

Patient Groups on Rheumatoid Arthritis and the NHS

A national survey of patient organisations
and other health campaigners
& APPENDIX



Conducted for the
National Audit Office
by PatientView

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Preface

This study undertaken for the National Audit Office (NAO) aims to look at the effectiveness of the RA services offered by the NHS—as perceived by patient and other voluntary groups, who represent the interests of people with RA and their carers. The results of the study should help identify how services can be improved. The study results have contributed to the NAO's final report and recommendations on NHS services for RA.

Dr Alexandra Wyke
PatientView
March 2009

Summary of findings

A survey of 30 patient and other voluntary groups representing the interests of people with RA from across England.

Diagnosis

People with RA usually first approach the GP when they are in discomfort and pain. But, according to 65% of the respondent groups (16 groups), 3 months or more pass between a person first experiencing symptoms and obtaining a correct diagnosis of RA. Despite the importance of early intervention, the time lag occurs partly because of a general lack of RA knowledge among the public. 25 of the 30 respondent groups believe that people with RA are able to see a consultant within the government 18-week target. Nonetheless, over half of the respondent groups (53%, or 16 groups) believe that the referral process remains inefficient and worthy of improvement. The respondents report that the main bottlenecks are: the GP; waiting times to see a consultant; complexities associated with RA and its diagnosis; difficulties in accessing specific diagnostic tests; and inadequate GP review criteria in directing the patient to appropriate specialist care. Urgent cases are not prioritised over non-urgent ones. To improve the speed and accuracy of diagnosis, the respondent groups suggest the following:

- Greater awareness of RA and the importance of early intervention among the public and health professionals.
- Better training for health professionals in RA.
- A greater supply of specialist health professionals, perhaps through the creation of dedicated specialist clinics.

Treatment and care

A majority (54%) of the respondent groups answering the question state that patients diagnosed with RA do not access the correct treatment and care within six months. Two groups say patients can wait for more than one year to get appropriate treatment and care. These delays are due to the difficulties faced in matching the right treatment to the patient (plus the fact that the medication takes some time to work). However, a general lack of public awareness, allied to long waiting times, also prevent people with RA from readily accessing RA healthcare services. The most popular means among respondents for helping speed up access to appropriate treatment include: ensuring that GPs are informed about the medical condition's referral pathways.

Groups reported that the most of the more common RA drugs are relatively easy for patients to access. Biologics (anti-TNFs) are not. Although more effective than other RA drugs, biologics are costly. Similarly, some surgical

procedures (such as arthroscopy, or hip or knee replacement) are more readily available than others (such as synovectomy, or finger, hand, or feet surgery). The majority of the respondents say that—with the exception of physiotherapy—complementary treatments are only sometimes, or are never, available.

Respondent groups believe that people with RA are mostly satisfied with the healthcare they receive from medical professionals. Respondents point out, though, that among health professionals, only rheumatologists, specialist nurses, and physiotherapists show a good (or very good) understanding of RA.

Long-term care

Respondent groups identify geographic variations as the key issue affecting patients' accessibility to RA reviews and other aspects of long-term care. Commenting on why this is the case, some respondents blame the 18-week referral target for new patients—which is implemented, they say, at the expense of existing patients. The National Rheumatoid Arthritis Society (NRAS) explains:

"[Existing] patients are being bumped off lists to enable units to meet the 18-week target for new patients."

Nearly 80% of the respondent groups also emphasise that most patients have to go via the GP if they wish to obtain a follow-up review appointment with the consultant—an overly bureaucratic hurdle. As an RA group from Yorkshire and North Humber states:

"Our members are very dissatisfied with the follow-up appointments booking system. Previously, a follow-up appointment was made after every consultation. But the new system does not allow this."

Respondents are evenly split as to whether RA reviews/appraisals are made in light of a person's changing medical/physical condition. Without such monitoring, people with RA can "slip quietly into disability", says the NRAS.

In the case of 'flare-ups', the situation for people with RA is worse. Although patients expect to be able to contact specialists about their flare-ups, 96% of the respondent groups insist that most people with RA end up consulting their GPs instead—who are often unable to deal with the situation.

Respondents' comments recommend that long-term care would be more effective if RA services and their delivery could be increasingly 'joined up'.

Employment

18 of the 22 respondent groups that felt able to comment on the subject of employment indicate that employers do not understand people with RA (just

four respondent groups believe that employers do). Only 2 of the 22 respondents say that employers “always” or “often” provide support to their employees with RA. The main barriers here appear to be a general lack of understanding of RA among employers, who also fear that providing support to employees with RA will prove to be a costly exercise.

Information and self-management

The majority of respondents regard virtually all types of health professionals as capable of supplying information to people with RA. The groups insist that people with RA would welcome more information on a large repertoire of issues associated with RA, including: treatment choices; how to take medication; the side-effects of medicines; and optimal diet and lifestyles. Respondent groups think that people with RA would most like to obtain this information from rheumatologists and specialist nurses. Only a minority of respondents, however, perceive health professionals as able to provide people with RA with valuable information on employment issues.

People with RA who also have other disabilities, and people with RA from different cultural or economic backgrounds, are all poorly served with information—which means that they are less able to self-manage their condition.

Final remarks

Some respondent groups add to their comments the advice that the National Institute for Health and Clinical Excellence (NICE), when assessing new technologies designed to alleviate RA, should be required to take into account the entire array of factors that influence the lives of people with RA—including employment status.

Respondents also suggest that a greater emphasis should be placed on complementary treatments, particularly those offered by occupational therapists, physiotherapists, and voluntary groups. Respondents believe that some alternative treatments (such as hydrotherapy) do offer benefits to people with RA.

Finally, a number of the respondent groups remark that NHS services to people with RA would be improved if the system collected more feedback from users, carers, and health professionals about ways of bettering RA services.

About the methodology

A significant drawback with existing methods of measuring patients' perspectives is that the questionnaires and surveys are usually designed without first exploring patients' opinions on the subject in question. PatientView, however, with the support of various academics and patient organisations, has developed a two-stage survey methodology that overcomes this problem. The process creates patient-friendly surveys that allow patient groups to contribute their viewpoints during the period of survey design. Details about the approach were published in a July 2008 article in a peer-reviewed journal [Alexandra Wyke, et al, 'What is 'Quality of Life' for Patients?', *The British Journal of Healthcare Management*, July 2008, volume 4, issue 7, pages 280–287]. The two-stage methodology is particularly effective at helping researchers discover the priorities (within the area of study) of different sub-categories of patients.

This current National Audit Office (NAO)-commissioned study of patients and carers aims to identify the potential for improving service delivery to people with Rheumatoid Arthritis (RA). Following the template described above, the study was undertaken in two parts:

- (1) During October–November 2008, an online and postal survey was conducted among 30 English patient groups with an interest in RA. The total number of people with RA (mainly the groups' members) represented by the respondents is 10,530. Through a series of open-ended questions, the respondent groups were asked to comment on their views of NHS services for people with RA. The findings of the patient group survey are published in a separate report (along with an appendix that contains nearly all of the comments received from the respondents). The contributions made by the 30 patient groups helped in the drafting of the second questionnaire—this one for people with RA and their carers.
- (2) The second questionnaire was used between November 2008 and end-January 2009, when a (primarily) online survey was conducted of 1,400 people with a confirmed diagnosis of RA (and the carers of such people). Respondent patients and carers were recruited with the support of relevant patient groups—notably the Arthritis Association, Arthritis Care, the National Rheumatoid Arthritis Society, plus numerous local groups with an interest in RA. Every effort was made to include the views of people from across England, people in employment (or out of work as a result of their RA), and people from ethnic minorities. Although individuals of all ages participated, the study's concern with employment issues allowed it to focus in particular on people of working age.

The main subject areas considered in both the patient group and the patient survey are:

- ⇒ Access to accurate diagnosis.
- ⇒ Access to treatment and care following a diagnosis.
- ⇒ Access to long-term care.
- ⇒ The employment experiences of people with RA.

Profiling questions

Profiles

Responses

- Total number of respondent groups completing the survey = 30.
- 4 of the respondent groups specialise exclusively in RA.
- 26 respondent groups specialise in arthritis in general.
- 3 groups specialise in arthritis as it affects younger people (aged 18+).
- 1 group specialises in visual impairment.
- Total number of people with RA (group members) represented by all respondents: at least 10,530 (see breakdown on next page).
- Range of RA membership numbers among the respondent groups: from 2 to 6,670.
- 21 groups have members of working age.
- 9 groups operate a UK-wide remit.
- 2 groups operate an England-only remit.
- 18 groups operate a regional/local geographic remit.

Geographic remit of the regional/local respondent groups based in England

Region	Number
South-west England	6
Southern England	2
South-east England	4
Greater London	2
East Anglia	2
East Midlands	3
West Midlands	7
North-west England	3
Yorkshire and North Humber	3
North-east England	2

Membership profile of patient groups

	Name of group (if happy to be attributed)	Number of members
1	Anonymous	500
2	Anonymous (Arthritis Care /NRAS members.)	0
3	Anonymous	About 60
4	Anonymous	About 156
5	Anonymous	About 25
6	Anonymous	About 65
7	Anonymous	51
8	Anonymous	10
9	Anonymous	About 35
10	Anonymous	More than 100
11-12	Anonymous (2 separate answers)	2 out of 45
13	Anonymous	20
14	Anonymous	10
15	Arthritis Care	About 6,670
16	Arthritis care, Winsford	47
17	Arthritis Research Campaign Andover Branch	0
18	Arthritis Self Help	10
19	Arthritis self help, Wiltshire	2
20	Birmingham Arthritis Resource Centre	9
21	Community Leicester Arthritis Self Help (CLASH)	7
22	Dudley Arthritis Care	About 40
23	Dudley Rheumatoid Arthritis Support Group	34
24	Furtherance of Rheumatic Therapy (FORTH)	600
25	HERAC (Hull East Riding Arthritis Care)	30
26	Hereford Branch Arthritis Care	6
27	National Rheumatoid Arthritis Society	More than 2,000
28	Plymouth and District Rheumatoid Arthritis Group Support	About 35
29	Waltham Forest Blind Association	More than 10
30	Young Arthritis Support Isle of Wight (response –led)	0

Number of respondent groups contacted by primary care trusts (PCTs) seeking opinions on future redesign and innovation in RA services

"Yes" = 5 groups.

"No such contact" = 25 groups.

Levels of PCT consultation do not reflect on the authority of the groups concerned. A late 2008 survey of local patient groups conducted by PatientView for the Royal College of Nursing and National Voices found that less than half of the 226 respondent groups had some experience of PCT local healthcare commissioning. That experience ranged from simply attending a meeting, to full patient representation on a commissioning board*.

The finding from the above survey is mirrored in this RA survey. Groups' dealings with PCTs are sporadic, and not always effective at ensuring useful patient and public involvement at PCT level.

[For a full set of respondents' comments to this question, see *Appendix*, page 4.]

Groups that asked to be named in this report as survey respondents

Groups are cited as they describe themselves in their responses to the survey

A

- ARMA.
- Arthritic Association, The.
- Arthritis Care.
- Arthritis Care Chester Branch.
- Arthritis Care, Chippenham, Wiltshire Branch.
- Arthritis Care, Deal, Kent Branch.
- Arthritis Care, Dudley, West Midlands Branch.
- Arthritis Care, Felixstowe, Suffolk Branch.
- Arthritis Care, Hereford Branch.
- Arthritis Care, Winsford, Cheshire Branch.
- Arthritis Research Campaign, Andover, Hampshire Branch.
- Arthritis Self Help.
- Arthritis Self Help, Wiltshire.
- Arthritis Support Group.

B

- Birmingham Arthritis Resource Centre.

C

- Community Leicester Arthritis Self Help (CLASH).

D

- Dudley Rheumatoid Arthritis Support Group.

E

- Furtherance of Rheumatic Therapy (FORTH).

H

- HERAC (Hull, East Riding Arthritis Care).
- Highfield Health Promotion Group.

N

- National Rheumatoid Arthritis Society.

P

- Plymouth and District Rheumatoid Arthritis Group Support.

W

- Waltham Forest Blind Association.
- Wolverhampton Rheumatology Support Group.

Y

- York Rheumatoid Arthritis Support Group (YORKRA).
- Young Arthritis Support, Isle of Wight.

* *Local healthcare commissioning: grassroots involvement?* was prepared for the Royal College of Nursing and National Voices by PatientView, published on February 18th, 2009.

<http://www.nationalvoices.org.uk/press-releases/plans-involve-patients-local-healthcare-decisions-are-failing>

I. Questions on obtaining diagnosis

QUESTION 1: What generally prompts people who are eventually diagnosed with RA to seek medical help?

Respondent groups' comments list four reasons why people who are eventually diagnosed with RA first seek medical help:

1. Symptoms such as pain, discomfort, and loss of mobility (the opinion of the vast majority of respondents).
2. A desire to understand what is wrong.
3. A wish to take control of their disease.
4. To obtain access to physiotherapy and/or pain-killers.

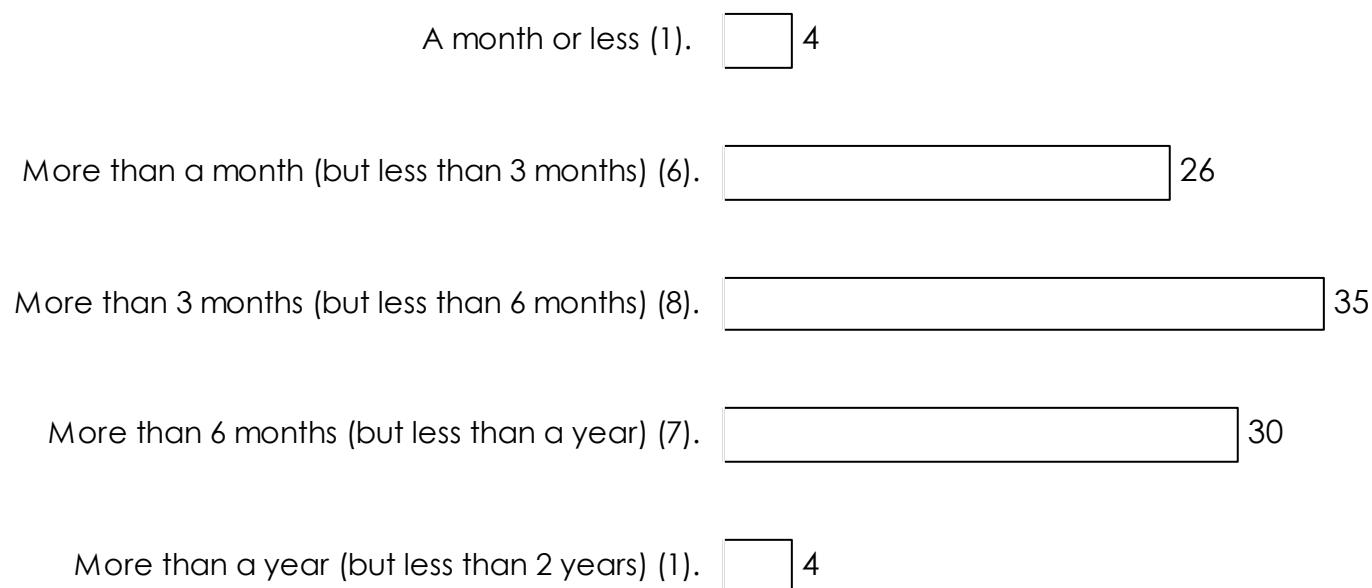
The majority of the groups answering this question report that people usually first approach their GP for medical help. One respondent, a Wiltshire arthritis self-help group, refers to "a lack of help from local GPs".

First point of contact	Number of mentions out of 29 respondents
Doctor / GP / GP practice	26
Hospital / local hospital	2
Pharmacist	1
Patient group	1
Rheumatology clinic	1

[For a full set of respondents' comments to this question, see *Appendix*, pages 6-7.]

QUESTION 2: How long does it usually take between a person first experiencing symptoms of RA (for example, pain and swelling in the joints, stiffness in the mornings, feelings of fatigue, etc) and their receiving a correct diagnosis?

*% of responses from patient and disability groups based in England (excluding "don't know").
Number of respondents answering the question = 23. Number of "don't know" = 3.
The number in brackets denotes how many groups answered this category of the question.*



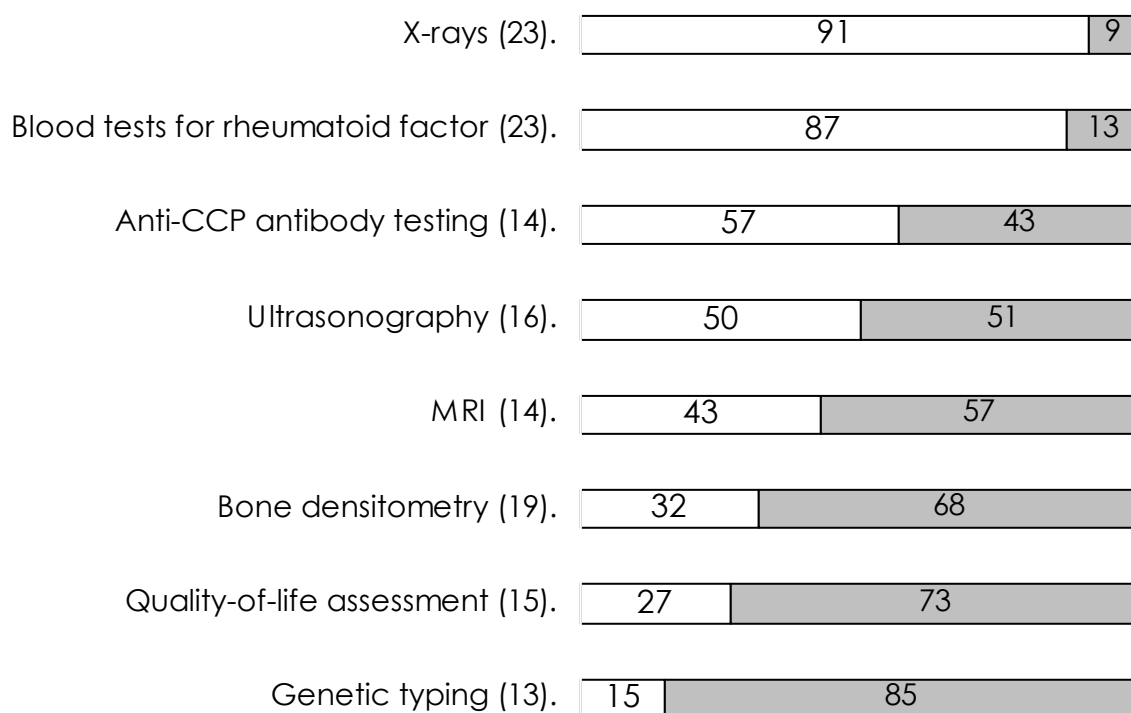
The majority of the respondent groups (65%) indicate that 3 months to a year typically passes between a person's first symptoms of RA and receipt of a correct diagnosis.

Respondents' comments add the point that individual experiences can vary significantly. Respondents suggest six factors that prolong the process of RA diagnosis (figure in brackets indicates number of comments in category):

1. The public lacks awareness and knowledge of RA (6).
2. GPs take months to decide whether to refer a patient to an RA consultant (6).
3. To meet the '18-week referral deadline', hospital resources have had to be diverted from accommodating the needs of the more urgent cases (1).
4. Waiting times for patients referred to an RA consultant can be lengthy (3).
5. The condition is complex to diagnose (2).
6. Test results also take too long to arrive (3).

QUESTION 3: How easy or difficult is it for people with RA to obtain the following diagnostic tests/scans, if their doctor recommends them?

% of responses from patient and disability groups based in England (excluding "don't knows"). The number in brackets denotes how many groups answered this category of the question, excluding don't knows.



Very easy/straight forward. Quite/very difficult.

Most of the respondent groups regard obtaining blood tests and X-rays as "very easy" or "straight forward". But most also consider that tests which look at bone density or genetic profiles (or even quality-of-life assessments) are "quite difficult" or "very difficult" to obtain. Reasons include (figure in brackets indicates number of comments in category):

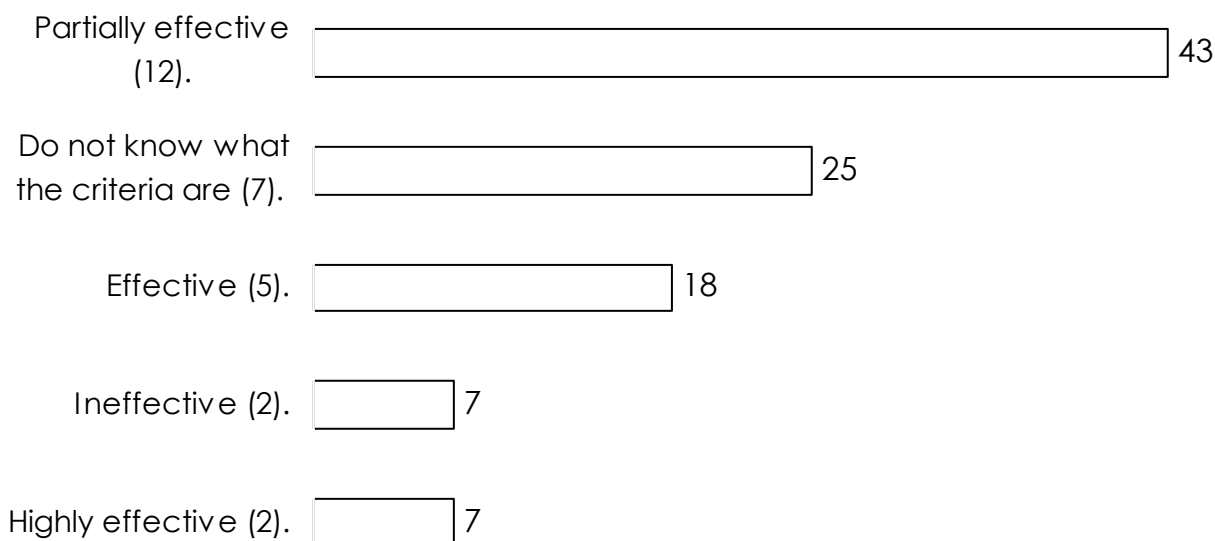
1. A lack of patient information (2).
2. GPs are not always reliable providers of RA services (2).
3. Access to testing equipment is limited (2).
4. Some tests are only conducted in hospitals (1).
5. Testing procedures are not systematically applied nationwide (4).

[For a full set of respondents' comments to this question, see Appendix, pages 10-11.]

QUESTION 4: Turning to the review criteria that GPs apply when referring people with suspected RA: how effective or ineffective are these criteria in directing patients to appropriate specialist care?

% of responses from patient and disability groups based in England.

Number of respondents answering the question =28. The number in brackets denotes how many groups answered this category of the question, excluding don't knows.



Only 18% of the 28 respondent groups answering this question believe that the review criteria which GPs apply when they refer people with suspected RA are "effective". A further 43% of the respondents think that the criteria are only "partially effective", while 14% see the criteria as either "ineffective" or "highly ineffective".

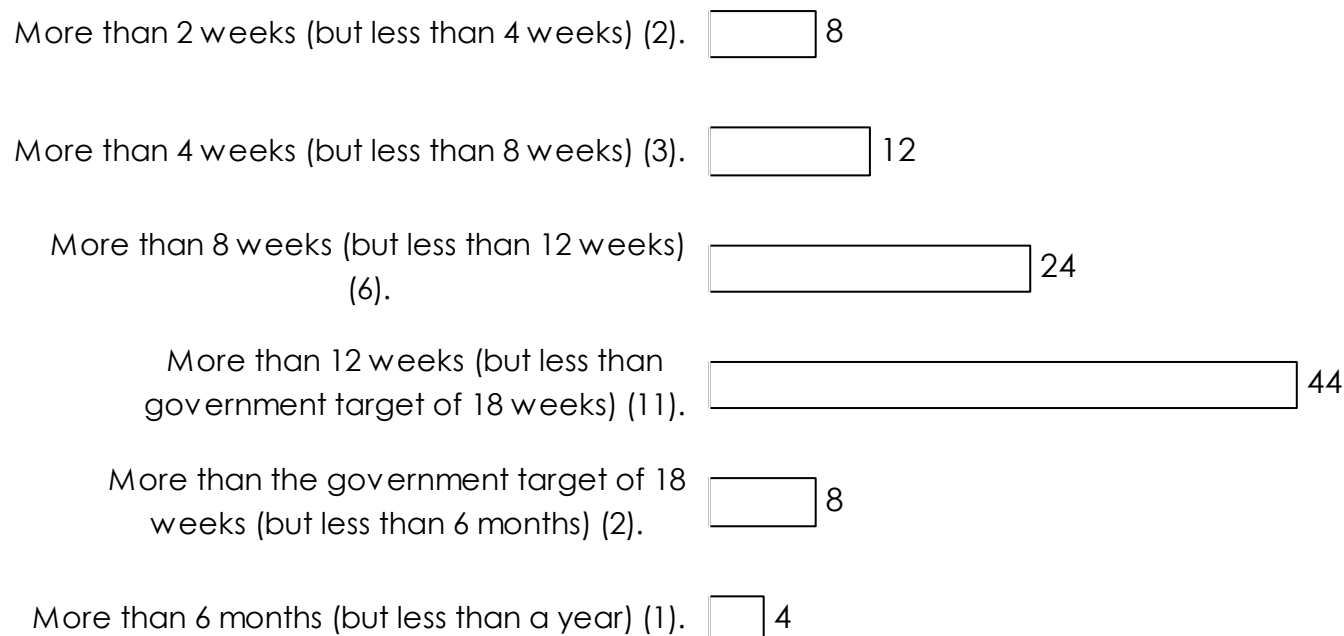
Respondents' comments highlight the following points (figure in brackets indicates number of comments in category):

1. A lack of communication between patients, GPs, and rheumatology clinics (4).
2. Patients have problems gaining access to the appropriate specialist (1).
3. Review criteria are only effective if up to date (1).
4. The latter are also only effective if the proper tests are carried out (1).
5. GPs can lack the training to implement effective review criteria @).

[For a full set of respondents' comments to this question, see *Appendix*, page 12.]

QUESTION 5: How long do patients with suspected RA typically have to wait to get a referral to a specialist (to obtain a diagnosis)?

% of responses from patient and disability groups based in England (excluding "don't knows"). Number of respondents answering the question =25. Number of "don't knows" = 5. The number in brackets denotes how many groups answered this category of the question, excluding don't knows.



The 25 respondent groups answering this question believe that patients with suspected RA are usually seen by a specialist within the government target period of 18 weeks.

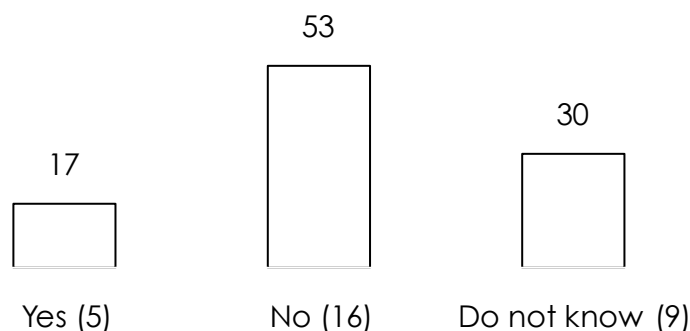
Comments from most respondents, though, indicate a conviction that further improvement is possible, and identify the following causes of inequity in access to RA consultants (figure in brackets indicates number of comments in category):

1. Lack of appropriate healthcare professionals (4).
2. Long waiting times (3).
3. Resources have had to be diverted away from meeting the needs of follow-up patients in order to accommodate the '18-week rule' (1).
4. A too-bureaucratic NHS (1).

[For a full set of respondents' comments to this question, see *Appendix*, page 13.]

QUESTION 6: Are people with RA referred quickly enough to avoid long-term damage from the condition?

% of responses from patient and disability groups based in England (excluding "don't knows"). Number of respondents answering the question =30. The number in brackets denotes how many groups answered this category of the question.



Over half of the respondent groups (16) answering this question, or 76% excluding don't knows, estimate that people with RA are not referred quickly enough to avoid long-term damage from the condition

Comments from several of the respondent groups offer explanations for their pessimistic outlook (figure in brackets indicates number of comments in category):

1. Lack of awareness of RA among GPs and the public alike (1).
2. A reluctance by GPs to refer quickly enough (1).
3. Overly long waiting times to see a specialist (and to receive test results) (5).
4. Failure of health professionals to make quality-of-life assessments (1).
5. Over-emphasis on conducting blood tests, rather than focusing on symptoms (1).

Only 24% of the respondents (5 groups) insist that patients are referred quickly enough. However, even these groups comment that the speed of referral can vary, and is dependent on the experience of the GP, and on whether the doctors involved put enough priority on the need to alleviate patient pain (or to avoid long-term damage as a result of RA).

[For a full set of respondents' comments to this question, see Appendix, pages 14-15.]

QUESTION 7: Have you any suggestions as to how diagnosis could be delivered more QUICKLY and more ACCURATELY?

The respondent groups suggest a number of ways to speed up diagnosis, and to make diagnosis more accurate (figure in brackets indicates number of comments in category. Some groups provided more than one comment):

- Greater awareness of RA among GPs and the public alike** (5). Suggested interventions include(4): more education for GPs and the general public on the importance of bone health, clarifying the distinction between general arthritis and the RA condition, emphasising the fact that RA does not necessarily occur in old age, and more funding for support organisations.
- Better education and training in RA for GPs** (12): focusing specifically on specialist health professionals with a declared interest in RA. Might include better knowledge of relevant diagnostic tests, improved tools to recognise RA symptoms early and improve referral, training days, ongoing professional development.
- More specialist services in primary care (such as rheumatology nurse specialists in GP practices)** (5): By having more specialist healthcare professionals available in primary and secondary care, patients might be able to access RA services directly.
- Implement national referral protocols** (1): in other words, better policing of these protocols.
- More joined-up working between primary and secondary care** (5): Such as telephonic communication between GPs and specialist services, or RA nurses working within a surgery setting. This would enable speedier delivery of test results and improve doctor-patient relationships, says one respondent.
- Reduce the length of waiting times to see specialists** (3): This could be achieved, says one respondent, by having more local RA clinics or offering patients appointments at alternative hospitals.
- Dedicate clinics (or specialist staff) to RA referral** (5):.Such clinics might be charged with conducting diagnostic tests and/or oversee triage.
- Improve the experience and the qualifications of staff in RA clinics** (2).

QUESTION 7 (continued):

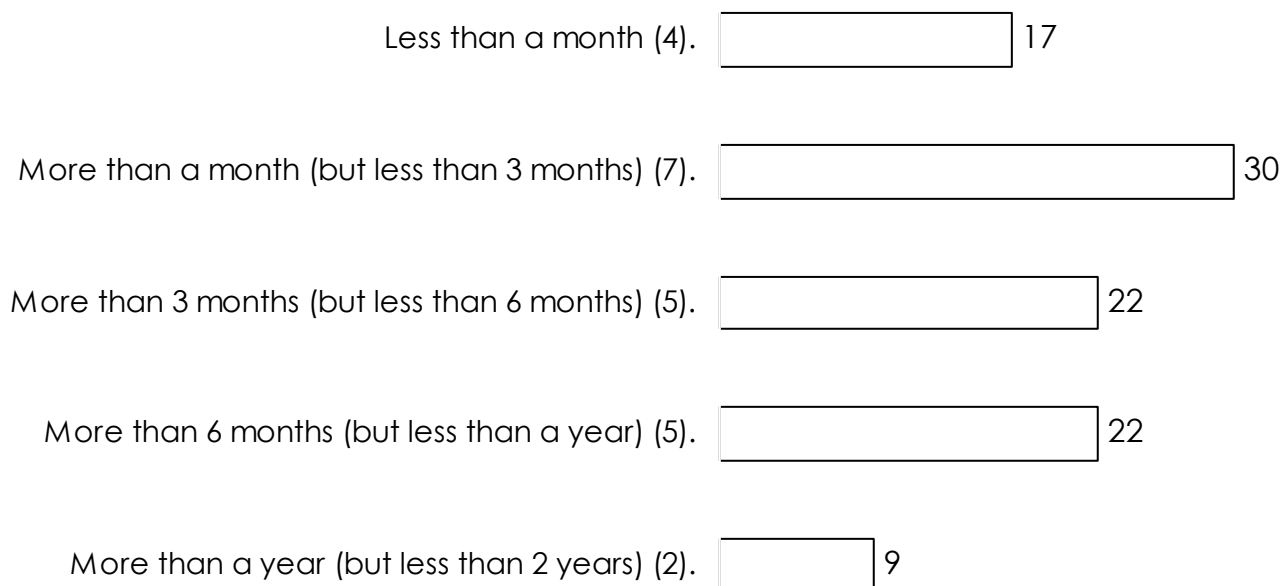
- Base diagnosis on individual need (and symptoms), not government targets (2):**
And taking the patient seriously.
- Include quality-of-life assessments when making diagnoses (1):** Such as joint pain.
- Initiate tests more quickly (1).**

[For a full set of respondents' comments to this question, see *Appendix*, pages 16-19]

II. Questions on treatment and care

QUESTION 8: Typically, how long does it take between a person with RA receiving diagnosis, and their obtaining the correct treatment?

% of responses from patient and disability groups based in England (excluding "don't knows"). Number of respondents answering the question = 23. Number of "don't knows" = 6. The number in brackets denotes how many groups answered this category of the question.



A majority (54%) of the respondent groups answering the question state that patients diagnosed with RA are do not access the correct treatment and care within six months. Two groups say patients can wait for more than one year to get appropriate treatment and care.

Respondents' explanations for such delay include (figure in brackets indicates number of comments in category):

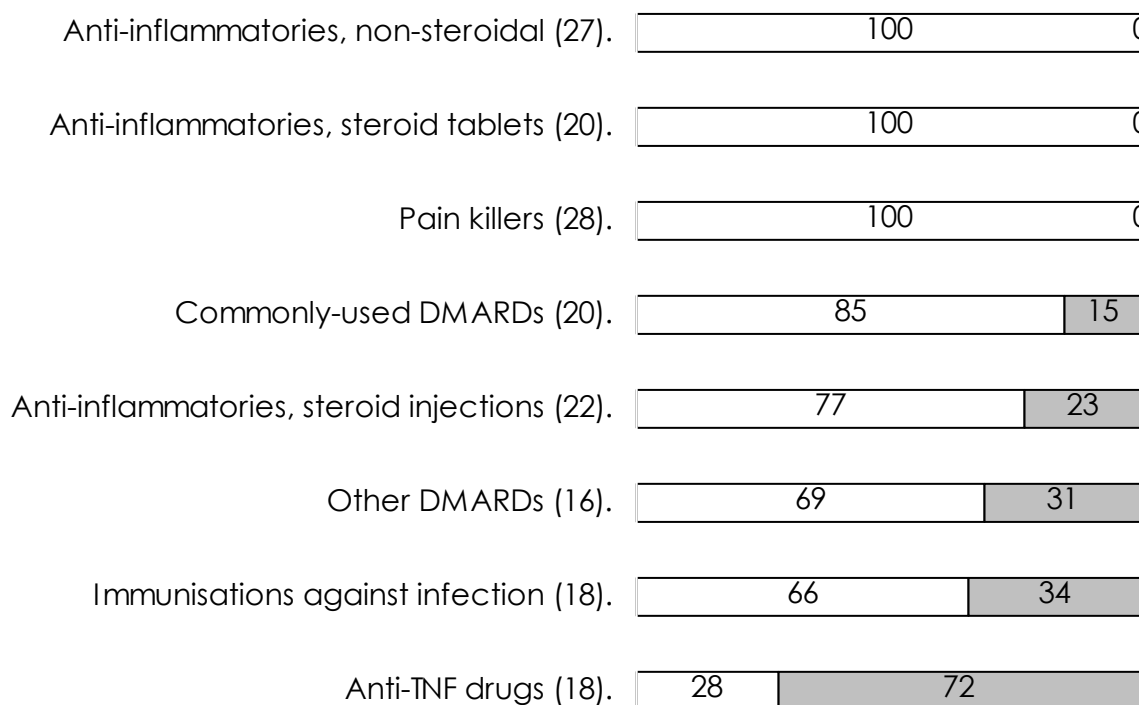
1. Failure of people with RA to themselves come forward for care (2).
2. Limited GP budgets (1).
3. Lengthy waiting times to see a consultant (2).
4. Time delays for a medication to work (2).
5. Finding the correct treatment that suits the individual patient can take time (2).

[For a full set of respondents' comments to this question, see Appendix, page 21]

QUESTION 9a: How easy or difficult is it for people with RA to obtain the following, once the doctor recommends their use?

Treatments

% of responses from patient and disability groups based in England (excluding "don't know").
The number in brackets denotes how many groups answered that category of the question.



Very easy/straightforward. Quite/very difficult.

Footnote:

Pain killers (such as codeine, ibuprofen, and paracetamol).

DMARDs (disease-modifying drugs).

Commonly-used DMARDs (such as gold injections, gold tablets, hydroxychloroquine, leflunomide, methotrexate, penicillamine, and sulfasalazine).

Other DMARDs (such as azathioprine, cyclophosphamide, and cyclosporin).

Anti-TNF drugs (such as adalimumab, anakinra, etanercept, and infliximab).

QUESTION 9a (continued):

The majority of the respondent groups answering this question consider that accessing most RA treatments is “easy” or “straightforward”. The exception is anti-TNF drugs.

Other caveats outlined in respondents' comments include (figure in brackets indicates number of comments in category):

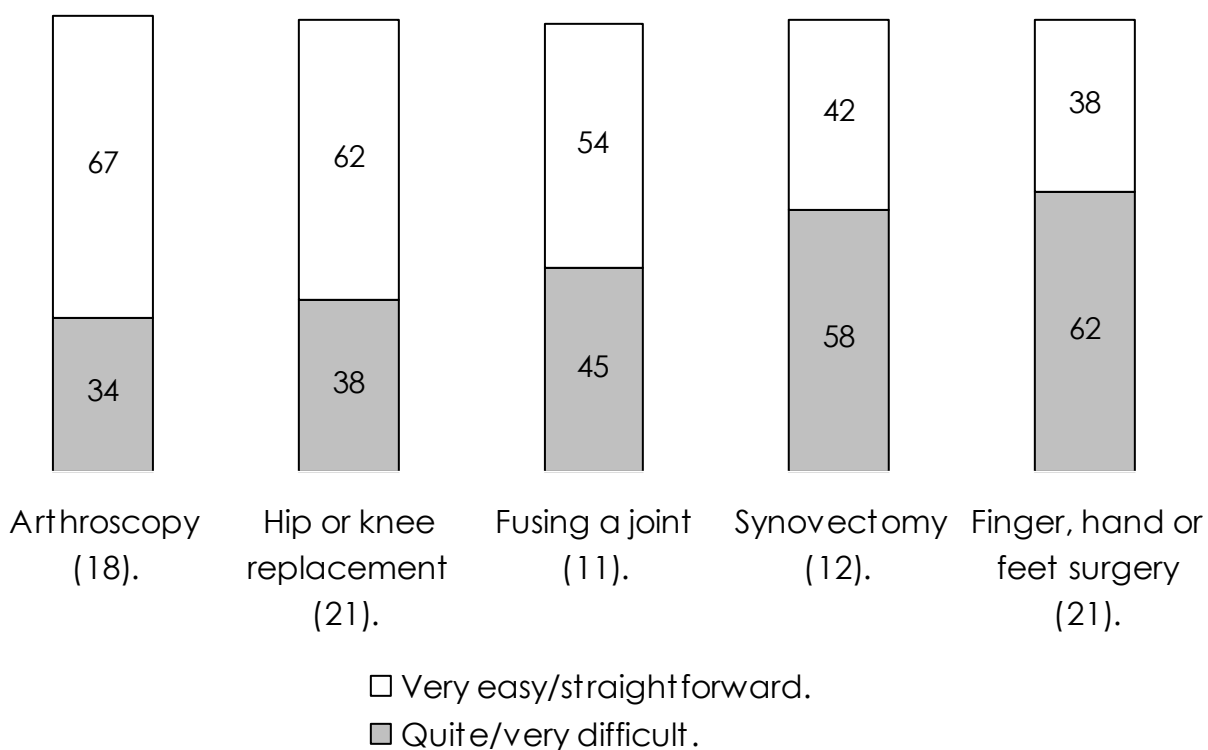
1. A lack of information about GP prescribing habits makes assessing the scale of RA treatment in primary care impossible (1).
2. Some medicines have side-effects (1).
3. Co-proxamol is difficult to access (1).
4. DMARDs can be difficult to access, because of the special tests and appointments required with nurse specialists (1).
5. Post-code lottery still occurs. Certain RA drugs are therefore difficult to access in various parts of the country (2).
6. Patients may need to try several different treatments before they find one that works for them. This could be a lengthy process (4).

[For a full set of respondents' comments to this question, see *Appendix*, pages 22-23.]

QUESTION 9b: How easy or difficult is it for people with RA to obtain the following, once the doctor recommends their use?

Surgery

% of responses from patient and disability groups based in England (excluding "don't know"). The number in brackets denotes how many groups answered that category of the question.



Footnote:

Arthroscopy (removal of debris or inflamed tissue).

Synovectomy (removal of inflamed tendons).

Surgery to fuse a joint (for instance, in the neck).

QUESTION 9b (continued):

The majority of the respondent groups rate some operations as difficult to access—notably surgery of the finger, hand, or feet, and the removal of inflamed tendons (synovectomy).

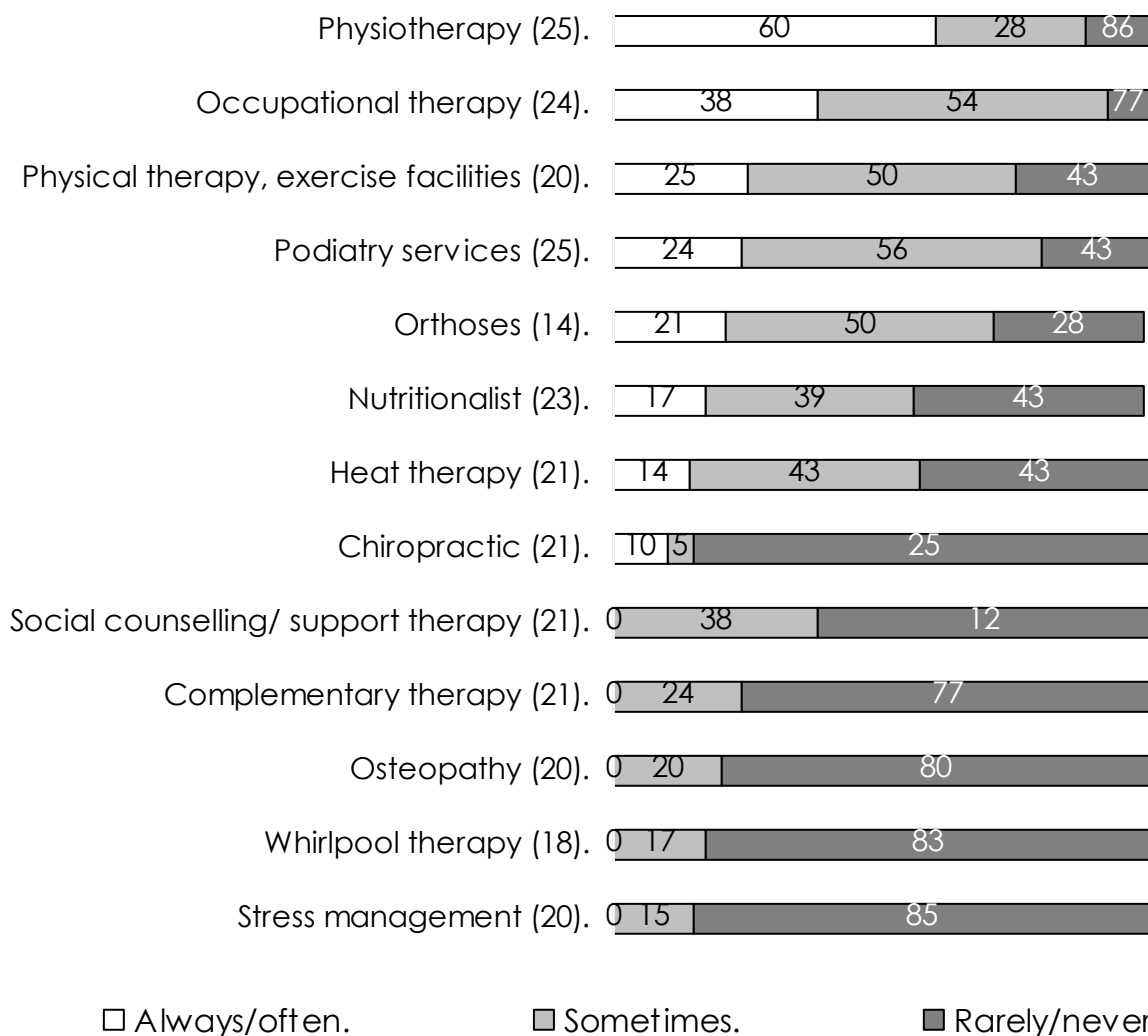
Comments about these and other difficulties include (figure in brackets indicates number of comments in category):

1. Lengthy waiting times for an initial appointment with a surgeon (1).
2. Surgical procedures may not be provided locally, obliging some patients to make long journeys to hospital (1).
3. Not all operations are equally accessible (as mentioned above). One of the problems is the small number of surgeons who specialise in certain types of RA surgery (3).
4. Some patients (primarily people who are young, overweight, or who have other health problems) may find surgery difficult to access (1).
5. Sometimes surgery is only available when medical treatment fails (1).
6. In a few cases, the outcomes of surgery can be disappointing from the patients' perspective (1).

[For a full set of respondents' comments to this question, see *Appendix*, pages 24-25.]

QUESTION 10: Do doctors typically offer the following types of support to their patients with RA?

% of responses from patient and disability groups based in England (excluding "don't knows"). The number in brackets denotes how many groups answered that category of the question.



QUESTION 10 (continued):

Respondent groups report that all non-medical or complementary treatments (with the possible exception of physiotherapy) are difficult to access on the NHS—despite a high value being placed upon these procedures by patients and the respondent groups.

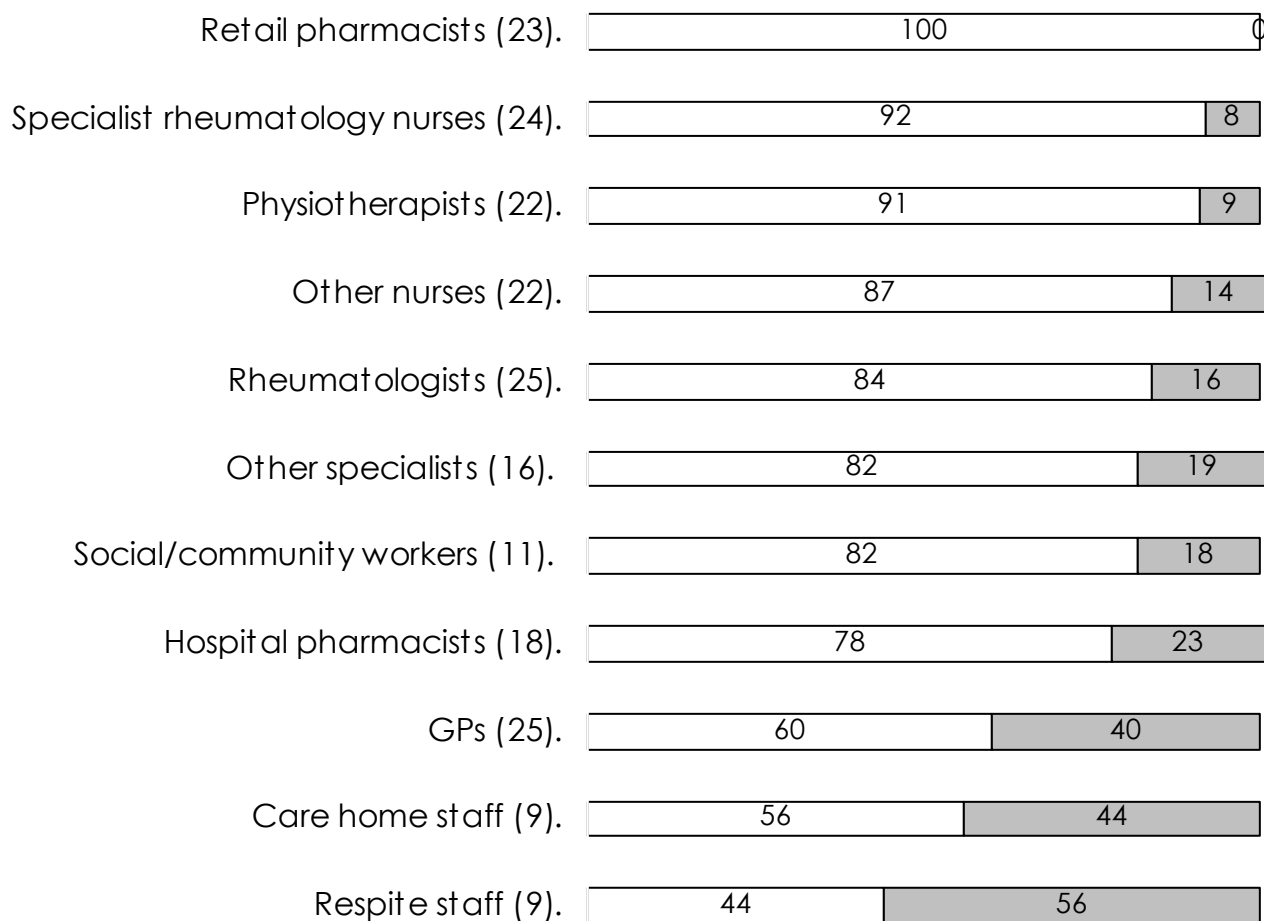
Respondents offer comments on the following subjects (figure in brackets indicates number of comments in category):

1. GPs lack understanding of the benefits of non-medical/complementary therapies (2).
2. Not all health professionals have access, or are willing to refer, to these services (6).
3. Non-medical/complementary treatments are often not given to patients long enough to be effective (1).
4. Although some non-medical types of support can be provided by patient groups, the NHS does not exploit this supply (2).

[For a full set of respondents' comments to this question, see *Appendix*, pages 26-27.]

QUESTION 11: Generally speaking, how satisfied or dissatisfied are RA patients with the care they receive from the following healthcare (or healthcare-related) professionals?

% of responses from patient and disability groups based in England (excluding "don't know"). The number in brackets denotes how many groups answered that category of the question.



Very satisfied/satisfied.

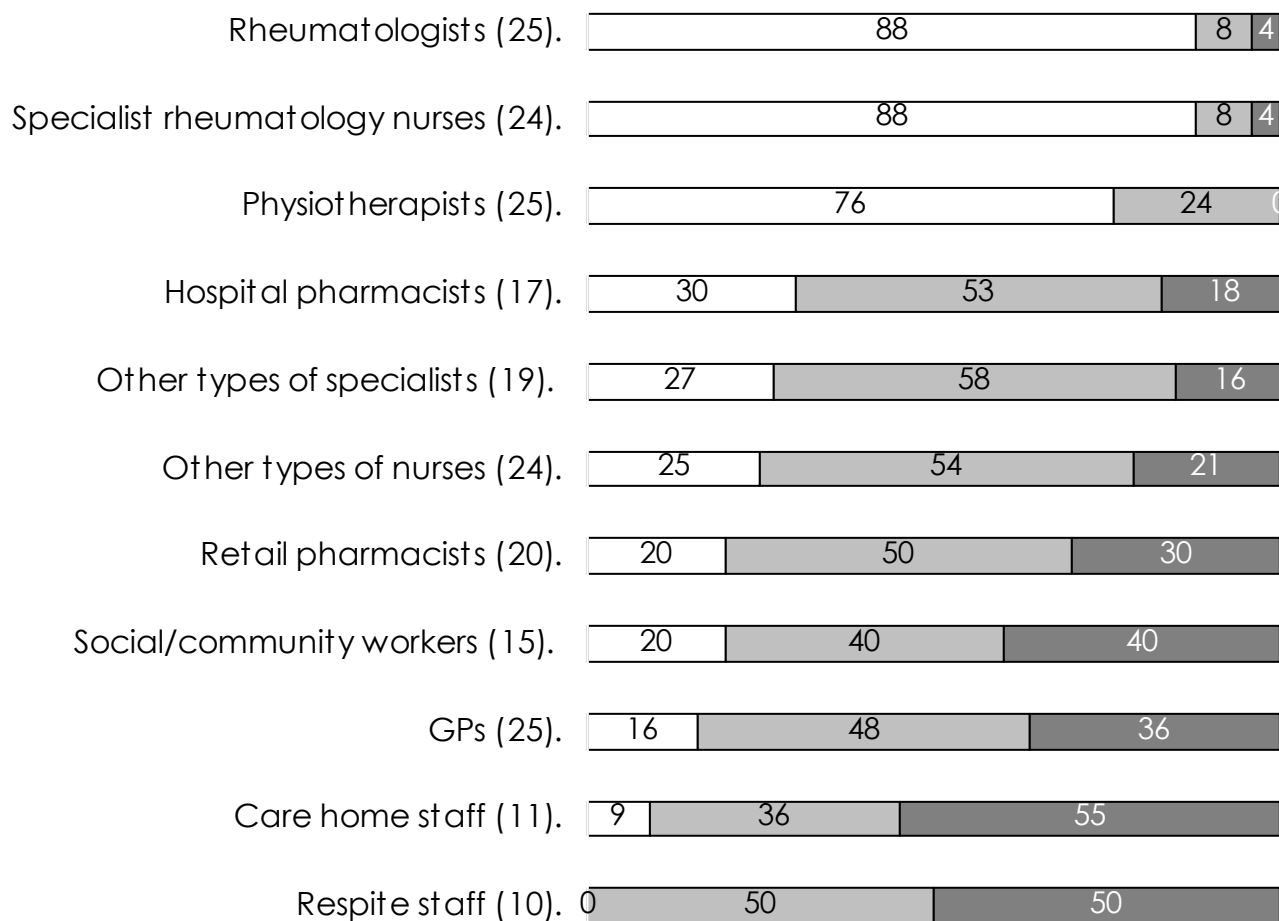
Dissatisfied/very dissatisfied.

Respondent groups are, on the whole, satisfied with the services supplied by a broad range of healthcare professionals. GPs are deemed to be the least satisfactory of the front-line NHS staff. The poorest-performing category of staff of all, however, is respite staff (though the results are ambiguous here, since only nine groups felt equipped to comment on these professionals).

Several respondents comment that access to many of the healthcare professionals listed can be limited, and dependant on the personal inclinations of the patient's doctor. Comments about GPs, hospital pharmacists, occupational therapists, retail (community) pharmacists, rheumatology physiotherapists, and specialist nurses can be found in the *Appendix*, page 28.

QUESTION 12: To what extent do the following types of healthcare (or healthcare-related) professionals generally understand RA?

% of responses from patient and disability groups based in England (excluding "don't knows"). The number in brackets denotes how many groups answered that category of the question.



Very good/good understanding. Adequate understanding. Poor understanding.

Over three quarters of the respondents maintain that consultant rheumatologists, specialist rheumatology nurses, and physiotherapists all have a "very good" or "good" understanding of RA. Respondents perceive the RA knowledge levels of other health professionals (including GPs) as being very much poorer.

[For a full set of respondents' comments to this question, see Appendix, page 29.]

QUESTION 13a: If people with RA are to avoid long-term damage caused by the condition, they need prompt access to the correct treatment and care. What barriers hinder people with RA from getting such access?

Respondent groups' comments identify the following major hurdles to accessing prompt treatment and care (figure in brackets indicates number of comments in category):

1. Long waiting times to see specialists and a poor rate of referral from some GPs (18).
2. Lack of public awareness of RA (7).
3. Lack of knowledge of RA among GPs (3).
4. Lack of locally-accessible services (3).
5. Delays in diagnosis (1).
6. A low priority given by the NHS to musculo-skeletal diseases (and their impact on patients' quality of life) (2).

[For a full set of respondents' comments to this question, see *Appendix*, pages 30-32.]

QUESTION 13b: What has helped secure prompt access to correct treatment and care?

Two respondent groups claim that nothing has been done to improve access to correct treatment care. A number of the other groups draw attention to the following recent improvements (figure in brackets indicates number of comments in category):

1. High-quality information delivered appropriately (1).
2. Greater public knowledge of RA (1).
3. Informed GPs working with referral pathways (10).
4. More rheumatologists. (2)
5. Continuity of high-quality care (1).
6. Adequate funding (1).
7. The involvement of local support groups (3).

[For a full set of respondents' comments to this question, see *Appendix*, pages 33-34.]

QUESTION 14: Have you any suggestions as to how correct treatment and care can be delivered to RA patients quickly?

The respondent groups suggest a number of ways to speed up access to care and treatment (figure in brackets indicates number of comments in category. Some groups provided more than one comment):

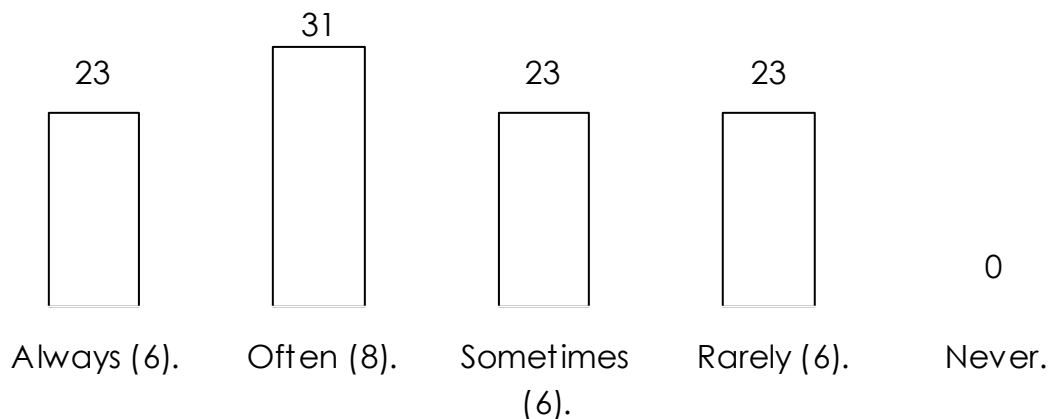
- **Raise public awareness of RA** (3), notably that RA is distinct from generic arthritis and of the importance of people to seek help early.
- **Improve communications between healthcare providers and patients** (1), so people feel more comfortable talking to their doctors.
- **Provide GPs with RA training** (5) at the beginning of their medical education and throughout their careers, to enable prompt referrals.
- **Refer directly to RA clinics for diagnosis (and for continuity of care)** (3), even for initial assessment.
- **Provide more consultants (and related healthcare staff)** (8), to speed up referral procedures.
- **Expanding the NICE remit** (1) to consider RA's wider costs to society.
- **Implement agreed standards for RA treatment and care nationwide** (3), to reduce the huge variability in the way the disease is treated, particularly following initial diagnosis.
- **Involve user groups more** (1), so that patients can use them for support.

[For a full set of respondents' comments to this question, see Appendix, pages 35-36.]

III. Questions on long-term care

QUESTION 15: Is the effectiveness of the treatment of people with RA reviewed regularly?

% of responses from patient and disability groups based in England (excluding "don't knows"). Number of respondents answering the question = 30. Number of "don't knows" = 4. The number in brackets denotes how many groups answered that category of the question.



Respondents say that people with Rheumatoid arthritis (RA) are regularly reviewed in some parts of England, whilst in other parts of the country, RA seems rarely to be reviewed on a regular basis.

The quality of the reviewing also appears to vary nationwide. Arthritis Care, a national patient group, thinks that the process does not occur ...

“... at a health-service level. Good-quality audits, or PCTs analysing patient pathways, are not undertaken routinely. Pharmacological effectiveness is reviewed sometimes, though.”

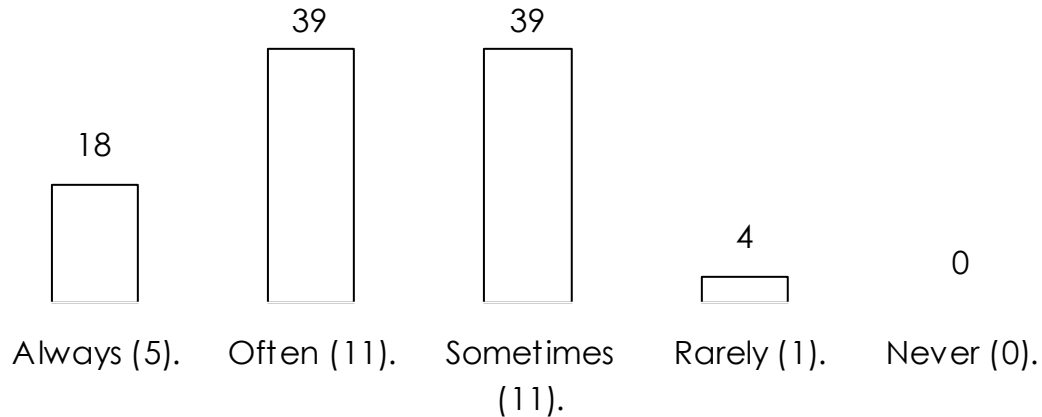
Thus, regular, high-quality review of RA is inconsistently implemented England-wide. Some respondents blame this on the presence of the 18-week new-patient waiting target, and believe that new patients are being prioritised at the expense of existing patients. The National Rheumatoid Arthritis Society explains:

“Patients are being bumped off lists to enable units to meet the 18-week target for new patients.”

[For a full set of respondents' comments to this question, see *Appendix*, page 38.]

QUESTION 16: Is the treatment of people with RA adapted as the person’s medical condition and physical state progresses or changes?

% of responses from patient and disability groups based in England (excluding “don’t knows”). Number of respondents answering the question = 30. Number of “don’t knows” = 2. The number in brackets denotes how many groups answered that category of the question.



18% of the survey’s 30 respondent groups are sure that the treatment of RA is “always” adapted as a person’s medical condition and physical state progresses or changes. A further 39% believe that such adaptation happens “often”. The remaining respondents—43%—think that the treatment of RA is only “sometimes” or “rarely” adapted to take account of changing medical condition/physical state.

The National Rheumatoid Arthritis Society estimates that services required to ensure continuity of care are patchy across the UK:

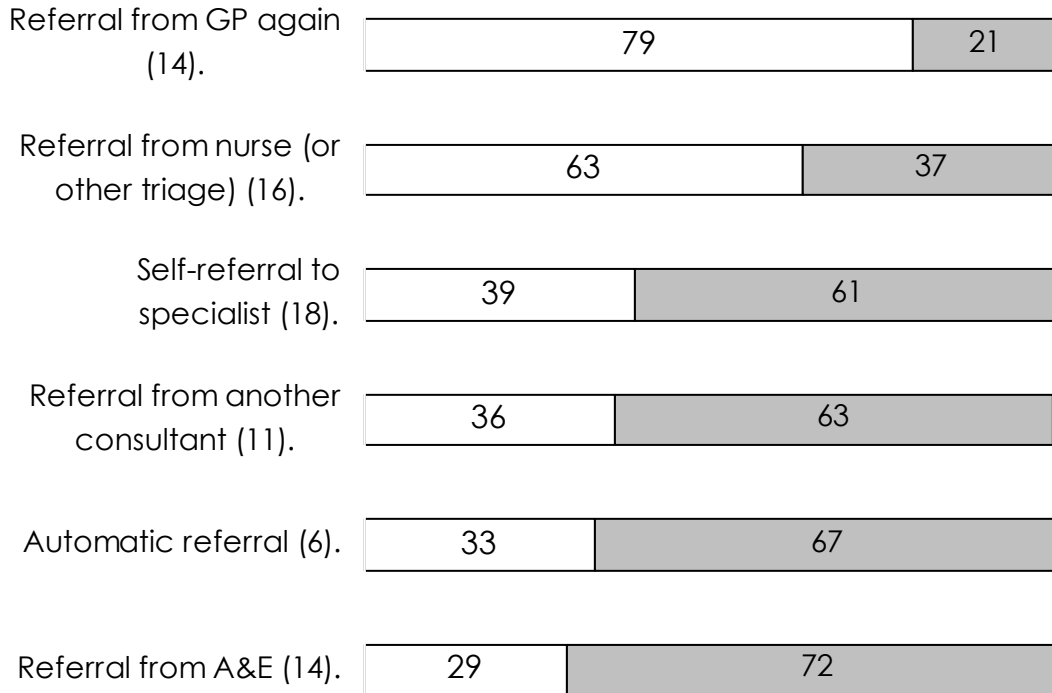
“It should be often—but, again, this is variable throughout the UK, and we see too many patients slipping quietly into disability because they are not being tightly enough monitored.”

Aside from problems with monitoring, other factors that respondents mention as impeding treatment reviews include: the fact that patients have to prompt a treatment re-evaluation themselves; the failure of healthcare providers to listen to, and understand, their patients; whether patients are being cared for within a primary-care, rather than a secondary-care setting (patients managed at the latter level receive more services); and whether consultant rheumatologists are willing to adopt state-of-the-art practice.

[For a full set of respondents’ comments to this question, see Appendix, page 39.]

QUESTION 17: Once people with RA have been seen by a specialist, by what means do they typically obtain a follow-up appointment to the specialist?

% of responses from patient and disability groups based in England (excluding "don't know"). The number in brackets denotes how many groups answered that category of the question.



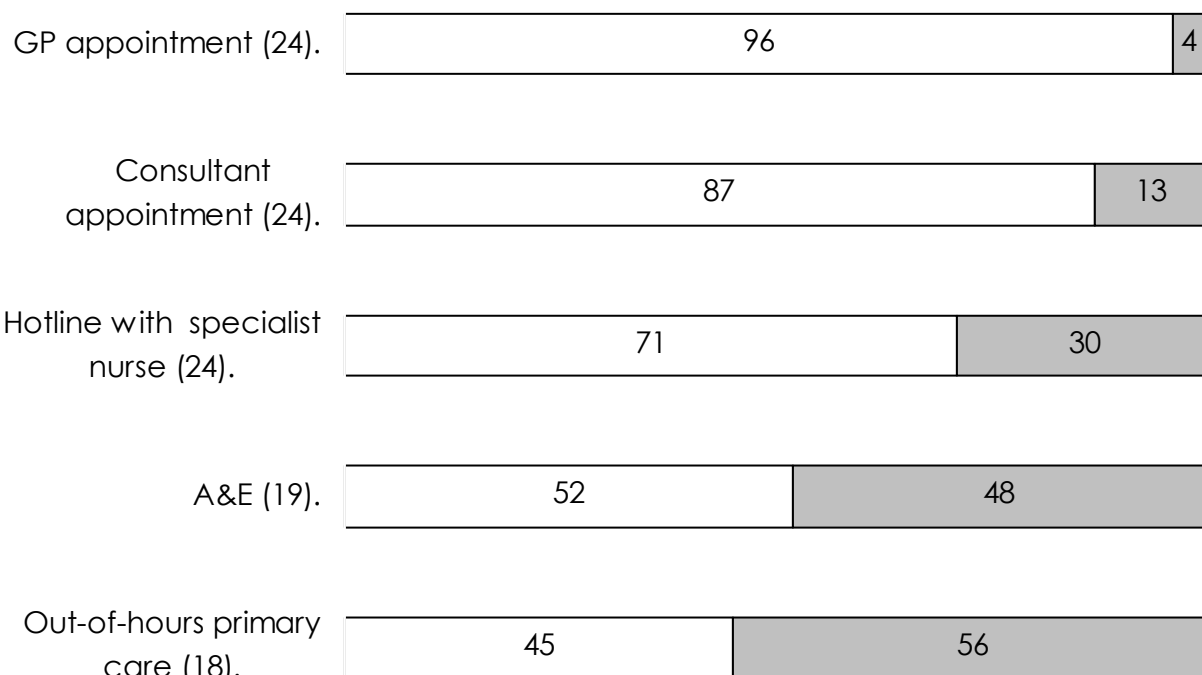
Usually/sometimes happens. Rarely/does not happen.

Respondents indicate that most people with RA are obliged to seek a follow-up appointment with a specialist via a GP or nurse. The National Rheumatoid Arthritis Society believes that few stable patients are provided with the annual review recommended by guidelines. Three groups comment that the current follow-up appointment system is ineffective. An RA support group from Yorkshire and North Humber, for example, states:

“Our members are very dissatisfied with the follow-up appointments booking system. Previously, a follow-up appointment was made after every consultation. But the new system does not allow this. Patients are contacted by letter when their appointment becomes due (for instance, every three months). They are then invited to call the hospital to make an appointment. This means that patients have to wait much longer than three months, because appointments are usually not available immediately. Also, it is not uncommon for patients not to receive this follow-up letter, or for it to be lost in the post.”

QUESTION 18: Which of the following services do you expect people with RA to access in the event of a flare-up?

% of responses from patient and disability groups based in England (excluding "don't know"). The number in brackets denotes how many groups answered that category of the question.



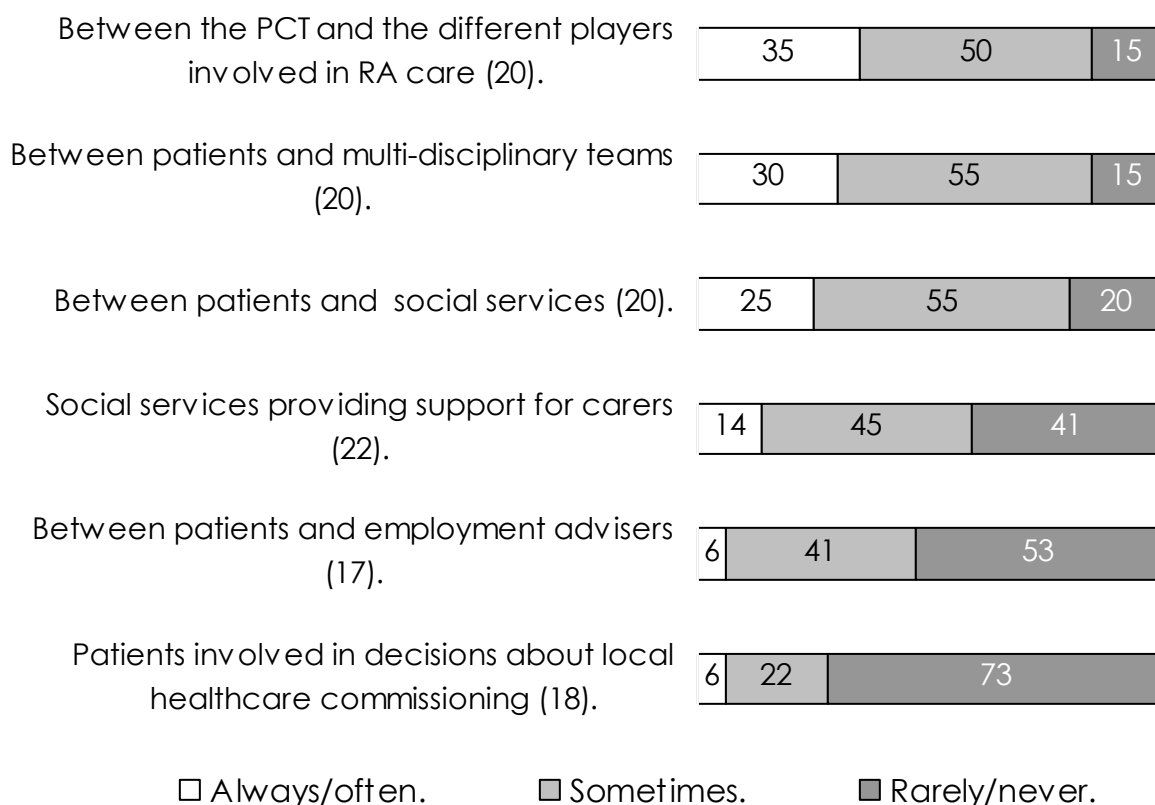
Usually/sometimes happens. Rarely/ does not happen.

Respondents' answers suggest that patients expect to be able to contact specialists, nurses, and GPs (or even A&E) in the event of a flare up. Respondents' comments, however, illuminate practical difficulties, including: newly-diagnosed patients may not know who to contact; specialist nurses can be telephoned, but may not be available to reply. As a result, some patients resort to the private sector. The National Rheumatoid Arthritis Society summarises:

"Unfortunately, because people know how difficult it is to get effective help quickly in event of a flare-up, many just take themselves to bed and wait it out. If very severe, they will contact their nurse specialist or GP. GPs, however, are often not very helpful or proactive in these circumstances, and may just advise contacting the rheumatology team. The nurse-led helplines usually get back to patients within 24 or 48 hours, and are very helpful. But, if the flare-up is really severe, urgent help is needed straight away."

QUESTION 26: When referring to the delivery of long-term RA care: can you indicate whether joint working occurs locally in the following cases?

% of responses from patient and disability groups based in England (excluding "don't knows"). The number in brackets denotes how many groups answered that category of the question.



The main message from respondents' comments seems to be that the occurrence of joint working varies across the country (and even within regions). Comments isolate particular obstacles to joined-up working, including: doctors who are insensitive to patients' wishes; and a high turnover of staff. Arthritis Care comments:

"The multidisciplinary team in secondary care generally works very well, as people are clear about roles and responsibilities. The relationship between primary and secondary care is less effective. The joint working between patients and social services tends to be one way. This may change with devolved personalised budgets."

[For a full set of respondents' comments to this question, see Appendix, page 42.]

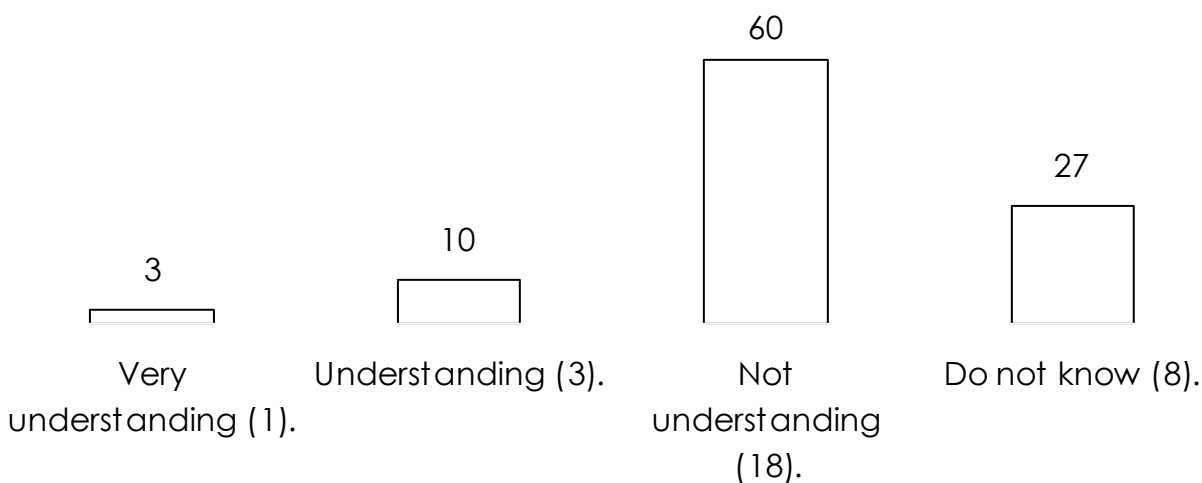
IV. Questions on employment

QUESTION 19: Generally, how understanding would you say employers are towards people with RA?

% of responses from patient and disability groups based in England.

Number of respondents answering the question = 30.

The number in brackets denotes how many groups answered that category of the question.



60% of the respondents rate employers as “not understanding” towards people with RA.

Nine of the eleven comments from respondents advise that employers lack comprehension of RA. These respondents regard employers as ignorant of the condition, eager to get rid of employees diagnosed with it, and—mostly—failing to offer flexible working conditions.

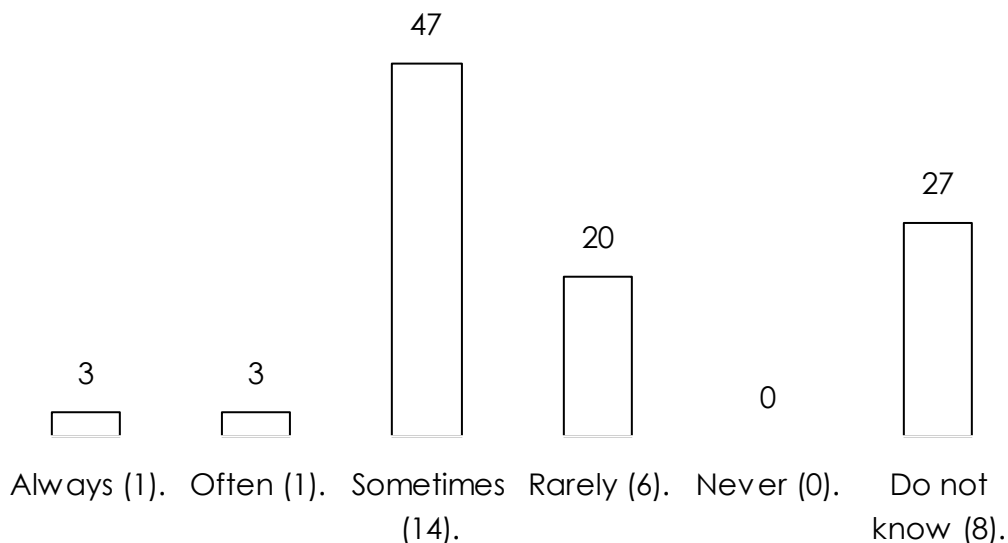
Only one comment—from the respondent representing the interests of Dudley Rheumatoid Arthritis Support Group—details understanding from an employer. But, the comment describes a single personal experience:

“My current employer helps people get back to work when they’ve been ill—so they are understanding regarding many conditions.”

[For a full set of respondents’ comments to this question, see *Appendix*, page 44.]

QUESTION 20: How often do employers generally provide support to people with RA, to help them continue in employment?

*% of responses from patient and disability groups based in England.
Number of respondents answering the question = 30
The number in brackets denotes how many groups answered that category of the question.*



Twenty respondents judge that employers only “sometimes” or “rarely” provide support to people with RA.

Respondents list the following types of support provided by employers: permission to switch jobs; flexible working hours; time off work when needed; and provision of specialised working equipment and adjustments to the physical environment of the workplace.

[For a full set of respondents' comments to this question, see Appendix, page 45.]

QUESTION 21: What are the main barriers to employers providing support?

Respondents' comments feature three main barriers that prevent employers from providing support to people with RA (figure in brackets indicates number of comments in category. Some groups provided more than one comment):

- Employers' lack of understanding of RA, and their lack of knowledge of the services available to them to assist people with RA** (16), furthermore the employers appear to lack the willingness to find out more about RA.

- A fear among employers that supporting people with RA will be costly to them, and disruptive to business** (9).

- Employers' lack of awareness of legal responsibilities towards people with a disability** (1), a problem which seems particular to SMEs.

[For a full set of respondents' comments to this question, see *Appendix*, pages 46-47.]

QUESTION 22: Regarding support for people with RA to remain in work: can you name any good-practice employers who provide support for people with RA to remain in work?

If you have been able to name any, what are the main characteristics of the support offered by these particular employers (as opposed to other employers)?

Good-practice employer	Main characteristics of the support offered
BT	"Fast support service, with continued assessment and support for managers, as well." —Arthritis group, UK-wide.
Plymouth Social Services	"Adapting work space to minimise physical stress; and the use of an occupational therapist to assess and respond to workplace needs." —Plymouth and District Rheumatoid Arthritis Group Support.
BT Arthritis Care Royal Mail	"Good knowledge of arthritis; good policies (such as disability leave); flexible working policies; openness to discussion about the impact of arthritis on wider life, rather than making assumptions; good role models within the organisation; frequent prompts to managers as to their responsibilities." —Arthritis Care, UK-wide.
Seetec, Dudley	"Flexibility in allowing RA sufferers to attend appointments, or to alter their working hours." —Dudley Rheumatoid Arthritis Support Group.
One member of a respondent group who has a supportive employer works for the Prison Service ; another works for a solicitor specialising in employment law	"Understanding of RA; special equipment provided; flexible hours; and time off for appointments." —RA Support group, Yorkshire and North Humber.
Local authorities and the voluntary sector	"Ergonomic improvements; change of job; and change of hours." —Young Arthritis Support, Isle of Wight.
Large employers with occupational health departments	"Keeping their job open for them during sickness; and ergonomic assessment." —Arthritis group, West Midlands.

QUESTION 23: What support does the NHS provide to people with RA, to help them continue in employment?

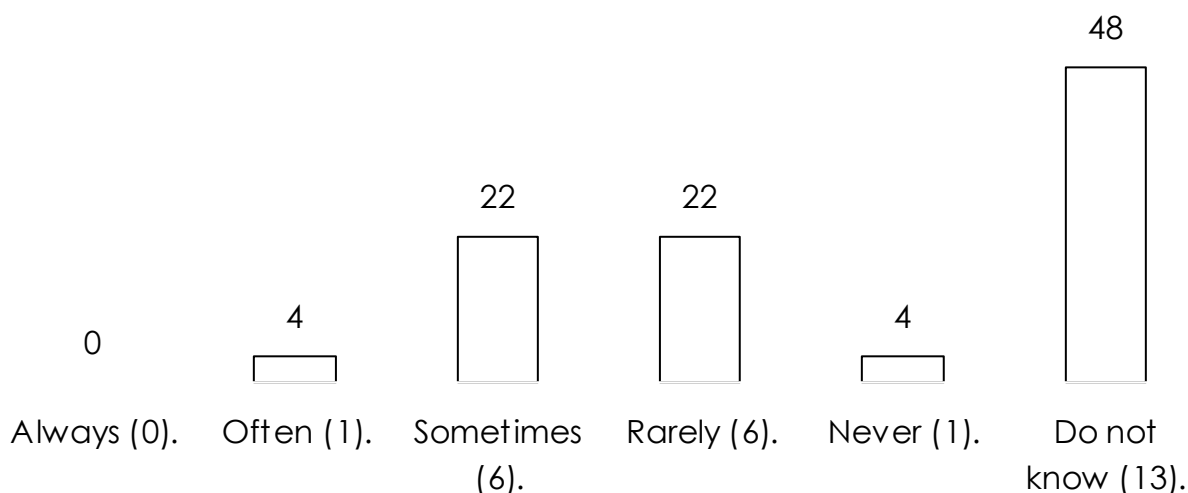
Eight of the respondents' comments emphasise that people with RA get little support from the NHS to help them continue in employment (figure in brackets indicates number of comments in category. Some groups provided more than one comment):

Comments from two or three respondents do, however, identify NHS efforts to provide courses and information, fitness programmes, hydrotherapy, physiotherapy, and the necessary medication.

[For a full set of respondents' comments to this question, see *Appendix*, page 49.]

QUESTION 24: How often does the NHS provide support to people with RA, to help them continue in employment?

*% of responses from patient and disability groups based in England.
Number of respondents answering the question = 27
The number in brackets denotes how many groups answered that category of the question.*



Only 14 groups (52% of the respondents answering the question) felt able to specify the frequency with which they believe the NHS provides support to people with RA to help them continue in employment.

Dudley Rheumatoid Arthritis Support Group answered “often”. In a comment to question 23, the representative from this group mentions personally receiving a good deal of support in the form of physio- and hydrotherapy, and fitness programmes.

The remaining respondents consider that the NHS provides support “sometimes”, “rarely”, or “never”.

Arthritis Care explains the reluctance of the NHS to become involved in work-related rehabilitation:

“Partly because work issues are not prioritised by the NHS, and partly because the NHS does not see that it has a major role to play in this area.”

[For a full set of respondents' comments to this question, see Appendix, page 50.]

QUESTION 25: What are the main barriers to the NHS helping people with RA continue in employment?

Respondents' cite three main barriers facing the NHS when (and if) it supplies support to people with RA to get back to work:

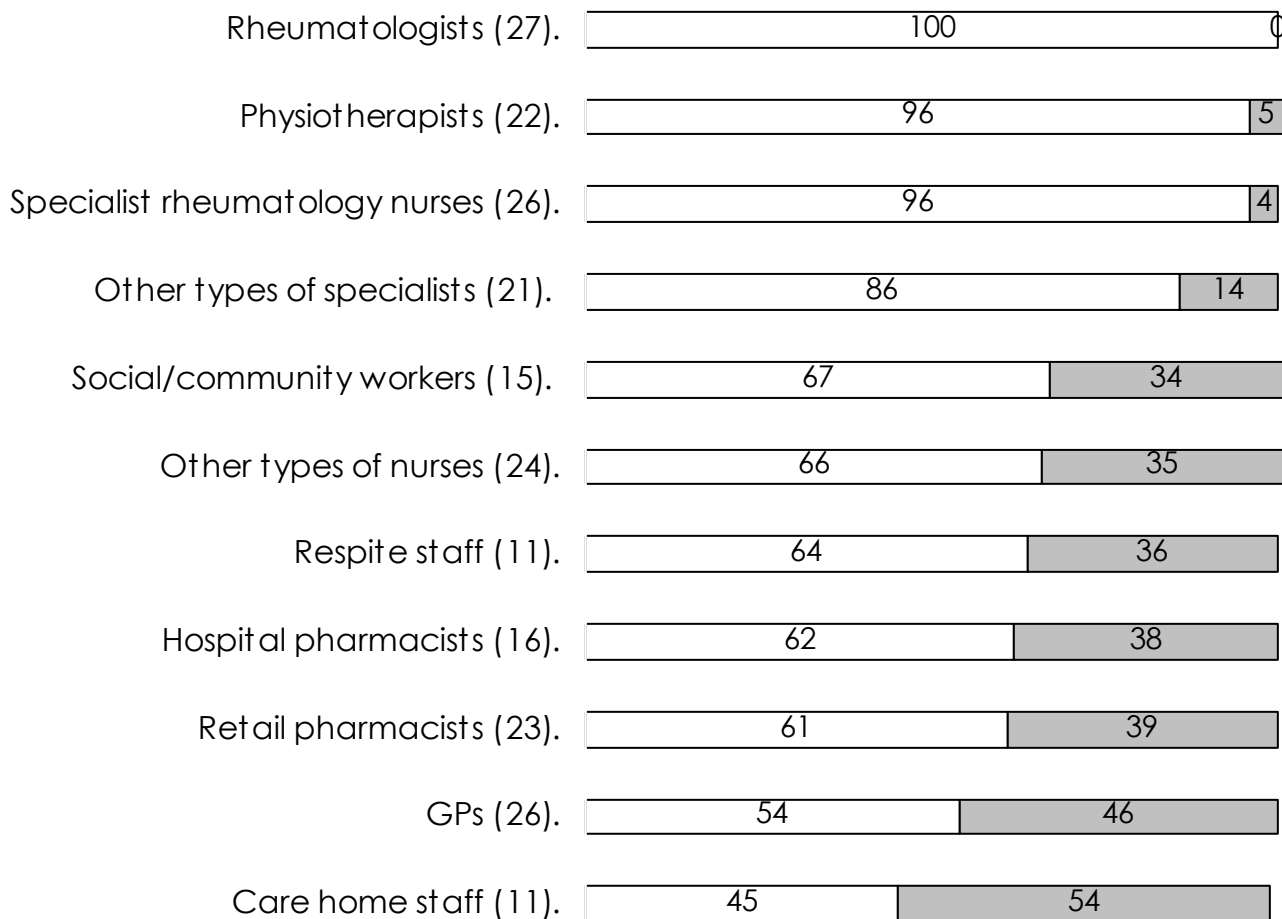
- A lack of NHS resources and staff time (10).**
- A lack of appropriate knowledge and skills among NHS staff (6).**
- Helping people with RA continue in their employment is not a strategic priority for the NHS. The organisation currently has few incentives to move in such a direction (3).**

[For a full set of respondents' comments to this question, see *Appendix*, pages 51-52.]

V.
Questions on information and
self-management

QUESTION 27: How helpful or unhelpful are the following in supplying information on RA to people with RA?

*% of responses from patient and disability groups based in England (excluding "don't knows").
The number in brackets denotes how many groups answered that category of the question.*



Very/quite helpful.

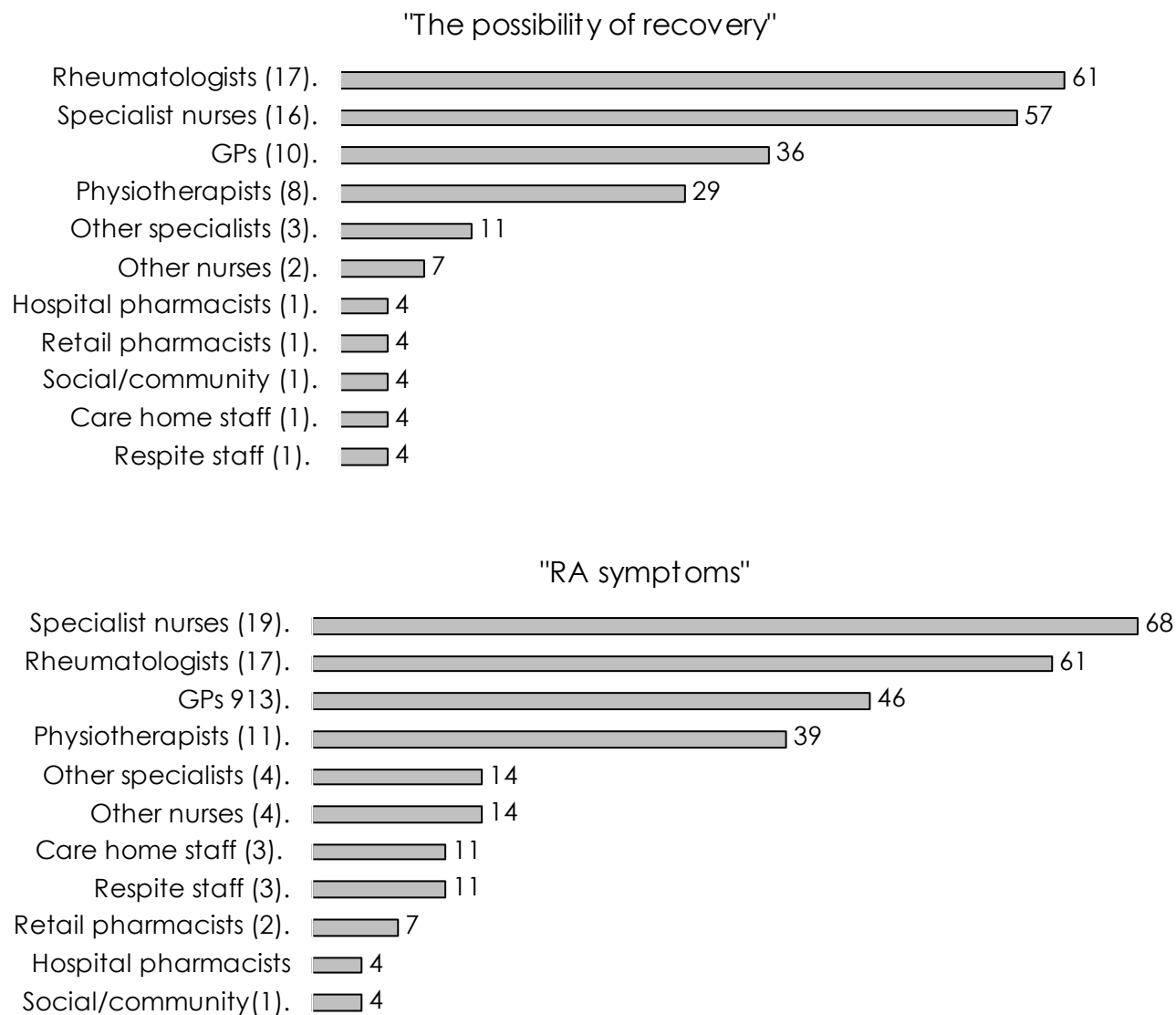
Quite unhelpful/not at all helpful.

Respondents' comments suggest that most health professionals are helpful in supplying relevant information to people with RA. The National Rheumatoid Arthritis Society, a UK-wide organisation, notes that most professionals "are not deliberately unhelpful, but their helpfulness is hindered by a lack of knowledge and expertise".

[For a full set of respondents' comments to this question, see Appendix, page 54.]

QUESTION 28: Would people with RA like to receive more of the following types of information from the following sources?

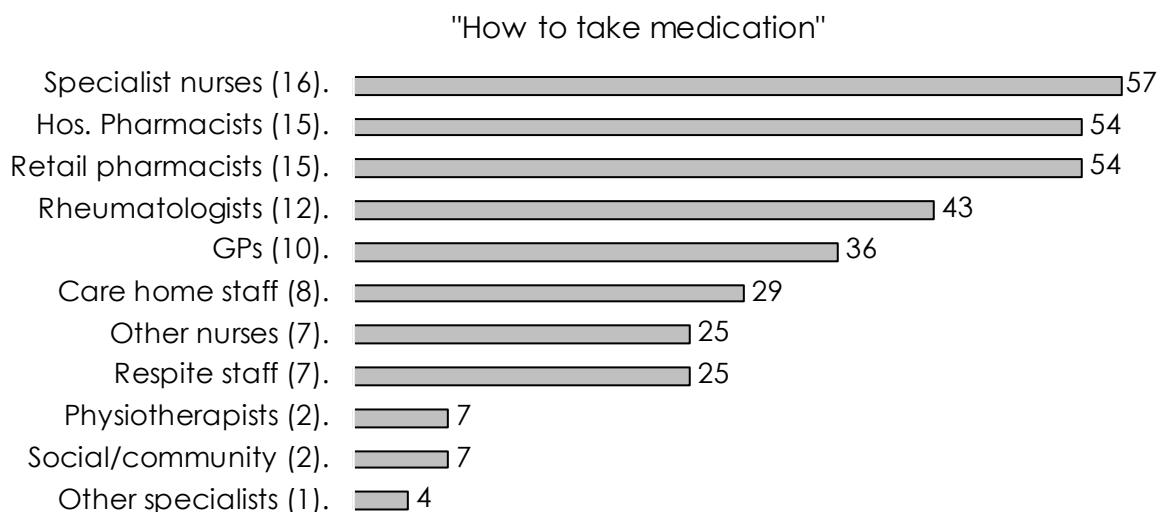
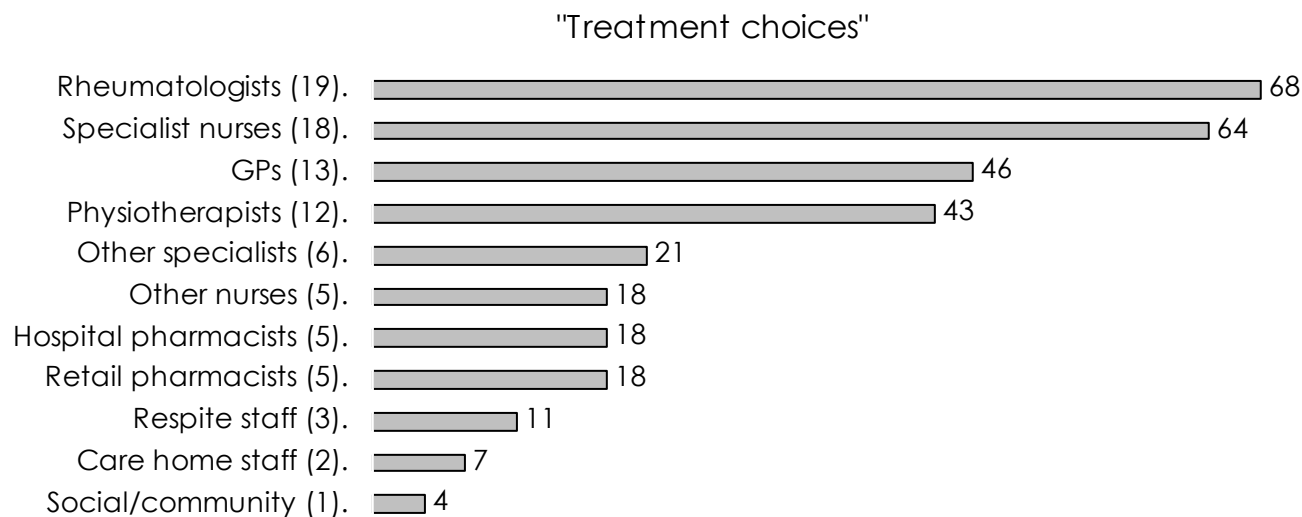
*% of responses from patient and disability groups based in England (excluding "don't know").
Number of respondents answering the question = 28.
The number in brackets denotes how many groups answered that category of the question.*



Footnote:
Specialist nurses = specialist rheumatology nurses.
Social/community = social community workers.

QUESTION 28: Would people with RA like to receive more of the following types of information from the following sources? [comments, continued]

*% of responses from patient and disability groups based in England (excluding "don't know").
Number of respondents answering the question = 28
The number in brackets denotes how many groups answered that category of the question.*

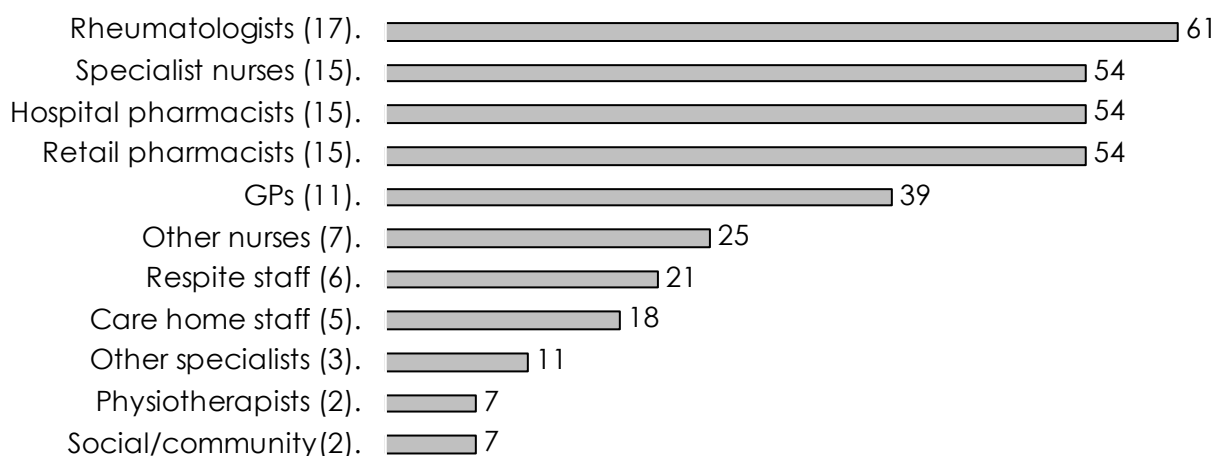


Footnote:
Hos. pharmacists = hospital pharmacists.
Specialist nurses = specialist rheumatology nurses.
Social/community = social community workers.

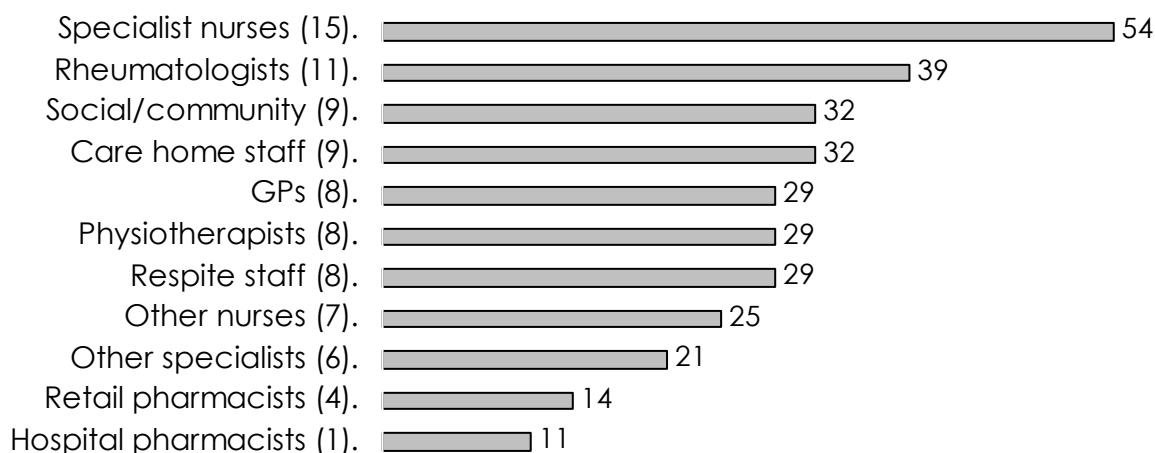
QUESTION 28: Would people with RA like to receive more of the following types of information from the following sources? [comments continued]

*% of responses from patient and disability groups based in England (excluding "don't know").
Number of respondents answering the question = 28
The number in brackets denotes how many groups answered that category of the question.*

"Side-effects of medication"



"Diet and lifestyle"



Footnote:
Specialist nurses = specialist rheumatology nurses.
Social/community = social community workers.

QUESTION 28: Would people with RA like to receive more of the following types of information from the following sources? [comments, continued]

*% of responses from patient and disability groups based in England (excluding "don't know").
Number of respondents answering the question = 28
The number in brackets denotes how many groups answered that category of the question.*



On the whole, the respondent groups think that people with RA would prefer to receive extra information on the symptoms of RA, on treatment choices, on the possibility of recovery, and on the side-effects of medication. Most would like to see rheumatologists and specialist nurses provide the information. Only one third of the respondents (36%)—at most—want patients to be given more information about employment from the health professionals listed above.

Respondents' comments emphasise that "accurate" information should be provided, "as and when it is needed", by "all of the professionals", who would "work jointly" to achieve these goals.

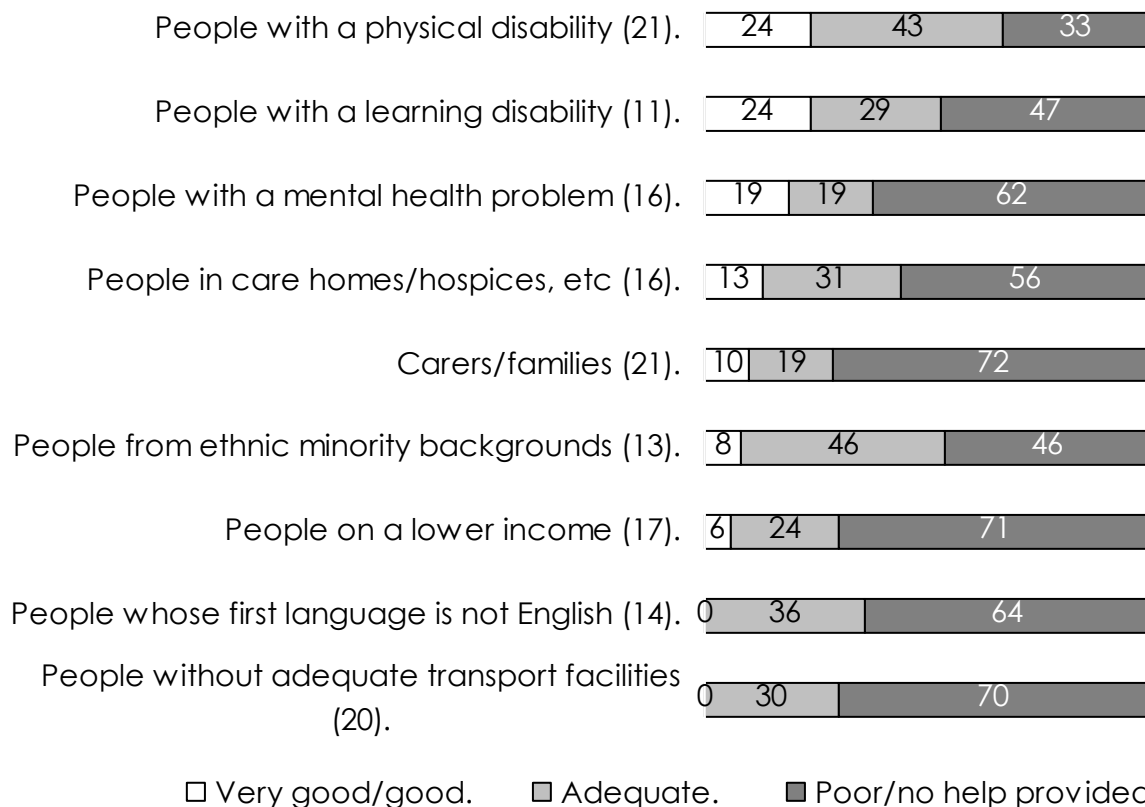
[For a full set of respondents' comments to this question, see *Appendix*, page 55.]

Footnote:
Specialist nurses = specialist rheumatology nurses.
Social/community = social community workers.

VI. Final questions

QUESTION 29: Certain sections of the public might require extra help in developing the skills to self-manage RA. How good or poor is the help with RA provided to the following (broad) categories of people?

% of responses from patient and disability groups based in England (excluding "don't knows"). The number in brackets denotes how many groups answered that category of the question.



Most respondent groups do not believe that good help is provided to the categories of people with RA who might require extra support in developing the skills needed to self-manage RA. Rather, any help is merely "adequate", "poor", or "non-existent". Arthritis Care attributes the lack of support to an inability by the NHS to promote notions of self-management:

"The NHS (with perhaps nurse specialists and allied health professionals as exceptions) is not geared up to promoting self-management across the board. GPs are ambivalent, at best, about the concept. Many people are therefore effectively left to get on with it by themselves, or rely on organisations like Arthritis Care to signpost them to effective tools."

Several groups mention that the voluntary sector does make a contribution.

[For a full set of respondents' comments to this question, see Appendix, page 57.]

QUESTION 30: Finally, is there *anything else* you would briefly like to tell Parliament about services for people with RA which has not been covered in this survey?

Sixteen groups from across the country summarise the factors that they believe could improve services for people with RA [full comments can be found in the *Appendix*, pages 58-60]. The main conclusions are:

Greater awareness about RA is needed among professionals, as well as the public. Two facts—that RA is NOT exclusive to the elderly, and that it is a long-term inflammatory condition affecting the whole body—should both be more widely communicated. A change of name for the condition (for instance, to rheumatoid disease) might be useful.

Improving the standards of care for musculo-skeletal conditions should be a higher priority within the NHS, and should attract more funding.

The National Institute for Health and Clinical Excellence (NICE) should acknowledge the sum total of costs associated with RA, instead of taking just a proportion of the costs into account. Its cost appraisals should include the economic value of retaining people with RA at work.

NICE and health professionals should take more account of the importance of the quality of life experienced by people with RA.

Waiting times for diagnosis and treatment should be shortened.

More of the care of people with RA should be shifted from GPs into the hands of specialists in the condition—even if this entail extra travel for patients. Similarly, greater emphasis should be placed on multidisciplinary teams.

People with severe RA who are unable to work should not be obliged to wade through quite as much bureaucratic paperwork to obtain disability benefit.

People with RA should be entitled to free prescriptions (as received by patients with other long-term conditions).

Follow-up care should be given more priority, and should take into account the complexity of the condition.

Greater value should be placed on the health contributions offered by occupational therapists, physiotherapists, and voluntary groups, and on the benefits from certain complementary treatments, such as hydrotherapy.

More feedback should be sought from users, carers, and health professionals, with the aim of determining further ways of improving services.

Appendix

This Appendix consists of respondents' comments to the survey's questions

Comments are ordered into categories
identified by the respondents themselves

Profiling questions

Comments from respondent groups on the subject of contact with PCTs

"Only contacted via membership."

UK-wide group.

"Presently working with PCT lead for patient involvement in respect to current services and will be looking at future services and information prescription."

"PCTs have approached us to help them get the views of people with RA on occasion. It has tended to be relatively late in the consultation process and has not been systematic - each PCT has their own way of working with us and have not collaborated even with neighbouring PCTs, on the whole. It has also not recognised (financially and in terms of human resources/ opportunity costs to not delivering other activities) the additional work that is involved for us to support them."

UK-wide group.

"PCTs are not very good at engaging with patients in regard to service re-design. We have to do a lot of work to get these people up to speed in terms of what standards and guidelines they need to be aware of, how to engage effectively etc. The PCTs themselves do not do any of this work and I believe they should offer training to people who join service re-design planning groups."

UK-wide group.

"I do attend some PCT meetings."

"We had what seemed to be positive feedback from local PCT consultations regarding the delivery of services for people with arthritis in general. There has been little forthcoming collaboration since regarding our involvement in future service planning."

I.
Questions on
obtaining diagnosis

QUESTION 1: What generally prompts people who are eventually diagnosed with RA to seek medical help?

1. Symptoms such as pain, discomfort, and loss of mobility

"Pain, discomfort, loss of mobility."
UK-wide group.

"Pain, Discomfort, Stress."

"Pain and fatigue."
UK-wide.group

"Pain fatigue and stiffness."

"Continuing pain, reduced functioning and fatigue."

"The pain and the inflammatory effects will be the main factors as people often don't recognise that the fatigue as one of the symptoms, especially given the age profile of most presenting."
UK-wide group.

"Pain and swelling."

"Pain."

"Usually pain and inflammation which continues despite pain killing medication."

"Pain & mobility problems."

"Pain, weakness, fatigue, disability, stiffness, swelling."

"Unable to cope with the pain any more."

"Joint pain which does not resolve itself, generalised pain, feelings of extreme tiredness, flu like symptoms."
UK-wide group.

"Painful joints. Loss of mobility."

"RA is complicated disease and varies from person to person. Pain. Fatigue. Stiffness. Swelling of joints."

"Joint pain."

QUESTION 1: What generally prompts people who are eventually diagnosed with RA to seek medical help? [comments, continued]

1. Symptoms such as pain, discomfort and loss of mobility [continued]

"Pain discomfort tiredness."

.

"Pain stiffness in joints generally feeling unwell."

.

"Pain loss of function and mobility."

.

"Pain decreased mobility."

"Joint pain."

.

"Pain."

.

"Pain."

"Joint pain."

.

2. A desire to understand what is wrong

"Pain and a desire to understand."

3. A wish to take control of their disease

"To take control of their disease and to self manage their condition."

.

4. To obtain access to physiotherapy and/or pain-killers

"Physio Therapy, pain killer medicine."

Other

"Lack of help from local GP's."

.

QUESTION 2: How long does it usually take between a person first experiencing symptoms of RA (for example, pain and swelling in the joints, stiffness in the mornings, feelings of fatigue, etc) and their receiving a correct diagnosis?

1. The public lacks awareness and knowledge of RA

"Lack of awareness and knowledge and unable to recognise symptoms and importantly unable to convey symptoms to GP."

"There is a lot of variation, partly because of the length of time people may take to present to the GP in the first place (joint pain is not often taken very seriously)."
UK-wide group.

"The patient would have already experienced the effects of the illness prior to receiving the diagnosis."

"Ignorance."

"The answer I have given reflects the average. Many people can wait long than 12 months, sometimes even years! People delay going to seek medical help."
UK-wide group.

"Many people will struggle on until they cant cope."

2. GPs can take months to decide whether to refer a patient to an RA consultant

"Some time it takes much longer. Person sent home with Paracetamol never see a RA Consultant."

"Some do take longer depending on knowledge level of GP in which case it could be years."
UK-wide group.

"Being treated for symptoms before being tested, perhaps a lack of knowledge on the part of some GPs of RA."

"3 months was the most common answer to this question. However, variable. including one member who stated less than a month, and another who said more than 2 years. The main reason for delays was quoted as misdiagnosis by a GP."

"Frequently GPs delay referring."
UK-wide group.

"GPs are often not trained to recognise the symptoms, especially as they can be non-specific (fatigue, pain) and in a cohort that often experiences these symptoms for other reasons."
UK-wide. group

**QUESTION 2: How long does it usually take between a person first experiencing symptoms of RA and their receiving a correct diagnosis?
[comments, continued]**

3. To meet the '18-week referral deadline', hospital resources have had to be diverted from accommodating the needs of the more urgent cases

"They have to meet the 18 week wait for all patients which sometimes delays more urgent cases from being seen earlier."

4. Waiting times for patients referred to an RA consultant can be lengthy

"A big queue for services."

"GP does initial investigation then refers on to Rheumatologist - appointments are taking up to 13 weeks."

"Work load of rheumatologists can lead to delays in getting expert advice."

5. The condition is complex to diagnose

"Difficulty to diagnose symptoms and condition."
UK-wide group.

"GPs are often not well trained to recognise the symptoms, especially as they can be quite non-specific (fatigue, pain) and in a cohort that often experiences these symptoms for other reasons."
UK-wide group.

6. Test results also take too long to arrive

"Time taken for the results of tests. Doctors will not give an answer until results are in."

"Time needed for blood test, X-rays and reports which is variable."

"But there is a wide spectrum still sometimes delayed by too much reliance on blood tests & x-rays which may be normal early on. Failure to spend sufficient time absorbing the extent of symptoms as well as time to examine patient."

QUESTION 3: How easy or difficult is it for people with RA to obtain the following diagnostic tests/scans, if their doctor recommends them?

Difficult; problematic; conditions vary:

1. A lack of patient information

"Lack of information prevents patients from seeking further help."

"We feel the time given to patients is not long enough and therefore not explained in enough detail."

2. GPs are not always reliable providers of RA services

"Some members find it difficult to get quick appointments for blood tests at their GP practices, so some have to travel to the hospital."

"Depends on which GP practice you attend."

3. Access to testing equipment is limited

"For the bone densitometry and MRI it is less about referral and more about access to the machinery."

UK-wide group.

Delay of at least 6 weeks for MRI. Patients not routinely sent for these tests."

4. Some tests are only conducted in hospitals

"Anti ccp antibody testing only at hospitals."

5. Testing procedures are not systematically applied nationwide

"If you manage one reasonable, its the IF THATS THE PROBLEM."

"Varies greatly around the country - bone densitometry many have to be referred back in by GP -waste of time."

UK-wide group.

"Blood testing is not normally too difficult as most GP practices now offer testing services. There is sometimes a reluctance to send people for x-ray but it is usually easy enough to go the departments we are unaware of any quality of life assessments."

**QUESTION 3: How easy or difficult is it for people with RA to obtain the following diagnostic tests/scans, if their doctor recommends them?
[comments, continued]**

5. Testing procedures are not systematically applied nationwide [continued]

"Anti-CCP testing is relatively new and would not normally be offered unless there is a reason to do it and it is not available in some areas at all. It has been recommended in strictly limited circumstances in the NICE RA Guidelines being published in 2009. It is possible to self refer for bone densitometry but I believe females in the menopause age range with RA should have their bone density measured as Osteoporosis is a risk factor for RA. MRI is expensive and most people will have normal x-rays unless there is a specific reason to do an MRI. Ultrasound is increasingly popular and can detect sub-clinical synovitis and should therefore be used as a diagnostic tool where pain persists and synovitis is not detectable upon physical examination in my view."

UK-wide group.

No problems:

1. Waiting times to see a consultant are good

"Usually good once referred by GP."

2. No problems with testing procedures

"So far, have not heard of anyone not receiving proper medical exploration, but we are not doctors, we provide help after the diagnosis, so that patients can learn to care for themselves, and we give Stress Therapy, Exercise, and Occupational Therapy, all."

QUESTION 4: Turning to the review criteria that GPs apply when referring people with suspected RA: how effective or ineffective are these criteria in directing patients to appropriate specialist care?

1. A lack of communication between patients, GPs, and rheumatology clinics

"Improve communication between patient, GP and rheumatology clinic."

"Sufferers often feel their doctor is not sympathetic to their suffering, often brushing them off, and telling them that it is part of growing old. They sometimes seem reluctant to offer tests or further support."

"Some GPs have good referral protocols set up with secondary care units but these protocols are generally arranged and promoted by the consultant led teams in an area (often where there is a research unit). Unfortunately in many areas these protocols either are not set up or not followed and many people experience delays in GP referral."

UK-wide group.

"Several of our members who have been diagnosed with RA were referred to the Rheumatologist by other consultants (dealing with eye problems etc.). Their RA had not been diagnosed by their GP."

2. Patients have problems gaining access to the appropriate specialist

"Some people are never referred to the appropriate specialist Drs choice, But once in appointments are regular cancelled."

3. Review criteria are only effective if up to date

"Effective when updated - use of map of medicine to be encouraged."

UK-wide group.

4. Review criteria are also only effective if the proper tests are carried out

"Usually dependant on blood tests."

5. GPs can lack the training to implement effective review criteria

"In our experience, GPs are not clear what the criteria are and need more direction from accepted standards of care and from clinical specialists. Needs to be more preliminary training for GPs as it currently only amounts to three hours on average."

UK-wide group.

"Some members have experienced long delays between GP referral and rheumatology out patients appointment. Some were not referred at all, and others were misdiagnosed by GP."

QUESTION 5: How long do patients with suspected RA typically have to wait to get a referral to a specialist (to obtain a diagnosis)?**1. Lack of appropriate healthcare professionals**

"Lack of information, communication and resources."

"Shortage of Consultants? long lists?"

"Difficult to say in this area, it can vary greatly dependent on the availability of spaces in the appointments diary."

"Very limited time in local out patients clinic with Rheumatologist with best reputation."

2. Long waiting times

"High elderly population on the Isle of Wight Sometimes 6 weeks just to see a GP!!."

"Again, it varies dramatically across the country and some people can wait a year or more."
UK-wide group.

"Difficult to give typical times as most of the members were diagnosed some time ago and have waited varied times but perhaps more than 6 months."

3. Resources have had to be diverted away from meeting the needs of follow-up patients in order to accommodate the '18-week rule'

"The 18 week target seems to be working reasonably well, unfortunately the requirement to meet this target is negatively impacting on follow up patients."
UK-wide group.

4. A too-bureaucratic NHS

"Bureaucracy."

Other comments

"On average depends on the nature of onset of RA This can vary from acute to insidious over months. This affects speed of referral."

QUESTION 6: Are people with RA referred quickly enough to avoid long-term damage from the condition?

Groups replying "Yes":

1. Dependent on GP experience

"Usually - again varies a lot depending on GPs experience we still have some in our area who did rheumatology as a vocational training scheme which helps."

"I have answered yes, which is the majority experience. However, this is not always the case, as some members were initially misdiagnosed (in one case, for more than 2 years)."

2. Prompt referrals, when doctors want to avoid long-term damage

"Avoid long-term damage and quick treatment."

3. Prompt referrals, to alleviate pain

"To alleviate pain."

**QUESTION 6: Are people with RA referred quickly enough to avoid long-term damage from the condition?
[comments, continued]**

Groups replying "No":

1. Lack of awareness of RA among GPs and the public alike

"Patients frequently do not think of RA as the cause of their symptoms and self treat, followed by GPs treating until symptoms become acute and need referral."

2. A reluctance by GPs to refer quickly enough

"Reluctance by GP's to refer on quickly enough."

3. Overly long waiting times to see a specialist (and to receive test results)

"Prompt referral and early diagnosis and effective treatment may lead to remission - many have to wait far too long and are not treated aggressively enough."

UK-wide group.

"Waiting for tests and referral to specialist."

"Presentation, recognition of symptoms, access to diagnostics and referral to rheumatologist usually adds up to a wait of more than four months which can result in long term damage."

UK-wide group.

"Waiting times."

"NHS waiting times to see specialist consultant."

UK-wide group.

4. Failure of health professionals to make quality-of-life assessments

"I have largely explained barriers above, however, an additional barrier is that RA is not including in any QoF measurements and is therefore not a priority."

UK-wide group.

5. Over-emphasis on conducting blood tests, rather than focusing on symptoms

"Too much emphasis on blood test to identify RA factor and often patient's symptoms are ignored."

QUESTION 7: Have you any suggestions as to how diagnosis could be delivered more QUICKLY?**Greater awareness of RA among GPs and the public alike**

"Educate the GP's and general public about RA. Cause and effect and the impact of the disease."

"Greater awareness amongst the public of RA. Disassociating RA from the generic arthritis family and thus removing the belief that 'arthritis' is related to old age and something we will get. Giving prominence to the disease and its effects both personally and socially as well as the long term financial impact. Heightened awareness training for GPs of the above and the importance of early diagnosis and treatment."

"Public information about the importance of bone and joint health."
UK-wide group.

"Better understanding of the illness, instead of GP's telling them 'It's your age, and you have to respect it!'"

Better education and training in RA for GPs

"More GP education which gives them the tools to know how to filter through to specialist services - both preliminary education and ongoing CPD as the field is rapidly moving."
UK-wide group.

"GP training days."

"Improved GP training re RA Perhaps some kind of direct patient access to rheumatology services, which sometimes happens in other specialities Improved hospital appointments systems Improved numbers of NHS rheumatologists and nurse specialists."

"GP training updated to recognise symptoms early."

Implement national referral protocols

"National referral protocols which are actually implemented."
UK-wide group.

More joined-up working between primary and secondary care

"Less paperwork between GPs and local hospitals."

"Better integration between primary and secondary care."
UK-wide group.

QUESTION 7: Delivered more QUICKLY [comments, continued]**More joined-up working between primary and secondary care [continued]**

"Speedier test results & better communication between specialist, GP & patient."

Reduce the length of waiting times to see specialists

"Reduction of waiting list times to see a rheumatologist."

"More local clinics or offer patients an appointment at one of the other hospitals if that is available more quickly. A patient was told that she could not book an appointment using 'choose and book' because none were available within the required timescale."

"Speed up referral process & the responses to deal with."

Dedicate clinics (or specialist staff) to RA referral

"Referral R A clinic's Bloods / X Rays etc."

"Triage by appropriate clinically up to date staff."
UK-wide group.

"Bypass the current referrals to OT's Physios, Pain Clinic etc and straight to Specialist department where the patient can see a surgeon as well as those above."

"Create step-in clinics and polyclinics. Where a specialist nurse could signpost."

"In a paper consultation document, I supported the idea of specialist clinics for people with long-term conditions believing that an initial point of reference for individuals with pain and swelling in the joints, stiffness in the mornings, feelings of fatigue, etc could attend a specialist arthritis clinic and see a specialist nurse. Specialist clinics could collaborate with national bodies for specific long term conditions."

Base diagnosis on individual need (and symptoms), not government targets

"On individual patient's needs rather than Government targets."

"More rheumatologists and more GPs willing to take patients symptoms seriously."

Include quality-of-life assessments when making diagnoses

"Inclusion of joint pain (or another measure) in QoF."
UK-wide group.

QUESTION 7: Have you any suggestions as to how diagnosis could be delivered more ACCURATELY?**Greater awareness of RA among the public**

"Public awareness and organisations like BARC need long term funding and joint working to educate and to raise awareness of this chronic illness."

Better and more GP education and training

"Updating for GPs more Clinicians doing outreach clinics in primary care."
UK-wide group.

"Improved GP training, with a requirement for GPs to update their ongoing professional development at frequent intervals."
RA support group, Yorkshire and North Humber.

"Train more specialists doctors and nurses instead of seconding reluctant professionals to the case."

"Once referred, most patients can be diagnosed accurately by Consultant Rheumatologists, but sometimes it can take time in undifferentiated inflammatory disease."
UK-wide group.

"Better education on RA for GP's."

"GPs having the knowledge to order the relevant tests prior to referral to the consultants."

"GP training days."

"Christian Mallen at Keele University has received funding from ARC to produce a guide for GPs. I endeavoured to ask him to complete a survey but received an automated email that he is out of the office until 24th November. I have been following the development of this project. A care plan approach similar to the one adopted for people with diabetes on initial diagnosis would help to monitor & manage arthritis, RA, OA or any other form."

More joined-up working between primary and secondary care.

"More specialist services within primary and secondary care, particularly GPwSIs telephonic access for GPs to specialist services."
UK-wide group.

"More joined up working between primary and secondary care, e.g. rheumatology nurse specialist within the surgery setting."
UK-wide group.

QUESTION 7: Delivered more ACCURATELY
[comments, continued]

Initiate tests more quickly

“Undertake tests more promptly.”
UK-wide group.

Improve the experience and the qualifications of staff in RA clinics

“RA clinic Better qualified staff.”

“Expert clinical assessment.”

II. Questions on treatment and care

QUESTION 8: Typically, how long does it take between a person with RA receiving diagnosis, and their obtaining the correct treatment?**1. Failure of people with RA to themselves come forward for care**

"Poor communication in general because people from disadvantaged background eg low income, low education families and people from minority ethnic groups tend to have reservations about accessing healthcare and language and cultural barriers are major factors in communication breakdown. Also pain and disability are perceived differently by different communities."

"My answer is influenced by data just published by the Early Rheumatoid Arthritis Network and information from our helpline. Reasons for delays: patients delaying seeking help because they don't identify their pain as RA (most don't know what RA is and in my view a public health campaign would help) and then delays in referral caused by GPs."

UK-wide group.

2. Limited GP budgets

"High demand and GPs budgets."

3. Lengthy waiting times to see a consultant

"Long time between seeing Consultant after first test Long lists?."

"If a patients were seen by a rheumatologist fairly quickly, then treatment was commenced quickly, but some members had a longer wait, and one was not referred at all until seen by a different GP."

4. Time delays for a medication to work

"The drugs are given and monitored but take up to 3 months to begin to work."

"NSAIDS to Anti TNF over a period of 1 year."

5. Finding the correct treatment that suits the individual patient can take time

"Once diagnosed by consultant treatment is followed rapidly with a possible short delay for patients to consider treatment options offered by the consultant."

"Early access to treatments is usually good once within a specialist setting, but if that first line of therapy does not work, it can be difficult getting follow ons with rheumatologists, and the ratio seems to be falling which is causing concern."

UK-wide group.

QUESTION 9a: How easy or difficult is it for people with RA to obtain the following, once the doctor recommends their use?
Treatments

1. A lack of information about GP prescribing habits makes assessing the scale of RA treatment in primary care impossible

"Details of GP prescribing is unknown. Consultant prescribing is rapid and unhindered. Anti TNF is readily available in this area providing the patient meets the NICE guidelines."

2. Some medicines have side-effects

"Not happy with the side effects Lack of info in respect of side effects lack of info full stop."

3. Co-proxamol is difficult to access

"Co-proxamol - access is very difficult even though the MHRA said that it should be available for those patients who have been unable to find alternative painkillers. This is a live issue for around 70,000 people with arthritis (no estimate for proportion of people with RA). Some people respond very well to first line therapies and others don't. There is a strong element of trial and error, due to clinical response rather than clinical practice. There are significant variations in access due to postcode."

UK-wide group.

4. DMARDs can be difficult to access, because of the special tests and appointments required with nurse specialists

"For NSAIDs, steroid tablets and pain killers, there seems to be no difficulty. DMARDs understandably take longer, due to the need for special test and appointments with the nurse specialists, which members understand are vital for their safety. The same applies to anti-TNFs, with the additional problem of the requirement for special assessments (which sometimes show misleading results, and PCT approval for funding, which can cause additional delays. However, once these criteria are met, treatment seems to be provided fairly quickly."

5. Post-code lottery still occurs. Certain RA drugs are therefore difficult to access in various parts of the country

"Postcode lottery as to willingness to provide medication and treatment. GPs and consultants."

QUESTION 9a: Treatments
[comments, continued]**5. Post-code lottery still occurs. Certain RA drugs are therefore difficult to access in various parts of the country [continued]**

"There is no problem once recommended by the clinician in patients accessing the standard range of treatments as described above. Access to biologic therapies can be problematic and post code prescribing is still alive and well in the UK. This has been less of a problem since the PCTs have dealt with their deficits and are now back in the black. It was very clear however that they were more concerned about balancing their books than delivering good quality patient care."

UK-wide group.

6. Patients may need to try several different treatments before they find one that works for them. This could be a lengthy process

"Anti -TNF. Patients need to be able to try a second and possibly third type if the first isn't successful."

"Easy for them to be prescribed but often takes ages before the correct medication is found on a trial and error basis and has the right effect."

"Once the patients have received any of these treatments they have usually seen improvements in their condition. But often several things need to be tried before the best results are obtained. one suits one doesn't always suit others."

Slow access to anti-TNF (with a few exceptions)

"Still slow access to anti TNF in some units - reluctance of clinicians to prescribe."

UK-wide group.

"The Anti-TNF drugs are quite well provided by Wolverhampton PCT."

"Details of GP prescribing is unknown. Consultant prescribing is rapid and unhindered. Anti TNF is readily available in this area providing the patient meets the NICE guidelines."

"We have not heard of any patient having any difficulty getting the medication which the rheumatology staff feel is appropriate. There is concern over the NICE guidelines on Anti TNF medication - if the first one is not effective will they be permitted to try an alternative? There have been some issues about whether GP's are able/willing to provide repeat prescriptions - instance where they will reluctantly provide methotrexate (told patient 'this is nasty stuff - people have died') but not leflunomide."

QUESTION 9a: How easy or difficult is it for people with RA to obtain the following, once the doctor recommends their use?**Surgery****1. Lengthy waiting times for an initial appointment with a surgeon**

"It was quite sometime before seeing the surgeon but once on the waiting list it was a reasonable time to wait for the operation."

2. Surgical procedures may not be provided locally, obliging some patients to make long journeys to hospital

"Quite often surgery cannot be provided locally. Patients have to travel to the mainland."

3. Not all operations are equally accessible (as mentioned above). One of the problems is the small number of surgeons who specialise in certain types of RA surgery

"Very few specialists in hand, finger or feet surgery which holds up access. arthroscopy is no longer recommended practice so it is very difficult to access, except where someone's knees locks. synovectomy - depends on whether there is a specialist to advise and take forward."
UK-wide group.

"Some members had a long wait for joint replacement surgery, which resulted in one member paying for private treatment."

"With RA surgery, what is crucial to achieve best outcomes is the need to have a surgeon who specialises in the particular procedure you need. This is why hips and knees are relatively straightforward, whilst complex hand and foot and neck surgery requires a surgeon with expertise in those areas and they are thinner on the ground, particularly the feet and neck."
UK-wide group.

4. Some patients (primarily people who are young, overweight, or who have other health problems) may find surgery difficult to access

"There are still reports of some orthopaedic surgeons being unwilling to operate on younger people, patients who are overweight or who have other health problems with RA. Hips and knees are the most common operations - waiting times have come down and patients are not in hospital very long. In some cases support offered when discharged has failed to come up to expectation and people have struggled to cope."

QUESTION 9a: *Surgery*
[comments, continued]

5. Sometimes surgery is only available when medical treatment fails

“Will only be requested in the event of failure of medical treatment therefore its not a question one can answer in timesof care but appropriateness.”

6. In a few cases, the outcomes of surgery can be disappointing from the patients’ perspective

“Most have received immediate relief from replacement surgery although one or two have not been successful suffering nerve damage etc. in the main most have been very please with treatment and aftercare.”

QUESTION 10: Do doctors typically offer the following types of support to their patients with RA?***Non-medical/complementary treatments*****1. GPs lack understanding of the benefits of non-medical/complementary therapies**

"Lack of understanding of the possible benefits of these types of therapies."

UK-wide group.

"Lack of understanding from GPs. Look at the actual area of pain not the whole body."

2. Not all health professionals have access, or are willing to refer, to these services

"Podiatry can be a great need, but problems with it lack of interest by staff / money shortages blamed Depends on the Consultant referred to."

"Most members commented that it is usually staff other than doctors who refer patients for many of the above. For example, nurse specialists often refer for physiotherapy, and physiotherapists often refer for OT. Many members would very much like to be referred to a dietician, but this appears to virtually never happen, and many doctors seem to be disapproving of complementary therapies, or seem to know little about them. However, a number of members have self-referred to private complementary therapists, and found them to be beneficial in helping them to cope with RA, and sometimes in reducing the number of painkillers required. One member had been referred by a GP, but only when she insisted. Sadly, a significant number of members had, prior to joining our support group, been unaware that physiotherapy and OT were available to them."

"Only additional service available to patients with RA was a hydrotherapy group which ran 6 weeks on 6 weeks off but that was withdrawn because of cost."

"GPs don't have ready access to the above. Hospital consultants do use above as appropriate."

"All consultants should have access to the basic multidisciplinary team comprising: specialist nurse, physio, OT, podiatry. Unfortunately not all units have access to these disciplines with specialist expertise in rheumatology. Patients value their input hugely, especially the nurse specialist who is usually the main practitioner responsible for patient education. Often access to OT, podiatry, orthotics can be patchy."

UK-wide group.

"We feel complimentary therapies are invaluable to improve the quality of life for sufferers of RA, but unfortunately are rarely offered."

**QUESTION 10: *Non-medical/complementary treatments*
[comments, continued]**

3. Non-medical/complementary treatments are often not given to patients long enough to be effective

“Access to hydrotherapy is very poor and declining - often one of the first services to be closed in cut backs. people are often referred to physiotherapy, but it is only generally for short six week courses rather than how long it is clinically necessary. May be an age barrier, so older people are less likely to be referred. access to specialist podiatry is very rare, but people with RA do get access to general podiatry sometimes.”

UK-wide group.

4. Although some non-medical types of support can be provided by patient groups, the NHS does not exploit this supply

“Social counselling and support does not need to be offered through the NHS, but there are providers who could easily fulfil this role, such as organisations like Arthritis Care.”

UK-wide group.

“Counselling and stress management are seldom offered and it would help to “prescribe” groups like ours. Some practices are reluctant to display posters leaflets etc.”

QUESTION 11: Generally speaking, how satisfied or dissatisfied are RA patients with the care they receive from the following healthcare (or healthcare-related) professionals?**Generally poor access**

"Poor general support all round."

"In the do not know column. I have never seen any of these healthcare professionals."

Depends on the doctor seen

"Depending what you go to the Dr for and who you see some good some indifferent in attitude."

"It really all depends on experience a sensitive issue."

Comments on specific health professionals

"**Rheumatology nurse specialists** are easier to contact for urgent or general advice. Members also found it easier to communicate with them than with doctors. Special **rheumatology physios** were considered to be very helpful, but there is often a long wait for."

"**Hospital pharmacists** can be frustrating, waiting for dispensation, so dissatisfied with processes. **GPs** generally receive high satisfaction ratings, but not in terms of specialist treatments and understanding of the impact of the condition."

UK-wide group.

"Most of the feedback we get through our helpline relates to the multi-disciplinary team. Most RA patients get their medication on prescription and so am not sure what proportion would seek help from a **community pharmacist** for example. Most will approach the specialist nurse for help."

UK-wide group.

"Very satisfied with **occupational therapy**."

QUESTION 12: To what extent do the following types of healthcare (or healthcare-related) professionals generally understand RA?

Most healthcare professionals know little about RA, unless they are specialists

"Lack of interest know very little."

"Many healthcare staff are either poorly informed or lack understanding."

"The majority of the general public have a poor understanding of the impact of RA or the nature of this disabling disease. Even health professionals not directly involved in RA have a poor understanding of its impact."

UK-wide group.

Not all specialists are knowledgeable about RA

"Other types of specialists - depends on which is included in this group. Orthopaedic surgeons will have a very good understanding, cardiovascular surgeons maybe only adequate."

UK-wide group.

QUESTION 13a: If people with RA are to avoid long-term damage caused by the condition, they need prompt access to the correct treatment and care. What barriers hinder people with RA from getting such access?

1. Long waiting times to see specialists (and a poor rate of referral from some GPs)

"Referral waiting times and lack of contact with specialists."
UK-wide group.

"Poor referrals from GPs."

"Lack of knowledge of the disease, slow referral for diagnosis and consultant treatment."

"Waiting lists."

"Referral by GP. Area lived in."

"Again the difficulty in actually getting to the rheumatology clinic in the first place."

"Appointment time."

"Long waiting list of Hospital specialist."

"Problems with GPs, resulting in referral delays (sometimes years)."

"COST LOCATION QUALITY OF SERVICES."

"Lack of referral and shared care protocols between primary and secondary care."
UK-wide group.

"GP's failure to diagnose and refer patients on. Delay in getting an appointment at a Rheumatology clinic."

"GPs not referring patients to hospital rheumatology dept early enough."

"The time taken between first symptoms and getting to see rheumatology and then the time taken to control the condition."

"Hospital waiting lists."

"Referral waiting times and lack of contact with specialists."
UK-wide group.

"Money, Shortage of Consultants."

QUESTION 13a: If people with RA are to avoid long-term damage caused by the condition, they need prompt access to the correct treatment and care. What barriers hinder people with RA from getting such access? [continued]

1. Long waiting times to see specialists (continued):

"Long waiting list of Hospital specialist."

2. Lack of public awareness of RA

"Lack of awareness and fear of the unknown."

"Lack of knowledge of the disease, slow referral for diagnosis and consultant treatment."

"Poor understanding of the condition by public."
UK-wide group.

"Sometimes patients delay seeking medical advice. For example, older patients sometimes mistake RA for normal ageing processes, or 'wear and tear'."

"Lack of public awareness about the severity and commonness of this disease."
UK-wide group.

"Lack of awareness that treatment is available."

"Sufferers themselves could do with better education as often they defer going to GP or believe no help available (also an info problem)."

3. Lack of knowledge of RA among GPs

"Poor GP training."
UK-wide group.

"Lack of knowledge about RA amongst GPs."
UK-wide group.

"Patients & GPs are often unaware of necessity for speedy action / referral."
Arthritis group.

4. Lack of locally-accessible services

"COST LOCATION QUALITY OF SERVICES."

"Unsympathetic doctors. facilities not being easily accessible locally."

"Sufficient rheumatology services locally transport to the centres."

QUESTION 13a: If people with RA are to avoid long-term damage caused by the condition, they need prompt access to the correct treatment and care.

What barriers hinder people with RA from getting such access?

[comments, continued]

5. Delays in diagnosis

"Poor and slow initial diagnosis slow treatment to remission."

UK-wide group.

6. A low priority given by the NHS to musculo-skeletal diseases (and their impact on patients' quality of life)

"Low prioritisation of musculoskeletal conditions by NHS/policy makers/Government."

"Restrictive NICE guidance, e.g. sequential and early use of anti-TNFs poor implementation of agreed standards of care produced by the British Society of Rheumatology and ARMA."

UK-wide group.

"Lack of priority given to inflammatory arthritis by the government (QOF), lack of ICP for commissioners, lack of care plan and understanding by patient of next steps in care, lack of resources and funding to deliver appropriate treatment for those who fail on standard treatment, lack of patient education."

UK-wide group.

Other

"COST LOCATION QUALITY OF SERVICES."

QUESTION 13b: What has helped secure prompt access to correct treatment and care?

1. High-quality information delivered appropriately

“Right information at the right time and confidence in taking it forward to seek firm diagnosis.”

2. Greater public knowledge of RA

“PERSISTENCE SELF-KNOWLEDGE.”

3. Informed GPs working with referral pathways

“Referral pathways triage and better education for GPs.”
UK-wide group

“The ARMA local networks have helped improve services locally. 18 weeks pathway.”
UK-wide group.

“Has got better since 18 week system in place.”

“Rapid GP referral.”

“Knowledgeable GP, good referral protocols, short referral times/access to an early RA clinic. People sign posted to correct pathway of care.”
UK-wide group.

“A health care professional being adequately experienced in the diagnosis of RA to spot the disease and make the referral to a specialist.”

“More informed GPs testing facilities in local health centre, physiotherapy locally etc.”

“Sometimes the relationship with the musculoskeletal clinics and the surgeon.”

“Sympathetic doctors.”

“Sympathetic and prompt attention.”

4. More rheumatologists

“More Rheumatologists.”

“Diagnosis by hospital rheumatologist.”

**QUESTION 13b: What has helped secure prompt access to correct treatment and care?
[comments, continued]**

5. Continuity of high-quality care

"Units who follow guidelines and practise tight control until disease stabilised."
UK-wide group.

6. Adequate funding and giving RA priority

"Adequate funding."

7. Involvement of local community support groups

"The ARMA local networks have helped improve services locally."
UK-wide group.

"Support groups for sufferers."

"Access to NRAS early on so good information/support can be provided."
UK-wide group.

8. Nothing

"Nothing."

"Nothing to date but ongoing awareness by support groups and national charities will impact over time."

QUESTION 14: Have you any suggestions as to how correct treatment and care can be delivered to RA patients quickly?**1. Raise public awareness of RA**

"By raising awareness of the disease, its impacts at so many levels and separation from the generic arthritis family to give it a self prominence. This will place the importance on the disease that it deserves."

"Public awareness campaigns prioritisation of musculoskeletal conditions by NHS/policy makers/Government."

UK-wide group.

"Public awareness campaign to get people to seek help early, and GP education to ensure rapid referral to specialist for early diagnosis and starting treatment (window of opportunity)."

UK-wide group.

2. Improve communications between healthcare providers and patients

"Improve communication between health providers and produce a conducive environment so that people feel more comfortable talking to their doctor and projects like Birmingham Arthritis Resource Centre needs to be recognised. BARC empowers patients to effectively articulate their symptoms to their GPs."

3. Provide GPs with RA training

"More and ongoing GP."

UK-wide group.

"Not all Gp's will acknowledge RA from an early visit."

"Improved GP training and refreshers. Shorter hospital appointment waiting times More specialist nurses and rheumatologists Improved public awareness of RA, and especially the differences between RA and osteoarthritis."

"GPs could be more thorough and refer patients to hospital quicker."

"More prompt referral to consultants."

4. Refer directly to RA clinics for diagnosis (and for continuity of care)

"Direct referral to the rheumatology department for assessment in the first instance."

"Give them weekly appointment to see the RA specialist. and proper medication."

"Quicker diagnosis."

QUESTION 14: Have you any suggestions as to how correct treatment and care can be delivered to RA patients quickly? [comments, continued]

5. Provide more consultants (and related healthcare staff)

"Yes, More money, Consultants list shortened Clinics for R A."

"Even more Rheumatologists."

"More health care staff at the sharp end."

"MORE SPECIALISTS."

"More education on RA for frontline staff - GP's, Practice nurses, health visitors."

"Specialist nurses."

"More prompt referral to consultants and more hospital beds for rheumatology patients."

"Better access to local doctors & hospitals."
Arthritis group.

6. NICE should consider RA's wider costs to society

"Forward looking NICE guidance NICE remit to include wider costs to society."
UK-wide group.

7. Implement agreed standards for RA treatment and care nationwide

"Central push for implementation of agreed standards of care produced by the British Society of Rheumatology and ARMA local service user/service provider involvement in the development of new services."
UK-wide group.

"More rigorous application and implementation of guidelines. There is huge variability in the way in which this disease is treated, particularly following diagnosis."
UK-wide group.

"Full implementation of musculoskeletal framework for ALL RA patients - not just newly diagnosed."

8. Involve user groups more

"Give patients more information from the outset and get them in touch with a user group for support."
UK-wide group.

III. Questions on long-term care

QUESTION 15: Is the effectiveness of the treatment of people with RA reviewed regularly?

1. Only when patients are desperate

"A desperate patient in pain."

2. Regular review is hampered by the 18-week target

"Existing patients are seen less often due to the 18 week waiting target."

"It should be reviewed often especially in the early days, but the 18 week pathway is making this much more difficult as follow up patients are being bumped off lists to enable units to meet the 18 week target for new patients."

UK-wide group.

"It certainly should be regularly but even in hospital depts due to pressures of seeing new patients & making diagnosis should be the follow ups get put off of postponed often when i see them they have an entirely new problem like a new patient again."

3. RA reviews are irregular and vary in effectiveness across the country

"Not at a health service level - good quality audits or PCTs analysing its patients pathways are not undertaken routinely. pharmacological effectiveness is reviewed sometimes."

UK-wide group.

"My own treatment is reviewed regularly but others say they havent had a review in years."

Case studies: good practice

"In this area all patients on mxt are blood tested monthly and likeise for anti tnf 3 monthly at the hospital."

"Regular blood tests for people on certain drugs."

Case studies: poor practice

"VERY POOR FOLLOW-UP."

"Sometimes the gps like to handle the RAs and so not refer to a consultant."

QUESTION 16: Is the treatment of people with RA adapted as the person's medical condition and physical state progresses or changes?

1. With regular monitoring

"Regular monitoring ensures that patients receive the appropriate treatment."
Plymouth and District Rheumatoid Arthritis Group Support.

"Depends on follow up ratio. does not consider the wider impact, so change in personal circumstances."
UK-wide group.

2. When promoted by the patient

"When prompted by the patient."

3. Dependent on whether health provider is a good listener, and understands

"Depends of providers and whether they understand and can listen."

4. Dependent on whether the patient is in the care of a specialist or a GP

"It depends if the consultant is in charge of the patient or not If the GP is in charge then the patient receives less of the services."

"In rheumatology dept this is the purpose of follow ups regularly."

5. Dependent on whether specialists are aware of state-of-art practice

"It is important that Rheumatologists and their team are kept up to date with progress in the management of RA - in the past there was a tendency to stick with treatments they were familiar with."

6. Dependent on whether medication does not appear to be working

"Tablets are changed if necessary."

No

"RA is a forgotten problem."

"It should be often but again this is variable throughout the UK and we see too many patients slipping quietly into disability because they are not being tightly enough monitored."
UK-wide group.

QUESTION 17: Once people with RA have been seen by a specialist, by what means do they typically obtain a follow-up appointment to the specialist?**1. The current follow-up appointment system is ineffective**

"Our members are very dissatisfied with the follow up appointments booking system. Previously, a follow up appointment was made after every consultation, but the new system does not allow this. Patients are contacted by letter when their appointment becomes due (eg 3 monthly), they are then invited to call the hospital to make an appointment. This means that patients have to wait much longer than eg 3 months, because appointments are usually not available immediately. Also, it is not uncommon for patients not to receive the letter, or for it to be lost in the post."

"Can be a year wait."

"There needs to be a standard mechanism whereby the patient/client can go back to a specialist in the future."

2. Depends on disease state (an annual review is recommended for stable patients)

"Most people are given a routine follow up and the time between follow ups will vary according to their disease state at the last follow up. For stable patients, they should have a minimum of a holistic annual review (ARMA standards of care, BSR guidelines) but very few units are yet operating an annual review of this kind with access to the full MDT."

UK-wide group.

3. Follow-ups can be required to gain access to a surgeon

"This pathway is often necessary for referral from rheumatology to orth surgeons."

QUESTION 18: Which of the following services do you expect people with RA to access in the event of a flare-up?**On out-of-hours primary care**

"Out of hours gets you nowhere."

On the availability of hotlines/telephone contacts/email

"Our hospital does not have a hotline, although all our members are in favour of one. For newly diagnosed patients, it is often difficult for them to know who to contact. Most longer term patients contact the specialist nurse, either directly by phone (if the nurse isn't busy elsewhere) or email, which is usually responded to quite quickly. Others contact the medical secretaries (which takes longer for a response). Others wait for a GP to make contact with the hospital."

On self-management and GPs

"Self-referral to NON-NHS services and self-medication."

"Unfortunately because people know how difficult it is to get effective help quickly in event of a flare, many just take themselves to bed and wait it out. If very severe they will contact their nurse specialist or GP, however, GPs are often not very helpful or proactive in these circumstances and may just say, 'contact your rheumatology team'. The nurse led helplines usually get back to patients within 24 or 48 hours and are very helpful but if the flare is really severe you need urgent help straight away!"

UK-wide group.

QUESTION 26: When referring to the delivery of long-term RA care: can you indicate whether joint working occurs locally in the following cases?

1. Varies across the country (and even within regions)

"Differs between areas and needs enthusiastic committed people."
UK-wide group.

"We have experience of excellent and effective working in some units and in some areas however, access to uniformly excellent care is very patchy as previously indicated in other answers."
UK-wide group.

"Varies from patient to patient. Different responses to questions noted."

2. Team working is necessary

"Better team working ethos."

"The multidisciplinary team in secondary care generally works very well as people are clear about roles and responsibilities. The relationship between primary and secondary care is less effective. The joint working between patients and social services tend to be one way. This may change with devolved personalised budgets."
UK-wide group.

Case studies: good practice

"Getting better."

"Locally there is good networking between the team and patients this creates a sense of safety for patients and reduces duplication of questions, access to different team members is easier and treatment is more joined up."

"Members commented that, between patients and multi-disciplinary teams, joint working does often occur, but it is more likely with nurse specialists, physios and OTs, for example than with doctors, who are not always totally sensitive to, or flexible, re patients' wishes."

Case studies: poor practice

"Poor quality services due to high turnover of staff. Therefore individual knowledge is not passed on."

"Not very effective as little seems to be seen by the public from the meetings consultations etc."

IV. Questions on employment

QUESTION 19: Generally, how understanding would you say employers are towards people with RA?**Comments from groups that answered "Understanding/very understanding"**

"My current employer helps people get back to work when they've been ill so they are understanding regarding many conditions."

Comments from groups that answered "Not understanding"

"IGNORANCE."

"Quick to get rid."

"Need to be offered appropriate seating flexible hours and time to stretch."
UK-wide group.

"Lack of awareness of RA and its impact and unpredictability."

"Arthritis Care's recent survey showed that understanding amongst employers was very low."
UK-wide group.

"They do not have the first idea about the disease usually unless the employee has actual physical disfigurements such as bad hands etc."

"We had a mixed response to this question. Only a small percentage of our members have been able to continue to work since diagnosis, and of these, only 2 stated that their employer was understanding."

"The word arthritis to many employers is a poisoned chalice. (I have many many true stories)."

"We conducted a survey on Work and RA in 2007 which we are happy to provide you."
UK-wide group.

"General lack of awareness of the effects and management of RA."

QUESTION 20: How often do employers generally provide support to people with RA, to help them continue in employment?**Types of support supplied by employers**

“Chair, wrist rests and leg rests when using computer.”

“Time off for appointments.”

UK-wide group.

“If employers offer support at all, they tend to do it well and offer the following as support - flexible hours, working from home, limited workplace adjustments. For many, offer very little if anything and we found a significant amount of refusal of reasonable adjustments. We will be sending the NAO a copy of the survey.”

UK-wide group.

“Allows me to attend appointments and I can adjust my hours when required.”

“Sometimes special equipment is provided, eg ergonomic keyboard, wrist supports etc, but few employers seen to be aware that grants are available for resources for people with RA.”

“Change of job. Early retirement (lots of cases).”

“Sometimes, ergonomic keyboard/mouse, chair but difficulty in accessing OT workplace assessments and general lack of knowledge about RA is a problem. They don't understand the variability of the disease, i.e. one week you can do something, next week you can't. Colleagues also find this difficult to understand.”

UK-wide group.

“Flexible working/home working Adaptations to working environment and equipment.”

“Equipment to make tasks easier, correct seating flexible working (acceptance of need for rest etc).”

QUESTION 21: What are the main barriers to employers providing support?**1. Employers' lack of understanding of RA, and their lack of knowledge of the services available to them to assist people with RA**

"Patience and greater understanding of condition and flare-ups in symptoms."

"Lack of knowledge and feeling that that employee will be taking lots of time off unable to provide flexible hours."

UK-wide group.

"Not understanding the condition."

"Lack of understanding if the disease and of the services available to them to assist employees."

"Lack of awareness of RA."

UK-wide group.

"Profit."

"Some employers have a lack of understanding of how illnesses can affect people day to day."

"Lack of understanding and reluctance to find about more about RA."

"Lack of awareness of specific problems of RA. It is often confused with osteoarthritis, and the severity of the illness, with its multiple symptoms, tends not to be recognised."

"Lack of knowledge about RA, lack of knowledge about what help there is and what services they can access. Some, sadly, want to get rid of people found to have a LTC like RA when they find out."

UK-wide group.

"Uncertainty re absence or duration of absence."

"Ignorance of the condition size of business - unable to offer flexible hours etc."

"Knowledge of condition."

"Lack of understanding."

"Lack of perception of the problem & lack of urgency."

"Lack of knowledge about the condition Economic climate."

**QUESTION 21: What are the main barriers to employers providing support?
[comments, continued]****2. A fear among employers that supporting people with RA will be costly to them, and disruptive to business**

"Concerns about the cost of reasonable adjustments."
UK-wide group.

"Support for a patient could interfere with the running of the business in a lot of cases."

"Patience and greater understanding of condition and flare-ups in symptoms."
The Arthritic Association.
Cost and apathy."

"Money."

"Costs."

"Pressure of work."

"COST PRODUCTIVITY COLLEAGUE IGNORANCE."

"Unsure what effect this will have on employee attendance."

"Perceived cost implications."

"Finance."

3. Employers' lack of awareness of legal responsibilities towards people with a disability

"Lack of awareness of Access to Work concerns about the cost of reasonable adjustments lack of awareness of RA lack of awareness of responsibilities under the DDA lack of access to affordable occupational health service and advice, especially true of SMEs."
UK-wide group.

QUESTION 22: Regarding support for people with RA to remain in work: can you name any good-practice employers who provide support for people with RA to remain in work?

If you have been able to name any, what are the main characteristics of the support offered by these particular employers (as opposed to other employers)?

Good-practice employer	Main characteristics of the support offered
BT	"Fast support service, with continued assessment and support for managers, as well." —UK-wide group.
Plymouth Social Services	"Adapting work space to minimise physical stress; and the use of an occupational therapist to assess and respond to workplace needs."
BT Arthritis Care Royal Mail	"Good knowledge of arthritis; good policies (such as disability leave); flexible working policies; openness to discussion about the impact of arthritis on wider life, rather than making assumptions; good role models within the organisation; frequent prompts to managers as to their responsibilities." —UK-wide group.
Seetec, Dudley	"Flexibility in allowing RA sufferers to attend appointments, or to alter their working hours."
One member of a respondent group who has a supportive employer works for the Prison Service ; another works for a solicitor specialising in employment law	"Understanding of RA; special equipment provided; flexible hours; and time off for appointments."
Local authorities and the voluntary sector	"Ergonomic improvements; change of job; and change of hours."
Large employers with occupational health departments	"Keeping their job open for them during sickness; and ergonomic assessment."

QUESTION 23: What support does the NHS provide to people with RA, to help them continue in employment?**1. Little or none**

"Not aware of anything specific."
UK-wide group.

"I don't think they do."

"Very little, there is some occupational therapists, but these tend to be focused on home rather than workplace. Even within the NHS it is poor. Poor provision of musculoskeletal services hinders people from remaining or returning to work. Some GPs and nurse specialists will undertake the time to ask about the impact of arthritis on an individual's whole life which can have a positive impact on them remaining in work."
UK-wide group.

"Other than general care and treatment, none of our members had received any NHS support to continue in employment."

"Very little. Our two employment booklets are distributed by rheumatology teams but this is often the sum total of help which most people would experience. OTs provide support in some centres but there aren't enough of them, especially those with employment experience."
UK-wide group.

"Am not aware of any. Most specialist clinics and tests are carried out during the normal working day."

"Very little."

"Apart from OTs not a lot."

2. Courses and information

"AFTER DIAGNOSTIC CASE. "NOT JUST DUMPED" -COURSES AND INFORMATION."

3. Fitness programmes and hydrotherapy

"I've received a lot of support, physio, hydrotherapy, fitness programme for local gym."

4. Physiotherapy

"Medication physiotherapy."

5. Medication

"Necessary drugs."

QUESTION 24: How often does the NHS provide support to people with RA, to help them continue in employment?

Patients' employment-related issues are not a priority for the NHS

"Partly because work issues are not prioritised and partly because it does not see that it has a major role to play in this area."

UK-wide group.

"CAN'T REALLY AFFORD TO DO SO . LACK OF FORESIGHT."

QUESTION 25: What are the main barriers to the NHS helping people with RA continue in employment?**1. A lack of NHS resources and staff time**

"Time and resources."
UK-wide group.

"Money."

"Lack of staff."

"Haven't experienced any barriers personally but would suspect money and waiting lists."

"Costs."

"COST EXPERTISE."

"Money and resources."

"Lack of resource and expertise also not a priority (but it should be!)."
UK-wide group.

"Financial and organisational - staff and facilities are traditionally only available at these times."

"Pressure of work re specified targets."

2. A lack of appropriate knowledge and skills among NHS staff

"None really except who would do it - in the old days of the medical social worker it might have happened but it is rare now."
UK-wide group.

"Capacity, expertise, culture, incentives."
UK-wide group.

"Wide range of services."

"Lack of resource and expertise also not a priority (but it should be!)."
UK-wide group.

"Lack of knowledge employers concern."

"Lack of knowledge of the patients working environment."

**QUESTION 25: What are the main barriers to the NHS helping people with RA continue in employment?
[comments, continued]**

3. Helping people with RA continue in their employment is not a strategic priority for the NHS

"Capacity, expertise, culture, incentives."

UK-wide group.

"Amongst our members, nobody had been offered any support, so it would appear not to be a priority consideration when patients are assessed."

"Lack of resource and expertise also not a priority (but it should be!)."

UK-wide group.

V.
Questions on
information and
self-management

QUESTION 27: How helpful or unhelpful are healthcare professionals in supplying information on RA to people with RA?

1. A lack of general interest in, and understanding of, RA

"Lack of interest in R A."

"Everyone doesn't understand the condition."

"I've met so-called qualified professionals. Can you catch RA!!!!!!."

"Unfortunately your headings don't quite fit the bill here. Most of the above people are not deliberately unhelpful, but their helpfulness is hindered by their lack of knowledge and expertise."

UK-wide group.

2. On specialist nurses

"Specialist nurses are not only more likely to pass on information, they are more likely to give them better information (sourced from patient groups often) and to spend time talking through the information with the patient. People with arthritis tell us that they wish to get a referral to an organisation like Arthritis Care as they then get access to information from people who have RA themselves and get peer support."

UK-wide group.

3. On GPs

"My GP is fantastic. So is my consultant and specialist nurse. Other members of staff do not always want to help."

"GPs do not seem to pass on information where access advice social support etc the emotional effects of RA are often ignored and few people seem aware of what support groups are available."

4. On occupational therapists

"Occupational therapists are extremely helpful & practical."

QUESTION 28: Would people with RA like to receive more of certain types of information from healthcare professionals?

1. More information is welcome but must be accurate, and ideally delivered through the joint working of health professionals

"Knowing anything is better than nothing."

"The information would need to be accurate."

"Joint working and shared resources is the way forward."

"Most patients would like to be able to ask about all the above issues with their consultant led multidisciplinary team and their primary care team. Pharmacists are more likely to be asked about symptoms and then side effects of medication etc."

UK-wide group.

"Our members seem most satisfied with information received from nurse specialists, commenting that they seemed more approachable, and good communicators. However most would appreciate as much information as possible, as and when required, from all the prof."

2. More information relevant to people's whole life

"People with arthritis tell us that the quality of information that they receive is generally good, but that they would like more information that relates to their whole life."

UK-wide group.

3. Information about medication

"How to take and side effects of medication are often not explained correctly. Some medication is best taken at certain times some pharmacists now offer review services."

4. Other

"I dont think the info is provided or necessarily needs to be provided other groups as above. but they should know what info on often for individual patients."

VI. Final questions

QUESTION 29: Certain sections of the public might require extra help in developing the skills to self-manage RA. How good or poor is the help with RA provided to the following (broad) categories of people?

1. Disadvantaged people need to know more about the merits of self-management

"Those groups from a disadvantaged background tends rely on medication and the concept of self management is NOT fully understood eg regular exercise, balanced diet and changing attitudes."

2. The NHS is inexperienced at promoting self-management

"The NHS (with perhaps nurse specialists and allied health professionals as exceptions) is not geared up to promoting self-management across the board. GPs are ambivalent, at best, about the concept. Many people are therefore effectively left to get on with it by themselves, or rely on organisations like Arthritis Care to signpost them to effective tools. However, if the NHS and Government are to bring self management to a wider population, voluntary sector providers must be supported to maintain the quality of the resource."

UK-wide group.

"All this help varies between adequate and precarious depending on what you are."

3. Contributions from self-help groups

"Cannot speak of any other facilities, but we do help with skills."

"Best support comes from charities/vol sector as many understand and have arthritis themselves."

4. Children are a special case

"People caring for children - this can be quite a difficult issue, where lots of support is required, but sometimes difficult to access."

QUESTION 30: Finally, is there anything else you would briefly like to tell Parliament about services for people with RA which has not been covered in this survey?

(Respondent groups offering comments are listed in alphabetical order, using the form of name they themselves supplied)

"Standards of care for RA are poor and unevenly implemented. Musculoskeletal conditions are not prioritised or incentivised, and the BMJ recently acknowledged this to be the case. Conditions which are not in the quality and outcomes framework receive a poorer quality of service from the NHS. NICE ignores 65% of costs associated with RA in its cost and clinical effectiveness adjudication, this makes it much less likely that people can remain in work. NICE relies on hard clinical outcomes and overemphasises RCT data which can again ignore the quality of life impact which can help people remain in work."

"People with RA do not qualify for help with the prescription charge though they are dependant on their medication to be able to carry out normal day to day activities."

"1. Do not under estimate Occupational therapists 2. recognise the educational role of voluntary organisations such as Arthritis Care for both patients & doctors & self management for patients."

"RA is a long term condition though it is not seen as such in the Darzi review. It is seen as a disease of old people that nothing can be done for - which is very untrue. If care were more proactive many could remain in work and productive instead of becoming needy. We need a musculoskeletal csar and for arthritis to go on the QOF. DH and DWP need to work more closely together."

"It is a Cinderella Service with insufficient funding."

"People with RA should get free prescriptions as they usually have to take several medicines together and often are on low incomes because of the restrictions caused by RA."

QUESTION 30: Finally, is there anything else you would briefly like to tell Parliament about services for people with RA which has not been covered in this survey? [continued]

"Please advise GP's not to give patients the idea that help is not available to elderly sufferers."

"Improve communication by engaging patients, carers, medical students and other health specialists."

"In my view the main problems are:- 1 See all new points written 2 pay attention to adequate follow up care a dangerous statistic has arisen (no real evidence for it) that follow up to new ratio should be 3:1 it is likely in view of the complexity of RA to be greater for optimal care 4. enough time for the rheumatology care team to meet weekly , continually audit their work & having time for courses etc."

"Very little is done always a shortage of money some towns do better then others Shoes are a problem they waste £ and of no use."

"More information re financial benefits available for RA sufferers unable to work regularly or full time."

"Many of the problems I have highlighted are things which may not take huge amounts of money to resolve. A lot of it is to do with RA having no priority and lack of education of patients and professionals."

"People with RA who receive benefits feel under constant threat of losing benefits and being forced back to work when they know they know they can not do that. At a time when the illness is most severe and people need to make a claim they are at a point when they can least deal with the complex form filling and interviews. This creates extra stress which can add to the impact of the disease. There is a general lack of knowledge of the disease in the benefit agencies which if training and awareness were provided may reduce some of the negativity. Simpler forms would also help."

QUESTION 30: Finally, is there anything else you would briefly like to tell Parliament about services for people with RA which has not been covered in this survey? [continued]

"Avoid long waiting queue for treatment, provide prompt physiotherapist treatment."

"1. Recognise that RA is a life-long condition, a "progressive inflammatory disease". As per guideline in DWP leaflet. Some DWP officers do not recognise RA as so. 2. The Dutch government offers its RA patients vouchers to be redeemed at Rheuma Spas or such like. Dutch RA patients travel to the Black Sea Area for Spa treatments. That's far more beneficial than a work placed interview, which creates enormous stress and unrealistic targets."

"One of the main concerns amongst members and other RA sufferers, is the suggestion that GPs will be responsible for a greater proportion of RA care, under proposals to provide more localised services. This is causing genuine fear amongst sufferers, who, as you will see from several comments made in this questionnaire, have not always received adequate care from GPs. In our experience, RA sufferers, on the whole, are saying that they would prefer to see hospital specialists, even though it entails some travel, rather than seeing GPs near their homes. This is sometimes highlighted by comments made by housebound sufferers, who often feel that they should have more access to rheumatology nurse specialists, for example, who are able to see patients at home, rather than relying so heavily on GP services. Although some of the answers given seem very negative, we would also have liked more of an opportunity to express our appreciation for care given by many members of the multidisciplinary team, who often provide excellent care, despite being very overworked. They have also provided much support to us since we established our support group, with several professionals giving their free time to attend our meetings, and give talks. (our entire rheumatology team recently received an NRAS award at the House of Commons, after we nominated them, in recognition of this help and support). One final comment: RA patients suffer very much from a lack of understanding amongst the general public, regarding the huge differences between RA, which is a 'whole body', disease, which doesn't only affect the joints, and the general 'wear & tear' arthritises. For this reason, it would make a big difference if the name could be changed. We have, for example, heard of some experts who have suggested that it could be changed to something like 'rheumatoid syndrome', or 'rheumatoid disease', which might help to prevent such misunderstanding."

Patient group survey

March 2009

