NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Spondyloarthritis

Output: Prioritised quality improvement areas for development.

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Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for spondyloarthritis. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

Spondyloarthritis in over 16s: diagnosis and management. NICE guideline NG65.

Published February 2017. Recommendation 1.2.7 was amended in July 2017 to clarify advice on what magnetic resonance imaging should be done.

2 Overview

2.1 Focus of quality standard

This quality standard will cover diagnosis and management of spondyloarthritis in adults who are 16 years or older.

2.2 Definition

Spondyloarthritis is a group of inflammatory conditions that have a range of manifestations. Spondyloarthritis may be predominantly:

- axial:
    - radiographic axial spondyloarthritis (ankylosing spondylitis)
    - non-radiographic axial spondyloarthritis or
- peripheral:
    - psoriatic arthritis
    - reactive arthritis
    - enteropathic spondyloarthritis.

People with predominantly axial spondyloarthritis may have additional peripheral symptoms, and vice versa.

2.3 Incidence and prevalence

Spondyloarthritis has a reported prevalence in Western Europe of between 0.8% and 1.7%, and is more common than rheumatoid arthritis. Most people with spondyloarthritis have either psoriatic arthritis or axial spondyloarthritis, which includes ankylosing spondylitis. The resource impact report supporting the guideline estimates the prevalence of diagnosed axial spondyloarthritis as 1.25% of the adult population.

Less common subgroups are enteropathic spondyloarthritis, which is associated with inflammatory bowel disease (Crohn's disease and ulcerative colitis), and reactive arthritis, which can occur in people after gastrointestinal or genitourinary infections. The final subgroup is people who have undifferentiated spondyloarthritis

2.4 Management

Prompt diagnosis of spondyloarthritis is a challenge. Healthcare professionals in non-specialist settings do not always recognise the signs and symptoms of spondyloarthritis. This can lead to substantial delays in diagnosis and treatment with consequent disease progression and disability. Some forms of spondyloarthritis are estimated to take 8 to 10 years to diagnose.

Once spondyloarthritis is suspected, patients are referred to a rheumatologist for investigation, diagnosis and management. A range of tests and tools can be used to investigate further to reach a diagnosis, but no single sign, symptom or test is useful for diagnosis in isolation of other information.

Management is usually based on which joints (axial or peripheral) are most affected and includes:

- physiotherapy and other manual therapies
- analgesics
- non-steroidal anti-inflammatory drugs (NSAIDs)
- corticosteroids
- standard disease-modifying anti-rheumatic drugs (DMARDs)
- biological disease-modifying anti-rheumatic drugs, such as tumour necrosis factor (TNF) inhibitors
- surgery (including joint replacement and spinal surgery)

2.5 Resource impact

The resource impact report for the development source, NICE guideline NG65, identified that implementation is anticipated to raise awareness of spondyloarthritis among GPs. This should result in people being referred with suspected spondyloarthritis to a specialist earlier and therefore diagnosed sooner.

There are no available data on undiagnosed axial spondyloarthritis therefore illustrative calculations were provided in the report which set out the anticipated cost per each additional 1,000 people diagnosed with spondyloarthritis earlier. These costs would have always have been incurred by the NHS. However, the impact of the guideline was estimated to bring costs forward by identifying people for appropriate treatment earlier than is current practice.

Assumptions were made about cost of diagnosis and the proportion of people receiving NSAIDs, TNF-alpha inhibitors, chronic pain management, physiotherapy and hydrotherapy. The cost for 1,000 additional people diagnosed was estimated to be £2.2m in the first year and £2.6m from the second year onwards.

The benefits from implementing the guideline are expected to include increased quality of life, reduced disease progression and disability and reduced inappropriate investigations and treatments. It was assumed that 10% of people with undiagnosed spondyloarthritis would otherwise have been receiving chronic pain management and so the cost of this is saved.

2.6 National outcome frameworks

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS outcomes framework 2016–17

Domain	**Overarching indicators and improvement areas**
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition **Improving functional ability in people with long-term conditions** 2.2 Employment of people with long-term conditions*, ** **Enhancing quality of life for carers** 2.4 Health-related quality of life for carers** **Improving quality of life for people with multiple long-term conditions** *2.7 Health-related quality of life for people with three or more long-term conditions***
4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4a Patient experience of primary care i GP services 4b Patient experience of hospital care 4c *Friends and family test* *4d Patient experience characterised as poor or worse* *I Primary care* *ii Hospital care* ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving hospitals' responsiveness to personal needs** 4.2 Responsiveness to inpatients' personal needs **Improving access to primary care services** 4.4 Access to i GP services
Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 2 Public health outcomes framework for England, 2016–2019

Domain	Objectives and indicators
1 Improving the wider determinants of health	***Objective*** Improvements against wider factors which affect health and wellbeing and health inequalities ***Indicators*** 1.08 Employment for those with long-term health conditions including adults with a learning disability or who are in contact with secondary mental health services*, **
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities ***Indicators*** 2.23 Self-reported well-being
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities ***Indicators*** 4.13 Health-related quality of life for older people
Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 3 Adult social care outcomes framework 2016–17

Domain	Overarching and outcome measures
1 Enhancing quality of life for people with care and support needs	***Overarching measures*** 1A Social care-related quality of life** ***Outcome measures*** **People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation**
2 Delaying and reducing the need for care and support	***Overarching measure*** 2A Long-term support needs met by admission to residential and nursing care homes, per 100,000 population ***Outcome measures*** **Everybody has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs** **Earlier diagnosis, intervention and reablement means that people and their carers are less dependent on intensive services**

Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework

* Indicator is shared

** Indicator is complementary

3 Summary of suggestions

3.1 Responses

In total, 22 stakeholders (including specialist committee members) responded to the 2-week engagement exercise 03/10/17–17/10/17.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 4 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendix 3 for information.

Table 4 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Recognition and referral	AbbVie, BSR, BRIT-PACT, LTH, RCGP, SCM1, SCM2, SCM3, SCM4, SCM5, TH, UCB, UHS
Diagnosis	
• Investigations	AbbVie, SCM1, SCM2, SCM3
• Imaging	BSS, PCRS, SCM1, SCM5, UCB, UHS
Management	
• Non-pharmacological management	AbbVie, BSS, CSP, SCM3, SCM5, LTH, PRCA, UHS
• Pharmacological management	Celgene, SCM4
• Managing flares	BSS, LTH, SCM2, SCM3, SCM4, SCM5
Information & support	BSR, SCM2, SCM4, SCM5, SCM6
Organising care	BRIT-PACT, BSS, LTH, MHL, PCRS, PRCA, UHS
Additional areas	
• Assessment for gut inflammation	AbbVie
• Examining for extra articular manifestations	AbbVie
• Multidisciplinary teams	AbbVie, UCB, SCM4, SCM5, SCM6
• Shared decision making	BSR
• Care plans	BSR
• Measuring outcomes / participation in research and audit	BRIT-PACT

Suggested area for improvement	Stakeholders
- Incentivised GP assessments for psoriatic arthritis	Celgene
- Monitoring of disease / assessment of comorbidities	PCRS, SCM3, TH, UHS
- Treat To Target	SCM3

AbbVie, AbbVie Ltd
BRIT-PACT, British Psoriatic Arthritis ConsorTium
BSR, British Society for Rheumatology
BSS, British Society for Spondyloarthritis
Celgene, Celgene UK Ltd
CSP, Chartered Society of Physiotherapy
LTH, Leeds Teaching Hospitals NHS Trust
MHL, Moorlands Home Link
PCRS, Primary Care Rheumatology Society
PRCA, Podiatry Rheumatic Care Association
RCGP, Royal College of General Practitioners
RCN, Royal College of Nursing
SCM, Specialist Committee Member
TH, Torbay Hospital
UCB, UCB Pharma Ltd
UHS, University Hospitals Southampton

Notes
Comments from SCM2 were submitted jointly on behalf of the Psoriasis and Psoriatic Arthritis Alliance
Comments from SCM5 were submitted jointly on behalf of the National Ankylosing Spondylitis Society
2 stakeholders responded to topic engagement but did not wish to make further comments at this stage:

- Merck Sharp & Dohme Ltd
- Royal College of Nursing

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1639 papers were identified for spondyloarthritis. In addition, 84 papers were suggested by stakeholders at topic engagement and 8 papers internally at project scoping.

Of these papers, 8 have been included in this report and are included in the current practice sections where relevant. Appendix 2 outlines the search process.

4 Suggested improvement areas

4.1 Recognition and referral

4.1.1 Summary of suggestions

Stakeholders identified delays in diagnosis as a key area for quality improvement. Spondyloarthritis can have diverse symptoms and be difficult to identify; and therefore improved recognition is required by GPs and other healthcare professionals to ensure referral to a rheumatologist and reduce delays in diagnosis.

Some stakeholders suggested the key focus was recognition and early referral for peripheral spondyloarthritis; up to 50% of psoriatic arthritis cases remain unrecognised according to one stakeholder. Others suggested the specific focus should be axial spondyloarthritis, as this is often confused with low back pain and time to diagnosis can be 8-9 years.

Onward referral by specialists outside rheumatology, such as ophthalmologists, gastroenterologists and dermatologists, was highlighted as a key area by a stakeholder. Such specialists may be treating extra-articular manifestations (such as uveitis, psoriasis and inflammatory bowel disease) but not recognising the relationship with spondyloarthritis.

4.1.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

Statement 5 of the psoriasis quality standard already covers an annual assessment for psoriatic arthritis. Recommendations relating to subsequent referral from the psoriasis: assessment and management guideline are included below, as no statement covers this.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Recognition and referral	**Referral for suspected axial spondyloarthritis** NICE NG65 Recommendations 1.1.5, 1.1.6 **Referral for suspected psoriatic arthritis and other peripheral spondyloarthritides**

	NICE NG65 Recommendations 1.1.8 to 1.1.10 **Assessment and referral for psoriatic arthritis** NICE CG153 Recommendation 1.2.2.3 **Case-finding in people with acute anterior uveitis** NICE NG65 Recommendation 1.1.14

Referral for suspected axial spondyloarthritis

NICE NG65 – Recommendation 1.1.5

If a person has low back pain that started before the age of 45 years and has lasted for longer than 3 months, refer the person to a rheumatologist for a spondyloarthritis assessment if 4 or more of the following additional criteria are also present:

- low back pain that started before the age of 35 years (this further increases the likelihood that back pain is due to spondyloarthritis compared with low back pain that started between 35 and 44 years)
- waking during the second half of the night because of symptoms
- buttock pain
- improvement with movement
- improvement within 48 hours of taking non-steroidal anti-inflammatory drugs (NSAIDs)
- a first-degree relative with spondyloarthritis
- current or past arthritis
- current or past enthesitis
- current or past psoriasis.

If exactly 3 of the additional criteria are present, perform an HLA‑B27 test. If the test is positive, refer the person to a rheumatologist for a spondyloarthritis assessment.

NICE NG65 – Recommendation 1.1.6

If the person does not meet the criteria in recommendation 1.1.5 but clinical suspicion of axial spondyloarthritis remains, advise the person to seek repeat assessment if new signs, symptoms or risk factors listed in recommendation 1.1.5 develop. This may be especially appropriate if the person has current or past inflammatory bowel disease (Crohn's disease or ulcerative colitis), psoriasis or uveitis (see recommendation 1.1.12 for guidance on referral for immediate [same‑day] ophthalmological assessment for people with acute anterior uveitis).

Referral for suspected psoriatic arthritis and other peripheral spondyloarthritides

NICE NG65 – Recommendation 1.1.8

Urgently refer people with suspected new‑onset inflammatory arthritis to a rheumatologist for a spondyloarthritis assessment, unless rheumatoid arthritis, gout or acute calcium pyrophosphate (CPP) arthritis ('pseudogout') is suspected. If rheumatoid arthritis is suspected, see referral for specialist treatment in the NICE guideline on rheumatoid arthritis in adults.

NICE NG65 – Recommendation 1.1.9

Refer people with dactylitis to a rheumatologist for a spondyloarthritis assessment.

NICE NG65 – Recommendation 1.1.10

Refer people with enthesitis without apparent mechanical cause to a rheumatologist for a spondyloarthritis assessment if:

- it is persistent or
- it is in multiple sites or
- any of the following are also present:
    - back pain without apparent mechanical cause
    - current or past uveitis (see recommendation 1.1.12 for guidance on immediate [same‑day] ophthalmological assessment for people with acute anterior uveitis)
    - current or past psoriasis
    - gastrointestinal or genitourinary infection
    - inflammatory bowel disease (Crohn's disease or ulcerative colitis)
- a first-degree relative with spondyloarthritis or psoriasis.

Assessment and referral for psoriatic arthritis

NICE CG153 – Recommendation 1.2.2.3

As soon as psoriatic arthritis is suspected, refer the person to a rheumatologist for assessment and advice about planning their care. Also see the NICE guideline on spondyloarthritis in over 16s.

Case-finding in people with acute anterior uveitis

NICE NG65 – Recommendation 1.1.14

If the person meets either of the criteria in recommendation 1.1.13, establish whether they have psoriasis or skin complaints that appear psoriatic on physical examination

- If they do, refer the person to a rheumatologist for a spondyloarthritis assessment.
- If they do not, perform an HLA‑B27 test. If the test is positive, refer the person to a rheumatologist for a spondyloarthritis assessment.

4.1.3 Current UK practice

Current practice information identified relates either to axial or peripheral spondyloarthritis.

Axial spondyloarthritis

Results from a survey of rheumatologists and people with ankylosing spondylitis[1] were published in 2011. Two thousand non-health-care professional members of the National Ankylosing Spondylitis Society (NASS) were sent a questionnaire asking about their experiences surrounding diagnosis, treatment and access to therapies (response rate 40%). A separate questionnaire was sent to a consultant rheumatologist at every acute NHS trust in the UK, asking about services offered to patients with ankylosing spondylitis (response rate 68%). The survey found that there was a mean delay between a person consulting a health care professional with symptoms and diagnosis of 8.57 years.

A survey of GPs in Leicestershire[2] (151 respondents) found that only 35% were confident in diagnosing inflammatory back pain. Failure to recognise inflammatory back pain can lead to delays in referral and diagnosis of axial spondyloarthritis. Results published in 2013 also found that patients visited a GP on average 3 times before being referred to secondary care, with an average delay of 9 months.

A survey of all GPs in Norfolk[3], covering a population of 0.5 million people, found inconsistencies in their perceptions and approach to the diagnosis and management of ankylosing spondylitis. A response rate of 62% was achieved (186 GPs). Only 5% of GPs could identify all eight features indicative of inflammatory back pain and there

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[1] Hamilton L, Gilbert A, Skerrett J, Dickinson S, Gaffney K (2011) Services for people with ankylosing spondylitis in the UK—a survey of rheumatologists and patients. Rheumatology 50(11), 1991–1998,

[2] Moorthy A, Joseph C (2013) Is there a Knowledge Gap in Diagnosing Inflammatory Back Pain in Primary Care? - Regional Survey Among GPs in Leicestershire, UK. Annals of the Rheumatic Diseases 72 (Suppl. 3): THU0507(Abstract)

[3] Jois R et al (2008) Recognition of inflammatory back pain and ankylosing spondylitis in primary care. Rheumatology 47(9), 1364–1366

were different views regarding the utility of a positive family history, HLA-B27, use of X-ray and physiotherapy in patients with suspected inflammatory back pain. For example, whilst most GPs felt the HLA-B27 test was important, 18% never checked it and 33% rarely checked it in routine clinical practice.

NASS carried out a State of the Nation Survey in 2016 and submitted findings in response to topic engagement (see appendix 2). The survey asked participants diagnosed with axial spondyloarthritis within the past 5 years questions about their journey to diagnosis. Of the 488 respondents, 38% saw a healthcare professional within 6 months of symptom onset and 28% waited 3 years or more before seeking medical attention. The interval between seeing a healthcare professional about their symptoms and obtaining a formal diagnosis also varied with a median delay of 8.5 years reported between symptom onset and diagnosis. The final diagnosis was made by rheumatologists in 87% of cases, and by primary care physicians in 6% of cases.

Peripheral spondyloarthritis

A survey of adults with psoriasis managed in primary care[4] was conducted in Scotland over 12 months between 2012 and 2013. The survey covered 27 GP practices in the West of Scotland, and 905 patients completed the survey. Patients invited to participate completed a Psoriasis Epidemiology Screening Tool (PEST) questionnaire. According to PEST scores, 259 patients (28.6 %) had symptoms suggestive of psoriatic arthritis requiring rheumatology referral. However, 109 of these patients did not have a recorded diagnosis of psoriatic arthritis. The study suggested this may be due to the absence of a referral to a rheumatologist and a lack of a definitive diagnosis.

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[4] Wade et al (2016) Severity and management of psoriasis within primary care. BMC Family Practice 17, 145

4.2 Diagnosis

4.2.1 Summary of suggestions

Investigations

The importance of making a diagnosis was emphasised as this helps ensure effective treatment, and allows people to plan and make life decisions. Stakeholders identified investigations of people with suspected spondyloarthritis in secondary care as a key area for quality improvement. Diagnoses can be missed, even by generalist rheumatologists, as protocols for investigating spondyloarthritis are different to other types of arthritis.

A stakeholder suggested there is a common misunderstanding about diagnostic investigations where spondyloarthritis is ruled out on the basis of negative blood tests for HLA B27 and a lack of raised inflammatory markers.

Imaging

Imaging was suggested as a key area for both axial and peripheral spondyloarthritis. Some stakeholders identified the full sequence of imaging, from initial investigations using plain film x-ray to subsequent investigations using ultrasound and magnetic resonance imaging (MRI), as the key area.

MRI for suspected axial spondyloarthritis was suggested as the key area for improvement by some stakeholders. Comments stated that the MRI protocol differs from standard lumbar spine MRI protocols, and that requesting the wrong type of imaging will lead to delays in diagnosis. The importance of having access to expert musculoskeletal radiologists was also highlighted by stakeholders.

Imaging for suspected psoriatic arthritis and other peripheral spondyloarthritides was also suggested as a key area for improvement. A stakeholder noted that there is a tendency for psoriatic arthritis / peripheral spondyloarthritis to be investigated like rheumatoid arthritis, but this can miss active psoriatic arthritis / peripheral spondyloarthritis outside of the hands and feet.

One stakeholder suggested initial imaging should commence in primary care, with requests for plain film imaging accompanying referrals for specialist assessments of spondyloarthritis.

4.2.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the committee’s discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Investigations	**Diagnostic criteria for suspected spondyloarthritis** NICE NG65 recommendations 1.2.2, 1.2.3 **Antibody testing for suspected reactive arthritis** NICE NG65 recommendation 1.2.16
Imaging	**Imaging for suspected axial spondyloarthritis** **Initial investigation using X‑ray** NICE NG65 recommendation 1.2.4 to 1.2.6 **Subsequent investigation using MRI** NICE NG65 recommendation 1.2.7 to 1.2.8 **Other types of imaging for diagnosing axial spondyloarthritis** NICE NG65 recommendation 1.2.10 **Imaging for suspected psoriatic arthritis and other peripheral spondyloarthritides** NICE NG65 recommendations 1.2.11, 1.2.14, 1.2.15

Diagnostic criteria for suspected spondyloarthritis

NICE NG65 – Recommendation 1.2.2

Do not rule out a diagnosis of spondyloarthritis solely on the basis of a negative HLA‑B27 result.

NICE NG65 – Recommendation 1.2.3

Do not rule out a diagnosis of spondyloarthritis if a person's C‑reactive protein (CRP) and erythrocyte sedimentation rate (ESR) are normal.

Antibody testing for suspected reactive arthritis

NICE NG65 – Recommendation 1.2.16

Do not routinely test for infective antibody status to diagnose reactive arthritis in people with a history of gastrointestinal infection.

Imaging for suspected axial spondyloarthritis

Initial investigation using X‑ray

NICE NG65 – Recommendation 1.2.4

Offer plain film X‑ray of the sacroiliac joints for people with suspected axial spondyloarthritis, unless the person is likely to have an immature skeleton.

NICE NG65 – Recommendation 1.2.5

Diagnose radiographic axial spondyloarthritis (ankylosing spondylitis) if the plain film X‑ray shows sacroiliitis meeting the modified New York criteria (bilateral grade 2–4 or unilateral grade 3–4 sacroiliitis).

NICE NG65 – Recommendation 1.2.6

If the plain film X‑ray does not show sacroiliitis meeting modified New York criteria (bilateral grade 2–4 or unilateral grade 3–4 sacroiliitis), or an X‑ray is not appropriate because the person's skeleton is not fully mature, request unenhanced MRI using an inflammatory back pain protocol.

Subsequent investigation using MRI

NICE NG65 – Recommendation 1.2.7

Radiologists receiving a request for an inflammatory back pain MRI should perform short T1 inversion recovery (STIR) and T1 weighted sequences of the whole spine (sagittal view), and sacroiliac joints (coronal oblique view).

NICE NG65 – Recommendation 1.2.8

Use the ASAS/Outcome Measures in Rheumatology (OMERACT) MRI criteria to interpret the MRI as follows:

- If the MRI meets the ASAS/OMERACT MRI criteria:
  - Diagnose non-radiographic axial spondyloarthritis.
- If the MRI does not meet the ASAS/OMERACT MRI criteria:
  - do not exclude the possibility of axial spondyloarthritis
  - consider specialist musculoskeletal radiology review if there is disparity between the clinical suspicion and imaging findings, particularly in people with an immature skeleton
  - offer an HLA‑B27 test if it has not already been done. If positive, base the diagnosis of non-radiographic axial spondyloarthritis on clinical features, for example, using the clinical 'arm' of the ASAS axial classification criteria.

Other types of imaging for diagnosing axial spondyloarthritis

NICE NG65 – Recommendation 1.2.10

Do not offer scintigraphy for people with suspected axial spondyloarthritis.

Imaging for suspected psoriatic arthritis and other peripheral spondyloarthritides

NICE NG65 – Recommendation 1.2.11

Offer plain film X-ray of symptomatic hands and feet for people with suspected peripheral spondyloarthritis in these areas.

NICE NG65 – Recommendation 1.2.14

Interpret a positive HLA-B27 result as increasing the likelihood of peripheral spondyloarthritis.

NICE NG65 – Recommendation 1.2.15

If a diagnosis of peripheral spondyloarthritis is confirmed, offer plain film X-ray of the sacroiliac joints to assess for axial involvement, even if the person does not have any symptoms.

4.2.3 Current UK practice

Investigations

A survey of all GPs in Norfolk[5], found inconsistencies in their perceptions and approach to the diagnosis and management of ankylosing spondylitis. There were different views regarding the utility of a positive family history, HLA-B27 and use of X-ray. For example, whilst most GPs felt the HLA-B27 test was important, 17.7% never checked it and 32.7% rarely checked it in routine clinical practice.

Imaging

A survey of UK radiologists[6] was undertaken to describe current practice in the use of MRI for assessment of axial spondyloarthritis. Results from 269 radiologists showed that 11% used contrast as standard, 91% used T1 and short-tau inversion recovery, and 64% also used T2 sequences. Of the respondents, 5% scanned only sacroiliac joint; 33% scanned sacroiliac joint and lumbar spine; 29% scanned

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[5] Jois R et al (2008) Recognition of inflammatory back pain and ankylosing spondylitis in primary care. Rheumatology 47(9), 1364–1366

[6] Bennett A, Marzo-Ortega H, Kaur-Papadakis D, Rehman A (2017) The Use of Magnetic Resonance Imaging in Axial Spondyloarthritis: Time to Bridge the Gap Between Radiologists and Rheumatologists. The Journal of Rheumatology 44(6), 780-785

sacroiliac joint and thoracolumbar spine; and 30% scanned sacroiliac joint and the whole spine. 18% of radiologists did not use the subchondral bone marrow edema of the sacroiliac joint to help diagnose axial spondyloarthritis and 18% did not use the inflammatory vertebral corner lesions to assist diagnosis. Awareness of axial spondyloarthritis was reported by 75% of radiologists, and awareness of definitions for positive MRI of sacroiliac joint and spine by 31% and 25%, respectively.

A survey of consultant rheumatologists[7] at all acute trusts in the UK explored professional views and service delivery relating to axial spondyloarthritis. The 2016 survey achieved a response rate of 48% (83 out of 172 consultants).The results showed that the first-line investigation is MRI in 37% of departments; X-ray in 22%; and both in 34% of departments. When requesting MRI scans, 53% of radiologists said they ask for full spine, 9% sacroiliac joint, and 29% both, while 9% would request other sequences.

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[7] Derakhshan MH Et al (2017) What services do rheumatology departments offer axial spondyloarthritis patients in the UK? Rheumatology Volume 56 (Suppl 2), 109

4.3 Management

4.3.1 Summary of suggestions

Management of spondyloarthritis was identified as a key area for quality improvement by stakeholders. General suggestions included early and evidence based treatment to improve outcomes. Specific examples have been summarised under sub-headings below.

Non-pharmacological management

Access to specialist physiotherapy and to hydrotherapy was suggested by stakeholders as a key area for quality improvement. Comments stated that specialist physiotherapy is a key non-pharmacological management strategy, especially for the treatment of axial spondyloarthritis. Physiotherapy can reduce the impact of the disease, maintain function and quality of life.

Other suggestions by stakeholders included self-management activities (such as exercise programmes) and involvement of other specialties including occupational therapy, podiatry and clinical psychology.

Pharmacological management

A stakeholder highlighted NSAIDs in conjunction with a gastro-protective agent as a key area for quality improvement. NSAIDs are the first-line pharmacological strategy in the management of axial spondyloarthritis. The stakeholder suggested that recent publicity about NSAID side effects could lead to reluctance to offer regular NSAID, or switching to alternative NSAID with higher cardiovascular risk.

Some stakeholders suggested pharmacological areas that are too broad to address through a quality statement.

Managing flares

Stakeholders recognised that flares of spondyloarthritis can occur and therefore people need to be able to access services to manage them quickly. Flares were described as a period where there is the fastest deterioration of physical function; greatest level of progressive joint damage; and highest impact on work and social life. Flare management plans were suggested by some stakeholders as a way of making the greatest impact, but provision of plans was described as variable.

4.3.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Non-pharmacological management	**Non-pharmacological management of spondyloarthritis** NICE NG65 recommendation 1.5.1
Pharmacological management	**Pharmacological management of spondyloarthritis** **Axial spondyloarthritis** **NSAIDs** NICE NG65 recommendation 1.4.1
Managing flares	**Information about disease flares** NICE NG65 recommendations 1.3.3 and 1.3.5 **Managing flares** NICE NG65 recommendations 1.7.1 to 1.7.2

Non-pharmacological management of spondyloarthritis

NICE NG65 – Recommendation 1.5.1

Refer people with axial spondyloarthritis to a specialist physiotherapist to start an individualised, structured exercise programme, which should include:

- stretching, strengthening and postural exercises
- deep breathing
- spinal extension
- range of motion exercises for the lumbar, thoracic and cervical sections of the spine
- aerobic exercise.

Pharmacological management of spondyloarthritis

Axial spondyloarthritis

NSAIDs

NICE NG65 – Recommendation 1.4.1

Offer NSAIDs at the lowest effective dose to people with pain associated with axial spondyloarthritis, and think about appropriate clinical assessment, ongoing monitoring of risk factors, and the use of gastroprotective treatment.

Information about disease flares

NICE NG65 – Recommendation 1.3.3

Advise people with spondyloarthritis about the possibility of experiencing flare episodes and extra-articular symptoms.

NICE NG65 – Recommendation 1.3.5

When discussing any flare management plan, provide information on:

- access to care during flares (including details of a named person to contact [for example, a specialist rheumatology nurse])
- self-care (for example, exercises, stretching and joint protection)
- pain and fatigue management
- potential changes to medicines
- managing the impact on daily life and ability to work.

Managing flares

NICE NG65 – Recommendation 1.7.1

Manage flares in either specialist care or primary care depending on the person's needs.

NICE NG65 – Recommendation 1.7.2

When managing flares in primary care, seek advice from specialist care as needed, particularly for people who:

- have recurrent or persistent flares
- are taking biological DMARDs
- have comorbidities that may affect treatment or management of flares.

4.3.3 Current UK practice

Non-pharmacological management

The BSR / HQIP national clinical audit for rheumatoid and early inflammatory arthritis covered patients aged 16 and over who presented for the first time in rheumatology departments where early inflammatory arthritis was suspected (following an assessment within the clinic). The audit included patients with rheumatoid arthritis, psoriatic arthritis, spondyloarthropathy with peripheral arthritis and undifferentiated arthritis. Nationally, 129 rheumatology providers participated in the audit. Of those, 72% had access to physiotherapy, 76% access to occupational therapy and 51% had access to podiatry.

The 2016 NASS State of the Nation Survey found that only 46% of respondents had seen a physiotherapist for their ankylosing spondylitis in the last 12 months.

An earlier published survey of NASS members[8] in 2013 was completed by 1630 people with ankylosing spondylitis. Results showed that 60% of patients had not been able to access physiotherapy during the previous 12 months.

Results from a survey of rheumatologists and people with ankylosing spondylitis[9] published in 2011 showed that 57% of rheumatology departments offered hydrotherapy on-site, and 24% off-site. The survey of people with ankylosing spondylitis showed that 28% had not been seen by a physiotherapist in the last year; 6% had never been seen by a physiotherapist; and 38% could not self-refer during a flare.

Pharmacological management

A survey of consultant rheumatologists[10] at UK acute trusts explored professional views and service delivery relating to axial spondyloarthritis. The 2016 survey achieved a response rate of 48% (83 out of 172 consultants). Respondents reported that 30% of their axial spondyloarthritis patients were receiving anti-TNF therapy, however 39% reported restricted access. Seventy-nine percent treat non-radiographic axial spondyloarthritis with biologics; 97% treat MRI-positive patients, 25% MRI-negative / CRP-positive; only one centre would treat if MRI negative/CRP negative.

Managing flares

The 2016 NASS State of the Nation Survey found that 27.2% of respondents were able to self-refer to physiotherapy during a flare-up of their ankylosing spondylitis. The 2011 survey of rheumatologists and people with ankylosing spondylitis reported that 82% of rheumatology departments said patients could self-refer if they experienced a flare.

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[8] Dickinson S, Gaffney K, Cook D (2014) Current Management of Ankylosing Spondylitis in the UK: The Patient Perspective. Rheumatology 53 (Suppl. 1), i143

[9] Hamilton L, Gilbert A, Skerrett J, Dickinson S, Gaffney K (2011) Services for people with ankylosing spondylitis in the UK—a survey of rheumatologists and patients. Rheumatology 50(11), 1991–1998

[10] Derakhshan MH Et al (2017) What services do rheumatology departments offer axial spondyloarthritis patients in the UK? Rheumatology Volume 56 (Suppl 2), 109

4.4 *Information & support*

4.4.1 Summary of suggestions

Stakeholders said that information and education should be on-going, personalised and relate to the stage of a person's condition. This can help to ensure a person is actively involved in their own healthcare. Suggestions for the content included information about the diagnosis, prognosis, treatment and contact details of an appropriate patient support group. One stakeholder suggested advice on coping with fatigue is a key unmet information need, adding that fatigue is described as burdensome as pain by patients, but is often not discussed in appointments.

4.4.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 8 to help inform the committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Information & support	**Information about spondyloarthritis** NICE NG65 Recommendation 1.3.1, 1.3.2 **Information about disease flares** NICE NG65 recommendation 1.3.5

Information about spondyloarthritis

NICE NG65 – Recommendation 1.3.1

Provide people with spondyloarthritis, and their family members or carers (as appropriate), with information that is:

- available on an ongoing basis
- relevant to the stage of the person's condition
- tailored to the person's needs.

For more guidance on providing information to people and discussing their preferences with them, see the NICE guideline on patient experience in adult NHS services.

NICE NG65 – Recommendation 1.3.2

Provide explanations and information about spondyloarthritis, for example:

- what spondyloarthritis is

- diagnosis and prognosis
- treatment options (pharmacological and non-pharmacological), including possible side effects
- likely symptoms and how they can be managed
- flare episodes and extra-articular symptoms
- self-help options
- opportunities for people with spondyloarthritis to be involved in research
- which healthcare professionals will be involved with the person's care and how to get in touch with them
- information about employment rights and ability to work
- local support groups, online forums and national charities, and how to get in touch with them.

Information about disease flares

NICE NG65 – Recommendation 1.3.5

When discussing any flare management plan, provide information on:

- access to care during flares (including details of a named person to contact [for example, a specialist rheumatology nurse])
- self-care (for example, exercises, stretching and joint protection)
- pain and fatigue management
- potential changes to medicines
- managing the impact on daily life and ability to work.

4.4.3 Current UK practice

The BSR / HQIP national clinical audit for rheumatoid and early inflammatory arthritis found that 97% of rheumatology providers had a telephone advice line for patients, but only 43% of providers had access to patient education and self-management services.

A survey of NASS members with ankylosing spondylitis[11] contained questions about information and education. Out of 807 UK patients who completed the questionnaire, 15% of patients had attended a patient education session about ankylosing spondylitis at any time (most sessions were hospital based). Those who attended such sessions found them useful (99%). In spite of a small proportion of people attending formal education sessions, 80% of respondents reported understanding ‘a lot’ or ‘quite a lot’ about ankylosing spondylitis.

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[11] Hamilton L et al (2011) Services for people with ankylosing spondylitis in the UK—a survey of rheumatologists and patients. Rheumatology 50(11), 1991–1998

4.5 Organising care

4.5.1 Summary of suggestions

Multidisciplinary collaboration across settings and specialties to optimise care was suggested by stakeholders as people will be seen in primary and secondary care, and in multiple specialities such as rheumatology and dermatology. Communication between GPs and providers who administer medication in the community, and between hospitals and GPs, were suggested as the focus for improvement by a stakeholder. Some stakeholders suggested the key area for improvement was access to services as this is variable across the country: access to a specialist department for adequate treatment options; access to multi-specialist input including ophthalmology, gastroenterology and dermatology; and access to biologic treatments for spondyloarthritis where delays are present.

4.5.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 9 to help inform the committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Organising care	**Coordinating care across settings** NICE NG65 Recommendations 1.91 to 1.94

Coordinating care across settings

NICE NG65 – Recommendation 1.9.1

Commissioners should ensure that local arrangements are in place to coordinate care for people across primary and secondary (specialist) care. These should cover:

- prescribing NSAIDs and standard DMARDs
- monitoring NSAIDs, standard DMARDs and biological DMARDs
- managing flares
- ensuring prompt access to specialist rheumatology care when needed
- ensuring prompt access to other specialist services to manage comorbidities and extra-articular symptoms.

NICE NG65 – Recommendation 1.9.2

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 (see section 1.7 for arrangements for managing flares).

NICE NG65 – Recommendation 1.9.3

Ensure that there is effective communication and coordination between all healthcare professionals involved in the person's care, particularly if the person has comorbidities or extra-articular symptoms.

NICE NG65 – Recommendation 1.9.4

Ensure that there is communication and coordination between rheumatology and other relevant specialities (such as dermatology, gastroenterology and ophthalmology). This is particularly important for people who:

- are already receiving standard DMARDs or biological DMARDs for another condition
- need to start taking standard DMARDs or biological DMARDs for another condition.

4.5.3 Current UK practice

A 2017 survey of consultant rheumatologists[12] at UK acute trusts explored professional views and service delivery relating to axial spondyloarthritis. The 2016 survey achieved a response rate of 48% (83 out of 172 consultants). Results showed that 61% of rheumatology departments had at least one clinician with special interest in axial spondyloarthritis; 58% offered a dedicated axial spondyloarthritis clinic and 63% had an MDT with responsibility for axial spondyloarthritis. Sixteen departments (19%) had combined clinics; a combined clinic with dermatology being the most common type.

Results from a 2011 survey of rheumatologists[13] at acute trusts in the UK showed that 53% of rheumatology departments had a clinician with a special interest in ankylosing spondylitis, and 41% of departments ran a dedicated ankylosing spondylitis or spondyloarthritis clinic. Most departments (62%) had a multidisciplinary team with responsibility for ankylosing spondylitis patients, but only 33% offered multidisciplinary clinics. A dedicated musculoskeletal radiologist was present in 79% of departments.

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[12] Derakhshan MH Et al (2017) What services do rheumatology departments offer axial spondyloarthritis patients in the UK? Rheumatology Volume 56 (Suppl 2), 109

[13] Hamilton L, Gilbert A, Skerrett J, Dickinson S, Gaffney K (2011) Services for people with ankylosing spondylitis in the UK—a survey of rheumatologists and patients. Rheumatology 50(11), 1991–1998,

4.6 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 22 November 2017.

Assessment for gut inflammation

Annual assessment for gut inflammation was suggested by a stakeholder who added that diagnosis of spondyloarthritis can be achieved by the recognition of its subclinical gut manifestation. However, there are no recommendations in the source guidance to address this.

Examining for extra articular manifestations

The importance of examining for extra articular manifestations, such as psoriasis and inflammatory bowel disease, when people are diagnosed with spondyloarthritis was suggested as a key area for quality improvement. However, there are no recommendations in the source guideline to support this.

Multidisciplinary teams

Stakeholders identified multidisciplinary teams (MDTs) as a key area for quality improvement. Some suggested the specific area for improvement as being the role of the MDT in on-going assessment, and the regular review and addressing of extra articular manifestations. Access to the multidisciplinary team was also suggested as the focus for quality improvement. Comments suggest there is national variability with regards to availability of a specialist MDT for people with spondyloarthritis, and that lack of a specialist MDT leads to fragmented care. Some stakeholders specified what the composition of an MDT should be. Although the source guidance covers coordination of care across settings, specialities and disciplines, there are no recommendations which specifically refer to an MDT.

Shared decision making

A stakeholder suggested patient-centred, shared decision making involving a care coordinator and MDT. People with spondyloarthritis would be cared for by a specialist led multi-disciplinary team, and given a single point of contact responsible for managing their care. There are no recommendations on provision of care by an

MDT in the source guidance. Shared decision making is covered by statement 6 of the patient experience in adult NHS services quality standard. Statement 14 of the same quality standard covers making patients aware of who to contact, how to contact and when to make contact about their healthcare needs.

Care plans

A stakeholder suggested that people with spondyloarthritis should have a personalised, long-term care plan which includes co-morbidities. There are no recommendations in the source guidance that cover long-term care plans.

Measuring outcomes and participation in research and audit

Monitoring of disease outcomes was suggested by a stakeholder as a key area for quality improvement. Encouraging people with spondyloarthritis to participate in research and audit was also suggested. These suggestions have not been progressed. Participation in research and audit, and measuring outcomes, are methods by which quality improvement can be evidenced. Quality statements focus on actions that demonstrate high quality care or support, not the methods by which evidence is collated. However, outcome measures are identified for areas that are progressed as statements, and audits may be referenced as suggested data sources for quality measures.

Incentivised GP assessments for patients with psoriatic arthritis

A stakeholder recommended GP incentives for annual screening of patients with psoriasis using a validated tool, and for annual assessment to monitor a patient's disease status. Statement 5 of the psoriasis quality standard covers annual assessment for psoriatic arthritis (which may form part of a holistic review of response to treatment and disease severity and impact). Quality standards do not make recommendations on whether assessments should be incentivised.

Monitoring of disease / assessment of comorbidities

Stakeholders suggested areas relating to monitoring and assessment including regular monitoring of the disease by specialists; and monitoring and assessment of comorbidities. This would help ensure that appropriate interventions are offered to patients when needed. Long term monitoring of axial spondyloarthritis was also suggested, including the need to define responsibilities between review appointments; and also between primary and secondary care. These have not been progressed as the only recommendations relating to monitoring in the source guidance are specific to pharmacological treatments. There are no recommendations specific to monitoring of the disease, comorbidities, or long-term monitoring in the source guidance that could be used to develop a statement in line with the stakeholder suggestions.

Developmental area of emergent practice ‘Treat To Target’

A stakeholder suggested ‘Treat To Target’ for psoriatic arthritis, and said there is increasing evidence of improved patient outcomes. Another stakeholder commented that few healthcare professionals are measuring outcomes and are not treating to target. There are no recommendations in the source guidance that cover this area.

Appendix 1: Glossary

Ankylosing spondylitis: An inflammatory condition predominantly involving the spine from the sacroiliac joints upwards. It causes progressive restriction of spinal movement due to calcification of spinal ligaments and bony change and fusion of the spinal joints. It may affect peripheral joints and be associated with inflammation in other areas including the eye and gut.

Axial spondyloarthritis: An inflammatory condition primarily affecting the spinal joints, including the sacroiliac joints. The term includes ankylosing spondylitis and non-radiographic axial spondyloarthritis. Axial joints include hips and joints around the sternum. Peripheral joints and entheses may also be involved.

Enteropathic spondyloarthritis: Spondyloarthritis associated with Crohn's disease or ulcerative colitis.

Inflammatory back pain: Back pain characteristic of axial spondyloarthritis, often chronic and associated with stiffness, which may improve with exercise or movement and NSAIDs but be worse at rest.

Non-radiographic axial spondyloarthritis: Axial spondyloarthritis where sacroiliitis or spinal inflammatory disease is not detectable on plain X-ray.

Peripheral spondyloarthritis: An inflammatory condition primarily affecting the peripheral joints (non-axial joints), which is distinct from conditions like Rheumatoid arthritis. Psoriatic arthritis, enteropathic arthritis and reactive arthritis are usually predominantly peripheral, though may have some axial involvement.

Psoriatic arthritis: Peripheral spondyloarthritis associated with psoriasis (N.B. In some cases, psoriatic arthritis will occur before psoriasis develops or there is only a family history of it).

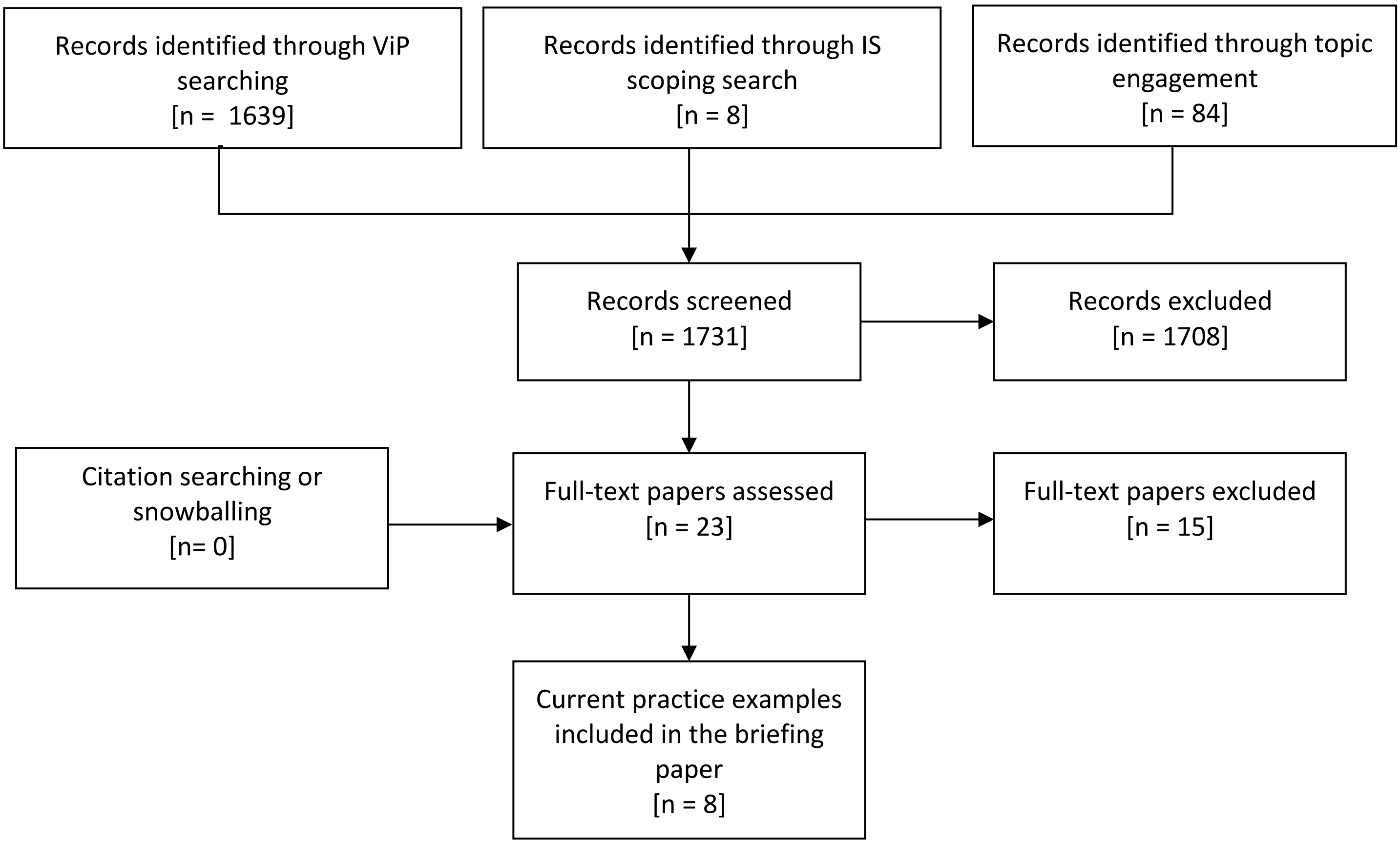
Reactive arthritis: Arthritis arising from an abnormal immune response triggered by some infections. Bacterial triggers within the scope of the source guideline are Campylobacter, Chlamydia, Salmonella, Shigella, and Yersinia.

Sacroiliitis: Inflammation of the sacroiliac joint at the base of the spine.

Spondyloarthritis: Group of conditions characterised by inflammatory arthritis, excluding rheumatoid arthritis. The group includes ankylosing spondyloarthritis, non-radiographic axial spondyloarthritis, psoriatic arthritis, enteropathic arthritis, reactive arthritis and undifferentiated spondyloarthritis. Historically referred to as seronegative arthropathies.

Undifferentiated spondyloarthritis: Spondyloarthritis which does not fit into any of the other diagnostic categories.

Appendix 2: Review flowchart



Appendix 3: Suggestions from stakeholder engagement exercise – registered stakeholders

Recognition and referral					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
1	AbbVie	The importance of appropriate referral of patients with symptoms suggestive of spondyloarthritis by GPs to a rheumatologist. Suggested quality standard wording: If a person has low back pain that started before the age of 45 years and has lasted fRefor longer than 3 months, refer the person to a rheumatologist for a spondyloarthritis assessment if 4 or more of the additional criteria outlined in the NICE spondyloarthritis guideline are present (NG65, recommendation 1.1.5)	Minimising the delay in diagnosis of patients leads to quicker treatment reducing patient suffering and morbidity	Recommendation 1.1.5. in the NICE guideline on spondyloarthritis (NG65)	
2	British Society for Rheumatology	To improve referral quality with the aim of early identification, specialist referral and organisation of care	An ideal service would achieve earlier targeted referral and diagnosis, with identification of likely IBP within primary care and increase awareness of SpA in secondary care. The care should be organised and	There is an average delay of 8.5 years between symptom onset and diagnosis, with only around 15% of suspected Spondyloarthritis (SpA) cases receiving a diagnosis within 3 months of initial presentation(1) With the recent availability of	1 Hamilton L, Gilbert A, Skerrett J, Dickinson S, Gaffney K. Services for people with ankylosing spondylitis in the UK- a survey of rheumatologists

Recognition and referral					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
			coordinated in an integrated and seamless manner, crossing boundaries between primary and secondary care. Use of Validated Inflammatory Back Pain (IBP)assessment tools can aid further in the earlier diagnosis which can be diagnosed using published criteria (5). Rheumatologists should have access to diagnostics including bloods and imaging. This includes the recommended MRI sequence .(5) A programmed education in both primary and secondary care along with Public Awareness is necessary to improve early detection of SpA. The application and uptake requires a dedicated team led by an expert. (6).	highly effective therapies there is an urgent need to address this delay (2,3) Lack of awareness of the clinical features of SpA in both primary and secondary care, is a likely contributory factor to lengthy delays. (4).	and patients. Rheumatology (Oxford) 2011;50:1991-8.doi.1093/rheumatology/ker 013pmid:421687. 2 Weiß A , Song IH, Haibel h, Listing J and Sieper J. Good correlation between changes in objective and subjective signs of inflammation in patients with short- but not long duration of axial spondyloarthritis treated with tumor necrosis factor-blockers. Arthritis Res Ther. 2014;16:R35. 3 Glintborg B, Ostegaard M, Krogh NS, Dreyer L, Kristensen HL, Hetland ML.Predictors of treatment response and drug continuation in 842 patients with ankylosing spondylitis treated with anti-tumour necrosis factor: results from 8 years' surveillance in the Danish nationwide DANBIO registry. Ann Rheum Dis. 2010;69(11):2002-8. 4 Jois RN, Macgregor AJ, Gaffney K. Recognition of inflammatory back pain and

Recognition and referral					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
					ankylosing spondylitis in primary care. Rheumatology (Oxford). 2008 Sep;47(9):1364-6. doi: 10.1093/rheumatology/ken224. Epub 2008 Jun 24 5 National Institute for Helath and Care Excellence. Spondyloarthritis in over 16s: diagnosis and management (NICE guideline NG65). www.nice.org.uk/guidance/ng65. 6 Adshead R, Tahir H, Donnelly S. UK Best Practice Model for Diagnosis and Treatment of Axial Spondyloarthritis . EMJ Rheumatol. 2015;2(1):103-110.
3	BRIT-PACT	Shorten time to diagnosis by active screening, earlier referrals, and earlier diagnosis of PsA	Delays in diagnosis and treatment lead to worse outcomes. There may be a window of opportunity to treat this disease early.	Observational evidence suggests: Up to 50% of existing cases of psoriatic arthritis remain unrecognised Delay in referral leads to worse outcomes 25 years later Delay in treatment leads to worse outcomes	1. Reich K, Kruger K, Mossner R, Augustin M. Epidemiology and clinical pattern of psoriatic arthritis in Germany: a prospective interdisciplinary epidemiological study of 1511 patients with plaque-type psoriasis. Br J Dermatol. 2009; 160:1040-1047. 2. Gladman D, Thavaneswaran A, Chandran V, Cook RJ. Do patients with

Recognition and referral					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
					psoriatic arthritis who present early fare better than those presenting later in the disease? Ann Rheum Dis. 2011; 70(12):2152-2154. 3. Haroon M, Gallagher P, Fitzgerald O. Diagnostic delay of more than 6 months contributes to poor radiographic and functional outcome in psoriatic arthritis. Ann Rheum Dis. 2014; 72(5):736-740. 4. Coates LC, Savage L, Waxman R, Moverley A, Worthington S, Helliwell P. Comparison of screening questionnaires to identify psoriatic arthritis in a primary-care population: a cross-sectional study. The British journal of dermatology. 2016; 175:542-548.
4	SCM1	Increased awareness of signs and symptoms which raise suspicion of and which should not be used to exclude Axial SpA by non-specialist health professionals	There is evidence that delay to diagnosis for many people with SpA is still currently 8-9 years despite significant improvements in imaging and treatments. Health professionals assessing and managing people with musculoskeletal problems, particularly persistent back pain need to have a greater awareness of signs and symptoms that should raise the	Finding suggests that there is underrecognition of SpA Earlier diagnosis allows more timely introduction of effective treatments which can improve long-term outcomes such as spinal function and damage, fatigue, function and quality of life. Diagnostic delay may cause patients to miss the chance of early appropriate treatment for AxSpA	National Ankylosing Spondyloarthritis Society survey Martindale & Goodacre (2014) The journey to diagnosis in AS/axial SpA: the impact of delay

Recognition and referral					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
			suspicion that a person may have spondyloarthritis. NICE guidance has made recommendations that provide criteria to support suspicion of AxSpA and it is important to ensure clinicians are aware of these criteria and that clinical assessments of people with persistent back pain are assessed for the possibility of AxSpA.	and consequently have poorer prognosis which include disability, increased limitation of axial movements, pain, poor quality of life, and functional status. People with undiagnosed SpA may be inappropriately referred for chronic pain management which may also cause a delay in eventual diagnosis- particularly since the LBP and sciatica guidelines and quality standards are recommending the use of a back pain stratifying tool in primary care for onward referral that would send people with chronic back pain symptoms into a MDT pain management pathway. Delayed diagnosis and intervention may also be significant regarding unaddressed complications and risk factors that are associated with SpA which may also not be addressed including CVD, osteoporosis, fracture risk in the longer term.	http://onlinelibrary.wiley.com/doi/10.1002/msc.1080/full FALLAHI et al 2016 Diagnostic Delay in Ankylosing Spondylitis: http://onlinelibrary.wiley.com/doi/10.1002/msc.1080/full Garrido-Cumbrera, M., Hillmann, O., Mahapatra, R., Trigos, D., Zajc, P., Weiss, L., ... & Coates, L. C. (2017). Improving the Management of Psoriatic Arthritis and Axial Spondyloarthritis: Roundtable Discussions with Healthcare Professionals and Patients. Rheumatology and Therapy, 1-13. https://link.springer.com/article/10.1007/s40744-017-0066-2 Patient seeking to have the time to diagnosis improved Stolwijk, C., van Onna, M., Boonen, A., & van Tubergen, A. (2016). Global Prevalence of Spondyloarthritis: A Systematic Review and

Recognition and referral					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
					Meta-Regression Analysis. Arthritis care & research, 68(9), 1320-1331. http://onlinelibrary.wiley.com/doi/10.1002/acr.22831/full
5	SCM1	Suspicion and Recognition of peripheral SpA by non-specialist health professionals	Raising awareness amongst clinicians in primary care who assess and teat people with musculoskeletal problems of the early signs and symptoms of spondyloarthritis – this should improve the likelihood of a person with spondyloarthritis receiving a prompt and correct diagnosis and appropriate management. NICE guidance has made the following recommendation: Refer people with enthesitis without apparent mechanical cause to a rheumatologist for a spondyloarthritis assessment if: it is persistent or it is in multiple sites or any of the following are also present: back pain without apparent mechanical cause current or past uveitis (see recommendation 5.1 for guidance on immediate [same-day]	Peripheral spondyloarthritis is often misdiagnosed as an unrelated tendon or joint problem. Symptoms can often move around between areas or flare and settle. Rapid referral of people with suspected persistent enthesitis/dactylitis/joint synovitis is important to avoid delay in diagnosis and increase the likelihood of early treatment initiation and reduce suffering. As with Rheumatoid arthritis, there can be potentially devastating effects of delayed diagnosis in terms of pain, fatigue, joint and tendon damage and quality of life, people with these symptoms and signs should be considered to need urgent action. Diagnostic delay may cause patients to miss the chance of early treatment for peripheral SpA and consequently have poorer prognosis which include disability, pain, fatigue, poor quality of life, functional status and interference with the ability to work. People with co-existing extra-articular conditions may also be given more appropriate choice of medication that may also improve joint problems if SpA is also diagnosed	

Recognition and referral					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
			ophthalmological assessment for people with acute anterior uveitis) current or past psoriasis gastrointestinal or genitourinary infection inflammatory bowel disease (Crohn's disease or ulcerative colitis). a first-degree relative with spondyloarthritis or psoriasis.		
6	SCM1	Screening and onward referral of suspected spondyloarthritis to rheumatologist by specialist health professionals who manage conditions that can be associated with spondyloarthritis, including ophthalmologists (uvieitis), gastroenterologists (Inflammatory bowel disease- Crohns disease and colitis) and dermatologists (psoriasis).	Specialists treating extra-articular conditions associated with SpA may not be screening for or recognising the possible relationship of joint problems as part of the inflammation condition. Improved screening and recognition by these specialists may help to reduce the delay in diagnosis currently experienced by many people with extra-articular conditions who are not recognised as having SpA NICE guidance makes the following recommendation Be aware that peripheral spondyloarthritis may be missed, even if the onset is associated with established comorbidities (for example, psoriasis, uveitis, inflammatory bowel disease [Crohn's disease or ulcerative colitis] or a	Research shows that a significant number of people with extra-articular conditions are not being recognised as having possible SpA A significant increased risk in AS among patients with uveitis has been observed, with a time lag of up to 7.9 years between the diagnosis of uveitis and subsequent diagnosis of AS(Lu et al. 2017) There is evidence that case-finding strategies and algorithms in people with acute anterior uveitis improves the recognition of undiagnosed SpA. Similar case finding may improve recognition and diagnosis of SpA in people with other associated extra-articular conditions including psoriasis and inflammatory bowel disease. Karreman et al. 2017 found that Spondyloarthritis occurs in up to 13% of patients with IBD. Ankylosing spondylitis is the least	Lu, M. C., Hsu, B. B., Koo, M., & Lai, N. S. (2017). Higher risk of incident ankylosing spondylitis in patients with uveitis: a secondary cohort analysis of a nationwide, population-based health claims database. Scandinavian Journal of Rheumatology, 1-6. http://www.tandfonline.com/doi/abs/10.1080/03009742.2017.1282686 Haroon, M., O'rourke, M., Ramasamy, P., Murphy, C. C., & FitzGerald, O. (2015). A novel evidence-based detection of undiagnosed spondyloarthritis in patients presenting with acute anterior uveitis: the DUET (Dublin

Recognition and referral					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
			gastrointestinal or genitourinary infection). Ophthalmologists should ask people with acute anterior uveitis whether they have: consulted their GP about joint pains or experienced chronic low back pain that started at under 45 years and has lasted for longer than 3 months. If the person meets either of the criteria in recommendation 6.1, establish whether they have psoriasis or skin complaints that appear psoriatic on physical examination. If they do, refer the person to a rheumatologist for a spondyloarthritis assessment. If they do not, perform an HLA-B27 test and refer the person to a rheumatologist for a spondyloarthritis assessment if this test is positive.	common [3%] followed by sacroiliitis [10%] and peripheral arthritis [13%]. Presence of joint problems and extra-articular manifestations and comorbidities may have consequences for the treatment and support improved management	Uveitis Evaluation Tool). Annals of the rheumatic diseases, 74(11), 1990-1995. http://ard.bmj.com/content/74/11/1990.full Karreman, M. C., Luime, J. J., Hazes, J. M., & Weel, A. E. (2017). The prevalence and incidence of axial and peripheral spondyloarthritis in inflammatory bowel disease: a systematic review and meta-analysis. Journal of Crohn's and Colitis, 11(5), 631-642. Ossum, A. M., Palm, Ø., Lunder, A. K., Cvancarova, M., Banitalebi, H., Negård, A., ... & Høivik, M. L. (2017). Ankylosing spondylitis and axial spondyloarthritis in patients with long-term inflammatory bowel diseaseResults from 20 years of follow-up in the IBSEN study. Journal of Crohn's and Colitis.

Recognition and referral					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
7	SCM2 / Psoriasis and Psoriatic Arthritis Alliance	Recognition of symptoms of psoriatic arthritis	To avoid irreversible joint damage and long-term disability.	Early recognition of psoriatic arthritis in people with psoriasis was recognised as important in the psoriasis guideline GD153. But little improvement appears to have taken place since.	For each of these key areas my views are based on some personal experience of having psoriasis and psoriatic arthritis and anecdotal evidence, following conversations through my work with PAPAA and the support of people with psoriasis and psoriatic arthritis.
8	SCM2 / Psoriasis and Psoriatic Arthritis Alliance	Early referral to appropriate services	Access to the expertise and therapy, which is appropriate to the condition.	People need to see the correct person/speciality. It is a waste of an individual’s time and the healthcare provider’s time, if they are not able to help improve outcomes due to lack of knowledge or appropriate resources.	Ditto
9	SCM3	Early referral of patients with AxSpA (peripheral and axial)	Recommended within NICE SpA guidance. Split into axial and peripheral. Axial – delayed diagnosis is currently around 8 years Peripheral – covered to a degree by RA quality standards – but these exclude monoarthritis, enthesitis and dactylitis	Without prompt diagnosis – inflammatory arthritis progresses and causes more disability (physical and work). Patients with earlier disease respond better to interventions (including biologics)	NICE SpA guidance
10	Leeds Teaching Hospitals NHS Trust	Early diagnosis	Delayed diagnosis is one of main obstacles to appropriate care for people with SpA, this refers not only to axSpA but also PsA. Patients rate	Prompt diagnosis leads to better outcomes as shown by better response to treatment and longer duration of response.	Rapid assessment in SpA leads to increase likelihood of early treatment intervention

Recognition and referral					
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			this as one of the main areas of unmet need for them.	In PsA, earlier treatment leads to less functional impairment	Please see : nice.org.uk/guidance/ng65
11	Torbay Hospital	Promoting early identification of axial spondyloarthropathy	Promoting early identification of axial spondyloarthropathy	Evidence suggests prolonged delay to diagnosis in significant percentage of patients and diagnosis can be difficult. Because the public can increasingly “self refer” to allied health professions bypassing GPs it is important for NICE recommendations to be targeted at allied health professions and not just medical profession. It would be helpful if the guidelines could have a small addition about how to design processes which improve early diagnosis and access to specialist secondary care. The guidelines do not appear to mention if it improves early diagnosis for specialist rheumatology services to be located in either primary or secondary care.	
12	SCM5 / National Ankylosing Spondylitis Society	Early diagnosis and referral in Axial Spondyloarthritis (AxSpA) (including ankylosing spondylitis)	The current delay to diagnosis in the UK is an average of 8.5 years.(Delay to Diagnosis in Axial SpA: Are We Improving in the UK? Sykes M, Doll H, Sengupta R, Gaffney K. Rheumatology (Oxford). 2015; 54(12):2283-4)	The NASS State of the Nation Survey carried out in 2016 (2000 patients with a diagnosis of AxSpA) concluded that delay to diagnosis and prompt referral to rheumatology was still a big issue. NOTE – NASS is very happy to supply the results of this survey to NICE for consideration.	In the NASS State of the Nation Survey, 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 healthcare professional within 6 months and 27.5% waiting 3 years or more before doing this. The interval between

Recognition and referral					
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					seeing a healthcare professional about their symptoms and obtaining a formal diagnosis also varied widely; one-third (30.1%) waited 10 years or more for a formal diagnosis. Overall, there was a median delay of 8.50 (IQR: 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 (PCP) in 5.9% of cases.
13	Royal College of General Practitioners	Increased public awareness of spondyloarthritis	There is good evidence Surrounding diagnostic delay in spondyloarthritis, and that delayed diagnosis results in worse patient outcomes.	GPs lack expertise and Confidence in recognition of spondyloarthritis; this can result in diagnostic delay. Improving public recognition of the symptoms of spondyloarthritis, and GP ability to recognise these symptoms and appropriately refer on to secondary care, is key in reducing delays to diagnosis.	Hamilton L, Macgregor A, Warmington V, et al. The Prevalence of inflammatory back pain in a UK primary care population. Rheumatology (Oxford) 2014;53:161-4. Sykes M, Sengupta R, Gaffney K. Rheumatology (Oxford). 2015; 54(12):2283- Hamilton L, Gilbert A, Skerrett J, Dickinson S, Gaffney K. Services for people with Ankylosing Spondylitis in the UK.

Recognition and referral					
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					Rheumatology 2011; 50: 1991-8. Jois RN, Gaffney K. Recognition of Inflammatory Back Pain and Ankylosing Spondylitis in Primary Care. Rheumatology 2008: 47; 1364-6.
14	SCM4	Appropriate timely referral to a Rheumatologist	Due to the heterogenous nature of the disease diagnosis is often delayed. NICE guidance emphasises the importance of early referral to a Rheumatologist. NICE Guidance 65 Feb 2017 – Specialist referral in patients below the age of 45 years with symptoms of greater than 3 months duration in accordance with stated criteria in the guidance.	Spondyloarthritis can have diverse symptoms and be difficult to identify, which can lead to delayed or missed diagnoses. People may present late due to a lack of knowledge of the types of symptoms associated with this group of diseases. Practitioners in primary care and secondary care may vary in their level of knowledge of disease presentation or have limited, timely access to a Rheumatologist skilled in the diagnosis and management of spondyloarthropathies.	There is still a substantial gap of 5–8 years between the onset of symptoms and the diagnosis of axial spondyloarthritis (axSpA). One of the major reasons for such a delay is a late referral of patients to a rheumatologist by general practitioners and other physicians encountering patients with back pain. This late referral can be caused by the referring doctor and/or by the patient. Poddubnyy D et al Ann Rheum Dis 2015 74:1483-1487 NASS Research Priorities: Evaluate different ways of improving GP and health care practitioner understanding of Ankylosing Spondylitis

Recognition and referral					
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15	UCB Pharma Ltd	Earlier Recognition of Spondyloarthritis and onward referral e.g. an annual audit of people who have a diagnosis of non-specific back pain who first consulted their GP for back symptoms under the age of 45. These people would be referred for a full rheumatological assessment in accordance with NG65	Spondyloarthritis encompasses a group of inflammatory conditions which includes ankylosing spondylitis and axial spondyloarthritis. The latter often undiagnosed due to lack or radiographic markers. These conditions can have diverse symptoms such as psoriasis, uveitis, dactylitis and enthesitis and can be difficult to identify. The average time to diagnosis of spondyloarthritis is eight and a half years, despite a better understanding of these conditions, advances in imaging and effective treatments. These conditions are often mistaken as chronic back pain, tendonitis or joint problems. Symptoms can also be intermittent. They can move around peripheral areas and flare and settle, mimicking acute or recurrent back pain or tendon/joint problems. Due to the heterogeneous presentation of the disease, monitoring should include a broad variety of assessments.	Spondyloarthritis conditions and their diverse symptoms are important to recognise to enable early management to reduce the impacts and improve outcomes. According to NASS: • 26% of people with Ankylosing Spondylitis (AS) have acute anterior uveitis & 40% of people with acute anterior uveitis have spondyloarthritis • 9% of people with AS have psoriasis There are also evidence that undiagnosed axSpA incurs an equally substantial economic impact on society and individual patients, with costs driven mainly by the reduced capacity to work observed in these patients who are typically of working age at disease presentation.	NICE Guidance NG65 Haibel H, Rudwaleit M, Listing J, et al. Efficacy of adalimumab in the treatment of axial spondylarthritis without radiographically defined sacroiliitis: results of a twelve-week randomized, double-blind, placebo-controlled trial followed by an open-label extension up to week fifty-two. Arthritis Rheum 2008;58:1981-91. Kiltz U, Baraliakos X, Karakostas P, et al. Do patients with non-radiographic axial spondylarthritis differ from patients with ankylosing spondylitis? Arthritis Care Res (Hoboken) 2012;64:1415-22. Rudwaleit M, Haibel H, Baraliakos X, et al. The early disease stage in axial spondylarthritis: results from the German Spondyloarthritis Inception Cohort. Arthritis Rheum 2009;60:717-27.

Recognition and referral					
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					van der Heijde D, Ramiro S, Landewé R, et al. 2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis. Annals of the Rheumatic Diseases 2017;76:978-991.
16	University Hospitals Southampton	Early referral of patients with suspected spondyloarthritis	Evidence that early treatment improves clinical outcomes	Variation across the UK in access to early arthritis clinics	
17	Royal College of General Practitioners	Early diagnosis of inflammatory spinal pain in primary care	Surrounding diagnostic delay in spondyloarthritis, and that delayed diagnosis results in worse patient outcomes.	Confidence in recognition of spondyloarthritis; this can result in diagnostic delay. Improving public recognition of the symptoms of spondyloarthritis, and GP ability to recognise these symptoms and appropriately refer on to secondary care, is key in reducing delays to diagnosis.	Prevalence of inflammatory back pain in a UK primary care population. Rheumatology (Oxford) 2014;53:161-4. Sykes M, Sengupta R, Gaffney K. Rheumatology (Oxford). 2015; 54(12):2283- Hamilton L, Gilbert A, Skerrett J, Dickinson S, Gaffney K. Services for people with Ankylosing Spondylitis in the UK. Rheumatology 2011; 50: 1991-8.

Recognition and referral					
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					Jois RN, Gaffney K. Recognition of Inflammatory Back Pain and Ankylosing Spondylitis in Primary Care. Rheumatology 2008: 47; 1364-6.

Diagnosis					
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18	SCM1	Appropriate MRI imaging for suspected axial SpA	AxSpA can often be mistaken for chronic, mechanical low back pain. Importantly, the MRI protocol to investigate for inflammatory back pain/sacroiliitis differs from standard lumbar spine MRI protocols. Routine protocols used for lumbar spine imaging will not detect signs of axial structure inflammation or sacroiliitis which is a critical factor in supporting earlier diagnosis and management decisions relating to suspected Ax SpA NICE guidance makes the following recommendation to support correct MRI investigations in people with possible Ax SpA, NICE Guidance makes the following recommendation:	There is a risk of delay to diagnosis if the wrong kind of imaging is requested, or it is not interpreted by a specialist with knowledge of spondyloarthritis. This may lead to an avoidable repeat of imaging being required. If performed, the entire spine should be imaged because any region can be affected, but the thoracic levels appear to be the most commonly affected areas (Schueller-Weidekamm et al.2014) and are often not investigated in patients with back with the correct MRI protocol to investigate for inflamm changes	Schueller-Weidekamm C, Mascarenhas VV, Sudol-Szopinska I, et al. Imaging and interpretation of axial spondylarthritis: the radiologist’s perspective—consensus of the Arthritis Subcommittee of the ESSR. Semin Musculoskelet Radiol 2014;18(3):265–279

Diagnosis					
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			The MRI protocol should perform T1 and short T1 inversion recovery of both the sacroiliac joints (coronal oblique view) and cervical, thoracic and lumbar spine. If a disparity occurs between clinical suspicion and imaging findings, consider having the imaging reviewed by a specialist MSK radiologist		
19	SCM1	Dispelling clinical misunderstandings that the incidence of AxSpA is higher in men however the condition present equally and misunderstandings about blood tests of HLA B27 needing to be positive and inflammatory markers- ESR & CRP needing to be raised for the diagnosis of SpA	NICE has made the following recommendation: 7. Blood tests for spondyloarthritis Do not rule out a diagnosis of spondyloarthritis solely on the basis of a negative HLA-B27 result. Do not rule out a diagnosis of spondyloarthritis even if a person's C-reactive protein (CRP) and erythrocyte sedimentation rate (ESR) are normal.	There is a common clinical misunderstanding that inflammatory markers need to be raised to be suspicious and make a diagnosis of SpA however evidence suggests these tests are normal in many people diagnosis with SpA	See guideline evidence review
20	SCM2 / Psoriasis and Psoriatic Arthritis Alliance	Making a positive diagnosis.	For patients it is important to have a name for their condition. Any ambiguity or mystery of a collection of symptoms can cause a worse case scenario anxiety. Ruling out other conditions can reassure people, as long as they know what they have.	Often people worry about the future, reassurance so people can plan and make life decisions, particularly around therapy, work and personal life choices.	Ditto

Diagnosis					
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21	SCM3	Investigation of patients with AxSpA (peripheral and axial)	Recommended within NICE SpA guidance Split in axial and peripheral Axial – ensure that patients receive x-rays and if negative MRI SIJs and whole spine with specific protocol (frequently not done in non-specialist centres) + re MRI if clinical suspicion is high as MRIs fail to pick up 50% of patients with AxSpA on first MRI Peripheral – similar to RA quality standards – using clinical, then x-rays then ultrasound to determine diagnosis. But additional focus on non-hand/foot imaging as these areas are not always inflamed in peripheral SpA Additional element in SpA guidelines that is not in routine clinical UK care - xray of SIJs in peripheral SpA irrespective of presence of back pain. Detects axial inflammation in these patients approx. 30%	Without appropriate investigations in secondary care (but often by generalist rheumatologists rather than SpA specialists) – then diagnoses can be missed – further extending delay to diagnosis. Some non-specialists may still progress to MRIs in patients with normal x-rays + those MRIs are often not performed on the correct protocol which hugely reduces the diagnostic benefit of those MRIs (i.e. routine lumbar spine MRI does not have any cuts through the SIJs / facet joints) There is a tendency for PsA / peripheral SpA to be investigated like RA. This can be appropriate – but because in RA arthritis almost always affects hands/feet – protocols are focussed on hand/feet assessment/imaging. In peripheral SpA individuals – hands and feet can be spared, with inflammation elsewhere – making RA protocols inappropriate and prone to miss active PsA / peripheral SpA Axial disease important to detect alongside peripheral SpA /PsA as many treatments for PsA (methotrexate/sulfasalazine/Leflunomide) have no benefit for axial inflammation – so patients can be 'treated' for their peripheral joint inflammation and 'untreated' for their axial inflammation.	NICE SpA guidance
22	SCM5 / National Ankylosing	Standardisation of MRI protocols	Diagnosis of AxSpA in the UK is often being missed because the	A national protocol for the use of MRI in AxSpA is needed to ensure that diagnosis is not missed.	The 'Use of MRI in AxSpA:Time to Bridge the Gap Between Radiologists

Diagnosis					
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	Spondylitis Society		incorrect sequences are being requested when an MRI is ordered.		and Rheumatologists' paper by BRITSpA, published in the Journal of Rheumatology in April 2017 showed that there is diverse practice in the use of MRI and limited knowledge of the features defining a diagnostic MRI for AxSpA among radiologists in the UK, suggesting that international guidance has not widely infiltrated national practice.
23	Primary Care Rheumatology Society	Initial imaging for suspected Spondyloarthritis should commence in primary care	Part of the diagnostic criteria for Spondyloarthritis includes imaging. Plain films are recommended as initial radiographic investigations. We recommend that these should be requested in primary care and should accompany any referral for specialist assessments of Spondyloarthritis. Some areas of the country have limited access to plain films of the back/SI joints which may lead to delays in diagnosis. Also, radiological investigations should be interpreted by radiologists with expertise in Musculoskeletal and rheumatological conditions to ensure consistency in interpretation and diagnosis.	Diagnosis of Spondyloarthritis can be delayed due to lack of recognition of symptoms. Further delays can be avoided if appropriate investigations are carried out promptly to aid the diagnostic process. We have examples from members of our society who are not allowed to request plain xrays of Sacroiliac joints for back pain thus potentially leading to missed opportunities for diagnosis. The quality of reporting of the radiological investigations is equally important to ensure consistency in diagnosis.	Recommendations in NICE guideline NG65: Spondyloarthritis in over 16s

Diagnosis					
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24	UCB Pharma Ltd	Access to expert musculoskeletal radiology for improved diagnosis	Diagnosis of axSpA in the UK is often being missed because the incorrect sequences are being requested when an MRI is ordered.	Awareness of axSpA was reported by 75% of radiologists, and awareness of definitions for positive MRI of SIJ and spine by 31% and 25%, respectively. These data highlight the need for better rheumatology-radiology collaboration on the identification of diagnostic axSpA MRI lesions and support the need for a consensus on the most appropriate MRI protocols for the assessment of axSpA.	The Use of Magnetic Resonance Imaging in Axial Spondyloarthritis: Time to Bridge the Gap Between Radiologists and Rheumatologists. The Journal of Rheumatology April 2017, jrheum.161337; DOI: Alexander N. Bennett, Helena Marzo-Ortega, Daljit Kaur-Papadakis and Amer Rehman on behalf of BRITSpA
25	University Hospitals Southampton	Improved access to expert musculoskeletal MRI	MRI assessment of axial disease often requires subspecialist radiology opinion	Over-diagnosis and missed disease on MRI are common	
26	British Society for Spondyloarthritis	One aspect of delayed diagnosis is imprecise reporting of spinal imaging. To gain optimum output, images need to be planned with appropriate local protocols and reported by expert musculoskeletal radiologists	It is commonplace for patients, especially those with axial disease, to have had suboptimal spinal imaging, with associated cost, and inexpert reporting. This may delay eventual referral or lead to misdiagnosis.	Radiologists are very conscious of the importance of getting the right images – especially on MRI scanning – but the absence of a team-approach allows substandard service especially to patients at the time of (potential) diagnosis.	

Management					
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27	British Society for Rheumatology	To treat early with the aim of secondary prevention, improvement in QoL and work productivity	People with SpA should have access to the full range of effective treatments. These should include physiotherapy and when necessary NSAIDS and Biologic drugs. People with SpA should be assessed for initiation and continuation of Biologic treatments in line NICE guidelines. Periodic treatment reviews should ensure that all individuals receive treatment, which is optimally effective and tolerated. People with SpA should be provided with written advice on early detection and management of disease flares including prompt access during the course of their disease to the MDT	A Validated disease activity assessment score, should be used at the time of review further supported by assessments of function, damage, quality of life and work productivity. (7) Management of people with SpA should include knowledge of the impact the disease on their ability to work, and treatment and support should be offered throughout their disease to optimise their chances of maintaining employment.	NICE guidelines ((TA383,TA407,TA433,TA199,TA220,TA340) 7 J Sieper J, Rudwaleit M, Baraliakos X , Brandt J, Braun J, Burgos-Vargas R, Dougados M,Hermann KG, Landewe R, Maksymowych W, Van der Heide D .The Assessment of SpondyloArthritis international Society (ASAS) handbook: a guide to assess spondyloarthritis. Annals of the Rheumatic Diseases 2009;68:ii1-ii44.
28	BRIT-PACT	Early and evidence based disease management.	Earlier intervention likely to improve outcome. Treat to target also gives improved outcomes	Audit of consultant practice in UK shows very few doctors/nurses measure appropriate outcomes and do not treat to target (see Coates article)	Gladman D, Thavaneswaran A, Chandran V, Cook RJ. Do patients with psoriatic arthritis who present early fare better than those presenting later in the disease? Ann Rheum Dis. 2011; 70(12):2152-2154. Coates LC, Moverley AR, McParland L, Brown S, Navarro-Coy N, O'Dwyer J, et al. Effect of tight control of inflammation in early psoriatic arthritis (TICOPA): a UK

Management					
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					multicentre, open-label, randomised controlled trial. Lancet. 2015; 386:2489-2498. Holland et al. Psoriatic arthritis is associated with diagnositc delay and worse outcome at three months when compared to rheumatoid arthritis: results from the UK national audit for inflammatory arthritis. Ann Rheum Dis;2017; 76, suppl 2, 685. Coates L, Helliwell P. Treating to target in psoriatic arthritis: how to implement in clinical practice. Ann Rheum Dis. 2016; 75:640-643.
29	British Society for Spondyloarthritis	During the period of years between onset of symptoms many people change/reduce their work and expectations and develop irreversible disease that could have been better managed with a rational treatment plan	Early introduction of anti-inflammatory and physical treatment is vital for retrieval and maintenance of well-being but access to specialist physicians and physiotherapists is limited	Back pain triage mechanisms could be very helpful here but fail to recognise spondylitis in many instances so that many patients are categorised without a diagnosis. Many patients have inappropriate investigations – eg MRI lumbar spine, and see inappropriate specialists equipped to manage mechanical but not inflammatory conditions.	
30	Celgene UK Ltd	Treatment choice with non-biologic DMARD	Treatment choice and monitoring for non-biologic DMARD should be in	Treatment choice should take into consideration patient status and comorbidities.	https://academic.oup.com/rheumatology/article/3053478/B

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			line with BSR/BHPR non-biologic DMARD guidelines 2016.		SR-and-BHPR-guideline-for-the-prescription-and?searchresult=1%20-%2061803365
31	Celgene UK Ltd	Treatment choice in line with NICE pathway	Treatment choice should be made in line with NICE pathway for managing peripheral Spondyloarthritis in adults.	NICE pathway incorporates evidence based guidance and allows for a consistent patient choice algorithm.	https://pathways.nice.org.uk/pathways/spondyloarthritis#path=view%3A/pathways/spondyloarthritis/managing-peripheral-spondyloarthritis-in-adults.xml&content=view-node%3Anodes-choice-of-non-biological-therapy
32	SCM4	People with pain associated with axial spondyloarthritis or psoriatic arthritis are offered NSAIDs in conjunction with a gastro-protective agent	NSAIDs are an important first-line pharmacological strategy in the management of axial spondyloarthritis. NICE GUIDANCE 65 Feb 17 • Offer NSAIDs at the lowest effective dose to people with pain associated with axial spondyloarthritis, and think about appropriate clinical assessment, ongoing monitoring of risk factors, and the use of gastroprotective treatment. • If an NSAID taken at the maximum tolerated dose for 2–4 weeks does not provide adequate pain relief, consider switching to another NSAID.	The use of NSAIDS is now known to be associated with an increase in cardiovascular risk. Although it is essential to consider the risks and benefits of this group of medicines, the recent publicity relating to their side effect may result in a reluctance to offer a regular NSAID by some physicians or consider switching to an alternative NSAID with a potentially higher cardiovascular risk People with spondyloarthropathies may be concerned about taking a continuous NSAID due to reports in the press about this group of medicines. There needs to be greater understanding in primary care with regards to the use of these medicines in this particular disease group.	-In patients with PsA, NSAIDs may be used to relieve musculoskeletal signs and symptoms (EULAR 2015 PsA– see above) -Patients suffering from pain and stiffness should use an NSAID as first-line drug treatment up to the maximum dose, taking risks and benefits into account. For patients who respond well to NSAIDs continuous use is preferred if symptomatic otherwise (EULAR axial spondyloarthritis 2016)

Management					
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33	AbbVie	The importance of educational and self-management activities for people with SpA. Suggested quality standard wording People with SpA are offered educational and self-management activities within 1 month of diagnosis.	The importance of non-pharmacological management of SpA is captured within the NICE spondyloarthritis guideline (NG65, recommendation 1.5.)	Recommendation 1.5. in the NICE guideline on Spondyloarthritis (NG65)	
34	SCM3	Access to specialist physiotherapy / hydrotherapy	Recommended within NICE SpA guidance This applies to flare but wider including Axial - helps maintain mobility (dry land and hydrotherapy) Peripheral – therapist assessment when required for functional disability / maintaining current ability	Axial SpA requires SpA specialist physiotherapy intervention to maintain function (generalist physiotherapists simply don't have the knowledge or skills) – this includes dry land and hydrotherapy. Peripheral SpA require rheumatology specialist physiotherapy / occupational therapy intervention when physical function is at risk / deteriorating (very similar to RA patient requirements)	NICE SpA guidance
35	Leeds Teaching Hospitals NHS Trust	Access to multidisciplinary service	People with SpA need to have access to adequate physiotherapy, hydrotherapy, occupational therapy, clinical psychology and work advice		Please see: nice.org.uk/guidance/ng65 Van der Heijde D, Ann Rheum Dis 2017;76(6):978-991

Management					
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					Gossec L; Ann Rheum Dis 2016;75(3):499-510
36	SCM5 / National Ankylosing Spondylitis Society	Access to physiotherapy and hydrotherapy services	Physiotherapy and hydrotherapy are the cornerstones of treatment for AxSpA. It is essential that patients have access to physiotherapy and hydrotherapy periodically during the lifetime course of their disease.	In the NASS State of the Nation Survey, nearly half of the 2000 respondents had not seen a physiotherapist for their AS during the previous 12-month period. Patients have told NASS is a separate survey how they benefit from regular physiotherapy and hydrotherapy. NASS is concerned that in some areas of the NHS, hydrotherapy services are becoming frequently under threat; the importance of these services needs to be emphasised.	In the State of the Nation Survey, 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 they did not want to see a physiotherapist. The reasons for this are unclear but may reflect the long disease duration of many respondents, while calls to the NASS helpline suggests that many are still 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.
37	Podiatry Rheumatic Care	Ensure that the foot health needs of people with spondyloarthritis are	This group of patients may present with a range of foot problems. Disease specific may be enthesitis-	NICE CG highlights the need to consider referral to podiatry when there is an impact on everyday activities. This is supported by the ARMA	http://www.prcassoc.org.uk/files/Full%20Colour%20Foot%20Health%20Standards.pdf

Management					
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	Association (PRCA)	assessed within 3 months of diagnosis and then throughout the course of the disease, including episodes of significant disease activity. As part of a patient's comprehensive annual review, foot health needs should be reviewed.	based and alteration in posture related. These can impact of daily activities including working. Inflammatory arthritis is associated with patients having a raised incidence of peripheral arterial disease. Tissue viability care needs also require assessment and monitored. Medication can contribute to tissue viability risk and complicate management of skin and soft tissue infections. People may need support with general foot care needs due to impact of disease on their ability to self manage.	standards of care for people with MSK foot problems. However, the data from year 2 of the RA and IA audit showed that only 51% of units had access to podiatry at all.	see page 24
38	Podiatry Rheumatic Care Association (PRCA)	People with spondyloarthritis should have timely access to podiatry specialist appropriate to their clinical need. Podiatry services should be available as part of an intergrated MDT with a clear pathway for referral to the service. This should include access to information and self management advice / information.	. This group of patients may present with a range of foot problems. Disease specific may be enthesitis-based and alteration in posture related. These can impact of daily activities including working. Inflammatory arthritis is associated with patients having a raised incidence of peripheral arterial disease. Tissue viability care needs also require assessment and monitored. Medication can contribute to tissue viability risk and complicate management of skin and soft tissue infections. People may need support with general foot care needs due to impact of disease on their ability to self manage.	NICE CG highlights the need to consider referral to podiatry when there is an impact on everyday activities. This is supported by the ARMA standards of care for people with MSK foot problems. However, the data from year 2 of the RA and IA audit showed that only 51% of units had access to podiatry at all.	http://www.prcassoc.org.uk/files/Full%20Colour%20Foot%20Health%20Standards.pdf see page 24

Management

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39	University Hospitals Southampton	Access to expert physiotherapy	Evidence that exercise programmes improve outcomes in axial SpA		
40	Chartered Society of Physiotherapy	Referral to and access to specialist physiotherapist following diagnosis and for management of axial spondyloarthritis (AxSpA)	Evidence suggests that specialist physiotherapy can have significant benefits for people diagnosed AxSpA NICE guidelines on spondyloarthritis make the following recommendation and includes physiotherapy in the pathway Offer physical therapies: Refer people with axial spondyloarthritis to a specialist physiotherapist to start an individualised, structured exercise programme, which should include: • stretching, strengthening and postural exercises • deep breathing • spinal extension • range of motion exercises for the lumbar, thoracic and cervical sections of the spine • aerobic exercise. In addition to NICE guidance, the ASAS/EULAR recommendations for management of SPA included the following key message concerning non-pharmacological strategies • Regular exercises may improve several outcomes.	Specialist physiotherapy is a key non-pharmacological management strategy for people diagnosed with AxSpA for education, advice and tailored exercise strategies to reduce the impact of the disease and maintain function and ability to work and participate to maintain their quality of life. However, there is currently a lack of access to specialist physiotherapy for people with axial spondyloarthritis. Currently, a large number of people with AS do not have access to physiotherapy (NASS patient survey 2013). The National Ankylosing Spondylitis Society (NASS) have identified that people with AS/AxSpA need more access to and support during a 'flare' of their condition. NASS found from patient/member surveys of people with spondyloarthritis that there is a significant lack of access to specialist physiotherapy. NASS is campaigning with a focus to improve: • Patient empowerment and self-management • Access to physiotherapy and exercise NASS highlights the need to encourage healthcare services for people with AS/AXSpA and commissioning bodies to implement the NICE recommendation on specialist physiotherapy. NASS states that 'We want to	Dagfinrud, H., Hagen, K. B., & Kvien, T. K. (2008). Physiotherapy interventions for ankylosing spondylitis. The Cochrane Library. Regel et al. 2016 ASAS/EULAR recommendations update - Efficacy and safety of non-pharmacological and non-biological pharmacological treatment: a systematic literature review http://rmdopen.bmj.com/content/3/1/e000397.full.pdf NASS represents the AS/AxSpA community in the UK and listening to people with AS and their families has highlighted the need to improve access to and provision of specialist physiotherapy and hydrotherapy in the UK. This unmet need and campaigning to improve the provision of this aspect of peoples' care is

Management					
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			This guidance concluded that regular exercises can improve disease activity, pain, function and spinal mobility.	see people with AS having better access to physiotherapy and hydrotherapy, being supported to self-manage their condition.' In addition Some people with AS/AxSPA cannot tolerate or are unresponsive to pharmacological therapies which makes specialist physiotherapy a core strategy in their care. Physiotherapy is also important not only for symptom management and reducing physical impacts that affect QoL and daily functioning, but also to help support and provide advice to help people remain in work or return to work. Specialist physiotherapy is also important not only for symptom management and reducing physical impacts that affect quality of life and daily functioning, but also to help support and provide advice to help people remain in work or return to work.	outlined in the NASS charity's strategy https://nass.co.uk/about-nass/2015--2019-strategy/ *NASS patient survey 2013 https://nass.co.uk/silo/files/working-with-as-survey-report.pdf https://www.researchgate.net/profile/Karl_Gaffney/publication/313294683_222_Current_Management_of_Ankylosing_Spondylitis_in_the_UK_The_Patient_Perspective/links/58bc11ae92851c471d561128/222-Current-Management-of-Ankylosing-Spondylitis-in-the-UK-The-Patient-Perspective.pdf https://academic.oup.com/rheumatology/article-abstract/doi/10.1093/rheumatology/kex062.103/4106607/103PATIENT-VOICE-AND-PATIENT-CHOICE-WHAT-DO-AXIAL

Management					
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41	British Society for Spondyloarthritis	There is good evidence that regular exercise generally throughout adult life improves well-being and mobility and inhibits ankylosis.	For many this requires regular supervision and motivation yet effective physical management may reduce the need for medication. Many patients find hydrotherapy more helpful than "dry land" exercise.	Hydrotherapy pools are disappearing from hospitals. Physiotherapy departments are often unable to provide repeated course of treatment or innovative ways of maintaining regular exercise regimes in these patients.	
42	SCM2 / Psoriasis and Psoriatic Arthritis Alliance	Urgent referral / re-access of care	Flares occur, and people need to be able to access services to manage symptoms quickly. Escalation of disease, could lead to joint damage and long-term irreversible consequence.	Chronic disease needs to be seen and a life-long journey where access at points along that route are recognised and made easily accessible. People are often discharged and have to re-enter each time an event occurs, which is inefficient and not useful.	Ditto
43	SCM3	Response to disease flares (axial/peripheral)	Recommended within NICE SpA guidance Access to specialist care a major patient problem (in NASS survey etc) and a common complaint in clinic. The expectation of 'flare management plans' would make a real difference to patients – with clear instructions on who to contact for what problem. It also ensures that centres think about prompt provision of services for flare treatment	When patients are flaring, this is the time when they have the fastest deterioration of physical function, greatest level of progressive joint damage and highest impact on work / social life. Many flares can be treated effectively and the duration of severe symptoms / associated long term damage reduced – but only if patients can access specialist care / treatment promptly.	NICE SpA guidance
44	Leeds Teaching Hospitals NHS Trust	Flare/rapid access	People with SpA experience disease flares which are still ill understood and should receive advice within 24-48 hours		Please see: Jacquemin C, RMD Open 2017; 39;3(1)
45	SCM5 / National Ankylosing	Support during an AxSpA Flare	The NASS State of the Nation Survey and indeed the trend of calls to the	Patients should have access to rheumatology advice during a flare. Currently GPs are unable	The NASS State of the Nation Survey showed that

Management					
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	Spondylitis Society		NASS Helpline indicates that access to care during a flare is one of the biggest issues for patients.	to provide the support that patients need during a flare and should this requirement fall to GPs then they would need adequate further training.	patients' satisfaction with rheumatology services reduced when specifically asking about access to services and support during a disease flare.
46	SCM4	People with spondyloarthritis should be provided with a flare management plan	NICE Guidance 65 Feb 2017 – People with spondyloarthritis should be provided with a flare management plan Advise people with spondyloarthritis about the possibility of experiencing flare episodes and extra-articular symptoms.	At present there is variability across the country with regards to whether a person is provided with a treatment plan to aid them in managing their condition. Current NHS recommendations state that all patients with a chronic condition should be provide with a written treatment plan to aid them in managing their condition. Disease flare is a key aspect of this group of diseases. The first port of call is likely to be the General Practitioner as the patient may not be able to access their rheumatology service in a timely manner. If the person has an individualised flare management plan this would assist the person and their General Practitioner in managing their flare and urgent referral to secondary care may not be required in minor disease flare.	NASS Research Agenda – Develop a self-management programme to help people manage their AS effectively
47	British Society for Spondyloarthritis	Access to physiotherapy or medical care urgently during periods of increased disease activity (Flare) is a major concern for patients (National Ankylosing Spondylitis Society)	Flare" in Spondyloarthritis is a difficult concept. In peripheral SpA it usually involves acute management of an acutely painful joint or enthesis. In axial disease symptoms maybe more variable but are disabling	The issue of flare in AS has been approached as below: Keat ACS. Axial Spondyloarthritis Flares - Whatever They Are. J Rheumatol. 2017 Apr;44(4):401-403	

Information and support					
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48	British Society for Rheumatology	To develop a patient education programme and encourage participation in research & audit	People with a new diagnosis of SpA should be offered personalised information, educational programme and exercise course led by a specialist Physiotherapist. People with SpA will be given opportunities for discussion throughout their care to help them understand their condition and be involved in self-management. People with SpA should be given information and contact details of an appropriate patient support group (e.g. National Ankylosing Spondylitis Society (NASS) People with SpA should have the opportunity to participate in national and local audits and research projects to improve the quality of their care and that of others.		
49	SCM6	People with a diagnosis of Spondyloarthritis, and their families and carers should have on going access to education and information about their diagnosis, prognosis and treatment.	NICE guidance states that Many patients wish to be active participants in their own healthcare, and to be involved in creating and managing their health strategy and use of services. Self-care and self-management are particularly important for people with long-term conditions. Good understanding of diagnosis and treatment options leads to a higher level of concordance.		

Information and support					
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50	SCM2 / Psoriasis and Psoriatic Arthritis Alliance	Patient education	For an individual to understand their condition and the consequences of it will help them to self-manage and provide and better dialogue with those they engage within the NHS. Moving towards a patient-centred approach where both patient and professional work together to manage what is individually appropriate.	Access to quality information about disease, management of symptoms and how to engage appropriately, will allow self-aware patients to make informed choices, of when and how to seek help. The lack of knowledge can cause a fear that creates anxiety and the need for a patient to seek urgent access, when perhaps a level of knowledge and the ability to manage situations such as flaring disease, could potentially ease the personal burden and pressure on out-of-hours care.	Ditto
51	SCM4	People and their carers should be provided with ongoing education appropriate to their stage of disease	NICE Guidance 65 Feb 2017 Provide people with spondyloarthritis, and their family members or carers (as appropriate), with information that is: available on an ongoing basis, relevant to the stage of the, person's condition tailored to the person's needs.	At the heart of the NHS agenda is that people and their carers can actively participate in making shared treatment decisions with their Clinician. People are only able to make these decisions if they are provided with appropriate understandable information to meet their needs. The provision of information should be a continuum throughout the course of the disease and be provided in a variety of formats.	Current evidenced based guidance emphasises the importance of education to enable shared decision making: 2016 Update of the ASAS-EULAR management recommendations for axial spondyloarthritis. Annals of Rheumatic Diseases, Vol 76, Issue 6, Van der Heide D, Ramiro S, Landewe R et al European League Against Rheumatism recommendations for the management of psoriatic arthritis with pharmacological therapies: 2015 update, Annals of Rheumatic Diseases 2016, 75: 499-510

Organising care					
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52	BRIT-PACT	Multidisciplinary collaboration	Patients with psoriatic arthritis may be seen in several settings: primary care, rheumatology, and dermatology. Recognition and communication are important to enable fulfilment of items 1 and 2. Improved multidisciplinary collaboration, especially with related specialities, such as dermatology, gastroenterology, ophthalmology will optimise diagnosis and treatment decisions taking the whole disease into account.	A recent 'benchmarking' report noted that one of the big problems was lack of communication and collaboration between specialities. Multidisciplinary care is important in diagnosis and management.	Favier G, Gladman D, Merola J, Armstrong AW, Boehncke WH, Helliwell P. Benchmarking Care in Psoriatic Arthritis — The QUANTUM Report: A Report from the GRAPPA 2016 Annual Meeting. J Rheum. 2017; 44:674–8.
53	Leeds Teaching Hospitals NHS Trust	Access to specialist department for adequate treatment options	People with SpA should have access to specialist care that allows for expert non pharmacological and pharmacological treatment such as biological to be accessed		Currently there is inequity of treatment access with areas of the UK not served by a specialist secondary specialist in SpA. This should include access to education and self-management which is likely to impact significantly at time of diagnosis. Please see: Hamilton L, Rheumatology 2017;56(2):313-6

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					Coates LC, Arthritis Rheumatol 2016;68(5):1060-71 Coates LC, Rheumatology 2013;52(10):1754-7
54	Leeds Teaching Hospitals NHS Trust	Access to multispecialist service	People with SpA need to have access to multi-specialist input including ophthalmology, gastroenterology and dermatology	Extra-articular manifestations such as uveitis and inflammatory bowel disease can occur in 40% and 10-30% respectively in SpA. In addition 10-20% of people with axSpA and 80% of those with PsA may have skin psoriasis. Often, clinical treatment decisions need to be taken together with other specialists and affected individuals.	
55	Moorlands Home Link	Improved communication from GPs to providers.	Providers often administer medication in the community and need to have up to date information to allow them to do this safely.	Our experience has shown that some GPs are reluctant to share information, which puts clients at risk of receiving the wrong medication, and staff at risk of making administration errors.	
56	Moorlands Home Link	Improving communication between hospital and GP surgeries	See above.	It can take several weeks for changes made to prescriptions in hospital, to be reflected in the community, which means that people aren’t receiving medication as prescribed.	
57	University Hospitals Southampton	Improved collaboration with specialties managing extra-articular disease	Biologic therapy options becoming increasingly complex with input required from dermatology, ophthalmology and gastroenterology		
58	British Society for Spondyloarthritis	Good management of SpA, especially axial disease, requires a multidisciplinary approach with regular monitoring with metrology and long-term sequential records	Spondyloarthritis clinics vary in constitution and frequency but many patients have very limited access to education about their condition, urgent treatment during exacerbations and regular, long-term metrics	Survey carried out jointly by the British Society for Spondyloarthritis and the National Ankylosing Spondylitis Society (Derakhshan et al. British Society for Rheumatology 2017) showed that 57.8% of responding British Rheumatology units had any kind of subspecialty spondyloarthritis clinic and 47% offered multidisciplinary care.	

Organising care					
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59	Primary Care Rheumatology Society	Access to biologic treatments for Spondyloarthritis	Biologic treatments are an integral part of the treatment of Spondyloarthrits but there remains significant variation around access to biologics across the country. NICE guideline NG65 is clear on the requirements for commencing Biologic therapy but in some areas, there are still delays usually due to funding by CCGs	Early, effective treatment can prevent long term joint damage and so delays in treatment can be devastating for the patient. There should be a consistent approach to accessing Biologic treatments across all CCGS in line with NICE guidelines	Recommendations in NICE guideline NG65: Spondyloarthritis in over 16s

Additional areas					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
60	AbbVie	The importance of recognising subclinical gut manifestation. Suggested wording of the quality standard: People with SPA may develop subclinical (macroscopic and microscopic) gut inflammation and must be assessed every year	The appropriate diagnosis of SpA can be achieved by the recognition of its subclinical gut manifestation. This needs to be seen in the context of common misdiagnosis of this disease.	The difficulty of achieving an appropriate diagnosis of SpA is indicated by the NICE spondyloarthritis guideline (NG65, recommendation 1.1.2.) The importance of micro and macroscopic gut inflammation in SpA is captured by the following references: Olivieri I, et al. Pharmacological treatment of spondyloarthritis: exploring the effectiveness of nonsteroidal anti-inflammatory drugs, traditional disease-modifying antirheumatic drugs and biological therapies. Autoimmun Rev. 2014;13:822–30	

Additional areas					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
				Van Praet L, et al. Microscopic gut inflammation in axial spondyloarthritis: a multiparametric predictive modelAnn Rheum Dis. 2013;72:414–7	
61	AbbVie	The importance of diagnosing extra articular manifestations in patients diagnosed with SpA. Suggested quality standard wording People diagnosed with SpA may develop extra articular manifestations (EAMs) such as psoriasis, inflammatory bowel disease and acute anterior uveitis and therefore must be examined for this on diagnosis	Diagnosis of these manifestations is important in ensuring their effective treatment. The decision as to the most appropriate biologic to treat SpA may be influenced by the existence of these manifestations for which certain biologics which are licensed to treat SpA (but not all) are indicated.	Recommendation 1.1. and 1.1.10-13 in the NICE guideline on Spondyloarthritis (NG65)	
62	AbbVie	The importance of multidisciplinary team assessment and the regular review of extra articular manifestations (EAM). Suggested wording of the quality standard People with SpA, must have a Multidisciplinary Team (MDT) assessment every 3 months to include an EAM assessment	The importance of the MDT in SpA is captured within the NICE spondyloarthritis guideline in terms of non-pharmacological management (NG65, recommendation 1.5.) and in terms of EAMs (NG65, 1.1. and 1.1.10-13).	NICE spondyloarthritis guideline (NG65, recommendation 1.5.) and in terms of EAMs (NG65, 1.1. and 1.1.10-13).	

Additional areas					
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63	British Society for Rheumatology	To have patient centered shared decision making with a care coordinator and MDT involvement	People with SpA should be cared for by a specialist led multi-disciplinary team (MDT), consisting of professionals with appropriate knowledge and skills and be given a single point of contact responsible for managing their care. People with SpA should be involved in shared decision making involving all aspects of their treatment with the MDT.	People with SpA symptoms should have access to a specialist Physiotherapist for guidance with an individualized exercise programme based on the best available models. It is expected that the Physiotherapist will have experience in treating this condition and be in good communication with the clinical team.	
64	British Society for Rheumatology	There should be a personalized long-term care plan which should include co-morbidities	People with SpA should receive long-term expert care and support, including annual holistic review of the social and biologic effects of their disease with an action plan to address issues identified. This should include social roles and work, disease activity, pain, mood, joint damage, functional ability, co-morbidities including (cardiovascular risk and osteoporosis) and extra-articular disease (e.g. iritis, inflammatory bowel disease and psoriasis). This will include referral to other specialities as necessary (8).		8 Keat A, Gaffney, Marzo-Ortega H, Cornell T, Mackay K, Skerrett J, Van Rossen L, Wordsworth P. Improving the treatment of ankylosing spondylitis in the UK. Rheumatology 2011:50:1936-1939
65	BRIT-PACT	Measure outcomes	Monitoring of disease outcomes, including disease activity and patient impact at timely intervals following initial assessment and treatment is necessary to assess disease status.	The benchmarking project highlighted this as one of the major obstacles to delivering good care in this disease	Favier G, Gladman D, Merola J, Armstrong AW, Boehncke WH, Helliwell P. Benchmarking Care in Psoriatic Arthritis — The QUANTUM Report: A Report from the GRAPPA 2016

Additional areas					
ID	**Stakeholder**	**Suggested key area for quality improvement**	**Why is this important?**	**Why is this a key area for quality improvement?**	**Supporting information**
					Annual Meeting. J Rheum. 2017; 44:674–8.
66	BRIT-PACT	Measure co-morbidities.	Co-morbidities, including cardiovascular, gastroenterological, psychological are important and are associated with increased morbidity and mortality.	This was one of the major findings of the benchmarking report. The higher morbidity and mortality have been highlighted in several publications	Wong K, Gladman DD, Husted J, Long JA, Farewell VT. Mortality studies in psoriatic arthritis: results from a single outpatient clinic. I. Causes and risk of death. Arthritis and rheumatism. 1997 Oct; 40(10):1868-1872. Peters MJ, van der Horst-Bruinsma IE, Dijkmans BA, Nurmohamed MT. Cardiovascular risk profile of patients with spondylarthropathies, particularly ankylosing spondylitis and psoriatic arthritis. [Review] [76 refs]. Seminars in Arthritis & Rheumatism34(3):585-92. 2004.
67	Celgene UK Ltd	Incentivised G.P. assessments for patients with Psoriatic Arthritis.	Diagnosis and referral Recommendation for target for annual primary care PEST (psoriasis epidemiology screening tool) screening for patients with psoriasis and appropriate and timely referral to secondary care for patients with psoriatic arthritis.	Currently, there is little assessment of patient disease status annually, meaning patients may be sub-optimally treated. Patients may also not be appropriately referred upon diagnosis of psoriatic arthritis. PEST is a validated screening tool for psoriatic arthritis (PsA) and it is recommended that patients with psoriasis who do not have a	http://www.bad.org.uk/shared/get-file.ashx?id=1655&itemtype=document

Additional areas					
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			Patient ongoing management Recommendation for an incentivised (G.P. contract) annual assessment by G.P. to monitor patient disease status – Skin / Joints / Co-morbidities and QoL impact, for patients treated with topicals/NSAIDs/ standard DMARDs. Management or referral to follow assessment as required. This would allow for effective management of patients' disease and reduce burden to the healthcare system due to suboptimal disease control.	diagnosis of PsA complete an annual PEST questionnaire (NICE psoriasis guidelines 2012). A score of 3 or more indicates referral to rheumatology should be considered.	
68	SCM6	People with a diagnosis of Spondyloarthritis should have access to the multidisciplinary team	Good access to the multidisciplinary team such as Specialist Nurses, Physiotherapists, Occupational therapists, Podiatrist, Pharmacists and Clinical Psychologists is core to patients receiving swift access to relevant advice and treatment helping them to manage their conditions, extra articular symptoms and reduce episodes of flare Patients also have needs other than the treatment of their specific health conditions. There should be recognition of the potential need for psychological and emotional support,		

Additional areas					
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69	SCM3	Specialist monitoring of disease (axial and peripheral)	Recommended within NICE SpA guidance Regular monitoring of disease by specialists to ensure that patients have adequately controlled disease should help prevent uncontrolled disease progression and ensure that appropriate interventions are offered to patients when needed (also impossible to TTT for PsA (see below) without this in place	Peripheral arthritis - similar to 2 - there is a tendancy for PsA / peripheral SpA patients to be monitored (if at all) on RA guidelines (i.e. DAS-28) This is inappropriate as it focusses on hand (MCP/PIP) inflammation, and ignores hand (DIPs), hips, feet – all areas which are commonly affected in PsA / peripheral SpA. Axial disease requires regular measurements to evaluate deterioration. Clinically it is all too easy to miss functional deterioration, restricted movements, active inflammatory symptoms without a specialist assessment (BASDAI/pain VAS/BASMI)	NICE SpA guidance
70	SCM3	Developmental: Treat to target in PsA	Increasing evidence of improved patient outcomes using TTT – with better health economic outcomes compared to initial paper as cost of biologics falling and follow up frequency reduced in patients who become stable Coates L, Helliwell P. Treating to target in psoriatic arthritis: how to implement in clinical practice. Ann Rheum Dis. 2016; 75:640-643. Gladman D, Thavaneswaran A, Chandran V, Cook RJ. Do patients with psoriatic arthritis who present	Faster, more frequent control of inflammatory joint disease with less joint damage and disability	

Additional areas					
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			early fare better than those presenting later in the disease? Ann Rheum Dis. 2011; 70(12):2152-2154		
71	Torbay Hospital	Long term monitoring of axial SpA- the diagnostic process and clinical risks	Long term monitoring of axial SpA- the diagnostic process and clinical risks	These current guidelines appear to lack the sufficient reference to the long term monitoring process . Greater detail is offered in NICE Rheumatoid Arthritis guidelines. In particular there is the need to more fully define the role and need for monitoring of risk factors such as cardiovascular risks , the routine use of repeat imaging for monitoring, and the optimal time interval and need for clinical re-examination as monitoring. In addition it would be helpful to state if the Bath indices remain valid and reliable measures for long tem monitoring, or if the NHS should be using different measures.	NICE guidelines on management of Rheumatoid Arthritis
72	Torbay Hospital	Long term monitoring of axial SpA-the multi-disciplinary team	Long term monitoring of axial SpA- the multi-disciplinary team	These current guidelines insufficiently define the role of the specialist multidisciplinary team. Point 1.5.3 NICE guideline NG65. suggests “referral to specialist therapist” but does not sufficiently identify this as “specialist in rheumatology”. The role of the multidisciplinary team (especially physiotherapy) in long term monitoring needs to be better defined. This is more explicitly defined in NICE RA guidelines	NICE guidelines on management of RA
73	Torbay Hospital	Long term monitoring of SpA- the optimal “pathway”	Long term monitoring of SpA- the optimal “pathway”	NICE guideline NG65. would benefit from expansion to include the need for urgent access to the specialist secondary care team if patients remain on long term “review”. In particular there is no mention of having a defined person who manages the case between review appointments or who provides a contact point between review appointments. It would be beneficial to define the	

Additional areas					
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				responsibility for long term monitoring between primary and secondary care.	
74	SCM5 / National Ankylosing Spondylitis Society	Establishing Multi-Disciplinary Teams (MDT) to give comprehensive, holistic patient care and to address the Extra-Articular Manifestations (EAMs) associated with AxSpA	Patients would benefit from seeing a physiotherapist, a rheumatology nurse and other specialist clinicians at the same time as seeing their rheumatologist. All too often, patients with EAMs such as uveitis, psoriasis or IBD, receive fragmented care and experience delays in their care due to unnecessary time between clinicians communicating with one another about the best course of treatment	Establishing MDTs and specialist AxSpA clinics would help resolve some of these issues and thus improve the patients' care	In the poster presented to the British Society for Rheumatology in April 2017 'What do rheumatology departments offer AxSpA patients in the UK'(Derakhshan, Pathak, Cook, Dickinson, Siebert and Gaffney), data from 83 rheumatology departments across the UK was presented. 53 (63.9%) of centres had an MDT. Sixteen (19.3%) had one combined clinic available with either gastroenterology, dermatology or ophthalmology. 20 units had no MDT for AxSpA patients. A wide variation in care was demonstrated.
75	Primary Care Rheumatology Society	Measurement of disease activity in patients with Spondyloarthritis	There has been a huge improvement in disease activity measurement in inflammatory arthritis, especially with rheumatoid arthritis and this has led to significant improvements in care. There is not the same emphasis on disease activity measurements in spondyloarthritis, for example using BASDAI measurements in Ankylosing Spondylitis.	The NICE spondyloarthritis guidelines describe a range of different diagnostic criteria for the diagnosis of Spondyloarthritis. There is no mention of disease activity monitoring in the same way as for rheumatoid arthritis. Different rheumatology departments tend to use different tools for both diagnosis and also	Recommendations in NICE guideline NG65: Spondyloarthritis in over 16s

Additional areas					
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			Furthermore, there is lack of consistency regarding the tools used for measuring disease activity in Spondyloarthritis. Improved measurements can lead to improvements in the quality of care for these patients	monitoring leading to variation in treatments and quality of care.	
76	SCM4	Access to multidisciplinary management co-ordinated by a Rheumatologist	NICE Guidance 65 Feb 2017 People with spondyloarthritis have access to specialist care in primary and secondary care settings throughout their disease course to ensure optimal long-term management. Refer people for an immediate (same-day) ophthalmological assessment if they have symptoms of acute anterior uveitis (for example, eye pain, eye redness, sensitivity to light or blurred vision).	National variability with regards to availability of a specialist MDT for people with spondyloarthropathies. Peripheral symptoms may affect the skin, gut or eye and it is important patients have access to specialist in these disease areas. Exercise is a key part of management in axial disease – all people with spondyloarthropathies should have access to appropriate physiotherapy resources Direct access to a named specialist nurse in rheumatology Access to a pharmacist who can provide information and support with medication. Access to occupational therapists to provide support both in the work and home environment. There is a high rate of job less 2-3 yrs post diagnosis.	Approximately 40% of the patients experience at least one extra-articular manifestation during the course of the disease. Some of these extra-articular manifestations require the immediate consultation of other experts, pointing to the presence of multidisciplinary networks for the best care of patients with axSpA. it is crucial that the rheumatologist is the coordinator in a multidisciplinary network of care for patients with axSpA.
77	UCB Pharma Ltd	Establishing Multi-Disciplinary Teams to address the Extra-Articular Manifestations (EAMs) associated with AxSpA	Patients all too often experience fragmented care and delay to treatment often in line with the heterogeneous way in which spondyloarthritis can present itself.	As stated above, Spondyloarthritis conditions and their diverse symptoms are important to recognise to enable early management to reduce the impacts and improve outcomes.	van der Heijde D, Ramiro S, Landewé R, et al. 2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis. Annals of

Additional areas					
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			Approximately 40% of the patients experience at least one extra-articular manifestation during the course of the disease. Some of these extra-articular manifestations require the immediate consultation of other experts, pointing to the presence of multidisciplinary networks for the best care of patients with axSpA		the Rheumatic Diseases 2017;76:978-991.
78	University Hospitals Southampton	Assessment of comorbidities	Comorbidities common in peripheral and axial SpA	Improve health outcomes	
79	SCM5 / National Ankylosing Spondylitis Society	Additional developmental areas of emergent practice: Fatigue	Patients advise NASS that fatigue is one of their biggest challenges.	This was highlighted in the NASS State of the Nation Survey. Fatigue is often not even discussed in appointments.	Only one-third of patients in the NASS State of the Nation Survey 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. Fatigue is described by patients as being as burdensome as pain.

Stakeholders who responded to say they had no comments at this stage
MSD (Merck Sharp & Dohme Ltd)
Royal College of Nursing