



National Audit Office

Services for people with rheumatoid arthritis

METHODOLOGY

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The evidence used in this report was collected between October 2008 and February 2009. Our examination was scoped to cover the services for people with rheumatoid arthritis, with a focus on adults of working age. The main aspects to our fieldwork were (where marked *, separate reports are available on our website at www.nao.org.uk/publications):

- **Two censuses of NHS trusts** carried out by the NAO. The questionnaires were developed in consultation with the Health and Social Care Information Centre Review of Central Returns (ROCR) Committee, which considered them to be useful and reasonable, in terms of the burden on NHS trusts (references ROCR-Lite 08/026 and ROCR-Lite 08/836). The Department of Health also reviewed the questionnaires. Questionnaires were piloted before despatch with rheumatology units in NHS trusts and PCTs respectively. The two censuses were:
 - **Census of 154 acute trusts providing services to people with rheumatoid arthritis***. 147 responses to the questionnaire were received (a 95 per cent response). In some cases, we used results from this census to extrapolate data to provide an estimated figure for acute trusts as a whole, in particular on questions about costs. We have produced individual feedback reports for each trust to enable them to assess their data against other trusts in the census population, and a summary of the results from the census is on our website.
 - **Census of 152 primary care trusts commissioning services for people with rheumatoid arthritis**. 108 responses to the questionnaire were received, covering 111 PCTs (a 73 per cent response rate).
- **A survey of people with rheumatoid arthritis***. Our findings about the experience of people with rheumatoid arthritis who use NHS and other services were informed by two pieces of work. These examined experience of diagnosis; treatment and care immediately after diagnosis; longer term care; and employment. On our behalf, PatientView carried out:
 - *A survey of patient groups with an interest in rheumatoid arthritis*. During October and November 2008 an online and postal survey was conducted covering 30 patient groups in England with an interest in rheumatoid arthritis. In total, these groups have over 10,000 members. Through a series of open-ended questions, the respondent groups were asked about their experience of NHS services for people with rheumatoid arthritis. The results from this questionnaire were used to inform the drafting of a second questionnaire, a survey of people with rheumatoid arthritis.
 - *A survey of people with rheumatoid arthritis*. Between November 2008 and January 2009 a (primarily) online survey was conducted of people with a confirmed diagnosis of rheumatoid arthritis (or carers responding on their behalf). Respondents were recruited with the support of relevant patient groups – notably Arthritis Care, the National Rheumatoid Arthritis Society, and numerous local groups with an interest in rheumatoid arthritis. A total of 1,400 responses were received.

- **A survey of GPs***. The survey covered GPs in England and was conducted during December 2008 and January 2009. It was carried out on behalf of the NAO by Medix. It examined training, knowledge, and ability of GPs to identify symptoms of rheumatoid arthritis; the activities of GPs in relation to rheumatoid arthritis; and the extent to which GPs were involved in long-term care and management. A total of 481 responses were received.
- **Visits and semi-structured interviews** with staff in ten NHS trusts' rheumatology units and associated services to gain a more in-depth understanding of services for people with rheumatoid arthritis and to identify good practice case examples of service provision. In NHS trusts, we typically interviewed rheumatology consultants, other specialist doctors, and specialist nurses. We also interviewed other associated professionals, such as occupational therapists, physiotherapists, and surgeons (orthopaedics).
- We also **commissioned analyses** of:
 - The General Practice Research Database (GPRD) to identify incidence, prevalence, referral rates and prescribing rates stratified by age, gender, and PCT, over the past 10 years, based on an analysis of 23,500 people in England with a diagnosis of rheumatoid arthritis on the GPRD.
 - The Hospital Episode Statistics database to examine, over time, the source and frequency of referrals in respect of rheumatoid arthritis, timeliness of consultations, nature of treatment and/or surgery, frequency of visits and costs of episodes.
 - The Norfolk Arthritis Register (with data between 1990 and 2005) to examine the characteristics of 2,037 people with rheumatoid arthritis, their behaviour (such as time between onset of symptoms and GP presentation) and progression of their disease over time. We also used NOAR data to inform our economic models.
- The Early Rheumatoid Arthritis Network (ERAN) data (with data between 2002 and 2008) to examine the characteristics of 1,009 people with recent onset rheumatoid arthritis, for example the Health Assessment Questionnaire (HAQ) distribution, age of onset distribution, and baseline treatment patterns. The consultant collected data derived from ERAN also informed our economic models.
- We undertook validity checks comparing incidence data and age of onset data between the ERAN and GPRD datasets and found a close match in these patterns between the two datasets.
- We estimated the **incidence of rheumatoid arthritis** to be 26,000 new cases each year in England. We derived this estimate by examining the reported incidence rate from the GPRD over the five years between 2003 and 2007. The reported incidence rate varied little from year to year and the average incidence estimate was 26,000 new cases. We chose to use the GPRD-based estimate as it is a national source which reflects regional differences in incidence of the disease, and we smoothed any year to year variations in incidence by taking a five year average.

Published literature has highlighted that GPRD is a reliable data source for incidence studies. When patients are referred for specialist care, GPs enter salient findings from the consultant visits into the GPRD once they receive a confirmed diagnosis about a patient. Therefore, even though the GPRD is based in general practice, diagnosis is typically established by a rheumatologist.¹

This figure of 26,000 derived from the GPRD is higher than some other estimates so we compared it against other possible sources of incidence data. In its work, the National Institute for Health and Clinical Excellence (NICE) has used an incidence estimate for the UK of 12,000 new cases of rheumatoid arthritis diagnosed annually (equivalent to 10,000 for England). This figure is derived from the Norfolk Arthritis Register (NOAR), based on 283 patients diagnosed with rheumatoid arthritis in the Norfolk area over the five year period 1990-1994.² It is based on formal classification criteria whereby consultants confirm cases using the American College of Rheumatology criteria.

1 Somers et al (2007). *Incidence of Systemic Lupus Erythematosus in the UK, 1990-1999*. *Arthritis & rheumatism* Vol. 57, No. 4, May 2007, pp 612-618.
 2 Wiles et al (1999). *Estimating the incidence of rheumatoid arthritis*. *Arthritis & rheumatism* Vol. 42, No. 7, July 1999, pp 1339-1346.

Using more recent population estimates from 2007 from the Office for National Statistics, we used this incidence estimate to derive an incidence figure of 18,000 new cases annually. Furthermore, we followed up with 12 acute trusts which had responded to our census to check the numbers diagnosed with rheumatoid arthritis in their trusts during 2007-08. These 12 trusts alone identified that they had diagnosed 3,300 new patients with rheumatoid arthritis in 2007-08. Since this represents just 8 per cent of the total number of trusts with a rheumatology service (154), this implies, on a simple calculation, that an incidence estimate of 10,000 for England must be too low. Therefore, we consider our estimate of 26,000 new cases annually to be robust.

- We estimated the **prevalence of rheumatoid arthritis** (total number of people with the disease) to be 580,000 for England. We derived this estimate by applying the GPRD incidence rate to the age and gender specific population and mortality estimates from the Office for National Statistics. We developed a lifelong Markov model covering the period from 1936 to 2020 to estimate today's rheumatoid arthritis population based on the known characteristics of the population with rheumatoid arthritis and the total population over the period 1981 to 2007. We assumed that the characteristics of the population prior to 1981 and after 2007 stayed the same – we tested this assumption through sensitivity analyses of alternative characteristics and found a variance against our estimated prevalence of less than ten per cent.

This prevalence figure of 580,000 for England is higher than some other estimates. NICE has used an estimate of 400,000 for the UK based on a local survey of 7050 people ('the Norfolk study', which is different from NOAR) of whom 66 had rheumatoid arthritis.³ Other estimates of UK prevalence are as high as 600,000.⁴ Applying the prevalence estimates from the Norfolk study to 2007 population data for England suggests prevalence in England of 337,000. However, given an incidence estimate of 26,000 this would suggest a mortality rate of six times higher than the population as a whole, whereas published literature suggest the actual mortality rate of people with rheumatoid arthritis is around 1.3-1.5 times that of the general population⁵.

We also examined prevalence data from the GPRD, which gave a figure of around one million cases. However, given the GPRD incidence data, this figure is unrealistically high as it suggests that the population with rheumatoid arthritis has a much lower mortality rate than the population as a whole. Other published studies have highlighted that whilst GPRD is a good source of incidence data, its use as a source for prevalence data can lead to overestimates of the prevalence of chronic relapsing-remitting disease, since people with such diseases are likely to be disproportionately represented on the database.⁶

- We built two **economic models*** to evaluate the potential financial impacts on the NHS, the wider economy, and the quality of life for patients of more early diagnosis and treatment of people with rheumatoid arthritis. Our *first model* examined the impact of reconfiguring services to promote rapid identification, referral and diagnosis of early cases of rheumatoid arthritis upon (i) the number of people diagnosed within three months and (ii) the associated costs to the NHS. Our second model compared current practice in treatment of people with early rheumatoid arthritis, and its costs, against more rapid treatment of people with early rheumatoid arthritis, and the impact this would have on NHS costs, quality of life, and productivity for the economy for people with rheumatoid arthritis of working age.
- We reviewed published literature to provide an overview of **international comparisons*** of rheumatoid arthritis in England, Scotland, Wales and Northern Ireland and nine other countries (Australia, Canada, France, Germany, Ireland, The Netherlands, Spain, Sweden and the USA). We sought to draw comparisons between countries and to shed light on the experience of England in the extent of, and approach to management of, the disease.
- **Review of secondary data** available from the Department of Health, NICE, the King's Fund, the Work Foundation, the National Rheumatoid Arthritis Society, Arthritis Care, the British Society for Rheumatology, and others.
- We prepared a DVD with **patient stories*** about the experience of people living with rheumatoid arthritis, covering the themes in the main NAO report.

3 Symmons D et al (2002). *The Prevalence of rheumatoid arthritis in UK: new estimates for a new century*. Rheumatology 2002; 41: 793-800.

4 www.arc.org.uk/news/pressreleases/13392.asp

5 Sokka T et al. (2008) *Mortality in rheumatoid arthritis: 2008 update*. Clinical Experimental Rheumatology 2008; 26 (suppl.51):s35-s61.

6 Nightingale et al (2006). *Systemic lupus erythematosus prevalence in the U.K.: methodological issues when using the General Practice Research Database to estimate frequency of chronic relapsing-remitting disease*. Pharmacoepidemiology and drug safety 2007. Volume 16, Pages 144 – 151.