Services for people with rheumatoid arthritis

INTERNATIONAL COMPARISONS
In this paper, the National Audit Office has reviewed published literature about rheumatoid arthritis and approaches to the disease to provide an international overview. The paper covers:

- Prevalence and incidence
- Approaches to diagnosis
- Approaches to treatment and management
  - Approaches to timescales for treatment
  - Costs and financial arrangements
- Attitudes towards rheumatoid arthritis
- Rheumatoid arthritis and work
- Overview of comparisons

Prevalence and incidence

Prevalence of rheumatoid arthritis has been estimated to be 0.5–1.5 per cent worldwide. It is normally two to three times more common in women than men and peak age of onset internationally is generally between the ages of 35 and 45. At present there is no evidence that explains unanimously the reasons for variations in prevalence of the disease (see Table 1 on page 6).

There are no accurate projections of the future prevalence of rheumatoid arthritis, and although some studies have suggested a fall in rheumatoid arthritis incidence in some countries, these are not conclusive. A Finnish study reported a ten per cent decline in rheumatoid arthritis between 1980 and 1990; research reported 1.3 million adults in the USA with rheumatoid arthritis in 2005 down from the 1990 estimate of 2.1 million and a UK study noted a fall in incidence, especially among women. Japanese and Finnish researchers have also pointed towards an increasing age of onset.

Approaches to diagnosis

Whilst there is consensus that diagnosis should be made as early as possible so that treatment can commence, there is no single European or international method of diagnosing rheumatoid arthritis and no single diagnostic test to detect it. Diagnostic tests are often selected by the patient’s GP or rheumatologist, depending on their assessment of the individual and the nature of their rheumatoid arthritis.

The UK, USA and Canadian GP curricula (Royal College of General Practitioners, American Academy of Family Physicians, The College of Family Physicians of Canada) stipulate that GPs should be able to recognise, diagnose and support the treatment of rheumatoid arthritis. The Royal Australian College of General Practitioners are drawing up a new curriculum but currently provide a rheumatoid arthritis specific guideline.

A selection of observational criteria (versions of the American College of Rheumatology criteria are most common in the countries within the Organisation for Economic Co-operation and Development) and then various scanning techniques are used (Magnetic Resonance Imaging is increasingly preferred to x-ray) alongside blood tests such as the Erythocyte Sedimentation Rate and C-Reactive Protein tests. The use of rheumatoid factor testing of blood is common, but clinicians advocate caution as around 25 per cent of people with rheumatoid arthritis will never have a positive rheumatoid factor.
Approaches to treatment and management

7 There is international consensus that a multidisciplinary approach is the best way to manage rheumatoid arthritis, although the way in which the treatment is delivered varies widely. Few Health Departments, with some exceptions, for example, England and Wales17, and Australia18, have published management guidelines for rheumatoid arthritis (Table 1).

8 Treatment should begin as soon as possible after symptom onset, and whilst there are many effective drugs used as part of rheumatoid arthritis treatment, the use of particular drugs and the time it takes to access new drugs varies widely. In countries with state-funded healthcare, government guidelines set out the pathway to biologics, often with a requirement to use conventional DMARDs (Disease-Modifying Anti-Rheumatic Drugs) first and limits on sequential use. Similar restrictions on the use of biologics exist in countries without a national health service, as a result of health insurance policy restrictions.

9 Surgery is universally used to treat irreversible joint damage, and to restore joint function and limit pain19. It is, however, becoming less common as a method of treating rheumatoid arthritis20. Revision is more frequent in hip replacement as joints loosen and dislocate early21 and there are problems with infection and continuing synovitis in knee replacement22.

10 There is no consensus as to the location or personnel that should be responsible for the follow-up treatment for people with rheumatoid arthritis; the importance instead rests on the skills which the medical staff possess and their ability to treat rheumatoid arthritis effectively. Follow-up after diagnosis in countries such as France and Germany is largely done by the GP, and Canadian healthcare is moving toward this; whereas The Netherlands and Scandinavia favour consultant rheumatologists. Specialist nurses, however, most often work in a hospital-based setting, in close liaison with a rheumatologist. Sweden has an extensive network of rheumatoid arthritis specialist nurses, nurse-led clinics and even an arthritis-specific hospital23.

11 Self-management and exercise programs are now more commonly used in rheumatoid arthritis treatment24 and the long-term maintenance of self-efficacy and psychological well-being have been reported through such programmes25. As a result, such programs are now promoted by each of the countries reviewed here, although they are usually run by arthritis charities rather than the healthcare system. In the USA, for instance, the American National Centre for Chronic Disease Prevention and Health Promotion funds arthritis programmes in twelve states26. American27 and Dutch28 researchers have demonstrated the benefit of exercise for rheumatoid arthritis patients, but no long-term studies have been done.

Approaches to timescales for treatment

12 There is consensus that the earliest diagnosis and shortest time to treatment after onset of symptoms enable treatment of rheumatoid arthritis to be most effective, and evidence that all therapies – monotherapy, combination DMARDs, biologics – work better in early disease than in long-established rheumatoid arthritis29. Published guidelines set out expected timescales for referral for diagnosis and treatment (Table 1). Countries with government-generated guidelines tend to be better at achieving target times, more so than those countries with advisory guidelines from independent bodies.

13 Guidelines all advocate the prescription of DMARDs within three months of diagnosis and each of the countries reviewed has clinical management guidelines for the use of each drug. France, Sweden and The Netherlands suggest a shorter time to the start of DMARD treatment than the UK30. Treatment strategies are moving towards earlier, more aggressive use of DMARDs, for example in the USA, The Netherlands and Sweden, and earlier treatment with biologics.

14 We found a lack of evidence about the length of time taken from symptom onset to treatment of people with rheumatoid arthritis. Few studies have established the length of time taken by people to present to either a GP or a rheumatologist, although there are sub-national studies such as the Early Rheumatoid Arthritis Network and the Norfolk Arthritis Register in the UK which provide valuable data about the patient journey. Waiting times for rheumatoid arthritis referrals are not separately identified and are usually measured as part of referral to treatment times for general rheumatology services. For example, in England, under the 18 week referral to treatment standard, the Department of Health collects data that shows the length of time people wait for the rheumatology specialty. As in other countries, collection of condition specific data would increase the data burden upon the NHS.
Costs and financial arrangements

Musculoskeletal diseases are universally within the top three costs to the healthcare system, when listed by disease. For people with rheumatoid arthritis, overall costs are significant because of the need for continuing monitoring of the disease throughout life, depending on the level of disease activity, and because of early withdrawal from the workforce owing to disability. The complex nature of care for rheumatoid arthritis makes it difficult to identify total costs for the healthcare of an individual with the disease; studies have however compiled expenditure figures by country for drugs and some medical costs. Other studies have reviewed the literature covering the health and cost burden of rheumatoid arthritis. Personal healthcare insurance policies have only recently started to fund biologics for rheumatoid arthritis patients. Basic compulsory insurance on the continent does now cover biologics, but social insurance in countries such as Germany requires that at least two DMARDs are trialled prior to biologics treatment. Within each country, no state healthcare system funds alternative therapies, although health bodies are starting to use hydrotherapy as part of rheumatoid arthritis treatment.

Attitudes towards rheumatoid arthritis

Despite the World Health Organisation Bone and Joint Decade 2000-2010 and fundraising schemes including ‘Arthritis Week’ and ‘Arthritis Walk’ proving popular in countries such as Australia and the USA, there is comparatively little public awareness of arthritis charities in the UK. Although there are active support groups in each country we have reviewed, there is a paucity of studies comparing international attitudes towards, and public awareness of, rheumatoid arthritis. Often voluntary support groups and charities provide the most easily accessible information about rheumatoid arthritis and national health department websites frequently provide links to arthritis charities. There is, however, still a lack of public knowledge about rheumatoid arthritis, mainly because its prevalence is dwarfed by that of osteoarthritis, which it is often confused with.

Rheumatoid arthritis and work

Evidence suggests that within ten years of onset, 50 per cent of people with rheumatoid arthritis will no longer be at work and such figures are similar among the countries reviewed. There is a lack of data covering the impact of rheumatoid arthritis on work and schemes to maintain the contribution of people with rheumatoid arthritis in the workplace; but studies from England and the Netherlands have highlighted the importance of occupational therapy, self-management techniques such as pacing, and the attitudes of employers and colleagues.

Overview of comparisons

In the literature, prevalence of rheumatoid arthritis in north America (Canada, USA) and northern and middle European countries is higher than in southern European countries. Prevalence and incidence data are, however, estimated as no country compiles national registers specifically recording numbers of people diagnosed with rheumatoid arthritis, although the UK is relatively well served for data about the rheumatoid arthritis population with the national GP Research Database and ongoing studies such as the Norfolk Arthritis Register (NOAR). The NHS in England has around one rheumatologist per 100,000 population, which is a lower ratio than countries such as France, Sweden and the USA, but higher than, for example, Spain and Ireland. Data from 2007 indicate that fewer people with rheumatoid arthritis in the UK receive biologics than in other comparable countries. There are, however, more detailed rheumatoid arthritis guidelines and pathways in the UK than elsewhere.

For the NHS in England, the 18 week referral to treatment standard is in the upper range of suggested times from referral to treatment, however this is a government set minimum standard rather than a purely advisory target time for intervention, as in some other countries. With regard to anti-TNF affordability the UK ranks behind several other OECD countries, mostly as a result of lower relative health expenditure per capita. Whilst many rheumatoid arthritis charities work more closely with the NHS than in many of the other countries we reviewed, the general lack of public awareness about the disease is a concern across OECD countries, with calls for increased public awareness and recognition of symptoms at an early stage.
### International comparisons of rheumatoid arthritis

| Estimated number of people with rheumatoid arthritis | Estimated adult prevalence 15+ (%)
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>England 580,000¹</td>
<td>1.40</td>
</tr>
<tr>
<td>Scotland 35,000²</td>
<td>0.83</td>
</tr>
<tr>
<td>Wales 21,000³</td>
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<tr>
<td>Northern Ireland 10,000⁴</td>
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<tr>
<td>Sweden 60,000⁵</td>
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<td>Germany 544,000⁵</td>
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<td>France 283,000⁵</td>
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<td>The Netherlands 108,000⁵</td>
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<tr>
<td>Ireland 40,000⁶</td>
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<tr>
<td>Spain 197,000⁵</td>
<td>0.53</td>
</tr>
<tr>
<td>Australia 400,000⁷</td>
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</tr>
<tr>
<td>USA 1,976,000⁸</td>
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</tr>
<tr>
<td>Canada 320,000⁸</td>
<td>1.20</td>
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</table>

<table>
<thead>
<tr>
<th>Number of rheumatologists per ‘000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>England 1/100¹¹</td>
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<tr>
<td>Scotland 1/113¹¹</td>
</tr>
<tr>
<td>Wales 1/106¹¹</td>
</tr>
<tr>
<td>Northern Ireland 1/115¹¹</td>
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<tr>
<td>Sweden 1/45¹²</td>
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<td>Germany 1/142¹³</td>
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<tr>
<td>France 1/25¹⁴</td>
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<tr>
<td>The Netherlands 1/80¹⁵</td>
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<tr>
<td>Ireland 1/227¹⁶</td>
</tr>
<tr>
<td>Spain 1/140¹⁷</td>
</tr>
<tr>
<td>Australia 1/88¹⁸</td>
</tr>
<tr>
<td>USA 1/50¹⁴</td>
</tr>
<tr>
<td>Canada 1/74¹⁹</td>
</tr>
</tbody>
</table>

### Notes

Estimated number of people with rheumatoid arthritis


Estimated adult prevalence

9. Prevalence figures have been calculated from the number of people with rheumatoid arthritis as a percentage of the adult population, according to 2005 population statistics from the United Nations. For England, Scotland, Wales, Northern Ireland, calculated for adults 16+ using mid 2007 population data from the Office for National Statistics.

Number of rheumatologists

10. These data are indicative since the registration required of rheumatologists varies between countries and the extent to which they use specialist nurses, for example, may differ. These data do not take account of these differences.
## Services for People with Rheumatoid Arthritis – International Comparisons

ARA/ACR – Classification criteria for rheumatoid arthritis were first proposed by the American Rheumatoid Association (ARA) in 1958. The 1958 criteria were revised in 1987 by the American College of Rheumatology (ACR). See Symmons, D, Mathers, C, Pfleger, B. (2003) The global burden of rheumatoid arthritis in the year 2000.

### Diagnostic criteria

<table>
<thead>
<tr>
<th>Diagnostic criteria</th>
<th>Are government guidelines applied to rheumatoid arthritis?</th>
<th>Suggested maximum referral to treatment guidelines/standard (weeks)</th>
<th>Is access to a specialist normally only on referral from a GP?</th>
</tr>
</thead>
<tbody>
<tr>
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<td>18</td>
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<tr>
<td>Revised 1987 ARA/ACR</td>
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<td>12</td>
<td>Yes</td>
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<tr>
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<td>Yes&lt;sup&gt;22&lt;/sup&gt;</td>
<td>18</td>
<td>Yes</td>
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<td>6</td>
<td>Yes</td>
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<td>6</td>
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<tr>
<td>1987 ARA/ACR</td>
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<td>6</td>
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<td>No&lt;sup&gt;27&lt;/sup&gt;</td>
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<tr>
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<td>Urgency dependent</td>
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<td>–</td>
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<tr>
<td>Modified ARA/ACR</td>
<td>Yes&lt;sup&gt;32&lt;/sup&gt;</td>
<td>–</td>
<td>Yes</td>
</tr>
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</table>

### Key

ARA/ACR – Classification criteria for rheumatoid arthritis were first proposed by the American Rheumatoid Association (ARA) in 1958. The 1958 criteria were revised in 1987 by the American College of Rheumatology (ACR). See Symmons, D, Mathers, C, Pfleger, B. (2003) The global burden of rheumatoid arthritis in the year 2000.

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### Guidelines applied to rheumatoid arthritis

- **EULAR** – recommendations for the management of early arthritis, EULAR * – European Action towards Better Musculoskeletal Health
- **20 Musculoskeletal Services Framework; NICE clinical guidelines and technology appraisals**
- **21 SIGN: Management of early arthritis; some NICE technology appraisals**
- **22 Service Development and Commissioning Directives: Arthritis and Chronic Musculoskeletal Conditions; NICE clinical guidelines and technology appraisals**
- **23 Strategic Review of Rheumatology Services in Northern Ireland 2005; NICE clinical guidelines and technology appraisals**
- **24 1998 National Guidelines; EULAR; EULAR * **
- **25 EULAR; EULAR * **
- **26 Société Française de Rhumatologie: Recommandations sur l’utilisation des anti-TNF-a; AFLAR: Support Medical : De la polyarthrite rhumatoïde à la crise de goutte; EULAR; EULAR * **
- **27 EULAR; EULAR * **
- **28 ACR Guidelines for the Management of Rheumatoid Arthritis**
- **29 GUICAR Group: Clinical practice guideline for the management of RA in Spain; EULAR; EULAR * **
- **30 Better Arthritis and Osteoporosis Care Initiative 2006-2009; National Improvement Framework for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis**
- **31 ACR Guidelines for the Management of Rheumatoid Arthritis**
- **32 Guidelines & Protocols Advisory Committee Rheumatoid Arthritis: Diagnosis and Management; ACR Guidelines for the Management of Rheumatoid Arthritis**

### Specialist access from a GP

## The medical cost burden of rheumatoid arthritis¹,²,³

<table>
<thead>
<tr>
<th>Country</th>
<th>Medical costs excluding drugs (million €)</th>
<th>Drug costs (million €)</th>
<th>Per cent of patients on anti-TNF drugs</th>
</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom</td>
<td>1,953</td>
<td>140</td>
<td>6</td>
</tr>
<tr>
<td>Sweden</td>
<td>125</td>
<td>137</td>
<td>12</td>
</tr>
<tr>
<td>Germany</td>
<td>1,649</td>
<td>1,051</td>
<td>4</td>
</tr>
<tr>
<td>France</td>
<td>2,101</td>
<td>1,259</td>
<td>8</td>
</tr>
<tr>
<td>Netherlands</td>
<td>265</td>
<td>64</td>
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<tr>
<td>Ireland</td>
<td>110</td>
<td>77</td>
<td>–</td>
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<tr>
<td>Spain</td>
<td>493</td>
<td>159</td>
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<tr>
<td>Australia</td>
<td>409</td>
<td>288</td>
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</tr>
<tr>
<td>USA</td>
<td>8,755</td>
<td>14,275</td>
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</tr>
<tr>
<td>Canada</td>
<td>701</td>
<td>562</td>
<td>7</td>
</tr>
</tbody>
</table>

### Notes

1. **Medical costs and drug costs**

2. **Per cent on anti-TNF**

3. The data are for indicative comparison as the studies on which the estimates are based were conducted at different points in time and cover different time periods/years. Drug costs are likely to have increased over time, in particular after the introduction of biologics. Data for the UK have not been amended to take account of NAO estimates for England.

### Endnotes


15 NHS, Central Manchester and Manchester Children's University Hospitals. www.cmmc.nhs.uk/directorates/labmedicine/departments/immunology/tests/40.pdf


38 ARC, 2008. Fifty per cent of rheumatoid arthritis patients give up work within ten years, says new study. www.arc.org.uk/news/DirectNews/Article.asp?ID=18456774&Year=2008&Month=2&NameOfMonth=February


