



National Audit Office

Services for people with rheumatoid arthritis

Background and main findings from National Audit Office (NAO) census of NHS Rheumatology units

CENSUS FINDINGS

NATIONAL AUDIT OFFICE STUDY - SERVICES FOR PEOPLE WITH RHEUMATOID ARTHRITIS

Background and main findings from National Audit Office (NAO) census of NHS Rheumatology units

1. The overall aim of the NAO's report *Services for people with rheumatoid arthritis (HC 823)* was to examine the potential for improving delivery of services for people with rheumatoid arthritis. As part of this, the NAO conducted a census of all NHS Trusts with a Rheumatology department between November 2008 and January 2009. The census focussed on activity during the financial year 2007-08. We had a 95 per cent response rate with only 7 Trusts failing to respond.
2. The NAO report examines the efficiency and effectiveness of services for people with rheumatoid arthritis in England, and acts as a marker to highlight the wider challenges faced in providing services for people with musculoskeletal diseases and long-term conditions. The timeliness and appropriateness of intervention has considerable implications for management of the disease in the long-term and therefore for improving overall wellbeing and capacity to work for people of working age. The census data supported our examination of whether people are diagnosed early in the course of the disease and the treatment and care available after diagnosis.

The questionnaire for the census was structured in the following sections:

SECTION A - Capacity of the trust including:

- Outpatients
- Day cases
- Inpatient services other than day case admissions
- Expenditure

SECTION B - Service Provision

SECTION C - Care and treatment of patients

SECTION D - Working with others in the rheumatoid arthritis community

SECTION E - Chief Executive sign off

This report presents the summary of responses to our census across all trusts. 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 cost.

We have also produced an individual feedback report for each trust to enable them to assess their data against other trusts in the census population.

PART A - CAPACITY OF YOUR TRUST

1. How many rheumatology departments/units are there within your trust? (147 trusts provided data)

0	1%
1	87%
2	8%
3	3%
4	1%

2. Does your trust provide services for people with rheumatoid arthritis exclusively in an acute setting (i.e. in a hospital)? (142 trusts provided data)

60% Yes	37% No
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3. If no, in what other settings does your trust provide services for people with RA (trusts are able to provide more than one response) (85 trusts provided data)

	Number of trusts providing a response
Community Hospitals	34
Community clinics and other community based services	29
Clinics at acute hospitals	12
General Practices	5
Provision of information e.g through website	2
Children's juvenile arthritis	1
Other	2

4. How many new rheumatology patients did the trust see in the financial year 2007-08 (1st April 2007 to 31st March 2008)? (146 trusts provided data)

Mean: 1824	Minimum value: 0	Maximum value: 5737
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5. What percentage of these new patients has been diagnosed with rheumatoid arthritis? (142 trusts provided data)

Mean: 18%	Minimum value: 2%	Maximum value: 90%
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5b. Indicate whether this is an actual or estimated figure? (137 trusts provided data)

Actual: 9%	Estimated: 84 %
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6. How many existing/follow up rheumatology patients did the trust see in the financial year 2007-08 (1st April 2007 to 31st March 2008)? (146 trusts provided data)

Mean: 7235	Minimum value: 0	Maximum value: 38426
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7. What percentage of these existing/follow up patients has rheumatoid arthritis? Please provide per cent or estimate. (141 trusts provided data)

Mean: 55%	Minimum value: 2%	Maximum value: 95%
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8. In the financial year 2006-07, was the number of new patients with rheumatoid arthritis greater, about the same or smaller in your trust than in 2007-08? (139 trusts provided data)

Greater than in 2007-08	10%
About the same	53%
Smaller than in 2007-08	32%

9. For 2008-09 (so far), please state whether the number of new patients is greater, about the same or smaller than in 2007-08? (141 trusts provided data)

Greater than in 2007-08	48%
About the same	38%
Smaller than in 2007-08	10%

10. Overall, how satisfied or dissatisfied are you that the GPs who refer to rheumatology in your trust, refer patients quickly enough? (131 trusts provided data)

Very satisfied	9%
Moderately satisfied	59%
Neither satisfied nor dissatisfied	14%
Moderately dissatisfied	14%
Very dissatisfied	1%

11. Overall, how satisfied or dissatisfied are you with the quality of information that GPs who refer to rheumatology in your trust provide with their referrals? (131 trusts provided data)

Very satisfied	9%
Moderately satisfied	48%
Neither satisfied nor dissatisfied	19%
Moderately dissatisfied	18%
Very dissatisfied	3%

12. At December 2008, what percentage of referrals comes from Choose and Book? (141 trusts provided data)

Mean 54%	Minimum value: 0%	Maximum value: 100%
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13. Overall how satisfied or dissatisfied are you with the quality of information provided with referrals made into the rheumatology service through Choose and Book? (144 trusts provided data)

Very satisfied	3%
Moderately satisfied	34%
Neither satisfied nor dissatisfied	33%
Moderately dissatisfied	23%
Very dissatisfied	5%

14. Does your trust have the capacity to offer all rheumatoid arthritis patients who need them follow-up appointments on a timely basis? (134 trusts provided data)

32% Yes	66% No
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15. If the answer to question 14 was no, please give up to three reasons why: (coded free text answers)

	Number of trusts providing a response
Lack of clinic appointments	36
Capacity of overall staff capacity	24
Lack of nursing staff	17
Lack of consultant capacity	17
Keeping new to follow-up ratio low	5
Emphasis on new patients	5
Complexity of condition	4
Other	2
Overall increase in referrals to unit/department	1
Lack of physical space	1
Lack of PCT planning	1
Lack of links/shared care with GPs	1

16. For the specialists below, what are your trust's staffing levels for rheumatology patients at December 2008 (WTE)?

	a. Mean WTE at December 2008	b. Mean vacancies at December 2008	c. How do current levels (at December 2008) compare to those during 2007-08? (Totals)		
			Higher	Lower	Unchanged
16.1 Consultant Rheumatologist	3	0.16	28	12	103
16.2 Specialist rheumatology nurses	2.5	0.19	30	11	103
16.3 Specialist Registrars	1.2	0.12	7	9	121
16.4 Trainee doctors (supervised by your team)	1.6	0.07	9	6	121
16.5 Physiotherapists	1.2	0.08	14	15	104
16.6 Occupational therapists	1.0	0.09	10	11	111
16.7 Podiatrists	0.2	0.00	4	2	118
16.8 Psychologists	0.1	0.01	3	0	122
16.9 Associate specialists	0.2	0.01	3	7	117
16.10 Others Please specify up to three other categories	1.2	0.10	10	6	65

17. If you go outside of the trust in order to access any of the above specialists please give brief details below and state why it is necessary to go outside of the trust: (coded free text answers)

	Number of trusts providing a response
Podiatry services provided by PCT/accessed via PCT	43
Trust only employs generalised podiatrist	3
Trust does not employ podiatrist	5
Podiatry - other	7
Occupational therapists services provided by PCT /accessed via PCT	20
Trust only employs generalist Occupational therapists	4
Trust does not employ Occupational therapists	3
Occupational therapists - other	7
Physiotherapy services provided by PCT /accessed via PCT	24
Trust only employs generalised physiotherapist	7
Trust does not employ physiotherapist	1
Physiotherapist - other	6
Specialist Registrars service provided by PCT /accessed via PCT	0
Trust only employs generalised Specialist Registrars	1
Trust does not employ Specialist Registrars	0
Specialist Registrars - other	0
Orthotics service provided by PCT /accessed via PCT	2
Trust only employs generalised Orthotics	0
Trust does not employ Orthotics	0
Orthotics - other	2
Psychological services provided by PCT /accessed via PCT	7
Trust only employs generalised Psychological services	6
Trust does not employ Psychological services	7
Psychological services - other	10
Other service provided by PCT /accessed via PCT	4
Trust only employs generalist - Other	3
Trust does not employ - Other	6
Others	15
Service moved to another hospital	1
Service share with another hospital	2
N/A	3

OUTPATIENTS

18. How many rheumatology outpatient appointments did your trust have in the financial year 2007-08 (1st April 2007 to 31st March 2008)? (144 trusts provided data)

Mean: 9780	Minimum value: 550	Maximum value: 42349
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19. What proportion (%) of these outpatient appointments were in respect of rheumatoid arthritis? (141 trusts provided data)

Mean: 50%	Minimum value: 4%	Maximum value: 95%
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20. Please describe the achievement of which you are most proud with respect to providing outpatient services for patients with rheumatoid arthritis: (coded free text answers)

	Number of trusts providing a response
Delivering multidisciplinary services	38
Short waiting times/ fast referrals/ early arthritis clinics	37
Good facilities/ equipment	28
Good practice in medication administration/ monitoring	24
Good staff	23
Help/ advice line	20
Good reputation/ high patient satisfaction	18
Patient information/ education	16
Good monitoring/ disease control	12
Flexible service	9
High quality service	5
Provision of services in the community	5
Good links with patient support groups/ the third sector	4
Other good practice in providing services	4
N/A	2
Reduced surgical rates	1

21. What would help you improve your provision of outpatient services for people with rheumatoid arthritis (up to three things) (coded free text answers)

	Number of trusts providing a response
Improved facilities/ equipment in the acute setting	34
Increased overall staff capacity	26
Increased specialist nurse capacity	21
Increased consultant capacity	21
Increased access to occupational therapy	9
Better provision of services in the community/ primary care	9
Increased access to physiotherapy services	8
Improved information recording/ database	7
A dedicated Arthritis Centre	7
Increased capacity to see follow-up patients	6
Increased other nurse capacity	5
Increased access to psychological services	4
Increased access to podiatry/ orthotics	4
Increased access to biologic therapies	4
Improved referral by GPs	3
Other	2
More education for patients/ clinicians	2
Improved appointment booking system	1

DAY CASES

22. How many day case beds/chairs does your trust have at December 2008? (128 trusts provided data)

Mean: 21	Minimum value: 0	Maximum value: 171
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23. How many rheumatology day case admissions did your trust have in the financial year 2007-08 (1st April 2007 to 31st March 2008)? (139 trusts provided data)

Mean: 569	Minimum value: 0	Maximum value: 4294
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24. What proportion (%) of these rheumatology day case admissions were in respect of rheumatoid arthritis? (139 trusts provided data)

Mean: 59%	Minimum value: 0	Maximum value: 100
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25. Please describe the achievement of which you are most proud with respect to providing day case services for patients with rheumatoid arthritis: (coded free text answers)

	Number of trusts providing a response
Development of day case unit	61
Infusion service	32
Rapid access to care and treatment for patients	22
Dedicated nurse service	18
Other	5
High quality service	5
N/A	4
Reduced inpatient admissions	3
Good reputation/ patient feedback	3
Reduced surgical rates	2
Patient education and self management	2
Patient monitoring service	1

26. What would help you improve your provision of day case services for people with rheumatoid arthritis (up to three things)? (coded free text answers)

	Number of trusts providing a response
Designated rheumatology day case unit	49
More specialist nurses	25
Increased overall staffing	16
Improved facilities/ equipment	15
More efficient management of day case services	12
Improved infusion service	9
Improved physical environment for patients	7
Other	6
Longer opening hours	4
N/A	2
Increased consultant capacity	2
Increased access to biologic and other therapies	2
Feasibility of treatment nearer patient home	2

INPATIENT SERVICES OTHER THAN DAY CASE ADMISSIONS

27. How many inpatient beds within your trust did rheumatology patients have access to at December 2008? (111 trusts provided data)

Mean: 24	Minimum value: 0	Maximum value: 505
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28. Has the number of inpatient beds for rheumatology patients within your trust changed within the last five years? (135 trusts provided data)

47% No	1% Yes, it has increased	44% Yes, it has decreased
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29. If the answer to question 28 was anything other than no, please state up to three main reasons for this change: (free text coded response)

	Number of trusts providing a response
Increasing use of day unit/ outpatient facilities	24
Pressure on general medical beds	22
Availability of improved/ earlier medical intervention	13
Restructuring of wards	8
Other	6
Financial constraints	2

30. How many inpatient admissions of rheumatology patients did your trust have in the financial year 2007-08 (1st April 2007 to 31st March 2008)? (131 trusts provided data)

Mean: 207	Minimum value: 0	Maximum value: 4304
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31. What proportion (%) of these rheumatology inpatient admissions were in respect of rheumatoid arthritis? (142 trusts provided data)

Mean: 42%	Minimum value: 0%	Maximum value: 100%
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32. Please describe the achievement of which you are most proud with respect to providing inpatient services with rheumatoid arthritis: (free text coded response)

	Number of trusts providing a response
High quality of care provided by team	42
Provision of a multidisciplinary service	32
Reducing inpatient admissions	21
N/A	20
Good specialist/ other nurse services	17
Provision of an inpatient service despite pressure on beds	15
Other	6
Speed of inpatient treatment	5
Good reputation/ patient satisfaction	3

33. What would help you improve your provision of inpatient services for people with rheumatoid arthritis (up to three things)? (free text coded response)

	Number of trusts providing a response
Provision of beds on a designated ward	51
Appropriately trained medical staff	17
Improved access to members of the multidisciplinary team	16
Appropriately trained nurses	15
Improved access to beds	11
Improved bed management	9
N/A	7
Design of a more coherent service	6
More consultant rheumatologists	4
Other	3
Improved communication/ links	3
More administrative support	1

EXPENDITURE

34. Do you know the total revenue expenditure of running all rheumatology services in your trust for the financial year 2007-08? (including operating expenses, staff costs, capital charges, depreciation, pharmacy costs, but excluding overheads) (143 trusts provided data)

74% Yes	15% No	8% Don't know
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35. If yes, what is the basis for this expenditure figure? (free text coded response)

	Number of trusts providing a response
Historical costings	44
Service line reporting	43
Other basis	28

36. If yes, what was the total revenue expenditure of running all rheumatology services in your trust for the financial year 2007-08? (£'000) (including operating expenses, staff costs, capital charges, depreciation, pharmacy costs, but excluding overheads) (PLEASE INCLUDE EXPENDITURE ON BIOLOGICS)

Mean: £2,777,000	Minimum value: £304,000	Maximum value: £11,030,000
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36b. Indicate if this is an actual or estimated figure? (100 trusts provided data)

Actual: 50%	Estimated: 18%
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37. Of this expenditure (in question 36), please estimate the proportion (%) relating to rheumatoid arthritis services only in 2007-08 (including operating expenses, staff costs, capital charges, depreciation, pharmacy costs, but excluding overheads) (100 trusts provided data)

Mean: 62%	Minimum value: 1%	Maximum value: 100%
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37b. Indicate if this is an actual or estimated figure? (81 trusts provided data)

Actual: 1%	Estimated: 54%
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38. Please state your trust's total biologics budget (drugs only) for rheumatoid arthritis only in 2007-08 (£'000)

Mean: £1,057,000	Minimum value: £4,000	Maximum value: £3,500,000
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38b. Indicate whether this is an actual or estimated figure (86 trusts provided data)

Actual: 35%	Estimated: 23%
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39. Please state your trust's total expenditure on biologics (drugs only) for rheumatoid arthritis only in 2007-08

Mean: £1,053,000	Minimum value: £0	Maximum value: £3,990,000
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40. If your answer to Question 39 differs from your answer to Question 38, please explain why. (free text coded response)

	Number of trusts providing a response
Expenditure organised through PCTs	23
Not possible to separate RA biologics budget	13
Variation in service provision compared with anticipated service provision	11
Other	7
Determined by clinical need in accordance with NICE	6
Difference insignificant/ immaterial/ not applicable	3
Overspend	2
Lack of biologics nurse/ other relevant staff	2
Underspend	1
Due to non-NICE/ exception use	1

PART B: SERVICE PROVISION

1. Can your trust identify times taken from GP referral of rheumatology to first specialist appointment within the trust? (142 trusts provided data)

95% Yes	2% No
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2. At December 2008, what is the average time taken from receipt of rheumatology referral into the trust until the first specialist appointment? (143 trusts provided data)

Mean: 6	Minimum value: 2	Maximum value: 13
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2b. Indicate whether this is an actual or estimated figure (125 trusts provided data)

54% Yes	31% No
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3. If relevant, please identify up to three internal factors which constrain you from providing a timely service (free text coded response)

	Number of trusts providing a response
Restricted outpatient capacity	24
Lack of medical staffing capacity (non-consultant)	17
Lack of consultant staffing capacity	17
Lack of flexibility to prioritise referrals	13
Problems caused by Choose and Book	9
N/A	7
Large volume of patients	7
Other administrative delays	6
Lack of administrative staff/ capacity	3
Problems with other booking systems	2
Other	1
Lack of nurse staffing capacity	1
Lack of facilities/ physical space	1
Lack of Allied Health Professionals staffing capacity	1

4. For the factors identified in question 3, please identify how each of these factors might be resolved: (free text coded response)

	Number of trusts providing a response
Increase consultant rheumatologist capacity	33
Increase in overall staff capacity	15
Effective service redesign/ planning	11
Rationalisation of referrals/ booking system	9
Increase in specialist/ other nurse capacity	9
Increased overall capacity	6
Improved links with GPs	6
Improvement in Choose and Book	5
Other	4
Increased clinic space	4
Expansion of services into the community	2
Early Arthritis Service	2
Improved staff training	1
Additional outpatient/ day facilities	1

5. At December 2008, has your trust achieved the 18 weeks target for:

	Yes	No
5.1 Outpatient rheumatology pathways	144	1
5.2 Inpatient rheumatology pathways	132	1

6. What impacts have the 18 weeks target had on your rheumatology service's provision for rheumatoid arthritis patients (for example, on follow up appointments)? (free text coded response)

a) What have been the main positive impacts of the 18 weeks target for your service?

	Number of trusts providing a response
New patients have continued to be seen in a timely manner	66
Imaging diagnostic tests available more quickly	20
Investigations are carried out on a timely basis	11
Provided the impetus for additional funding/ support/ other resources	10
Streamlined patient pathways	8
No impact	8
New patients continue to be treated early	7
Other	6
New patients continue to be diagnosed early	5
Target not relevant as new patients need to be seen more quickly than 18 weeks	3
Improved access to members of the multidisciplinary team	3
Reducing unnecessary follow-ups	1

b) What have been the main negative impacts of the 18 weeks target for your service?

	Number of trusts providing a response
Reduced emphasis on follow-up patients	51
Reduced flexibility to see patients in priority order	27
Not applicable/ no impact	13
Increased pressure on the volume of patients seen	13
Increased pressure on staff	8
Increased administration	8
Confusion over how the target applies to multidisciplinary care	8
Increased pressure on clinic capacity	4
Lack of continuity of care in the same locality	3
Increased pressure on other resources including funding	3
Other	2

PART C: CARE AND TREATMENT OF PATIENTS

1. Do you apply the following guidance on care pathways for rheumatoid arthritis patients within your trust?

	Yes	No
1.1 NICE	134	9
1.2 BSR	135	8
1.3 EULAR	59	65
1.4 ARMA	90	42
1.5 Don't use formal guidance	7	0
1.6 Other - please specify	26	0

2. If you provide formal guidance, how useful do you find this guidance with respect to providing services for people with rheumatoid arthritis?

	Very useful	Useful	Not very useful	Not at all useful
2.1 NICE	50	68	15	3
2.2 BSR	64	66	6	0
2.3 EULAR	25	67	13	1
2.4 ARMA	24	63	13	1
2.6 Other - please specify	16	8	1	0

3. Does your trust run an early arthritis clinic (or an urgent early clinic including arthritis)? (146 trusts provided data)

35% Yes	65% No
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4. Has your rheumatology service evaluated the benefits of an early arthritis clinic? (143 trusts provided data)

38% Yes	59% No
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5. If yes to question 4, please give brief details: (free text coded response)

	Number of trusts providing a response
Clinic has delivered improved services	20
N/A	13
Looking at potential to set up a clinic	12
Having faced problems with the clinic	9
Insufficient manpower/resources to run a clinic	7
Trialled a multi-disciplinary clinic	6
Close liaison with GPs	1

6. Please give an average waiting time and volume of rheumatoid arthritis patients for each of these procedures. Please provide an average time in weeks or give an estimate (use the drop down box to tell us whether this is an actual or estimated figure)

	Mean number of rheumatoid arthritis patients undergoing this procedure in 2007-08	Average waiting time per rheumatoid arthritis patient in 2007-08 (in weeks)
6.1 Blood test for rheumatoid factor	1327	0.6
6.2 Anti-CCP antibody testing	144	1.8
6.3 DAS or HAQ assessment	567	1.2
6.4 Magnetic resonance imaging	140	5.3
6.5 Bone densitometry	256	5.3
6.6 X ray imaging	953	0.7
6.7 Ultrasonography	133	4.8

7. For each of the following specialist procedures, please state the percentage of rheumatoid arthritis patients who needed the procedure but were not able to access it

Procedure	Mean % patients unable to access
7.1 Blood test for rheumatoid factor	0.7
7.2 Anti-CCP antibody testing	20.8
7.3 DAS or HAQ assessment	15.2
7.4 Magnetic resonance imaging	2.3
7.5 Bone densitometry	2.7
7.6 X ray imaging	0.8
7.7 Ultrasonography	7.9

8. Does your trust provide patients with rheumatoid arthritis with a plan of care detailing the pathway for ongoing care and treatment? (144 trusts provided data)

All	50%
None	30%
1-99%	18%

8. Specified percentage figures

Mean: 59%	Minimum value: 5%	Maximum value: 100%
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9. Does your trust provide information to rheumatoid arthritis patients on the following subjects?

	In writing	Verbally	In translation	Not provided
9.1 Education on the symptoms of rheumatoid arthritis	141	134	29	0
9.2 Education on treatment options including potential side effects of medication	144	135	27	0
9.3 Prognosis	74	140	17	1
9.4 Risk factors that exacerbate symptoms (e.g. obesity/smoking)	75	138	17	4
9.5 Long-term management including self-management	96	137	19	6
9.6 Information about continuing in employment	77	114	11	19
9.7 Information on social security benefits	57	96	10	34
9.8 Other - please specify	34	23	1	0

10. How do you advise your rheumatoid arthritis patients to access care in the event of a flare-up?

	Yes	No
10.1 Call our telephone advice line, staffed by a specialist nurse	140	5
10.2 Make a phone call to a consultant	118	11
10.3 Make an appointment with their GP/get a GP visit	87	46
10.4 Make an appointment to see a consultant/RA specialist	82	47
10.5 Go to our flare up or rapid access clinic	79	42
10.6 Contact a specialist nurse by email	59	74
10.7 Contact their out of hours primary care provider	51	75
10.8 Contact NHS direct	50	71
10.9 Attend Accident and Emergency at a hospital	42	81
10.10 Use prescriptive painkillers	36	85
10.11 Use 'over the counter' painkillers	30	96
10.12 Rest until they improve	31	0
10.13 Other - please specify	17	105

11. How many of your trust's rheumatoid arthritis patients qualified for biologics according to NICE criteria in 2007-08? (109 trusts provided data)

Mean: 109 Minimum value: 2 Maximum value: 560

12. For how many of these patients were you not able to prescribe biologics for rheumatoid arthritis? (114 trusts provided data)

Mean: 3 Minimum value: 0 Maximum value: 142

13. Please state up to three main barriers to prescribing biologics: (free text coded response)

	Number of trusts providing a response
NICE criteria being over-restricted/ incomplete fit with NICE guidelines	33
No real barriers	21
Lack of specialist nurse resource	19
Trust funding issues	9
Clinical unsuitability due to co-morbidity	7
PCT funding issues	7
Other PCT issues	6
Ease of access to an elective day case facility	5
Lack of staff generally	5
Other	5
Delays with patient processing/administration	4
Patient choice	4
Lack of database to record outcome data	1

14. Does your trust offer patients with rheumatoid arthritis a review appointment at least once per year in accordance with NICE guidance (including all the assessments and cross-referral recommended by this guidance)? (144 trusts provided data)

All	63%
None	8%
1-99%	27%

14. Specified percentage figures

Mean: 69% Minimum value: 3% Maximum value: 100%

15. What are the main barriers to providing an annual review in accordance with NICE guidance to all rheumatoid arthritis patients? (free text coded response)

	Number of trusts providing a response
Not applicable/ None	24
Lack of specialist/ other nurse resources	18
Lack of outpatient time slots	19
Emphasis on new over review patients	10
Lack of clinic space/ capacity	8
Lack of general staff capacity	8
Lack of overall capacity	6
Other	7
Lack of consultant capacity	4
Stable patients followed up according to clinical need	3
NICE guidance not published at time of census	2
Current clinic structures	2
Lack of capacity to provide multi-disciplinary service	2
Lack of appropriate information management	1

16. Does your trust offer rheumatoid arthritis patients with active disease a review appointment at least once per month in accordance with NICE guidance? (144 trusts provided data)

All	15%
None	27%
1-99%	57%

16. Specified percentage figures

Mean: 40%	Minimum value: 0%	Maximum value 95%
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17. What are the main barriers to providing monthly review to all rheumatoid arthritis patients with active disease? (free text coded response)

	Number of trusts providing a response
Lack of outpatient capacity/ limited clinical space	56
Emphasis on new patients rather than follow-ups	30
Lack of manpower/ limited medical and nursing provision	24
Lack of specialist/ other nurse capacity	16
Lack of consultant capacity	11
Not applicable	7
Monthly reviews not always appropriate/ not supported by evidence	7
Inefficiencies in booking system	2
Fitting patients with flare ups into existing clinics	1
Other	2

18. If you did not select 'All' in Question 16, what is the average frequency of review offered by your rheumatology service to rheumatoid arthritis patients with active disease? (122 trusts provided data)

Every two months	24%
Every three months	33%
Every four months	8%
Every five months	4%
Every six months	3%
Other, please specify	12%

19. Does your trust refer rheumatoid patients who require occupational therapy to an occupational therapist? (142 trusts provided data)

All	64%
None	5%
1-99%	27%

19. Specified percentage figures

Mean: 55%	Minimum value: 5%	Maximum value: 100%
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20. What are the main barriers to referral of rheumatoid arthritis patients to an occupational therapist? (free text coded response)

	Number of trusts providing a response
Lack of OT capacity/ slots available	41
Lack of OTs trained in specialist RA services	18
Not applicable/ no barriers	19
Waiting list	11
Reluctance to attend occupational therapy	7
OT services available but under-utilised	5
No OT service available	3
Lack of funding	3
OT needs/ issues addressed in course of long-term care	1

21. Does your trust refer rheumatoid arthritis patients who require psychological services (e.g cognitive behavioural therapy) to an appropriate specialist? (144 trusts provided data)

All	14%
None	53%
1-99%	31%

21. Specified percentage figures for those trusts who selected 1-99% from Question 21:

Mean: 20%	Minimum value: 0%	Maximum value: 99%
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22. What are the main barriers to referral of rheumatoid arthritis patients for psychological services? (free text coded response)

	Number of trusts providing a response
Lack of available psychological medical services	89
Long waiting times/ lists	14
Psychologists available only through chronic pain services	8
No psychologist with a specific role to care for rheumatoid patients	8
Cost/ funding implications/ affordability	7
No direct link/ contact with a Psychology and the Rheumatology Department	6
Shortage of skill/ knowledge within the rheumatology team on referrals to psychological services	3
N/A	3
Service provided within the rheumatology department	2
Referrals have to go via primary care/ GPs	3
Patient reluctance	1

23. Does your trust refer rheumatoid arthritis patients who require podiatry services to a podiatrist? (144 trusts provided data)

All	54%
None	11%
1-99%	33%

23. Specified percentage figures for those trusts who selected 1-99% from Question 23:

Mean: 48%	Minimum value: 5%	Maximum value: 100%
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24. What are the main barriers to referral of rheumatoid arthritis patients to a podiatrist? (free text coded response)

	Number of trusts providing a response
Lack of podiatrist capacity within the Trust	42
Long waiting times for review/ limited podiatry appointments	18
Not applicable/ None	17
No service provision locally	11
Specialist rheumatology podiatry services unavailable	9
No podiatrist available - service run by primary care	10
Other	5
Referrals have to go via primary care/ GPs	5
Service under-utilised by rheumatology department	3
Service not needed - an orthotist can provide the relevant service	1
Variable experience of the podiatrist	1
Need for podiatry assessed according to individual patients' needs	1

25. Does your trust provide orthoses for rheumatoid arthritis patients who need them? (146 trusts provided data)

All	84%
None	1%
1-99%	14%

25. Specified percentage figures for those trusts who selected 1-99% from Question 25:

Mean: 58%	Minimum value: 0%	Maximum value: 100%
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26. What are the main barriers to providing orthoses for rheumatoid arthritis patients? (free text coded response)

	Number of trusts providing a response
Long waiting lists/ delay in provision of orthoses due to demand	31
Not applicable/ no barriers	24
Lack of links/ communication between orthotics and rheumatology	8
Delays due to complexity of condition	5
Current orthotics service poor/basic	5
Lack of funding	4
No orthotics service available	3
Service currently provided by another department, e.g. physiotherapy	3
Other	4
Longer waiting lists for a community/ primary care based service	2

27. Does your trust refer rheumatoid patients who fulfil the relevant NICE criteria for a specialist surgical opinion? (143 trusts provided data)

All	81%
None	3%
1-99% - please specify the percentage of rheumatoid patients who fulfil the relevant NICE criteria who are referred for a specialist surgical opinion	13%

27. Specified percentage figures for those trusts who selected 1-99% from Question 27:

Mean: 64%	Minimum value: 5%	Maximum value: 100%
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28. What are the main barriers to referring rheumatoid arthritis patients for a specialist surgical opinion? (free text coded response)

	Number of trusts providing a response
N/A/None	32
GP referral of patients including referrals made via Choose and Book	10
Unspecified access problem	9
Lack of ability to directly refer routine patients within Trust	10
Lack of specialist surgical capacity within the Trust	7
Other	4
Lack of links between rheumatology and orthopaedics	2
Patient Choice	3

29. Do you have information on the demographic profile of the local population of your trust? (144 trusts provided data)

74% Yes	25% No
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30. If yes, do you review this information against the demographic profile of the rheumatoid arthritis patients that you see? (123 trusts provided data)

14% Yes	70% No
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31. Does your trust carry out any outreach initiatives, targeting vulnerable and traditionally hard to reach groups in respect of rheumatoid arthritis? (140 trusts provided data)

27% Yes	69% No
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32. If yes please give details (free text coded response)

	Number of trusts providing a response
Conduct outreach clinics in the community/ nurse-led support groups in the community	26
Home visits	12
Promoting services to GP/ primary care/ community healthcare services	8
Other	3
Liaising with GPwSIs in Rheumatology	1
Education of other health care professionals	1
Chasing of non-attenders/ vulnerable patients	1

33. Has your trust surveyed rheumatology patients within the last 12 months to determine their satisfaction with your services? (144 trusts provided data)

47% Yes	51% No
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34. If yes to question 33, has the rheumatology service made changes to the ways it delivers rheumatoid arthritis services as a result of the survey:

28% Yes

22% No

36. Does your rheumatology service run either volunteer patient programmes to train new rheumatologists or other activities involving patients to inform and educate staff in the delivery of rheumatology services?

Yes - volunteer patient programme	21
Yes - other activities which involve patients to inform and educate staff	45
No	87

37. If yes to question 36, please give brief details of the benefits of these programmes: *(free text coded response)*

	Number of trusts providing a response
Provides for training/ feedback to staff about the patient perspective	30
Provides for ongoing dialogue with patient groups about service provision	23
We have developed an expert patient programme	8
Provides for patient feedback about new approaches/ initiatives	5
N/A	3
Other	3
Patient groups have attended the clinic(s)	2

PART D: WORKING WITH OTHERS IN THE RHEUMATOID ARTHRITIS COMMUNITY

1. Has the Primary Care Trust involved your rheumatology services in discussions about service redesign and innovation? (145 trusts provided data)

60% Yes	37% No	1% Don't know
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2. Does your rheumatology service participate in the education and training of GPs? (145 trusts provided data)

93% Yes	5% No
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3. If yes to question 2, what form has this training taken?

	Yes	No
3.1 Courses	124	6
3.2 Seminars	98	26
3.3 On-the-job training within the trust	99	24
3.4 Consultants/other staff working within primary care	66	53
3.5 Ad hoc training e.g. a helpline	47	63
3.6 Other - please specify	42	22

4. If yes to question 2, does this training involve:

	Yes	No
4.1 Diagnostic criteria for rheumatoid arthritis	132	5
4.2 When to refer rheumatoid arthritis patients to specialist care	123	10
4.3 Information on co-morbidities associated with rheumatoid arthritis	122	15
4.4 Awareness of work issues concerning people with rheumatoid arthritis	114	23
4.5 The likely long term care required for a person with rheumatoid arthritis	113	22
4.6 An emphasis on a "holistic" approach to treating individuals with rheumatoid arthritis (e.g. the provision of mental health services)	74	58

5. What types of information are communicated between your trust and GPs of patients with RA? (free text coded response)

	Number of trusts providing a response
Information on patient status	112
Drug protocols	67
Treatment plan	33
Educational resources	35
Telephone based advice	21
RA referral	11
Management of co-morbidities (e.g. depression, cardiovascular disease, osteoporosis)	8
Other	7
Direct contact details	7
Management of early RA	4
Advice on self-management	3
GP survey results	1
Training on practical procedures such as joint injections	1

6. Does your trust have links with an academic research department? (142 trusts provided data)

77% Yes	20% No
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7. If yes please give brief details: (free text coded response)

	Number of trusts providing a response
Universities	68
Clinical research	39
University/ teaching hospitals/ medical schools	33
Other	14
Clinical Local Research Network (CLRN)	8
Other hospitals	1

8. Does your rheumatology service have agreed protocols to co-ordinate with social care agencies to provide care for rheumatoid patients? (144 trusts provided data)

10% Yes	88% No
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10. Does your rheumatology service have protocols or arrangements for liaising with patients' employers (for example, through an occupational therapist) (142 trusts provided data)

18% Yes	78% No
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11. If yes to Question 10, please give brief details: (free text coded response)

	Number of trusts providing a response
Via OT	17
By letter/ telephone at patients' request	6
We do not liaise routinely with patients' employers	2
Other	12

12. Has your rheumatology service identified any good practice employers in relation to patients with rheumatoid arthritis (for example, through an occupational therapist)? (143 trusts provided data)

2% Yes	95% No
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13. Does your rheumatology service promote its own services to employers? (145 trusts provided data)

3% Yes	95% No
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14. Is there awareness within your rheumatology service of any Department for Work and Pensions back to work schemes such as Pathways to Work? (142 trusts provided data)

56% Yes	41% No
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15. If yes, do you provide advice to patients about such schemes? (101 trusts provided data)

46% Yes	22% No
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16. Does your rheumatology service provide patients with details of voluntary organisations which can provide information and support to people with rheumatoid arthritis? (142 trusts provided data)

94% Yes	3% No
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17. What one change would you like to see in the way services in your trust and local area are provided in the next 2-3 years? (free text coded response)

	Number of trusts providing a response
More/improved integration between primary and secondary care services	35
Improved staffing capacity	32
Increased service capacity	27
Improved access times	17
More/improved community-based services	17
Improved overall access to services for patients	13
A more holistic/ multi-disciplinary service	13
Improved quality of service facilities	11
Other	9
Improved liaison/ relationship with PCT	7
Improved GP/ community capability for RA management	5
Improved drug monitoring	3
Open access/ walk-in clinics	2
Improved liaison/ relationship with Trust management	1
More support for self-management	1
NICE compliance	2

18. What one change would you like to see in the next 2-3 years in the way services are provided nationally? (free text coded response)

	Number of trusts providing a response
Recognition of specific and complex needs of RA services	36
Improved access to biological therapies	33
Adequate capacity and resources for management of RA	23
More appropriate tariff/ funding mechanism	12
Less restrictive NICE guidelines	9
Provision of a more holistic/ multi-disciplinary service	10
National service framework for all patients with inflammatory arthritis (not just RA)	10
Other	10
All services to be NICE compliant/ end postcode prescribing	10
Increase in trust and community specialist follow-up	7
Minimum standards for management of RA	4
Provision made to improve/maintain work fitness of patients	4
Better management between primary and secondary care	4
Better information for patients	1