NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Spondyloarthritis

Date of quality standards advisory committee post-consultation meeting:
21 March 2018.

2 Introduction

The draft quality standard for spondyloarthritis was made available on the NICE website for a 4-week public consultation period between 26 January and 23 February 2018. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 17 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically

not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

4. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Most stakeholders supported the quality standard and felt that it includes the key areas for quality improvement.
- The healthcare professionals involved in care could include podiatrists, and there should be a greater role for GPs, in particular around investigations, to reduce the burden on rheumatologists.

Consultation comments on data collection

- Data is not currently available on the number of people recently diagnosed with spondyloarthritis and there is no central data collection mechanism.
- Data should be available, either from hospital records in rheumatology departments or from primary care records.
- Data collection in general practice would be labour intensive and require additional resources.

Consultation comments on resource impact

- There are resource implications regarding access to specialist rheumatologists and physiotherapists, as clinics have long waiting times in most areas. There are also issues with access to investigations.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Adults with signs and symptoms of axial or peripheral spondyloarthritis are referred to a rheumatologist.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Young people (16 to 24) should be referred to a young adult service where possible.
- Make it clearer that people are referred for an expert clinical assessment, not just tests.
- Encouraging service providers to use target timeframes from first presentation of symptoms to referral would improve timely access to specialists and delayed diagnosis.
- It will be difficult to get an accurate number for the denominator in the process measure without coding of the symptoms of axial or peripheral spondyloarthritis.
- Joint replacement surgery is an outcome that is already being achieved. Measuring work productivity would be more useful.
- Podiatrists should be added to the audience descriptor for healthcare professionals.
- Specify in the patient audience descriptor that the 'scan' is an MRI scan.
- Rest pain should be added to the criteria in the definition for axial spondyloarthritis.
- A clearer definition of peripheral spondyloarthritis is needed and should mention psoriatic arthritis as an example. It should include the Classification of Psoriatic Arthritis (CASPAR) criteria and screening questionnaires for psoriatic arthritis.
- Awareness of the signs and symptoms of spondyloarthritis should be raised outside of primary care, in particular among professionals from ophthalmology, dermatology and gastroenterology services. Some stakeholders felt that education

and awareness campaigns are difficult to implement given limited resources. If included it would need to be organised nationally.

5.2 Draft statement 2

Adults with suspected axial spondyloarthritis and an X-ray that does not show sacroiliitis have an inflammatory back pain MRI.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- The statement would be difficult to implement due to issues with access to inflammatory back pain MRI and musculoskeletal radiologists in some parts of the country.
- The statement should say that an X-ray or inflammatory back pain MRI should be done. An X-ray is not needed if an inflammatory back pain MRI is done.
- There would be a resource issue around having a further clinic review and providing a musculoskeletal radiologist.
- Clarify in the rationale that X-rays and MRI can support diagnosis rather than diagnose on their own.
- Diagnosis by MRI could be more difficult in an immature skeleton and should be done by radiologists familiar with this.
- The patient audience descriptor is misleading and should say that MRIs can reveal evidence of axial spondyloarthritis even if X-rays cannot.

5.3 Draft statement 3

Adults with axial spondyloarthritis are referred to a specialist physiotherapist for a structured exercise programme.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- The statement should include hydrotherapy.
- The statement should not be about a one-off structured programme, but about ongoing support and advice from specialist physiotherapists when needed on exercise and self-management.

- Adults with axial spondyloarthritis should be able to self-refer to a specialist physiotherapist. Patients need to be made aware of physiotherapy support and how to access it when needed, as awareness is low.
- There will be a resource issue with ensuring there is enough capacity of specialist physiotherapists to meet demand and to run structured exercise programmes. Access is currently low, and support and follow-up is limited.
- The statement will be hard to measure and can only be measured through local data collection, as access to physiotherapy is not in national datasets.
- Local services should agree a multidisciplinary outcome measure and share the monitoring of it.
- Adults with axial spondyloarthritis who are obese and have difficulty mobilising should be mentioned in the patient audience descriptor.
- Core stability exercises and strength and balance exercises should be included in the structured exercise programme.

5.4 Draft statement 4

Adults with spondyloarthritis and a flare management plan are given information on how to access care during flares.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- The statement implies that not all people with spondyloarthritis have or need a flare management plan, when all of them will experience flares at some point and should have a plan.
- Broader information and support on spondyloarthritis should be provided, as inadequate information is being given to patients.
- Patients should have access to a telephone support line for advice during a flare. One stakeholder said that most rheumatology departments have specialist nurses or allied health professionals who run support lines.
- The numerator and denominator in the process measure are measuring the same thing, as the flare management plan will include information on how to access care.

- Measure the number of patients who receive general information and a care plan, as well as those who receive information on access to care.
- Include specialist physiotherapists and podiatrists in the healthcare professional audience descriptor.
- Commissioners should make sure that primary care practitioners can recognise and manage flares.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements:

- Pharmacological treatment
- Involvement of a multidisciplinary team
- Communication and coordination between all healthcare professionals involved in the person's care
- Referral to interventional spine specialists for diagnostic and therapeutic interventions if pain is persistent and not responding to initial treatment options
- Management for people with psoriatic arthritis
- Annual review, including assessment of mental health and fatigue, and review of employment status, disease activity and progression.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	AbbVie Inc	General	We think that these quality statements will be valuable in supporting optimal clinical care of spondyloarthritis patients.
2	Department of Health and Social Care	General	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.
3	Merck Sharp & Dohme Limited	General	No comment.
4	NHS England	General	We welcome the inclusion of outcome measure within the quality measures recognising that those identified are an example rather than a prescription
5	Royal College of General Practitioners	General	General: This is a condition with a range of symptoms and signs, including taking into account family history and conditions such as psoriasis. The risk is over burdening rheumatologists. The only real reference to General Practitioners is ensuring that specialist physiotherapy is in place. This is really an issue for commissioning and locality groups.
6	Royal College of Physicians	General	The RCP is grateful for the opportunity to respond to the above consultation. We would like to endorse the response submitted by the British Society for Rheumatology (BSR).
7	UCB Pharma	General	Thank you for the opportunity to comment on the draft for the above quality standard. UCB agrees with and supports the draft spondyloarthritis quality standard in this consultation.
8	NHS England	Question 2	Whilst measures may exist in general practice to collect the data as set out, this could be labour intensive – given the current pressures this would need resources invested in order to meaningfully achieve the desired outcome.
9	Novartis Pharmaceutical Ltd	Question 2	We would also like to highlight the importance of improving data collection in the area of spondyloarthritis. As revealed in the response to a recent Parliamentary Question, data is not currently available regarding the number of people recently diagnosed with spondyloarthritis conditions in the UK and there are no existing central data collection mechanisms to provide this information.
			We therefore hope that this Quality Standard encourages significant improvements in the level of available spondyloarthritis data, and that emphasis is placed upon this aspect within guidance to commissioners and service providers.

[1]PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
10	Primary Care Rheumatology Society	Question 2	We believe most local systems would be able to support the collection of the data for the proposed quality measures. A lot of the proposed measures are already being collected in rheumatology departments. Some of the information may be best collected from sources outside hospital such as GP records. For instance, the length of time from a flare to being treated may be more accessible from GP/community records rather than hospital records as majority of flares are seen and managed in the community and not in hospital. Using hospital records alone is likely to underestimate the figures for this group of patients.
11	Primary Care Rheumatology Society	Question 3	Yes, we believe that this Quality standard includes all the key ares for Quality improvement in the management of Spondyloarthropathies. There are however resource implications from the point of view of access to specialist rheumatologists and physiotherapists, where clinics already have long waiting times in most areas and also access to appropriate investigations. We feel there should be more of a role in primary care which includes working up the patient prior to referral. We think GPs especially GPSI's and musculoskeletal GPs should be able to access the necessary investigations including Dynamic MRI scan in the community prior to referral, so that referrals can be triaged effectively. This will reduce unnecessary pressure on specialist rheumatology clinics. At present, most areas of the country do not allow access for dynamic MRI scan from primary or intermediate care.
12	AbbVie Inc	Statement 1	Suggest including some specific wording regarding the importance of referring patients to a rheumatologist for a spondylitis assessment (NG65 1.1.8-1.1.10).
13	British Psoriatic Arthritis Consortium	Statement 1	Quality standards 1 and 4 refer to "spondyloarthritis" or "axial or peripheral spondyloarthritis". We are concerned that a wider medical audience outside rheumatology, predominantly in primary care may be unfamiliar with the spondyloarthritis (SpA) concept particularly in peripheral disease. This is particularly important for quality standard 1 as it pertains to early referral and is therefore aimed at people outside rheumatology. The majority of the evidence for this quality standard in peripheral arthritis relates specifically to psoriatic arthritis which is also the most common form of peripheral SpA. We believe that a clearer definition of peripheral spondyloarthritis, mentioning psoriatic arthritis (PsA) as an example, would benefit the document as a whole.
14	British Psoriatic Arthritis Consortium	Statement 1	Quality standard 1 refers to early diagnosis and suggests a structure to raise awareness of signs and symptoms of SpA in primary care and develop local referral criteria and pathways for referral to rheumatology. Despite clear evidence of the utility of screening for PsA using screening questionnaires for patients with psoriasis, these have not been mentioned. There is a large volume of work supporting the use of these quick and feasible questionnaires and we believe that their inclusion would give practical guidance to support early referral in PsA.
15	British Psoriatic Arthritis Consortium	Statement 1	The text related to quality standard 1 refers directly to the inflammatory back pain and AxSpA criteria but the guidance for referral of peripheral SpA do not mention screening questionnaires or the CASPAR criteria for PsA.

ID	Stakeholder	Statement number	Comments[1]
16	British Society for Rheumatology	Statement 1	We are happy with 1st quality statement. However, we envisage that there may be significant challenges and resource implication to deliver a structured education and awareness campaign by most rheumatology departments. A regional and national level awareness programme should be implemented with involvement from local units. Regarding the quality measure relating to the number of patients referred for joint replacements - we believe this has significantly reduced since the introduction of biological therapies and therefore may not be a good outcome measure. We advise measuring work productivity is a more useful outcome. Regarding the denominator in the process section of quality measures we advise that the number of adults with signs and symptoms of axial or peripheral Spondyloarthritis should be based on point prevalence in the local population. A true number for the denominator will not be easily counted or available. We would advise that Rest pain be added as one of the criteria for IBP in the diagnosis of Axial Spondyloarthritis – see definitions of terms used page 6.
17	British Society for Rheumatology (from British Society for Paediatric and Adolescent Rheumatology)	Statement 1	Referal for suspected spondyloarthritis in young people 16 to 24 should, where possible, be to a young adult service
18	The British Society for Spondyloarthritis	Statement 1	.....are referred to a rheumatologist for tests such as an X-ray or a scan. The referral most importantly leads to "expert clinical assessment"; the role of tests alone should not be overemphasised. The term "scan" should be clarified to mean "MRI scan" as other scans may be inappropriate or misleading
19	NHS England	Statement 1	This statement may be hard to measure because it would be very difficult to accurately identify the denominator (number of adults with signs and symptoms of axial of peripheral spondyloarthritis) without appropriate systems of coding/recording symptoms of axial and peripheral spondyloarthritis in place.

ID	Stakeholder	Statement number	Comments[1]
20	Novartis Pharmaceutical Ltd	Statement 1	Lack of awareness of the signs and symptoms of spondyloarthritis in primary care is one of the biggest barriers to accurate and timely diagnosis. Taking steps therefore to highlight these amongst primary care practitioners will help to support prompt referral to a specialist and improved outcomes more broadly. Spondyloarthritis can have diverse symptoms which can be hard to identify. It is therefore encouraging that this Quality Statement highlights the different 'signs and symptoms' associated with spondyloarthritis within the 'definitions of terms used in this quality statement' section. We would also suggest that this Quality Statement is linked to best practice and aligned with relevant existing guidance, such as NICE Guideline 59 on the assessment and management of low back pain management and sciatica in over 16s. Given the long lead-times to accurate diagnosis of spondyloarthritis at present – the average delay in diagnosis of ankylosing spondylitis is currently around 8.5 years – it would be useful for this Quality Statement to encourage the development of target timeframes for service providers in regards to the time between referral from first presentation of symptoms to referral. This will help to encourage optimum care and timely access to specialists in relation to the proposed 'Outcome' 'a' within this Statement. At present, much of the data included within this Quality Statement is not routinely collected. It will therefore be important to provide as much support as possible around putting in place the local data collection elements of this Statement, to help ensure meaningful assessments of its uptake can be carried out. Finally, the importance of encouraging collaborative working across the care pathway should also be highlighted. We would therefore recommend that in addition to primary care, steps should also be taken to raise awareness of the signs and symptoms of spondyloarthritis amongst other relevant parts of the system where referral may be appropriate, including ophthalmology, dermatology and gastroenterology services. We would like this to be in the form of a mandate for all Trust to have written pathways in place between these departments with a timeframe for implementation.
21	Podiatry Rheumatic Care Association	Statement 1	The current wording with in this draft Quality Standard is not reflective in full the range of health professionals that an individual with a spondyloarthritis may need to access as part of their holistic care. Given the level of lower limb conditions associated with both axial and peripheral disease, specific reference to podiatry may be considered appropriate . Reference to this could be made by specifically listing 'podiatrists' within: • QS1 'what the quality statement means for different audiences' / health care professionals (p5).
			• QS4, providing examples of health professionals including podiatry that contribute to a multidisciplinary team (p15).

ID	Stakeholder	Statement number	Comments[1]
22	Royal College of Nursing	Statement 1	Referral for suspected spondyloarthritis: Education and awareness campaign may be difficult to achieve especially for tertiary centres. There are resource implications that would need to be addressed i.e. time and staffing. Use of charities to provide some of this i.e. posters and info leaflets will cover a lot of it.
23	British Society for Rheumatology	Statement 2	We would advise that the QS statement be changed to as follows: Adults with suspected Axial Spondyloarthritis should have an imaging modality that is either an X-ray or IBP MRI. X-ray of the sacroiliac joint is recommended but should not be mandatory if an IBP MRI is done. The main advantage of this is that it potentially avoids a delay in diagnosis if one did a plain x-ray initially and then needed to progress to an MRI. This would also potentially have a resource issue (further clinic review required) if we stick with the current QS Statement Recommendations. In the section of quality measures we have concerns that there may be resource and training issues with the provision of a specialist Musculoskeletal Radiologist (page 8 in NICE QS).
24	British Society for Rheumatology (from British Society for Paediatric and Adolescent Rheumatology)	Statement 2	Diagnosis by MRI may be difficult in the immature skeleton and scans should be reported by radiologists familiar with changes in the immature skeleton and immature bone marrow
25	The British Society for Spondyloarthritis	Statement 2	Statements that "x-rays can diagnose....." and MRI using an inflammatory back pain protocol can diagnose..." are incorrect and may mislead. Better to read: "X-rays can support diagnosis..." and "MRI using an inflammatory back pain protocol can demonstrate changes of non-radiographic....." This is not pedantry as interpretation of X-ray and MRI appearances must take into account the entire clinical scenario
26	The British Society for Spondyloarthritis	Statement 2	Some major musculoskeletal units do not perform spinal and sacroiliac X-rays for axial SpA. Moreover, the 10 day rule often inhibits pelvic X-rays in young women at the time of the consultation, especially when the history is short so that pick-up from an X-ray is likely to be low. Therefore the implication that x-ray is always the first step would be unrealistic.
27	The British Society for Spondyloarthritis	Statement 2	The phrase "MRIs can often show if someone has a different type of axial....." is misleading. We assume that what is meant is: "MRIs can reveal evidence of axial spondyloarthritis even if X-ray appearances are normal".
28	The British Society for Spondyloarthritis	Statement 2	"An MRI performed using short T1...." should read "An MRI performed using short Tau...."
29	Novartis Pharmaceutical Ltd	Statement 2	Novartis supports the inclusion of this Quality Statement.

ID	Stakeholder	Statement number	Comments[1]
30	Primary Care Rheumatology Society	Statement 2	This statement would be difficult to implement as not all parts of the country have direct access to Inflammatory back pain MRI. Even where it exists, many radiology departments may not have access to a musculoskeletal radiologist. We however do not envisage that the information would be too difficult to measure
31	Royal College of Nursing	Statement 2	Diagnosis of axial spondyloarthritis using Magnetic Resonance Imaging (MRI): Small district general hospitals (DGH) may not have the specialist radiologist, so patients may have to travel to a larger DGH or specialist centre to get this service.
32	British Society for Rheumatology	Statement 3	We would advise that this QS statement be changed to incorporate pharmacological treatment and involvement of other Health Care Professionals in the management of SpA. Our recommendation would be that the QS reads as follows: Adults with Spondyloarthritis should be assessed for early pharmacological and non-pharmacological Multidisciplinary team treatment. We also believe that there will be a resource and training issue with the provision of specialised physiotherapy for patients with Spondyloarthritis. There needs to be a capacity and demand exercise to ensure that there is adequate provision of specialised physiotherapy before this quality statement can be a reality. We would advise that core stability exercises be included in the structured exercise programme advice.
33	The British Society for Spondyloarthritis	Statement 3	We agree with "What the quality statement means for different audiences" but the statement itself is too restrictive. Since lifelong regular exercise is key to management of axial SpA the statement needs to allow for both lifelong physical management and self-management. This could be achieved by: "Adults with axial Spondyloarthritis should be supported in a lifelong regime of appropriate exercise supported by a specialist physiotherapist".
34	The British Society for Spondyloarthritis	Statement 3	It is essential that ".....referred to a specialist physiotherapist for a structured exercise programme." is not seen as enough. Access to a specialist physiotherapist both initially at diagnosis and at sundry points along the course is essential. Moreover, the opportunity for that therapist to promote and support self-management is an essential element on management. Thus, we would prefer: "Commissioners (clinical commissioning groups) have service specifications for physiotherapy that ensure that adults with axial spondyloarthritis are referred to a specialist physiotherapist so that the therapist can advise on regular exercise and support self-management long-term. "
35	Chartered Society of Physiotherapy	Statement 3	I would suggest a statement about the physiotherapist being a source of knowledge and information, in particular to advise the individual on physical activity, including strength and balance exercise.
36	Chartered Society of Physiotherapy	Statement 3	Hydrotherapy is an important element of physiotherapy for this group. Many people with Spondyloarthritis find this therapy helpful and continue their programme at their local leisure pool or with a National Ankylosing Spondylitis Society (NASS) group
37	Chartered Society of Physiotherapy	Statement 3	Adults with axial spondylorarthritis should be able to refer themselves directly to a specialist physiotherapist, without the need for a medical referral first

ID	Stakeholder	Statement number	Comments[1]
38	Chartered Society of Physiotherapy	Statement 3	This is hard to measure because access to physiotherapy is not included within national data sets. This could only be captured through local data collection
39	Chartered Society of Physiotherapy	Statement 3	The local services should agree the multidisciplinary outcome measure, which can be used by all professions. The monitoring of the individual's outcome measure should be shared across the multidisciplinary team to improve communication and shared decision making
40	National Ankylosing Spondylitis Society	Statement 3	As spondyloarthritis is a lifelong condition which may result in different problems or issues at different times, it is very important that this statement should not be interpreted simply to mean a one-off structured session or short course of physiotherapy. People with spondyloarthritis need access to physiotherapy during flares and they need regular follow up sessions to pick up developing issues. In 2016 NASS carried out a survey of 2000 people in the UK with axial spondyloarthritis. We found that only 46% of people with axial spondyloarthritis had seen a physiotherapist in the past 12 months. This Quality Standard has the opportunity to ensure a far greater proportion of people with spondyloarthritis are able to regularly access physiotherapy, thus improving outcomes.
41	NHS England	Statement 3	We welcome the recognition and support of the role of physiotherapy in this quality standard.
42	Novartis Pharmaceutical Ltd	Statement 3	As recommended by the National Ankylosing Spondylitis Society, the British Society for Rheumatology and the Chartered Society of Physiotherapy, ensuring that adults with a diagnosis of axial spondyloarthritis have appropriate access to a specialist physiotherapist should be seen as a key component of patient care and ongoing management. Providing specialist physiotherapy for axial spondyloarthritis patients will not only help to improve an individual's pain management, flexibility and overall sense of mental wellbeing, but as a result will also support reductions in avoidable visits to primary care and can help those affected to maintain meaningful employment. Whilst there are a number of best practice examples across the country of axial spondyloarthritis care pathways incorporating effective delivery of specialist physiotherapist care, overall access to specialist physiotherapy remains low, and many patients are only offered limited physiotherapist support based around general back pain management, and often without any effective follow-up management.

ID	Stakeholder	Statement number	Comments[1]
			A 'State of the Nation' survey carried out by the National Ankylosing Spondylitis Society in 2016 for instance showed that over half (58%) of axial spondyloarthritis patients had not been reviewed by a physiotherapist during the previous year and almost two-thirds (65%) of patients said that they were not participating in sufficient regular exercise relative to their diagnosis, or to support their general wellbeing. To help support the implementation of this Quality Statement, appropriate resources will therefore need to be put in place to increase the availability of specialist physiotherapy care for axial spondyloarthritis patients, alongside education and training to support best practice. This should include advice around flare management and the importance of coordinating care for patients across primary and secondary care, in line with NICE guidelines. It is also essential to ensure that patients are aware of the availability of physiotherapy support and how to access it – only 27% of axial spondyloarthritis patients who had not been reviewed by a physiotherapist during the previous 12 months were aware that they could self-refer to a physiotherapist during a flare for instance.
43	Primary Care Rheumatology Society	Statement 3	Specialist physiotherapists for treating Spondyloarthritis are not always readily available in all local areas or in local trusts. Most district General Hospitals and rheumatology departments have access to general physiotherapists and not necessarily to specialist spondyloarthritis physios. There is certainly a very limited access to specialist physios from Primary care at present so we think this particular measure would be difficult to implement.
44	Royal College of Nursing	Statement 3	Adults with axial spondyloarthritis are referred to a specialist physiotherapist for a structured exercise programme: This is a wonderful standard to aspire to but a fair number of DGHs do not have the specialist physiotherapists and the capacity to run a structured programme.
45	Royal College of Nursing	Statement 3	Adults diagnosed with axial spondyloarthritis When discussing the physiotherapy for this group are we also including and considering the population suffering from obesity and morbid obesity who have been diagnosed with axial spondyloathritis. A mention of this group would identify the other areas for consideration such as weight management and difficulty mobilising to achieve the physiotherapy goals. This needs to be acknowledged somewhere in this section.
46	British Society for Rheumatology	Statement 4	We would advise that the QS statement be changed as follows: Adults with Spondyloarthritis are reviewed annually with an emphasis on psycho-social care, co-morbidities and have a flare management plan in place.

ID	Stakeholder	Statement number	Comments[1]
			The focus of this Quality Statement should not only be on flare management. This should instead include all other areas affecting patient care In the Process section under 'Proportion of adults with spondyloarthritis and a flare management plan who are given information on how to access care during flares', there needs to be more clarity on the measurement of flare management as the numerator and denominator are measuring the same thing. The flare management plan which is the denominator will include information on how to access care during the flare (the numerator).
47	The British Society for Spondyloarthritis	Statement 4	This implies that some people with axial Spondyloarthritis will not have or need a flare management plan. Not all patients may need to access support during a flare but most, if not all will experience flares of some sort. Therefore it would be rational for all patients to be educated about flares and to have opportunities to seek support. Thus we would prefer wording as:" Adults with axial spondyloarthritis should have a flare management plan and information on how to access care during flares."
48	The British Society for Spondyloarthritis	Statement 4	We very much support the elements of this standard. It is important that physiotherapists are also included in the list of those who might be contacted and who can give critical advice. Thus we would prefer "Healthcare professionals (rheumatologists and specialist rheumatology nurses) discuss flare....." to read: "Healthcare professionals (rheumatologists, specialist rheumatology nurses and specialist physiotherapists) discuss flare....."
49	National Ankylosing Spondylitis Society	Statement 4	The statement reads, 'Adults with spondyloarthritis and a flare management plan are given information on how to access care during flares'. This seems to imply that only those people with a management plan need to be given information on accessing care during flares. However, we strongly believe that, as axial spondyloarthritis is a complex condition, everyone with axial spondyloarthritis should have a management plan. In 2016 NASS carried out a survey of 2000 people in the UK with axial spondyloarthritis. We asked: "Has your rheumatology department provided you with an agreed treatment or management plan to help you manage the symptoms of your AS?" Only 12% had been given a written plan, with an additional 55% having verbally discussed a management plan. Additionally, 20% were not very or not at all satisfied with the help and advice they receive from their rheumatology department during a flare. The Quality Standard has the opportunity to significantly improve care during flares by altering statement 4 to read: "Adults with spondyloarthritis are given a flare management plan containing information on how to access care during flares"
50	National Ankylosing Spondylitis Society	Statement 4	Healthcare professionals are defined as rheumatologists and specialist rheumatology nurses. As physiotherapists play such an important role in spondyloarthritis it would be important to include them in this definition

ID	Stakeholder	Statement number	Comments[1]
51	Novartis Pharmaceutical Ltd	Statement 4	We would like to propose that the wording of the statement is tweaked, as it could be read that information only has to be provided to those with a flare management plan. Suggest "Adults with spondyloarthritis are provided with a flare management plan including information on how to access care during flares" Accessing appropriate care in a timely manner is critical for adults with spondyloarthritis during flare episodes. Research by the National Ankylosing Spondylitis Society revealed that 27% of axial spondyloarthritis patients said their overall care could be improved by being seen promptly during a flare episode and it is important that commissioners and service providers work together to facilitate improved access within local care pathways. Commissioners should also be encouraged to ensure that primary care practitioners are equipped to effectively recognise flares and manage them effectively, as many patients are likely to present in this setting. Ensuring that patients have access to telephone support lines is also an important consideration for this Quality Statement, due to the fact that a large proportion of patients seek care advice during flares in this way. This is particularly important in tertiary centres, where patients would otherwise have to make lengthy journeys in order to speak to a health professional. In addition to providing patients with information on how to access care during flares, it is important that information and support is provided to patients in regards to spondyloarthritis more broadly. Research from the National Ankylosing Spondylitis Society showed that only 12% of axial spondyloarthritis patients received a written care plan and almost half (45%) of patients did not discuss a plan verbally. This demonstrates a clear unmet need in regards to the provision of adequate information for spondyloarthritis patients. Including the measurement of the proportion of patients who receive information and care plans more broadly relating to spondyloarthritis within this Quality Statement – and not just how to access care during flares – would likely greatly improve quality of care and individual's abilities to self-manage their condition, fulfilling the ambitions of the Five Year Forward View.
52	Podiatry Rheumatic Care Association	Statement 4	The current wording with in this draft Quality Standard is not reflective in full the range of health professionals that an individual with a spondyloarthritis may need to access as part of their holistic care. Given the level of lower limb conditions associated with both axial and peripheral disease, specific reference to podiatry may be considered appropriate . Reference to this could be made by specifically listing 'podiatrists' within: • QS1 'what the quality statement means for different audiences' / health care professionals (p5).
			• QS4, providing examples of health professionals including podiatry that contribute to a multidisciplinary team (p15).

ID	Stakeholder	Statement number	Comments[1]
53	Royal College of Nursing	Statement 4	Access to care during flares: This should be easily achievable as most rheumatology departments have specialist nurses/allied health professionals who run support lines.
54	AbbVie Inc	Additional statement	We note that the QS doesn't reference the importance of communication and co-ordination between all the HCPs involved in patient's care. NG65 1.9.3 and 1.9.4 state "Ensure that there is communication and coordination between rheumatology… etc". We think it would be worth a quality statement regarding the management of spondyloarthritis patients.
55	British Psoriatic Arthritis Consortium	Additional statement	We remain disappointed that quality standards referring to the management of PsA have not been addressed. Whilst the guidance around early diagnosis and referral is key to identifying patients, there is clear evidence that management once patients are reviewed by a rheumatologist is key to maximising patient outcomes. The Tight Control of PsA (TICOPA) study confirmed the significant benefit of using a treat to target approach in PsA. This is feasible in clinical practice and has now been supported by a number of international treatment recommendations including those of the European League Against Rheumatism (EULAR).
56	British Society for Rheumatology	Additional statement	We would advise that this QS statement be changed to incorporate pharmacological treatment and involvement of other Health Care Professionals in the management of SpA. Our recommendation would be that the QS reads as follows: Adults with Spondyloarthritis should be assessed for early pharmacological and non-pharmacological Multidisciplinary team treatment.

ID	Stakeholder	Statement number	Comments[1]
57	Novartis Pharmaceutical Ltd	Additional statement	In addition to the four proposed Quality Statement areas, we suggest that a statement should be added to encourage the delivery of annual reviews for adults with spondyloarthritis within this Quality Standard for Spondyloarthritis. The provision of annual reviews by a member of a multidisciplinary specialist team would provide a valuable opportunity to assess an individual's broader holistic needs and should therefore look to incorporate mental health and fatigue assessments, as well as a review of employment status and ambitions. Where possible, these reviews should include patient-reported and objective measures and outcomes, and capture disease activity and progression. To note that these annual reviews do not need to be completed in a Trust based setting; community provision could potentially increase the likelihood of a patient attending a review and fit with the ambitions of the Five Year Forward View. Annual reviews should also recognise the differences between different diagnoses of spondyloarthritis, most notably between axial and peripheral conditions. It would for instance be much more important for an annual review of axial spondyloarthritis patients to include a hypertension assessment for instance, whereas reviewing metabolic syndrome would be more appropriate for patients with a peripheral spondyloarthritis diagnosis. A Quality Statement encouraging the delivery of annual reviews was incorporated within the NICE Quality Standard on Rheumatoid Arthritis, and feedback from experts has demonstrated how this has helped to improve the experience of patients in the area. Introducing something similar within this Quality Statement could be anticipated to have a similarly positive impact on the quality of care and overall outcomes for spondyloarthritis patients.
58	Spine Intervention Society	Additional statement	On behalf of the Spine Intervention Society, I would like to thank you for the opportunity to comment on the proposed Spondyloarthritis quality standard. We would like to call attention to the fact that while early referral to rheumatologists is critical in caring for patients with Spondyloarthritis, there are other specialists who may assist with the treatment of this condition. Sacroiliac joint injections, facet joint injections, and radiofrequency neurotomy of the nerves supplying these joints are often used as adjunct treatments for these patients, and therefore, we suggest addressing that referrals to interventional spine specialists may be considered for diagnostic and therapeutic interventions if pain is persistent and not responding to initial treatment options.

Registered stakeholders who submitted comments at consultation

- AbbVie Inc.
- British Psoriatic Arthritis Consortium
- British Society for Rheumatology (including the British Society for Paediatric and Adolescent Rheumatology)
- British Society for Spondyloarthritis
- Chartered Society of Physiotherapy
- Department of Health and Social Care
- Merck Sharp & Dohme Limited
- National Ankylosing Spondylitis Society
- NHS England
- Novartis Pharmaceutical Ltd
- Podiatry Rheumatic Care Association
- Primary Care Rheumatology Society
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Physicians
- Spine Intervention Society
- UCB Pharma