pool session. There are also great links with community exercise services and patient information signposting to these.

They provide simple onwards referral to all allied health professional services (Occupational Therapy, Hand therapy, Biomechanical Podiatry, Orthotics, Dietetics, Clinical Health Psychology, IAPT, Hydrotherapy) and to the axial SpA clinic. This allows patients confidently to self-manage knowing they can be picked up whenever self-management needs more support."

RECOMMENDATION FIVE:

Providers should encourage multi-disciplinary working, including patients in any service development ensuring that secondary care clinicians are able to access direct referrals to mental health services.

>>Example of best practice – University Hospital Southampton NHS Foundation Trust

The axial SpA (AS) service was established in January 2016 with the appointment of a new consultant and Rheumatology Specialist Physiotherapist. Before establishing the new service, we invited patients to attend a focus group to explore their views regarding the current service and what should be offered. As a result, changes were made to improve opportunities for patients to participate in research, the local NASS group format and structure were altered, and gym equipment was updated.

We run one consultant-led axial SpA (AS) follow-up clinic per week where patients alternate between seeing the consultant and physiotherapist, or see both if required. New referrals are seen in a separate clinic by the same consultant and are referred for urgent physiotherapy input in the AS clinic. Core outcome measures are recorded in line with international recommendations, including disease activity, quality of life, global health and work productivity. Patients attending the clinic have opportunities to participate in research.

Therapy input is provided either in the outpatient clinic or in the therapy department by the Rheumatology Specialist Physiotherapists. In 2017, we established a new therapy programme in the format of a rolling six-week exercise and advice group. Patients are assessed at their first session and given an individualised exercise circuit. They are monitored over the next five weeks and their exercises progressed or regressed accordingly. Hydrotherapy is offered. Each session includes a group warm-up, individual exercise circuit and educational talk (e.g. pathology, fatigue and pacing, work/sport/exercise, flare-up planning and introduction to the local NASS group) or practical session: including an introduction to yoga and tai chi. The group is available to newly diagnosed patients and those with longstanding disease. Evaluation of the service demonstrated a high level of patient satisfaction.

The multi-disciplinary team includes Clinical Nurse Specialists with an interest in biologic therapies and a Rheumatology Specialist Occupational Therapist. Podiatry services are available at another site. For psychology input, patients are directed to local Improving Access to Psychological Therapies (IAPT) NHS services.

Conclusion

This inquiry has found that the NICE guideline has not been implemented effectively across England. This risks continued delayed diagnosis for patients and poorer outcomes from sub-optimal care.

It is critically important that there is a clear pathway from primary to secondary care for inflammatory back pain with direct referral to rheumatology and not musculoskeletal triage.

This inquiry has found that when a patient is in the secondary care system, their diagnosis is relatively swift. However, standards of care when a patient reaches rheumatology and other secondary care services varies significantly; access to rheumatology physiotherapists and multi-disciplinary teams are not the norm in many areas. The recommendations set out in this report are the minimum required to ensure that fewer health inequalities exist in the diagnosis and treatment of axial SpA (AS).

Action is needed to ensure that best practice and knowledge is shared amongst health professionals treating people with axial SpA (AS). For example, the National Axial Spondyloarthritis Society (NASS) is working in strategic partnership with BRITSpA and sponsoring pharmaceutical companies AbbVie, Biogen, Novartis and UCB to bring a cohort of rheumatology departments together from across the UK as part of a service improvement programme entitled *Aspiring to Excellence*. The programme is designed to encourage and recognise service improvement in axial SpA (AS) care and will provide a focal point from which professionals can explore and test approaches to reduce the delay to diagnosis and improve axial SpA (AS) care and patient experience. The programme will support departments aspiring to achieve excellent care, understand what it is that they are doing well that others could learn from and the knowledge and experience generated will be shared in real-time across the UK and internationally to help stimulate across-the-board improvements in care.

The APPG calls upon CCGs and NHS Trusts to implement in full the recommendations in this report which will lead to a marked impact on the speed of diagnosis and quality of care and outcomes for patients. We will undertake a further inquiry in late 2020 to assess progress in implementation.

Glossary of terms

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

Ankylosing spondylitis - a term which pre-dates axial spondyloarthritis but is technically only correct if spinal fusion has occurred.

AStretch - a group of physiotherapists with a special interest in axial SpA.

Axial spondyloarthritis - axial SpA (AS) 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).

Biologic drugs - product that is produced from living organisms or contain components of living organisms.

BRITSpA - British Society for Spondyloarthritis - a group of health care professionals with a special interest in axial SpA. Clinical Commissioning Group - clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area in England.

Enthestitis - inflammation of tendons.

Musculoskeletal (MSK) conditions - a broad term, encompassing around 200 different conditions affecting the muscles, joints and skeleton.

National Axial Spondyloarthritis Society (NASS) - the only charity in the UK solely focussed 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.

Non-pharmacological - treatment which does not involve medication.

Pharmacological - treatment with medication.

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

STIR sequence MRI - Short tau inversion recovery (STIR) sequence in axial SpA (AS) highlights active inflammation as increased signal intensity (brightness) due to the presence of increased amounts of free water (inflammation related swelling in the bone marrow).

Sacroiliac joints - the joint between the sacrum and the ilium bones of the pelvis.

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 physician can provide.

NICE – National Institute for Health and Care Excellence, a public body which publishes guidelines in four areas: the use of new and existing medicines, treatments and procedures), clinical practice guidance, guidance for public sector workers on health promotion and ill-health avoidance andguidance for social care services and users.

Bath Indices – a set of measures to help clinicians to determine disease severity and progression. They include the Bath Ankylosing Spondylitis Measurements Index or BASMI (physical examination looking at range of movement), Bath Ankylosing Spondylitis Daily Activity Index or BASDAI (patient reported measuring things such as pain and fatigue) and the Bath Ankylosing Spondylitis Function Index or BASFI (patient reported measuring ability to carry out daily tasks such as getting dressed).

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NASS

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