

# NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

## QUALITY STANDARDS PROGRAMME

**Quality standard topic:** Rheumatoid arthritis

**Output:** Briefing paper

### **Introduction**

This briefing paper presents a structured evidence review to help determine the suitability of recommendations from the key development sources listed below, to be developed into a NICE quality standard. The draft quality statements and measures presented in this paper are based on published recommendations from this key development source:

[Rheumatoid arthritis](#). NICE clinical guideline 79 (2009).

### **Structure of the briefing paper**

The body of the paper presents supporting evidence for the draft quality standard reviewed against the three dimensions of quality: clinical effectiveness, patient experience and safety. Information is also provided on available cost-effectiveness evidence and current clinical practice for the proposed standard. Where possible, evidence from the clinical guideline is presented. When this is not available, other evidence sources have been used.

## 1 Referral for specialist assessment

### 1.1 NICE CG79 Recommendation 1.1.1.1 (KPI)

#### 1.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<p><b>Guideline recommendations</b></p>	<p>1.1.1.1 Refer for specialist opinion any person with suspected persistent synovitis of undetermined cause. Refer urgently if any of the following apply:</p> <ul style="list-style-type: none"> <li>- the small joints of the hands or feet are affected</li> <li>- more than one joint is affected</li> <li>- there has been a delay of 3 months or longer between onset of symptoms and seeking medical advice.</li> </ul>
<p><b>Proposed quality statement</b></p>	<p>People with suspected synovitis affecting the small joints of the hands or feet or more than one joint are seen by a specialist within 2 weeks of presentation.</p> <p><i>OR</i></p> <p>People with suspected synovitis are referred for a specialist opinion.</p>
<p><b>Draft quality measure</b></p>	<p><b>Structure:</b> Evidence of local arrangements to ensure that people with suspected synovitis affecting the small joints of the hands or feet or more than one joint are seen by a specialist within 2 weeks of presentation.</p> <p><b>Process:</b> The proportion of people with suspected synovitis affecting the small joints of the hands or feet or more than one joint who are seen by a specialist within 2 weeks of presentation.</p> <p>Numerator – The number of people in the denominator who are seen by a specialist within 2 weeks of presentation.</p> <p>Denominator – The number of people with suspected synovitis affecting the small joints of the hands or feet or more than one joint.</p>
<p><b>Questions for TEG</b></p>	<p>What is an aspirational but achievable timeframe for being seen by a specialist?</p> <p>Can “suspected synovitis” be defined in a way that is measurable? Can “specialist” be defined (e.g. rheumatologist)?</p> <p>Are there any outcome measures?</p>

#### 1.1.2 Clinical and cost-effectiveness evidence

A number of case-series studies showed that the key clinical features to facilitate identification of patients who are likely to have persistent synovitis and a poor prognosis include the number of joints affected and the presence of both swelling and tenderness in affected joints, particularly small joints. 3

case-series showed that delays in referral are associated with worse function at presentation and increased risk of damage to joints. The most significant factor in delaying start of DMARD was delay in referral to a rheumatologist. There was also evidence that the greatest delay in patients presenting to specialist care is in the patients attending their GP with symptoms in the first place.

The evidence for the need for early initiation of therapy also supports the recommendations about the need for urgent referral to specialist care of people with persistent synovitis.

### **1.1.3 Patient experience**

A secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis (38 interviews conducted in 2004/5 and an additional 14 in 2012)<sup>1</sup> found that several people with RA said that their GPs did not seem to take their symptoms very seriously, even if the GP advised them to return if symptoms persisted. The time that people waited for referral to a hospital specialist was highly variable (sometimes up to 18 months).

A report by the King's Fund for the Rheumatology Futures Group in 2009 indicated that patients want to be seen quickly by a core of specialist advice, including a doctor and nurse, for rapid assessment and intensive early management of RA.<sup>2</sup>

### **1.1.4 Patient safety**

No patient safety data identified.

### **1.1.5 Current practice**

People with rheumatoid arthritis visit a GP on average four times before being referred to a specialist for diagnosis, and 18 per cent of patients visit more than eight times. The average time from GP referral to first visit with a consultant has remained constant at around six weeks since 2003, with acute trusts' individual averages ranging from two weeks to thirteen weeks.

Less than half of people with rheumatoid arthritis are referred to a specialist within three months of the onset of symptoms, although it is difficult to determine what proportion of the delay in people being referred to a specialist is directly attributable to delays in GPs making a referral to secondary care. Data from a survey carried out by The King's Fund in 2008 indicate that once they have seen their GP, around half of people are referred to a specialist within three visits. Of the 1,200 respondents to the National Audit Office

---

<sup>1</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

<sup>2</sup> King's Fund (2009) [Perceptions of patients and professionals on rheumatoid arthritis care](#)

survey, half stated that their GP was the main reason for their diagnosis being delayed, reporting that their GP was unsure whether their symptoms were those of rheumatoid arthritis, that their condition was misdiagnosed by their GP, or that their GP took a long time to refer them to a specialist. Two thirds of acute trusts in the census were satisfied that GPs referred patients to them quickly enough.

A third of acute trusts reported operating an Early Arthritis Clinic where GPs in the local community rapidly refer patients with undifferentiated arthritis. One of these clinics, on average, sees new patients within two and a half weeks of referral.

Analysis of the Early Rheumatoid Arthritis Network database indicates that the probability of a person with rheumatoid arthritis being seen by a consultant within 12 weeks of GP referral has increased since 2005, whilst the probability of people being seen within eight weeks has decreased since 2006.<sup>3</sup>

The 10<sup>th</sup> report of the Public Accounts Committee on services for people with rheumatoid arthritis in 2010 concluded that GPs often fail to recognise the symptoms of rheumatoid arthritis, causing delay in referring to a specialist for a diagnosis, and recommended guidance to raise the awareness of GPs and other primary care professionals of the importance of referring people promptly to a specialist, if rheumatoid arthritis is suspected.<sup>4</sup>

An abridged report of a joint meeting in 2009 sponsored by the Department of Health, the Rheumatology Committee of the Royal College of Physicians and the British Society for Rheumatology to consider strategies for improving clinical effectiveness in the management of rheumatoid arthritis and osteoarthritis noted that insufficient knowledge amongst the primary health care team results in some patients with RA being referred late.<sup>5</sup>

Over half of the respondent groups to the Patient View Survey in 2009 believed that the referral process remains inefficient and worthy of improvement, noting that urgent cases are not prioritised over non-urgent ones.<sup>6</sup>

### **1.1.6 Current indicators**

None identified.

---

<sup>3</sup> National Audit Office (2009) [Services for people with rheumatoid arthritis](#)

<sup>4</sup> House of Commons Committee of Public Accounts (2010) [Public Accounts Committee – Tenth Report: Services for people with rheumatoid arthritis](#)

<sup>5</sup> Scott, D.L. (2009) [The Clinical Management of Rheumatoid Arthritis and Osteoarthritis: Strategies for Improving Clinical Effectiveness](#)

<sup>6</sup> Patient View (for NAO) (2009) [Patient Groups on Rheumatoid Arthritis and the NHS: A national survey of patient organisations and other health campaigners](#)

## 2 Investigations

### 2.1 *NICE CG79 Recommendation 1.1.2.2*

#### 2.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<b>Guideline recommendations</b>	1.1.2.2 Consider measuring anti-cyclic citrullinated peptide (CCP) antibodies in people with suspected RA if: <ul style="list-style-type: none"> <li>- they are negative for rheumatoid factor, and</li> <li>- there is a need to inform decision-making about starting combination therapy.</li> </ul>
<b>Proposed quality statement</b>	People with suspected rheumatoid arthritis who are negative for rheumatoid factor are offered anti-cyclic citrullinated peptide antibodies testing.
<b>Draft quality measure</b>	<p><b>Structure:</b> Evidence of local arrangements to ensure that people with suspected rheumatoid arthritis who are negative for rheumatoid factor receive anti-cyclic citrullinated peptide antibodies testing.</p> <p><b>Process:</b> The proportion of people with suspected rheumatoid arthritis who are negative for rheumatoid factor who receive anti-cyclic citrullinated peptide antibodies testing.</p> <p>Numerator – The number of people in the denominator who receive anti-cyclic citrullinated peptide antibodies testing.</p> <p>Denominator – The number of people with suspected rheumatoid arthritis who are negative for rheumatoid factor.</p>
<b>Questions for TEG</b>	<p>Is a “consider” recommendation robust enough to warrant a quality statement?</p> <p>Can we define “suspected rheumatoid arthritis”?</p> <p>Are there any outcome measures?</p>

#### 2.1.2 Clinical and cost-effectiveness evidence

Evidence from 3 case-series studies suggested that anti-CCP positivity is a predictor of prognosis, and that the principal strength of anti-CCP testing appeared to be in people who were seronegative for rheumatoid factor and in whom intensive combination therapy would be the initial treatment. The GDG considered that this group of patients may be reluctant to start intensive therapy without further specific tests relating to diagnosis and prognosis, and there was consensus among the GDG that testing for anti-CCP in this group of patients would therefore be appropriate.

### **2.1.3 Patient experience**

The GDG remarked that patients may be reluctant to accept drug treatment without a definite diagnosis of RA. However, a secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis<sup>7</sup> showed a spread of views, including a few people who had initially tested negative for rheumatoid factor but were personally convinced that they were experiencing RA and were keen to gain access to RA-appropriate drug treatment.

### **2.1.4 Patient safety**

No patient safety data identified.

### **2.1.5 Current practice**

The GDG noted that currently there is not universal availability for testing of anti-CCP antibodies.

### **2.1.6 Current indicators**

None Identified.

---

<sup>7</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

### 3 Initiation of treatment

#### 3.1 NICE CG79 Recommendation 1.4.1.1 (KPI)

##### 3.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<b>Guideline recommendations</b>	1.4.1.1 In people with newly diagnosed active RA, offer a combination of DMARDs (including methotrexate and at least one other DMARD, plus short-term glucocorticoids) as first-line treatment as soon as possible, ideally within 3 months of the onset of persistent symptoms.
<b>Proposed quality statement</b>	People with newly diagnosed active rheumatoid arthritis are offered a combination of disease modifying antirheumatic drugs within 3 months of the onset of persistent symptoms.
<b>Draft quality measure</b>	<p><b>Structure:</b> Evidence of local arrangements to ensure that people with newly diagnosed active rheumatoid arthritis receive a combination of disease modifying antirheumatic drugs within 3 months of the onset of persistent symptoms.</p> <p><b>Process:</b> The proportion of people with newly diagnosed active rheumatoid arthritis who receive a combination of disease modifying antirheumatic drugs within 3 months of the onset of persistent symptoms.</p> <p>Numerator – The number of people in the denominator who receive a combination of disease modifying antirheumatic drugs within 3 months of the onset of persistent symptoms.</p> <p>Denominator – The number of people with newly diagnosed active rheumatoid arthritis.</p>
<b>Questions for TEG</b>	<p>Can “active rheumatoid arthritis” be defined?</p> <p>Can “persistent symptoms” be defined?</p> <p>Are there any outcome measures?</p>

##### 3.1.2 Clinical and cost-effectiveness evidence

1 systematic review (SR), 3 RCTs and 3 cohort studies showed that for symptoms, joint damage, function and quality of life, delay in introducing DMARDs is inferior to early commencement. 1 RCT showed that prompt introduction of DMARDs can lead to benefits up to 5 years after the drugs are introduced when compared with a delayed start. 3 RCTs and 1 cohort study showed that early introduction of drugs also results in fewer adverse reactions and withdrawals.

Although there was no good evidence to support the concept of an upper limit by which time DMARD therapy should have been started in order to achieve long-term benefits on disease outcomes, the GDG felt that the initiation of DMARD therapy within 3 months of the onset of persistent symptoms was

supported by the evidence and should therefore be recommended as an ideal target.

There was some evidence from an RCT that combination therapies could extend the window of opportunity for DMARDs to be effective when compared with monotherapies. For symptoms, quality of life, ability to achieve remission and slowing joint damage, a variety of combination therapies appear to be superior to monotherapy (1 SR and 5 RCTs), although these studies also suggested that the type and combination of drug used was less important than the speed and intensity of the DMARD introduction. The SR and 4 of the RCTs identified no difference in tolerability between the two approaches.

The results of the health economic analysis demonstrated clear benefits of a combination strategy compared with monotherapy, and demonstrated that step-down combinations of DMARDs are likely to be very cost-effective or even cost-saving, and other DMARD combinations are very likely to be cost-effective.

### **3.1.3 Patient experience**

A secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis<sup>8</sup> showed that fear of joint deformity or disability is a common feeling in people diagnosed with RA and that patients found it reassuring when consultants explained that RA affects people differently and that modern interventions are often successful at preventing joint disfigurement. Conversely, patients whose acute symptoms have subsided by the time they see a rheumatologist may find it difficult to accept the chronic and recurring nature of the disease and therefore be reluctant to commence medication. Patients however may be reassured if doctors explain that it may take time to find the most suitable treatment for an individual.

A report by the King's Fund for the Rheumatology Futures Group in 2009 indicated that patients want to be seen quickly by a core of specialist advice, including a doctor and nurse, for rapid assessment and intensive early management of RA.<sup>9</sup>

### **3.1.4 Patient safety**

A patient safety incident is any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care (see appendix A). A comprehensive analysis of recent reported incidents (please see full accompanying report from the NPSA) identifies the following priority areas relating to patient safety:

---

<sup>8</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

<sup>9</sup> King's Fund (2009) [Perceptions of patients and professionals on rheumatoid arthritis care](#)

- Delays in treatment, and moderate harm where treatment delays were considered to have caused temporary or permanent disability.

### **3.1.5 Current practice**

The likelihood of people with rheumatoid arthritis being diagnosed and treated within the clinically recommended period of three months from the onset of symptoms has not improved in recent years. The median time from onset of symptoms to diagnosis and first treatment has remained constant at around nine months since 2003. Currently, 10% of people with the disease are treated within three months of symptom onset.<sup>10</sup>

The report in 2009 on strategies for improving clinical effectiveness in the management of rheumatoid arthritis and osteoarthritis noted that inadequate specialist care due to poor funding may result in excessive delays in consultation which delays early therapy in RA.<sup>11</sup>

Data collected from 337 sets of case notes and 331 surveys of patients with inflammatory arthritis by rheumatology services based at 10 hospital and community sites across Greater Manchester in 2010 showed that the vast majority of patients (90%) were receiving monotherapy.<sup>12</sup>

### **3.1.6 Current indicators**

None identified.

---

<sup>10</sup> National Audit Office (2009) [Services for people with rheumatoid arthritis](#)

<sup>11</sup> Scott, D.L. (2009) [The Clinical Management of Rheumatoid Arthritis and Osteoarthritis: Strategies for Improving Clinical Effectiveness](#)

<sup>12</sup> Gordon R et al (2010) [A supra-district audit of the management of rheumatoid arthritis in adults \(2009 NICE guidance\)](#)

## 4 Access to multidisciplinary team

### 4.1 *NICE CG79 Recommendations 1.3.1.1 and 1.3.1.2 (KPI)*

#### 4.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<b>Guideline recommendations</b>	<p>1.3.1.1 People with RA should have ongoing access to a multidisciplinary team. This should provide the opportunity for periodic assessments (see 1.5.1.3 and 1.5.1.4) 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 on sexual relationships) and help to manage the condition.</p> <p>1.3.1.2 People with RA should have access to a named member of the multidisciplinary team (for example, the specialist nurse) who is responsible for coordinating their care.</p>
<b>Proposed quality statement</b>	People with rheumatoid arthritis have ongoing access to a multidisciplinary team.
<b>Draft quality measure</b>	<b>Structure:</b> Evidence of local arrangements to ensure that people with rheumatoid arthritis have ongoing access to a multidisciplinary team.
<b>Questions for TEG</b>	<p>Can we define “ongoing” in a way that is measurable? Is it about patients knowing how to access services should they need them?</p> <p>We can define the multidisciplinary team as including a named member who is responsible for coordinating care.</p> <p>Are there any outcome measures?</p>

#### 4.1.2 Clinical and cost-effectiveness evidence

1 case-series study of patients with recent-onset RA found that after 2 years of MDT care, all patients experienced significant decreases in pain, and another found that patients who attended the MDT care programme had a significant increase in knowledge of RA at the 3-month follow up. Those with established RA were shown to have significant improvements in disease activity score at 3 months follow-up (1 case-series). A RCT found that the MDT care programme significantly improved HAQ disability score at 52 weeks and in terms of quality of life, 2 RCTs found that the MDT care group was significantly better for overall health at 12 weeks, and improved coping with illness, respectively.

Despite the lack of strong evidence of demonstrated benefit, and sometimes conflicting evidence, the GDG recognised the importance of the

multidisciplinary team in ensuring patients have access to a wide range of professionals with different knowledge and skills, and in monitoring and ensuring good disease control. The GDG consensus view supported that of the patient perspective in terms of the value of MDT partnership working to the seamless delivery of good patient care.

#### **4.1.3 Patient experience**

A secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis<sup>13</sup> identified several issues relating to access to multidisciplinary teams:

##### Access to MTD varies across NHS sites

Ease of access to specialist care within the MDT was reported to vary widely by people with RA. Experiences ranged from individuals who said they had bi-annual consultant appointments and interim GP monitoring, to others who had their nurse specialist's phone number, were able to book hospital appointments directly if they had a flare-up and were able to self-refer for occupational therapy.

##### Access to physiotherapists and occupational therapists

After diagnosis people usually had contact with physiotherapists and/or occupational therapists, although sometimes this was a one-off assessment. People liked to be reminded about important practical advice from physiotherapists that had slipped to the back of their minds over the years. Some said they were able to access physiotherapy/occupational therapy support directly and valued this, but many patients had no direct access to physiotherapists/occupational therapists and had to wait for needs to be identified at their annual review. Sometimes this meant that the prime period of need had already passed.

##### Lack of continuity of relationship with MDT members

Several people reported a lack of continuity in their relationships with members of the MDT, in particular physiotherapists and occupational therapists. Having to tell their story afresh each time when coming for an appointment can be frustrating especially for people who have lived with RA for many years. Different consultants were perceived to have different treatment preferences which worried some patients who thought they might need to move location. Some patients asked to be transferred to a different consultant because they felt poorly treated or because they had heard very positive accounts about another consultant.

---

<sup>13</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

### Young people may have different needs of the MDT

Young people sometimes have particular concerns such as body image, schooling, leaving home, relationships, alcohol or illicit drugs which they would like to have the opportunity to discuss, confidentially, with their care team.

Observational and qualitative studies reviewed by the GDG showed that areas of care deemed inadequate by patients were MDT care (lack of modified toilet in the practice, having access to their file, choice of care provider, information on RA, course of symptoms, aids and home adjustments, good care coordination and being open to questions).

#### **4.1.4 Patient safety**

A patient safety incident is any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care (see appendix A). A comprehensive analysis of recent reported incidents (please see full accompanying report from the NPSA) identifies the following priority areas relating to patient safety:

- Problems with access to podiatry/orthotics and occupational therapy.

#### **4.1.5 Current practice**

The National Audit Office's January 2009 census of acute trusts found that many are not able to provide appointments with all members of the multidisciplinary team, and that just 14% provide access to psychological services for all patients who need them, even though depression is common for people with rheumatoid arthritis. Around 54% provide podiatry access for all, and 64% provide occupational therapy for all.

The Musculoskeletal Services Framework of 2006 recommended a model of services delivery which utilised 'clinical assessment and treatment services (CATS)' in order to ensure integrated input from a coherent and specialist team for treating patients with musculoskeletal disorders.<sup>14</sup> The Arthritis and Musculoskeletal Alliance's 'Musculoskeletal Map of England' demonstrated the existence of local variations in quality in 2010, and showed that the implementation of CATS across the country had not been as widespread as expected, with pockets of good practice but less than two thirds of PCTs in some SHAs having a dedicated CATS service.<sup>15</sup> The National Rheumatoid Arthritis Society's survey of 2010 also showed that consultant rheumatologists and patients considered that access to OTs, podiatrists and physiotherapists needed to be improved.<sup>16</sup>

---

<sup>14</sup> Department of Health (2006) [The Musculoskeletal Services Framework](#)

<sup>15</sup> Arthritis and Musculoskeletal Alliance (2010) [The Musculoskeletal Map of England](#)

<sup>16</sup> National Rheumatoid Arthritis Society (2010) [One Year On Survey](#)

The Alliance's 2009 report however noted some confusion about the role of CATS, and that the definition of a clinical assessment and treatment service varies across the NHS, with levels of staffing varying accordingly. The Musculoskeletal Services Framework described CATS as bringing "together skilled health professionals from primary and secondary care – allied health professionals, extended-scope physiotherapists, GPs with special interests (GPwSIs), chiropractors, osteopaths and nurse practitioners", although exact staffing was left to local discretion. The report notes the potential for CATS to deliver multidisciplinary team care to musculoskeletal services patients although this was not borne out in the responses of trusts to its survey.<sup>17</sup>

A key issue that emerged from the King's Fund's 2009 report on patient and professional perspectives on rheumatoid arthritis care was the extreme range in the level of support available in different parts of the NHS, from a single-handed consultant with no support to full multi-disciplinary teams providing rapid and even patient-directed access. Podiatry was highlighted frequently by patients and professionals as an underused and under-resourced service.<sup>18</sup>

The 2010 Public Accounts Committee's report noted that the National Audit Office had identified inconsistency between Primary Care Trusts in the extent of multidisciplinary services. For example, while depression is common with rheumatoid arthritis, there is often no access to psychological services. It recommended the Primary Care Trusts should obtain better information about the numbers of people with rheumatoid arthritis and take action to ensure the necessary services are provided.<sup>19</sup>

The report in 2009 on strategies for improving clinical effectiveness in the management of rheumatoid arthritis and osteoarthritis noted that inadequate specialist care due to poor funding may result in incomplete teams unable to offer the full range of therapies.<sup>20</sup>

The majority of respondents to a survey of 30 patient and other voluntary groups representing the interests of people with RA from England in 2009 said that, with the exception of physiotherapy, complementary treatments are only sometimes, or are never, available.<sup>21</sup>

A national survey conducted by the National Rheumatoid Arthritis Society (NRAS) and Chartered Society of Physiotherapy of NRAS members showed that 32.2% of respondents waited over one year for a referral from a medical

---

<sup>17</sup> Arthritis and Musculoskeletal Alliance (2009) [Joint working?](#)

<sup>18</sup> King's Fund (2009) [Perceptions of patients and professionals on rheumatoid arthritis care](#)

<sup>19</sup> House of Commons Committee of Public Accounts (2010) [Public Accounts Committee – Tenth Report: Services for people with rheumatoid arthritis](#)

<sup>20</sup> Scott, D.L. (2009) [The Clinical Management of Rheumatoid Arthritis and Osteoarthritis: Strategies for Improving Clinical Effectiveness](#)

<sup>21</sup> Patient View (for NAO) (2009) [Patient Groups on Rheumatoid Arthritis and the NHS: A national survey of patient organisations and other health campaigners](#)

practitioner to see a physiotherapist and 31% of respondents said they had never been offered a referral to a physiotherapist. Only 10.6% of respondents reported waiting less than one month for a referral.<sup>22</sup>

#### **4.1.6 Current indicators**

None identified.

---

<sup>22</sup> National Rheumatoid Arthritis Society & Chartered Society of Physiotherapy (2011) [RA and physiotherapy: A national survey](#)

## 5 Education and self-management

### 5.1 NICE CG79 Recommendation 1.2.1.3

#### 5.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<b>Guideline recommendations</b>	1.2.1.3 People 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.
<b>Proposed quality statement</b>	People with rheumatoid arthritis are offered educational activities that include self-management programmes. <i>OR</i> People with rheumatoid arthritis are offered self-management programmes.
<b>Draft quality measure</b>	<b>Structure:</b> Evidence of local arrangements to ensure that people with rheumatoid arthritis are offered educational activities that include self-management programmes. <b>Process:</b> The proportion of people with rheumatoid arthritis who are offered educational activities that include self-management programmes. Numerator – The number of people in the denominator who are offered educational activities that include self-management programmes. Denominator – The number of people with rheumatoid arthritis.
<b>Questions for TEG</b>	Is the offer a “one-off” (e.g. at first diagnosis), or ongoing? Are there any outcome measures?

#### 5.1.2 Clinical and cost-effectiveness evidence

A Cochrane meta-analysis showed patient education had small, short-term effects on disability, joint counts, patient global assessment, psychological status and depression. There was no evidence (1 RCT) of long-term benefits. An RCT showed that a one-to-one education programme compared with standard care only resulted in improved patient knowledge and adherence to treatment, but no difference for a range of other outcomes. There was some evidence of short-term benefits in hand pain, number of disease flare-ups and global assessments, joint protection behaviour and a long-term (4 years) decrease in morning stiffness, and decreased visits to the GP, though there was no change in use of conventional drugs. The same studies showed less development of some hand deformities, and although there was no functional hand improvement, some short and long-term improvements in aspects of activities of daily living were seen. Another RCT found that the self-

management/occupational therapy programme was significantly better than the control (no intervention) groups for use of some self-management methods. A RCT of cognitive behavioural approaches showed apparent short-term benefits for mood and decreased sense of helplessness but other trials showed no improvement.

The GDG noted that the provision of programmes for patients that encourage self-management is now considered a fundamental aspect of care for all long-term conditions, and that there was evidence that group education, led by healthcare professionals using a behavioural approach, was effective in this regard for people with RA.

The GDG noted the lack of clear-cut evidence in many areas and the need for further research, but also noted the desire of patients to have access to a wide range of educational activities.

### **5.1.3 Patient experience**

A secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis<sup>23</sup> found that due to time constraints, some important issues such as how to cope with flare ups, stiffness, medication, painkillers, pacing, long-term effects, side-effects of medication, exercise etc, may not be comprehensively discussed during consultations. Those who had experienced group education sessions found them helpful and particularly valued advice on effective use of painkillers, suggestions for lifestyle changes that might improve their symptoms and finding out about the full range of services available to people with RA. Sessions also provided valued opportunities for peer advice and support.

Occupational therapists and Physiotherapists were reported to be important sources of practical and self-management advice. They were appreciated for providing motivation and encouragement about living with RA, and in some cases visiting people in their homes to suggest modifications e.g. to kitchens or bathrooms to ease daily activities.

There was some uncertainty as to how much physical activity was beneficial and reports of conflicting messages from different health professionals and a few people felt confused about whether warming or cooling the joints was more beneficial, as both are recommended strategies by physiotherapists.

Observational and qualitative studies reviewed by the GDG yielded the following findings for patients with RA: They often experienced a lack of information (especially AEs of medication, other options for treatment, aids

---

<sup>23</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

and devices and home adjustments). They also wanted more involvement in decisions about their management.

#### **5.1.4 Patient safety**

A patient safety incident is any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care (see appendix A). A comprehensive analysis of recent reported incidents (please see full accompanying report from the NPSA) identifies the following priority areas relating to patient safety:

- Self-management education to include understanding of how to avoid harm from treatment (e.g. correct dosing of methotrexate, importance of monitoring, recognising the signs of immunosuppression).

#### **5.1.5 Current practice**

The National Audit Office report showed that only a minority of PCTs (29%) commission services covering self-management for people with rheumatoid arthritis.<sup>24</sup>

The King's Fund report notes a common theme in ongoing care concerning patients' desire to be supported and educated so that they are better able to self-monitor and manage their condition. Of the patients surveyed 24.4% reported being offered teaching/education sessions about the disease and its treatments, and 13.5% were given details on how to contact the NHS Expert Patient Programme.<sup>25</sup>

#### **5.1.6 Current indicators**

None identified.

---

<sup>24</sup> National Audit Office (2009) [Services for people with rheumatoid arthritis](#)

<sup>25</sup> King's Fund (2009) [Perceptions of patients and professionals on rheumatoid arthritis care](#)

## 6 Measuring disease activity

### 6.1 NICE CG79 Recommendation 1.5.1.2 (KPI)

#### 6.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<b>Guideline recommendations</b>	1.5.1.2 In people with recent-onset active RA, measure CRP and key components of disease activity (using a composite score such as DAS28) monthly until treatment has controlled the disease to a level previously agreed with the person with RA.
<b>Proposed quality statement</b>	People with recent-onset active rheumatoid arthritis are offered monthly measurement of disease activity until the disease is controlled.
<b>Draft quality measure</b>	<p><b>Structure:</b> Evidence of local arrangements to ensure that people with recent-onset active rheumatoid arthritis receive monthly measurement of disease activity until the disease is controlled.</p> <p><b>Process:</b> The proportion of people with recent-onset active rheumatoid arthritis who received monthly measurement of disease activity until the disease was controlled.</p> <p>Numerator – The number of people in the denominator who received monthly measurement of disease activity.</p> <p>Denominator – The number of people with recent-onset rheumatoid arthritis and controlled disease.</p>
<b>Questions for TEG</b>	<p>Can we define “recent-onset active RA”?</p> <p>Are there any outcome measures?</p>

#### 6.1.2 Clinical and cost-effectiveness evidence

In 2 RCT studies of recent-onset RA, intensive treatment strategies with the aim of keeping the Disease Activity Score to low levels of activity resulted in substantially better outcomes when compared with usual care for most measures of disease activity, remission, function and radiological progression. The GDG were impressed by the evidence for frequent (monthly) measurements in patients with recent-onset active disease, where aggressive treatment strategies aimed at keeping DAS28 to low levels produced substantially better outcomes. Frequent monitoring of patients in the early stages of their disease was considered by the GDG as important in terms of better outcome.

### **6.1.3 Patient experience**

A secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis<sup>26</sup> found that people who have regular monitoring find it reassuring to think that any problems will be picked up early. In the longer term the inconvenience of regular visits may outweigh these advantages but in the initial stages after diagnosis regular testing was usually appreciated.

### **6.1.4 Patient safety**

No patient safety data identified.

### **6.1.5 Current practice**

In January 2009 15% of trusts reported that they were offering all patients with active disease a monthly review. The average frequency of review for patients with active rheumatoid arthritis across all trusts was once every three months.<sup>27</sup>

### **6.1.6 Current indicators**

None identified.

---

<sup>26</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

<sup>27</sup> National Audit Office (2009) [Services for people with rheumatoid arthritis](#)

## 7 Ongoing disease control

### 7.1 NICE CG79 Recommendation 1.5.1.1

#### 7.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<b>Guideline recommendations</b>	1.5.1.1 Measure CRP and key components of disease activity (using a composite score such as DAS28) regularly in people with RA to inform decision-making about: <ul style="list-style-type: none"> <li>- increasing treatment to control disease</li> <li>- cautiously decreasing treatment when disease is controlled.</li> </ul>
<b>Proposed quality statement</b>	People with rheumatoid arthritis are offered treatment to an agreed individualised disease activity target.
<b>Draft quality measure</b>	<p><b>Structure:</b> Evidence of local arrangements to ensure that people with rheumatoid arthritis receive treatment to an agreed individualised disease activity target.</p> <p><b>Process:</b> The proportion of people with rheumatoid arthritis who receive treatment to an agreed individualised disease activity target.</p> <p>Numerator – The number of people in the denominator who receive treatment to an agreed individualised disease activity target.</p> <p>Denominator – The number of people with rheumatoid arthritis.</p>
<b>Questions for TEG</b>	<p>How easily can this be measured, given that the timing, frequency and duration of treatment will vary between patients?</p> <p>Are there any outcome measures?</p>

#### 7.1.2 Clinical and cost-effectiveness evidence

In 2 RCT studies of recent-onset RA, intensive treatment strategies with the aim of keeping the Disease Activity Score to low levels of activity resulted in substantially better outcomes when compared with usual care for most measures of disease activity, remission, function and radiological progression. Another RCT showed that a similar approach in established disease also resulted in improved disease control. A case-series study showed that in established disease changes in disease activity correlate with changes in function, and this and another case-series demonstrated that indices that amalgamate several measures of disease activity show greater validity than out out-perform single measures of disease activity.

### **7.1.3 Patient experience**

A secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis<sup>28</sup> found that the opportunity to exercise informed choice is important to most patients but there are those who prefer not to be involved in decision making about drug treatment. Doctors need to discuss drug preferences and recognise that these may change once the patient has learnt more about their condition. Hearing about other patients' experiences of using a drug in combination with other information about the medicine, helped people to decide whether to accept the treatment.

Studies reviewed by the GDG showed that patients' views as to who should choose their medicine (patients who had not used anti-TNFs) were rheumatologists (41%); decide themselves (33%); unsure (18%); joint decision (7%). Men were significantly more likely to want rheumatologists and there was no significant difference between young and old patients. Some patients did not feel confident to make decisions without further support and discussion with healthcare staff. Of patients who had used anti-TNFs, all wanted to be involved; those who had been involved found shared decision making to be positive and beneficial.

### **7.1.4 Patient safety**

No patient safety data identified.

### **7.1.5 Current practice**

No current practice information could be identified.

### **7.1.6 Current indicators**

None identified.

---

<sup>28</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

## 8 Appropriate referral for surgery

### 8.1 NICE CG79 Recommendations 1.6.1.1 and 1.6.1.2

#### 8.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<p><b>Guideline recommendations</b></p>	<p>1.6.1.1 Offer to refer people with RA for an early specialist surgical opinion if any of the following do not respond to optimal non-surgical management:</p> <ul style="list-style-type: none"> <li>- persistent pain due to joint damage or other identifiable soft tissue cause</li> <li>- worsening joint function</li> <li>- progressive deformity</li> <li>- persistent localised synovitis.</li> </ul> <p>1.6.1.2 Offer to refer people with any of the following complications for a specialist surgical opinion before damage or deformity becomes irreversible:</p> <ul style="list-style-type: none"> <li>- imminent or actual tendon rupture</li> <li>- nerve compression (for example, carpal tunnel syndrome)</li> <li>- stress fracture.</li> </ul>
<p><b>Proposed quality statement</b></p>	<p>People with rheumatoid arthritis whose symptoms do not respond to optimal non-surgical management are referred for a specialist surgical opinion.</p>
<p><b>Draft quality measure</b></p>	<p><b>Structure:</b> Evidence of local arrangements to ensure that people with rheumatoid arthritis whose symptoms do not respond to optimal non-surgical management are referred for a specialist surgical opinion.</p> <p><b>Process:</b> The proportion of people with rheumatoid arthritis whose symptoms do not respond to optimal non-surgical management who are referred for a specialist surgical opinion.</p> <p>Numerator – The number of people in the denominator who are referred for a specialist surgical opinion.</p> <p>Denominator – The number of people with rheumatoid arthritis whose symptoms do not respond to optimal non-surgical management.</p>
<p><b>Questions for TEG</b></p>	<p>Are there any outcome measures?</p>

#### 8.1.2 Clinical and cost-effectiveness evidence

Evidence addressing the timing of surgical referral is of limited quality. A survey of hand surgeons and rheumatologists agreed on stage 3 MCP joint

disease being the most appropriate time for surgery, and 3-6 months of resistant synovitis for extensor tenosynovectomy.

The GDG felt that there was currently an enormous variation in thresholds for seeking surgeon's involvement in the formulation of management plans for patients who might eventually need surgery. The GDG felt that an early surgical opinion should always be obtained, particularly in cases where the outcome of a surgical procedure could be jeopardised by a delay in surgical referral.

### **8.1.3 Patient experience**

A secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis<sup>29</sup> identified several issues relating to appropriate referral for surgery:

#### Acceptance of the need for surgery

Several respondents who described surgery saw it as 'the final resort' when drug treatments had failed to alleviate problems. It was sometimes difficult for patients to accept the need for surgery when pain or mobility problems were still relatively mild, and some sought a second opinion before going ahead with surgery. Some chose to delay operations for as long as they could to avoid the need for further surgery if their prosthesis wore out. Patients who did not have the exact nature and extent of the planned surgery explained to them beforehand sometimes felt angry and badly treated. Several people remarked that the surgeons they had encountered were poor communicators. Those who had had repeated operations learned what to ask and had more detailed discussions before deciding whether to have an operation.

#### Concerns around undergoing surgery

Patients are sometimes very reluctant to have surgery and can be shocked when it is suggested that they have a series of operations. Those who had undergone several operations said they had greater concerns about the impact of surgery on their everyday lives than about the procedure itself. As surgery was typically followed by several weeks of rehabilitation, this usually meant being unable to fulfil work and family roles in this time. Those who had hand surgery found it difficult to be heavily reliant on help from others, e.g. with personal care, and those with foot surgery found it difficult to be confined at home. In the weeks following an operation, patients could feel depressed and at a loose end, especially as for some it took several months to experience any benefits from surgery. Post-operative pain was not always dealt with effectively.

---

<sup>29</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

### Impact of waiting times

Waiting times of between 9-18 months were not uncommon. While some patients thought a 12-month wait was acceptable, coping with pain was frustrating. Patients disliked having to step up their drugs as a result of prolonged waiting times. Loss of mobility was even more difficult to accept as it typically meant that people were unable to engage in a lot of the activities they usually enjoyed. Several patients had opted to have private treatment when pain or loss of function became too intolerable.

#### **8.1.4 Patient safety**

No patient safety data identified.

#### **8.1.5 Current practice**

In the National Audit Office census of acute trusts, 81% of trusts reported that they offer a referral for a surgical opinion to all patients with rheumatoid arthritis who meet the relevant NICE criteria. For the 15% of trusts that did not, this was reported to be due to general problems with access to surgeons, a lack of links between rheumatology and orthopaedics, and a shortage of surgical capacity.<sup>30</sup>

#### **8.1.6 Current indicators**

None identified.

---

<sup>30</sup> National Audit Office (2009) [Services for people with rheumatoid arthritis](#)

## 9 Symptom control

### 9.1 NICE CG79 Recommendation 1.4.4.1

#### 9.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<b>Guideline recommendations</b>	1.4.4.1 Offer analgesics (for example, paracetamol, codeine or compound analgesics) to people with RA whose pain control is not adequate, to potentially reduce their need for long-term treatment with non-steroidal anti-inflammatory drugs (NSAIDs) or cyclo-oxygenase-2 (COX-2) inhibitors.
<b>Proposed quality statement</b>	People with rheumatoid arthritis reporting inadequate pain control are offered analgesics.
<b>Draft quality measure</b>	<p><b>Structure:</b> Evidence of local arrangements to ensure that people with rheumatoid arthritis reporting inadequate pain control receive analgesics.</p> <p><b>Process:</b> The proportion of people with rheumatoid arthritis reporting inadequate pain control who receive analgesics.</p> <p>Numerator – The number of people in the denominator who receive analgesics.</p> <p>Denominator – The number of people with rheumatoid arthritis reporting inadequate pain control.</p>
<b>Questions for TEG</b>	<p>Is prescribing pain relief for people who are in pain a marker of quality? Is this not currently happening?</p> <p>How easily can this be measured given that the timing, frequency and duration of treatment will vary between patients?</p> <p>Are there any outcome measures?</p>

#### 9.1.2 Clinical and cost-effectiveness evidence

There are very few good quality trails of analgesics in RA. However, 2 RCTs and 2 case-series studies demonstrated that a variety of analgesics provide symptomatic benefit in RA (e.g. decreased pain, better sleep, improved activities of daily living, improved social activities, satisfaction with medication), and that analgesics appear to be well tolerated.

#### 9.1.3 Patient experience

A secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis<sup>31</sup> found that several people reported that they had benefitted from detailed expert advice on how to use, dose, time and combine analgesics most effectively.

<sup>31</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

A survey conducted by Arthritis Care in 2010 showed that arthritis-related pain causes significant difficulties for a large number of respondents and limits their ability to live life as fully as possible or to conduct many everyday activities. 77% of respondents said that pain prevents them sleeping through the night and nearly 50% said it prevents them from working. 63% said that they had difficulty having sex as a result of their pain, and nearly 58% said that they regularly hide their pain from those close to them. Nearly all respondents, regardless of age, gender, nationality or type of arthritis, said that they lived with at least mild pain every day, with many describing their everyday pain as severe.<sup>32</sup>

#### **9.1.4 Patient safety**

No patient safety data identified.

#### **9.1.5 Current practice**

No current practice information could be identified.

#### **9.1.6 Current indicators**

None identified.

---

<sup>32</sup> Arthritis Care (2010) [Arthritis Hurts](#)

## 10 Disease flares

### 10.1 NICE CG79 Recommendation 1.5.1.3

#### 10.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<b>Guideline recommendations</b>	1.5.1.3 Offer people with satisfactorily controlled established RA review appointments at a frequency and location suitable to their needs. In addition, make sure they: <ul style="list-style-type: none"> <li>- have access to additional visits for disease flares,</li> <li>- known when and how to get rapid access to specialist care, and</li> <li>- have ongoing drug monitoring.</li> </ul>
<b>Proposed quality statement</b>	People with satisfactorily controlled rheumatoid arthritis have access to additional visits for disease flares.
<b>Draft quality measure</b>	<b>Structure:</b> Evidence of local arrangements to ensure that people with satisfactorily controlled rheumatoid arthritis have access to additional visits for disease flares.
<b>Questions for TEG</b>	Can we define “satisfactorily controlled”? Is this element of care covered by draft statement 4 Access to multidisciplinary team? Are there any outcome measures?

#### 10.1.2 Clinical and cost-effectiveness evidence

One RCT found that rapid access (shared care with GP) was significantly better than traditional hospital regular review (every 3-4 months) for pain, change in pain and self-efficacy score at 2 years and for range of motion and patient satisfaction and confidence at 4 years. However, there was a lack of consistency in the evidence relating to frequency of review, place of review and assessment of aggressive treatment. The GDG noted that no one approach would be suitable for everybody.

#### 10.1.3 Patient experience

A secondary analysis of 52 qualitative interviews with people with rheumatoid arthritis<sup>33</sup> identified variability in the arrangements for rapid access. The sudden loss of function associated with a severe flare can be experienced as extremely disabling and frustrating for people with RA. A few people said they felt uncertain about how much physical activity they could/should engage in without worsening their symptoms. A couple of people of working age felt they

<sup>33</sup> University of Oxford (2012) A secondary analysis of qualitative interviews. Shared via communication with Angela Martin.

needed to carry on in their jobs regardless, despite excruciating pains, so as not to risk their job. People with young children also said they had to rely on help from friends and family during flares.

When experiencing flares, people with RA have particular information and support needs and require rapid specialist access. However, not all people with RA had adequate arrangements for this in place. Several people said they typically received steroid injections from their GP to bridge the time it took to see a consultant who could adjust their medication according to disease activity. In one extreme case, a woman was angry that she had to wait for several weeks for her GP to refer her to her consultant once blood tests had shown increased disease activity and then had to wait further until that consultation took place to receive the medication she knew she needed all along, despite her symptoms getting worse week by week. This was her third experience of a flare. Several other people reported examples of much more rapid and efficient access systems, e.g. phoning a hotline/helpline to make a clinic appointment.

#### **10.1.4 Patient safety**

A patient safety incident is any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care (see appendix A). A comprehensive analysis of recent reported incidents (please see full accompanying report from the NPSA) identifies the following priority areas relating to patient safety:

- Delays in treatment related to patients not being able to access rapid review in a flare-up and hospitals not having systems that allow a previously 'routine' patient to become an urgent one.

#### **10.1.5 Current practice**

66% of trusts in 2009 reported that they are not able to provide follow-up services to all people with rheumatoid arthritis who need them. The National Audit Office's review also suggested that the emphasis on getting new patients treated has diminished the capacity of rheumatology services to offer appointments to people who may need treatment for flare-ups. Appointments (other than for new patients) are in many cases not available for a few months by which time the flare-up will have passed.<sup>34</sup>

The Arthritis and Musculoskeletal Alliance's audit of the implementation of the Department of Health's musculoskeletal services framework in 2009 showed that of the few PCTs which had assessed waiting times for follow-up appointments there appeared to be an average wait of 4 to 6 months.<sup>35</sup> 66%

---

<sup>34</sup> National Audit Office (2009) [Services for people with rheumatoid arthritis](#)

<sup>35</sup> Arthritis and Musculoskeletal Alliance (2009) [Joint working?](#)

of National Rheumatoid Arthritis Society members responding to a 2010 survey reported that they were able to get help quickly and when they required it when experiencing a flare up.<sup>36</sup>

The King's Fund's 2009 study showed that patients experienced considerable variation in their care after having experienced a flare-up, with some able to access care within 24 hours while others took more than a few weeks. In the survey almost 90% of patients diagnosed for three years or longer had experienced a sudden flare-up or exacerbation of symptoms, yet an overall impression from the descriptions of patients and professionals was of an underlying uncertainty on how a flare-up should be managed. Some patients reported visiting the clinic and being seen on the day of presentation with a flare-up, while others had to book an appointment through their GP and waited several weeks for access to specialist advice by which time their flare-up has resolved. The patient who has frequent flare-ups as a result of poorly controlled disease may have to contend with time off work, potential risks to employment, disability and incur further joint damage before treatment plans are reviewed.<sup>37</sup>

The Public Accounts Committee's 2010 report into services noted that people with rheumatoid arthritis can experience intense pain when they suffer a flare-up but rapid access to specialist care is not always available when they most need it. It also concluded that rheumatology specialists do not have sufficient flexibility to prioritise appointments for patients according to clinical need, and that action should be taken to ensure that sufficient follow-up appointments are available to meet clinical need.

Respondent groups in the Patient View 2009 Survey identified geographic variations as the key issue affecting patients' accessibility to RA reviews and other aspects of long-term care. Although patients expect to be able to contact specialists about their flare-ups, 96% of the respondent groups insist that most people with RA end up consulting their GPs instead – who are often unable to deal with the situation. Nearly 80% of the respondent groups emphasise that most patients have to go via the GP if they wish to obtain a follow-up review appointments with the consultant.<sup>38</sup>

#### **10.1.6 Current indicators**

None identified.

---

<sup>36</sup> National Rheumatoid Arthritis Society (2010) [One Year On Survey](#)

<sup>37</sup> King's Fund (2009) [Perceptions of patients and professionals on rheumatoid arthritis care](#)

<sup>38</sup> Patient View (for NAO) (2009) [Patient Groups on Rheumatoid Arthritis and the NHS: A national survey of patient organisations and other health campaigners](#)

## 11 Annual review

### 11.1 NICE CG79 Recommendation 1.5.1.4

#### 11.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<b>Guideline recommendations</b>	1.5.1.4 Offer people with RA an annual review to: - assess disease activity and damage, and measure functional ability (using, for example, the Health Assessment Questionnaire [HAQ]) - check for the development of comorbidities, such as hypertension, ischaemic heart disease, osteoporosis and depression.
<b>Proposed quality statement</b>	People with rheumatoid arthritis have a face to face holistic annual review.
<b>Draft quality measure</b>	<b>Structure:</b> Evidence of local arrangements to ensure that people with rheumatoid arthritis have a face to face holistic annual review. <b>Process:</b> The proportion of people with rheumatoid arthritis who have a face to face holistic annual review. Numerator – The number of people in the denominator who have a face to face holistic annual review. Denominator – The number of people with rheumatoid arthritis.
<b>Questions for TEG</b>	What is included in a holistic annual review can be defined in the definitions sections. Are there any outcome measures?

#### 11.1.2 Clinical and cost-effectiveness evidence

The GDG noted the lack of consistency in the evidence relating to frequency of review, and a lack of evidence to support the content of reviews. In the absence of any evidence the GDG made a consensus recommendation about frequency and content of regular reviews.

#### 11.1.3 Patient experience

No patient experience information could be identified.

#### 11.1.4 Patient safety

No patient safety data identified.

### 11.1.5 Current practice

In January 2009 63% of acute trusts reported that they were offering all patients an annual review.<sup>39</sup> In 2010 57% of consultant rheumatologists reported that they had seen no change over the past year in access to holistic annual review, and 55% of patients surveyed reported no access to an annual review.<sup>40</sup>

The King's Fund's 2009 study of patient and professional perspectives on rheumatoid arthritis care noted that monitoring remains hugely variable, with some patients describing being 'left on the sidelines' for years with little assessment or support, and others having full annual 'MOTs' that included not only physical examination but also the wider consideration of health, personal and psychological issues. Several also cited a discrepancy in that there was a relatively good system for recently diagnosed patients, contrasting with that available for the large pool of existing patients, some of whom may assume 'nothing can be done'. The variation occurred in both specialist and general care. Assessment of co-morbidities also varied, with further uncertainty concerning who was in the best position to monitor co-morbidities.<sup>41</sup>

### 11.1.6 Current indicators

QOF [NM58](#) – The percentage of patients with rheumatoid arthritis who have had a face to face annual review in the preceding 15 months.

---

<sup>39</sup> National Audit Office (2009) [Services for people with rheumatoid arthritis](#)

<sup>40</sup> National Rheumatoid Arthritis Society (2010) [One Year On Survey](#)

<sup>41</sup> King's Fund (2009) [Perceptions of patients and professionals on rheumatoid arthritis care](#)

## **Appendix A: Definition of patient safety**

The National Patient Safety Agency (NPSA) defines patient safety in the following terms:

Every day more than a million people are treated safely and successfully in the NHS, but the evidence tells us that in complex healthcare systems things will and do go wrong, no matter how dedicated and professional the staff. When things go wrong, patients are at risk of harm, and the effects are widespread and often devastating for patients, their families and the staff involved. Safety incidents also incur costs through litigation and extra treatment, and in 2009/10 the NHSLA paid out approximately £827, 000,000 in litigation costs and damages. These incidents are often caused by poor system design rather than the error of individuals i.e. 'they are an accident waiting to happen'.

In short patient safety could be summarised as 'The identification and reduction of risk and harm associated with the care provided to patients 'or 'Preventing patients from being harmed by their treatment'. Examples of this might be 'operating on or removing the wrong organ, ten times the dose of an opioid, giving a colonoscopy to the wrong patient with the same name as someone else in the waiting room etc.' These risks are unlikely to be identified through clinical trials or traditional evidence bases and so other evidence sources, such as the National Reporting and Learning System, need to be analysed to highlight the risks and improve system development. This does not however give an accurate picture of prevalence in that way that methods such as casenote review may do.