



National Audit Office

Services for people with rheumatoid arthritis

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL | HC 823 Session 2008-2009 | 15 July 2009

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Amyas Morse
Comptroller and Auditor General
National Audit Office

13 July 2009

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This report can be found on the National Audit Office website at www.nao.org.uk

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Neil Betteridge (Chief Executive, Arthritis Care);

Stephen Bevan (Director of Research, The Work Foundation);

Ailsa Bosworth (Chief Executive and founder of the National Rheumatoid Arthritis Society);

Professor Paul Emery (Consultant Rheumatologist, Leeds Teaching Hospitals Foundation Trust and President Elect of the European League against Rheumatism);

Dr Alison Hammond (Occupational Therapist, Salford University);

Ros Meek (Director, The Arthritis and Musculoskeletal Alliance);

Dr Alan Nye (GP with a special interest in rheumatology, Pennine Musculoskeletal Partnership, Oldham);

Susan Oliver (Nurse Consultant, Chair, Royal College of Nursing Rheumatology Forum);

Professor Alan Silman (Medical Director of the Arthritis Research Campaign); and

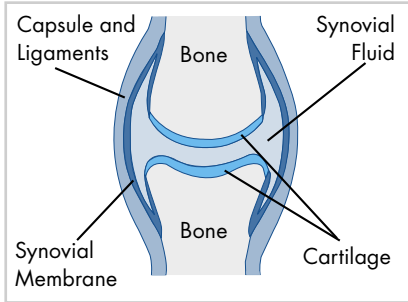
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CONTENTS

| | |
|---|-----------|
| SUMMARY | 5 |
| PART ONE The Department's approach to rheumatoid arthritis | 11 |
| PART TWO From onset of symptoms to treatment | 16 |
| PART THREE Treatment and care after diagnosis | 23 |
| PART FOUR Living well with rheumatoid arthritis | 29 |
| ENDNOTES | 37 |

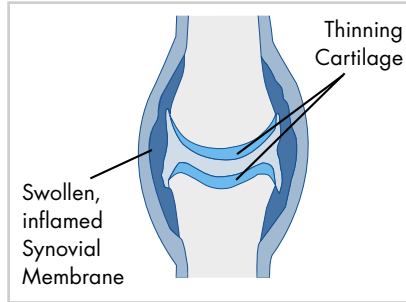
1 The nature of rheumatoid arthritis

A normal joint



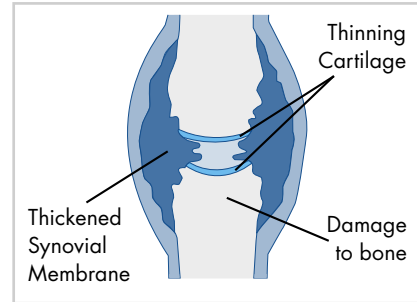
Good flexibility and mobility

Early stages of rheumatoid arthritis



Reduced flexibility and mobility

More advanced rheumatoid arthritis

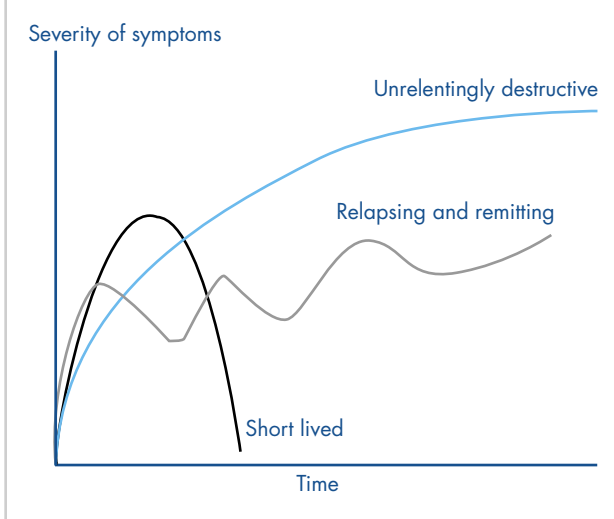


Poor flexibility and mobility leading to disability

- Rheumatoid arthritis is an autoimmune condition in which the immune system attacks the tissue within the joint, leaving it painful and inflamed. If left untreated, the joint can lose its shape and alignment, and can eventually be destroyed completely.¹
- Unlike osteoarthritis, which affects only joints, rheumatoid arthritis can also cause inflammation in other parts of the body, such as the tear glands, salivary glands and, importantly, can damage the lining of the heart and lungs, and blood vessels.² The disease process can also cause fatigue.³
- Rheumatoid arthritis is associated with a range of co-morbidities, including increased risk of cardiovascular disease, infection and osteoporosis. Severe rheumatoid arthritis can also shorten life expectancy by between six and ten years,⁴ equivalent to the impact of diabetes, stroke and coronary heart disease. Depression is also common amongst people with the disease.⁵
- Although there is no known cure for rheumatoid arthritis, the symptoms tend to come and go and vary considerably from person to person, depending on the manner in which the condition progresses.

- At times, people with rheumatoid arthritis may experience a severe flare-up, be in considerable pain and have difficulty carrying out everyday tasks. Flare-ups are unpredictable and can occur at any time of day and night.⁶
- Rheumatoid arthritis is most common after the age of 40, but can affect people of any age.⁸ Around three quarters of people with rheumatoid arthritis are first diagnosed when of working age,⁹ and women are more than twice as likely as men to have the disease.¹⁰
- Rheumatoid arthritis is difficult to diagnose and there is no single diagnostic test that can differentiate it from other types of arthritis. Early diagnosis relies on specialist knowledge, with blood and imaging tests sometimes helping to confirm the diagnosis.¹¹
- Once diagnosed, a range of drugs can be used to treat the disease, such as anti-inflammatories and disease-modifying anti-rheumatic drugs (DMARDs), including biologics. Currently, most DMARDs and all biologics can only be prescribed by specialists.
- In patients that have not responded to treatment, surgery may be required to relieve pain and improve joint function in severely deformed joints. A study published in 2002 found that within five years of treatment, 11 per cent of people on conventional drug therapy (i.e. not biologics) had undergone large or small joint surgery. Around 15 per cent of people also required appliances or or aids such as splints, home alterations or wheelchairs.¹²
- The 2002 study also found that within five years of treatment, between 10 to 15 per cent of people went into remission with no evidence of persistent disease. However, between 70 to 80 per cent of people had a relapsing and remitting type of rheumatoid arthritis, with a mixture of good and bad days, and a variable reduction in normal activities of daily living. The remaining 10 to 15 per cent had an unrelentingly destructive type of rheumatoid arthritis.¹³
- One third of people with the disease will have stopped working within two years of onset¹⁴ and around half will be unable to work through disability within ten years.¹⁵ A person with rheumatoid arthritis has an average of 40 days sick leave per year after disease onset, compared to an average of 6.5 days a year for people without the disease.

Possible trajectories for rheumatoid arthritis⁷



Source: National Audit Office. Pictures of joints are taken from the Arthritis Care Booklet 'Living with rheumatoid arthritis'. Available at www.arthritiscare.org.uk

SUMMARY

1 Rheumatoid arthritis is a progressive musculoskeletal disease that causes severe pain, swelling and inflammation of the joints, and can lead to reduced joint function and disability. It is a lifelong condition which, in most cases, initially affects the joints of the hands and feet; although any joint or other part of the body may later become affected (**Figure 1**). We estimate that in England some 580,000 adults have rheumatoid arthritis, with around 26,000 new diagnoses each year. We also estimate that rheumatoid arthritis costs the NHS around £560 million a year in healthcare costs, with the majority of this in the acute sector, and that the additional cost to the economy of sick leave and work-related disability is £1.8 billion a year.

2 The diagnosis and treatment of rheumatoid arthritis is led primarily by consultant rheumatologists based in acute hospitals. Treatment of rheumatoid arthritis should be started as early as possible to minimise damage to joints, and the clinical consensus is that for treatment to be most effective, it should commence within three months of symptom onset. Whether this happens in practice is dependent on the time taken from onset of symptoms to a person seeking medical help from their GP; the time taken for a person to be referred to a specialist by their GP; and the time taken from GP referral to the start of specialist treatment (**Figure 2 overleaf**). Once diagnosed, people with rheumatoid arthritis require:

- close management to maintain tight control of the disease, optimise treatment, and improve long-term prognoses; and
- education and support to enable them to come to terms with their diagnosis, and adjust to the impact the disease will have on their life, including their ability to work.

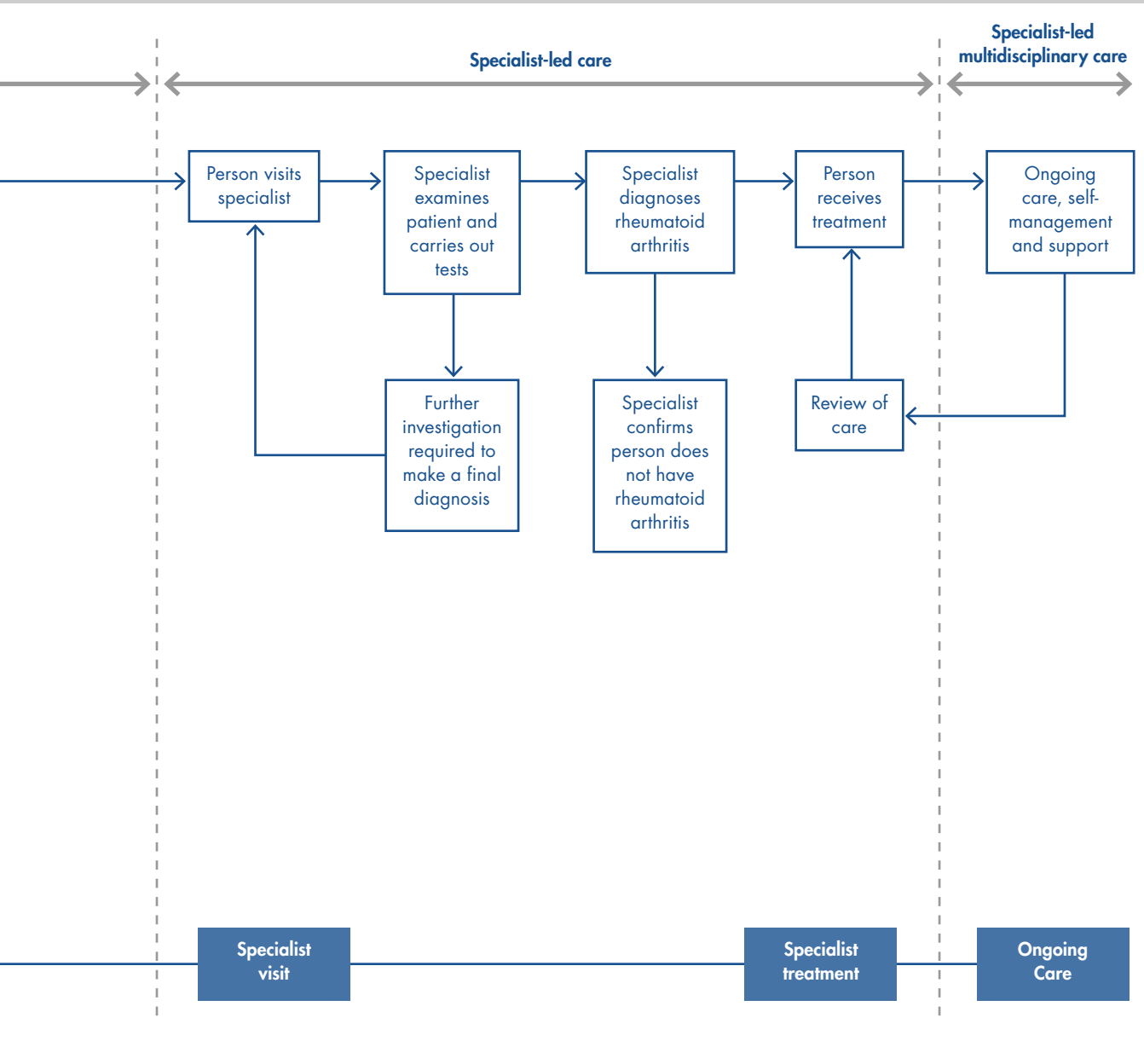
3 This report examines the efficiency and effectiveness of services for people with rheumatoid arthritis in England. It also acts as a marker for the wider challenges faced in providing services for people with musculoskeletal diseases and long-term conditions. Our methodology and reports on our economic modelling, census of acute trusts, survey of people with rheumatoid arthritis, survey of GPs, and international comparisons, can be found on our website at www.nao.org.uk/publications.

Overall findings

On whether people are diagnosed early enough in the course of the disease

4 **People who may have rheumatoid arthritis often delay seeking medical help from their GP.** Prompt early diagnosis and treatment can limit progression of the disease, yet people rarely associate symptoms such as joint pain, stiffness or swelling with a condition requiring prompt medical attention. Between half and three quarters of people with rheumatoid arthritis delay seeking medical help from their GP for three months or more following the onset of symptoms, and around a fifth delay for a year or more.

5 **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.** GPs play a vital role in determining whether people with rheumatoid arthritis are referred to a specialist in a timely manner, but the disease is difficult to diagnose and requires specialist knowledge. Given the incidence of rheumatoid arthritis, most GPs will have few opportunities to develop their skills in identifying the disease on the job because they are likely to see an undiagnosed case less than once a year. In our survey of GPs (481 respondents), a quarter told us that they do not have access to support and advice to help them identify new cases when it is needed.



6 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. There has also been no change in the average time from symptom onset to GP presentation in the last decade, and the average time from GP referral to first visit with a consultant has remained constant at around six weeks since 2003.

7 Productivity gains could be achieved and patient quality of life improved through better integration and coordination of services, leading to quicker diagnosis and earlier treatment, but in the short-term costs to the NHS would increase. Currently, ten per cent of people with the disease are treated within three months of symptom onset. Our economic modelling suggests increasing this to 20 per cent could initially increase costs to the NHS by £11 million over five years due to higher expenditure on drugs and the associated costs of monitoring people with the disease (after around nine years, earlier treatment could become cost neutral to the NHS). This increase in earlier treatment could, however, result in productivity gains of £31 million for the economy due to reduced sick leave and lost employment. On average, this could also increase quality of life by four per cent over the first five years, as measured by quality adjusted life years (QALY) gained.

On access to treatment and care after diagnosis

8 A lack of coordinated multidisciplinary services means that many people with rheumatoid arthritis do not have access to holistic care. Half of the 147 acute trusts which responded to our census reported that they provide care plans for all patients with rheumatoid arthritis, although 30 per cent do not provide a care plan for any. Just 14 per cent provide access to psychological services for all patients who need them, even though depression is common for people with rheumatoid arthritis.

9 Eighty six per cent of acute trusts are able to prescribe biologics to all patients in accordance with National Institute for Health and Clinical Excellence (NICE) technology appraisal guidance. NICE recommends use of biologics for patients who have not responded to other treatments. Trusts estimated that around 11,900 patients were eligible to receive biologics in 2007-08. Of these, all but around 350 people across all acute trusts were receiving them. We estimate that biologics cost the NHS around £160 million annually.

On the effectiveness of ongoing care

10 Clinical monitoring is not yet routinely carried out for all people with rheumatoid arthritis. In February 2009, NICE recommended that all people with rheumatoid arthritis should be offered an annual review, and that people with recent onset active rheumatoid arthritis should have monthly reviews until treatment has controlled the disease. At the time of our census, in January 2009, 63 per cent of acute trusts reported that they were offering all patients an annual review. Fifteen per cent of trusts reported that they were offering all patients with active disease a monthly review.

11 The NHS does not consistently provide support or information to people with rheumatoid arthritis to help them remain in or return to work. The Government's November 2008 response to Dame Carol Black's review of the health of the working age population committed the NHS to improving access to key services which can help people with musculoskeletal conditions return to work. Fifty six per cent of acute trusts were aware of Department for Work and Pensions schemes to help people back into work, and two thirds of these trusts provided advice to people with rheumatoid arthritis about such schemes. Only 20 per cent of people with rheumatoid arthritis considered that they had received sufficient information about employment issues.

On the effectiveness of the Department's incentives and levers for improving services for people with rheumatoid arthritis

12 The majority of primary care trusts (PCTs) lack epidemiological evidence to commission services for people with rheumatoid arthritis effectively. The Department's World Class Commissioning Framework envisages that PCTs will commission evidence-based services. However, only 11 per cent of the PCTs responding to our census had compared the number of people in their area with rheumatoid arthritis against the expected number of cases, meaning that the majority of PCTs do not know if they are effectively identifying people with the disease, or commissioning sufficient capacity to treat them.

13 Although the Department's strategy for long-term conditions is focussed on moving towards a patient-centred approach rooted in primary care, only 12 per cent of PCTs manage rheumatoid arthritis primarily in a primary care setting. Seventy one per cent of PCTs are seeking to develop more services in a primary care setting, but just a quarter of these have analysed the costs and benefits of doing so.

14 Our survey of 1,400 people with rheumatoid arthritis found there is a lack of coherence in the support and information available to help them self-manage their condition. The Department's strategy for long-term conditions seeks to empower people to manage their own condition and people generally considered they had sufficient information about the clinical aspects of rheumatoid arthritis, such as how to take their medication. But people wanted more information about living with the disease and 59 per cent of people also strongly agreed that a named person they could turn to when they had a flare-up would help them manage their disease better.

15 The 18 week referral to treatment standard has led to a significant increase in the percentage of rheumatology patients being seen and treated by a specialist within 18 weeks of referral. By December 2008, the percentage of rheumatology patients (of which about a fifth have rheumatoid arthritis) being seen and treated by a specialist within 18 weeks of GP referral had increased to 97 per cent. Acute trusts responding to our census reported that the average time from GP referral to being seen by a specialist for rheumatology patients is around six weeks, with acute trusts' individual averages ranging from two weeks to thirteen weeks.

Conclusion on value for money

16 The acute hospital-based model of delivering services for people with rheumatoid arthritis has become more economic to run as services have moved from inpatient to largely outpatient and day case care, and some innovative and effective services have been developed. Current services do not, however, always match the Government's vision of a 'systematic patient-centred approach' to caring for people with long-term conditions that is 'rooted in primary care settings', nor is the current pathway for rheumatoid arthritis, including the management of flare-ups, as efficient or effective as it could be. Ultimately, it is not where the care is delivered that matters but who provides it and what is provided.

17 Too many people with rheumatoid arthritis are not presenting, or being diagnosed and treated quickly enough. Better value for money could be achieved through increasing the number of people diagnosed within three months of onset of disease. Our modelling work suggests that increasing from 10 to 20 per cent the number of people treated within three months would initially increase overall NHS costs by £11 million over the first five years; but would improve people's quality of life and for the proportion that are of working age, earlier treatment would improve their chances of remaining in work, generating productivity gains for the economy of around £31 million. After around nine years, earlier

treatment could become cost neutral to the NHS, with ongoing benefits of: improved quality of life; and reduced demands on the NHS (for example for surgery).

Recommendations

18 On the basis of our examination, we recommend that action needs to be taken to improve overall outcomes for people with rheumatoid arthritis, which in a number of areas reinforces the February 2009 guidelines on the management of rheumatoid arthritis in adults issued by NICE. Some of the issues raised are also relevant to other long-term conditions which require specialist-led care. Overall, we have brigaded our recommendations under three issues:

There are opportunities to increase efficiency by addressing the delays in obtaining formal diagnosis and treatment for many people with rheumatoid arthritis. People who may have the disease are often not identified before irreversible damage has taken place. The reasons for delays include: low public awareness about rheumatoid arthritis and its symptoms; delay in presentation to the NHS in primary care; and delays in the time taken to refer to and be seen by a specialist and to begin effective treatment.

Recommendations

- a** **The Department of Health** should explore the cost-effectiveness of options for raising public awareness of the symptoms of inflammatory arthritis, including rheumatoid arthritis, to encourage people to present to the NHS promptly after symptom onset.
- b** **Primary care trusts** should improve awareness in primary care, in particular amongst GPs, of how to recognise the symptoms of inflammatory arthritis and of the need to refer suspected cases promptly, so that any delay from onset of symptoms to treatment is minimised.
- c** As GPs are likely to see less than one new case of rheumatoid arthritis a year, **the Department of Health and the Royal Colleges** should cover rheumatoid arthritis in the ongoing continuing professional development of primary healthcare professionals, and promulgate to them the need for early referral of suspected cases. For example, building on the information already available to them through the Map of Medicine, NHS Choices, and the commissioning pathway for inflammatory arthritis.

There is a lack of integration between primary care and secondary care. There is also a lack of impetus or incentive for changing the way services are currently configured, with little shared knowledge and understanding about the extent of the disease, or an evidence base as to the most cost-effective way of providing services to reflect different local needs.

There is a lack of coordinated holistic care to support people living with rheumatoid arthritis. Greater attention to enabling self-management to help people take greater charge of their own condition, alongside appropriate support mechanisms, would provide services which are more designed around people's needs, including helping people to remain in or return to work.

Recommendations

- d** **Primary care trusts** need to assess the number of people with rheumatoid arthritis in their population, and identify what specialist and multidisciplinary services they need and how to design and deliver them by engaging with patients, their families, carers, rheumatology specialists and groups representing people with rheumatoid arthritis.
- e** **Primary care trusts and acute trusts** need to review the arrangements for funding and delivering ongoing services for people with rheumatoid arthritis and to identify whether, according to local need and examination of costs and benefits, those services are best configured in a primary care setting, a secondary care setting, or some combination.
- f** **The Department of Health and primary care trusts** should build on our economic analysis to promote the benefits to long-term health and the economy of the early treatment of people with rheumatoid arthritis, and of supporting people with the disease to remain in or return to work. **Primary care trusts** should also examine the costs and benefits beyond their own budgets of greater use of early arthritis clinics in increasing the number of people with rheumatoid arthritis treated early, and build on the existing partnership between the NHS and Jobcentre Plus to increase participation in the NHS Condition Management Programme.

Recommendations

- g** **Primary care trusts and acute trusts** should strengthen contacts with local services which support people with musculoskeletal conditions, including rheumatoid arthritis, to remain in or return to work. They should also establish clearer links between NHS and Jobcentre Plus services, and improve awareness of these links in the NHS.
- h** **Primary care trusts** should work with providers to ensure that all people with rheumatoid arthritis are offered a personalised care plan. This plan should include a holistic assessment of the overall well-being of the individual designed around their needs, and support them to return to or remain in work. It should also provide for access to multidisciplinary services, including the services available in the event of a flare-up.

PART ONE

The Department's approach to rheumatoid arthritis

1.1 Rheumatoid arthritis is a progressive disease that can lead to reduced joint function and disability. Studies have shown that one third of people with the disease will have stopped working within two years of symptom onset. Although there is no known cure for rheumatoid arthritis, understanding of the disease has improved in recent years and, once diagnosed, there are now effective treatments that can slow damage to joints, help people maintain their mobility and independence, and decrease work-related disability.¹⁶

1.2 It is important that treatment is started early to minimise damage to joints, and there is increasing evidence that aggressive treatment very soon after the onset of symptoms can lead to remission.¹⁷ Some people will, however, not respond effectively to any treatment and surgery may be required to provide relief from pain, improve joint function or to prevent deterioration or deformity. Rheumatoid arthritis also requires close management, including regular evaluation of clinical indicators of disease progression and the control of associated co-morbidities. As a result, people with rheumatoid arthritis require a complex mix of NHS services delivered by a range of staff. People with the disease may also access support from patient groups, and Department for Work and Pensions schemes such as Pathways to Work and Access to Work, to help them remain in or return to work (Figure 3 overleaf).

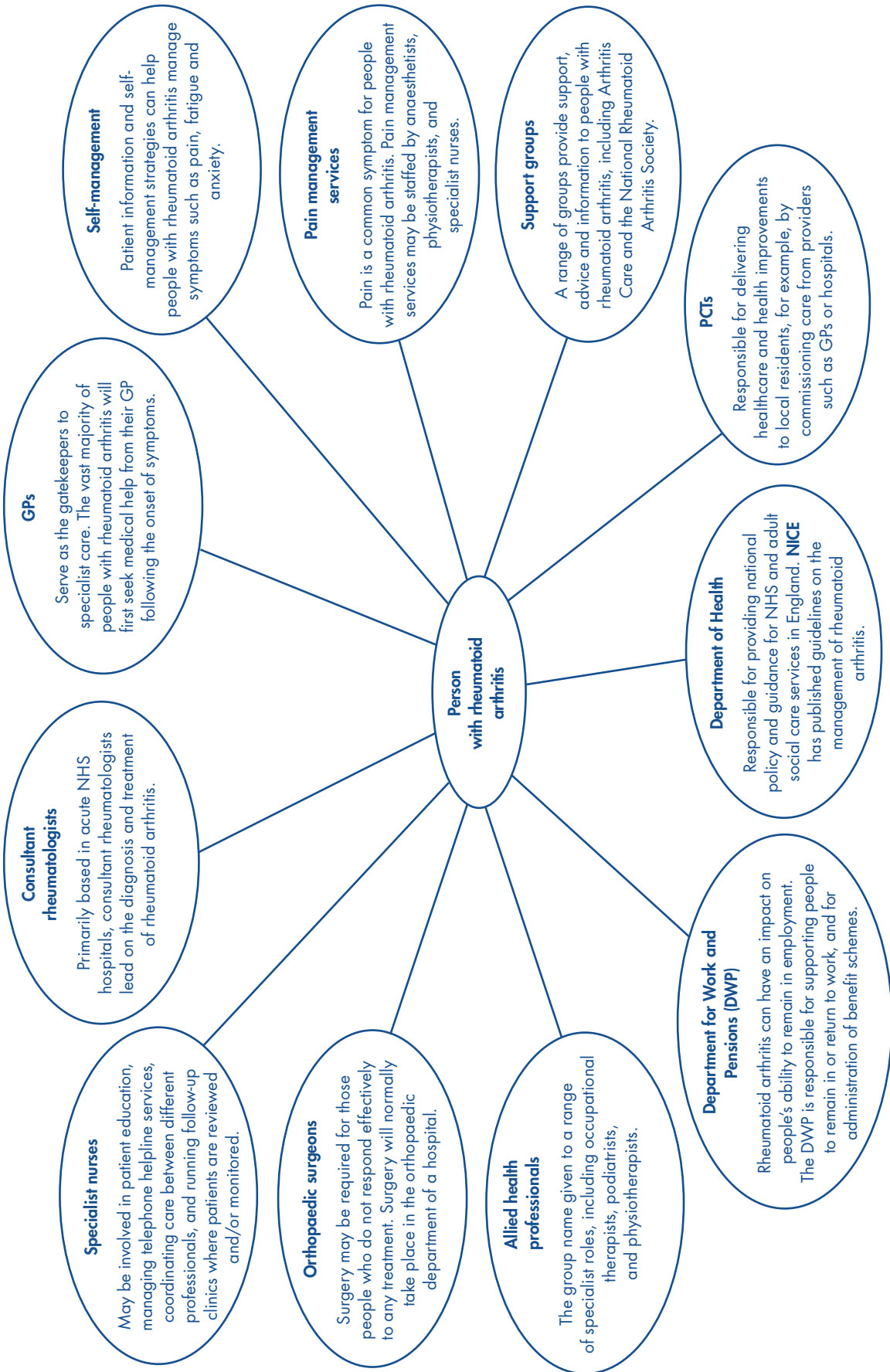
Department of Health policies relevant to rheumatoid arthritis

1.3 Rheumatoid arthritis is covered by two of the Department's main programme areas: the 18 week referral to treatment standard and long-term conditions. The 18 week referral to treatment standard was announced in *The NHS Improvement Plan* in June 2004, and guaranteed that by the end of 2008 no one would wait longer than 18 weeks from GP referral to the start of consultant-led treatment.^a With the diagnosis and treatment of rheumatoid arthritis led by rheumatologists who are overwhelmingly based in hospitals, the 18 week standard has a direct impact on the length of time taken between GP referral and specialist treatment. Although it was not set out as a specific commitment, *The NHS Improvement Plan* also suggested that waits from GP referral to initial outpatient consultation would not normally exceed six weeks, and that patients whose conditions require faster treatment would have shorter waits.

1.4 *The NHS Improvement Plan* also set out the Department's plans to improve care for people with long-term conditions by moving away from reactive care based in acute hospitals, towards a systematic patient-centred approach rooted in primary care. The Department's plans were further developed in its January 2005 policy document, *Supporting people with long-term conditions*, which promoted earlier detection; more effective medicines management; and improving quality of life by empowering people to manage their own condition.

^a People may wait longer than 18 weeks if it is clinically appropriate to do so, or if they choose to do so.

3 Roles and responsibilities in relation to rheumatoid arthritis



Source: National Audit Office

1.5 In July 2006, the Department published *The Musculoskeletal Services Framework* as part of its strategy for long-term conditions. It sets out the Department's plans to support the improvement of musculoskeletal services, including those for rheumatoid arthritis. It seeks to: support the development of a system to plan and manage patient flows through primary and secondary care, ensuring appropriate and timely referral for specialist treatment; use capacity in acute settings appropriately and develop a wider range of services in primary care, such as physiotherapy and pain management advice; and facilitate people's return to work where appropriate. In 2008, The World Class Commissioning Framework and Lord Darzi's *High Quality Care for All – NHS Next Stage Review Final Report* set out a framework for improving the quality and personalisation of care for all NHS patients.

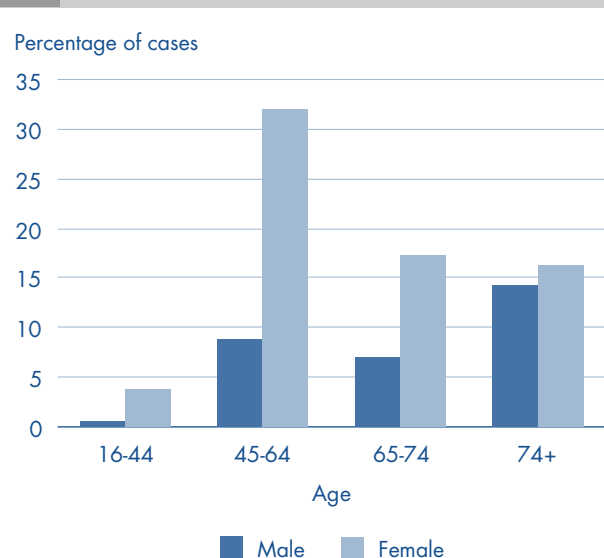
1.6 A literature review of international approaches to rheumatoid arthritis can be found on our website.

The extent and costs of rheumatoid arthritis

1.7 On the basis of our analysis of current population estimates and existing research on the prevalence and incidence of rheumatoid arthritis, we estimate that 580,000 people over the age of 16 have rheumatoid arthritis in England. Forty five per cent of these people are of working age, the majority of whom are female (**Figure 4**). Over 60 per cent of people with rheumatoid arthritis will have been living with the disease for more than ten years (**Figure 5**). We estimate that around 26,000 new cases of rheumatoid arthritis are diagnosed each year.^b Around three quarters of people are of working age when diagnosed (**Figure 6 overleaf**).

1.8 Our census of acute trusts and existing research indicate that there are around 460 consultant rheumatologists in England.¹⁸ This results in a consultant rheumatologist per head of adult population ratio of 1:100,000 which is lower than the 1:90,000 ratio recommended by the British Society for Rheumatology. However, the ratio is more favourable in England than in Scotland, Wales and Northern Ireland, which have ratios of 1:113,000, 1:106,000 and 1:115,000, respectively.

4 Percentage of cases of rheumatoid arthritis by age group and sex



Source: Age and gender specific prevalence predicted from Symmons et al (2002) and National Audit Office analysis of Office for National Statistics population estimates (mid-2007)

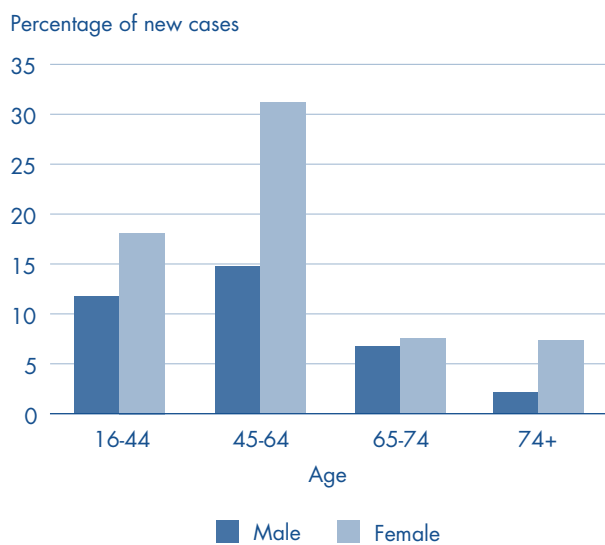
5 People with rheumatoid arthritis by disease duration

| Disease duration | Number of people with rheumatoid arthritis | Percentage of rheumatoid arthritis population over the age of 16 |
|----------------------------|--|--|
| Under five years | 125,000 | 21 |
| Between five and ten years | 105,000 | 18 |
| Between ten and 20 years | 157,000 | 27 |
| Over 20 years | 195,000 | 34 |
| Total | 582,000 | 100 |

Source: National Audit Office analysis of the General Practice Research Database and Office for National Statistics population estimates and mortality data

^b We derived an estimate of the number of new cases diagnosed each year by using the average reported incidence from the General Practice Research Database (GPRD) over the five years 2003-2007. We estimated prevalence by applying the GPRD-derived incidence rate to age and gender specific population and mortality estimates from the Office for National Statistics. Our estimates are higher than previous published estimates. See methodology on our website.

6 Percentage of new cases of rheumatoid arthritis by age group and sex

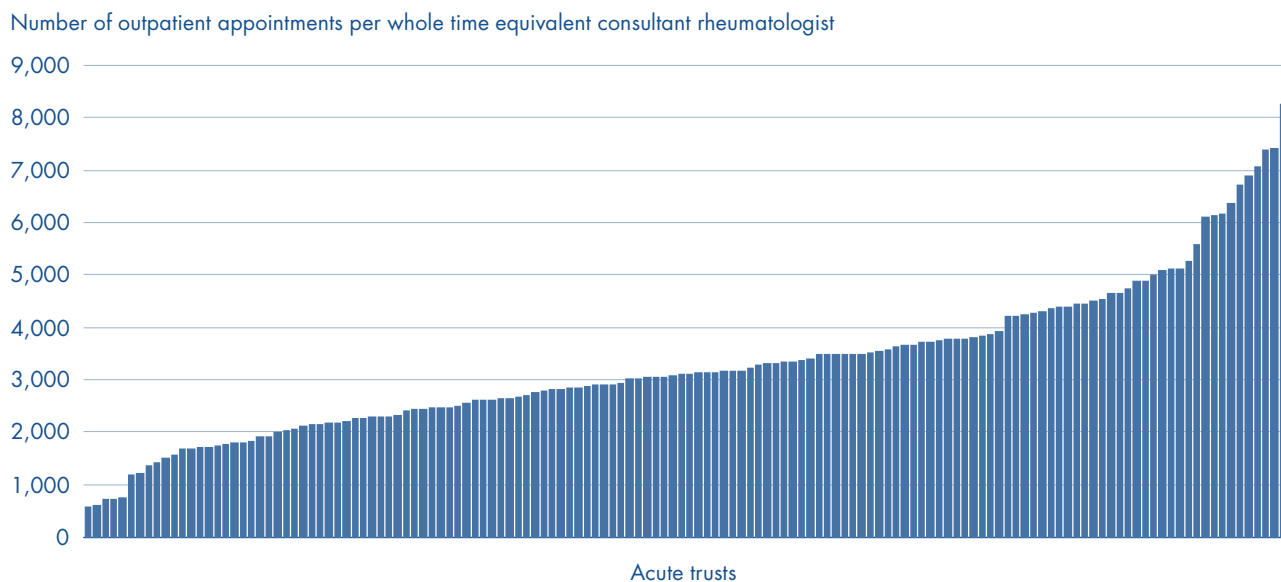


Source: Age and gender specific incidence predicted from Wiles et al (1999) which is based on data from the Norfolk Arthritis Register, and National Audit Office analysis of Office for National Statistics population estimates (mid-2007)

1.9 Our census of acute trusts identified a significant variation in the ratio of whole time equivalent consultant rheumatologists to rheumatology outpatient appointments reported by acute trusts in 2007-08 (Figure 7).^c Some of this variation may be explained by the fact that specialist nurses often undertake clinics under the rheumatology consultant. Our census indicates that there are a total of 377 specialist rheumatology nurses in England, ranging from zero to ten per acute trust (an average of 2.4 per acute trust).

1.10 We estimate that rheumatoid arthritis costs the NHS in England around £560 million annually in healthcare costs (Figure 8), with the wider cost to the economy of sick leave and work-related disability (lost employment) being £1.8 billion a year. The Department for Work and Pensions estimates that, in 2007-08, expenditure on incapacity benefits for people with rheumatoid arthritis was £122 million.¹⁹ Estimates of the total cost of rheumatoid arthritis to the UK economy, including NHS costs as well as carer costs, the costs of nursing homes, private expenditure, sick leave and work-related disability are as high as £3.8 to £4.8 billion a year.²⁰

7 Ratio of whole time equivalent consultant rheumatologists to rheumatology outpatient appointments reported by acute trusts in 2007-08



Source: National Audit Office census of 147/154 (95 per cent) acute trusts

^c The data from our census have not been subject to audit and some of the variations in information collected may be due to differences in interpretation by acute trusts responding to the census.

8 The estimated annual healthcare costs of rheumatoid arthritis to the NHS

| Activity | Basis of costing | Cost (£m) ¹ |
|--|---|------------------------|
| GP visits – unidentified cases prior to specialist referral | Unit cost of Health and Social Care 2007-08 (PSSRU) – People with undiagnosed rheumatoid arthritis will, on average, visit their GP four times prior to being referred to a specialist (King's Fund). | 6 |
| Tests carried out by GPs prior to specialist referral ² | General Practice Research Database (GPRD) – Blood tests for rheumatoid factor, x-rays. | 2 |
| GP visits – diagnosed cases | GPRD – patients visit their GP on average four times per year after diagnosis. | 146 |
| Monitoring tests carried out by GPs following diagnosis | GPRD – Some GPs carry out monitoring tests to check progress of the disease. | 17 |
| Drug costs in primary care | Market pricing applied to probability of prescription of, for example, DMARDs, steroids and analgesics. | 102 |
| NHS rheumatology units | Reported expenditure from National Audit Office census of acute trusts. Includes expenditure of £160 million on biologics. | 260 |
| Surgery | Extract from Hospital Episode Statistics covering surgery linked to primary diagnosis of rheumatoid arthritis. | 24 |
| Total NHS costs | | 557 |

NOTES

1 Based on National Audit Office estimates of incidence and prevalence.

2 Excludes anti-cyclic citrullinated peptide (CCP) antibody tests.

PART TWO

From onset of symptoms to treatment

2.1 One of the aims of the Department's strategy for long-term conditions is to treat people earlier in the course of disease through earlier detection and appropriate and timely referral to specialist care. For rheumatoid arthritis, the clinical consensus is that for treatment to be most effective, it should commence within three months of symptom onset. This part of the report examines whether cases of the disease are identified accurately and on a timely basis.

The time taken from onset of symptoms to referral to a specialist by a GP

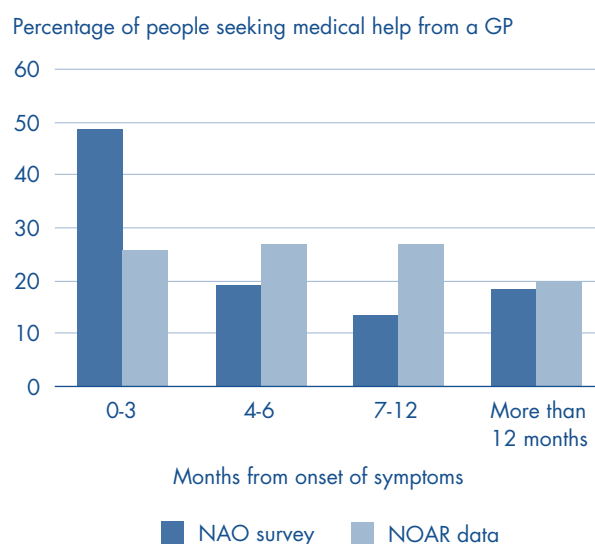
Onset of symptoms to presentation to a GP

2.2 Ninety four per cent of people with rheumatoid arthritis will first seek medical help from their GP following the onset of symptoms. However, between half and three quarters of people with rheumatoid arthritis delay seeking medical help from their GP for three months or more following the onset of symptoms (**Figure 9**). Around a fifth of people delay seeking medical help from their GP for a year or more. These delays can increase the risk of damage to joints and increase the need for more costly treatments and surgical intervention.²¹

2.3 We found that there was no relationship between the year of diagnosis and the length of time between onset of symptoms and GP presentation. We also found that there was no significant change in the time from symptom onset to GP presentation in the Norfolk Arthritis Register (NOAR) data collected between 1995-1999 and 2000-2005. This suggests that public awareness and public behaviour about the symptoms of rheumatoid arthritis have not improved over the last decade. There is only limited research into public awareness of rheumatoid arthritis (**Figure 10**), but a lack of awareness may mean that people do not distinguish it from osteoarthritis, or incorrectly assume that nothing can be done to help them.²²

2.4 Delays in people seeking medical help from their GP are a significant reason for delays in people with rheumatoid arthritis being seen by a specialist.²³ People are most likely to delay seeking help because they have only mild symptoms which initially have a limited impact on functional ability, or because they lack knowledge of the disease and its symptoms. People with early rheumatoid arthritis also rarely associate symptoms such as joint pain, stiffness and swelling with an underlying diagnosis that requires prompt medical attention.²⁴

9 Time from onset of symptoms to seeking medical help from a GP for people with rheumatoid arthritis



Source: National Audit Office survey of people with rheumatoid arthritis and National Audit Office analysis of data provided by the Norfolk Arthritis Register

NOTES

1 Information on the time taken to GP presentation was available for 799 people in the Norfolk Arthritis Register data.

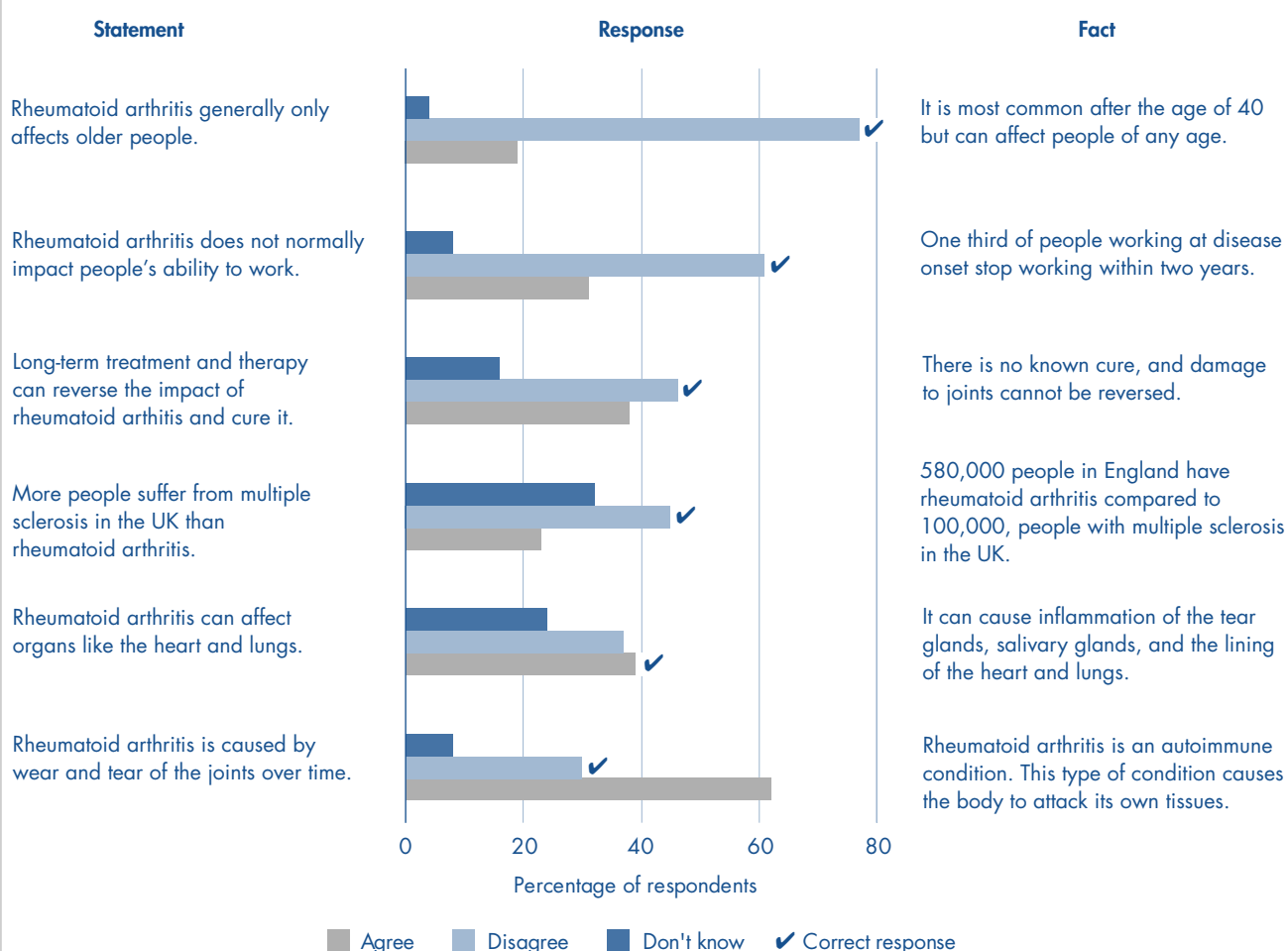
2 The National Audit Office survey data consists of 879 respondents who stated that they were formally diagnosed with rheumatoid arthritis within the last ten years.

Difficulties in identifying and diagnosing rheumatoid arthritis

2.5 GPs play a vital role in determining whether a person with rheumatoid arthritis is referred to a specialist in a timely manner. In the early stages the undifferentiated nature of the symptoms and range of inflammatory conditions make rheumatoid arthritis difficult to diagnose, and there is no single diagnostic test that can detect it or differentiate it from other types of arthritis. With around 26,000 new cases identified annually, many of the 34,000 GPs in England will also go a year or more without seeing an undiagnosed case of rheumatoid arthritis.

2.6 GPs may carry out diagnostic tests prior to making a decision on referral to a specialist. Our survey of people with rheumatoid arthritis found that half of patients had blood tests for rheumatoid factor, and ten per cent had x-rays. Blood and imaging tests can help to confirm a diagnosis, but x-rays, for example, may be normal in the early stages of the disease, and blood tests for rheumatoid factor detect less than half of people who will eventually be diagnosed with rheumatoid arthritis at presentation.²⁵ Diagnosis of the disease is therefore largely clinical and requires specialist knowledge, relying particularly in the early stages on the history and examination of the patient. Our survey of people with rheumatoid arthritis and our visits to acute trusts also indicate that tests carried out by GPs prior to referral may result in unnecessary delays and costs as they are usually repeated by specialists following referral.

10 Awareness of rheumatoid arthritis amongst the general public



Source: Telephone poll carried out for the National Rheumatoid Arthritis Society by ComRes

NOTE

Telephone interviews were carried out with 1,013 British adults between 6 and 9 March 2009.

Presentation to a GP to referral to a specialist

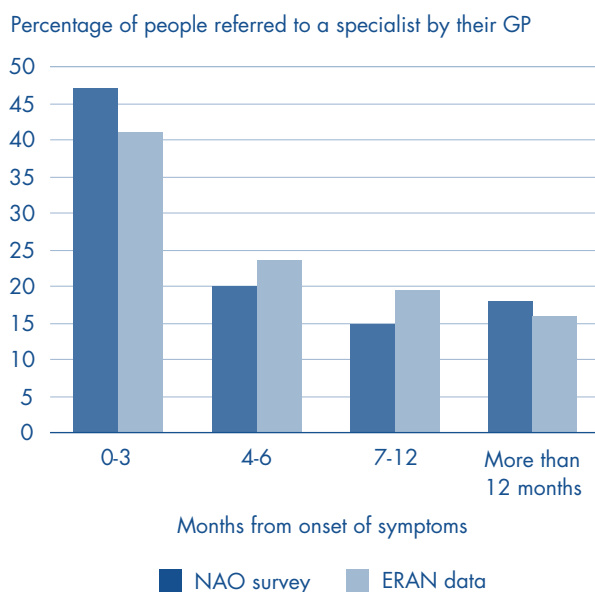
2.7 Less than half of people with rheumatoid arthritis are referred to a specialist within three months of the onset of symptoms (Figure 11). It is difficult, however, to determine what proportion of the delay in people being referred to a specialist is directly attributable to delays in GPs making a 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 (Figure 12). People with rheumatoid arthritis visit their GP on average four times before being referred to a specialist for diagnosis.

2.8 For the 1,200 respondents to our survey of people with rheumatoid arthritis who considered their diagnosis could have been made more quickly, half stated that their GP was the main reason for their diagnosis being delayed. Respondents reported 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 our census were satisfied that GPs referred patients to them quickly enough.

2.9 A third of acute trusts reported operating an Early Arthritis Clinic where GPs in the local community rapidly refer patients with undifferentiated arthritis. We visited one in Newcastle which is run by a clinical nurse specialist and, on average, sees new patients within two and a half weeks of referral. Whilst existing research indicates that having a rapid referral system in place can lead to a 30 to 50 per cent increase in referrals,^{26,27,28} it can shorten the length of time taken for people to see a specialist by reducing the number of visits to GPs and avoid the duplication of diagnostic tests by GPs and specialists.

2.10 Data collected at existing Early Arthritis Clinics suggests that around 50 per cent of referrals go on to be diagnosed as inflammatory arthritis, with rheumatoid arthritis accounting for around two thirds of these.²⁹ Of the two thirds of acute trusts that do not operate an Early Arthritis Clinic, one third of these had evaluated the benefits of running one. Our economic modelling, which is detailed in a separate report on our website, examined the potential impact that more widespread application of an Early Arthritis Clinic approach could have upon increasing the number of people with rheumatoid arthritis diagnosed early (paragraphs 2.21-2.23).

11 Time from onset of symptoms to people with rheumatoid arthritis being referred to a specialist by their GP

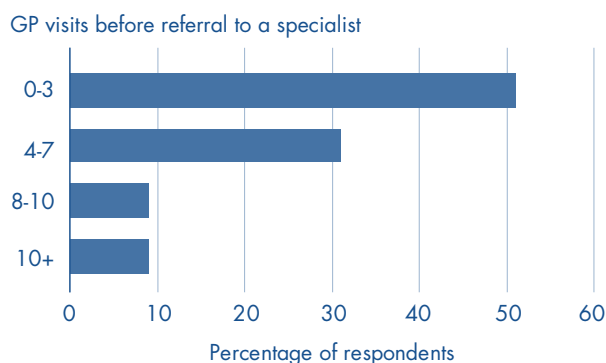


Source: National Audit Office survey of people with rheumatoid arthritis and National Audit Office analysis of data provided by the Early Rheumatoid Arthritis Network

NOTES

- Information on the time taken from onset of symptoms to referral to a specialist by a GP was available for 1,009 people in the Early Rheumatoid Arthritis Network data, collected between 2002 and 2008.
- The National Audit Office survey data consists of 879 respondents who stated that they were formally diagnosed with rheumatoid arthritis within the last ten years.

12 Number of GP visits before referral to a specialist for people with rheumatoid arthritis



Source: The King's Fund. Perceptions of patients and professionals on rheumatoid arthritis care (January 2009)

NOTE

236 people provided data on the number of times they saw their GP prior to being referred to a specialist.

GPs' knowledge of rheumatoid arthritis

2.11 One factor in determining the number of times a person will see a GP before they are referred to a specialist is the GP's knowledge of the disease. Our survey of GPs found that around three quarters had received pre-registration training covering rheumatoid arthritis, and that for two thirds of these their training was brief. Those GPs who received brief training with a practical element were equally likely to report having a very good knowledge of rheumatoid arthritis as those receiving in-depth training that did not involve a practical element. Research has shown that GPs prefer their continuing professional development to come from practical-based training, relating to the way in which their patients present.³⁰ One of the acute trusts we visited reported having successfully used a patient partners scheme where people with rheumatoid arthritis are trained to demonstrate their physical signs and talk about their experience of the disease with GPs.

2.12 Although musculoskeletal conditions are common and are estimated to form up to 25 per cent of a GP's workload,³¹ a June 2004 survey of trainee GPs found that they were receiving minimal post-registration teaching in musculoskeletal conditions and rated their training as inadequate. Seventy per cent of trainee GPs had tutorials on musculoskeletal conditions, receiving an average of two hours teaching. The most common tutorial topics were back pain, joint injections and osteoarthritis.³²

Support and guidance for GPs in identifying rheumatoid arthritis

2.13 Whilst three quarters of GPs responding to our survey had access, when required, to support and advice to help them identify new cases of rheumatoid arthritis, a quarter did not. Support for GPs was most commonly provided by consultants in rheumatology units and local patient groups. When asked to identify where they thought they should be able to access support and advice, GPs indicated that they would expect more support to be provided by the Royal College of General Practitioners, PCTs and GPs with a special interest in rheumatology.

2.14 GPs with a special interest supplement their core generalist role by delivering additional services beyond the scope of general practice, and were introduced as part of a wider programme to increase the range and amount of services available in primary care and community settings. The role of the GP with a special interest includes delivering services that may otherwise be delivered by specialists in an acute setting, such as joint injections or monitoring of patients in the community, and providing education and support for local GPs. Our census of PCTs found that 51 per cent of PCTs fund GPs with a special interest in musculoskeletal medicine, whilst 19 per cent fund GPs with a special interest in rheumatology (**Figure 13**).

2.15 Our survey of GPs found that 60 per cent of GPs do not use specific guidance or criteria to help them identify if a patient may have rheumatoid arthritis. For the 40 per cent of GPs that do use guidance, over three quarters of these used guidance issued by NICE, whilst one in seven used the American College of Rheumatology's 1987 classification criteria for rheumatoid arthritis. Clinical guidelines for the management of rheumatoid arthritis in adults issued by NICE in February 2009 have, however, stated that the ACR criteria were not designed, and are not appropriate, for the diagnosis of early rheumatoid arthritis.

The time taken from GP referral to the start of specialist treatment

2.16 In June 2004, *The NHS Improvement Plan* made a commitment that by December 2008 no one would have to wait longer than 18 weeks from GP referral to the start of consultant-led treatment. Performance against the 18 week standard is measured by the Department against minimum operational standards of 90 per cent for admitted patients and 95 per cent for non-admitted patients. Admitted pathways are those that end in an admission to hospital (either inpatient or day case) for treatment. Non-admitted pathways are those that end in treatment that did not require admission to hospital or where no treatment is required.

13 GPs with a special interest in musculoskeletal medicine and rheumatology

| Specialty | Percentage of PCTs funding GPs with a special interest | Mean number of GPs with a special interest per PCT | Minimum | Maximum |
|--------------------------|--|--|---------|---------|
| Musculoskeletal medicine | 51 | 2.4 | 1 | 7 |
| Rheumatology | 19 | 1.5 | 1 | 4 |

Source: National Audit Office census of 111/152 (73 per cent) primary care trusts

2.17 For rheumatology patients overall, the percentage of patients with completed pathways treated within 18 weeks of GP referral had increased to 97 per cent for both admitted and non-admitted pathways by December 2008 (Figure 14). The number of rheumatology patients being treated within four, eight and twelve weeks has also increased (Figure 15). In our census, acute trusts reported that the average time from GP referral to being seen by a specialist for rheumatology patients is around six weeks, although trusts' individual averages ranged from two to 13 weeks.

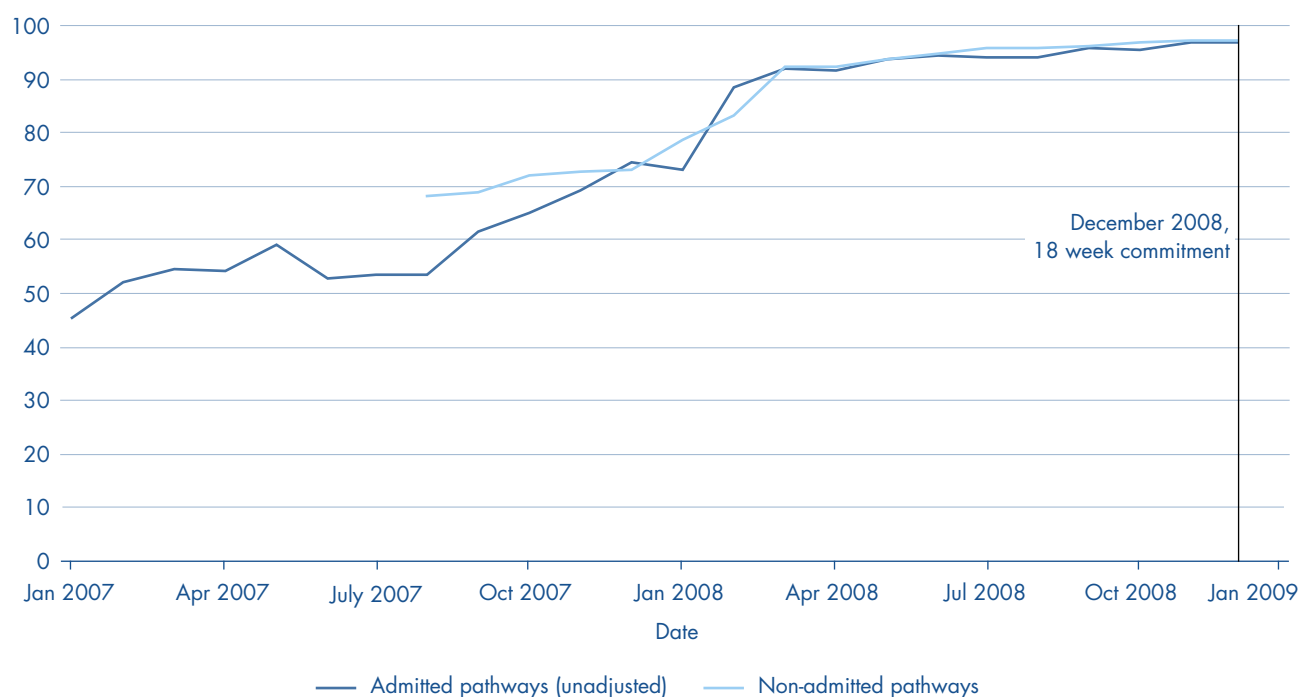
2.18 The Department set the 18 week referral to treatment standard as a minimum standard for primary care and acute trusts to achieve, with trusts responsible for organising pathways for patients requiring quicker treatment. In our census of acute trusts, we asked about the impact of implementing the 18 week standard. Trusts identified the benefits for patients of implementing the 18 week standard as being the promotion of timely investigations, in particular for new patients, and the quicker availability of diagnostic tests. However, trusts also considered that the 18 week standard was not relevant for rheumatoid arthritis as new patients need to be seen and treated more quickly than 18 weeks.

2.19 Acute trusts estimate that people with rheumatoid arthritis represent only around a fifth of all new rheumatology patients. So the majority of patients included within the 18 week data for rheumatology have other conditions, such as osteoarthritis or back pain, which are diagnosed and treated differently to rheumatoid arthritis. In common with other conditions, national referral to treatment times are not available specifically for people with rheumatoid arthritis. However, data on the time from GP referral to first consultant visit is included in the Early Rheumatoid Arthritis Network (ERAN) database.

2.20 Our analysis of the database indicates that, between 2003 and 2008, the average time from GP referral to first visit with a consultant for people with rheumatoid arthritis was around six weeks. Our analysis of the ERAN database also 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 (Figure 16).

14 Percentage of admitted and non-admitted rheumatology patients with completed pathways treated within 18 weeks of GP referral

Percentage of people treated within 18 weeks of GP referral

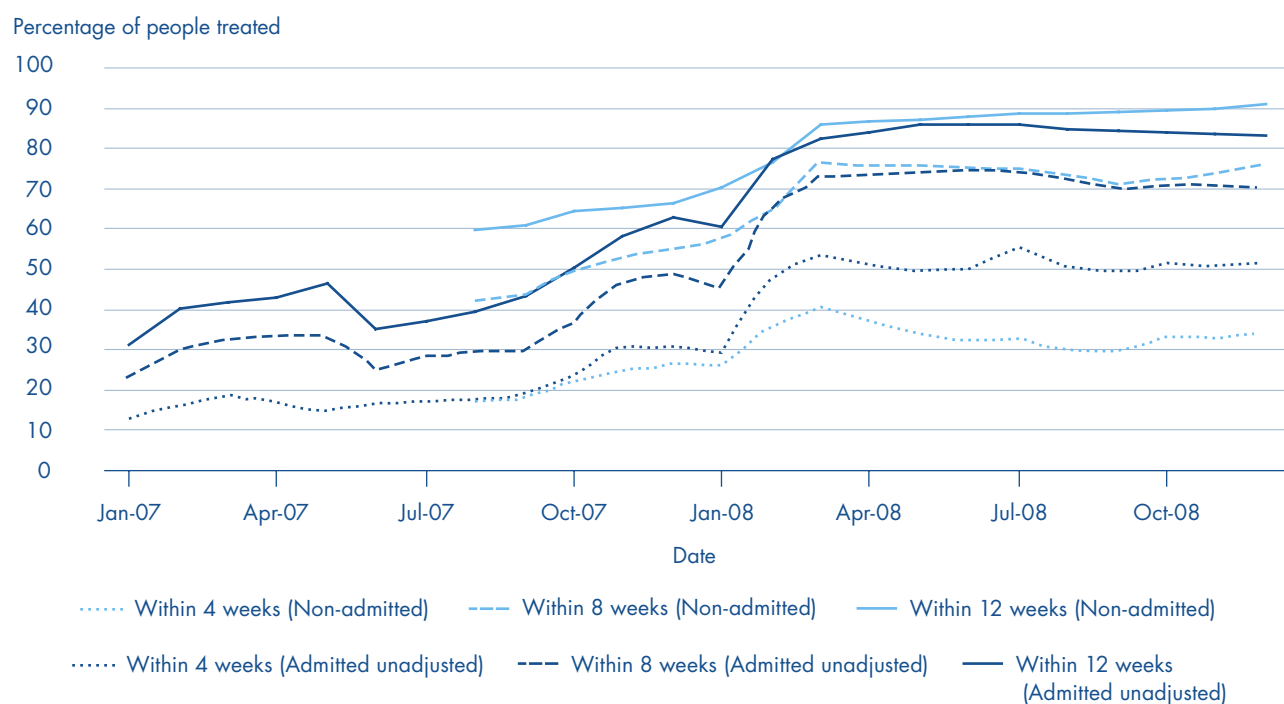


Source: Department of Health

NOTE

Data for non-admitted pathways is not available prior to August 2007.

15 Percentage of admitted and non-admitted rheumatology patients with completed pathways treated within 4, 8 and 12 weeks of GP referral

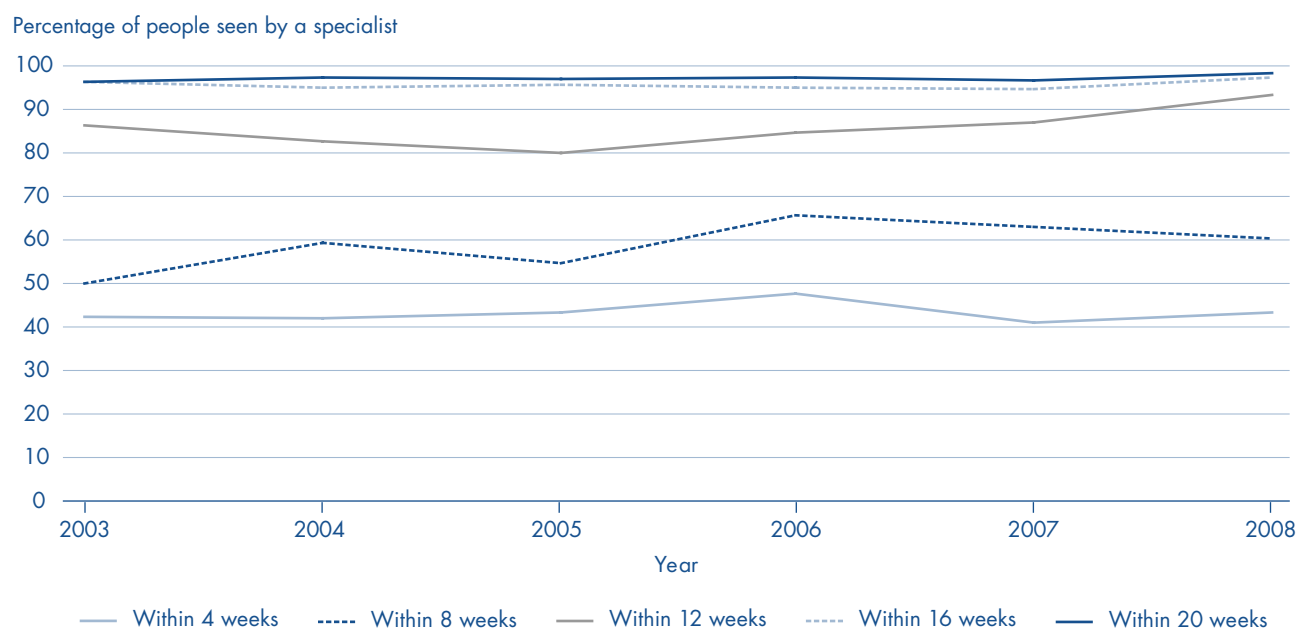


Source: Department of Health

NOTE

Data for non-admitted pathways is not available prior to August 2007.

16 Time between GP referral and first specialist visit for people with rheumatoid arthritis between 2003 and 2008



Source: National Audit Office analysis of data provided by the Early Rheumatoid Arthritis Network

NOTE

Information on the time taken from GP referral to first visit with a specialist was available for 837 people.

Increasing the number of people with rheumatoid arthritis diagnosed early and potential cost savings

2.21 We developed an economic model to examine the numbers of people with rheumatoid arthritis diagnosed within three months, and the impact a more efficient approach to referral and diagnosis would have on the number of people diagnosed early. Such an approach would provide a more effective diagnostic service by integrating GP and specialist activity, whereby GPs follow a well defined protocol for referring people with rheumatoid arthritis-like symptoms as suggested by research on Early Arthritis Clinics (currently operated by a third of acute trusts – see Figure 17). We also examined the impact this approach could have on costs to the NHS for diagnosis of rheumatoid arthritis more broadly. Full details of our economic modelling, including the assumptions used, are set out in a separate report on our website.

2.22 Our review of the evidence indicates that, on average, around 40 per cent of people with rheumatoid arthritis present to their GP within three months (10,400 people annually). Of these, 60 per cent are referred to a specialist within three months (around 6,200 people), and 40 per cent of these will be diagnosed within this period. Around 2,600 patients are currently diagnosed annually within three months of symptom onset (ten per cent of the annual incidence of the disease). Our model suggests that if the proportion of people referred to a specialist within three months were increased to 80 per cent by reconfiguring services towards an early referral and diagnosis approach, an additional 1,700 patients could be diagnosed within three months each year (an increase to 17 per cent of the annual incidence).

2.23 We estimate that the initial additional cost to secondary care of adopting an early referral and diagnosis approach, arising from a spike in GP referrals, could be in the region of £3.6 million across the two thirds of acute trusts that do not currently have an Early Arthritis Clinic. However, the adoption of this approach could result in an initial cost saving to primary care of at least £3 million through reduced GP visits and the avoidance of unnecessary diagnostic tests. We also estimate that, once a steady state is reached, this approach could generate annual savings for the NHS of around £2 million. The numbers of people identified by the NHS within three months of symptom onset could also potentially be increased through a public awareness campaign to encourage people with symptoms of early rheumatoid arthritis to present to their GP.

17 The Early Arthritis Clinic approach

We found several examples of Early Arthritis Clinics or Rapid Access and Treatment Centres. Typically, these:

- are nurse-led clinics, staffed by an experienced specialist rheumatology nurse, trained in joint assessment/disease management;
- are often supported by a registrar with access to a consultant;
- see patients within two weeks of referral;
- have sufficient administrative support to ensure patients can be directed rapidly into the clinic;
- run clinics twice a week, with appointments lasting 45 minutes to one hour;
- have rapid access to a musculoskeletal ultrasound machine and a trained radiologist or rheumatologist to assist in interpretation of results;
- promote communication and dialogue with GPs, providing clear and simple guidelines to encourage them to refer people who show symptoms of inflammatory arthritis immediately, rather than carry out their own investigations; and
- inform and educate patients and address patient anxieties (for example about home life and work life).

Source: National Audit Office

PART THREE

Treatment and care after diagnosis

3.1 One of the aims of *Supporting people with long-term conditions* is to control and minimise the effects of long-term disease. This part of the report examines whether people with rheumatoid arthritis have access to appropriate treatment and care after diagnosis.

Treatment of rheumatoid arthritis

3.2 Treatment and care for people with rheumatoid arthritis is primarily led by specialists, who are based in acute NHS hospitals. Acute trusts handled around 716,000 rheumatoid arthritis patient episodes as outpatients, inpatients or day cases in 2007-08: with the majority of these (665,000) being outpatients. Treatment and care for people with rheumatoid arthritis within hospitals has shifted from inpatient care to outpatient care and day case admissions. Of the total number of rheumatoid arthritis patient episodes in acute trusts, six times as many are day cases as are inpatients. Inpatients are just one per cent of outpatient episodes. The availability of new treatments has been a major factor in enabling trusts to reduce the need for inpatient capacity.

3.3 Depending on their specific disease presentation and progression, people with rheumatoid arthritis may be prescribed one or a combination of drugs. Because of the complexity of the disease, a number of drugs may be tried before a person responds effectively and the disease is brought under control. Use of appropriate drugs in a timely manner can delay, and in some cases prevent, the permanent and disabling joint damage which arises from rheumatoid arthritis (**Figure 18 overleaf**).

3.4 People typically have their disease monitored through visits to an outpatient clinic, often to a specialist nurse, and can have the drugs that they need administered in the clinic or on admission to a day case ward. For example, administering infliximab, one of the biologics, requires an intravenous drip which takes several hours and is usually given in a hospital day case unit. For some drugs, however, a greater level of self-management is possible with appropriate training (**Figure 19 on page 25**).

3.5 Conventional disease-modifying anti-rheumatic drugs (DMARDs) are the 'first line' treatment recommended by NICE in its February 2009 guidelines on the management of rheumatoid arthritis in adults, and clinical management guidelines across countries commonly advocate treatment with DMARDs within three months of diagnosis. Our survey of people with rheumatoid arthritis indicates that 69 per cent of people with rheumatoid arthritis had tried courses of DMARDs, with around half of these having had three or more different types. In its clinical guidelines on the treatment of rheumatoid arthritis, NICE recommends that patients who have not responded to two successive DMARDs should be offered a biologic.

3.6 Biologics can slow the destruction of joints and reduce inflammation far more quickly and successfully than conventional drugs.³³ As a result, they have radically altered the outlook for many people with rheumatoid arthritis. Our census of acute trusts indicates that budgets for biologics in acute trusts during 2007-08 ranged from £0.8 to £3.5 million. On the basis of an extrapolation of expenditure on biologics reported by respondents to our census, we estimate total spending by the NHS on biologics is around £160 million annually. Biologics for the treatment of rheumatoid arthritis now account for the highest pharmaceutical spend within some trusts. Our visits to acute trusts found that the costs of providing biologics to people with rheumatoid arthritis has focussed the attention of trust management upon this group of patients and the rheumatology units which typically coordinate their care.

18 Drugs used in treating rheumatoid arthritis

| Drug type | What they do | Common names | Approx NHS cost (£) ¹ | Access |
|--|--|---|--|--|
| Analgesics | <ul style="list-style-type: none"> ■ Painkillers ■ 'top up' the pain relieving effects of other drugs | <ul style="list-style-type: none"> ■ Paracetamol ■ Codeine | <ul style="list-style-type: none"> ■ 2 per course | <ul style="list-style-type: none"> ■ Commonly available over the counter |
| NSAID (around 20 different drugs available) <i>Administration:</i> Mostly by mouth | <ul style="list-style-type: none"> ■ Reduce pain ■ Reduce joint inflammation | <ul style="list-style-type: none"> ■ Ibuprofen ■ Diclofenac ■ COX-2 specific NSAIDs e.g. Celecoxib | <ul style="list-style-type: none"> ■ 5 per course ■ 20 per course | <ul style="list-style-type: none"> ■ Some are commonly available over the counter, others are prescribed ■ Lowest effective dose for the shortest period of time |
| Corticosteroid <i>Administration:</i> Injection into inflamed joint; Intramuscular or intravenous injection; By mouth | <ul style="list-style-type: none"> ■ Very powerful effect on reducing joint inflammation ■ Usually only for short-term usage ■ May mask other symptoms/progression of the disease | <ul style="list-style-type: none"> ■ Prednisolone ■ Prednisone | <ul style="list-style-type: none"> ■ 1 per course (24 days) ■ 5 (per injection) | <ul style="list-style-type: none"> ■ Often used to manage flare-ups ■ Can be used in combination therapy with DMARDs |
| DMARD (6 main conventional DMARDs) <i>Administration:</i> Mostly by mouth or injections | <ul style="list-style-type: none"> ■ Reduce pain ■ Reduce swelling ■ Reduce stiffness ■ Slow progression of the disease | <ul style="list-style-type: none"> ■ Methotrexate ■ Sulfasalazine ■ Hydroxychloroquine ■ Leflunomide ■ Gold injections | <ul style="list-style-type: none"> ■ Around 300 per year, per patient | <ul style="list-style-type: none"> ■ NICE recommends a combination of DMARDs as first line treatment in people with newly diagnosed active disease |
| Biologics (4 main types) <i>Administration:</i> Intravenous drip; Subcutaneous injections (can be self-injected) | <ul style="list-style-type: none"> ■ Reduce joint inflammation ■ Slow radiographic progression more dramatically than DMARDs ■ Increase functional benefit ■ Better symptom control ■ Remission occurs for a minority² | <ul style="list-style-type: none"> ■ Rituximab³ ■ Etanercept⁴ ■ Infliximab⁴ ■ Adalimumab⁴ | <ul style="list-style-type: none"> ■ Around 10,000 per year, per patient (less for rituximab) | <ul style="list-style-type: none"> ■ NICE recommends that patients who have not responded to two DMARDs should be offered a biologic |

Source: National Audit Office analysis

NOTES

1 Excluding costs of administration and monitoring.

2 Listing et al. (2006). Clinical and functional remission: even though biologics are superior to conventional DMARDs overall success rates remain low – results from RABBIT, the German biologics register, *Arthritis Res Ther.*, 8(3), R66.

3 NICE Technology appraisal published August 2007 www.nice.org.uk/TA126.

4 NICE Technology appraisal published October 2007 www.nice.org.uk/TA130.

3.7 Our census of acute trusts found that, in 2007-08, a total of 11,900 patients qualified for biologics according to the criteria set out in the technology appraisals issued by NICE, and on average 97 per cent received the drugs for which they qualified. Fourteen per cent of acute trusts stated that they were not able to provide biologics to all patients who qualified for them in accordance with criteria set by NICE: around 350 patients across all acute trusts.

3.8 Although consultants may wish to try patients on a further biologic if they have not responded to a first biologic, treatment with further biologics, other than rituximab, is not currently recommended by NICE. We found, however, that policies for the funding of additional biologics vary across PCTs (**Figure 20 overleaf**).

The benefits and cost impact of earlier treatment of rheumatoid arthritis

3.9 Our economic modelling, which is detailed in a separate report on our website, examined the extent to which, over a five year period, quicker diagnosis and early treatment would feed through to reduced lost working days and improved productivity for people with rheumatoid arthritis of working age. We also estimated the costs to the NHS.

3.10 The current median time from onset of symptoms to treatment is around nine months.^{34, 35} Currently, ten per cent of people are treated within three months of symptom onset. Our economic modelling suggests increasing this to 20 per cent (an additional 2,600 patients each year) could initially increase costs to the NHS by £11 million over five years. For those of working age, our model suggests that this earlier treatment could result in productivity gains of £31 million for the economy due to reduced sick leave and lost employment. If the treatment approach recommended by NICE were adopted, earlier treatment could become cost neutral to the NHS after around nine years.

3.11 As rheumatoid arthritis is a disease for which there is no known cure, the main objective of treatment is to improve quality of life. Our model suggests that, on average, a person treated within three months rather than nine months could see an improvement in quality of life of around four per cent over the first five years, as measured by quality adjusted life years (QALY) gained.^d

19 Example of self-management of drug administration, illustrating collaborative working across primary and secondary care

Historically, rheumatoid arthritis patients in the Salford PCT area requiring injectable methotrexate attended Salford Royal Hospital weekly for intra-muscular injections. Patients also attended a further appointment every month for monitoring. Following the licensing of methotrexate for sub-cutaneous injection, Salford PCT in collaboration with Salford Royal Foundation Trust developed a service for patients to self-administer methotrexate at home. Introduced in May 2008, the service is run by an external contractor who:

- trains patients to administer their own drugs; and
- delivers drugs directly to patients' homes.

Patients now only attend the clinic for a monthly monitoring appointment, and attend the hospital only when their dosage needs to be adjusted. The service has now been extended to cover patients living in other PCT areas. Initial patient feedback has been very positive. In January 2009, 74 patients were accessing the service, of which 51 were from Salford and 23 were from other areas. The service has generated reported cost savings for Salford PCT in 2008-09 of around £148,500, and savings of around £169,000 are forecast for 2009-10.

Source: National Audit Office census of primary care trusts

^d Quality adjusted life years (QALY) is a composite measure for both quantity and quality of life and is derived by weighting a year of life using utility values elicited from patients concerned or the general public. QALY is widely used in assessing the value for money of a medical intervention, and cost per QALY gained is the measure used by NICE.

Surgery for people with rheumatoid arthritis

3.12 For those people that do not respond effectively to any treatment and experience persistent pain due to joint damage, worsening joint function, and progressive deformity, surgery may be required. Around 11 per cent of people with rheumatoid arthritis on conventional drug therapy (i.e. not biologics) will need large or small joint surgery within five years of presentation, with the need for surgery linked to disease severity.³⁶ However, earlier and more aggressive treatment has been shown to reduce surgery rates.³⁷

3.13 Surgery will normally take place in the orthopaedic department of a hospital. In our census of acute trusts, 81 per cent of trusts reported that they offer a referral for a surgical opinion (for example, about the options for an operation to relieve pain) to all patients with rheumatoid arthritis who meet the relevant NICE criteria. For the 15 per cent 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.

3.14 Many people will have multiple surgeries due to the manner in which the disease progresses from joint to joint. Thirty one per cent of those in our survey had had surgery. **Figure 21** shows the proportion of people who had had different types of surgery.

Access to multidisciplinary treatment and management

3.15 As rheumatoid arthritis is a complex progressive condition, effective treatment and management requires access to a variety of healthcare professionals. NICE guidelines on the management of rheumatoid arthritis in adults published in February 2009 recommend that multidisciplinary care should include access to a named member of a multidisciplinary team who is responsible for coordinating care, and periodic reviews with specialist physiotherapy; specialist occupational therapy; psychological services; podiatry; and orthotics. Referrals to the different disciplines which may form the multidisciplinary team are usually made by rheumatologists or nurses in hospitals, or by GPs.

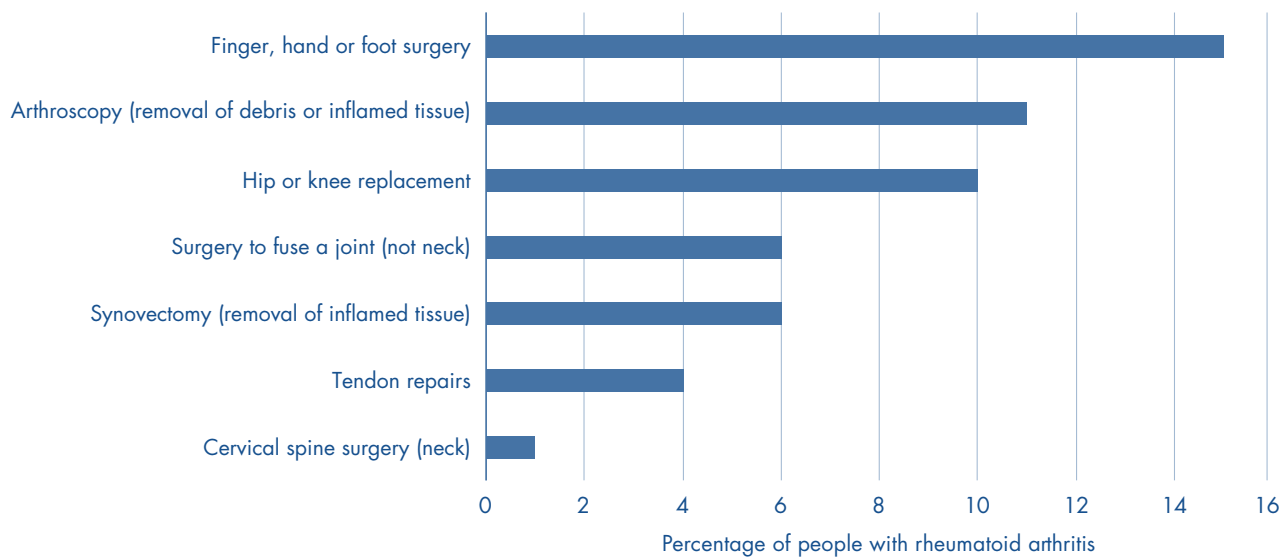
3.16 Our January 2009 census of acute trusts found that many trusts are not able to provide appointments with all members of the multidisciplinary team as now recommended by NICE (**Figure 22**). For example, just 14 per cent provide access to psychological services for all patients who need them, even though depression is common for people with rheumatoid arthritis.

20 PCT policies on access to additional biologics varies across England

| Strategic Health Authority (SHA) | Number of PCTs who fund further biologics in all cases | Number of PCTs who fund further biologics only in exceptional cases | Number of PCTs who do not fund further biologics | Number of responding PCTs in SHA area | Number of non-responding PCTs in SHA area |
|----------------------------------|--|---|--|---------------------------------------|---|
| East of England | 1 | 8 | 0 | 9 | 5 |
| South West | 2 | 8 | 1 | 11 | 3 |
| North West | 11 | 8 | 0 | 19 | 5 |
| London | 6 | 16 | 0 | 22 | 9 |
| South Central | 2 | 5 | 0 | 7 | 2 |
| West Midlands | 6 | 5 | 2 | 13 | 4 |
| East Midlands | 1 | 3 | 1 | 5 | 4 |
| North East | 3 | 3 | 0 | 6 | 6 |
| Yorkshire and the Humber | 4 | 9 | 0 | 13 | 1 |
| South East Coast | 3 | 0 | 0 | 3 | 5 |

Source: National Audit Office census of primary care trusts

21 Likelihood of different types of surgery for people with rheumatoid arthritis

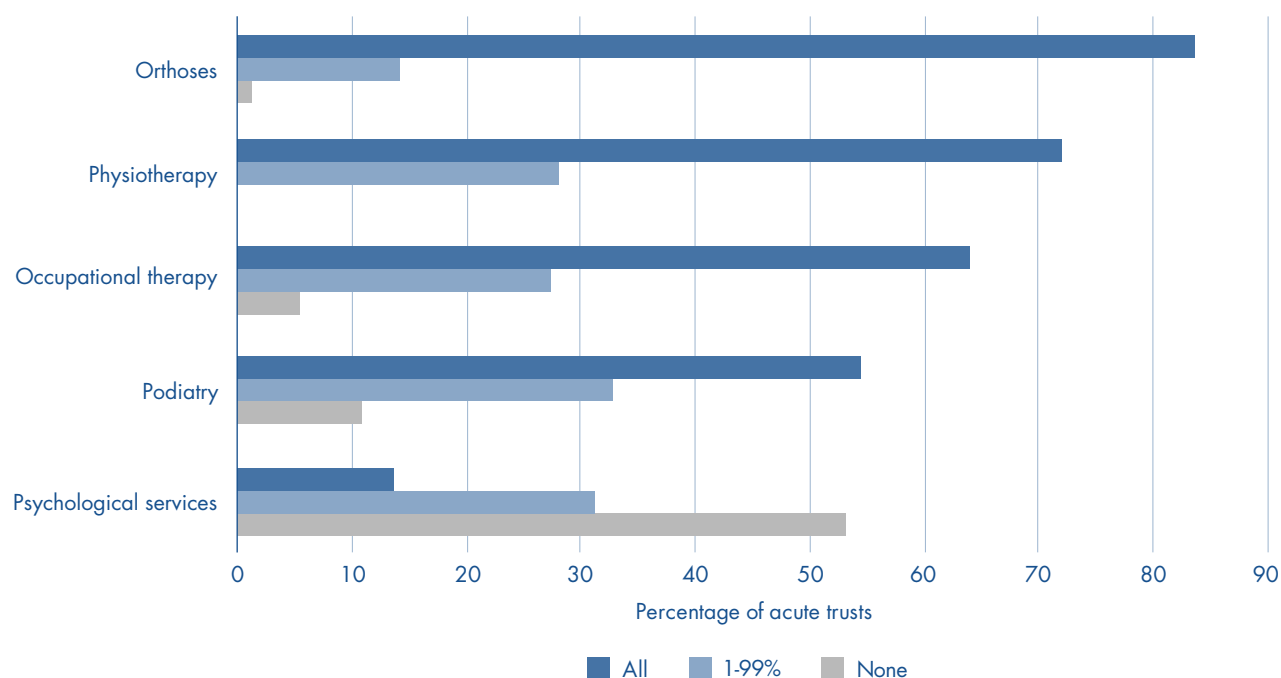


Source: National Audit Office survey of 1,400 people with rheumatoid arthritis

NOTES

- 1 Two thirds of those in our survey who have had surgery were diagnosed more than ten years ago.
- 2 Some people had had multiple operations of the same kind, or in more than one of the categories listed above.

22 Access to multidisciplinary care for people with rheumatoid arthritis reported by acute trusts



Source: National Audit Office census of 147/154 (95 per cent) acute trusts

3.17 NICE is scheduled to publish guidance on managing depression in people who have a long-term condition, including rheumatoid arthritis, by the end of 2009. The Department also told us that the Improving Access to Psychological Therapy programme, which is currently being rolled out, will provide access to psychological services. The service can be accessed by a referral from a GP, or through self-referral.

3.18 Some trusts face barriers which prevent the effective working of the multidisciplinary team. The main themes that emerged from acute trusts were a lack of capacity in the relevant service, coupled with waiting lists to access services. Other key barriers included a lack of specialist knowledge about rheumatoid arthritis amongst the multidisciplinary team, and a lack of links between rheumatology and other departments.

3.19 Specialist nurses play a central role in coordinating the multidisciplinary team. We found that specialist nurses are highly valued by people with rheumatoid arthritis for their understanding of the condition and the care they provide. However, a shortage of specialist nurses was a common barrier to providing access to the multidisciplinary team. During our visits to trusts, we found examples of NHS bodies which have reconfigured their services to provide better multidisciplinary care to people with rheumatoid arthritis (**Figure 23**).

23 Case study examples of multidisciplinary care

The Pennine Musculoskeletal Partnership is an Integrated Clinical Assessment and Treatment Service (ICATS) launched in March 2006, providing on-site access to: rheumatologists, orthopaedic and physiotherapist consultants, four GPs with special interests, nurse specialists, clinical specialist physiotherapists and podiatrists, and an occupational therapist. It provides individualised, multidisciplinary care across the acute trust, mental health trust and social services. Close cooperation of GP commissioners and the Partnership has resulted in effective local practice-based commissioning, with clinicians designing and delivering the service, and a coherent patient journey with shorter waiting times.

The Norfolk and Norwich University Hospitals Foundation Trust runs services for 6,100 people with rheumatoid arthritis from its central hospital and from local GP settings. It identified the importance of co-location at its hospital site to encourage joint working and strong links between rheumatology, orthopaedics, physiotherapy, radiology and occupational therapy departments. This approach to multidisciplinary care has been in place for 20 years. Specialist nurses coordinate integrated care between hospital departments and GPs in the community. Nurse practitioners facilitate GPs working closely with secondary care by running clinics in primary care surgeries, and answering further GP queries on a telephone helpline.

The Chapel Allerton Teaching Hospital, Leeds is a dedicated centre for the diagnosis, management and treatment of adults with upper and lower limb complaints. It has a full multidisciplinary team coordinated by specialist nurses, and further links to local services such as counselling. The service also has comprehensive diagnostic facilities on-site, including fixed and portable ultrasound, MRI, and a gait analysis for foot assessment of early arthritis patients. The service provides diagnosis and appropriate therapy at the earliest opportunity.

The Royal Cornwall Hospitals Trust empowers patients to become active in accessing multidisciplinary care through patient education, so that care is focussed on the individual's needs and concerns. Individuals understand the role of each member of the multidisciplinary team, how to contact them for help, and how to gain the most benefit from their expertise. The Trust also employs a pharmacist with special interest in rheumatology who can carry out consultations and issue prescriptions, enabling faster service times for patients.

Source: Interviews conducted by the National Audit Office

PART FOUR

Living well with rheumatoid arthritis

4.1 The Department's strategy for long-term conditions aims to personalise services for people living with a long-term condition. This Part of the report considers the effectiveness of ongoing care, and how well PCTs are placed to improve rheumatoid arthritis services going forwards.

Monitoring of people with rheumatoid arthritis

4.2 The progressive and unpredictable nature of rheumatoid arthritis means that, once an individual has been diagnosed with the disease, periodic reviews are required so that treatment can be modified as appropriate. The important factor in monitoring people with rheumatoid arthritis is the skill which medical staff possess and their ability to treat rheumatoid arthritis effectively, rather than the location of personnel providing treatment.

4.3 Guidelines for the treatment of rheumatoid arthritis in adults issued by NICE in February 2009 recommend that in people with recent onset active rheumatoid arthritis, disease activity should be reviewed monthly until treatment has controlled the disease, whilst people with satisfactorily controlled established rheumatoid arthritis should be offered review appointments at a frequency and location suitable to their needs. NICE also recommends that all people with rheumatoid arthritis should be offered an annual review to:

- assess disease activity and measure functional ability;
- check for the development of co-morbidities;
- assess symptoms that suggest complications;
- organise appropriate cross-referral within the multidisciplinary team;
- assess the need for referral for surgery; and
- assess the effect the disease is having on a person's life.

4.4 In our January 2009 census of acute trusts, 15 per cent of trusts reported that they were offering monthly review appointments for all people with active rheumatoid arthritis in 2007-08. The average frequency of review for patients with active rheumatoid arthritis across all trusts was once every three months. Trusts reported that the main barriers to offering monthly reviews were a lack of outpatient capacity/limited clinical space (57 per cent), an emphasis on new patients rather than follow-ups (34 per cent), and limited medical and nursing provision (28 per cent).

4.5 Sixty three per cent of acute trusts reported that they were offering an annual review appointment meeting NICE guidelines to all patients with rheumatoid arthritis. Trusts reported that the main barriers to offering annual reviews were a lack of specialist nurses (18 per cent), a lack of outpatient time slots (16 per cent), and a lack of outpatient capacity/limited clinical space (12 per cent).

4.6 Sixty six per cent of trusts also stated that they are not able to provide follow-up services to all people with rheumatoid arthritis who need them. The Department considers that gaps in access to follow-up services are an issue of capacity and demand management, and that if more capacity is required trusts can take steps to address this, including acute trusts looking to develop new models of service delivery and PCTs commissioning more activity to meet demand.

4.7 Some acute trusts also reported that both the 18 week standard and Choose and Book have had a negative impact on access to follow-up services for people with rheumatoid arthritis. Half of trusts stated that the 18 week standard had resulted in a reduced emphasis on follow-up patients with rheumatoid arthritis. Twenty seven per cent of trusts stated that the introduction of the standard had reduced flexibility for rheumatology professionals to prioritise the patients that they ought to see according to clinical need. The trusts we visited also considered that this reduced flexibility for rheumatologists to prioritise their caseload was compounded by the operation of the Choose and Book system.

Self-management of rheumatoid arthritis

4.8 Educating people with rheumatoid arthritis to practice self-management is important to allow them to take control of their condition in order to help manage symptoms such as pain, fatigue and anxiety. The Department has put in place general initiatives to aid patients' long-term self-management, such as the Expert Patient Programme, although there has not yet been any formal evaluation of the benefits of these initiatives. Information on rheumatoid arthritis is also available electronically. For example, through the NHS Choices website or NHS Information Prescriptions. **Figure 24** shows the extent to which people with rheumatoid arthritis considered they had sufficient information to manage their disease.

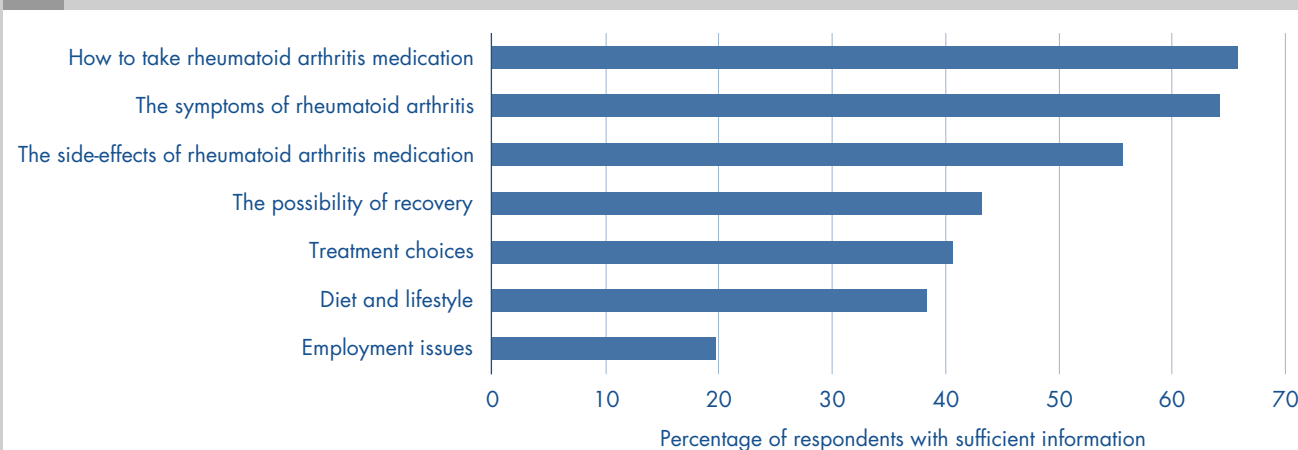
4.9 NICE guidelines on the management of rheumatoid arthritis in adults recommend that people with rheumatoid arthritis have access to additional visits for disease flare-ups, and know when and how to get rapid access to specialist care. Our visits to acute trusts suggested that the emphasis on getting 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. Where rheumatology services lack capacity, the Department considers it is the role of acute trusts and PCTs to review their referral pathways and models of service provision before determining whether additional capacity is required to meet demand.

4.10 The inconsistency in services for people having a flare-up of their rheumatoid arthritis undermines people's capacity for self-management. Our survey of people with rheumatoid arthritis found that they take a range of approaches to dealing with flare-ups. These included self-medicating, resting until they improved, and accessing NHS services (for example, contacting their GP or a helpline staffed by a specialist nurse). When asked what interventions would make a real difference to improving self-management of their condition, 59 per cent of people with rheumatoid arthritis strongly agreed that having a named person they could turn to when they had a flare-up would help them to self-manage their disease better.

4.11 Almost half of GPs in our survey considered that the NHS is not effective at providing patients with information about self-management. However, 95 per cent of acute trusts responding to our census reported that they provide verbal or written information to patients about long-term management, including self-management of their condition, which suggests a lack of coordination in the way that advice about self-management is provided. Our visits to ten acute trusts highlighted ways in which acute trusts are trying to support self-management (**Figure 25**). Only a minority of PCTs (29 per cent), however, commission services covering self-management for people with rheumatoid arthritis.

4.12 Lord Darzi's *High Quality Care for All - NHS Next Stage Review Final Report* recognised the need for everyone with a long-term condition to be offered a personalised care plan, agreed by the patient and a named professional, which will provide a basis for the NHS to organise services around the needs of individuals. Half of acute trusts reported that they provide a care plan for all patients with rheumatoid arthritis, although 30 per cent do not provide a care plan for any patients with the disease.

24 Availability of information for people with rheumatoid arthritis



Source: National Audit Office survey of 1,400 people with rheumatoid arthritis

Understanding of rheumatoid arthritis by employers and support provided on employment

4.13 An employed person with rheumatoid arthritis has on average 40 days sick leave per year,³⁸ and reduced productivity at work.³⁹ Comparisons of productivity loss for people with rheumatoid arthritis in employment indicate that, on average, those who respond to treatment have up to 24 fewer sick days per year than those who do not.⁴⁰

4.14 Data held by the Department for Work and Pensions in respect of claims made for incapacity benefit and severe disablement allowance indicate that at February 2007 there were 26,470 claimants whose medical condition was recorded as 'other rheumatoid arthritis'. Information on the disabling condition is also collected for claimants of disability living allowance, but is not separately recorded for rheumatoid arthritis.⁴¹

4.15 Dame Carol Black's March 2008 review of the health of Britain's working age population, *Working for a healthier tomorrow*, recognised the risks to long-term health if people are not supported early to address issues that could stop them from working. The November 2008 Government response committed the NHS to improving access to key services which can help people with musculoskeletal conditions manage their return to work.⁴²

4.16 Twenty three per cent of those in our survey of people with rheumatoid arthritis were either medically retired or unemployed because of their disease. For those in work, 91 per cent of people stated that their employer knew about their rheumatoid arthritis. Two thirds of these said their employer was understanding, whilst one quarter felt that their employer was not. Most respondents' employers were willing to listen to the rheumatoid arthritis-related problems of their employees and to give them time off work to attend appointments, but were much less likely to switch work tasks to reflect physical needs, or to provide retraining to enable people with the disease to take on new tasks more suitable for them.

4.17 In acute trusts, Allied Health Professionals, such as occupational therapists and physiotherapists, typically provide support to help people with fitness for work as part of treatment. Even though studies have highlighted the importance of occupational therapy, promoting self-management techniques and attitudes of employers and colleagues as important in maintaining the contribution of people with rheumatoid arthritis in the workplace, our evidence indicates that support from the NHS for people with rheumatoid arthritis to remain in work could be significantly improved.

25 Examples of improved self-management and education

The **Queen Alexandra Hospital, Portsmouth** is part of a trust that sees 5,000 people with rheumatoid arthritis solely in acute settings and provides information about self-management during hospital consultations. It recognises that some of the most popular sources of information about self-management are through support groups and works closely with the local Arthritis Care Group to offer self-management programmes. The hospital currently runs its own pain management programme and intends to implement the dedicated self-management programme being developed by the National Rheumatoid Arthritis Society and the Expert Patient Programme.

About a third of people seen in the rheumatology department of **Sandwell and West Birmingham Hospitals NHS Trust** are of South Asian origin, around half of whom find it difficult to communicate in English. Nursing staff run a helpline specifically for Urdu, Punjabi and Hindi speakers and provide written information on self-management in these languages. A South Asian patient

group has been set up and meets with the rheumatology department to discuss the specific needs of its community, and nurses and rheumatologists currently speak at the local temples and other community venues about rheumatoid arthritis to help improve knowledge and awareness of self-management.

Self-management care designed around patient needs:

- **St. Peter's Hospital, Chertsey** tailors patient pathways and educational programmes to individuals. Those finding it difficult to cope with or adjust to living with rheumatoid arthritis can be provided with extra one-on-one sessions with a consultant nurse, providing care tailored to their needs.
- **King's College Hospital, London** consults people with rheumatoid arthritis, using the results to mould services around patient preference and need. As a result, medical staff and therapists now run a series of sessions and information groups about rheumatoid arthritis.

Source: Interviews conducted by the National Audit Office

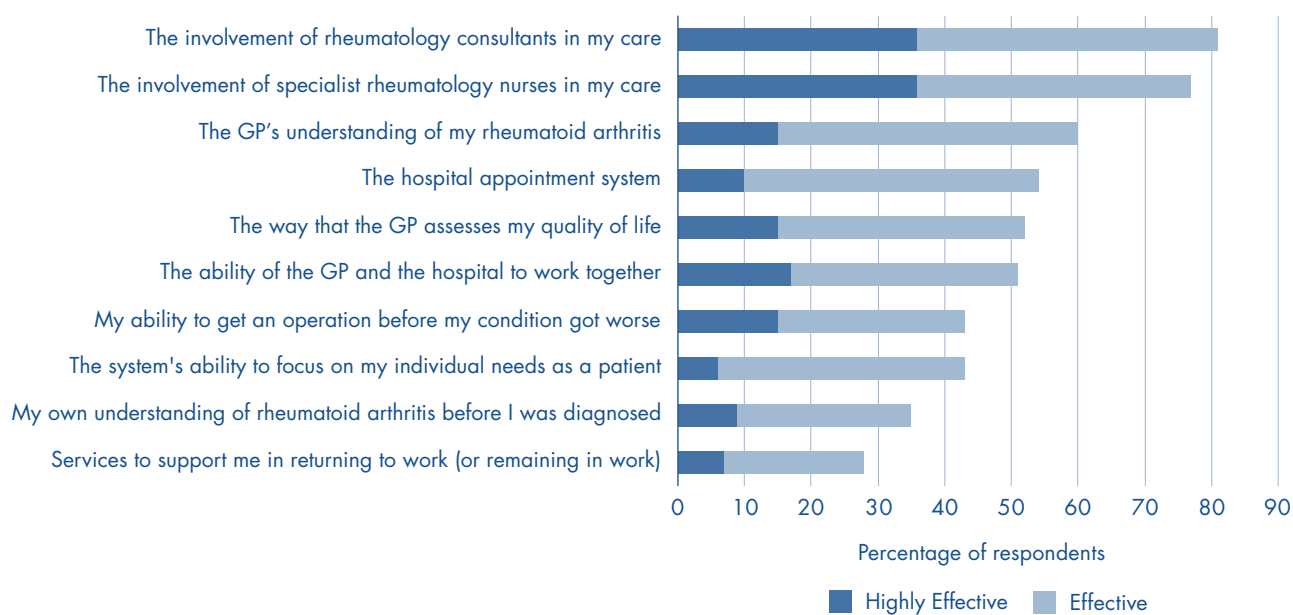
4.18 Newly diagnosed patients do not always receive information or advice about maintaining fitness for work. Only 12 per cent of GPs we surveyed stated that they give patients newly diagnosed with rheumatoid arthritis information about continuing in employment. Eighty nine per cent of acute trusts reported that they provide verbal or written information on continuing in employment to people with rheumatoid arthritis. Only 20 per cent of respondents to our survey of people with the disease, however, considered that they received sufficient information about employment issues. Respondents rated services to support them to remain in work as the least effective services compared with other aspects of their care (**Figure 26**).

4.19 Links between the NHS and back to work service providers (including the Department for Work and Pensions) lack coherence and in many cases depend on personal contacts. Only 56 per cent of acute trusts were

aware of Department for Work and Pensions schemes to help people back into work, such as Pathways to Work and Access to Work, and two thirds of these provided information about these schemes to people with rheumatoid arthritis. The number of people with musculoskeletal conditions who have participated in the NHS Condition Management Programme is low. In 2008-09, the number of referrals from Jobcentre Plus to the NHS Condition Management Programme was 31,055, of which around a quarter were people with musculoskeletal conditions.

4.20 With the right support arrangements in place between GPs, specialists, and individuals, employers can play a key role in enabling people with rheumatoid arthritis to continue to make a contribution in their working lives. During our fieldwork we found examples of employers taking proactive approaches to addressing musculoskeletal conditions amongst their workforce (**Figure 27**).

26 How people with rheumatoid arthritis perceive the effectiveness of different aspects of their patient journey



Source: National Audit Office survey of 1,400 people with rheumatoid arthritis

27 Case study examples of employers

British Telecommunications plc has three main strands to its service for people with long-term musculoskeletal conditions:

- Employees are encouraged to define their own needs for working effectively and, if specialist assessment is required, the occupational health service provides advice focussing on capability for work rather than solely on health.
- Line managers make or facilitate arrangements for modifying work, including adjustments such as keyboard adaptations or help with mobility. E-enable is a support service providing practical solutions on how to overcome day-to-day issues presented by the condition.
- People experiencing more acute problems, such as flare-ups or ongoing disabilities, can self-refer to BT's rehabilitation service. This is a physiotherapy-based service which focusses on helping employees regain as much functional capacity as possible, usually through regular restorative sessions.

GlaxoSmithKline (GSK)'s mission statement is 'help people do more, feel better, live longer' and this drives its occupational health strategy. GSK offers a structured return to work approach for people with long-term conditions, including phased return, workplace assessments, and provision of additional equipment. Employees may also be referred to physiotherapy and counselling. For long-term conditions such as rheumatoid arthritis, an employee can refer themselves to Cigna, GSK's private medical insurance company, to assist with management of the condition. Employees also have access to psychological therapies. For long-term conditions, including rheumatoid arthritis, cognitive behavioural therapy with a focus on chronic pain management may be offered. GSK uses the biopsychosocial model to formulate its occupational health strategy and run programmes for employees encouraging them to look holistically at their lives.

The Royal Mail Group has based its functional restoration programme for chronic musculoskeletal conditions on a biopsychosocial approach. Employees with musculoskeletal disorders and repeated absences, long-term sick leave or long-term modified duties, are referred to Occupational Health, and to RehabWorks, the Royal Mail's service provider for delivery of the programme. Entry to the programme is voluntary. Participants agree their specific goals for the programme during an initial assessment of their clinical, functional and psychosocial condition. The assessment comprises:

- an interview looking at the biological history of the injury, causal beliefs, coping strategies, social support, issues of stress and work, hopes and expectations; and
- a clinical evaluation and functional assessment of risk factors for ongoing musculoskeletal problems, and an evaluation comparing current function to the demands of the job.

If appropriate, people attend sessions at RehabWorks specialist rehabilitation centres at Royal Mail sites. Group sessions, usually over 6-12 weeks, encourage participants to share their experiences. Participants have specific, tailored, exercise plans for their injury covering both work and personal goals. 'Work hardening' is an important component to the plan allowing practice of work activities in a controlled environment and development of tolerance to these activities. Education sessions using cognitive behavioural therapy principles help participants understand their injury and how they can begin to self-manage. They also help participants examine fear avoidance attitudes, regain control of their pain, reduce the impact of injury on their lives and develop stress management strategies. When appropriate, return to duties plans are developed, providing a key tool for managers to help manage an employee's return to work.

By the end of 2008, a total of 1,606 people had been referred to the scheme across four Royal Mail sites. Of the 968 who completed the programme, 80 per cent returned to full duties, with improvements in health behaviour and work status sustained for at least two years. The programme has delivered a return on investment and participants report personal and social benefits, with 79 per cent reporting a score of at least 7/10 in terms of full recovery (0= no better, 10= fully recovered).

Source: Interviews conducted by the National Audit Office

4.21 Eighteen per cent of acute trusts' rheumatology services have arrangements for liaising with patients' employers. Trusts are often involved in the signposting of support to those with rheumatoid arthritis who are in work. Of those trusts we visited, some refer to external employment advisory bodies, whilst others work with other hospital staff specialising in employment and work-related matters (**Figure 28**).

Commissioning services for people with rheumatoid arthritis

4.22 Our census of PCTs found that they lack epidemiological evidence to commission services for people with rheumatoid arthritis effectively. Seventy one per cent had not carried out a local needs assessment for rheumatology services overall (**Figure 29**) and 73 per cent had not undertaken any assessment to establish the number of people with rheumatoid arthritis living in their area.

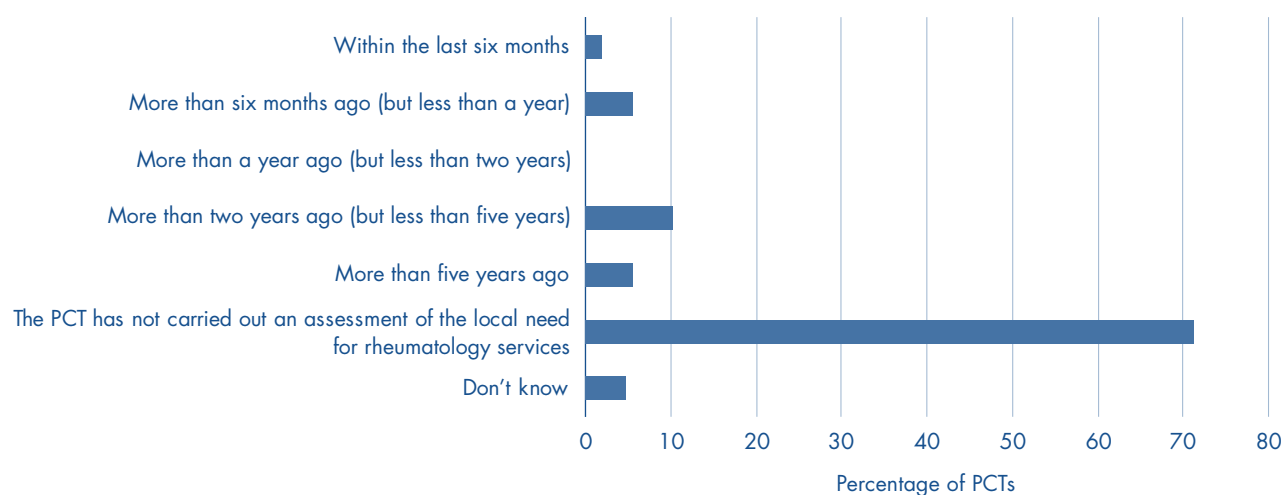
28 Case study examples of trusts which provide services to people with rheumatoid arthritis concerning employment

Ability to continue in work is discussed during assessments at the **Norfolk and Norwich University Hospital**. The 207 people newly diagnosed with rheumatoid arthritis in 2007-08 were offered appointments in the early arthritis clinic, which combines occupational therapy and physiotherapy services. It signposts and provides information to individuals about local services available to support them to remain in or return to work. Patients return to the hospital for clinical assessment and consultation concerning work and well-being and, with the help of the consultant, agree a list of priorities to help them stay in work. In addition to physical and occupational therapies, people can be referred to psychological therapies and counselling to ensure a holistic approach is taken towards their well-being. The hospital can refer directly to the Disability Employment Advisory Service, and together they run a clinic once a month for people with rheumatoid arthritis.

The Derbyshire Royal Infirmary, one of the seven rheumatoid arthritis clinics in community hospitals run by the Derby Hospitals Trust, conducts work assessments as part of a wider programme aimed at improving general mobility for the 3,400 people with rheumatoid arthritis currently seen by the trust. Occupational therapists work with colleagues specialising in work assessments at the individual's place of work. As part of its Condition Management Programme, the Derbyshire Royal Infirmary offers cognitive behavioural therapy, providing a service focussed on well-being to help people with rheumatoid arthritis manage the psychological and motivational aspects of remaining in, or returning to, work.

Source: Interviews conducted by the National Audit Office

29 Timing of PCTs' latest assessment of need for rheumatology services



Source: National Audit Office census of 111/152 (73 per cent) primary care trust

4.23 Those PCTs that had sought to establish the number of people with rheumatoid arthritis in their area used a variety of methods to do so. These included applying national incidence and prevalence figures to their local population; analysing the usage of drugs used to treat rheumatoid arthritis; and analysing hospital or GP practice activity data. However, only 11 per cent of PCTs had compared the number of people with rheumatoid arthritis in their area with the number of cases expected on the basis of national incidence and prevalence figures, so the majority of PCTs do not know if they are effectively identifying people with the disease.

4.24 The Department's strategy for long-term conditions, the *Musculoskeletal Services Framework* and the White Paper, *Our health, our care, our say* set out plans for more care to be delivered in the community. Twelve per cent of PCTs reported that rheumatoid arthritis is a condition which they manage primarily in a primary care setting, whilst 17 per cent manage it primarily in an acute setting. The remaining 71 per cent of PCTs reported that although their current services for rheumatoid arthritis are primarily acute based, they are seeking to develop more services in primary care. However, just a quarter of these had analysed the costs and benefits of doing so.

4.25 Although the majority of care for people with rheumatoid arthritis is based in acute hospitals, one third of PCTs do currently provide some services for people with rheumatoid arthritis to support them in the community. In the majority of cases these services are shared care protocols for the administration of DMARDs in the community, but a range of other services have been developed by some PCTs (**Figure 30**).

4.26 The World Class Commissioning Framework envisages that people will have choice and control over the services they use, and that PCTs will work with others to improve the effectiveness of the care they deliver. We asked PCTs to rate their effectiveness in involving a range of stakeholders in the design of rheumatology services (**Figure 31 overleaf**).

4.27 We also asked PCTs to rate the effectiveness of their joint working with a range of stakeholders in the delivery of ongoing care for people with rheumatoid arthritis. PCTs most commonly rated themselves as being effective in working with rheumatology units and GPs, and not effective in working with employment advisers and Department for Work and Pensions Pathways to Work pilot schemes (**Figure 32 overleaf**).

30 Examples of community-based services commissioned by PCTs for people with rheumatoid arthritis

Cumbria PCT – Each patient diagnosed with rheumatoid arthritis has an occupational therapy assessment to ensure their needs are addressed for living with their condition. Individuals also have access to self-management information and a patient helpline.

Tameside and Glossop PCT commissions a consultant-led rheumatology service in primary care.

North Staffordshire PCT has transferred rheumatology services from secondary care to a community hospital setting. The PCT has also commissioned a community pain management service for musculoskeletal patients.

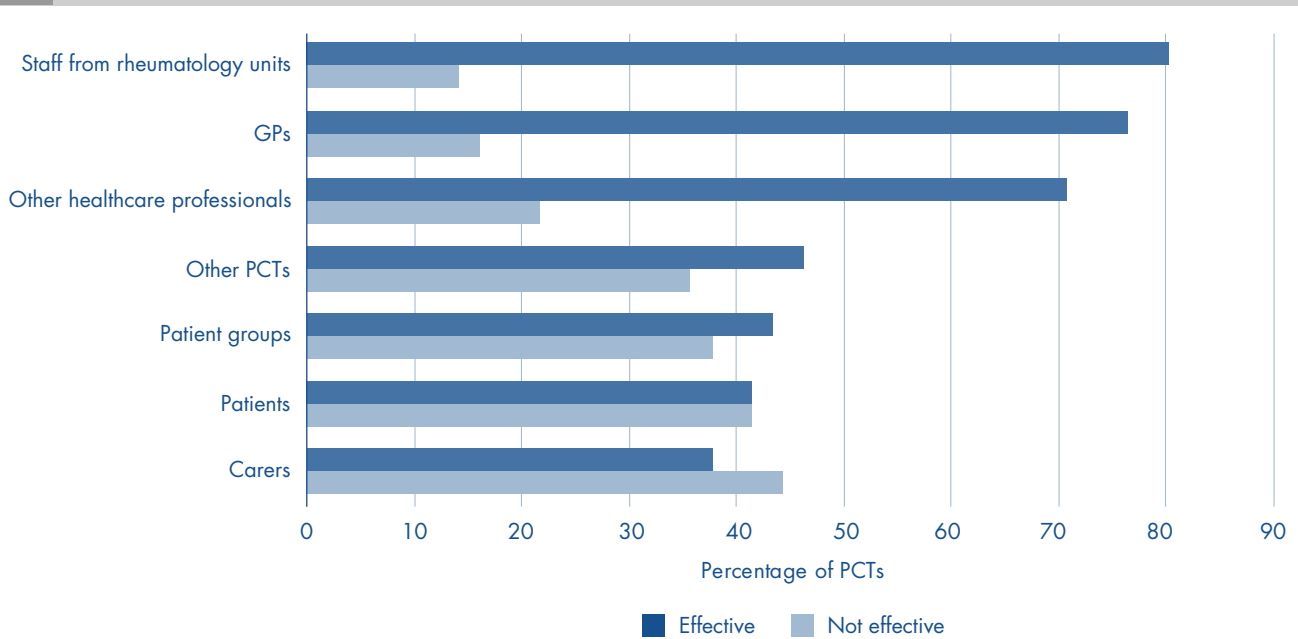
Westminster PCT employs a clinical specialist physiotherapist who specialises in treating rheumatoid arthritis hands and runs community clinics.

North Yorkshire and York PCT – Whitby Community Hospital runs a monthly rheumatology clinic with a local GP, a nurse, and a doctor from James Cook Hospital. It also runs a second clinic with a nurse, a rheumatology physiotherapist, an occupational therapist, and a podiatrist.

East and North Hertfordshire PCT and West Hertfordshire PCT – People with rheumatoid arthritis have pathways into podiatry and pain management services.

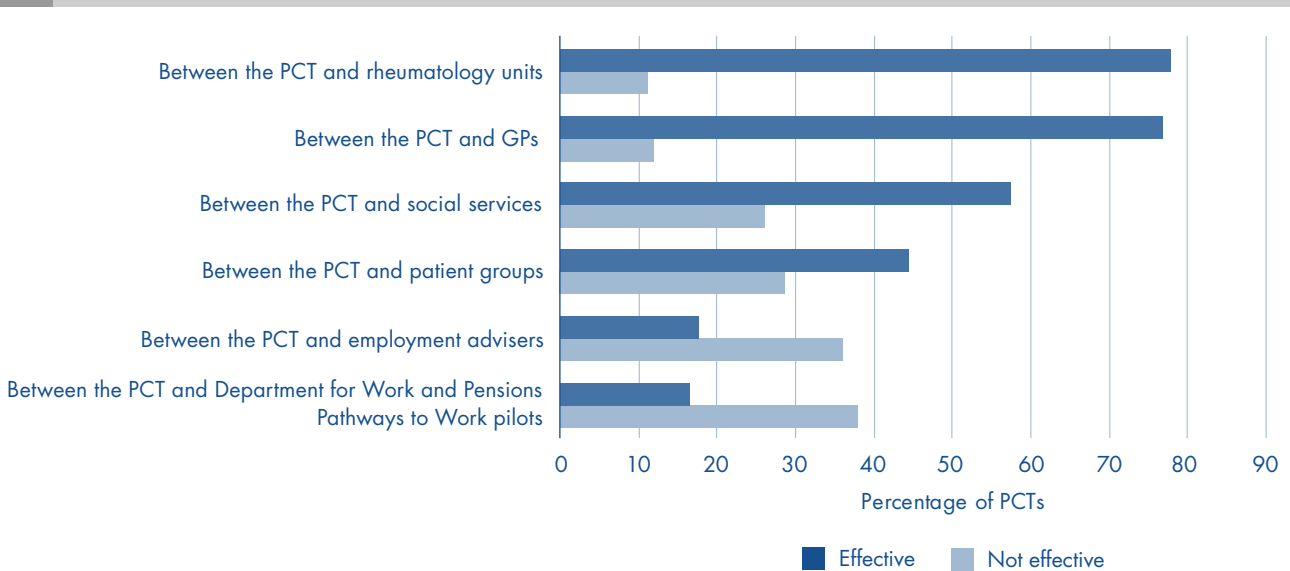
Source: National Audit Office census of primary care trusts

31 PCTs' rating of their effectiveness in involving a range of stakeholders in the planning and design of rheumatology services



Source: National Audit Office census of 111/152 (73 per cent) primary care trusts

32 PCTs' rating of the effectiveness of their joint working with a range of stakeholders in the delivery of ongoing care for people with rheumatoid arthritis



Source: National Audit Office census of 111/152 (73 per cent) primary care trusts

ENDNOTES

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