



Derakhshan, M. H., Pathak, H., Cook, D., Dickinson, S., Siebert, S. and Gaffney, K. (2018) Services for spondyloarthritis: a survey of patients and rheumatologists. *Rheumatology*, (doi:[10.1093/rheumatology/kex518](https://doi.org/10.1093/rheumatology/kex518))

This is the author's final accepted version.

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/157926/>

Deposited on: 26 February 2018

Enlighten – Research publications by members of the University of Glasgow  
<http://eprints.gla.ac.uk>

## Services for spondyloarthritis: A survey of patients and rheumatologists

Mohammad H. Derakhshan<sup>1</sup>, Himanshu Pathak<sup>2</sup>, Debbie Cook<sup>3</sup>, Sally Dickinson<sup>3</sup>, Stefan Siebert<sup>1</sup>,  
Karl Gaffney<sup>2</sup>

On behalf of NASS and BRITSpA investigators

<sup>1</sup>Institute of Infection, Immunity & Inflammation, University of Glasgow, Glasgow, UK,

<sup>2</sup>Department of Rheumatology, Norfolk and Norwich University Hospital, Norwich, UK,

<sup>3</sup>National Ankylosing Spondylitis Society, -, London, UK

### Correspondence:

Dr M. H. Derakhshan, MD, MD (UK), FRSPH  
Institute of Infection, Immunity & Inflammation,  
University of Glasgow, Glasgow, UK  
Mohammad.derakhshan@glasgow.ac.uk

## ABSTRACT

**Objectives:** There have been significant advances in axial spondyloarthritis (axSpA), with implications for service delivery. We evaluated the state of axSpA rheumatology services and how people with axSpA perceive their care.

**Methods:** An online patient survey was emailed to all members of the National Ankylosing Spondylitis Society and advertised widely via social media. Separately, a Web-based questionnaire about axSpA services was sent to rheumatologists at all 172 acute hospital trusts in the UK.

**Results:** From the National Ankylosing Spondylitis Society survey, data for 1979 surveys (56% males) were available for analysis. The majority of respondents had longstanding disease and identified their diagnosis as AS, with only 44% aware of the term axSpA. Eighty-two per cent of respondents were currently attending a rheumatologist, with 43% on biologic agents. Satisfaction scores for rheumatology care were high. Respondents' concerns included access during disease flares and adverse effects of analgesics. From the rheumatology survey, the concept and terminology of axSpA was widely accepted by respondents (88%). The majority of centres had at least one rheumatologist with a specialist interest in axSpA (62%), dedicated axSpA clinics (58%) or a multidisciplinary team for axSpA (64%). BASDAI (99%), BASFI (74%) and BASMI (65%) were routinely performed. All centres had access to MRI scans, but scanning protocols varied and were often sub-optimal.

**Conclusion:** Although overall satisfaction with rheumatology care was high, the results indicate significant unmet patient needs and discrepancies in service provision. This information will inform the development of quality standards for axSpA in order to improve quality and deliver equitable care for all patients.

**Keywords:** spondylitis, axial spondyloarthritis, survey, service quality, rheumatology departments, rheumatology consultants, National Ankylosing Spondylitis Society

### Rheumatology key messages

1. People with axial SpA are generally satisfied with their rheumatology care.
2. There is significant unmet need and discrepancy in service provision for axial SpA.
3. There is a need to develop quality standards and indicators for axial SpA.

## INTRODUCTION

Axial spondyloarthritis (axSpA) is a chronic inflammatory disease involving the spine, peripheral joints, entheses and extra-articular systems. It is part of a group of heterogeneous conditions, collectively termed spondyloarthritis. The term axSpA itself is a spectrum, which incorporates both AS (verifiable by radiographic changes on X-ray fulfilling the modified New York criteria [1]) and non-radiographic axSpA (diagnosed using MRI and/or clinical criteria [2]). Although a significant proportion of axSpA patients develop spinal fusion, this is not an inevitable consequence [3, 4].

There have been significant advances in axSpA during the past decade, most notably the ability to establish an earlier diagnosis using MRI, which is supported by revised classification criteria [2], and the availability and efficacy of an increasing number of biologic agents [5]. In order for these advances to be translated into meaningful improvements in patient care, they need to be implemented into clinical practice, which inevitably lags behind scientific evidence, thereby leading to variations in practice. Although rheumatology services have established early RA and biologics clinics driven by national guidance and standards of care [6–8], advances in axSpA have been implemented largely in an ad hoc manner, based on local expertise and resources. Advances in our understanding of divergent pathophysiology, extra-articular manifestations, co-morbidities, disease-specific outcome measurements and biologic therapies mean that optimal management of axSpA can no longer be delivered effectively in general rheumatology clinics and therefore requires dedicated specialist axSpA services.

In 2011, we published data on the medical services for people with AS in the UK [9]. Key findings included the fact that one-third of patients were not under the care of specialist rheumatology services, the diagnosis was frequently delayed and that access to TNF inhibitors (TNFi) was rationed in some areas [9]. In view of recent advances in our understanding of this debilitating disease and the availability of newer therapies during the past 5 years, we wished to evaluate how axSpA is currently managed, understand how people with axSpA perceive their care and identify unmet needs in service provision and delivery. National Institute for Health and Care Excellence (NICE) have recently announced that they will be developing quality standards for spondyloarthritis, so there is a need for published information about the status of current services to help inform this process. It should be noted that this work was carried out before the publication of the updated NICE and BSR guidelines for the use of biologics in axSpA [10, 11] and the NICE spondyloarthritis clinical guideline [12].

## **METHODS**

### **National Ankylosing Spondyloarthritis Society survey**

The National Ankylosing Spondyloarthritis Society (NASS) is one of the largest and most active patient organizations [13] in Europe, with >4000 members, and is the only patient organization solely representing people with axSpA in the UK. The 2016, the NASS State of the Nation Survey survey was open to all people with axSpA living in the UK. All NASS members in the UK with registered email addresses were sent the survey link, which was also advertised via the NASS website and social media. The survey was completed online, with only one reply being accepted from an individual IP address, and the first 2000 replies were analysed. The survey comprised 63 questions regarding aspects of care and service delivery. The questions were chosen based on two strategies: topics frequently discussed and challenged by professionals involved in the management and service delivery, and questions modified to allow comparison with a previously published report [9]. The survey questions targeted aspects of care and service delivery, including basic demographics, diagnosis, rheumatology services, patients' satisfaction and expectations, access to physiotherapy services, medications and patient information. Unless otherwise indicated, the terms AS and axSpA are used interchangeably when reporting the survey results.

### **Rheumatology department survey**

E-mails were sent to a named rheumatologist at all 172 acute hospital trusts in the UK. Consultants with a known interest in axSpA were included preferentially. The email contained a link to a Web-based survey comprising 47 questions regarding professional views and service delivery relating to axSpA. Reminders were sent to non-responders.

### **Analysis**

Data collected in Survey Monkey were exported to Microsoft Excel. Statistical analysis was performed using IBM-SPSS version 22 (TX, USA).

### **Ethical approval**

For this survey, ethics approval was not deemed necessary, according to guidance from the National Health Service (NHS) health research authority [14].

## RESULTS

### NASS survey

#### Demographics

After exclusion of 21 (1.05%) questionnaires with missing data about either age or sex, 1979 (98.95%) surveys, including 1111 (56.1%) male and 868 (43.9%) female participants, were analysed. The age range of respondents was 18–80 years, with the majority (52.6%) <55 years of age. Female responders were significantly younger than male responders, with 15.6% <35 years and 38.3% <45 years of age, compared with 8.5 and 22.6% of male participants, respectively. Two hundred and sixteen (12.1%) respondents were current smokers. Respondents' weighted average score was 5.5 for overall severity of AS, 4.55 for severity of pain today and 5.97 for daily fatigue on 10-point scales ranging from 1, not severe at all, to 10, very severe.

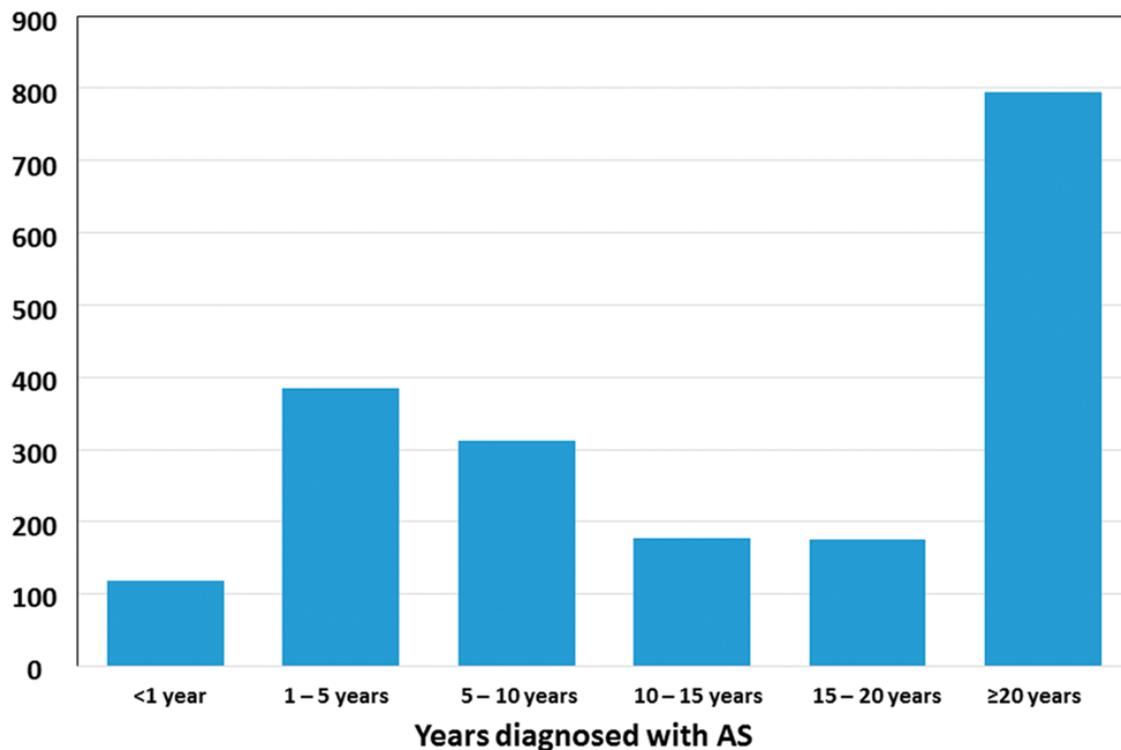
#### Diagnosis

The diagnostic nomenclature of axSpA has changed in recent years with adoption of the ASAS classification criteria [2]. The majority of respondents (92.5%) stated their given diagnosis as AS, with only 2.7% reporting axSpA, 2.2% non-radiographic axSpA and 2.8% spondyloarthritis. Undifferentiated spondyloarthritis was the diagnosis reported by 0.7%. A hundred and five patients reported more than one diagnosis.

When asked about their knowledge of axSpA, 43.8% of respondents had previously heard the term axSpA, whereas 49.4% had not heard this term previously and 6.8% were not sure. Interestingly, only 7.1% of respondents were very confident about the meaning of the term axSpA, 21.2% were fairly confident, 35.3% were not very confident and 36.3% were not confident at all.

The majority of respondents had longstanding disease; 58.5% were diagnosed  $\geq 10$  years ago and 40.3%  $\geq 20$  years ago. However, one-quarter (25.6%) had been diagnosed within the past 5 years and 6.0% within the past year (Fig. 1). Participants diagnosed within the past 5 years were also asked further questions about their journey to diagnosis. Of these respondents (488), the time interval between symptom onset and seeking medical attention varied significantly, with 37.6% seeing a health-care professional within 6 months and 27.5% waiting  $\geq 3$  years before doing this. The interval between seeing a health-care professional about their symptoms and obtaining a formal diagnosis also varied widely; one-third (30.1%) waited  $\geq 10$  years for a formal diagnosis. Overall, there was a median [interquartile range (IQR)] delay of 8.50 (3.0–16.0) years reported between symptom onset and diagnosis. The final diagnosis was made by rheumatologists in 86.5% and by primary care physicians in 5.9% of cases. People with axSpA can also present to other specialities as a consequence of extra-articular manifestations, but respondents reported that the diagnosis was made by orthopaedic surgeons in only 2.0%, gastroenterologists in 0.8%, ophthalmologists in 0.8% and dermatologists in 0.4%. The diagnosis was made by a physiotherapist in only two (0.4%) cases and by an osteopath/chiropractor in one case.

**Fig 1: Time since the first diagnosis of axial SpA**



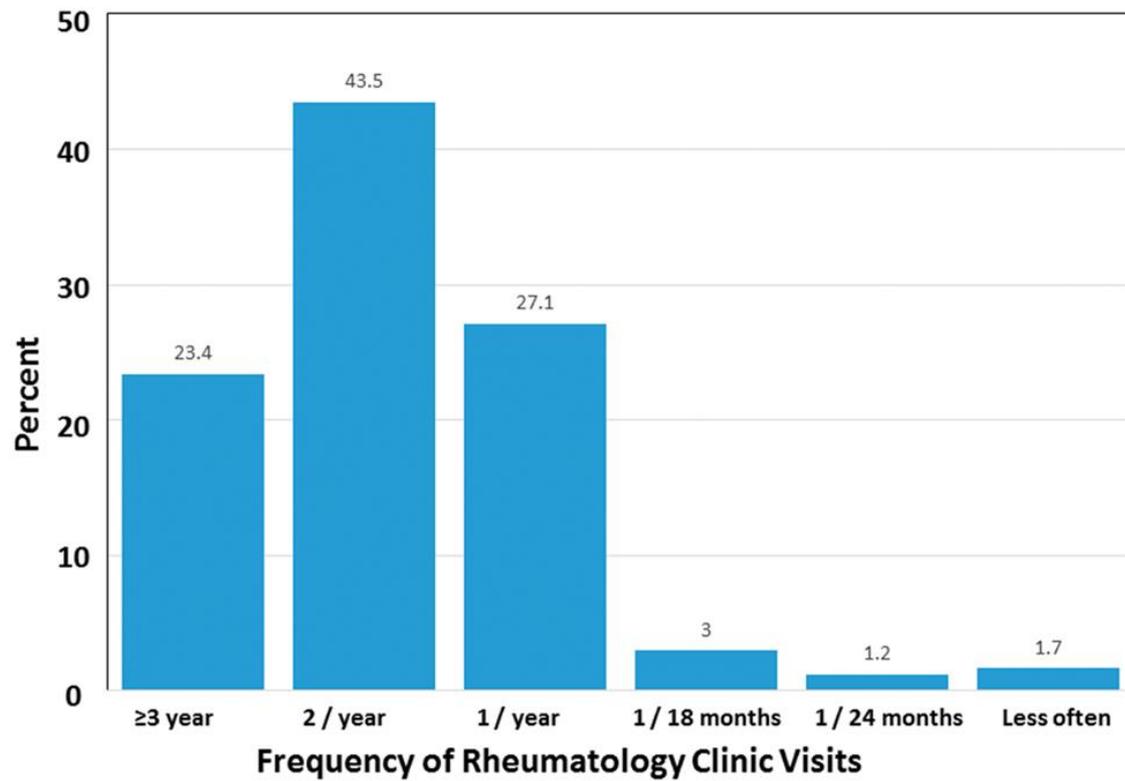
In 490 participants who responded to the question, the diagnosis was confirmed by MRI scan in 44.9%, X-ray in 18.0% or both in 25.9%. Thirty-seven (7.6%) respondents reported not being diagnosed by either of these imaging modalities, whereas 18 (3.7%) were not sure of or did not recall their imaging history.

### **Rheumatology services**

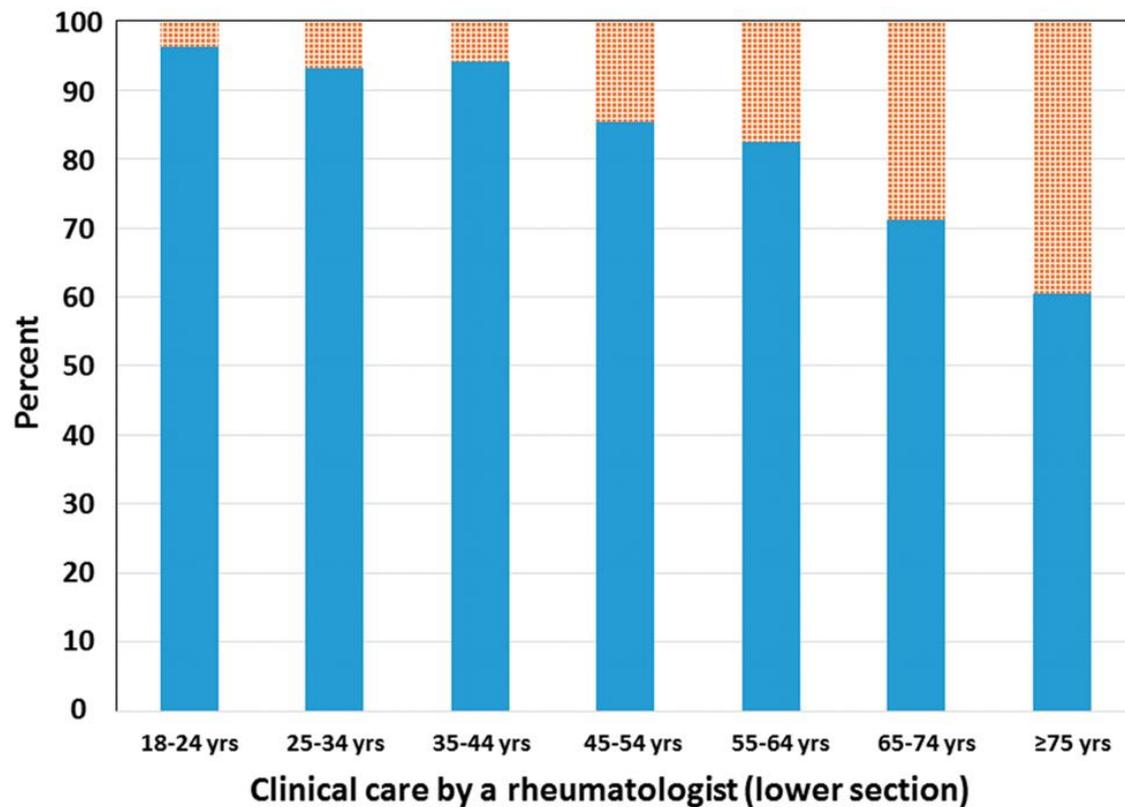
The vast majority of respondents (82.1%) were currently under the care of a rheumatologist. Of those not currently under the care of a rheumatologist, 18.0% had never been referred and 41.6% had been discharged from the rheumatology clinic. A variety of other reasons accounted for the remaining 44.8% of those not currently attending rheumatology.

Of those currently under the care of a rheumatologist, the majority (93.3%) were reviewed at least once a year by a member of their rheumatology team; 23% three or more times a year, 43.2% twice a year and 26.9% only once a year (Fig. 2). As shown in the Fig. 3, the frequency of rheumatology clinic review decreased with increasing age. Factors associated with higher likelihood of being under the care of a rheumatologist were age <65 years [odds ratio (OR) = 2.05, 95% CI: 1.55, 2.72;  $P < 0.001$ ], female gender (OR = 1.43, 95% CI: 1.09, 1.88;  $P = 0.010$ ) and having a diagnosis of AS for <20 years (OR = 2.36, 95% CI: 1.78, 3.12;  $P < 0.001$ ).

**Fig 2: Frequency of rheumatology clinic visits in patients with axial SpA**



**Fig 3: Percentage of axial SpA patients under care of a rheumatologist by age group**



## **Patient satisfaction and expectations of rheumatology services**

Patients were asked to rate their satisfaction with their rheumatologist on a five-point scale, ranging from 1 (not satisfied at all) to 5 (very satisfied). The median (IQR) satisfaction score was 4 (3–5), with 42.8% very satisfied, 29.7% scoring 4, 18.0% scoring 3, 6.2% scoring 2 and 3.4% not satisfied at all.

Participants were offered a list of options they wished their rheumatologist would do differently. Interestingly, 32.8% of respondents did not want their rheumatologist to do anything different. The most commonly requested changes related to clinic visits; 18.0% wanted to be seen quickly when in flare, 17.0% wanted to be seen by the same rheumatologist every time and 7.1% wanted more frequent clinic appointments. The other desired changes related mainly to communication; 12.2% wanted more advice, 8.3% wanted their rheumatologist to listen actively and read their notes and 4.8% wanted their rheumatologist to communicate better verbally with them.

Disease flares are a major issue for patients with axSpA [15–17]. Patients were asked who they were able to contact during a flare; 43.1% were able to contact the rheumatology helpline for this, 37.3% could contact their rheumatologist for advice by telephone (26.6%) or email (10.7%), and 29.1% were able to ask for an earlier appointment. Only 2.8% of patients preferred to contact their primary care physicians first, and 23.1% of respondents reported that they had other routes for contacting health-care professionals during flare-ups.

Respondents were asked to rate their satisfaction with the help and advice they receive from their rheumatology department during disease flare-ups on a five-point scale ranging from 0, not satisfied at all, to 5, very satisfied. The majority of respondents were satisfied, scoring either 4 (26%) or 5 (26.9%). However, a significant number were unsatisfied, scoring 1 (9.2%) or 2 (10.6%). The median (IQR) satisfaction score was 4 (3–5), with a weighted average of 3.51.

## **Access to physiotherapy services**

Only 46.1% of respondents had seen a physiotherapist for their AS during the past 12 months. However, when asked whether they would like to see a physiotherapist for their AS, only 41.9% of respondents said they would like to, 22.0% were not sure and 36.1% replied that they did not want to see a physiotherapist. The reasons for this are unclear but might reflect the long disease duration of many respondents, whereas calls to the NASS helpline suggest that many are unsure what help a physiotherapist will give them. Only 27.2% of respondents were able to self-refer to physiotherapy during a flare-up of their AS, with 34.8% unsure and 38.0% not able to self-refer to physiotherapy for this.

## **Medication**

Participants were asked about their current medications being taken for their AS. The most commonly used group of medications were NSAIDs, including cyclooxygenase-2 selective agents, which were currently being taken by 60.7%. A significant proportion of patients were currently taking medication for pain: simple analgesics (31.2%), co-codamol and opioid preparations (41.1%)

and/or neuropathic analgesics (such as gabapentin; 17.3%). Only 3.6% were currently taking steroid tablets, and 7.4% had received steroid injections. Current use of synthetic DMARDs (mainly MTX and SSZ) was reported by 15.8%. Forty-three per cent of respondents were receiving a TNFi, with adalimumab (20.2%) and etanercept (13.5%) the most commonly reported. Although the majority (80.1%) of those currently taking TNFi knew who to contact if they had any concerns or problems relating to their biologic, 12% were unsure and 7.9% did not know who to contact. Only 6.6% were not taking any medication for their AS.

Participants were asked to rate their satisfaction with the efficacy of their current medications for their AS symptoms. The majority indicated that they were satisfied (30.9%) or very satisfied (29.2%) with their medications. Participants also felt that dose reduction of TNFi in stable patients was an important area for research. When asked how willing they would be to reduce their TNFi dose if they were stable and their rheumatologist suggested this strategy, two-thirds indicated that they would be either quite willing (33.4%) or very willing (29.4%). Of the remaining third, 14.9% would not be very willing and 9.9% would not be at all willing; 12.4% were unsure.

Participants were also asked about their concerns relating to their medications taken for pain (Table 1). Concerns about side-effects of painkillers were common, with 27.1% very worried and 17.8% worried. In addition, 22.1% were very worried and 19% were worried about the number of painkillers they were taking. Respondents were generally confident of which tablets they were taking for pain and how often to use these.

**Table 1**

<b>Table 1. Frequency of pain-killer intake by patients with axSpA</b>			
	<b>Daily</b>	<b>As needed</b>	<b>Don't take / No response</b>
Paracetamol	243 (12.3%)	607 (30.7%)	1129 (57.0%)
Oral NSAIDs	455 (23.0%)	411 (20.8%)	1113 (56.2%)
Oral Cox-2 anti-inflammatories	249 (12.6%)	88 (4.4%)	1642 (83.0%)
Topical anti-inflammatory gels, creams or sprays	66 (3.3%)	361 (18.2%)	1552 (78.4%)
Co-codamol or Co-dydramol	165 (8.3%)	343 (17.3%)	1471 (74.3%)
Codeine or Dihydrocodeine	89 (4.5%)	137 (6.9%)	1753 (88.6%)
Tramadol	135 (6.8%)	123 (6.2%)	1721 (87.0%)
Morphine	52 (2.6%)	43 (2.2%)	1884 (95.2%)
Oxycodone	14 (0.7%)	7 (0.4%)	1958 (98.9%)
Nerve pain medications	290 (14.7%)	72 (3.6%)	1617 (81.7%)
Morphine type patches	63 (3.2)	20 (1.0%)	1896 (95.8%)

The use of non-prescription medications was common; 66% buy non-prescription medications for pain (Table 2). The most commonly reported over-the-counter medications for pain were paracetamol (43%), oral anti-inflammatories (such as ibuprofen; 24%), topical anti-inflammatory gels (22%), rubefacients (12%) and natural or herbal remedies (9%).

**Table 2**

<b>Table 2. Medication bought without prescription to help with axSpA-related pain</b>		
	<b>N</b>	<b>%</b>
Oral NSAIDs	402	20.3
Topical anti-inflammatory gels, creams or sprays	358	18.1
Rubefacient	193	9.8
Paracetamol	705	35.6
Aspirin	80	4.0
Co-codamol e.g. Solpadeine	157	7.9
Glucosamine and or Chondroitin	105	5.3
Natural medicine (e.g. Turmeric, Willow Bark)	152	7.7
Don't buy any medicine from supermarket	557	28.1
Other	97	4.9

### **Patient information**

The majority of respondents (76.2%) felt that they had the opportunity at their last few rheumatology clinic visits to discuss issues relating to their AS that are important to them; 15.7% did not and 8.1% were unsure. Although most participants (67.1%) had been provided with an agreed treatment plan for their AS, this was verbal in 55.2%, and only 11.9% had received a written care plan. A quarter (25.6%) of respondents had no agreed treatment plan.

Overall, most participants felt that they had received all (35.8%) or most (31.0%) of the information they needed regarding AS from their rheumatology department. However, a quarter (23.3%) reported that they had received only some of the information, and 10% had not received the information they needed. The most common items participants felt they would like more information on were as follows: coping with fatigue (39%), long-term prognosis (35%), understanding which symptoms should be investigated further (32%), avoiding flares (29%), coping with pain (27%) and how to access other services such as physiotherapy and ophthalmology (20%) (Table 3).

**Table 3**

<b>Table 3: Further information requirements of people with axSpA</b> (Note: Values overlap, as patient can choose more than one answer)		
	<b>n</b>	<b>%</b>
Avoiding and managing flares	572	28.9
Coping with pain	537	27.1
Coping with the fatigue	778	39.3
Coping with the mobility issues	342	17.3
Long term prognosis	687	34.7
Understanding which symptoms should be investigated further	631	31.9
How to access help	404	20.4
Information on patient support	235	11.9
No more information	251	12.7
Other	127	6.4

### **Rheumatology department survey**

#### **Demographics**

Eighty-three out of 172 invited departments participated in the survey, yielding a 48% response rate. The participating centres were from 47 (56.6%) district general hospitals, 28 (33.7%) teaching hospitals, 7 (8.4%) tertiary referral centres and 1 (1.2%) rehabilitation centre. Only one professional from each department completed the survey; the respondents were 73 (88.0%) consultant rheumatologists, 6 (7.2%) physiotherapists, 2 (2.4%) specialist nurses and 2 (2.4%) specialist registrars.

#### **AxSpA clinics and multidisciplinary management**

In 51 centres, (61.5%) there was at least one clinician with a special interest in axSpA, and in 48 (57.8%) there was a dedicated axSpA clinic. In all centres, with one exception, consultant rheumatologists reviewed and led the management of patients with axSpA.

The frequency of rheumatology clinic review varied between units; 9.6% of centres review patients every 3–4 months, 65.1% every 6 months, 1 (1.2%) centre every 9 months and 22.9% annually. In addition, 83% of centres reported that patients could self-refer during flare-ups.

There was a multidisciplinary team (MDT) involved in the management of patients with axSpA in 63.9% of centres. In those units with an axSpA MDT, this included the following members: consultant rheumatologist (98.1%), physiotherapist (100%), rheumatology specialist nurse (86.8%),

occupational therapist (56.6%) and clinical psychologist (7.5%). In addition, 87% of centres reported having regular musculoskeletal (MSK) radiology MDT meetings.

Patients with axSpA often have other extra-articular manifestations requiring input from other specialists. Only 20% of centres had at least one combined clinic for patients with SpA-related conditions; combined Rheumatology–Dermatology (13 centres), Rheumatology–Ophthalmology (3 centres) and Rheumatology–Gastroenterology (5 centres) clinics. However, 80% provided no combined clinics with other medical specialities for their axSpA patients. Eighty-three percent of units had access to specialist orthopaedic spinal surgery for axSpA; of whom, 30% in the same trust, 65% in a tertiary centre and 5% in other centres.

### **Diagnosis and imaging**

Centres were asked about their opinions regarding the axSpA concept and nomenclature. Although 88% of respondents accepted the concept of axSpA as described by ASAS [2], 7.2% did not and 4.8% were unsure. When diagnosing a new patient, 31.7% of rheumatology departments used the term AS, 56.1% axSpA and 12.2% a variety of terms. Whenever a patient fulfilled the ASAS classification criteria for non-radiographic axSpA [2], 72.3% of respondents would use this term, 15.7% would not and 12.1% were unsure. The majority of departments (81.9%) received their new patient referrals from primary care, 12.1% from MSK triage clinics and 6% from other hospital specialists.

The early diagnosis of axSpA relies on specialist imaging modalities, with patients being able to fulfil criteria for axSpA by appropriate features on either X-ray or MRI [2]. In patients presenting with suspected axSpA, 40.3% of the respondents would order an MRI and 23.4% a plain X-ray as the first-line imaging investigation. A third (36.4%) of respondents would request both MRI and X-ray as first-line investigation. All sites had access to MRI, which was on site in 90.9% and off site in 9.1%. The waiting time for MRI scans was 1–3 months for 55.8% and <1 month in 39.0% of centres. However, in 2.6% of centres, the waiting time for MRI scans was >3 months.

When sacroiliac joint X-rays are normal, respondents are able to order MRI in 98.7% of centres. The current consensus is that in suspected axSpA, an MRI of the whole spine and sacro-iliac joints should be performed [18, 19]. Of the responding centres, 53.3% would request a full spine MRI, 9.1% MRI of sacroiliac joints and only 28.6% MRI of the whole spine and sacro-iliac joints.

### **Clinical assessment**

The management of axSpA requires regular disease-specific assessments of disease activity and function. BASDAI was performed routinely by 98.8%, BASFI by 74.1% and BASMI by 65.4% of centres. Fifteen (18.8%) centres also reported routinely assessing work status using the work productivity and activity impairment questionnaire [20]. Overall, 65% of rheumatology departments performed at least three disease-specific assessments (BASDAI, BASMI and BASFI) routinely.

### **Access to treatment and advice**

Anti-TNF therapy and biosimilars. Respondent centres estimated that ~30% (IQR: 22.0–47.5%) of their axSpA patients were currently receiving anti-TNF therapy. Although 39.5% of departments (39.5%) reported restricted ability to prescribe biologic therapies for axSpA, in only 7% of these cases were restrictions genuine, with the majority of restrictions being related to eligibility criteria set by NICE and/or the BSR guidelines [10, 11]. At the time of the survey (before the introduction of s.c. biosimilar TNFi), 57.1% of centres were using biosimilar infliximab, and the majority of respondents felt quite confident (49.4%) or very confident (26.0%) about using biosimilar TNFi.

Non-radiographic axSpA and biologics. Although the survey preceded the publication of the updated NICE guidance and BSR treatment guidelines, 79.2% of respondents reported being able to treat non-radiographic axSpA patients with biologics. Patients can fulfil a diagnosis of non-radiographic axSpA via a number of routes, with evidence for efficacy of TNFi limited to those with positive MRI and/or raised CRP [21–24]. The majority of centres would consider using TNFi to treat non-radiographic axSpA in patients who were MRI positive (98.7%) or MRI negative and CRP positive (25%). Only one centre reported that they would treat patients even if both MRI and CRP were negative.

### **Additional services and information**

Additional physical activity services offered to patients with axSpA include hydrotherapy (on site: 57.1%; off site: 23.4%) and intensive physiotherapy treatment programmes (26%). The main advisory services offered to patients were patient education programmes (52%), employment advice (39%) and driving advice (29.9%). The majority of units also directed patients to NASS (93.5%) or other charity (18.2%) resources.

The majority of responding centres (93.5%) had a patient advice line, aiming to respond the same (25%) or next (62.5%) working day. Just over half the responding centres (55.3%) reported that they were involved in research related to axSpA, although two-thirds (69.7%) contributed data to the BSR biologics registers in ankylosing spondylitis (BSRBR-AS) register [25].

## **DISCUSSION**

Our understanding of axSpA has expanded greatly in the last decade and, in parallel, we have witnessed significant advances in management, including the availability of biological therapies for both AS and axSpA. These advances have driven the development and publication of a number of international and national guidelines relating to disease classification and management of axSpA [2, 11, 26]. An important aspect of health-care delivery is the measurement of quality of care, which should always be considered within a given health-care setting, be multidimensional and reflect all stakeholders. Best possible care should be driven by consensus, evidence, protocols and guidelines accessible to all, and this must encompass adequate measures to drive and maintain quality [27].

Developing quality standards requires information about the status of current services to help this process.

We have attempted to ascertain the level of understanding of new disease nomenclature, care needs and services received by a large cohort of axSpA patients. It is clear that there is a lack of awareness and confidence with the term axSpA among patients, with a majority neither aware of nor confident with the term. Among rheumatologists, 88% accepted the concept of axSpA [2], although only 55% would use this term for a newly diagnosed patient. This indicates that there is a discrepancy between the terminology that rheumatologists use and communicate to their patients and what patients accept and understand. Furthermore, for those diagnosed within the past 5 years, the median delay to diagnosis remains high at 8.5 years; this long interval between symptom onset and diagnosis is consistent with other recent publications [28]. Although the majority were diagnosed by rheumatologists, a few patients report being diagnosed by physiotherapists, which is worrying given that in many areas people with back pain are now triaged by MSK physiotherapists who may not have the expertise or access to the appropriate investigations, including MRI. In addition, very few patients are being diagnosed by other secondary care specialties, which is of concern given the high prevalence of extra-articular manifestations among axSpA patients and the fact that many patients first present with an extra-articular manifestation [2]. These facts all indicate urgent and important educational needs.

Specialist axSpA clinics are offered by only 57% of NHS Trusts, although this figure has improved from 41% in 2011 [9]. Likewise, 61% of Trusts now indicate that they have at least one rheumatologist with a special interest in axSpA, compared with 53% in 2011. Sixty-three per cent now have an MDT with responsibility for axSpA, compared with one-third in 2011. Combined clinics with any other relevant speciality are being offered in only 20% of centres. Although there is a close working relationship with MSK radiologists, only one-third are undertaking the recommended MRI protocol [18]. This fact has also recently been identified by Bennett et al. [19] in a survey of MSK radiologists. Patient-reported outcome measures are now being undertaken in >95% of centres, with 66% performing at least three assessment tools at each visit. Overall, the satisfaction levels with rheumatology care remain high, and >80% of patients are now under the current care of a rheumatologist, which is an improvement from 68% in the 2011 survey [9] and the estimate of 35% reported by Dean et al. [29] in 2016 using population-level data. Patients rely on rheumatology for their on-going care; however, they report difficulty in accessing care and express concerns regarding the need to be seen promptly during flare. This is in contrast with the rheumatologists' view of patients' ability to self-refer during flare. Interestingly, when patients having a flare do access rheumatology, the majority are satisfied with flare management.

Physiotherapy is considered to be a core treatment in axSpA [12]. Surprisingly, only 42% of patients had seen a physiotherapist within the past year and consistently recognize that they do not exercise sufficiently. Patients and rheumatologists alike report good access to biological therapies; one-fifth of patients were receiving TNFi in 2011, and this figure has now increased to between 30 and 40%. However, a considerable number of rheumatologists continue to report restricted access to therapy, although this may have been ameliorated by the subsequent publication of the updated NICE and BSR guidelines for the use of biologics in axSpA [10, 11] and the NICE clinical guidelines for SpA [12].

Three-quarters of rheumatologists were confident with biosimilars and >50% had already gained experience at the time of the survey. The majority of centres are active in axSpA-related research and contribute data to the BSRBR-AS [25]. In general, patients are comfortable with the concept of TNFi, and two-thirds would consider dose tapering; however, there are on-going concerns regarding long-term use of analgesia.

Empowering patients and self-management are key aspects in the management of chronic disease. Integral to this is access to information and education about the disease and management thereof. Only one-third of patients considered that they had received all the information they needed, and key unmet needs included advice on coping with fatigue, information on prognosis, flare management and pain control.

Personalized care planning for long-term conditions empowers individuals, promotes independence and helps people to be more involved in decisions about their care. Personalized care planning is about addressing an individual's full range of needs [30], and development of a care plan is a key NASS objective [31]. However, a written plan is still an exception (12%), although some form of care plan had been discussed with 55% of patients, indicating an on-going educational and long-term disease management need.

Our work has a number of limitations. This survey was carried out in the UK, so the results may not be generalizable to all countries. However, international treatment recommendations are broadly similar throughout Europe and North America, so the principles and issues are relevant and likely to be similar across these areas. The response rate for the unit survey was only 48%, introducing the risk of participation bias. Units or individuals with a specialist interest in axSpA are more likely to respond to an axSpA survey, so the results presented here are likely to represent some of the better-performing units, and results might therefore be worse among non-responders. The anonymization process does not allow us to compare units that responded with non-responders. As highlighted previously, this survey was carried out before the publication of the updated NICE and BSR guidelines for the use of biologics in axSpA [10, 11] and the 2017 NICE spondyloarthritis guidelines [12], so some units may have changed their practice subsequently in response. The forthcoming National Health Quality Improvement Partnership clinical audit of rheumatoid and early arthritis (including axSpA) [8] will serve to identify areas where service improvements are required using criteria derived from NICE and best practice tariffs, together with patient-recorded outcome and experience measures.

Although the NASS survey achieved the response target, there will inevitably be some participation bias in the first 2000 people to respond. Response rates for individual questions also varied, introducing the risk of reporter bias. The responses were self-reported and could not be verified, but as we were primarily interested in people's perceptions of their service, we do not feel that this is a significant issue. A significant proportion of participants had very long disease duration, so may have different experiences, needs and perceptions from those with more recent disease onset. Furthermore, people with axSpA who are NASS members might be more likely to attend

rheumatology services and therefore they might be better informed about new developments and therapies than non-members.

## Conclusion

Although there have been major advances in understanding the concept of axSpA, specifically in relationship to diagnosis and treatment, we have identified significant unmet patient needs, discrepancies and gaps in service provision that will help to inform the development of quality standards.

**Funding:** This work was supported by an educational fund (grant number: AXHUR 161013) from AbbVie. The funder had no role in the design, conduct or analysis of the study.

**Disclosure statement:** K.G. has received research grants, consultancy and speaker fees from AbbVie, Celgene, Pfizer, Union Chimique Belge (UCB), Merck Sharp & Dohme and Novartis. S.S. is a medical advisor for NASS, has received research grant funding from Pfizer, Janssen, Celgene, Bristol-Myers Squibb, UCB and Boehringer Ingelheim, and consultancy/speaker fees from Abbvie, UCB, Pfizer, Janssen, Boehringer Ingelheim, Novartis and UCB. S.D. is employed by the National Ankylosing Spondylitis Society. D.C. is employed by NASS and is the Director of NASS. All other authors have declared no conflicts of interest.

## REFERENCES

- 1 van der Linden S, Valkenburg HA, Cats A. Evaluation of diagnostic criteria for ankylosing spondylitis. A proposal for modification of the New York criteria. *Arthritis Rheum* 1984;27:361–8.
- 2 Rudwaleit M, van der Heijde D, Landewé R et al. The development of Assessment of SpondyloArthritis international Society classification criteria for axial spondyloarthritis (part II): validation and final selection. *Ann Rheum Dis* 2009;68:777–83.
- 3 Poddubnyy D, Rudwaleit M, Haibel H et al. Rates and predictors of radiographic sacroiliitis progression over 2 years in patients with axial spondyloarthritis. *Ann Rheum Dis* 2011;70:1369–74.
- 4 Poddubnyy D, Haibel H, Listing J et al. Baseline radiographic damage, elevated acute-phase reactant levels, and cigarette smoking status predict spinal radiographic progression in early axial spondylarthritis. *Arthritis Rheum* 2012;64:1388–98.
- 5 Toussirot É. Biologics in spondyloarthritis: TNF $\alpha$  inhibitors and other agents. *Immunotherapy* 2015;7:669–81.
- 6 National Institute for Health and Care Excellence. Rheumatoid arthritis in adults: management. <https://www.nice.org.uk/guidance/cg79> (1 June 2017, date last accessed).
- 7 National Institute for Health and Care Excellence. Rheumatoid arthritis in over 16s. <https://www.nice.org.uk/guidance/qs33> (1 June 2017, date last accessed).

- 8** Healthcare Quality Improvement Partnership. <http://www.hqip.org.uk/> (1 June 2017, date last accessed).
- 9** Hamilton L, Gilbert A, Skerrett J, Dickinson S, Gaffney K. Services for people with ankylosing spondylitis in the UK—a survey of rheumatologists and patients. *Rheumatology* 2011;50:1991–8.
- 10** National Institute for Health and Care Excellence. TNF-alpha inhibitors for ankylosing spondylitis and non-radiographic apic axial spondyloarthritis. 2016. pp. 1–70. <https://www.nice.org.uk/guidance/ta383> (1 June 2017, date last accessed).
- 11** Hamilton L, Barkham N, Bhalla A et al. BSR and BHPR guideline for the treatment of axial spondyloarthritis (including ankylosing spondylitis) with biologics. *Rheumatology* 2017;56:313–6.
- 12** National Institute for Health and Care Excellence. Spondyloarthritis in over 16s: diagnosis and management. 2017. <https://www.nice.org.uk/guidance/ng65> (1 June 2017, date last accessed).
- 13** Ankylosing Spondylitis International Federation, List of current members, <http://www.asif.info/en/index.cfm/member-organisations/list-of-members/> (1 June 2017, date last accessed).
- 14** NHS Health Research Authority. Determine whether your study is research. <http://www.hra.nhs.uk//research-community/before-you-apply/determine-whether-your-study-is-research/> (1 June 2017, date last accessed).
- 15** Stone MA, Pomeroy E, Keat A et al. Assessment of the impact of flares in ankylosing spondylitis disease activity using the Flare Illustration. *Rheumatology* 2008;47:1213–8.
- 16** Cooksey R, Brophy S, Gravenor MB et al. Frequency and characteristics of disease flares in ankylosing spondylitis. *Rheumatology* 2010;49:929–32.
- 17** Cooksey R, Brophy S, Dennis M et al. Severe flare as a predictor of poor outcome in ankylosing spondylitis: a cohort study using questionnaire and routine data linkage. *Rheumatology* 2015;54:1563–72.
- 18** Mandl P, Navarro-Compán V, Terslev L et al. EULAR recommendations for the use of imaging in the diagnosis and management of spondyloarthritis in clinical practice. *Ann Rheum Dis* 2015;74:1327–39.
- 19** Bennett AN, Marzo-Ortega H, Kaur-Papadakis D, Rehman A. BRITSpA. The use of magnetic resonance imaging in axial spondyloarthritis: time to bridge the gap between radiologists and rheumatologists. *J Rheumatol* 2017;44:780–5.
- 20** Reilly MC, Gooch KL, Wong RL, Kupper H, van der Heijde D. Validity, reliability and responsiveness of the Work Productivity and Activity Impairment Questionnaire in ankylosing spondylitis. *Rheumatology* 2010;49:812–9.
- 21** Sieper J, van der Heijde D, Dougados M et al. Efficacy and safety of adalimumab in patients with non-radiographic axial spondyloarthritis: results of a randomised placebo-controlled trial (ABILITY-1). *Ann Rheum Dis* 2013;72:815–22.
- 22** Landewé R, Braun J, Deodhar A et al. Efficacy of certolizumab pegol on signs and symptoms of axial spondyloarthritis including ankylosing spondylitis: 24-week results of a double-blind randomised placebo-controlled Phase 3 study. *Ann Rheum Dis* 2014;73:39–47.

- 23** Dougados M, van der Heijde D, Sieper J et al. Symptomatic efficacy of etanercept and its effects on objective signs of inflammation in early nonradiographic axial spondyloarthritis: a multicenter, randomized, double-blind, placebo-controlled trial. *Arthritis Rheumatol* 2014;66:2091–102.
- 24** Sieper J, van der Heijde D, Dougados M et al. A randomized, double-blind, placebo-controlled, sixteen-week study of subcutaneous golimumab in patients with active nonradiographic axial spondyloarthritis. *Arthritis Rheumatol* 2015;67:2702–12.
- 25** Macfarlane GJ, Barnish MS, Jones EA et al. The British Society for Rheumatology Biologics Registers in Ankylosing Spondylitis (BSRBR-AS) study: Protocol for a prospective cohort study of the long-term safety and quality of life outcomes of biologic treatment. *BMC Musculoskelet Disord* 2015;16:347.
- 26** Ward MM, Deodhar A, Akl EA et al. American College of Rheumatology/Spondylitis Association of America/Spondyloarthritis Research and Treatment Network 2015 Recommendations for the Treatment of Ankylosing Spondylitis and Nonradiographic Axial Spondyloarthritis. *Arthritis Rheumatol* 2016;68:282–98.
- 27** Zochling J, Braun J. Quality indicators, guidelines and outcome measures in ankylosing spondylitis. *Clin Exp Rheumatol* 2007;25(6 Suppl 47):147–52.
- 28** Sykes MP, Doll H, Sengupta R, Gaffney K. Delay to diagnosis in axial spondyloarthritis: are we improving in the UK? *Rheumatology* 2015;54:2283–4.
- 29** Dean LE, Macfarlane GJ, Jones GT. Differences in the prevalence of ankylosing spondylitis in primary and secondary care: only one-third of patients are managed in rheumatology. *Rheumatology* 2016;55:1820–5.
- 30** Department of Health. Personalised care planning: information sheet 1. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215946/dh\\_124048.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215946/dh_124048.pdf) (1 June 2017, date last accessed).
- 31** National Ankylosing Spondylitis Society. 2015–2019 Strategy. <http://nass.co.uk/about-nass/2015-2019-strategy/> (1 June 2017, date last accessed).