



National Audit Office

Services for people with rheumatoid arthritis

LONDON: The Stationery Office
£14.35

Ordered by the
House of Commons
to be printed on 13 July 2009

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.

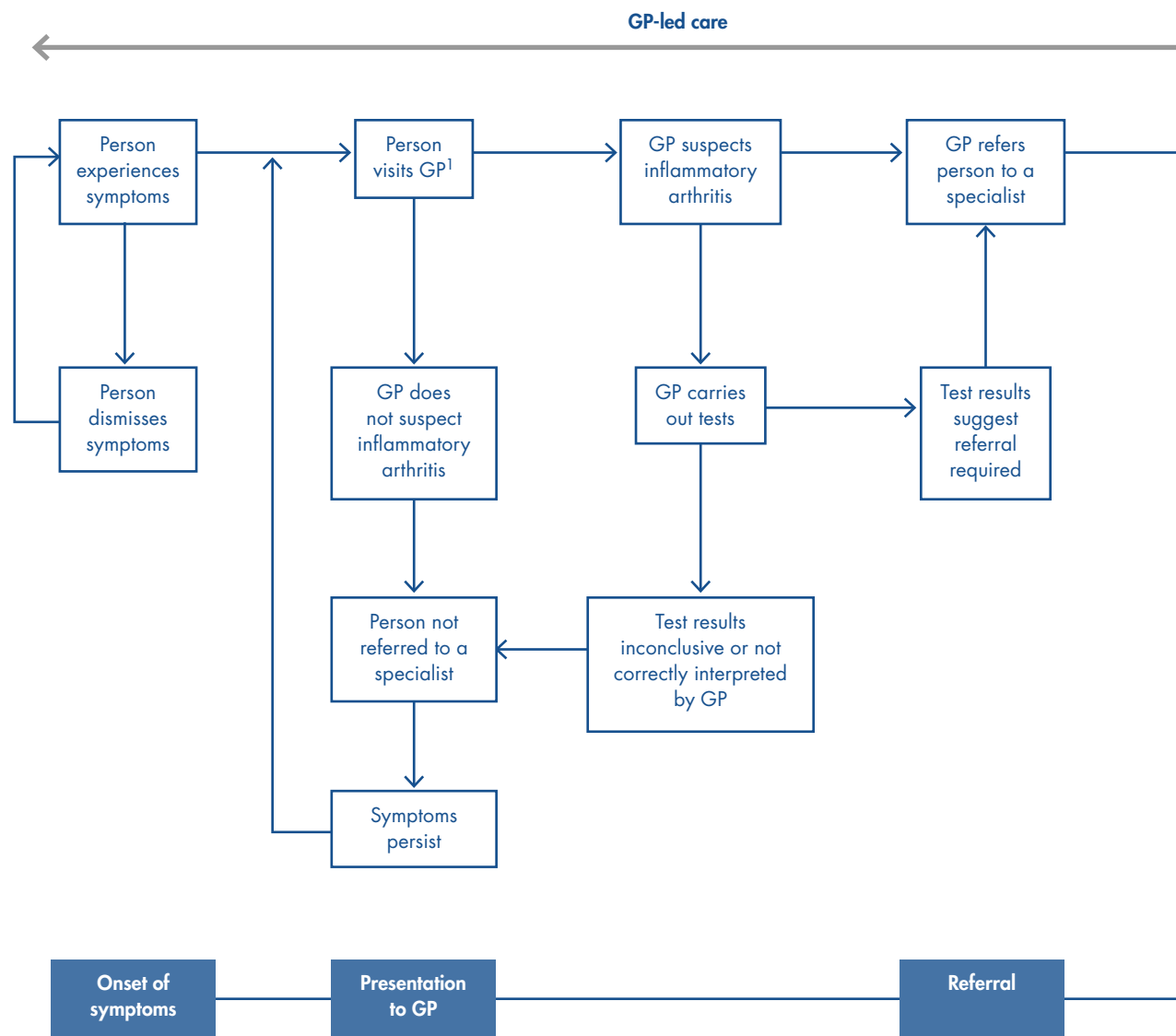
Overall findings

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.

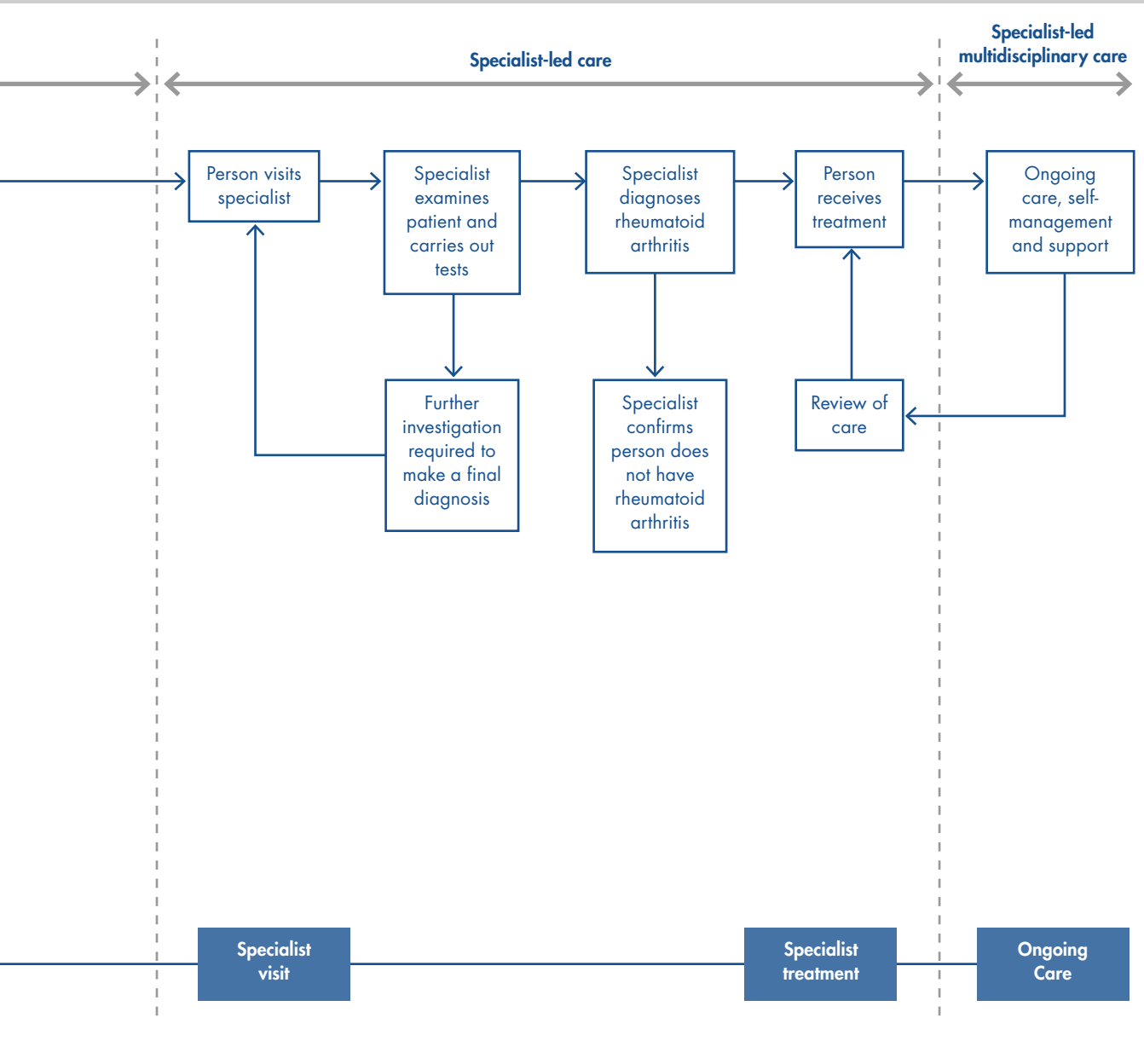
2 The typical diagnosis and treatment pathway for people with rheumatoid arthritis



Source: National Audit Office

NOTE

1 People may also first present to a practice nurse.



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.