NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards

Briefing paper

Quality standard topic: Rheumatoid arthritis in over 16s.

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 rheumatoid arthritis in over 16s. 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:

Rheumatoid arthritis in adults: management. NICE guideline NG100.

Published July 2018.

2 Overview

2.1 Focus of quality standard

This quality standard will cover assessment, diagnosis and management of rheumatoid arthritis in over 16s. It will update and replace the existing NICE quality standard for rheumatoid arthritis in over 16s (QS33)

2.2 Definition

Rheumatoid arthritis is an inflammatory disorder largely affecting synovial joints. It typically affects the small joints of the hands and the feet, and usually affects both sides equally and symmetrically although any synovial joint can be affected. It presents with swelling, stiffness, pain and progressive joint destruction. There is a rapid loss of muscle around the joint and this along with pain and swelling, leads to loss of function. There may be periods when symptoms become worse (flares) and this can be difficult to predict. Pain and joint stiffness are usually worse in the morning and after a period of inactivity.

Rheumatoid arthritis can affect the whole-body including eyes, lungs and heart causing for example vasculitis or severe lung fibrosis. It may also be associated with other conditions such as Sjorgren's syndrome (dryness of the eyes and mouth), carpal tunnel syndrome and the presence of rheumatic nodules (hard lumps particularly over surfaces such as the elbow).

2.3 Incidence and prevalence

Rheumatoid arthritis (RA) affects 0.5 to 1% of the population in the UK and there are over 400,000 adults living with the condition in the UK. Around 1.5 men and 3.6 women develop RA per 10,000 per year. Approximately 12,000 people are diagnosed per year. 15% have severe disease. The peak age of incidence in the UK is in the 70s, but people of all ages can develop the disease. Prevalence increases with age.

RA can result in a wide range of complications for those with the disease and their carers. The personal impact of RA includes dealing with the physical effects of the disease as well as coping with having various treatments, hospital appointments and the alteration of life plans, reduced employment prospects and uncertainty about the future of their disease and its impact of their lives[1]. Approximately one-third of people stop work because of the disease within 2 years of onset and after 10 years 30% of people are severely disabled. The economic impact of this disease includes direct cost to the NHS and healthcare support services and cost to the economy with the effect of early mortality and lost productivity. The total costs of RA in the UK including indirect costs and work-related disability have been estimated at between £3.8 billion and £4.75 billion.

RA is an autoimmune condition but the trigger for it is unknown. There is an increased risk for developing RA if there is a family history of the condition, if the person is overweight or obese, and if the person smokes. The life expectancy of people with RA is reduced by 5-10 years compared to people without the condition and they are at greater risk of cardiovascular disease.

2.4 Management

Referral from primary care is suggested for adults with persistent joint swelling of unknown cause, and urgent referral when the small joints of the hands and feet are affected, if more than one joint is affected or if there has been a delay in presentation of 3 months or longer

Persistent joint swelling is identified by clinical examination but other investigations can help in diagnosis. Blood tests can identify inflammation and X-rays can be used

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[1] National Rheumatoid Arthritis Society (2018) Emotional health and wellbeing matter: A UK wide survey of adults with rheumatoid arthritis and juvenile idiopathic arthritis on the impact of their disease on emotional health and well-being.

to identify bone damage. Tests such as these may be also performed once RA is diagnosed to establish a baseline before treatment.

The management goal for RA is to achieve disease remission and this can be defined in many ways based on different scoring systems. A composite score such as Disease Activity Score calculator (DAS28) and measurement of serum C-reactive protein (CRP) is one example. The longer the remission period and the least amount of disease activity that can be detected, then the better the long-term outcome.

Conventional disease modifying anti-rheumatic drugs (cDMARDs) can be helpful in slowing down the disease process. Other medications, known as biological DMARDS are often used in combination with cDMARDS. Steroids may also be prescribed.

Supportive treatments such as occupational therapy and physiotherapy can help with mobility and keeping up with daily activities. Surgery may be considered to correct severe joint problems and can be an effective solution for pain relief, restoration of function and for improvement in quality of life.

3 Summary of suggestions

3.1 Responses

In total 12 registered stakeholders responded to the 2-week engagement exercise 02/04/19-16/04/19. 8 of these registered stakeholders provided areas for quality improvement and 3 advised they had no comment to make. 1 stakeholder endorsed the suggestions made by another. We also received comments from 5 specialist committee members.

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 1 for further consideration by the committee.

Full details of all the suggestions provided are given in appendix 2 for information.

Table 1 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Referral and diagnosis	
• Referral from primary care	KEELE, NRAS, Sanofi, SCM 1, SCM2, SCM 3, SCM 4, SCM 5.
• Early diagnosis in specialist services	BDA, NRAS, Sanofi, SCM 4.
Treatment	BSR, NRAS, SCM 2, SCM 3, SCM 4, SCM 5, UCB.
The multidisciplinary team	BAPO, BDA, KEELE, SCM 1, SCM 2.
Patient education	
• Education and self-management	ABB, BDA, BSR, NRAS, SCM 1, SCM 4, UCB.
• Patient activation and shared decision making	NRAS, Sanofi.
Monitoring and review	
• Rapid access to services for disease flares or drug related side effects	ABB, BSR, SCM 5.
• Monitoring	ABB, Sanofi, SCM 1, SCM 3, SCM 4, SCM 5.
• Annual review	BSR, KEELE, NRAS, Sanofi, SCM 1, SCM 2, SCM 4, SCM 5, UCB.
Additional area	
• Use of imaging including ultrasound, MRI and isotope scanning	SCM 5.
ABB, Abbvie Ltd. BAPO, British Association of Prosthetists and Orthotists. BDA, The British Dietetic Association. BSR, British Society for Rheumatology. KEELE, Keele University/Midlands Partnership Foundation Trust. NRAS, National Rheumatoid Arthritis Society. RCGP, Royal College of General Practitioners - submitted a response (no comments). RCN, Royal College of Nursing - submitted a response (no comments). RCP, Royal College of Physicians - endorses the response from BSR. RCRad, Royal College of Radiologists - submitted a response (no comments). Sanofi. SCM, Specialist Committee Members 1-5. UCB, UCB Pharma Ltd.	

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 632 papers were identified for rheumatoid arthritis in over 16s. In addition, 38 papers were suggested by stakeholders at topic engagement and 26 papers internally at project scoping.

Of these papers, 12 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

3.3 Resource impact

It is not anticipated that the guideline update (NG100) and update to QS33 will have a significant resource impact. Expert clinical opinion is that the recommendations are in line with existing practice for most centres, therefore we do not think practice will change substantially as a result of the update.

Where clinical practice does change as a result of the guideline and QS updates, there will not be a significant change in resource use.

Implementing the guideline and QS may lead to the following benefits:

- Improved treatment of recent-onset RA should result in the avoidance or delayed onset of disability and may reduce the severity of the disability. This will have consequent savings for the NHS and social services.
- Access to specialist care promptly when needed may result in fewer future interventions, resulting in consequent savings to the NHS. It is not possible to quantify these savings.
- Better control of recent-onset RA may also help to reduce working days lost due to pain or disability, with a consequent positive impact on the economy.

4 Suggested improvement areas

4.1 Referral and diagnosis

4.1.1 Summary of suggestions

Referral from primary care

Stakeholders highlighted that early diagnosis is vital as early treatment results in better outcomes such as minimal joint damage and better functional outcome and quality of life. Rapid referral and assessment of those with suspected RA are needed to avoid delay in treatment. Stakeholders suggested that the referral of people to specialist services should be targeted and precise as waiting times are long and clinic provision is suboptimal.

Early diagnosis in specialist services

Early diagnosis and treatment are vital to ensure better outcomes for people with RA such as minimal joint damage, retention of function and improved quality of life. Stakeholders stated that if people can be treated within 12 weeks of onset of symptoms better long-term outcomes can be achieved. Stakeholders highlighted the early inflammatory arthritis best practice tariff criteria that a patient must be seen within 3 weeks of referral.

4.1.2 Selected recommendations from development source

Table 2 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 2 to help inform the committee's discussion.

Table 2 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Referral from primary care	**Referral from primary care** NICE NG100 Recommendation 1.1.1
Early diagnosis in specialist services	**Investigations for diagnosis** NICE NG100 Recommendations 1.1.2 - 1.1.4

Referral from primary care

<u>NICE NG100 – Recommendation 1.1.1</u>

Refer for specialist opinion any adult with suspected persistent synovitis of undetermined cause. Refer urgently (even with a normal acute-phase response, negative anti-cyclic citrullinated peptide [CCP] antibodies or rheumatoid factor) if any of the following apply:

- the small joints of the hands and feet are affected
- more than one joint is affected
- there has been a delay of 3 months or longer between onset of symptoms and seeking medical advice.

Early diagnosis in specialist services

Investigations for diagnosis

NICE NG100 – Recommendation 1.1.2

Offer to carry out a blood test for rheumatoid factor in adults with suspected rheumatoid arthritis (RA) who are found to have synovitis on clinical examination.

NICE NG100 – Recommendation 1.1.3

Consider measuring anti-CCP antibodies in adults with suspected RA if they are negative for rheumatoid factor.

NICE NG100 – Recommendation 1.1.4

X-ray the hands and feet in adults with suspected RA and persistent synovitis.

4.1.3 Current UK practice

Referral from primary care

The National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis (NEIAA) sampled people aged 16 and over who presented for the first time in rheumatology departments with suspected early inflammatory arthritis[2]. Data was collected at presentation and for 3 months follow-up. 97% of providers in England and Wales were registered to participate. The data from the 2016 audit represents 5002 patients. Follow-up was limited to those positive for anti-CCP antibodies or polyarthritis affecting five or more joints. The following findings relate to this quality improvement area:

- Nationally, 20% of people were referred to specialist services within 3 days of presentation at GP compared with 17% in 2015[3]. The median time between presentation and referral was 20 days in 2016 compared with 34 days in 2015.

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[2] The British Society for Rheumatology (2016) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.

[3] The British Society for Rheumatology (2015) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis

- Clinicians were asked if referral letters raised the possibility of an inflammatory arthritis diagnosis. In 12% of referrals there was no mention of inflammatory arthritis, however this was lower in those patients seen within the three-week recommendation.

A national survey of GPs was performed by Scott et al. (2014) asking 12 questions about challenges in diagnosing and referring suspected RA patients[4]. A questionnaire was sent to 5000 GPs with 1388 completed questionnaires returned (28% response rate). This survey found that most GPs organise tests for investigation of suspected RA before referring to rheumatology services. It was stated that to enable suspected RA patients to be referred within 3 days, there needs to be a shift in the GP approach to referral decision, with a focus on clinical history such as small joint swelling and pain rather than acute phase markers and serology results. Only 26% of GPs in this survey referred people immediately without tests.

Early diagnosis in specialist services

The NEIAA report in 2016 found that 37% of people are seen within 3 weeks of referral from primary care[5]. This figure was 38% in 2015[6]. The overall median waiting time from referral is 4 weeks but this varies throughout England with three-quarters of people seen within 3-7 weeks.

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[4] Scott IC, Mangat N, MacGregor A et al. (2018) Primary care challenges in diagnosing and referring patients with suspected rheumatoid arthritis: a national cross-sectional GP survey. Rheumatology Advances in Practice 0:1-6

[5] The British Society for Rheumatology (2016) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.

[6] The British Society for Rheumatology (2015) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis

4.2 Treatment

4.2.1 Summary of suggestions

Stakeholders suggested a treat-to-target strategy for rheumatoid arthritis is an area for quality improvement. It was proposed that it would be beneficial to have recognition of patient goals as these may be different (perception of disease control, broader well-being etc.). Early, aggressive, targeted treatment of early arthritis is essential to achieve better disease remission.

Stakeholders suggested that treatment should be started within 6 weeks of referral from primary care or within 6 weeks of specialist review, and within 12 weeks of symptoms onset to reduce impact on patient quality of life and damage to joints. It was noted that this may be difficult to measure as symptom duration is not straight forward. Stakeholders stated that conventional disease modifying anti-rheumatic drugs (cDMARDs) should be given within 12 weeks of onset of symptoms as this will help to reduce disease progression. Stakeholders highlighted the early inflammatory arthritis best practice tariff target of DMARD treatment within 6 weeks of referral.

Stakeholders commented that monotherapy is associated with fewer side effects than combination therapy. Poor drug adherence during the initial treatment period was highlighted by stakeholders. This is reduced when a short-term glucocorticoid is used. Stakeholders commented that people with rheumatoid arthritis should be escalated to biologic treatment in a timely manner.

4.2.2 Selected recommendations from development source

Table 3 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 3 to help inform the committee’s discussion.

Table 3 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Treatment	**Treat-to-target strategy** NICE NG100 Recommendations 1.2.1 and 1.2.3 **Initial pharmacological management** NICE NG100 Recommendations 1.4.1 – 1.4.3 **Further pharmacological management** NICE NG100 Recommendations 1.5.4 – 1.5.5

Treatment

Treat-to-target strategy

NICE NG100 recommendation 1.2.1

Treat active RA in adults with the aim of achieving a target of remission or low disease activity if remission cannot be achieved (treat-to-target).

NICE NG100 Recommendation 1.2.3

In adults with active RA, measure C-reactive protein (CRP) and disease activity (using a composite score such as DAS28) monthly in specialist care until the target of remission or low disease activity is achieved.

Initial pharmacological management

NICE NG100 Recommendation 1.4.1

For adults with newly diagnosed active RA:

- Offer first line treatment with conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy using oral methotrexate, leflunomide or sulfasalazine as soon as possible and ideally within 3 months of onset of persistent symptoms.
- Consider hydroxychloroquine for first-line treatment as an alternative to oral methotrexate, leflunomide or sulfasalazine for mild or palindromic disease.
- Escalate dose as tolerated.

NICE NG100 Recommendation 1.4.2

Consider short-term bridging treatment with glucocorticoids (oral, intramuscular or intra-articular) when starting a new cDMARD.

NICE NG100 Recommendation 1.4.3

Offer additional cDMARDS (oral methotrexate, leflunomide, sulfasalazine or hydroxychloroquine) in combination in a step-up strategy when the treatment target (remission or low disease activity) has not been achieved despite dose escalation.

Further pharmacological management

NICE NG100 Recommendation 1.5.4

Offer short term treatment with glucocorticoids for managing flares in adults with recent-onset or established disease to rapidly decrease inflammation.

NICE NG100 Recommendation 1.5.5

In adults with established RA, only continue long-term treatment with glucocorticoids when:

- the long-term complications of glucocorticoid therapy have been fully discussed, and
- all other treatment options (including biological and targeted synthetic DMARDs) have been offered

4.2.3 Current UK practice

The NEIAA in 2016 reported that 89% of people with RA were set treatment targets and these were agreed with 92% of people[7]. Treatment targets were achieved in 52% of people with RA (for whom data was available) within 3 months of specialist care. Data was not available on 25% of people however, so findings may be limited. The audit also reported on the Rheumatoid Arthritis Impact of Disease Score (RAID) which is a patient reported outcome assessing pain, function, wellbeing and fatigue. RAID scores range from 0-10, with 10 indicating more severe symptoms. The audit recorded baseline scores for all patients as well as follow-up on those with diagnosed RA.

- RAID scores were available for 87% of people at baseline and the mean score for those with RA was 6.1. This was comparable nationally.

The NEIAA in 2016 showed that nationally 68% of people with RA started treatment with DMARDS within 6 weeks of referral from their GP[8]. This is an increase from 53% reported in the 2015 audit[9]. There may be an element of coding differences in the years of the audit which may have contributed to this improvement.

The 2016 national audit showed 46% of patients are prescribed combination DMARDs and 86% are prescribed steroids[10]. These rates showed little variation nationally. 78% of people were prescribed steroids at baseline.

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[7] The British Society for Rheumatology (2016) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis

[8] The British Society for Rheumatology (2016) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.

[9] The British Society for Rheumatology (2015) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis

[10] The British Society for Rheumatology (2016) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.

4.3 The multidisciplinary team

4.3.1 Summary of suggestions

Stakeholders commented that allied health professionals (AHPs) should be involved in care from time of diagnosis to throughout the care pathway. This includes podiatry, physiotherapy and occupational therapy. Diet, exercise and assistance with daily activities are essential for the wellbeing of people with rheumatoid arthritis and timely intervention by AHPs can improve their quality of life and reduce the burden of healthcare. It was felt that physical activity advice and weight management advice is often lacking in rheumatology clinics and a stakeholder suggested incentivisation of physiotherapy referral or advice on physical activity. Other areas for support highlighted were hand function, managing daily activities, foot health and psychological support.

Stakeholders highlighted treatment goals, such as reducing pain in the feet and improving foot function, as an area for quality improvement. Podiatry and orthotic intervention should be considered to maintain mobility and quality of life. There is a window of opportunity in RA, such as for other treatments, for effective podiatry intervention.

4.3.2 Selected recommendations from development source

Table 4 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 4 to help inform the committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
The multidisciplinary team	**The multidisciplinary team** NICE NG100 Recommendation 1.7.1 **Non-pharmacological management** NICE NG100 Recommendations 1.8.1, 1.8.2, 1.8.5 - 1.8.7

The multidisciplinary team

<u>NICE NG100 Recommendation 1.7.1</u>

Adults with RA should have ongoing access to a multidisciplinary team. This should provide the opportunity for periodic assessments (see 1.9.2 and 1.9.3) of the effect of the disease on their lives (such as pain, fatigue, everyday activities, mobility, ability to work or take part in social or leisure activities, quality of life, mood, impact of sexual relationships) and help to manage the condition.

Non-pharmacological management

NICE NG100 recommendation 1.8.1

Adults with RA should have access to specialist physiotherapy, with periodic review (see 1.9.2 and 1.9.3), to:

- improve general fitness and encourage regular exercise
- learn exercises for enhancing joint flexibility, muscle strength and managing other functional impairments
- learn about the short-term pain relief provided by methods such as transcutaneous electrical nerve stimulators (TENS) and wax baths.

NICE NG100 Recommendation 1.8.2

Adults with RA should have access to specialist occupational therapy, with periodic review (see 1.9.2 and 1.9.3), if they have:

- difficulties with any of their everyday activities, or
- problems with hand function.

NICE NG100 recommendation 1.8.5

All adults with RA and foot problems should have access to a podiatrist for assessment and periodic review of their foot health needs (see 1.9.2 and 1.9.3).

NICE NG100 Recommendation 1.8.6

Functional insoles and therapeutic footwear should be available for all adults with RA if indicated.

NICE NG100 recommendation 1.8.7

Offer psychological interventions (for example, relaxation, stress management, and cognitive coping skills) to help adults with RA adjust to living with their condition.

4.3.3 Current UK practice

In a 2017 survey of 194 rheumatology departments by Ndosi et al. only 17% had access to a full MDT and the survey found that inclusion of allied healthcare professionals is variable across the UK[11]. The paper found that podiatry access for people with RA is lacking, with podiatrists only available in 48% of multidisciplinary teams in the UK. The paper suggested a full complement of healthcare professionals would be consultant rheumatologist and/or specialist registrar, a specialist nurse, a physiotherapist, and occupational therapist and a podiatrist. A survey in 2018 by Arthritis Action showed that out of 808 people with RA surveyed, 40% had received advice or support from a physiotherapist[12].

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[11] Ndosi M, Ferguson R, Backhouse MR et al. (2017) National variation in the composition of rheumatology multidisciplinary teams: a cross-sectional study. Rheumatology International 37:1453-59

[12] Arthritis Action (2018) Arthritis: The impact on daily life.

4.4 Patient education

4.4.1 Summary of suggestions

Education and self-management

Stakeholders highlighted information, education and advice for people with rheumatoid arthritis as an area for quality improvement. It was suggested that this is vital to ensure that they are well-informed and helps in the management of the disease to obtain the best long-term outcomes. Stakeholders commented that education should be given to women of childbearing age on treatment for RA. Referral to patient organisations at an early stage of disease was also raised as an important area.

Stakeholders said that people with RA should be offered advice on self-management activities early in the disease process for example information on sleep and functional activities. They commented that self-management needs should be part of a jointly owned care plan and the needs of the person should be regularly reviewed.

Stakeholders referred to the early inflammatory arthritis best practice tariff target of offer of disease education within one month of diagnosis

Patient activation and shared decision making

Stakeholders commented that shared decision making is an area for quality improvement. It ensures that patients understand the care, treatment and support options available as well as the risks and benefits and consequences of these options. This enables patients to engage with their treatment and allows decisions to be made based on evidence and on personal preferences. This means that individuals are more likely to adhere to their treatment regimes. Stakeholders highlighted patient activation measurement as an important developmental area of emergent practice and noted that NHS England have piloted this measurement of patient engagement. Stakeholders noted that improving patient activation is key in helping with engagement but that health professionals may not know how to do this.

4.4.2 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.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Education and self-management	**Communication and education** NICE NG100 Recommendations 1.3.2 and 1.3.3
Patient activation and shared decision making	**Communication and education** NICE NG100 Recommendation 1.3.1

Education and self-management

Communication and education

NICE NG100 Recommendation 1.3.2

Offer verbal and written information to adults with RA to:

- improve their understanding of the condition and its management, and
- counter any misconceptions they may have.

NICE NG100 Recommendation 1.3.3

Adults with RA who wish to know more about their disease and its management should be offered the opportunity to take part in existing educational activities, including self-management programmes.

Patient activation and shared decision making

Communication and education

NICE NG100 Recommendation 1.3.1

Explain the risks and benefits of treatment options to adults with RA in ways that can be easily understood. Throughout the course of their disease, offer them the opportunity to talk about and agree all aspects of their care, and respect the decisions they make.

4.4.3 Current UK practice

Education and self-management

The NEIAA in 2016 found that 67% of patients were offered educational support within 1 month of diagnosis[13]. This is an increase from 59% in 2015[14]. The audit does not collect data on the format of any education or self-management materials offered.

A survey of RA patients in Staffordshire was performed by Packham et al. in 2017 to measure patient attitudes and experiences of information received during drug counselling[15]. 679 patients were sent postal questionnaires, and 264 responded (39% response rate). It found that people with RA were generally satisfied with the information received but found that knowledge of medication before diagnosis was poor. Patient knowledge of adverse drug effects was poor, with poor identification of side effects.

Patient activation and shared decision making

A small survey by McBain et al. (2018) of 886 people with rheumatoid arthritis and 117 healthcare professionals showed that:

- 50% of people agreed that they worked collaboratively with members of the rheumatology team to set goals and develop action plans on how to manage their arthritis.
- Over 70% of people agreed that they had been provided with information and education about their condition from their rheumatology team, or that they had worked collaboratively to solve any problems relating to their condition.
- All healthcare professionals surveyed felt that patients should be actively involved in their own care but 60% were not able to offer self-management support due to lack of staffing (35%) and funding (17%)[16].

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[13] The British Society for Rheumatology (2016) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.
[14] The British Society for Rheumatology (2015) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis
[15] Packham J, Arkell P, Sheeran T et al. (2017) Patient experiences, attitudes and expectations towards receiving information about anti-TNF medication: a quantitative study. Clinical Rheumatology 36:2595-2600
[16] McBain HB, Newman SP, Shipley M. (2018) Clinicians and patients views about self-management support in arthritis: a cross-sectional UK survey. Arthritis Care and Research. doi: 10.1002/acr.23540

4.5 Monitoring and review

4.5.1 Summary of suggestions

Rapid access to services for disease flares or drug related side effects

Rapid access to clinics or rheumatology services for advice on disease flares or drug related side effects was highlighted as being critically important for people with rheumatoid arthritis and there were concerns that not all people have access.

Monitoring

Stakeholders highlighted that regular disease assessment improves drug adherence and helps to decide on treatment escalation which lead to improved disease progression in the long term. Stakeholders commented that review targets are not being met although tight control of the disease is required to minimise joint damage.

Annual review

Stakeholders suggested that annual review provision for people with rheumatoid arthritis is an area for quality improvement. Annual review is important to ensure all aspects of the disease are under control and gives people an opportunity to request further support that they may need to maximise quality of life. Stakeholders suggested this should include functional assessment, vaccinations and assessment of work. Stakeholders highlighted the importance of annual review in recognition and management of comorbidities. One stakeholder suggested that the annual review should include discussion about family planning with women of childbearing age who have achieved their treatment target. This should include discussion of concerns about continuing treatment when pregnant or when breastfeeding.

4.5.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 8 to help inform the committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Rapid access to services for disease flares or drug related side effects	**Investigations following diagnosis** NICE NG100 Recommendation 1.1.6
Monitoring	**Monitoring** NICE NG100 Recommendations 1.9.1 - 1.9.2.

Annual review	**Monitoring** NICE NG100 Recommendation 1.9.3

Rapid access to services for disease flares or drug related side effects

Investigations following diagnosis

NICE NG100 Recommendation 1.1.6

If anti-CCP antibodies are present or there are erosions on X-ray:

- advise the person that they have an increased risk of radiological progression but not necessarily an increased risk of poor function, and
- emphasise the importance of monitoring their condition, and seeking rapid access to specialist care if the disease worsens or they have a flare

Monitoring

NICE NG100 recommendation 1.9.1

Ensure that all adults with RA have:

- Rapid access to specialist care for flares
- Information about when and how to access specialist care, and
- Ongoing drug monitoring.

NICE NG100 Recommendation 1.9.2

Consider a review appointment to take place 6 months after achieving treatment target (remission or low disease activity) to ensure the target has been maintained.

Annual review

Monitoring

NICE NG100 Recommendation 1.9.3

Offer all adults with RA, including those who have achieved the treatment target, an annual review to:

- assess disease activity and damage, and measure functional ability (using, for example, the Health Assessment Questionnaire [HAQ])
- check for development of co-morbidities, such as hypertension, ischaemic heart disease, osteoporosis and depression
- assess symptoms that suggest complications, such as vasculitis and disease of the cervical spine, lung or eyes
- organise appropriate cross referral within the multidisciplinary team

- assess the need for referral for surgery (see section 1.10)
- assess the effect the disease is having on a person's life.

4.5.3 Current UK practice

Rapid access to services for disease flares or drug related side effects

The NEIAA 2016 reported that 92% of patients have access to urgent advice. This has fallen from 99% of patients nationally with access to urgent advice reported in 2015. The findings also showed that 97% of providers have a telephone advice line for patients.

Monitoring

A regional survey of 19 rheumatology units across East and West Midlands by Tugnet et al. (2013) found that 99% of patients had a baseline CRP checked and 61% continued to have it checked monthly. 25% of people overall had monthly DAS28 checked.

Annual review

The NEIAA report in 2016 findings showed that nationally 82% of providers offer a comprehensive annual review that is coordinated by the rheumatology service[17]. This varies from 67% in Wales to 94% in London (the figure reported from Wales is based on a small number of health boards).

The Quality and Outcomes Framework from NHS England includes indicators for rheumatoid arthritis, including RA002: The percentage of patient with rheumatoid arthritis, on the register, who have had a face-to-face review in the preceding 12 months[18]. Data from the Quality and Outcomes Framework shows that at the end of March 2017, 85.4% of people with RA had had a face-to-face review in the preceding 12 months[19].

A national survey of general practice was performed in 2013 by Hider et al. to assess what measures are included in an annual review for people with rheumatoid arthritis[20]. 5000 randomly selected GPs were set a brief questionnaire investigating their management strategies for people with RA. 1388 questionnaires were returned (response rate 27.8%). This showed that 89% of annual reviews included a medication review, 82% a cardiovascular risk assessment including blood pressure

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[17] The British Society for Rheumatology (2016) National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis.

[18] NHS England (2019) 2019/20 General Medical Services (GMS) contract Quality and Outcomes Framework (QOF)

[19] NICE CG79 Uptake of recommendation 1.5.1.4

[20] Hider SL, Blagojevic-Bucknall M, Whittle R et al. (2016) What does a primary care annual review for RA include? A national GP survey. Clinical Rheumatology 35(8): 2137-2138

measurement, 81% an osteoporosis risk assessment. Uncommon components were assessment for RA disease activity and disease complications.

4.6 Additional area

4.6.1 Summary of suggestions

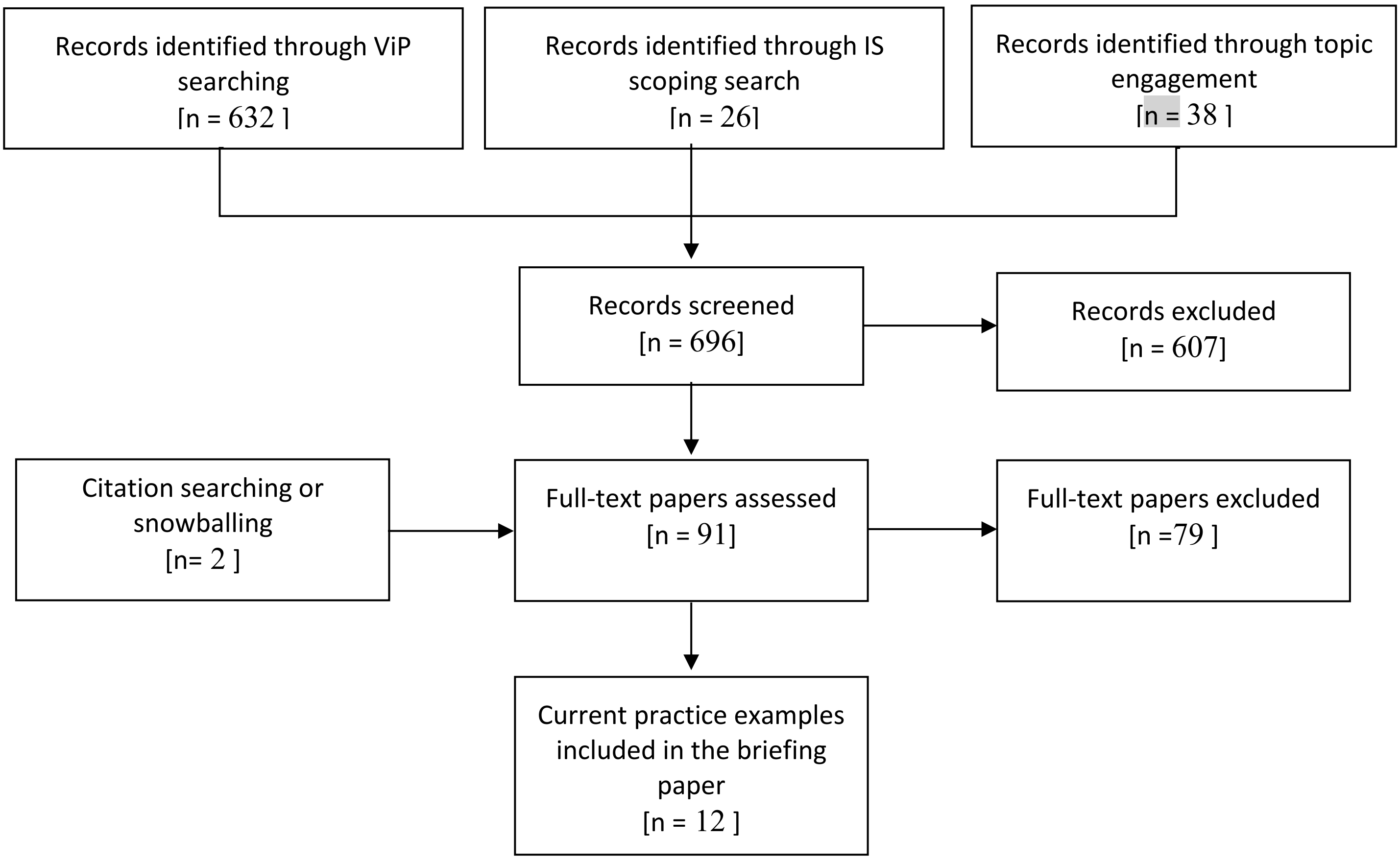
The improvement area below was suggested as part of the stakeholder engagement exercise.

There will be an opportunity for the committee to discuss this area at the end of the session on 6 June 2019.

Use of imaging including ultrasound, MRI and isotope scanning

One stakeholder suggested the use of imaging techniques is an area of emergent practice but that the place of such techniques is not established. There are no relevant recommendations in the source guidance. Use of ultrasound in monitoring and diagnosis are research recommendations in NG100 and so a quality statement in this area cannot be progressed.

Appendix 1: Review flowchart



Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Referral and diagnosis					
1	Keele University/ Midlands Partnership Foundation Trust	Key area for quality improvement 3	Optimising early referral in patients with suspected RA- guidelines recommend that primary care refer all patients with "persistent synovitis" especially if involves hands/feet	BSR HQUIP data suggests that this is still not occurring. However, studies are needed to determine which patients are most at risk of inflammatory arthritis to ensure these patients are prioritised for early access to appointments.	Please see https://www.hqip.org.uk/a-z-of-nca/rheumatoid-early-inflammatory-arthritis-audit/#.XK9eCDBKjX4 for data on quality indicators.
2	National Rheumatoid Arthritis Society	Key area for quality improvement 1 Rapid referral from Primary Care – needs to be precise and targeted rather than just 'urgent' It is well documented that if patients can be treated within 12 weeks of onset of symptoms, better long-term outcomes can be achieved and irreversible joint damage is minimised or has not yet happened.	Continuation of same referral time from primary care – the existing QS states referral within 3 days – I think it's important to retain this QS	In the BSR/HQIP national audit which ran from 2013-2016 no clinically meaningful difference in referral time or on the percentage achieving this target was observed between year 1 and 2. Small differences were apparent and largely reflect a subtle change in reporting - in year 1, the audit reported delay in 'days', whilst year 2 reports 'working days'. The average wait did however fall slightly from 23 to 20 working days nationally, although more than 1/4 of patients waited over 70 days for their referral. This suggests that rheumatology health professionals need to continue to work closely with GPs to raise awareness of the early signs and symptoms of inflammatory arthritis and prioritise early referral to a specialist.	Refer to BSR HQIP audit which ran between 2013 and 2016 The audit is on-going, and we await shortly the first-year data on the new audit which started May 2018.

3	SCM 1	Appropriateness of referrals	CCG guidelines are available but not actively implemented	Referrals to our service have increased by about 30% in recent years, leading to long waiting times for first appointment	No additional information provided by stakeholder.
4	SCM 2	Key area for quality improvement 1	Early referral for suspected RA	National audit suggest that this is an area for improvement; only 22% referred within 3 days. Some ambiguities in the guidance as many presentations of IA do not progress to RA; What is persistent synovitis; how long should it be there before the GP refers? Can we help discriminate progressive IA?	National audit office audit of early inflammatory arthritis
5	SCM 3	Key area for quality improvement 1 Urgent referral to Rheumatology specialist service	There is good evidence that early referral to specialist improves disease outcomes and quality of life. Urgent referral should be sent from primary care to specialist even if the blood tests show normal inflammatory markers and antibody profile if small joints are involved and symptoms have persisted beyond 3 months. This has been recommended in the NICE guidance	British Society for Rheumatology (2016) National clinical audit for rheumatoid and early inflammatory arthritis has shown that there is a delay in diagnosis of Rheumatoid arthritis due to delay in referral from primary care. This is particularly relevant when the investigations are normal. The report reveals that nationally just 20 per cent of patients who see a GP with suspected rheumatoid and early inflammatory arthritis are referred to specialist services within the three-day limit recommended by the National Institute for Health and Care Excellence (NICE). For some health providers, this wait is over 20 weeks for a quarter of their patients.	No additional information provided by stakeholder.

6	SCM 4	Key area for quality improvement 1 People presenting with signs of an early rheumatoid arthritis such as persistent swelling, tenderness and stiffness for more than 30 minutes in the morning for one week are referred immediately to a rheumatology service	Urgent referral recommended in NICE guidance for RA (2018) Referral within one week of persistent symptoms supports treatment within 12-week window of opportunity Unrealistic time frame for primary care to achieve at 3 days.	Referral to avoid delay in diagnosis so treatment is initiated as appropriate to reduce joint damage and disabilities Improve quality of life	Recommendations based on the National Institute for Health and Care Excellence (NICE) Rheumatoid arthritis in adults: management [NICE, 2018a], Diagnosis and early management of inflammatory arthritis [Ledingham, 2017]. 2018/19 General Medical Services (GMS) contract Quality and Outcomes Framework (QOF) RA001
7	SCM 4	Key area for quality improvement 2 People with suspected persistent synovitis are assessed in a rheumatology service within 3 weeks of onset of persistent symptoms	Early diagnosis in line with proposed recommendations EULAR, ACR, BSR, Best practice Tariff, NICE	Diagnosis early diagnosis Treat to reduce potential impact on joints and avoid disabilities Improve quality of life	Recommendations based on the National Institute for Health and Care Excellence (NICE) Rheumatoid arthritis in adults: management [NICE, 2018a], The NICE Quality Standard Rheumatoid arthritis in over 16s [NICE, 2018c], Diagnosis and early management of

					inflammatory arthritis [Ledingham, 2017]. European League Against Rheumatism (EULAR) 2016 update of the EULAR recommendations for the management of early arthritis (Combe, 2016) The American College of Rheumatology (ACR) Guideline for the treatment of rheumatoid arthritis (ACR, 2015),
8	SCM 5	Key area for quality improvement 1	Rapid Referral to Rheumatology for suspected synovitis	Patients deteriorate if synovitis is not treated promptly. Some doctors in primary care arrange investigations and only refer if results are abnormal. Investigations may be negative in early RA and may distract from the diagnosis.	https://www.nice.org.uk/guidance/ng100 https://www.nras.org.uk/data/files/For%20professionals/Publications/bsr_hqip_report.pdf
9	The British Dietetic Association	Key area for quality improvement 3	Early diagnosis is vital in controlling the illness	People with RhA should be able to be assessed and diagnosed with speed as studies show that even a 4-week delay can impact upon health, wellbeing and the burden to the NHS	Breaking Down Barriers: Rheumatoid Arthritis and Public Awareness www.nras.org.uk 2013
10	National Rheumatoid Arthritis Society	Key area for quality improvement 2 It is important that once referred from primary care that the person is	Patient seen within 3 weeks of referral within a rheumatology unit	In the first early RA audit, only 37% of patients were seen within 3 weeks of referral. The audit results from the first year have helped us understand that higher numbers of consultants in a	Refer to the BSR-HQIP audit 2nd year report – first audit 2013-2106

		seen within secondary care in a timely way for the same reason as explained under 1 – the window of opportunity Symptom onset to treatment start should ideally be within 12 weeks		provider and the availability of a clinic specifically for early arthritis were factors which are associated with shorter waiting times to first appointment. In reporting the second year of audit data in 2016, there was a further reduction in the average ratio of consultants to the population (from an average of 1.1 consultants per 100,000 population to 0.86). Even at the highest staffing levels, consultant numbers fall short of the recommendation by the Royal College of Physicians of one rheumatologist per 86,000 people in the local population. It has been apparent that a number of providers have used the audit data to make a case to increase the number of consultants available. The number of patients seen within 3 weeks needs to improve significantly and we hope that the first-year audit data of the second audit, to be published in May 2019, will see an improvement over the data from 2016.	
11	Sanofi	Times to referral and treatment remain important as they are still not being met universally	As noted in current QS, rapid referral and assessment in a rheumatology department are important to avoid delays in early treatment. Given the potential for joint damage and reduce quality of life, early treatment should be prioritised.	Current quality standards are not consistently being met. In Jan 2016, only 68% of patients were being offered glucocorticoids or DMARDs within 6 weeks of referral and only 37% of patients with suspected persistent synovitis were assessed in a rheumatology service within three weeks of referral.	Patients with uncontrolled RA experience persistent joint inflammation, resulting in pain, stiffness and swelling (Curtis et al, 2011). Optimising treatment of RA is very important

				Further evidence is available: 1. In the UK 62% wait >3 weeks from referral to see rheumatologist; ~50% treated in ≤6 weeks 2. 47% patients initiated on DMARDs >6 weeks after referral (Rheumatologists delay in initiating DMARDs) 3. Early prevention of structural damage is necessary to preserve patient function 4. Early, aggressive treatment with DMARDs can reduce the need for intermediate surgical interventions (ERAS/ERAN Cohorts, UK Studies) 5. Early intervention improves long-term functional outcome	and if not adequately treated, RA can lead to permanent joint damage and disability (NICE TA195, Curtis et al 2011). A quarter of people with RA give up work due to their disease within one year of diagnosis (NRAS 2014). Early detection and treatment are therefore key to maximising patient outcomes. Refs: 1,2: Ledingham JM, et al. Rheumatol (Oxford) 2017;56:223–230 3.Emery P, et al. Ann Rheum Dis 2002;61:290–297 4. Nikiphorou E, et al. Arthritis Rheumatol 2014;66:1081–1089 5. NICE Guideline NG100

Treatment					
12	British Society for Rheumatology	Quality Statement 3 as it stands is not measurable, as symptom duration is not straightforward to collect. We recommend that QS3 is altered to treatment commencement within 6 weeks of rheumatology review.	No additional information provided by stakeholder.	No additional information provided by stakeholder.	No additional information provided by stakeholder.
13	British Society for Rheumatology	Retain existing QS2 and QS3 with amendment to QS3 to reflect new guidelines (no monotherapy with hydroxychloroquine, but also no need for combination DMARDs in all)	No additional information provided by stakeholder.	No additional information provided by stakeholder.	Please see: BSR DMARD guidelines https://www.rheumatology.org.uk/practice-quality/guidelines
14	British Society for Rheumatology	The new Best Practice Tariff requires collection of at least one patient reported outcome measure within 3 months of diagnosis. We recommend that this is added as an extra quality statement so that there is symmetry between the QS and the tariff.	No additional information provided by stakeholder.	No additional information provided by stakeholder.	No additional information provided by stakeholder.

15	British Society for Rheumatology	Ensure appropriate guidelines (i.e. immunisations and tests) are followed for those initiating DMARDs.	No additional information provided by stakeholder.	No additional information provided by stakeholder.	Please see: BSR DMARD guidelines https://www.rheumatology.org.uk/practice-quality/guidelines
16	National Rheumatoid Arthritis Society	Key area for quality improvement 3 Treatment start should be no more than 6 weeks from referral date from primary care. Once again this is linked to the window of opportunity Symptom onset to treatment start should ideally be within 12 weeks	People with newly diagnosed rheumatoid arthritis should be offered short-term glucocorticoids (steroids) and a combination of disease-modifying anti-rheumatic drugs by a rheumatology service within 6 weeks of referral.	In the first national audit, data in relation to this standard was presented just for those patients who had a confirmed diagnosis of RA (3,185 patients/ 64% of patients recruited to the audit). This is because there is good evidence that the early use of steroids and/or disease modifying treatment in RA makes the greatest difference to how well patients do in the longer term. 86% were given steroids to alleviate early symptoms and 69% were started on DMARDs. There remains scope for improvement in regard to this standard	Refer to BSR HQIP audit which ran between 2013 and 2016 The audit is on-going, and we await shortly the first-year data on the new audit which started May 2018.
17	SCM 2	Key area for quality improvement 4	Treat to target	No current measurement of performance by Rheumatology units around treat to target; this would improve disease control.	NICE 100; RA
18	SCM 3	Key area for quality improvement 2 Treat-to-target strategy	Early, aggressive, targeted treatment achieves better disease remission and improves quality of life and disease progression in the long run.	A treat-to-target strategy is current best practice in most NHS settings. The 2016 National Clinical Audit for Rheumatoid Arthritis and Early Inflammatory Arthritis indicated that healthcare professionals set a treatment target for about 90% of their patients. This target achievement	No additional information provided by stakeholder.

19			Treat-to-target strategy is within NICE recommendation. Target can be either low disease activity or disease remission. For patients with poor prognosis (presence of anti-CCP antibodies or erosions on X-ray at baseline assessment), disease remission should be considered over low disease activity as target.	has been uneven throughout the various centres in UK.	
19	SCM 3	Key area for quality improvement 3 Conventional disease-modifying anti-rheumatic drug within 3 months of onset of persistent symptoms	There is a window of opportunity for Rheumatoid arthritis and DMARD initiation will help with disease progression and quality of life. Monotherapy may have fewer side effects than combination therapy. NICE recommends first-line treatment with conventional disease-modifying anti-rheumatic drug (cDMARD) monotherapy using oral methotrexate, leflunomide or sulfasalazine as soon as possible and ideally within 3 months of onset of persistent symptoms. Additional cDMARDs (oral methotrexate, leflunomide, sulfasalazine or	There is a variation about the start of DMARDs in various centres in UK according to the 2016 National Clinical Audit for Rheumatoid Arthritis and Early Inflammatory Arthritis. Evidence from randomised controlled trials (RCTs) in people who had never had a DMARD showed no consistent differences in the effectiveness of methotrexate, leflunomide and sulfasalazine as monotherapies. The drugs also had similar costs.	No additional information provided by stakeholder

			hydroxychloroquine) in combination in a step-up strategy when the treatment target (remission or low disease activity) has not been achieved despite dose escalation as clinically beneficial.		
20	SCM 3	Key area for quality improvement 5 Short-term bridging treatment with glucocorticoids	The disease modifying drugs (DMARD) take 8-10 weeks to show effect, steroids can be used as bridging therapy during this time. This will help symptom control, drug adherence and thus improving quality of life. NICE recommends considering short-term bridging treatment with glucocorticoids (oral, intramuscular or intra-articular) when starting a new cDMARD.	Drug adherence is a major issue especially during the initial treatment period as seen in various studies. There is some evidence that fewer people withdrew from the studies due to inefficacy or adverse events when they were taking glucocorticoids which have been stated in the NICE guidelines.	No additional information provided by stakeholder.
21	SCM 4	Key area for quality improvement 3 Commence conventional disease modifying anti-rheumatic drugs (cDMARD)	Early treatment to curb the potential effects of an active inflammatory arthritis on joint destruction and progression and reduction in disability within 12 weeks of symptom onset and window of opportunity	To enable treat to target Avoid effects of uncontrolled inflammatory arthritis on joints and reduce disabilities Improve quality of life	BTT: 2019/2020 National Tariff payment system – a consultation notice: annex DtD. Guidance on best practice tariff (Early inflammatory arthritis)

22		monotherapy within 6 weeks of referral			National Institute for Health and Care Excellence (NICE) guideline Rheumatoid arthritis in adults: management (NICE, 2018a]) The American College of Rheumatology (ACR) Guideline for the treatment of rheumatoid arthritis (ACR, 2015), European League Against Rheumatism (EULAR) 2016 update of the EULAR recommendations for the management of early arthritis (Combe, 2016)
22	SCM 5	Key area for quality improvement 2	Treat to a target of remission, or low disease activity if remission not achievable	This is an essential focus of treatment. Many patients may have persistent low grade disease but this is associated with poor outcome.	https://www.nice.org.uk/guidance/ng100 Stoffer et al Ann Rheum Dis. 2016 Jan;75(1):16-22
23	UCB Pharma Ltd	Patients with newly diagnosed RA should be offered conventional DMARDS and escalated where appropriate to biologic	No additional information provided by stakeholder.	No additional information provided by stakeholder.	No additional information provided by stakeholder.

		treatments in a timely fashion			
The multidisciplinary team					
24	British Association of Prosthetists and Orthotists	Key area for quality improvement 1. Goals for the management of the RA foot are aimed at reducing the pain in the feet and improving foot function	Podiatry and orthotic intervention should be considered to maintain mobility and quality of life using safe and cost-effective treatments, such as: - palliative foot care, prescribed foot orthoses and specialist footwear aimed at preventing any deterioration in the tissues and in joint alignment (Grondal et al 2008, Woodburn and Helliwell 1997).	Woodburn et al also suggest that there is "Window of Opportunity" in early rheumatoid arthritis for effective podiatry intervention. The foot health needs for the patient with RA are varied and range from simple foot care advice, palliative care for nails and skin and orthotic / specialist footwear provision through to management of ulceration and infection (Helliwell 2003, Korda and Balint 2004).	Woodburn, J., Hennesey, K., Steultjens, M., McInnes, I. & Turner, D. 2010. Looking through the 'window of opportunity': is there a new paradigm of podiatry care on the horizon in early rheumatoid arthritis? J Foot Ankle Res, 3, 8. Woodburn J, Barker S and Helliwell PS (2002 a) A randomized controlled trial of Foot Orthoses in Rheumatoid Arthritis. The Journal of Rheumatology. 29; 7:1377-1383 Woodburn J, Helliwell P.S and Barker S.(2002b) Three-dimensional kinematics at the ankle joint complex in rheumatoid arthritis patients with painful valgus deformity of the rearfoot

					Rheumatology;41:1406 –1412 Woodburn J, Stableford Z. Helliwell P., (2000) Preliminary investigation of debridement of plantar callosities in rheumatoid arthritis Rheumatology 2000@39;652-654 Woodburn J, Helliwell P. Foot problems in rheumatology. B J of Rheumatology 1997; 36:932–3 Grondal L; Tengstrand B; Nordmark B; Wretenberg P; Stark A (2008) The foot: still the most important reason for walking incapacity in rheumatoid arthritis: Distribution of symptomatic joints in 1,000 RA patients Informa 2008, Vol. 79, No. 2, Pages 257-261 Helliwell P (2003) Lessons to be learned:

					a review of a multidisciplinary foot clinic in rheumatology. Rheumatology;42:1426-1427 Hennell S.L., Brownsell C, Dawson J.K (2004); Development validation and use of a patient knowledge questionnaire for patients with early rheumatoid arthritis. Rheumatology. (2004);43;467-471. Korda J, Bálint GP (2004) When to Consult the Podiatrist. Best Pract Res Clin Rheumatol. 2004 Aug;18(4):587-611.
25	British Association of Prosthetists and Orthotists	Key area for quality improvement 2 The Arthritis and Musculoskeletal Alliance (ARMA 2004) recommends that all patients with suspected RA should be seen by a	No additional information provided by stakeholder.	No additional information provided by stakeholder.	No additional information provided by stakeholder.

		specialist in rheumatology within 12 weeks to confirm diagnosis and enable prompt and effective treatment, and have access to a full multidisciplinary team (MDT) assessment and intervention early in the disease process, including foot health assessment. Further to this, Woolf et al (2007) suggest that management requires an integrated coordinated multidisciplinary, multi-professional approach, with care focussed upon the needs of the affected person, providing access to a combination of expertise and competencies			
26	The British Dietetic Association	Key area for quality improvement 1 AHP involvement at time of diagnosis and throughout the continuum of care	Diet, exercise, and assistance with activities of daily living are essential to enable people with RhA to keep well nourished, remain optimally active and part of their community	People with RhA are at risk of malnutrition (over or underweight) loss of muscle mass through poor diet and inactivity. Timely intervention can minimise this and both improve their QOL as well as reduce the burden on the NHS.	Gossec et al (2006) Nonpharmacological treatments in early rheumatoid arthritis: clinical practice guidelines based on published evidence and expert opinion J.

					Joint and bone spine 73:4:396-402 Managing Rheumatoid Arthritis with Dietary Interventions Khanna et al (2017) frontiers in nutrition 4:52
27	Keele University/ Midlands Partnership Foundation Trust	Key area for quality improvement 2	Current guidelines appropriately emphasise the importance of the MDT team in managing patients with early arthritis	Access to physiotherapy, OT and podiatry is limited- better quality of data is needed to reduce inequalities in access to care	No additional information provided by stakeholder.
28	SCM 1	AHP access	Physiotherapy and Podiatry waiting times are excessive	Beneficial to patients	No additional information provided by stakeholder.
29	SCM 2	Additional developmental areas of emergent practice	Activity /weight management in RA.	Physical activity advice often lacking in Rheumatology clinics. We could incentivise referral to physical activity / advice / physio	No additional information provided by stakeholder.
Patient education					
30	AbbVie Ltd	Key area for quality improvement 1 • Statement 4 People with rheumatoid arthritis are offered educational and self-management activities within 1 month of diagnosis	AbbVie consider that this statement should be altered to align with the NHSE universal personalised care policy and be part of a jointly owned care plan (not just an annual review, as in statement 7). As part of the care plan self-management needs should be constantly reviewed.	Quality Standards have set a high priority improvement target for people with RA to be offered educational and self-management activities within one month of diagnosis. These could include referral to a patient support group, provision of paper-based resources or introducing the individual to a formal education group. It would also be useful to ensure patients are equipped to address holistic	No additional information provided by stakeholder.

				elements of the management of their disease, including impact on function, sleep, etc. However, one-third are not offered this service within one month, leaving the person with RA in the backseat of their own care. If constantly reviewed, the impact of this can be limited.	
31	The British Dietetic Association	Key area for quality improvement 4	Myth busting and advice on evidence-based information is vital to ensure people are well informed. The supply of the right information in the most appropriate format is essential	People with RhA may be susceptible to the spurious advice and interventions on social media. They may access these sources if they have not received good information from health professionals. Non-conventional interventions have the potential for great harm.	Complementary and Alternative Medicine Use in Rheumatoid Arthritis: Considerations for the Pharmacological Management of Elderly Patients (2017) Zhao et al Apr;34(4):255-264
32	The British Dietetic Association	Key area for quality improvement 2	Adequate and timely information about the illness, treatments and options	A well-informed patient can make decisions about their care and can become proactive in their treatment	Educational preferences, psychological well-being and self-efficacy among people with rheumatoid arthritis (2002) Barlow et al [Patient Education and Counseling](#) 46:1:11-19
33	British Society for	Strengthen recommendations on	No additional information provided by stakeholder.	The previous NEIAA found that only 59% of patients were offered structured	Please see: https://www.rheumatolo

	Rheumatology	access to access to patient education.		education and self-management within 1 month of diagnosis. It also found that only 46% of trusts considered they provide timely access to patient education.	gy.org.uk/practice-quality/audits/neia-audit
34	National Rheumatoid Arthritis Society	Key area for quality improvement 4 Patients require access to education and self-management resources at an early stage following diagnosis and throughout their journey with RA. Effective supported self-management is as important as the clinical medical management of their disease to obtain the best long-term outcomes.	Communication and education – access to self-management Patients with rheumatoid arthritis should be offered educational and self-management activities within 1 month of diagnosis. (current standard)	67% of people in the first audit were offered some kind of structured education in line with QS33 but it was very unclear as to what form this took. NRAS would like to see more detail on what form education takes and would like to see more on shared decision making, care planning and referral to appropriate patient organisations at an early stage included in this standard. There is no doubt from the conversations we have with rheumatology teams, particularly the nurse specialists, that resources are stretched, in many cases to breaking point, and under those circumstances often the things that get left out are things like self-management that fall outside the clinical medical pathway (at the moment!). Shared decision making and measuring patient activation are not a one size fits all and we know from feedback from the NHSE pilots on patient activation measurement that whilst health professionals may be able to measure PAM, they are less sure what to do with the results. We know from the pilots and other research that improving activation	Refer to BSR HQIP audit which ran between 2013 and 2016 The audit is on-going, and we await shortly the first-year data on the new audit which started May 2018.

				is going to help patients become more engaged with their health.	
35	National Rheumatoid Arthritis Society	Additional developmental areas of emergent practice	Measuring Patient Activation	This is an important part of Shared Decision Making	NHSE have piloted PAM and are keen to introduce it more widely.
36	Sanofi	Shared decision making processes should be in place to enable patients to best engage with their treatment	Shared decision making ensures that patients understand the care, treatment and support options available and the risks, benefits and consequences of those options. It also allows them to make a decision about a preferred course of action, based on evidence-based, good quality information and their personal preferences. Shared decision making ensures that individuals are supported to make decisions based on their personal preferences and are, therefore, more likely to adhere to evidence based treatment regimes, more likely to have improved outcomes and less likely to regret the decisions that are made (NHS England, Shared Decision Making Summary Guide, January 2019)	EULAR guidelines now include recommendations on shared decision making as an identified element of good practice Treatment of patients with RA should aim at the best care and must be based on a shared decision between the patient and the rheumatologist (EULAR, 2017) Shared decision making in RA include: Sharing information on RA and its risks Discussing modalities of disease assessment Choosing a shared target and potential means to reach it Developing management plan, including involvement of multi-disciplinary team Discussing benefits and risks of individual therapies	Ref: EULAR 2017 Smolen JS, et al. Ann Rheum Dis 2017;76:960–977

37	SCM 1	Patient education	Education on condition and management of flares could decrease number of help line calls and emergency appointments	Patient empowerment to deal with condition	No additional information provided by stakeholder.
38	SCM 4	Additional developmental areas of emergent practice Formal education and self-management advice within 6 weeks of diagnosis	Early arthritis process ensures the education of people on rheumatoid arthritis and how to self-manage but supports early referrals to allied health professionals.	Education on rheumatoid arthritis, medication, monitoring and self-management via the specialist nurse. Re-enforce self-management with referral for assessment and advice on exercise, hand function, managing daily activities/work, foot health, diet and psychological support from health professionals specialising in these fields	Recommendations based on the National Institute for Health and Care Excellence (NICE) Rheumatoid arthritis in adults: management [NICE, 2018a],
39	UCB Pharma Ltd	Patients with RA should be offered educational and self-management activities as soon as possible after diagnosis	No additional information provided by stakeholder.	No additional information provided by stakeholder.	No additional information provided by stakeholder.
40	UCB Pharma Ltd	Patient education on family planning and pregnancy related issues.	With an increasing number of effective therapies for inflammatory rheumatic disease, women with rheumatoid arthritis (RA) can consider starting a family. However, there are risks which need to be discussed and considered. The European League Against Rheumatism (EULAR) [1] has highlighted the overarching points to consider	Although NICE Guideline 100 (NG 100) [3] advocates communication, education and self-management courses, there is no mention of education and discussion in relation to family planning, pregnancy and breast feeding whilst receiving treatment for RA. This topic should be highlighted as an area of discussion with female patients of child bearing age.	Patient education on family planning and pregnancy related issues.

			for use of antirheumatic drugs before and during pregnancy, and lactation, as: A. Family planning should be addressed in each patient of reproductive age and adjustment of therapy considered before a planned pregnancy. B. Treatment of patients with rheumatic disease before/during pregnancy and lactation should aim to prevent or suppress disease activity in the mother and expose the foetus/ child to no harm. C. The risk of drug therapy for the child should be weighed against the risk that untreated maternal disease represents for the patient and the foetus or child. D. The decision on drug therapy during pregnancy and lactation should be based on agreement between the internist/rheumatologist, gynaecologist/obstetrician and the patient, and including other healthcare providers when appropriate.		

Monitoring and review					
41	AbbVie Ltd	Key area for quality improvement 3 Prioritisation of quality standards	AbbVie would prioritise statements 1-5 in the existing quality standards however acknowledge that statement 6 in the existing quality standards is critically important for patients.	Statement 6 in the existing quality standards states the following: People with rheumatoid arthritis and disease flares or possible drug related side effects receive advice within 1 working day of contacting the rheumatology service. Rapid access to clinics is considered significantly important by patients and has been outlined as a concern as not all patients are receiving this access. Therefore, it would be useful to ensure this is captured in the revised quality standards.	No additional information provided by stakeholder.
42	British Society for Rheumatology	Strengthen recommendations about access to urgent care for people initiating immunosuppression.	Access to urgent care should be available to patients requiring treatment as it can impact patient outcomes.	The previous National Early Inflammatory Arthritis Audit (NEIAA) found that only 53% of patients were starting DMARDs within 6 weeks.	Please see: https://www.rheumatology.org.uk/practice-quality/audits/neia-audit
43	SCM 5	Key area for quality improvement 4	Rapid access for treatment of flare	Relapse with a flare of disease is common in RA and as in Quality improvement 1 the patients need rapid treatment	https://www.nice.org.uk/guidance/ng100 Bykerk VP et al RMD Open. 2016 May 26;2(1):e000225
44	AbbVie Ltd	Key area for quality improvement 2	AbbVie propose that it would be beneficial to have recognition of patient	Driven by advances in treatment and understanding of the underlying disease processes, RA care is becoming more complex. As a consequence, disease	Key area for quality improvement 2

		Statement 5 People who have active rheumatoid arthritis have their C-reactive protein (CRP) and disease activity measured monthly in specialist care until they are in remission or have low disease activity.	treatment goals reflected in this statement.	and treatment monitoring has become increasingly dominated by objective and validated disease activity assessment tools, as clinical teams look to determine when to escalate or change treatment in pursuit of clinical goals. These can leave patients feeling unable to talk about what matters most to them about their experience of taking a treatment; perception of disease control; or their sense of broader well-being, all of which are important to consider.	Statement 5 People who have active rheumatoid arthritis have their C-reactive protein (CRP) and disease activity measured monthly in specialist care until they are in remission or have low disease activity.
45	Sanofi	Monitoring of patients during treatment remains key and should be more frequent than an annual review Statement 5 recommends that CRP levels should be monitored monthly until patients are in remission or have low disease activity	Patients should be treated to a disease activity target, or until they are diagnosed as 'in remission', through measurement of CRP monthly. At the last data collection point, Jan 16, this was happening in 89% of patients, but the indicator was archived in July 2018. (BSR National Clinical Audit Data)	Some patients do not respond to a given treatment and therefore should be managed with alternative medication or other options. Most recent data therefore suggest that approximately 10% of patients may not be offered treatment escalation or monitoring.	BSR National Clinical Audit Data published as uptake of NICWE QS33. NG100 recommends that patients who do not respond to initial treatment with a csDMARDs should be offered bDMARDs. The consequences of not achieving disease remission include disease progression, decreased functional ability and an increased likelihood of orthopaedic surgery.

					Moreover, approximately 30% of patients receiving first line anti-TNFa treatment fail to respond adequately. (Mewar et al, Jobanputra et al). Patients' response to treatment will only be identified through regular monitoring, which can ensure medicines optimisation in an area of high cost drug use.
46	SCM 1	Tight control of early arthritis	Review targets are not being met due to above and understaffing	Tight control is important in early synovitis to prevent joint damage	No additional information provided by stakeholder.
47	SCM 3	Key area for quality improvement 4 People who have active rheumatoid arthritis have their C-reactive protein (CRP) and disease activity measured monthly in specialist care until they are in remission or have low disease activity.	Regular disease assessment and CRP measurement will improve drug adherence and dose escalation leading to improving disease progression in the long run. It will also enable use of short-term bridging treatment with glucocorticoids for active disease. NICE recommends to measure C-reactive protein (CRP) and disease activity (using a composite score such	The 2016 National Clinical Audit for Rheumatoid Arthritis and Early Inflammatory Arthritis shows variation in practice for monitoring disease activity.	A regional survey (Tugnet 2013) reported that about two-thirds of people with RA received monthly CRP monitoring but only a quarter had monthly monitoring of disease activity (with about 40% in dedicated early arthritis clinics) until disease control was achieved. The committee were unsure whether these rates reflected practice across

			as DAS28) monthly in specialist care until the target of remission or low disease activity is achieved.		England and noted that practice had improved since the survey was conducted in 2011
48	SCM 4	Key area for quality improvement 4 People who have active rheumatoid arthritis have their disease activity reviewed six weekly by specialist care until they are in remission or have low disease activity with urgent review for flares or review of possible side effects	Monitor disease activity Monthly CRP measurement is achievable as it does not require clinic attendance and people are having cDMARDs monitored Monthly internals between follow ups is not achieved by the majority of centres - national early arthritis audits. Time frame between follow up has been reviewed monthly versus three monthly reviews. NICE support treat to target approach which is the current standard. Urgent review on advice line for management of possible side effects Urgent clinic review for flare management. Step up approach with cDMARD or escalate to biologics if	Treat to target low disease activity aiming for remission Step up/bridging of treatment to gain control of condition	BTT: 2019/2020 National Tariff payment system – a consultation notice: annex DtD. Guidance on best practice tariff (Early inflammatory arthritis) National Institute for Health and Care Excellence (NICE) guideline Rheumatoid arthritis in adults: management (NICE, 2018a]) HQUIP A patient and public guide, National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis, 2nd annual report (2016) National Institute for Health and Care Excellence (NICE) Rheumatoid arthritis in adults: diagnosis and management. Evidence

			appropriate to manage symptoms and achieve remission or low disease activity Bridging treatment where appropriate		review C Treat to target (July 2018) NICE rheumatoid arthritis biologic guidance
49	SCM 5	Key area for quality improvement 3	Monthly follow up until target is met	Although part of NICE guideline since 2009, adherence in many rheumatology units is poor. Best outcome is dependent on frequent follow up	https://www.nice.org.uk/guidance/ng100 https://www.nras.org.uk/data/files/For%20professionals/Publications/bsr_hqip_report.pdf
50	British Society for Rheumatology	Clarify requirements of an annual review	This should include CV risk, bone health, functional assessment, flu jab, pneumococcal vaccination and assessment of work, +/- signpost to national cancer screening programmes, assessment of mental health, as needed by patients. Certain assessments may not be required every year. For example, GPs asked to undertake CV risk assessment when it is needed, and FRAX only done every 2-3 years. Annual review	No additional information provided by stakeholder.	No additional information provided by stakeholder.

			Additional screening, such as assessment of disease activity, must be performed in secondary care. Annual reviews are an efficient means of monitoring long term conditions and possible comorbidities.		
51	Keele University/ Midlands Partnership Foundation Trust	Key area for quality improvement 1	NICE guidelines recommend that patients with rheumatoid arthritis should have an annual review- but where and how this should occur is not clearly established.	Evidence suggests that this is variably implemented leading to duplication and redundancy (e.g. Hider SL, Blagojevic-Bucknall M, Whittle R, Clarkson K, Mangat N, Stack R, Raza K, Mallen CD. What does a primary care annual review for RA include? A national GP survey. Clin Rheumatol. 2016 Aug;35(8):2137-2138.	CPRD/Hospital data
52	National Rheumatoid Arthritis Society	Key area for quality improvement 5 Annual Reviews are important mechanisms to pick up co-morbidities at an early stage and prevent these from taking hold or becoming worse incurring cost both to the individual (in terms of quality of life) and the NHS in financial terms.	People with rheumatoid arthritis should have a comprehensive annual review that is coordinated by the rheumatology service.	In our experience the numbers of rheumatology units who are carrying out proper holistic annual reviews in line with NICE NG100, where things are measured such as cardiovascular disease risk, osteoporosis risk and emotional/mental health, are fewer than the many. This is an important area of disease management that we believe can be improved upon. Preventing co-morbidity is good for everyone including the NHS. Where audit has been done on such reviews, pre-diabetes and other issues were being detected and referred	Refer to BSR HQIP audit which ran between 2013 and 2016 The audit is on-going, and we await shortly the first-year data on the new audit which started May 2018.

				back to primary care or on to other specialties.	
53	Sanofi	The annual review remains important and is still not being met in many areas	As stated in the current QS, Annual review is important to ensure that all aspects of the disease are under control. It provides a regular opportunity to holistically assess the patient in terms of the current management of the disease, and any further support they may need in the future, in order to enable them to maximise their quality of life.	From April 15, to the last data point in January 16, the achievement of this standard dropped from 100% to 82%. An example: Developing an Annual Review Clinic for People with Rheumatoid Arthritis - Dr Martin Lee, Newcastle upon Tyne Key findings: 1. 3% of patients have had a new diagnosis of osteoporosis and have been started on treatment as a result of Annual Review. 2. 17% of people were found to have an increased risk of cardiovascular disease and have been referred back to their GP for further investigation / management as appropriate	As above, patients who do not receive an annual review may be experiencing disease progression or be having a reduced response to treatment. Patients who are adequately treated require fewer hospital appointments and a approx. one third of those inadequately treated will go on to have surgery (National Audit Office, 2009). NICE TA 375 Sarilumab NICE Guidelines NG100 https://www.nice.org.uk/sharedlearning/developing-an-annual-review-clinic-for-people-with-rheumatoid-arthritis
54	SCM 1	Annual review of all patients	Should include cardiovascular risk, osteoporosis risk etc	Increased c/v risk in rheumatoid patients Increased OP risk etc	No additional information provided by stakeholder.

55	SCM 2	Key area for quality improvement 3	QOF Ra 12 monthly review is not carried out effectively by GPS	Poor management by Primary Care	QOF.
56	SCM 2	Key area for quality improvement 2	Co-morbidities such as CV disease need better management	Not clear who should manage GP/consultant ? need better guidance on managing the risks for GPs	No additional information provided by stakeholder.
57	SCM 4	Key area for quality improvement 5 All People with rheumatoid arthritis should have a comprehensive annual review coordinated by the rheumatology service	NICE recommendation for comprehensive annual review	Current NICE guidance supports all people with rheumatoid arthritis have a comprehensive annual review co-ordinated by the rheumatology service. By meeting this standard quality care is delivered and assessment of cardiovascular disease, osteoporosis and GI complications in the same way as other long-term conditions. This review ensures there is no overlap in investigations and management between primary and secondarAbbviey care. This assessment also enables the review of pain, mood, social and employment concerns but also assessing for signs of complications to the eyes, lungs, vasculitis, cervical spine.	National Institute for Health and Care Excellence (NICE) guideline Rheumatoid arthritis in adults: management (NICE, 2018a]) 2018/19 General Medical Services (GMS) contract Quality and Outcomes Framework (QOF) RA002
58	SCM 5	Key area for quality improvement 5	Annual review of all RA patients	Despite meeting the target some patients may have gradual deterioration. A full annual assessment will ensure maintenance of optimal treatment	https://www.nice.org.uk/guidance/ng100 Symmonds D et al Rheumatology, 2006;45:558–565
59	UCB Pharma Ltd	Annual review of symptoms, treatment,	As noted by EULAR [1] and The British Society of Rheumatology (BSR) and	Although NG 100 [3] advocates communication, education and self-management courses, there is no	References Götestam Skorpen, C. et. al. (2016). The

		lifestyle and family planning	British Health Professionals in Rheumatology (BHPR) [2] there are considerations when managing RA in women who are pregnant or planning to become pregnant. The annual review, for those women with RA who have achieved the treatment target and who are of child bearing age should include discussions about: whether they are considering starting a family in the coming year whether they have any concerns about continuing treatment while pregnant the safety of women/infants breastfeeding while on treatment	mention of education and discussion in relation to family planning, pregnancy and breast feeding whilst receiving treatment for RA.	EULAR points to consider for use of antirheumatic drugs before pregnancy, and during pregnancy and lactation. Ann Rheum Dis. 75(5):795-810. Flint. J., et al. (BSR and BHPR Standards, Guidelines and Audit Working Group). (2016). Rhemuat National Institute for Health and Care Excellence. (2016). Rheumatoid arthritis in adults: Rheumatoid arthritis in adults: management (NICE Guideline 100). Available at: https://www.nice.org.uk/guidance/ng100 [Accessed 09 April 2019].
Additional area					
60	SCM 5	Additional developmental areas of emergent practice	Evaluate the value of imaging including ultrasound	The place of US, MRI and isotope scanning is not established. Generating data to	https://www.nice.org.uk/guidance/ng100 Simpson E et al Health Technol Assess. 2018 Apr;22(20):1-258

61	RCP	Responded. They endorse the comments by BSR.
62	Royal College of Radiologists	Responded. No comments submitted.
63	Royal College of General Practitioners	Responded. No comments submitted.
64	Royal College of Nursing	Responded. No comments submitted.