

People with Rheumatoid Arthritis, their carers, and the NHS

A national survey of
patients with RA and their carers

Conducted for the
National Audit Office
by PatientView

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Preface

Rheumatoid Arthritis (RA) is a condition relating to inflammation of joints, and is usually progressive and chronic. Many people with RA are first diagnosed while still at working age. Existing and new treatments are effective when appropriately administered, can improve quality of life, and have led to a reduction in in-patient care.

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 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

of a survey of 1,400 people with a confirmed diagnosis of rheumatoid arthritis (RA) living in England.

Diagnosis

- Pain (47%) and joint swellings (28%) are the main reasons why people who are eventually diagnosed with RA come forward for treatment and care.
- Most respondents (94%) first seek help from the GP.
- Reasons for delays to diagnosis include the following: one third (32%) of people with RA admit that they delayed going to their GP for 6 months or more once symptoms appeared; one third wait 6 months or more to obtain a referral to a specialist; 28% blame GP uncertainties about RA; 16% mention initial misdiagnoses by the GP; and 16% of people with RA insist that their symptoms were not taken seriously enough by primary-care health professionals.
- Following specialist consultation, further delays slow the process of obtaining a final diagnosis (one in ten respondents report waiting a year or more).
- Over a quarter (27%) of patients seek a diagnosis privately—sometimes at the suggestion of their NHS GP (28% of the people going privately).

Treatment and care

- Obtaining effective treatment and care took more than three months for over half of people with RA (54%). For 32%, six months or more were needed, and 23% had to wait over a year.
- 69% of respondents report having taken a course of disease-modifying anti-rheumatic drugs (DMARDs); 31% have been prescribed biologics.
- The pattern of prescribing varies for DMARDs and biologics across England. Lowest prescribing volumes for both types of treatment occur in north-west England: 67% of people with RA living in the north west report having tried a course of DMARDs. The equivalent figure for south-central England (the top prescribing area) is 81%. Only 22% of people with RA from north-west England have been prescribed a biologic, against 38% of those from Greater London.
- Overall, 31% of respondents report having surgery. 32% of people with RA in Greater London have had surgery, compared to 21% in north-east England.
- Half of the respondents undergoing surgery say that they had to wait more than three months for surgery once the consultant recommended the procedure. Over one quarter (27%) went privately for their RA operation.
- The majority of respondents find non-medical interventions helpful, yet many of the 'alternative' forms of care are not generally available on the NHS. Only 7% of respondents report receiving social counselling/support. Yet 83% of these particular individuals confirm that it helps them at least a little, while 43% think that the intervention helps them a lot.

- The majority of respondents are satisfied/very satisfied with the care they receive from health professionals. Specialist RA nurses emerge as the most highly-regarded of the professionals, with 54% of respondents very satisfied with them. Only 54% of respondents consider their hospital appointment system to be effective, with 57% of respondents believing that the system is unable to cope with their individual needs. 72% claim that services to support them getting back to work are not very effective or are ineffective.

Long-term care

- 75% of respondents have a review more often than once a year, primarily with an NHS consultant. Similar percentages appear among people with RA who are in employment, people with stable RA, or those who have had RA for 10 years or more.
- The majority of respondents (66%) say that they have had a flare-up within the last three months. But only 42% of these saw a consultant for help with their flare-up.
- When asked what would make a real difference to improving self management of their RA, 62% of the respondents with RA strongly agree that "a consistent approach to dealing with RA throughout the NHS" is needed, and 60% approve of greater consultation with people with RA on how to improve NHS RA services. Also high on the list of requirements for people with RA (59%) is having someone to turn to for help in the event of a flare-up.

Employment

- According to 68% of the employed respondents, their employers are very or fairly understanding about their RA. One quarter are not.
- Most employers (66%) listen to the problems of their employees with RA, and give them time off to attend appointments (81%).
- Employers were much less likely to switch work tasks to reflect physical needs, or to provide the re-training necessary if their employees with RA are to take on new tasks (16%).

Improving the system

Respondents to this survey identify a number of ways in which the NHS could improve its services to people with RA. Most important are:

- Faster referral by GPs to a rheumatologist (improves the speed of diagnosis).
- Better access to the best medication/choice of treatment.
- Faster and easier access to secondary care (ensures better long-term care). And,
- Making RA services more convenient, so that people with RA can continue to work.

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.
- ⇒ Recommendations on how to improve RA services.

Profiling questions

Profiles of respondents

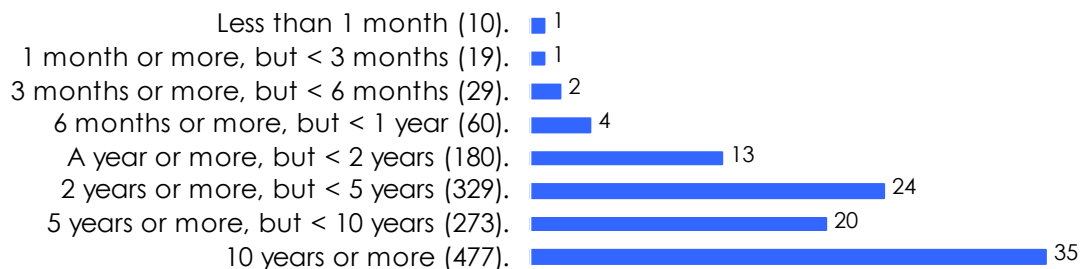
The demographics of the surveyed population of people with RA (and their carers) is diverse.

- 1,400 people with diagnosed RA (and living in England) responded to the survey. 54% of the respondents have stable RA (the disease's symptoms can be managed by the patient, and do not appear to be worsening). Another 43% have an unstable form of the condition (symptoms are not manageable by the patient, and/or the condition appears to be worsening).
- 82% of the 1,400 respondents completed all of the survey's questions.
- 95% of the respondents are people with RA. 1% of the respondents are paid carers. Another 4% are informal carers. Each carer answered on behalf of the person with RA whom they were looking after.
- The vast majority of respondents (96%) have been living for at least six months with a formal diagnosis of RA [see chart below]. 79% had their diagnosis two or more years ago.

How long since you received this diagnosis?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total; total number of responses = 1,277, excluding 3 "Don't know"s.



- Several other conditions that can contribute to disability (or even death) are common in people with RA. The most important of these co-morbidities are: cardiovascular disease (which, in turn, may be associated with platelet aggregation); hypertension (high blood pressure); hyperglycaemia (higher than normal level of glucose in the blood); hyperlipidaemia (raised serum levels of cholesterol); and raised serum homocysteine (a type of an amino acid which has been linked to cardiovascular disease). Also occurring can be: gastrointestinal disease; infection; cancer (notably leukaemia, lymphoma, and multiple myeloma); and osteoporosis.

766 of the survey's respondents (or just over half) report having another medical condition than RA. High blood pressure is by far the most common other condition.

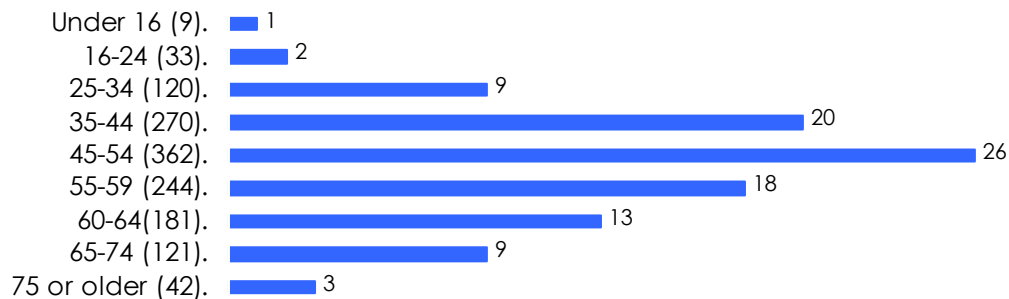
Profiles of the people with RA (and carers) in this study (continued)

- 20% of the respondents with a confirmed diagnosis of RA are men, and 80% are women—roughly the proportion that would be expected, given that RA is more prevalent in women than in men. The survey methodology may, however, have generated a small bias, since the patient respondents were recruited through patient organisations. Patient group membership, regardless of medical condition, is generally dominated by women.
- 91% of the respondents are white British, 5% other white, and 4% non-white.
- The age profile of the study's respondent sample is typical for people with this condition. RA usually begins to affect people between the ages of 30 to 55. 46 per cent of respondents to our survey were in the age range 35 to 54. Younger people can also be diagnosed with the condition, and 11 per cent of the respondents were aged 16 to 34. The condition can also strike teenagers [see chart below].

Which age range do you fall into?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total; total number of responses = 1,382.



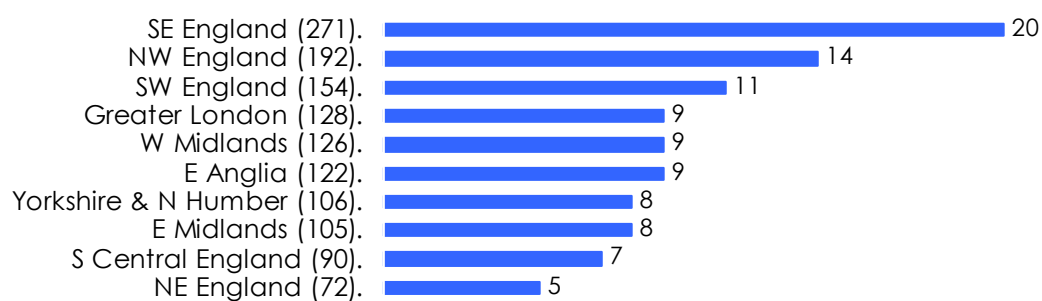
Profiles of the people with RA (and carers) in this study (continued)

- The survey's respondents come from across England, in approximate proportion to the country's overall population distribution.
 - ⇒ 20% of the survey's respondents live in south-east England, for instance. The National Statistics Office notes that this part of the country holds 16.3% of the English population aged 15 or over.

Where do you live?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total; total number of responses = 1,366.



Profiles of the people with RA (and carers) in this study (continued)

- 269 (or 23% of) respondents are unemployed or medically retired as a result of their RA.
- 562 respondents are in full- or part-time employment (excluding those claiming incapacity benefit). Of these, one third are employed in small enterprises (1-24 employees); 38% in medium-sized organisations (25-499 employees); and 29% in larger enterprises (500 or more employees) [see chart below].

Which of the following broad categories would you say best describes your employment status?

All respondents with a formal diagnosis of rheumatoid arthritis
% of total; total number of responses = 1,297.

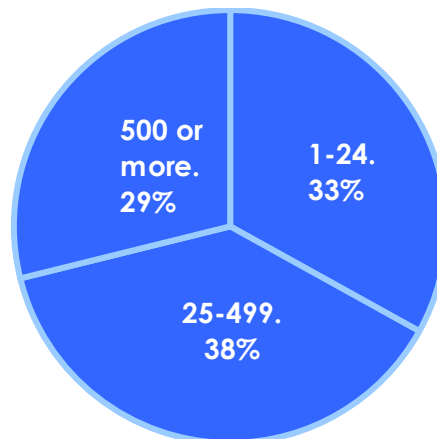
An employee.	39
Medically retired because of RA.	12
On incapacity benefit.	12
Unemployed because of RA.	11
Retired (over 5 years).	8
Self-employed.	6
Retired (within the past 2 years).	4
Retired (2-5 years).	4
Unemployed (not because of RA).	4

Which of the following broad categories would you say best describes your employment status?

All respondents with a formal diagnosis of rheumatoid arthritis in full- or part-time employment

% of total; total number of responses = 576.

Categories relate to number of employees in full- or part-time employment in the company where the respondent works.



Questions on obtaining a diagnosis

*"The route to diagnosis was full of delays.
My blood tests were coming back high with RF, yet one of my blood tests didn't show inflammation.
But my joints were extremely painful, and with limited movement.
My GP recommended that I take the tests again in a couple of months.
When I did, two months later, the blood tests were lost, and I was not contacted about this.
So, by the time I redid the tests, it was another month lost.
I paid for a consultant, as I didn't want to wait for an NHS appointment and have delays.
But the appointment system in the NHS was also a major problem. The hospital had issues with the
appointment system, and, as I did not exist on the system, I had to wait for the bureaucracy to sort itself
out before I could be given an appointment—another 3 months before I could even book an
appointment. Though the appointment was made very quickly once on the system, time was wasted.
Then the consultant needed a forceps to do a diagnostic test. This tool had to come from America,
and so another 2 months was lost. Then I had mobility problems, and I started on steroids.
Then, from not meeting the full criteria, I was told in one visit in a matter-of-fact way
(the consultant looking at the screen/records) that I had RA, and it was incurable.
No tea, no sympathy, no schedule of support (as you might expect with a long-term illness).
Just live with it.
My faith in the NHS, and my own confidence in dealing with the disease, crumbled."*

—Man with RA, living in London, aged 35-44.

Diagnosis

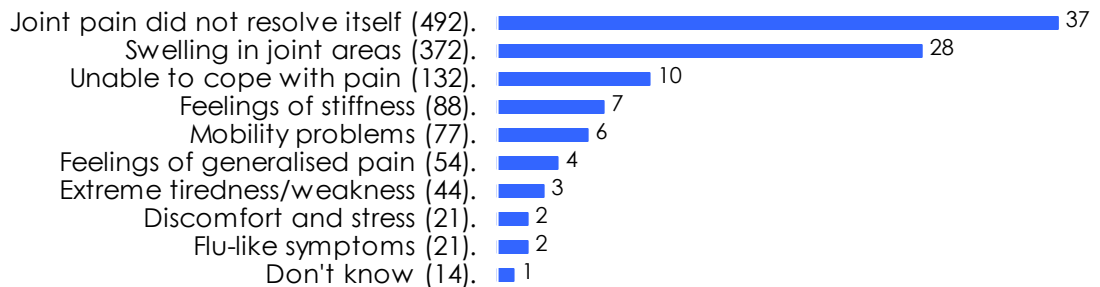
Time taken to get a diagnosis

- The study's respondents identify three main reasons as to why people who eventually get a diagnosis of RA seek medical help initially: joint pain that does not resolve itself (37% of respondents); swelling in joint areas (28%); and an inability to cope with the pain (10%) [see chart below].

What is the main reason that first caused you to seek medical help for your RA?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses; total number of responses = 1,315.

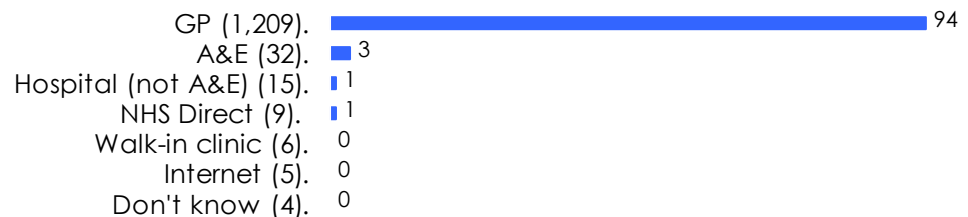


- When people with RA first seek medical help about their early symptoms of RA, the opening point of contact for the vast majority (94%) is the GP [see chart below].

Where did you first go to seek medical help for your RA?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses; total number of responses = 1,280.

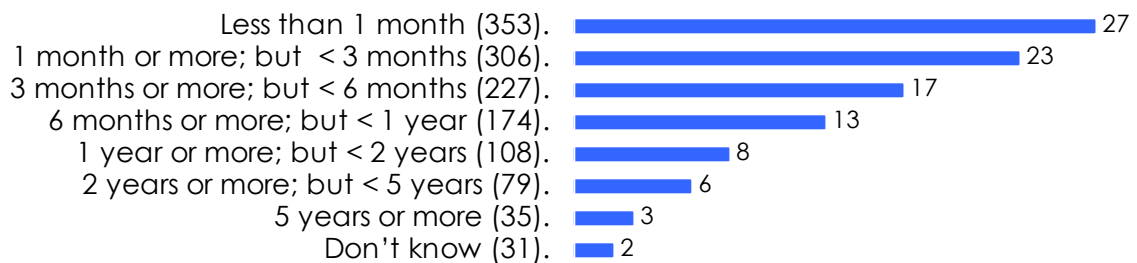


Time taken to diagnosis (continued)

- Half of the respondents waited 3 months or less between first experiencing symptoms and then reporting them to the GP. However, as many as 32% of the respondents waited six months or more before approaching their GP, while 17% waited a year or more [see chart below].

How much time was it from when you first experienced symptoms and going to see your GP?

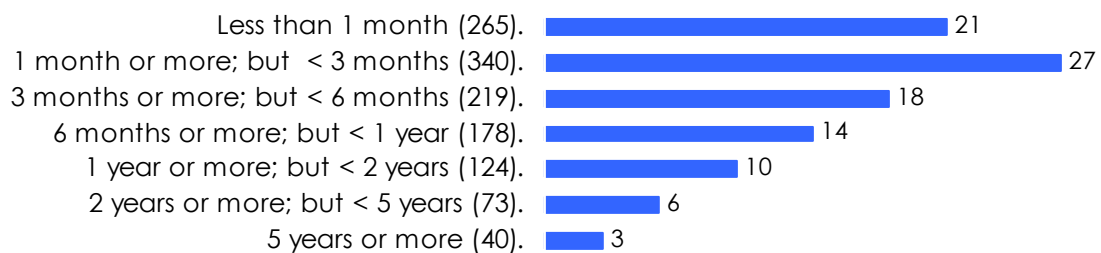
All respondents with a formal diagnosis of rheumatoid arthritis
% of total responses; total number of responses = 1,313.



- One third of respondents waited six months or more between first experiencing symptoms and getting a referral to a specialist. Nearly one in five (19%) waited 2 years or more [see chart below].

How much time was it from when you first experienced symptoms, to your GP referring you to an NHS consultant/RA specialist?

All respondents with a formal diagnosis of rheumatoid arthritis
% of total responses; total number of responses = 1,239, excluding 56 "Don't knows".



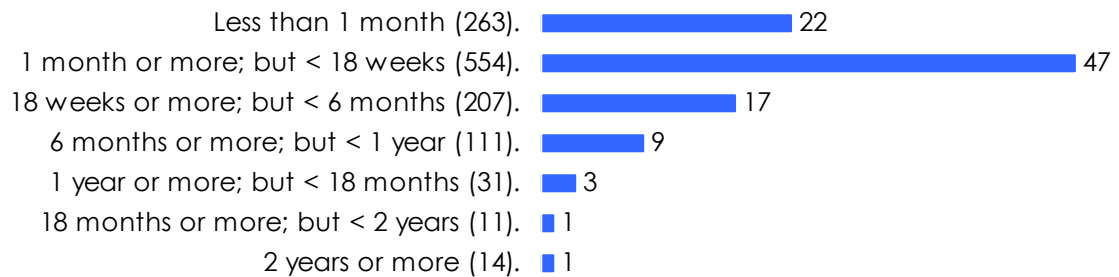
Time taken to diagnosis (continued)

- 22% of the respondents were seen by a specialist (after GP referral) within one month, and 14% of respondents waited six months or more to see a specialist after being referred by their GP. 5% waited a year or more [see chart below]. A substantial number of respondents (7%) appear unaware of the time lapse between GP referral and their seeing a consultant.

How much time was it from when you were referred by your GP to seeing an NHS consultant/RA specialist?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses; total number of all responses = 1,191, excluding 83 "Don't know"s.



Time taken to diagnosis (continued)

- 27% of of the respondents with RA (371) went privately for a referral— a large number if translated to the national population with RA. Of those who went privately, 28% were following a suggestion from their NHS GP.

If you went privately for a referral, was this ...?

All respondents with a formal diagnosis of RA

<i>% of respondents (number in brackets is total responding to question)</i>	
Went privately for a referral, of which ...	All (371)
... at own instigation	72
... on the recommendation of the NHS GP	28

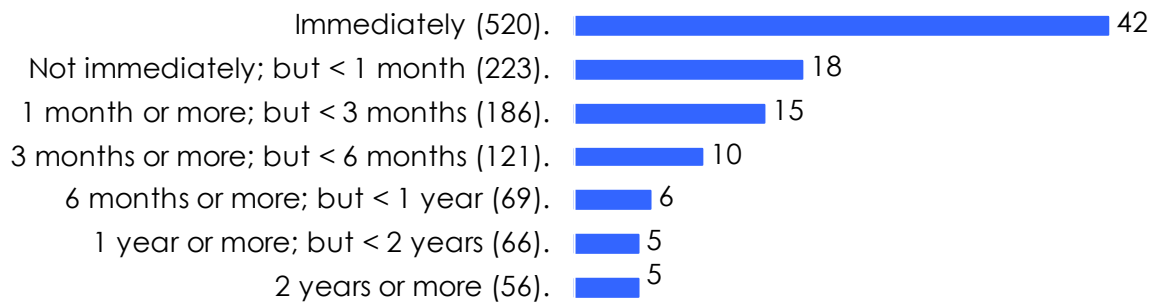
Time taken to diagnosis (continued)

- Although a significant percentage of respondents (42%) obtained an immediate diagnosis from their consultant, over one quarter (26%) say that it took three months or more. One in ten mention one year or more.

How much time was it from when you FIRST saw an NHS consultant/RA specialist to receiving a diagnosis?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses; total number of all responses = 1,241, excluding 47 "Don't know"s.



Time taken to diagnosis (continued)

- 28% of all respondents insist that delays to their diagnosis occurred because the GP was unsure whether the symptoms were those of RA. 16% feel that the doctor/nurse did not take their condition seriously enough. And 16% believe that their GP initially misdiagnosed their condition. In nearly 10% of cases, the GP either took a long time to recommend referral, and/or the RA tests took time to be carried out. For 15% of respondents, the delays to diagnosis are the result of failing to seek medical help themselves.

If you feel that your diagnosis could have been made more quickly, what were the main reasons?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses; total number of all responses = 1,172, excluding 62 "Don't know"s.

[Figure in brackets is number of responses.]

To begin with, the GP was unsure whether my symptoms were RA (329).

28

I felt that the doctor/nurse did not take my medical condition seriously (188).

16

My RA was initially misdiagnosed by the GP (185).

16

I myself delayed going to seek medical help (170).

15

The GP took a long time to refer me to a consultant (103).

9

My RA tests took a long time to be carried out (101).

9

I was referred to the wrong type of consultant (56).

5

I had to change GP practice to get the referral that I thought I needed (24).

2

The waiting times to see a GP are long where I live (16).

1

On specific diagnostic tests

- The most common tests undertaken by GPs are blood tests for rheumatoid factor (RF) (49% of all respondents), and/or physical examinations (42%). As would be expected, a higher percentage of people had a range of tests conducted on them by NHS consultants/RA specialists.

Were any of the following tests carried out on you, and, if so, who carried them out?

Note: respondents could choose more than one option for each test.

- Total possible number of all qualifying respondents = 1,400.
- Total possible number of respondents in work = 562.
- Total possible number of respondents out of work due to RA = 269.

<i>% of respondents who said that the tests listed below were conducted on them.</i>					
	Blood tests for RF	Physical exam	Simple Squeeze	Questions on QoL	X-rays
GPs					
All qualifying respondents with a confirmed diagnosis of RA.	49	42	27	25	9
Consultants					
All qualifying respondents with a confirmed diagnosis of RA.	60	67	50	52	69

Questions on access to treatment and care immediately following a diagnosis

*"I work as a nurse in the NHS, and I feel that my knowledge of the system has helped me access care.
It would have been hard to negotiate without that. My rheumatologist is great,
and answers my e-mails with questions about starting treatment, blood results, etc.
Without that facility, I would feel unsupported.
Apart from her, I feel alone and scared for my future.
I have not been offered any other support, not even when I had bad side effects, etc.
I feel that I support my own patients (I specialise in people with HIV)
far better than I have been supported—except by my rheumatologist,
and I obviously cannot see her that often.
I feel that there is a need for a more holistic service,
and [for the system] not to presume that the people who appear to be coping really are."*

—Woman with RA, living in South-East England, aged 45-54.

Treatment and care

On the timeliness of treatment and care

- 33% of all respondents with a confirmed RA diagnosis say that they received treatment (which improved their condition) within at least the first month, if not immediately. But 54% say that it took more than three months. For almost one third (32%), six months or more were needed. For almost a quarter (23%) of the respondents, effective treatment took over a year to obtain. One in ten of respondents report "not feeling better despite treatment".

After formal diagnosis of your RA by an NHS consultant/RA specialist, how much time did it take to get treatment that produced improvement in your condition?

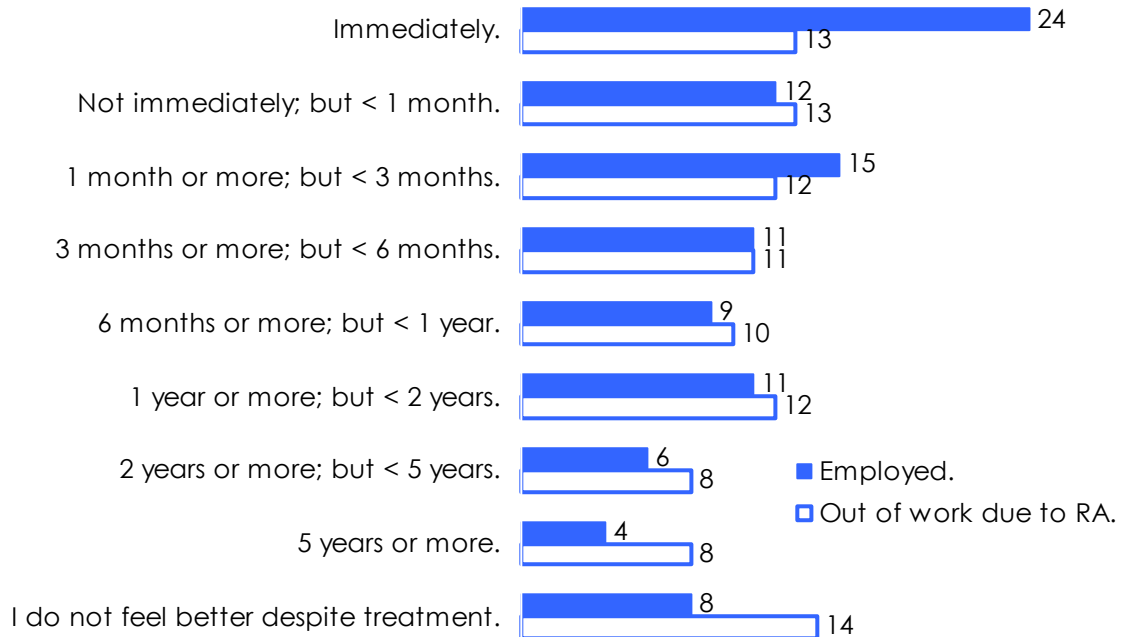
Employed people with RA

Total = 549, excluding 7 "Don't know"s.

versus

Respondents who are out of work due to RA

Total = 263, excluding 21 "Don't know"s.

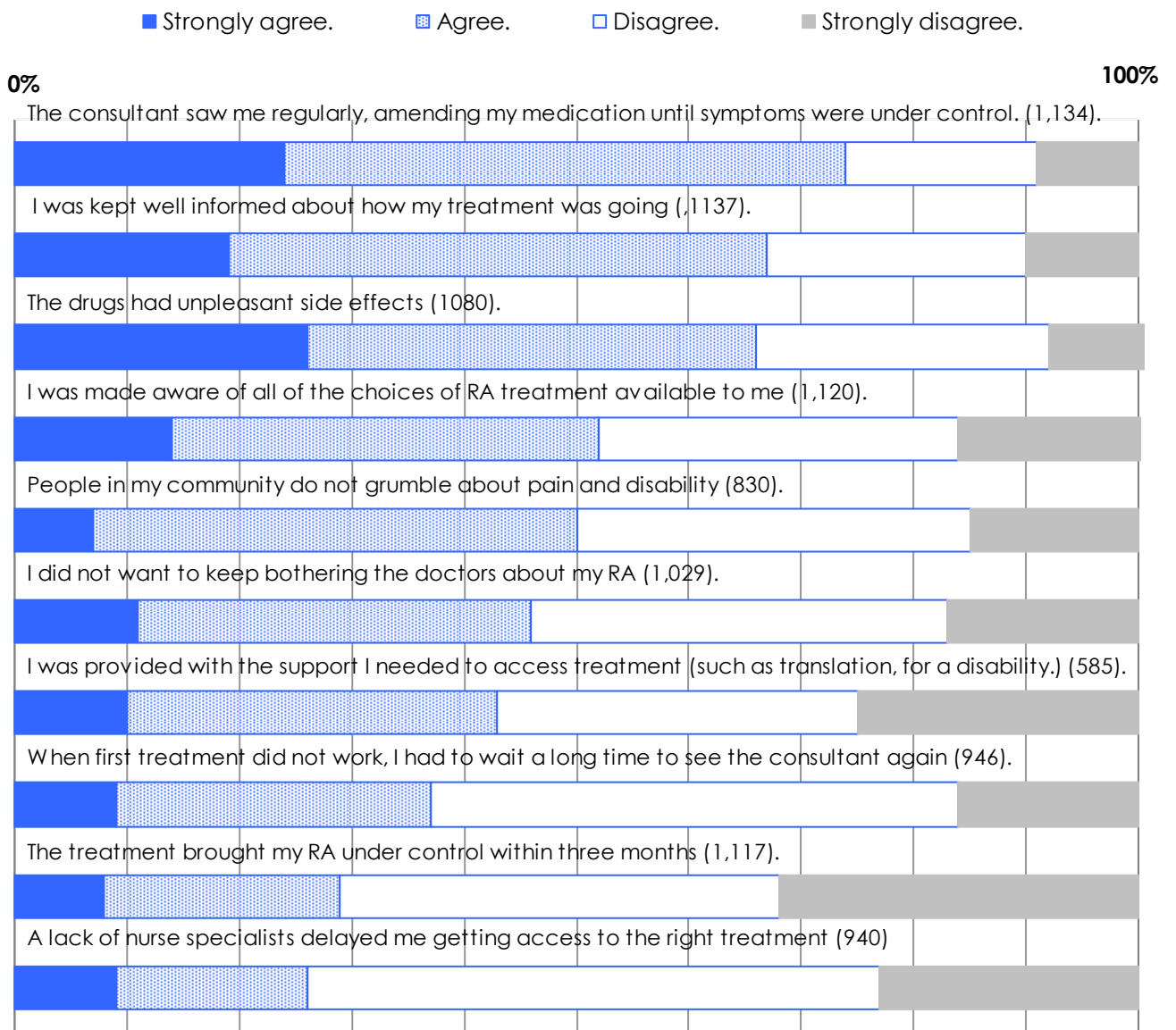


On the timeliness of treatment and care (continued)

To what extent do you agree or disagree with each of the following statements about your experience of treatment/care after diagnosis?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses, excluding "Don't know"s and "Not applicable to me"s.



For comments on the above chart, see next page ...

On the timeliness of treatment and care (continued)

- *On the positive side*, the majority of all respondents with a confirmed diagnosis of RA affirm that:
 - ⇒ They feel well informed about how their treatment is progressing.
 - ⇒ They are made aware of all of the choices of RA treatment available.
 - ⇒ They are willing to bother doctors about their RA
 - ⇒ The consultant sees them regularly, and will amend medication until symptoms are brought under control.
 - ⇒ Waiting times to the consultant after first-line therapy fails to work are not too onerous.
 - ⇒ Nurse specialists do not appear to be in short supply (if they were, access to treatment might be delayed).

On the negative side, the majority of all respondents with a confirmed diagnosis of RA affirm that:

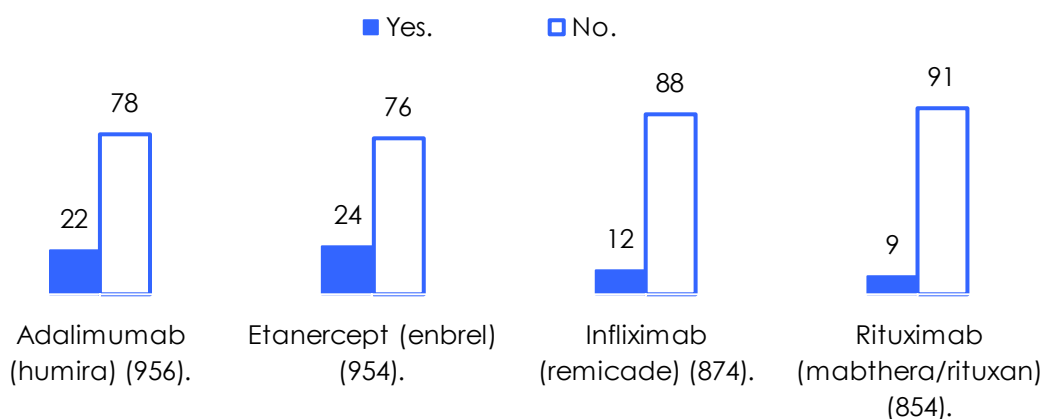
- ⇒ The drugs they receive have unpleasant side effects.
- ⇒ They were not provided with the support they needed to access treatment (support such as translation, or support for a disability not related to RA).
- ⇒ Treatment did not bring their RA under control within three months.

On biological drugs

- 419 (30%) of the 1,400 respondents with a confirmed diagnosis of RA have been prescribed at least one biologic drug. Ethnaercept (enbrel) is the most commonly prescribed, followed by Adalimumab (humira), then Infliximab (remicade), and, finally, Rituximab (mabthera/rituxan), the newest of the four treatments. Fourteen respondents (1%) have been prescribed all four drugs.

Have you been prescribed the following biological drugs?

All respondents with a formal diagnosis of rheumatoid arthritis
% of total responses, excluding "Don't know"s.



⇒ The pattern of prescription of biologics appears to vary across England. The highest rate of prescription (38%) occurs in Greater London. The lowest (22%) is in north-west England. However, these figures do not take into account other possible variables, such as the different levels of prevalence of RA across the country.

The pattern of consumption of biologics across England

% of respondents who say that they have been prescribed biologics, as a proportion of all respondents per geographic area of England.

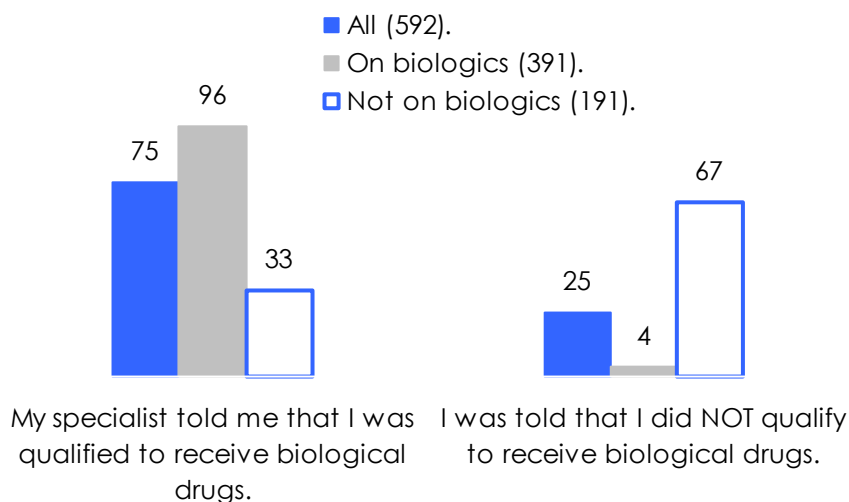
	No. on biologics	No. in region	% taking biologics
Greater London.	48	128	38
Yorkshire & N Humber.	39	106	37
S Central England.	31	90	34
SE England.	88	271	32
W Midlands.	40	126	32
NE England.	22	72	31
E Midlands.	32	105	30
E Anglia.	35	122	29
SW England.	41	154	27
NW England.	43	192	22
	419	1,366	

On biological drugs (continued)

- The responses to the question on whether people with RA had been informed by their specialist about their eligibility for biologic drugs suggest that people with RA are mostly well informed about their suitability to receive biologic drugs [see chart below]. However, several anomalies appear:
 - ⇒ 4% of people with RA who ARE taking biologics believe that their specialist told them that they DID NOT qualify for the drugs.
 - ⇒ One third of people with RA who ARE NOT taking biologics say that their specialist told them that they DID qualify for the drugs.
 - ⇒ 43% of people with RA who ARE NOT taking biologics are unable to specify whether the specialist had informed them about their suitability to take such drugs.
 - ⇒ 5% of people with RA who ARE taking biologics are unable to specify whether the specialist had informed them about their suitability to take such drugs.

What did the NHS consultant/RA specialist tell you about your qualification for treatment with biological drugs?

All respondents with a formal diagnosis of rheumatoid arthritis
% of total responses for each subcategory, excluding "Don't know"s.
[Total responses for each category are in brackets.]



On DMARDs

- 69% of all diagnosed respondents (972 of the 1,400 respondents) had tried courses of DMARDs, with around half of these having had three or more different types. However, a small percentage (7%) had tried more than six different courses of DMARDs in search of one that would work for them.

**If you have been prescribed conventional DMARDs ...
how many different courses of DMARD treatment did you try
before you found the treatment that was right for you?**

Number of courses tried	% (excluding six "Don't know"s)
1	23
2	25
3	23
4	13
5	7
6	2
More than 6	7

Total number of respondents = 972, excluding don't knows.

- The survey has found that the prescribing pattern of DMARDs varies across England—from 81% of the respondents in south-central England receiving them, to 63% of those in the East Midlands. These figures, however, do not take into account other possible variables such as the different levels of prevalence of RA across the country.

The pattern of consumption of DMARDs across England

All respondents with a formal diagnosis of rheumatoid arthritis

% of respondents who say that they are taking DMARDs, as a proportion of all respondents per geographic area of England. (Note that the total in the table below does not tally with the that in the chart above, because not all respondents indicated where they lived.)

	Number prescribed DMARDs	Total in region	% of total
S Central England.	73	90	81
Yorkshire & N Humber.	83	106	78
W Midlands.	93	126	74
E Anglia.	88	122	72
SE England.	186	271	69
NE England.	49	72	68
Greater London.	87	128	68
SW England.	103	154	67
NW England.	128	192	67
E Midlands.	66	105	63
	956	1,366	

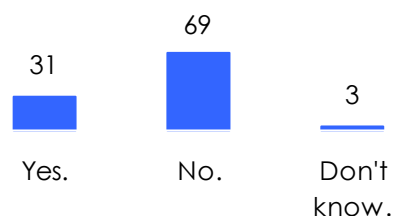
On Surgery

- Surgical treatment is usually only prescribed after joint damage has occurred, and is deployed to relieve pain or increase the activity of the affected joint. 368 (31%) of the respondents indicate that they have had surgery to treat their RA.

Have you had surgery to treat your RA?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses;
total number of responses = 1,201.



- The percentage of respondents who have had surgery differs across the country. In Greater London, 32% of respondents say that they have had surgery. In north-east England, the equivalent is 21%. These figures, however, do not take into account other possible variables such as the different levels of prevalence of RA across the country.

The pattern of surgery across England

All respondents with a formal diagnosis of rheumatoid arthritis

% of respondents who say they have had surgery, as a proportion of all respondents per

% of responses	No. had surgery	No. in region	% had surgery
Greater London.	41	128	32
Yorkshire & N Humber.	31	106	29
E Anglia.	35	122	29
SW England.	44	154	29
S Central England.	25	90	28
NW England.	50	192	26
E Midlands.	27	105	26
SE England.	68	271	25
W Midlands.	28	126	22
NE England.	15	72	21
	364	1,366	

geographic area of England.

On Surgery (continued)

Prevalence of different types of surgery

All respondents with a formal diagnosis of rheumatoid arthritis

Type of surgery	% of total respondents who have this type
Finger, hand, or foot surgery	58
Arthroscopy (removal of debris or inflamed tissue)	40
Hip or knee replacement	39
Synovectomy (removal of inflamed tissues)	22
Surgery to fuse a joint (not neck)	22
Tendon repairs	17
Cervical spine surgery (neck)	4

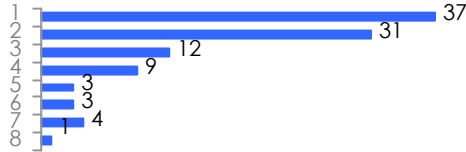
- **Finger, hand, or foot surgery** is the most common type of surgery reported by the respondents. 215 (or 15% of all respondents diagnosed with RA, and 58% of the 368 respondents who have had surgery) declare that they have had such an operation. 37% of the 215 say that they have had one operation, a further 31% have had it twice, while the remainder have undergone three or more such procedures.
- **Arthroscopy** is the process whereby tiny incisions are used to insert an instrument for viewing the inside of a joint. Surgery to remove debris or inflamed tissue may be performed at the same time. Arthroscopy is less injurious than open surgery, thanks to the small size of its incisions. 148 respondents say that they have undergone arthroscopy (11% of all respondents, and 40% of the respondents who have had surgery). Some 52% of the 148 mention having had one operation, while 25% have had two (again, the balance have experienced three or more such procedures).
- **Hip/knee replacements** are undertaken when a damaged joint has to be replaced with an artificial joint (prosthesis), which can last about 15 years. 143 respondents have had a hip or knee replacement (10% of all RA respondents, and 39% of the 368 people with RA who have undergone surgery). The majority of the 143 have undergone just one or two such operations (34% and 36% respectively).
- **Synovectomy** is the removal of inflamed tissues to prevent erosion of cartilage and bone. 81 respondents have had the operation (6% of all RA respondents, and 22% of respondents with RA who have had surgery). Most of the respondents who report being given this type of surgery had only one (57%) or two (26%) operations.

On Surgery (continued)

- **Bone or joint-fusion surgery** is performed to relieve pain in the ankles, fingers, hips, spine, thumbs, or wrists. Two bones on each end of a joint are fused, eliminating the joint itself. 80 respondents have undergone this type of surgery (6% of all respondents, and 22% of the respondents who have had surgery). The vast majority of the 80 (73%) had had only one such operation.
- **Tendon repairs** are most frequently performed on the hands. Damaged tendons are repaired by attaching them to healthy, intact tendons. 62 of the respondents have had tendons reconstructed (4% of all respondents, and 17% of respondents who have undergone surgery). 60% of the 62 have had the operation once; 29% twice.
- When RA affects the cervical spine, surgery may be undertaken to stabilise the spine and neck, as well as reduce pain by removing compression in the spinal cord. 15 respondents have had **cervical spine (neck) surgery** (1% of all RA respondents, and 4% of all respondents having had surgery). In all, 10 of the 15 (73%) have had the operation once; two people (16%) have had it twice.

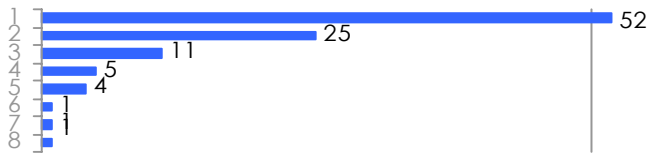
Finger, hand, or foot surgery, number of operations

% of responses among respondents who have had finger, hand, or foot surgery; total = 215.



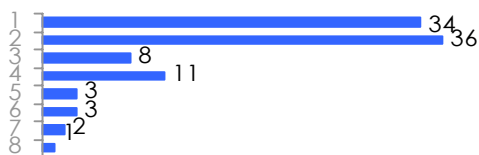
Arthroscopy (removal of debris or inflamed tissue), number of operations

% of responses among respondents who had arthroscopy; total = 148.



Hip or knee replacement

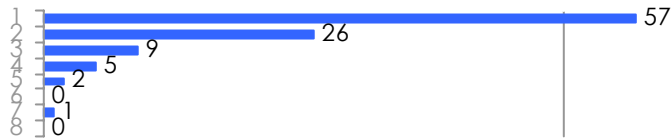
% of responses among respondents who had hip and knee replacement; total = 143.



On Surgery (continued)

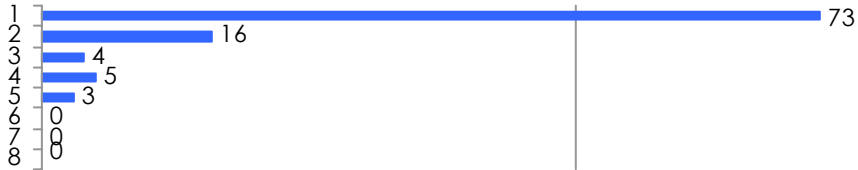
Synovectomy (removal of inflamed tissues)

% of responses among respondents who had synovectomy; total = 81.



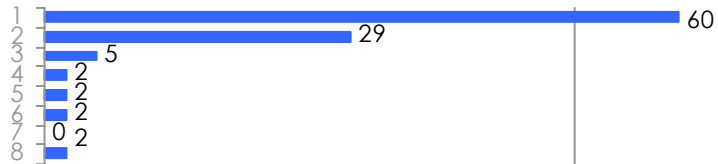
Surgery to fuse a joint (not a neck joint)

% of responses among respondents who had surgery to fuse a joint (not a neck joint); total number of responses = 80.



Tendon repairs

% of responses among respondents who had tendon repairs; total = 81.



Cervical spine surgery (neck)

% of responses among respondents who had cervical spine surgery; total = 15.



On Surgery (continued)

- On the *positive* side, virtually all of the respondents with RA who have had surgery (93%) appear to have gained access to a specialist in the appropriate surgical field, and many (78%) were operated upon in a local hospital.
- On the *negative* side, half of the respondents who have had surgery say that they waited more than three months for the procedure once it had been recommended by the consultant.

Among the other findings: only 36% of people with RA who have had an operation were able to choose the surgeon; well over one quarter of the respondents who have had surgery (27%) say that they went to the private sector for their operation/s; and no differences occur in the pattern of responses for employed people with RA (who have undergone surgery) and those out of work due to RA (and who have also undergone surgery).

If you have had surgery: are any of the following statements true about your most recent operation?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses, excluding "Don't know"s.

[Number in brackets is total number of respondents, excluding "Don't know"s.]

My surgeon was a specialist in the field (for instance, in hand/feet surgery) (370).



I had my operation in my local hospital (383).



I waited more than 3 months for surgery, once it was recommended (357).



I was able to choose the surgeon I wanted to carry out my operation (342).



I went privately for my operation (327).



On other types of treatment and care

- Apart from medicines and surgery, the most common therapy received by people with RA is physiotherapy (44% of all respondents), followed by occupational therapy (40%), and podiatry services (for foot and leg disorders, 28%).

If you received any of the following treatments for your RA on the NHS

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses—excluding “Don’t know”s, those who “paid for the service privately”, and those who say that they “did not have that type of treatment”.

Physiotherapy.	44
Occupational therapy.	40
Podiatry services (treatment of foot and leg disorders).	28
Hydrotherapy.	24
Heat therapy.	18
Physical therapy (exercise facilities).	17
Orthoses.	13
Advice from a dietician.	12
Complementary therapy.	9
Social counselling and support.	7
Chiropractic.	5
Stress management.	4

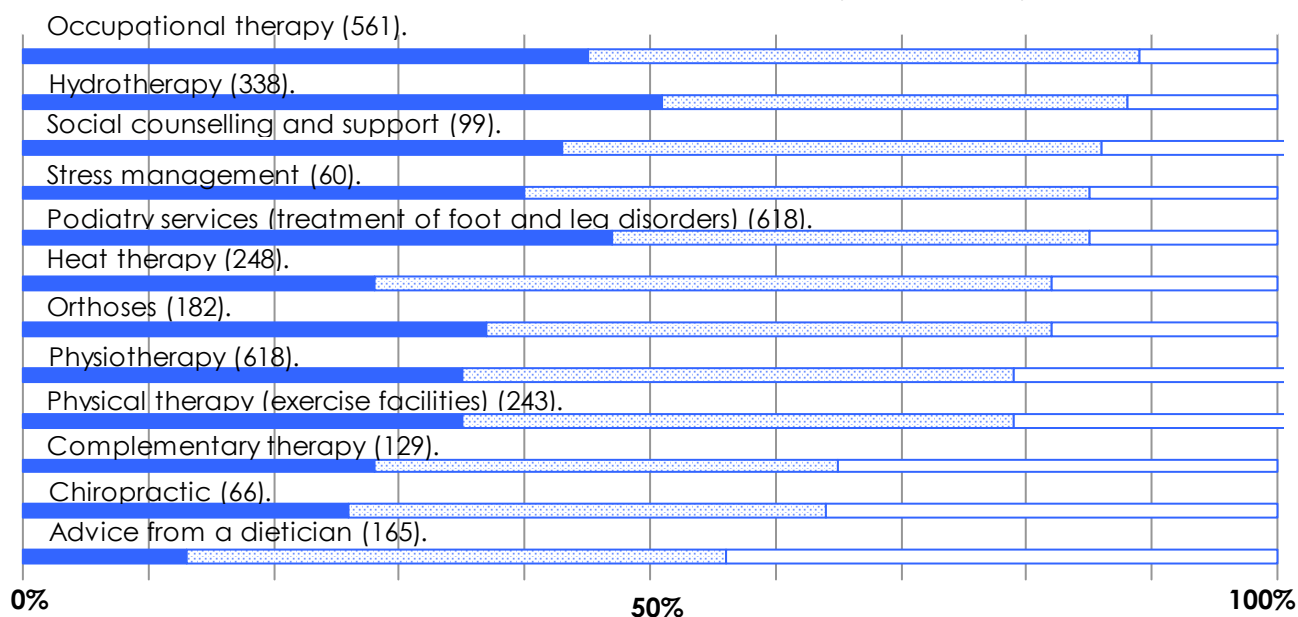
- The chart below shows that occupational therapy appears to be the most highly-valued service of all.

Did the treatment help, or not?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses—excluding “Don’t know”s, those who “paid for the service privately”, and those who say that they “did not have that type of treatment”.

■ Helped a lot. ■ Helped a little. □ Did not help.



On other types of treatment and care (continued)

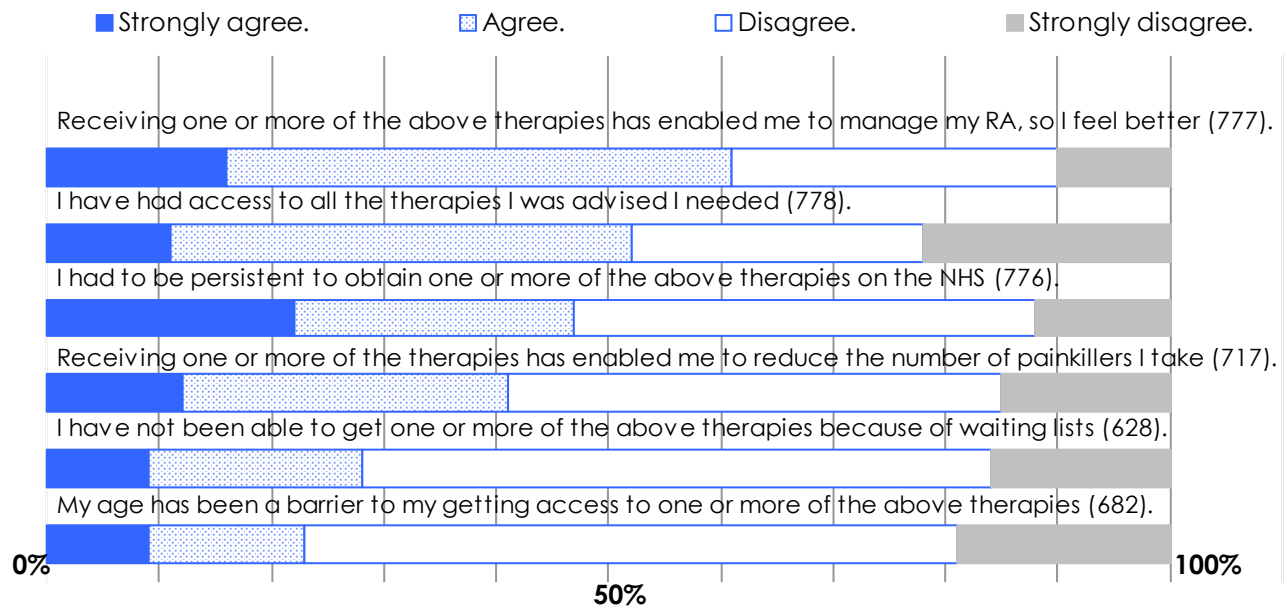
- The majority of respondents paint a positive picture about access to alternative therapies via the NHS.
 - ⇒ 61% of respondents insist that non-medical/non-surgical treatments like hydrotherapy or physiotherapy make them feel better and more able to manage their RA.
 - ⇒ A significant minority of respondents (41%) regard the improvements brought about by alternative therapies as great enough for them to be able to reduce the number of painkillers they take.
 - ⇒ 78% of respondents do not consider age to be a barrier to accessing alternative treatments such as hydrotherapy or physiotherapy.
 - ⇒ 72% do not think that waiting lists prevent them from accessing such therapies.
 - ⇒ 52% of the respondents do not believe that they have to make persistent requests to get access to alternative therapies.
 - ⇒ And as many as 52% judge that they have access to all the alternative therapies they are advised that they need.

A significant number of people with RA (albeit a minority) do not have access to all of the alternative therapies they need (48%), or have to be persistent to gain access to them (47%).

To what extent do you agree or disagree with the following statements about alternative treatments?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses, excluding "Don't know"s, and those who say "Not applicable to me".

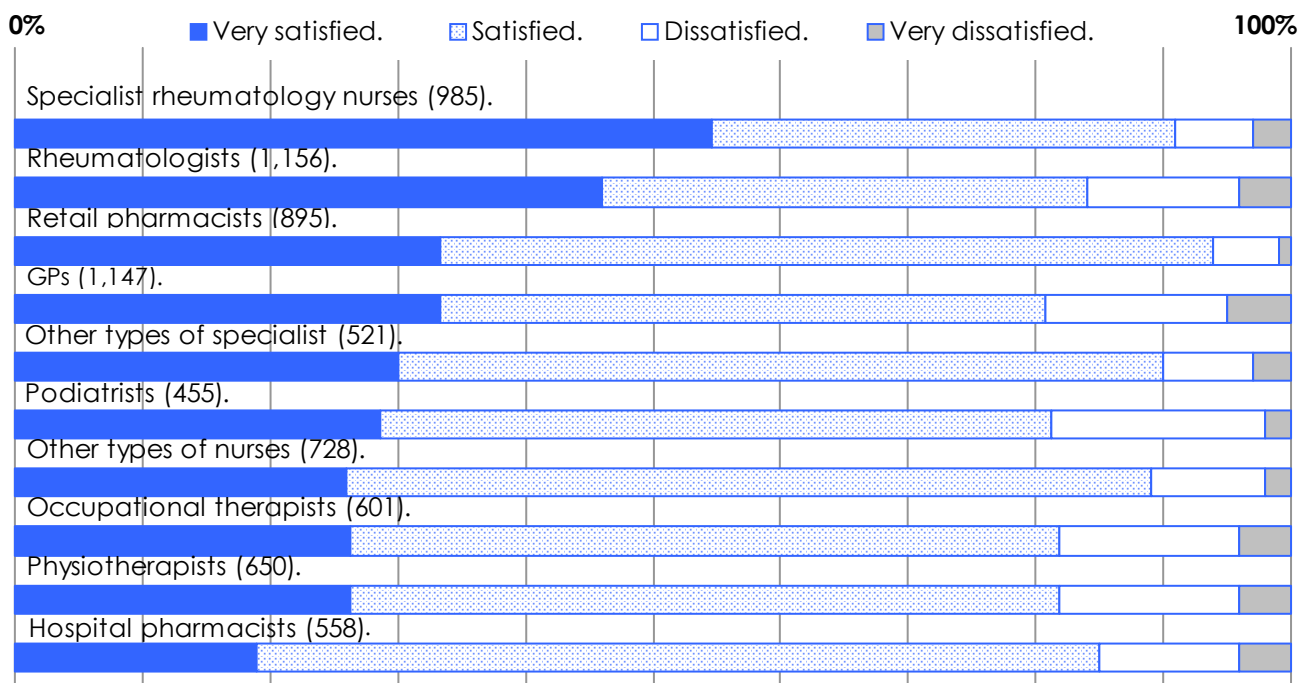


On the healthcare professionals who deliver care

- 80%-plus of the respondents say that they are *satisfied* or *very satisfied* with the care received from all types of health professionals. The staff who generate the most patient satisfaction are specialist rheumatology nurses—54% of respondents say that they are *very satisfied* with the care offered by these professionals.

How satisfied or dissatisfied are you with the RA care you have received from the following healthcare professionals?

All respondents with a formal diagnosis of rheumatoid arthritis
% of total responses, excluding "Don't know"s.

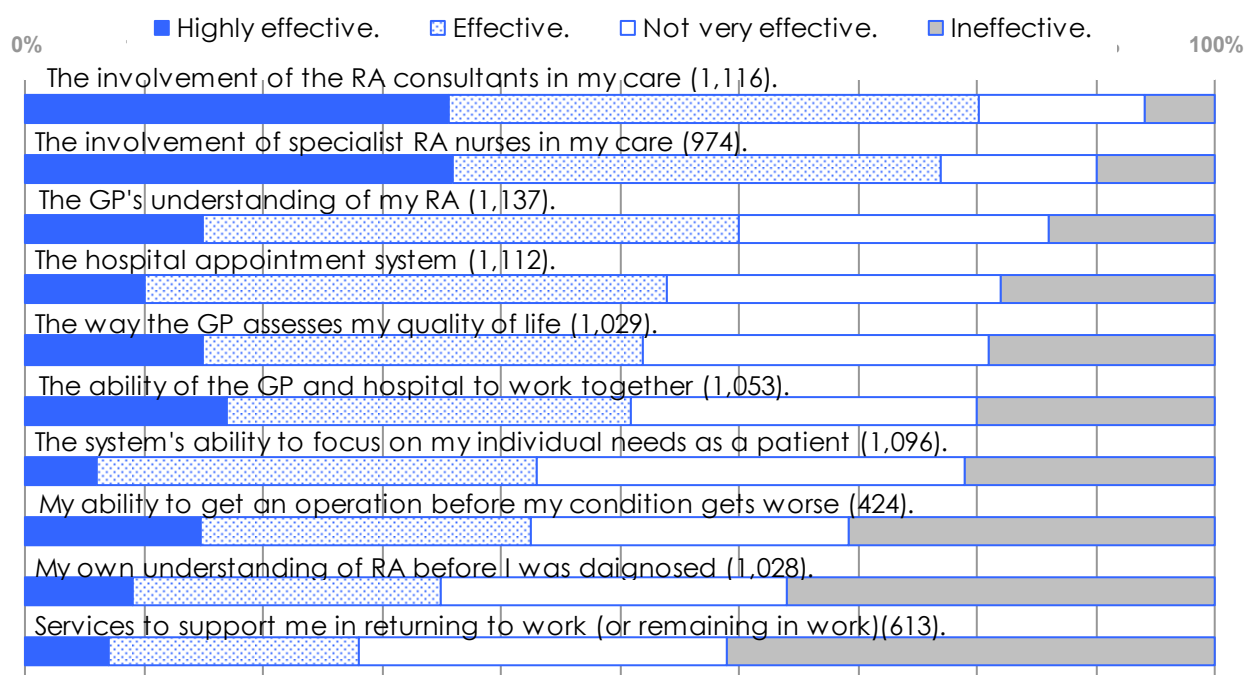


On the patient journey

- 72% of the respondents claim that services which could support them in getting back to work (or in remaining in work) are not very effective, or are ineffective.
- A significant minority of respondents (40%) think that their GP does not (or did not) understand their RA. Only 52% describe the methods by which GPs assess their quality of life (QoL) as effective. And only 51% believe that GPs and hospitals work together effectively.
- Only 54% of the respondents consider their hospital's appointment system effective.
- 80% view RA consultant involvement in their care as effective (77% say as much for specialist RA nurses). Even so, 57% of respondents consider the secondary-care system to be not very effective or ineffective at focusing on their individual needs as a patient.
- Only 34% of respondents with RA see themselves as having an effective understanding of RA before diagnosis.
- 58% of respondents judge the healthcare system as ineffective or not very effective at getting them an operation before their condition worsens.

In your experience, how do you rate the effectiveness (or otherwise) of the following, in respect to your patient journey?

All respondents with a formal diagnosis of rheumatoid arthritis
% of total responses, excluding "Don't know"s.



Questions on long-term care

*"I feel it is very unfair that we have to pay for temporary care at home during a severe flare-up, when there is no place in hospital, and we have to stay at home. There is no help—not even short-term—if one lives alone and needs 24-hour care and help during a flare-up.
I paid over £100 for a week's agency help, because the local hospital had no rheumatology beds. General hospital wards and daycare wards are not geared to disability, either staff-wise, or environmentally, if one is admitted for any reason."*

—Woman with RA, living in South-West England, aged 75 or older.

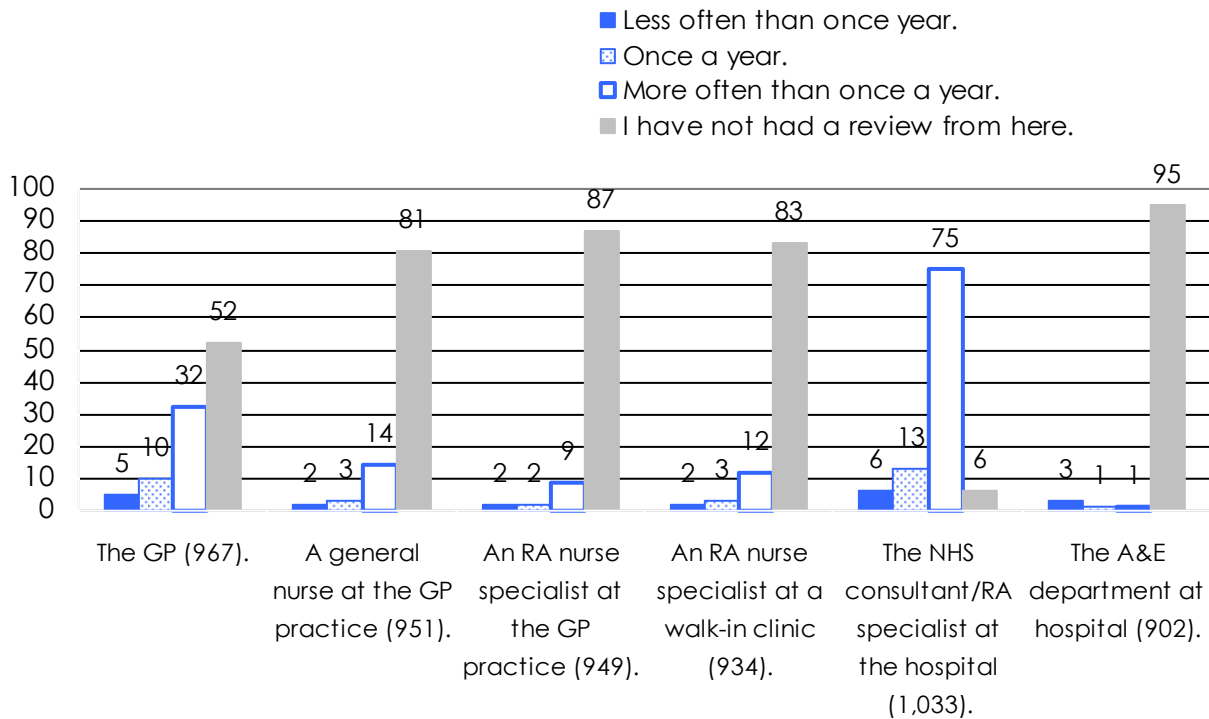
Long-term care

On monitoring

- The findings from this study suggest that, on the whole, systematic reviews of people with RA are taking place. 75% of respondents state that they have a consultant review more often than once a year, with another 13% reporting a review at least once a year. Similar results are obtained for people with RA who are in employment, those with stable RA, and people who have had RA for 10 years or more.

How often do the following people review your RA?

All respondents with a formal diagnosis of rheumatoid arthritis
% of total responses, excluding "Don't know"s.



On self-management

- 43% of respondents have had a 'flare-up' in the last month. 35% of these respondents regard their RA as stable (despite intermittent medical problems). Over one third (34%) of the respondents who have had a flare-up in the last month have lived with RA for 10 years or more (another 55% have lived with it for 5 years or more). The majority of people reporting a flare-up in the past month are aged between 35 and 59. Over one third (35%) of the latter group of respondents are on DMARDs (another 16% of them are on biologics).

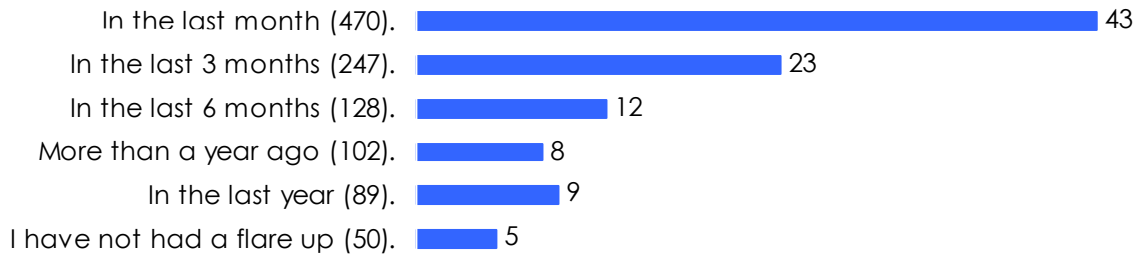
Have you had a flare-up (or extreme pain) as a result of your RA?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses, excluding "Don't know"s.

Total number of responses = 1,086, excluding three "Don't know"s.

[Number in brackets is total responding to question.]



On self-management

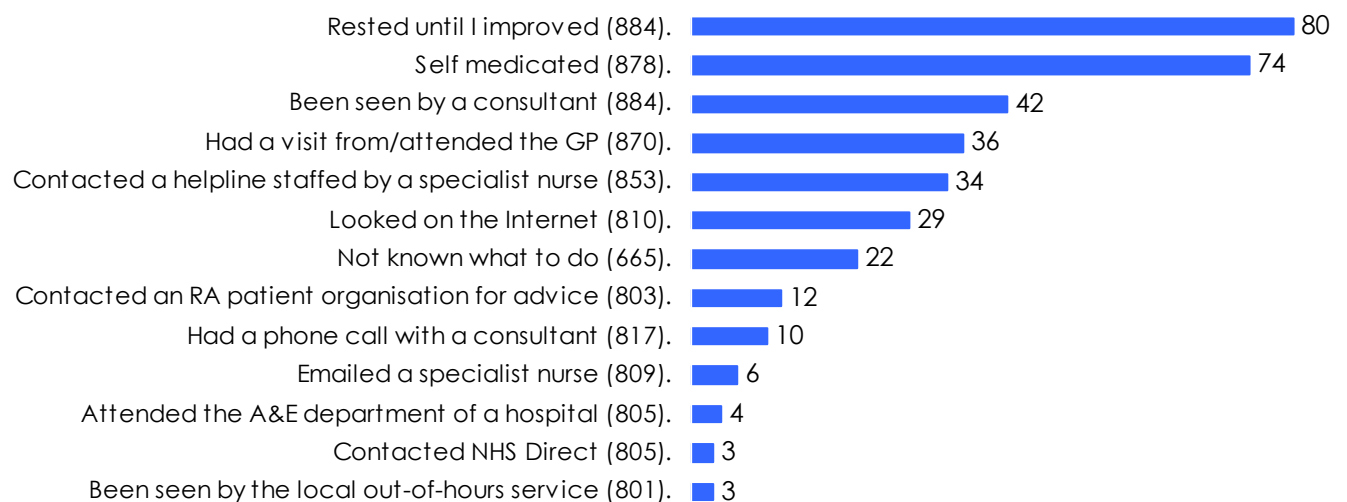
- Most people with RA who experience flare-ups self manage the incident. 80% say that they do this by resting until they improve, and 74% self medicate. Only 42% see a consultant. Respondents' comments tell a story of significant difficulties in gaining access to a specialist quickly enough for the flare-up to be treated professionally before it diminishes of its own accord.

Did any of the following happen during your most recent flare-up?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses saying "Yes", excluding "Don't know"s.

[Number in brackets is total responding to question.]



On self-management (continued)

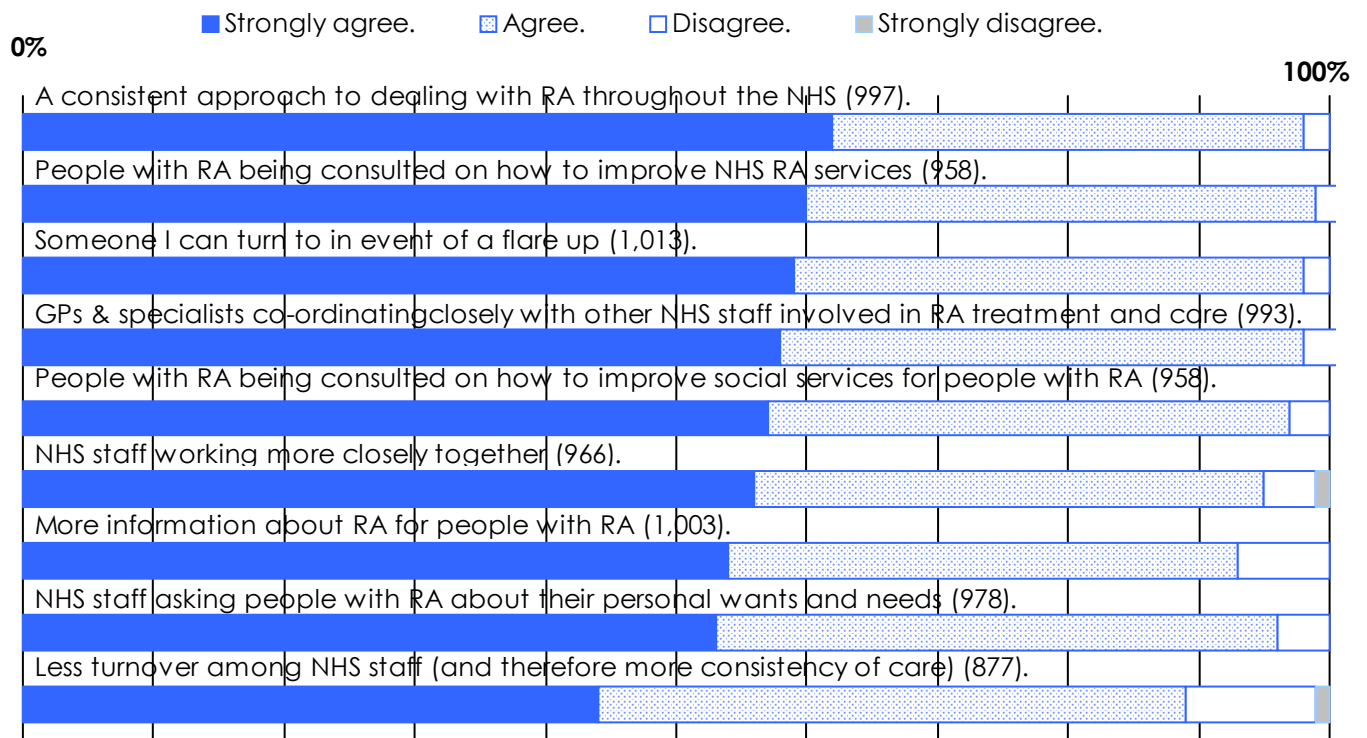
- When asked what interventions would make a real difference to improving self management of their RA, 62% of the respondents with RA strongly agree that "a consistent approach to dealing with RA throughout the NHS" is needed. 60% think that people with RA should be consulted on how to improve NHS RA services. Also high on the list (59%) is having someone who people with RA can turn to for help in the event of a flare-up.

To what extent would the following things make a difference to you in improving self management of your RA?

All respondents with a formal diagnosis of rheumatoid arthritis

% of total responses.

[Number in brackets is total responding to question.]



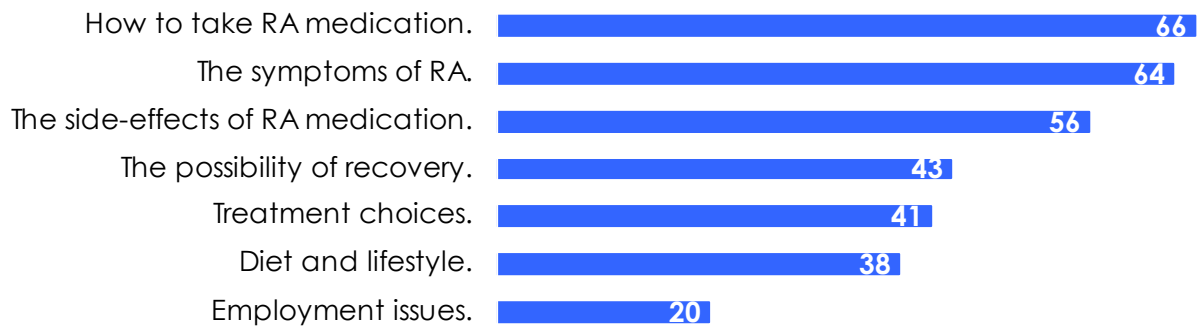
On self-management (continued)

- More than half of the total number of respondents with a confirmed diagnosis of RA say that they have either sufficient or more than enough information on the following topics: how to take their RA medication (66%); the symptoms of RA (64%); and the side-effects of RA medication (56%). The biggest gaps in knowledge centre around employment issues (38%); diet and lifestyle (37%); and treatment choices (36%). 48% of the people who are unemployed/medically retired due to RA say that they do not have enough (or have no) information on employment issues; 56% of the employed respondents with RA say the same.

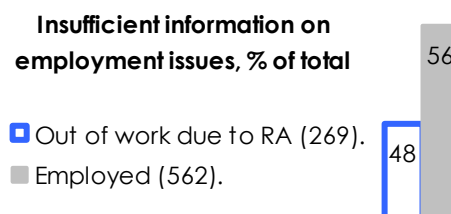
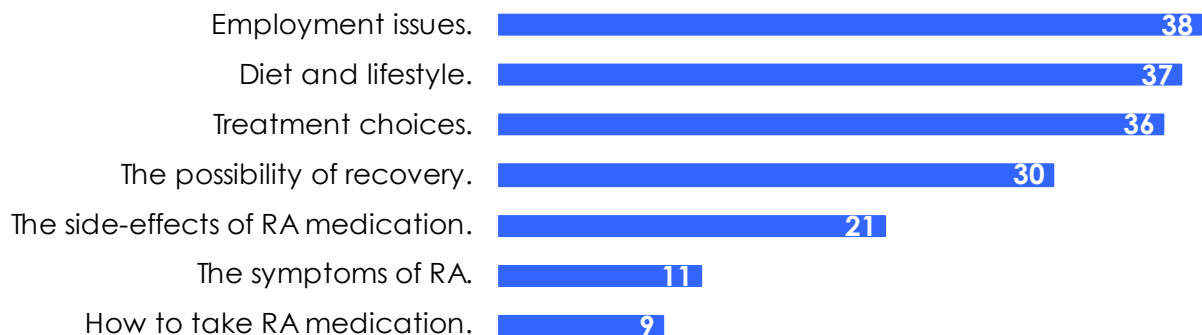
Do you feel that sufficient or insufficient information has been made available to you on the following aspects of RA?

All respondents with a formal diagnosis of rheumatoid arthritis
% of total responses; total = 1,400.

Sufficient / more than enough information:



Insufficient / no information:



Employment issues

"I had worked for my employer (taking little time off) for 2 years after being diagnosed with RA. I had asked for a transfer to lighter duties. Then my employer dismissed me 4 months after I was off sick (having written for medical reports after 2 weeks) because the diagnosis was that my RA would not improve. I had been at the company for 8 years."

—Man with RA, living in South-West England, aged 54-59.

Employment

On employers

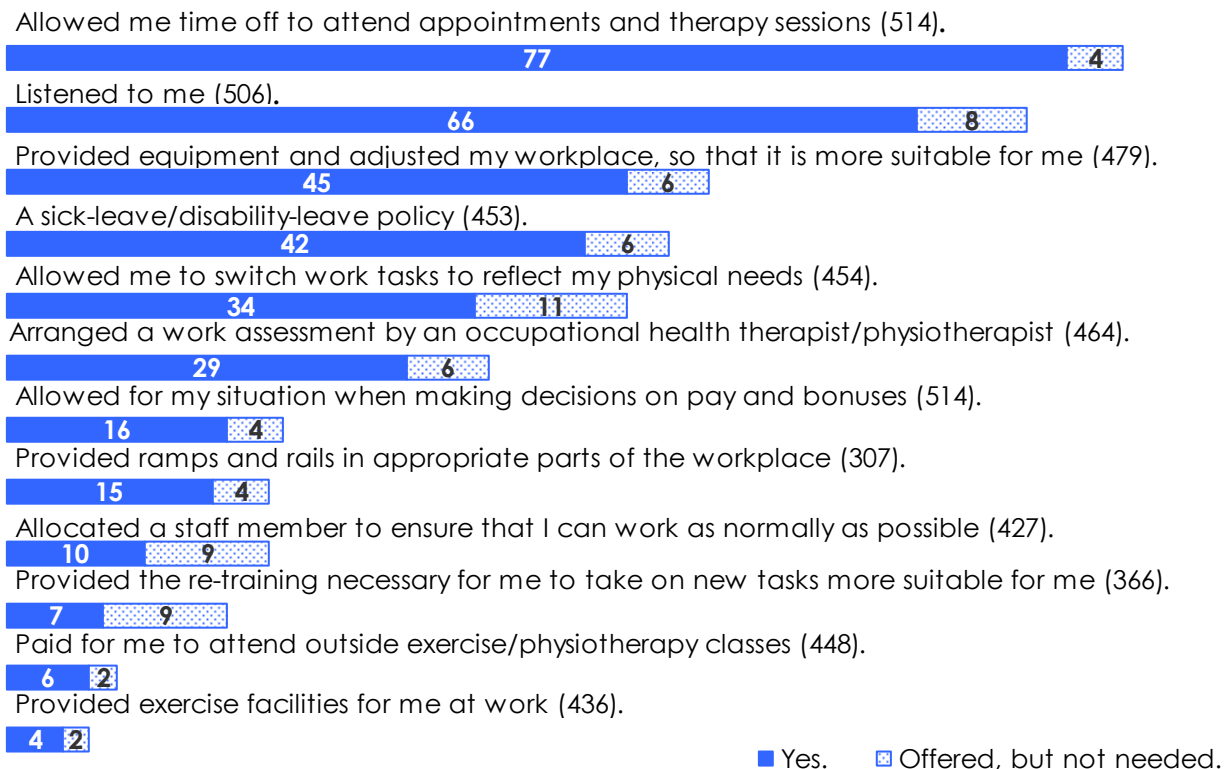
- 91% of the 581 respondents with RA who are in full- or part-time employment say that their employer knows about their RA. 68% of these respondents think that their employer is either very or fairly understanding about their RA. One quarter feel that their employer is not very or not at all understanding.
- Most of the respondents' employers appear willing to listen to the RA-related problems of their employees with RA (74%), and to give them time off work to attend appointments (81%). Employers, however, were much less likely to switch work tasks to reflect physical needs, or to provide retraining to enable people with the disease to take on new tasks more suitable for them [see chart below].

**If your employer knows about your RA ...
how understanding or non-understanding would you say your employer has been
(or last employer was) towards your situation with RA?**

Respondents with a formal diagnosis of rheumatoid arthritis who are employed

% of total responses, excluding "Don't know"s and "Not applicable"s.

[Number in brackets is total respondents to question.]

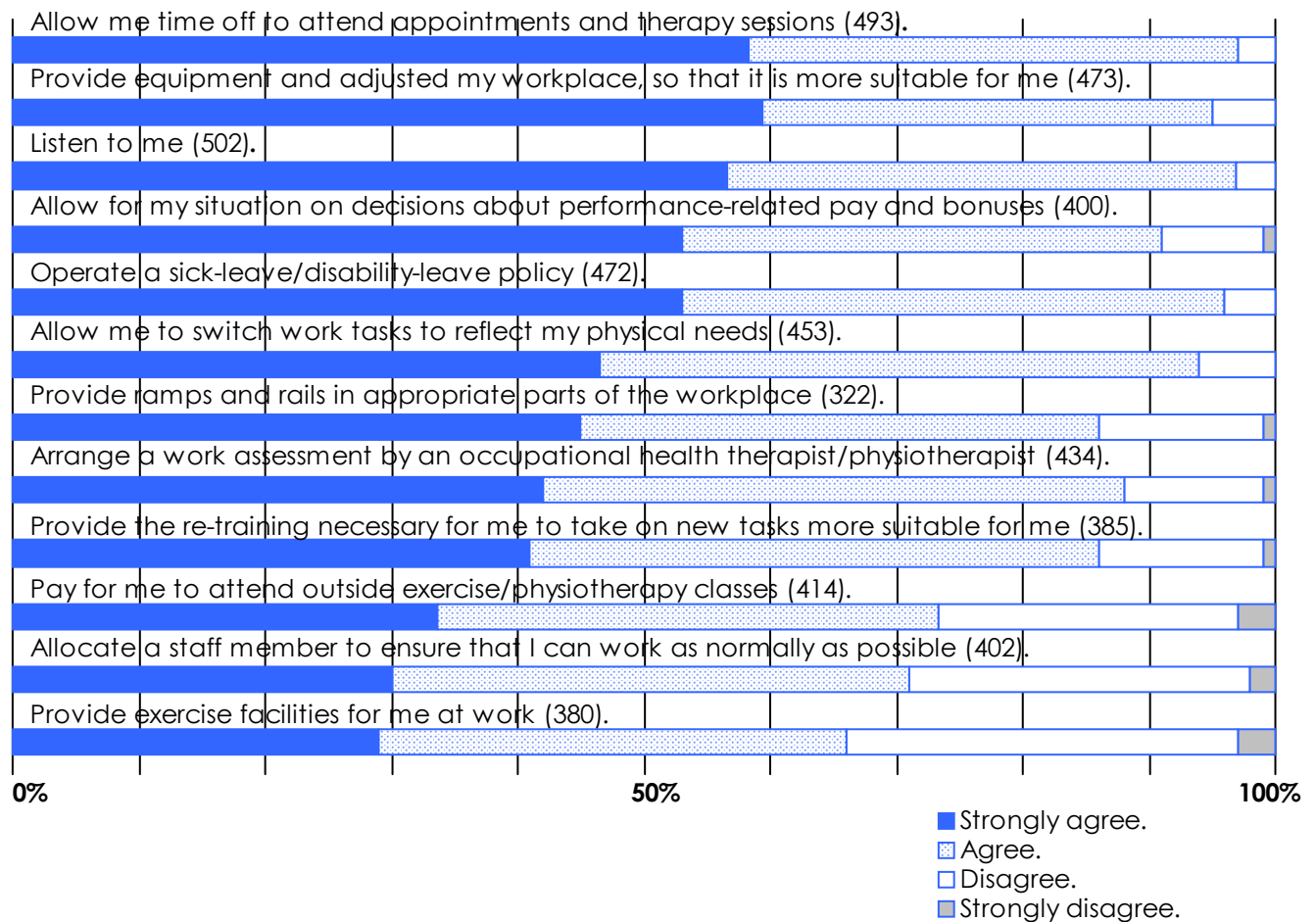


On improving employment practice

- When asked what their employer could do to improve employment conditions for them, 60% of the employed respondents with RA request that their employer allow them time off work to attend medical appointments. 56% say the same about the need for their employer to listen to them. Respondents also rate highly the need for equipment and adjustments to the workplace (60%), as well as having their medical situation taken into account when decisions are made about performance-related pay and bonuses (53%).

What would you like employer to do to improve your employment conditions (in respect of your situation with RA)?

All respondents with a formal diagnosis of rheumatoid arthritis who are employed
% of total responses, excluding "Don't know"s and "Not applicable"s.
[Number in brackets is total respondents to question.]



Improving the system

*“When a flare-up occurs, it would be wonderful to be able to contact someone and get rapid help.
I have phoned in despair, and been told ‘OK, we will send you an appointment’
—only for nothing at all to happen, or for the appointment to be for 8 months later
(and I will have heard nothing by 6 months!).”*

—Woman with RA, living in South-West England, aged 54-59.

Comments on improving the system

Respondents were asked to suggest one change to current services for RA. A total of 890 people with RA (and their carers) supplied comments to this question. Each comment was coded, and then ranked according to the number of times the comment's subject was mentioned by other respondents. In all, 65 different types of comments were obtained [see Appendix]. The 65 categories were then further grouped under the questionnaire's four subject areas: diagnosis, treatment and care, long-term care, and employment [see below]. (Some respondents named more than one change.)

Rank		Mentions
Diagnosis		
1	Faster referral by GPs to rheumatologists.	26
2	GPs should be more knowledgeable about RA.	22
3	Better screening for RA and facilities to undertake that screening.	4
Treatment and care immediately after diagnosis		
1	Access to the best medication/choice of treatment.	80
2	Access to alternative therapies.	40
3	Better access to biologic drugs.	28
4	Medication to be changed more quickly.	22
= 5	A consistent national approach to treatment and care.	20
= 5	Exemption from prescription charges.	20
7	Greater awareness of/information on RA for patients and providers.	18
8	Not having to fight for treatment, care or support.	5
9	More research required (especially on pregnancy and RA).	1
Long-term care		
1	Faster and easier access to secondary care	130
2	Better doctor-patient relationships.	58
3	Access to supplementary services: <i>counseling (29); helplines(10), etc.</i>	50
4	More information from medical professionals	49
5	Access to a dedicated nurse specialist.	35
6	Better communication among medical professionals.	28
7	Integrated services.	28
8	Financial assistance: <i>heating (4); household adaptations (2); sick pay 2), etc.</i>	22
9	Greater length of time in the consulting room.	16
10	Continuity of care.	15
11	Other general (multiple) observations on making living with RA easier.	13
12	More self-help/patient-support groups.	12
13	Being treated holistically.	11
= 14	Better record keeping.	2
= 14	More opportunity for patient self management.	2
Employment		
1	Making services more convenient to (mostly) enable continued employment.	54
2	Better awareness of the condition among the public and employers.	33
3	More work-oriented help for people with RA.	13
4	More suitable working conditions.	2

APPENDIX I

QUESTION 19: YOUR SUGGESTED CHANGE

If there was **ONE** thing that ***YOU*** could change about current services for rheumatoid arthritis —what would it be (and why)?

(Note a number of respondents commented on a more than one subject. Comments have not been edited other than removing personal details or names of institutions.)

Contents of Appendix I

1. Faster and easier access to secondary care 84 comments	page 52
2. Access to the best medication/choice of treatment 80 comments	page 59
3. More information from medical professionals 49 comments	page 65
4. GPs should be more knowledgeable about RA 43 comments	page 69
5. Better doctor-patient relationship required 39 comments	page 72
6. Access to a dedicated nurse specialist 35 comments	page 75
7. More frequent consultations 31 comments	page 78
8. Other services: counselling 29 comments	page 80
9. Better access to biological drugs 28 comments	page 83
10. Better communication among medical professionals 28 comments	page 85
11. Integrated services 28 comments	page 88
12. Alternative therapies 26 comments	page 91
13. Better awareness of the condition: among the public 26 comments	page 94
14. Faster referral by GPs to rheumatologists 26 comments	page 96
15. Medication to be changed more quickly 22 comments	page 98
16. A consistent national approach to treatment and care 20 comments	page 100
17. Exemption from prescription charges 20 comments	page 102
18. Employment issues 17 comments	page 104
19. Greater length of time in the consulting room 16 comments	page 106
20. Continuity of care 15 comments	page 107
21. More information/education 15 comments	page 108
22. Care should be based at primary-care level 14 comments	page 110
23. Other financial assistance 14 comments	page 111
24. Access to hydrotherapy 13 comments	page 113
25. More work-oriented help for people with RA 13 comments	page 114
26. Multiple points 13 comments	page 115
27. More rheumatologists 12 comments	page 118

28. More self-help/patient support groups 12 comments	page 119
29. Being treated holistically 11 comments	page 120
30. Better understanding by rheumatologists of patients 11 comments	page 121
31. Other services: helpline 10 comments	page 122
32. Appointments scheduled more conveniently 7 comments	page 123
33. Better awareness of the condition: among employers 7 comments	page 124
34. Better understanding by other medical professionals 7 comments	page 125
35. Not having to fight for treatment, care or support 5 comments	page 126
36. Financial assistance for heating 4 comments	page 126
37. Shorter waiting times for other services 4 comments	page 127
38. Other services: podiatry 4 comments	page 127
39. Care should be based at secondary-care level 3 comments	page 128
40. Car parking facilities 3 comments	page 128
41. Other services: orthotics 3 comments	page 128
42. Other support and understanding. 3 comments	page 129
43. Better awareness of the condition: among PCTs 2 comments	page 129
44. Better quality of rheumatologists 2 comments	page 129
45. Better RA services in rural locations 2 comments	page 130
46. Better record keeping 2 comments	page 130
47. Blood tests should consider the possibility of RA 2 comments	page 130
48. Financial assistance for household adaptations 2 comments	page 131
49. More opportunity for patient self-management 2 comments	page 131
50. More suitable working conditions 2 comments	page 131
51. Other services: physiotherapy 2 comments	page 131
52. Extension of statutory sick pay 1 comment	page 132
53. Increased blood testing facilities 1 comment	page 132
54. More information for parents of affected children 1 comment	page 132
55. Better access to repeat prescriptions 1 comment	page 132
56. More research required: pregnancy 1 comment	page 132

Appendix I: Your one suggested
change

Patient and carer views
of RA services

57. Other services: access to wheelchair	page 133
1 comment	
58. Other services: chiropractic	page 133
1 comment	
59. Other services: exercise facilities	page 133
1 comment	
60. Patient involvement in decision-making	page 133
1 comment	
61. Relieve hospital closure plans	page 133
1 comment	
<i>Other comments</i>	
62. Other	page 134
12 comments	
63. The ultimate goal: wellness	page 135
5 comments	
64. Respondents diagnosed before current medication	page 135
2 comments	
65. Satisfied with existing care and services	page 136
13 comments	

1. Faster and easier access to secondary care for existing patients/shorter waiting times for rheumatology appointments

Major sub-themes in this category:

- a. Appointment system—its weaknesses and inconvenience to patients.
- b. Length of time waiting to see the rheumatologist.
- C. The apparent reluctance of the system to allow patients to access what they regard as the best medication.
- d. Length of time to diagnosis.

"walk in clinic as if you have to wait for an appointment you are usually over the episode by then"

Female. 54-59. Diagnosed. A year or more, but less than 2 years. RA currently stable. Depression. Hiatis hernia. East Anglia.

"Easy access to RA clinics when a flare up occurs."

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Raised cholesterol- dry eyes-dry cough ? asthma currently under investigation. East Anglia.

"BETTER ACCESS TO A SPECIALIST NURSE OR CONSULTANT WHEN NEEDED, I HAVE HAD ALMOST A YEAR BETWEEN APPOINTMENTS IN THE PAST WHICH IS FINE IF EVERYTHING IS STABLE BUT NOT IF YOU HAVE A FLAIR UP. IN THIS CIRCUMSTANCE IT CAN BE VERY DIFFICULT TO GAIN ACCESS TO A CONSULTANT WITHOUT A LONG WAIT."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Greater London.

"The NHS works incredibly slowly. I would like things to be available quicker, as they are in the private medical system."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. underactive thyroid, possible sjogrens syndrome. Greater London.

"Easier access to NHS consultants"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. Greater London.

"I think the most important change would be to have access to the specialist when I need it. It is not satisfactory having to wait 2-3 months when you're in such pain, and in many cases unable to work because the pain can be so disabling."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. High blood pressure. Greater London.

"I would insist, that waiting times at rhuematology improve."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. East Midlands.

"To be able to be seen quicker when ther is a problem rather than having to wait until it is rtoo late and the damage is done"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Greater London.

"I think waiting list would be shorter and consult take a serious about patient condition ."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. My both knees are osteoarthritis and affect my walking distance and up and down stairs. Greater London.

"quicker access to see R A specialist."

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. osteoporosis coeliac depression and anxiety. North-east England.

"More access to consultants, and a regular consultant, not locums as I have had to see for the past two years."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. North-west England.

"More individual focussed care to diagnose quicker and get treatment ASAP"

Male. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-west England.

1. Faster and easier access to secondary care for existing patients/shorter waiting times for rheumatology appointments [Continued 1]

"Appointments with consultants are continually being postponed."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. No other illness. North-west England.

"At the hospital I attend they are always altering your appointment."

Male. 45-54. Diagnosed. 10 years or more. RA currently stable. North-west England.

"Seeing the specialist without a long wait that I would have had if I hadn't paid"

Male. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. High blood pressure, asthma. North-west England.

"Shorter waiting times to see your consultant when you need to see him urgently because of a flare up."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. Hormonal Migranes. North-west England.

"Appointments system at my local hospital - it can be very confusing! Can also take a long time to get through!"

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. I have difficulty walking a short distance. South-east England.

"Make it easier to obtain specialist advice when needed for flare ups"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

"More availability to a consultant as the GP does not have the detailed knowledge of the condition"

Male. 60-64. Diagnosed. A year or more, but less than 2 years. RA currently stable. No other problems. South-east England.

"Ability to see a specialist asap for any problems/flare ups/ problems with meds etc eg ring and be seen within 48hrs"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. mild hypertension. South-east England.

"quicker access to NHS Hospital operations for RA damage"

Male. 60-64. Diagnosed. 10 years or more. RA currently stable. South-east England.

"IMMEDIATE help when a flare occurs. The pain is sometimes unbearable."

Female. 60-64. Diagnosed. A year or more, but less than 2 years. RA currently stable. Hypertension Hypothyroidism. South-east England.

"quicker access to see a RA nurse or consultant"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. endometriosis. South-east England.

"To be assessed for any immediate help. I had a three year old and a six week old baby that I was struggling to manage without help from my family. Thank god they only live 15 minutes away!"

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. I am anaemic due to RA. South-west England.

"less waiting time in out patient clinics, but I know this is often unavoidable"

Female. 75 or older. Diagnosed. A year or more, but less than 2 years. RA currently stable. asthma rheumatoid lung disease. South-west England.

"Not having to wait so long to receive an operation when needed."

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. osteoarthritis my r.a. is called cystic r.a.. South-west England.

"When a flare occurs, it would be wonderful to be able to contact someone and get rapid help. I have phoned in despair and been told OK we will send an appointment only for nothing at all to happen or the appointment to be for 8 months later. I have also had to chase up appointments when the rheumatologist has said recall in 3 months and having heard nothing by 6 months. !"

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. High blood pressure, under active thyroid, macular disease. South-west England.

"better appointment service"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. I.B.S and Fybromyalga. South-west England.

"Confirmed appointments with RA consultant that don't change."

Male. 54-59. Diagnosed. 10 years or more. RA currently stable. West Midlands.

1. Faster and easier access to secondary care for existing patients/shorter waiting times for rheumatology appointments [Continued 2]

"There should be a refined pathway to avoid the journey i went on as like i say if i had a full time job at the time i would have with no doubt had to have given up my home as i wouldn't have been able to have afforded to continued with my mortgage having been off sick for so long. I wouldn't have been able to claim any benefits either as there was no diagnosis. " [Also filed under 'Other financial assistance' and 'Employment issues'.]

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. West Midlands.

"I am not at all happy with the appointment system at the hospital and feel this could be improved."

Female. 60-64. Diagnosed. A year or more, but less than 2 years. RA currently stable. I have frequent chest infections which have to be treated with antibiotics. I am also a Sjorgens Syndrome sufferer. West Midlands.

"More access and consistent access to treatments on NHS."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. West Midlands.

"I think it has to be the waiting times for appointments (this includes referrals to other agencies)."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. hypothyroidism, fibromyalgia, IBS, patulous eustacian tube (PET). superior semi circular canal dehiscence syndrome. Yorkshire and the Humber.

"Being able to see same consultant every time."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. underactive thyroid pernicious anaemia. Yorkshire and the Humber.

"More efficient appointments system because the present one is beset by "unforseen cicumstances"."

Male. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Hypertension. Yorkshire and the Humber.

"make diagnosis to operation a lot quicker. I was in terrible pain for 2 years"

Male. 75 or older. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. slight asthma and high blood pressure, kept under control medically. Yorkshire and the Humber.

"Access to specialists very quickly when flare ups occur."

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Osteoarthritis. Yorkshire and the Humber.

"More childrens specialist units and more GP awareness of JRA so children get a faster diagnosis and better care so less damage is done to joints." [Also listed under 'GPs should be more knowledgeable about RA']

I am an informal carer for someone with RA. Male. Under 16. 2 years or more, but less than 5 years. The RA is currently stable. North-east England.

"Walk in centres or appointments for treatment and advice within say 3 days."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Vitamin B12 deficiency High Blood Pressure. East Anglia.

"Drastic improvement and full manning of the LOCAL hospital (not a national version through NHS Direct)"

Female. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. East Anglia.

"That you can get help with pain at any time of the day or night not being told you have to wait and everyone knowing a bit more what to do in the health service"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. just disability from Ra as all its symptoms make things harder to do. East Midlands.

"to find a cure for it and that if you see other consultants which don't know much about RA like my foot special said because i take Morphine he said your not in much pain I said you want it i don't take tablet usless i've got to because of my chronic IBS caused by the tablets with lactose i take anti sick and diahorrea tables I rattle"

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. fibromyalgia asthma, angina(mild) Irritable bowel, thyriod depression eczma menopause. Greater London.

"quicker access to diagnostic measures, to facilitate faster diagnosis"

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. controlled hypertension. North-east England.

"have the option to see a person that knows and can prescribe the relevant drugs."

Male. 60-64. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. kidney removal 1996. Benign tumour.. North-west England.

1. Faster and easier access to secondary care for existing patients/shorter waiting times for rheumatology appointments [Continued 3]

"That the hospital would stick to the appointment that they first give me instead of constantly revising my appointments and moving them further and further back eg had an appointment for 5th Jan 2009, letter came saying moved to February 2009, then 3rd letter saying moved to April 2009! i have had to ring to explain can't possibly go that long am currently being monitored on medication and flaring have had to make one with the nurse specialist for 16/1/09 just so that she can bring the consultant in to see me it's ridiculous if I had waited til April which I doubt I would manage til then I would probably be on my knees!"

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. currently 'flaring' in right elbow, shoulder, wrist and basal joint, have been doing so now since july 08 been back to consultant and ra nurse three times now, was steroid injected in august to see if physio could help but no improvement and they now want. East Midlands.

"the amount of time it takes to diagnosis, i have come across so many peoples who's story are the same as mine takes more then a few years to be diagnosis. i know very well that it is hard to diagnosis especially when a person is sero-negative like myself but the longer it is left the more damage that is done!"

Female. 25-34. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. North-east England.

"shorter waiting lists to see a consultant. I was referred in April and did not see a Rheumatologist until Mid August by which time I was unable to work due to RA symptoms. I live in a rural area and we have a visiting consultant from another hospital in a main town, I believe this lengthens waiting list times." [Also filed under 'Better RA services in rural locations' and 'Employment issues'.]

Female. 45-54. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. multiple cerebral aneurysms (three surgically treated four low risk aneurysms being monitored). High blood pressure under control with medication. North-east England.

"Haveing someone to talk to would have been brilliant when i was first diagnosed , and when I am feeling down and in a lot of pain , the hospital nurses and doctors are always to busy to listen .And I feel like i am putting them out if I ring to see if i can have an injection to help , they dont ring me back till the end of the day or even the nect day , it's always on answer phone and you just feel neglected.and alone ." [Also filed under 'Other services: counselling'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Ashma ,and diverticular disease. North-east England.

"To be able to just go to clinic when flared and feeling unable to cope."

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. osteo arthritis neck, hands. North-west England.

"The best drugs possible for all patients regardless of price! (i'm dreaming!). Realistically I think the time taken waiting for consultant appointments could be speeded up." [Also filed under 'Access to the best medication/choice of treatment'.]

Male. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. vitiligo. North-west England.

"A more flexible approach so that accessibility to professionals is readily available when a flare up occurs."

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"Access to specialist care."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. North-west England.

"More help and support should be given to enable people with RA to stay in employment. Employees must be forced to work with the employee and OT to achieve the best outcome for everyone.Immediate treatment should be available, not having to wait 6-8 weeks, as in my case to recieve treatments to enable me to function some what normally." [Also filed under 'More work-oriented help for people with RA'.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"It would be better if appointments to see the consultant weren't cancelled all the time."

Female. 35-44. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. North-west England.

"to have a specialist i could contact a any time i have a flare up for addvice"

Male. 65-74. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. hart bypass+ asthma. North-west England.

1. Faster and easier access to secondary care for existing patients/shorter waiting times for rheumatology appointments [Continued 4]

"I would like the appointments with the consultant to be 3 monthly when they say that is what is needed. Especially when newly diagnosed and the medication is being amended at each visit. I know from regular blood test results and my physical well being that my medication could still be improved but it is now 4 months since my last visit when the consultant said I want to see you in 12 weeks." [Also filed under 'More frequent consultations'.]

Female. 54-59. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. Type 2 diabetes. South-central England.

"I Would Like to see a consultant, as i only saw one after my initial diagnosis over three years ago."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Infertility Problem. South-east England.

"Reduced waiting list to see RA consultant"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. South-east England.

"direct access to rheumatology services"

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. South-east England.

"for them to help with pain for a better lifestyle" [Also filed under 'Access to the best medication/choice of treatment'.]

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. diverticulitis bowens cancer o/a. South-east England.

"Speeding up getting diagnosis. So much pain could be removed from my life completely if I had been diagnosed and received steroid treatment much sooner"

Female. 25-34. Diagnosed. 10 years or more. RA NOT currently stable. Diagnosed with Ankylosing Spondylitis in 1996/7 with sero-negative RA at same time. South-east England.

"Easier Access to Rheumatologists"

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Fibromyalgia,Chronic Fatigue,IBS. South-east England.

"Assessment and pain control should be available within a few days on the NHS at the local hospital if the symptoms are very severe. Urgent referrals should NOT have to wait for 8 - 10 weeks before help is available. The GP is only a mechanic not an engineer!"

Female. 65-74. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Pernicious anaemia Hypothyroid Osteoarthritis Sjogren's syndrome (mouth) Neutropenia with Sulfasalazine ITP (1970's). South-west England.

"easier access to treatment"

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. sjergons syndrom. South-west England.

"Offer MRI scans to all patients who complain of symptoms of RA."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. underactive thyroid, high blood pressure, osteoarthritis. South-west England.

"RA department has been the same for many years.Its about time it changed. By putting the departments needed for patience care alot closer by. when you see the constlant they tell you to make an appointment for 6 months time , but when you go to make it, you can omly get it in about 8 months time."

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. I know unable to take lots drugs for RA as my body has reacted badly towards them. I have got asthma and having problems with my shoulder. South-west England.

"Faster initial appt with the rheumatologist! Five weeks seems like nothing when some people wait months and months. But five weeks of increasing pain and stiffness and swelling isn't fun."

Female. 25-34. Diagnosed. One month or more, but less than 3 months. RA NOT currently stable. West Midlands.

"Easier access to professionals, especially doctors, as nurses can assume they KNOW when they actually don't!!"

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. fibromyalgia, trochanteric bursitis, raised BP. West Midlands.

1. Faster and easier access to secondary care for existing patients/shorter waiting times for rheumatology appointments [Continued 5]

"To speed up the funding of anti-tnf drugs. I am currently in limbo waiting to hear whether or not the hospitals application for me to go onto Enbrel has been approved. It is likely that it may take a number of weeks more!"

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. Lupus. West Midlands.

"I would eliminate the withholding of medication on grounds of cost! If patients can benefit from a particularly treatment, then they should be entitled to have it with no question about funding!"

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. West Midlands.

"A fast track service for people who are working and are afraid of losing their jobs because they cannot get medical treatment quickly enough." [Also filed under 'Employment issues'.]

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. ulcerative colitis - stable. West Midlands.

"There should be a fast track system to see the rheumatologist at the hospital as I felt that the 9 weeks I had to wait for my first appointment was wasted time."

Female. 60-64. Diagnosed. RA NOT currently stable. a year or more, but less than 2 years. No. West Midlands.

"When you ask for help with medication and keeping the RA under control, to be given more quickly!"

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. underactive thyroid. West Midlands.

"Faster service for referrals and quick access to treatment when experiencing flare ups. I have been lucky enough to have private healthcare, but don't know how I would have coped if I hadn't!!!! Please do something about it!!"

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Flare ups in knees and hands cause inability to walk of use mt right hand. West Midlands.

"Someone to see when u have a flare up."

Female. 25-34. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. West Midlands.

"change the consultation period with medical professionals so that it is patient led and not appointment led. I have waited ages to see the consultant and had a progressive worsening of my joints while waiting for an appointment. and have also been feeling well enough at times NOT to have to see a doctor or for a junior doctor who doesn't know me ask a whole barrel of questions that I have already answered." [Also filed under 'Continuity of care'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. West Midlands.

"Having a more open approach to being able to contact my consultant although the specialist nurse is very good. She has given advice about contacting the GP to get certain tests done before next appointment with the consultant which should speed up next course of action. Every step seems to take forever." [Also filed under 'Access to a dedicated nurse specialist'.]

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Yorkshire and the Humber.

"To be able to see a specialist within one or two weeks after diagnosis instead of having to wait months in excruciating pain."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Yorkshire and the Humber.

"easier access to hospital appointments. it would help if you are in severe pain to be able to get an injection to get you going again and back to work." [Also filed under 'Employment issues'.]

Female. 54-59. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. psoriatic arthritis sjogren's syndrome collapsed back muscles hypertension underactive thyroid anxiety/depression/panic attacks. Yorkshire and the Humber.

"Speed of diagnosis and treatment to prevent early joint damage"

I am an informal carer for someone with RA. Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. The RA is NOT currently stable. North-west England.

"stop consultant appointments being cancelled and having to wait 6 months for the next one"

I am an informal carer for someone with RA. Female. 35-44. Diagnosed. 10 years or more. The RA is NOT currently stable. South-east England.

1. Faster and easier access to secondary care for existing patients/shorter waiting times for rheumatology appointments [Continued 6]

"Its got to be dealing with a flare There is a real lack of joined up thinking in this area. It tends to work like this We phone the hospital help line (useful this service for medicine enquiries) They send us to the GP (ok) He comes out (he has to the wife can't get to him thats the problem) (ok) He rings the help line and talks to another doctor They arrange a plan (ok) If the plan does not inc going to the hosp we are not going to improve just get worse. We know this its happened consistently for years. Getting into the hosp is the hiccup. In the last couple of years my wife was twice carried into the hospital on a stretcher and that means in pain and totally imobile. Incidentally I got the hard words of the consultant." [Also filed under 'Better communication among medical professionals'.]

I am an informal carer for someone with RA. Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. The RA is NOT currently stable. North-east England.

I would quite like to be seen by a specialist doctor rather than always the nurse."

Female. 65-74. hypertension, hypothyroidism and early signs of osteoporosis. Yorkshire and the Humber.

"The hospital appointment system, when a date has been agreed do not change it to the detriment of the patient."

2. Access to the best medication/choice of treatment [A similar category to 'Better access to biological drugs'—in many cases, respondents who mention "best drugs", "most powerful drugs", "cost", or "qualification", etc. are really referring to biological drugs.]

A few respondents point out that access to the best treatments does not just improve their own quality of lives, but also that of their dependants, too.

Another sub-theme is NICE.

"wish my medication was right 1st time and the deformities could have been avoided."
Female. 45-54. Diagnosed. 10 years or more. RA currently stable. amputee diabetes. East Anglia.

"Access to the latest and best treatment not just the cheapest!"
Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. East Midlands.

"I think no one should be denied the top drugs, what ever the cost."
Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. East Midlands.

"I would like to be able to get the right drugs immediately and not to have to worry that these would not be available to me."
Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. High Blood Pressure. Greater London.

"The certainty that ANY of the RA drugs could be available to me at any time, as clinically indicated. Because I know that a drug can be effective for a period and then cease to control RA, and that over time I could need different drugs to have an independent life."
Female. 60-64. Diagnosed. A year or more, but less than 2 years. RA currently stable. North-east England.

"To be given a choice as to which drugs are available."
Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. East Anglia.

"Return back to 'gold' injections."
Male. 65-74. Diagnosed. 10 years or more. RA currently stable. East Midlands.

"No choice/discussion on medication - you are told what to take."
Male. 35-44. Diagnosed. 6 months or more, but less than a year. RA currently stable. East Midlands.

"fairness in allocation and access to drugs across country"
Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-east England.

"for new drugs to be prescribed and not let cost get in the way."
Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. high blood pressure depression. North-east England.

"That drugs should be given before damage is done to joints which then need surgery."
54-59. Diagnosed. 10 years or more. RA currently stable. North-east England.

"no postcode lottery for provision of drugs and NICE to provide anti tnf therapy for all people who need it" [Also filed under 'A consistent national approach to treatment and care'.]
Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. North-west England.

"More availability of latest drugs.No post code lottery!" [Also filed under 'A consistent national approach to treatment and care'.]
Female. 45-54. Diagnosed. 6 months or more, but less than a year. RA currently stable. North-west England.

"Access to good, appropriate drugs. If the government charged people for wasted/missed appointments, there would probably be enough money for people like me to have the drugs they need. If only we had a government which had the courage to do this!"
Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Hypothyroidism. South-east England.

"Better access to newer treatment, treatments based on what's best to treat you, not based on cost and budget your PCT has. I don't know a single person who has been offered anti-tnf. Surely prevention of joint deterioration would be more cost effective than joint replacements."
Female. 35-44. Diagnosed. 10 years or more. RA currently stable. South-east England.

2. Access to the best medication/choice of treatment [Continued 1]

"Better pain killers for people with other health problems. e.g. I cannot use Ibuprofen due to only one kidney"

Male. 75 or older. Diagnosed. Less than a month. RA currently stable. diabetes, only one kidney, two heart attacks, diverticulosis, no spleen, need I go on?. South-east England.

"Better drugs available to all RA sufferers not mainly those which are the cheapest unfortunately for us we have it for life - not out of choice!"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Polymyalgia Rheumatica Glaucoma Osteoporosis. South-east England.

"Access to retuximab. The medication I am on at the moment has many side affects. I am only 28 therefore I will be on it for a very long time."

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. South-east England.

"I would like to think that all new drugs would be made available to every sufferer of RA but twice when I have asked about a new one I have been told "you are not bad enough for that drug" how is that known unless it is tried. My pain level is quite high but even so I often hurt."

Female. 65-74. Diagnosed. A year or more, but less than 2 years. RA currently stable. I also have asthma. South-east England.

"Anti-TNFs more available - this will save the NHS money in the long-run!"

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-east England.

"if the diagnosis and swift action is taken early you really can live normally, that almost amounts to a cure, perhaps we should allow our consultants the opportunity to prescribe the best course of action rather than an unrelated authority."

Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

"to treat people who have just been diagnosed with the latest drugs straight away instead of the process of try it and see with the less expensive drugs until by the time you get around to giving the person the expensive drugs such as Rituximab this terrible disease has taken over and ruined another life"

Male. 60-64. Diagnosed. 10 years or more. RA currently stable. South-east England.

"No restrictions on new forms of treatment due to cost."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Type 1 insulin diabetes Colon problems due to long term steroid use. South-east England.

"people with RA are and will always be the poor relations in hospitals. We never have enough equipment to help with our infusions."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. have had a hip replacement and two operations on my feet and another due in February 09. South-east England.

"more access to new medicaments"

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. anemia. South-east England.

"Allow drugs to be available to everyone regardless of expense."

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. South-east England.

"More consistent and transparent care. X-rays, bone density tests on an annual or bi-annual basis would be a good baseline. These seem to be ad-hoc."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Reynouids and hiatus hernia. South-east England.

"That all options of help would be offered, so that I could judge if I needed them or not"

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-east England.

"New drugs that are proven to work to become available more readily."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. asthma, eczema, IBS. South-west England.

"Easier access to the new drugs which really help people and have minimal side effects"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. South-west England.

"Use more powerful (expensive?) drugs immediately on diagnosis instead of trialling weaker drug for many months while irretrievable damage is done to tissue/joints before the disease is halted."

Male. 75 or older. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Osteoarthritis Osteopaenia. South-west England.

2. Access to the best medication/choice of treatment [Continued 2]

"Speedier use of more powerful drugs on diagnosis to mitigate damage to joints done in the waiting period"

Male. 75 or older. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. osteoarthritis osteopaenia. South-west England.

"For younger patients in employment quicker access to the best drugs." [Also filed under 'Employment issues'.]

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. West Midlands.

"access to the best meds available without having to jump through hoops to prove you are ill enough to need them would save a lot of pain discomfort and heartache."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. West Midlands.

"Stop the cutbacks on outpatient services, stop changing prescription drugs to alternatives brands that have side effects for patients with allergies."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Allergies. West Midlands.

"Lack of help in some areas at the onset of the illness. If I had been offered an anti TNF drug fairly early after diagnosis and trying other medications it would have saved the expense of being hospitalized several times and needing the services of various departments"

Female. 65-74. Diagnosed. 10 years or more. RA currently stable. Yorkshire and the Humber.

"The best drugs for my condition, not just the ones I can manage on. Because I would like to have the best quality of life available to me."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Osteoporosis High Blood Pressure. Yorkshire and the Humber.

"Imm. prescribing of DMARDS"

Female. 65-74. Diagnosed. A year or more, but less than 2 years. RA currently stable. Yorkshire and the Humber.

"The drug funding is not cost effective. I have been unable to work for 3 years now - but am only 45. If there was access to the medication which would actually help then I could stop claiming benefits and get on with work and life." [Also listed under 'Employment issues']

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. other autoimmune diseases - underactive thyroid premature menopause psoriasis herpes rosacea. Yorkshire and the Humber.

"access to more expensive treatments for everyone who needs them, and at an earlier stage - not as a last resort , after all ra is a progressive disease, and being given disease modifying drugs earlier could make a huge difference."

I am an informal carer for someone with RA. Female. 60-64. 10 years or more. The RA is currently stable. lupus. East Anglia.

"Remove the restrictions which exist on which may or may be used particularly in the anti TFN group"

I am an informal carer for someone with RA. Female. 65-74. 5 years or more, but less than 10 years. The RA is currently stable. Osteoarthritis Depression. East Anglia.

"Speedier availability of anti TNF therapy"

I am an informal carer for someone with RA. Female. 16 to 24. A year or more, but less than 2 years. The RA is currently stable. Myalgic encephalomyelitis (ME) Pernicious anaemia. Yorkshire and the Humber.

"All I want is to be able to continue with my career as a teacher. However, increasingly over the last 6 years the RA has damaged my joints to the extent that most things in my daily life are now difficult to complete. Use of DMARDS earlier in my diagnosis might have prevented some of this damage." [Also filed under 'Employment issues'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Coeliacs. East Anglia.

"for government to recognise RA as a QOF chronic disease and take it seriously and give more funding , especially thru NICE for RA drugs to be available to all who need them"

Female. 45-54. Diagnosed. 10 years or more. osteoarthritis. RA NOT currently stable. East Midlands.

"Review of the assessment for ANTI TNF therapy! ASAP! As it stands the pain in my other joints don't matter apparently so I just have to live with it! I therefore do not feel that i am treated as a individual in my care and treatment as i don't fit into the box!"

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. East Midlands.

2. Access to the best medication/choice of treatment [Continued 3]

"I am told that Anti Tnf drugs are expensive and are not always given despite their ability to work on RA, this should change. Money should not be an issue."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Sjogerns syndrome. East Midlands.

"Improve NICE guidelines re anti tnfs. Give anti tnfs earlier on down the route."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. FIBROMYALGIA, SIJORGRENS SYNDROME AND MENIERES DISEASE. East Midlands.

"The current very simplistic testing for the rationing of anti-TNF therapy. Indeed, the rationing of this treatment at all."

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. East Midlands.

"Quicker diagnosis and not having to wait for new treatments and being told its a funding issue, the quicker we get the new treatments the less time we need to spend being looked after and depending on other people and can become more self sufficient"

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. East Midlands.

"Medication and their potential side effects should be explained clearly. You should be able to choose your own treatment plan - and not be given medication and told to take it without explanation. I have had very positive experience of the NHS treating my RA generally, but I think much of that has been because I have done so much research myself so that I am always well-informed before seeing a doctor. I am currently not taking medication due to trying for a baby, this has made my RA unstable. My doctors have not been particularly helpful in this situation - they tend to give quite vague information and I tend to end up making my own decisions. I think any situation which becomes 'specialist' or different tends to present challenges that don't always get looked at properly. Apart from that, I am more than satisfied and I get very annoyed with the current trend of moaning about the NHS - most people don't have anything to complain about and are lucky to get the service they do!" [Also filed under 'More information/education from medical professionals'.]

Female. 25-34. Diagnosed. 10 years or more. RA NOT currently stable. Polycystic Ovarian Syndrome. Greater London.

"The offer of more effective drugs and greater frequency of consultant appointments as the damage which can occur within 6 months can be quite considerable and irreversible." [Also filed under 'More frequent consultations'.]

Male. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. North-east England.

"I would change the guidelines which state who qualifies for a joint replacement. This is because I have been turned down for knee replacements. According to x-rays there is not enough damage to warrant a knee replacement but the pain and swelling still exists."

Female. 16 to 24. Diagnosed. 10 years or more. RA NOT currently stable. North-east England.

"The best drugs possible for all patients regardless of price! (i'm dreaming!). Realistically I think the time taken waiting for consultant appointments could be speeded up." [Also filed under 'Faster and easier access to secondary care'.]

Male. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. vitiligo. North-west England.

"Availability of all relevant drugs asap to try & delay damage to joints"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Sjogren's Syndrome. North-west England.

"More respect for the illness, and if people require medication give it to them, stop penny pinching"

Male. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. feet problems plantar fasciitis. South-central England.

"Medication with less side effects"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. South-central England.

"to stop denying sufferers access to new medication when they could make such a huge difference to the quality of peoples lives"

Male. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. North-west England.

2. Access to the best medication/choice of treatment [Continued 4]

"That the more modern treatments be more readily and more quickly available, rather than having had to fail on so many standard treatments first. If the people at NICE had to suffer the pain, perhaps the attitude would change."

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. angina, asthma, high blood pressure. North-west England.

"One team.. specialist doctor, nurse & GP that follow up, know me and care about my personal situation and also realise that although I may not fulfill the criteria for the new drugs that I have two children under 5 they would improve the life for all 3 of us!" [Also filed under 'Integrated services'.]
[Respondent emphasises that qualification criteria for treatment should not just take account of patient's situation, but also the impact of treatment/non-treatment on patient's family.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. Fibromyalgia. South-central England.

"Let me have the treatment I need to lead a fairly normal life so I am capable of caring for my son who relies on me for everything due to his disabilities."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. South-east England.

"for them to help with pain for a better lifestyle" [Also filed under 'Faster and easier access to secondary care'.]

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. diverticulitis bowens cancer o/a. South-east England.

"The Consultant has to view my situation from a medical perspective. I know that my symptoms will be brought under control but in the meantime while I'm searching for work it would make a huge difference if a steroid injection into knees could be made available during interview period. While I understand I cannot have steroid injections on demand it may be the difference between obtaining employment or not. I'm sure the RA will be brought under control but I am very anxious to get back into work having spent over a year at home." [Also filed under 'Employment issues'.]

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. South-east England.

"please give us back co-proxamol"

Female. 65-74. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. osteoporosis. South-east England.

"I would put people on the best drugs going so it would not cost the NHS so much money in the long run ,trying out different drugs etc,Not make it a money thing.I had to write to my MP about the drugs that I needed to treat me ,which I don't think should happen."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. Diagnosed. Gyne problems. South-east England.

"for people with RA to get the care they need from the good old government"

Male. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. disc degeneration, and abnormal joints. South-east England.

"Medication to treat not only the disease but the patient and resultant abilities."

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. South-west England.

"Rapid use of the most effective treatments to prevent permanent damage even for newly diagnosed without rationing."

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. South-west England.

"I would have a treatment that worked!! the only ones make me so sick and affected my blood badly (methotrexate and sulfasalazine) I have had steroids but they won't give me more. they are the only thing that work. I do not qualify for the new drugs."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. my grip is weakened, have to use kitchen aids such as an electric tin opener and ring pull device ect. often need help with jars and taps. South-west England.

"NICE" to deregulate its imposed restrictions of drugs for the treatment of RA."

Male. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. South-west England.

"Please let consultants and nurses listen to patients and at least give them option of choice and they should not mention cost after all it's not the fault of the patient having RA so do not blame them" [Also filed under 'Better doctor-patient relationship required'.]

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. West Midlands.

2. Access to the best medication/choice of treatment [Continued 5]

"This miracle new drug to be available now so that I can live the rest of my life without this selfish preoccupation with the pain I am in."

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. West Midlands.

"Availability of all existing and new drugs to be driven by their perceived benefits and not by their cost and the age of the patient, thus eliminating the 'post code' lottery." [Also filed under 'A consistent national approach to treatment and care'.]

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. Heart attack 13 years ago has left me with heart damage and angina. Yorkshire and the Humber.

"I would ask that the most effective medication be prescribed at the earliest possible moment (regardless of cost) in order to improve the RA sufferer's quality of life. We won't mind being in pain when we're old and feeble if we've had the chance to live a little first."

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. high blood pressure, psoriasis and skin cancer. Yorkshire and the Humber.

"to be allowed the new injection thats suposed to be a "cure""

Female. 45-54. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. chrinic disk degeneration shrograms syndrome acute anemia rheydoids syndrome. Yorkshire and the Humber.

"I would change 'postcoding' mediations and allow everyone, no matter where they live to have access to the drugs if they qualify. I know they are expensive, but aren't we all entitled to e good quality of life???" [Also filed under 'A consistent national approach to treatment and care'.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. Irritable Bowel Syndrome Migraine. Yorkshire and the Humber.

"It is extermley difficult for RA consultants to secure funding to provide the most up to date and effective treatment to patients. Often a better treatment is only provided after serious deterioration in condition or a sustained pressure on consultants to improve treatment. It seems to be bit of a lottery as to who receives hte best medication who stays on original perscription for years, even if that medicaiton is not fully effective. patients have to continually ""

I am an informal carer for someone with RA. Female. 45-54. Diagnosed. 10 years or more. The RA is NOT currently stable. High Blood pressure. East Anglia.

"make the more effective drugs available"

I am an informal carer for someone with RA. Female. 60-64. Diagnosed. A year or more, but less than 2 years. The RA is NOT currently stable. Greater London.

"being allowed a better treatment when needed and not being told you cannot have it when it would improve your life"

I am an informal carer for someone with RA. Female. 75 or older. Diagnosed. 5 years or more, but less than 10 years. The RA is NOT currently stable. Asthma. North-west England.

"Honest information about all the drugs available. I believe there are drugs that could help me stay in employment for longer which I am not being offered because of the cost, which is crazy - I will end up disabled and on benefits instead of well and in work and paying taxes." [Also filed under 'More information/education from medical professionals', and 'Employment issues'.]

I am an informal carer for someone with RA. Male. 45-54. Diagnosed. 5 years or more, but less than 10 years. The RA is NOT currently stable. diabetes. West Midlands.

"instant access to the drugs that are supposed to be the answer to RA and forget the eligibility criteria, why make ANYBODY suffer like this whatever their age, disability, status in life - it is tortuoous, cruel and downright inhuman to let people suffer like this if there is an answer (even if it IS expensive - I would have paid for it given the choice!!!)"

I am an informal carer for someone with RA. Female. 75 or older. Diagnosed. 2 years or more, but less than 5 years. The RA is NOT currently stable. Heart Disease (mitral valve) osteoporosis - crumbling spine. Yorkshire and the Humber.

3. More information/education from medical professionals

One of the largest sub-categories of information requested by respondents is information on the side effects of medication. Other sub-categories include pain management, and treatment options.

"More information about podiatry." [Also filed under 'Other services: podiatry'.]

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. East Anglia.

"The anti tnf is good and seems to be working, but really needed to know more about it, went to meeting held by nras in norwich, brilliant a collection of sufferers all asking different questions i learnt a lot that day, local consultant answering the questions honestly - that what you need."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. amputee diabetes. East Anglia.

"With hindsight I think it would have helped when I was first diagnosed to have had pro-active advice from a consultant/nurse about diet and life styles and a wider discussion on the likley effects on my lifestyle of the disease. I have had no such advice at any stage of my care although equally I have not asked for it, having made my own investigations through the internet etc. There has always been an underlying assumption that I understand the condition and the jargon and that I know the likley outcome of any treatment given to me but no such explanation or information has been given to me at any time by an NHS consultant although the consultant I initially saw privately did help greatly"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. East Midlands.

"more information needs to be available on treatment options"

Male. 45-54. Diagnosed. 10 years or more. RA currently stable. East Midlands.

"Not enough warnings of side effects of drugs."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Kidney failure. Greater London.

"More comprehensive communication and support from the Consultant and hospital. Otherwise, because of the nature of the illness, you are basically left on your own to deal with what is an uncertain situation."

Female. 54-59. Diagnosed. 3 months or more, but less than 6 months. RA currently stable. Greater London.

"Better explanation of what the medications can do. I took too low a dose of methotrexate for a year or so, because I thought I was meant to use the anti-inflammatories to control my pain. No one really explained the treatment intention."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. I have mild asthma. Greater London.

"more aware of choice of treatments and also other treatments to relieve pain"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Greater London.

"More information and explanaiion of the different treatments"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Osteoporosis, Osteoarthritis (cervical osteophytes). Greater London.

"Education and training in pain management available to all patients."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. chronic renal disease cataracts. North-east England.

"More advice on working life with RA." [Also filed under 'More work-oriented help for people with RA'.]

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. No other illness. North-west England.

"Ensure people taking NSAIDS are prescribed omeprazole or something similar, so that they do not end up with extra problems as I did."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. stomach ulcer. North-west England.

3. More information/education from medical professionals [Continued 1]

"Try to confront the fear of those newly diagnosed by giving them much more information and advice."
Female. 65-74. Diagnosed. 10 years or more. RA currently stable. hearing impairment, and tinnitus. North-west England.

"More information about the scale of seriousness, so that I can understand where I am in relation to the population of sufferers. So that I can measure for myself, how serious my condition is." [Also filed under 'More opportunity for patient self-management'.]
Male. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. North-west England.

"more information about the deterioration the condition causes. instead of just getting injections for the pain every six months, being offered the new medications if i am able to take them or at least have a discussion about them, what they can do, how they may be able to help me or why they cannot help me."
Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. asthma, fibromyalgia. North-west England.

"Better explaining in less medical jargon what is wrong with you right from the start."
Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Anemia. North-west England.

"more detail on the longer term outlook-no one seems willing to discuss the range of scenarios"
Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

"Give more information."
Male. 60-64. Diagnosed. A year or more, but less than 2 years. RA currently stable. repetitive sympathetic disorder,(Chronic Pain) Knee just rebuilt Sarcoindosis, Breathing problems waiting operation on nose. South-east England.

"More info about the new wonder drugs that are being tested presently which have rave reviews in the media that could save a lot of money for the NHS in the long run."
Male. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. I am currently on medication for high blood pressure. South-east England.

"More information on how diet and exercise could be incorporated into your lifestyle."
Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Reynouds and hiatus hernia. South-east England.

"Being told about different treatments available."
Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. feet are disformed and twisted but overall MUCH better than last year NO PAIN!!!. South-west England.

"To be given more information at the onset"
Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Asthma. South-west England.

"After being diagnosed it would be great to have a little bit of support ideas for coping in the home, how to manage fatigue, coping with pain, what to do in a flare up. I felt very alone when I was first diagnosed, It was down to my husband to help me, whilst looking after a young child and holding down a job."
Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. under active thyroid and asthma. South-west England.

"Immediate support from a specialist nursing team to help through the bewildering and frightening initial stages of this disease. Any help I have had I have fought to get by my own volition and know that at initial diagnosis everyone is very frightened and needs to speak to professionals for support and guidance."
Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. West Midlands.

"To be given a menu of all available drugs (including side affects and safety) and also services available to me as a patient to make life easier and manage RA in a positive way."
Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. West Midlands.

"Better communication to me as the patient."
Female. 35-44. Diagnosed. 6 months or more, but less than a year. RA currently stable. Hypothyroidism. Yorkshire and the Humber.

"Consistency-more info available"
Female. 35-44. Diagnosed. 10 years or more. RA currently stable. 10 years or more. Yorkshire and the Humber.

3. More information/education from medical professionals [Continued 2]

"A little more time spent explaining the various options, treatments etc by the relevant medical staff."
Male. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Sleep Apnoea. Yorkshire and the Humber.

"more info on side effects of drugs."
Female. 45-54. Diagnosed. 10 years or more. RA currently stable. psoriasis. Yorkshire and the Humber.

"It would have been more helpful to me if, when I asked on diagnosis "will I have it forever", I had been told "yes, almost certainly" instead of "well, it can burn itself out in time". Because they had left this possibility, I spent the first 10 years or so thinking I might wake up one day and find it gone!!"
Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. diabetes (steroid induced following treatment for RA.) Underfunctioning thyroid (unrelated). East Anglia.

"A one stop shop in my hospital where I could receive advice about living with RA, treatments, Occupational Therapy Physiotherapy etc." [Also filed under 'Integrated services'.]
Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. Bronchiectasis Primary Immune Deficiency. East Anglia.

"Designated facility for one stop treatment or advice" [Also filed under 'Integrated services'.]
Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. East Anglia.

"A lot more information from the specialist he just says i am going to give you these or i am giving you a cotzone injection not why or why it will help you"
Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. diabetes, high blood pressure, incontinence, cracked knee cap, endometriosis. East Midlands.

"More information in best ways to take your medications. I believe this information is out there, but easier access to it will be better than patients having to look for it."
Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Greater London.

"More options about the treatments available."
Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Osteoporosis Raynaud's disease. Greater London.

"Medication and their potential side effects should be explained clearly. You should be able to choose your own treatment plan - and not be given medication and told to take it without explanation. I have had very positive experience of the NHS treating my RA generally, but I think much of that has been because I have done so much research myself so that I am always well-informed before seeing a doctor. I am currently not taking medication due to trying for a baby, this has made my RA unstable. My doctors have not been particularly helpful in this situation - they tend to give quite vague information and I tend to end up making my own decisions. I think any situation which becomes 'specialist' or different tends to present challenges that don't always get looked at properly. Apart from that, I am more than satisfied and I get very annoyed with the current trend of moaning about the NHS - most people don't have anything to complain about and are lucky to get the service they do!" [Also filed under 'Access to the best medication/choice of treatment'.]
Female. 25-34. Diagnosed. 10 years or more. RA NOT currently stable. Polycystic Ovarian Syndrome. Greater London.

"knowing how to deal with the pain"
Female. 35-44. Diagnosed. One month or more, but less than 3 months. RA NOT currently stable. Asthma, endometriosis, degenerative disc disease. Greater London.

"tell patients more about how it will affect their life's and all types of different treatments more or better support to get people over the shock of what has happened to them"
Male. 60-64. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. North-east England.

"I would like to be treated as an individual and therefore given as much information, treatment and help as possible" [Also filed under 'Better doctor-patient relationship required'.]
Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"communication and making people aware of the extreme pain that people with RA sufferer."
Male. 54-59. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. I have renal problems and high blood pressure. North-west England.

"MORE INFORMATION GIVEN TO PATIENTS"
Female. 25-34. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. CURLING TOES AND VERY PAINFUL FEET. South-central England.

3. More information/education from medical professionals [Continued 3]

"That they took more notice of the severe side effects of the drugs that are given and that more information and help was given on the severe fatigue of having RA. Having a counsellor that was also just for RA help would also be good because most counsellors don't know much about it." [Also filed under 'Better doctor-patient relationship required', and 'Other services: counselling'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Agorophobia Irritable bowel. North-west England.

"Clearer information about the drugs and - especially - their unwanted side effects. My kidneys suffered from prolonged high doses of diclofenac, which I took at maximum dose without any demur from the consultant, for 17 years. I and my GP picked this up from my test results - no-one else noticed. And no-one told me about the effects of sulphasalazine on my hair. It has thinned dramatically, and has knocked my confidence and self-esteem considerably. Indeed, when I found reference to this online, my consultant poohed-poohed it, and said that no-one had ever reported this to her. I did take methotrexate for a year, and was told my hair would recover from that immediately. It did not, and has become steadily worse through taking sulphasalazine. When I asked for an alternative, I learned that all DMARDs thin hair. I feel a freak."

Female. 65-74. Diagnosed. RA NOT currently stable. 10 years or more. South-central England.

"MORE SUPPORT AND HELP FOR THE CONDITION, ESPECIALLY LETTING PATIENT KNOW IN DETAIL WHAT IS HAPPENING TO THE BODY WITH RHEUMATOID ARTHRITIS"

Female. 65-74. Diagnosed. One month or more, but less than 3 months. RA NOT currently stable. I ALSO HAVE A CONDITION CALLED POLYMYALGIA RHEUMATICA PLUS DEPRESSION. South-east England.

"A better understanding of how the medication works and how it affects your daily life. Also an understanding of if it doesn't work, what next!"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Hypothyroidism. South-west England.

"I would very much like to be kept informed of drugs which can help rather than being told by my GP just to keep taking the pain killers regularly, when in fact they really do not help" [Also filed under 'GPs should be more knowledgeable about RA'.]

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. South-west England.

"more information about the drugs and the possible side effects"

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. blood pressure. Yorkshire and the Humber.

"look at the patient as a whole - as mentioned before be pro-active not re-active. better medication advice/ dietary alternatives etc" [Also filed under 'Being treated holistically'.]

I am an informal carer for someone with RA. Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. The RA is NOT currently stable. Greater London.

"Honest information about all the drugs available. I believe there are drugs that could help me stay in employment for longer which I am not being offered because of the cost, which is crazy - I will end up disabled and on benefits instead of well and in work and paying taxes." [Also filed under 'Access to the best medication/choice of treatment' and 'Employment issues'.]

I am an informal carer for someone with RA. Male. 45-54. Diagnosed. 5 years or more, but less than 10 years. The RA is NOT currently stable. diabetes. West Midlands.

4. GPs should be more knowledgeable about RA [A similar category to 'Faster referral by GPs to rheumatologists']

"That GP's actually know about it!! I have to explain to my current one, who openly admits that he doesn't know much about it."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Other forms of immune system problems, including b12/iron deficiencies and thyroid problems. East Anglia.

"Better training for GPs in recognition of symptoms."

Female. 45-54. Diagnosed. 6 months or more, but less than a year. RA currently stable. Hashimoto's thyroiditis'. East Anglia.

"The need for an earlier diagnoses and better training for GPs to recognise the symptoms. (I am no longer with the GP who let me down so badly) - my current GP knows about RA and is very supportive."

Female. 60-64. Diagnosed. 6 months or more, but less than a year. RA currently stable. Angina (under control), Asthma (under control), thyroid disease (under control). East Anglia.

"Make GPs in all clinics nation wide aware of RA in young adults, so that there can be a potentially earlier diagnosis"

Female. 16 to 24. Diagnosed. 6 months or more, but less than a year. RA currently stable. East Anglia.

"More awareness overall in GPs."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. Back injury. East Midlands.

"Would like more help from GP without always having to look for it first in Internet."

65-74. Diagnosed. 10 years or more. RA currently stable. East Midlands.

"Make GP's and the various staff in their surgeries more aware of both osteo and rheumatoid arthritis - treatments and drugs. I have experienced drugs being reduced or withdrawn - even though they have been prescribed following a consultation with A NHS specialist rheumatologist. There seems to be a deliberate avoidance of what the rheumatologist recommends!."

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Generalised degenerative lumbar spine problems/disc protusion/posterior ligamental hypertrophy/impingement on existing nerve roots on right side. Greater London.

"Better training for GPs!"

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Greater London.

"RA education for ALL - professionals AND society generally. RA is made all the more devastating because it is so misunderstood and so belittled."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Raynauds, Sjogrens, Scleroderma (CREST), Ileostomy. Greater London.

"Encourage GPs to gain a better understanding of RA and related diseases/syndromes."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. Fibromyalgia Irritable bowel syndrome. Greater London.

"Provide consistent information to GPs and offer full suite of services (as outlined in RA literature) to all NHS patients. I have had nothing outside private consultancy and drug treatment and found it very difficult to obtain further help."

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. Greater London.

"Improved knowledge by GP's for a quicker diagnosis or referral."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-east England.

"my GP knowing more about the drugs I take, so when I visit him he can help me more efficiently."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. under active thyroid. North-east England.

"That GP's would be more aware of the condition and the fact that young people can have it too because if I had personally been promptly treated and the doctors believed that I did have a condition and wasn't just wasting their time I wouldn't have joint damage as a result of the treatment that they gave me."

Female. 16 to 24. Diagnosed. A year or more, but less than 2 years. RA currently stable. anemia and lack of B12. North-west England.

"more traing and understaning by gps i applied for incapacity benenfit and was told i didnt qualify by my gp who said i had to be very very disabled to qulify."

35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. North-west England.

4. GPs should be more knowledgeable about RA [Continued 1]

"For GP's to be more aware of the symptoms of RA first hand."

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-west England.

"GPs need to have more awareness of the symptoms of RA so that speedier referrals to the correct people are made."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-west England.

"More recognition of its difference from osteo arthritis as this is widely unknown with resultant confusion causing difficulties"

Male. 65-74. Diagnosed. 10 years or more. RA currently stable. Asthma and hypertension. North-west England.

"Education GP's and Nurses about the symptoms of RA."

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. depression and anxiety but under control at the moment with medication. South-west England.

"greater GP awareness. (My current GP is excellent)"

65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-west England.

"There is a total lack of understanding and support of living with R.A within the NHS. There needs to be more education about this devastating disease to all medical professionals and the impact it has not only on a physical level but also emotionally." [Duplicated under 'Better understanding of RA among other medical professionals']

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-west England.

"Understand my condition" [Duplicated under 'Better understanding of RA among other medical professionals']

45-54. Diagnosed. 10 years or more. RA currently stable. Hayfever, Rhinitis. South-west England.

"More understanding from GPs"

Female. 54-59. Diagnosed. A year or more, but less than 2 years. RA currently stable. Depression. West Midlands.

"My main issue is about my initial diagnosis and I am not really sure how this could have been improved given the GP misdiagnosed in the first place."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. West Midlands.

"better understanding of RA at gp's surgery."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. atrial fibrillation osteo arthritis osteoporosis. West Midlands.

"GPs taking it seriously and referring for help instead of just saying there's nothing more they can do." [Also listed under 'Faster referral by GPs to rheumatologists']

I am an informal carer for someone with RA. Female. 75 or older. 10 years or more. The RA is currently stable. angina, blood pressure problems. East Midlands.

"More childrens specialist units and more GP awareness of JRA so children get a faster diagnosis and better care so less damage is done to joints." [Also listed under 'Faster and easier access to secondary care']

I am an informal carer for someone with RA. Male. Under 16. 2 years or more, but less than 5 years. The RA is currently stable. North-east England.

"For GP's to understand more about RA flare ups and how quickly they can occur. To investigate the underlying causes for side effects like hair loss of the patient and to act on tests."

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. I am suffering from hair loss. East Midlands.

"GP's knowing when to send you to an Orthopedic or Rhumatology clinic to get the correct diagnosis much faster. I suspect I had RA years & years before anyone realised."

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Osteo arthritis was diagnosed as well approx 30 years ago. East Midlands.

"Better knowledge at GP's when diagnosed - I have had to explain everything to GP and have had to ask for flu jab although GP wasn't sure if I needed one or not and told me to speak to the nurse."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Greater London.

4. GPs should be more knowledgeable about RA [Continued 2]

"Gp to be more aware and understanding. He told me I was far too young to have ra (I was 35, prime age for onset) and did nothing to help me, only hinder my referral. I eventually had to go private, I was DESPERATE for help but no one would listen to me. Stropky receptionists and uninterested gp."
Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. North-east England.

"more information for about current drugs for GP's because in my experience they know very little."
Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. under active thyroid. North-east England.

"Better understanding of RA within General practice"
Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. North-west England.

"Training for GP's to improve their awareness of RA and the recent developments in treatment."
Male. 54-59. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. North-west England.

"Better help and services from my GP who knows me well and would be more able to deal with my problems than someone I see infrequently"
Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"Please dont dismantle specialist rhuematology services-- Gps cannot build up the amont of knowledge needed"
Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. North-west England.

"To increase GP's knowlege of RA and how it affects patients. I should have been refered at least a year ago." [Also listed under 'Faster referral by GPs to rheumatologists']
Female. 60-64. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. South-central England.

"More understanding from the GP to start with, I was made to feel like I was making it up, more information/support on coping/living with RA."
Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Asthma, menorrhagia. South-east England.

"GP's need to be better informed about treatments etc. When I went to discuss treatment options with mine he told me he knew nothing about anti TNF's as they no longer do study days just refer you on."
Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. South-east England.

"Making GP's more effective with RA"
Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. South-east England.

"Proper rheumatology units with beds for respite care and admission for tests and assessment to save all the travelling up and down. Sorry but here's a second one - regular enforced education for ALL nurses, GPs and personnel on how to help people with RA." [Also filed under 'Integrated services'.]
Female. 75 or older. Diagnosed. 10 years or more. RA NOT currently stable. Atrial fibrillation Rheumatoid lung Sjogren's syndrome (all complications). South-west England.

"GP to be more helpful when you want a doctor note and you are in a flare up but you feel a fraud asking for one"
Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. South-west England.

"I would very much like to be kept informed of drugs which can help rather than being told by my GP just to keep taking the pain killers regularly, when in fact they really do not help" [Also filed under 'More information/education from medical professionals'.]
Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. South-west England.

5. Better doctor-patient relationship required [A similar category to "Greater length of time in the consulting room", 'GPs should be more knowledgeable about RA', 'Better understanding among rheumatologists of the patients' predicament', and 'Better understanding of RA among other medical professionals'.]

"GP taking my symptoms seriously even though I am seronegative."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. Chronic fatigue and being referred for investigation of possible thrombocythaemia. East Anglia.

"LISTENING!"

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. multiple allergies. thyroid problems. East Midlands.

"that the doctors listened to their patients more."

Female. 16 to 24. Diagnosed. 2 years or more, but less than 5 years. raynauds phenomenon and sjorgen syndrome. North-west England.

"A more positive and hopeful attitude - people do improve and it is possible to have good quality of life and the individual can know what is right for them and being treated with dignity and respect is essential. Sorry this is not one thing!"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. South-east England.

"Talk to us as if we have a brain as well."

Male. 60-64. Diagnosed. A year or more, but less than 2 years. RA currently stable. repetitive sympathetic disorder, (Chronic Pain) Knee just rebuilt Sarcoindosis, Breathing problems waiting operation on nose. South-east England.

"a bit more of one to one more understanding GPs and nurses"

Female. 54-59. Diagnosed. 6 months or more, but less than a year. RA currently stable. Breast cancer. South-east England.

"Treat the person as an individual not as a patient number."

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. Osteoarthritis PCOS. South-east England.

"The patient needs to be listened to more, and treated as a human being, not as something to pump drugs into and to hell with the consequences. I have several friends who have been made so ill by their medication that their lives are worse than if they hadn't taken it, and one has actually stopped taking meds, and feels a lot better for it."

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. fibromyalgia, osteoarthritis, spinal stenosis, auto-immune hepatitis, prolapsed lumbar discs.. South-west England.

"an interest in patients life style and support with that side of life would make a huge difference, it should not be just about drugs. You could access better occupational help and support services for family and carers, benefits and home adaptations. These practical things really make a massive difference to quality of a difficult life."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. I have high cholesterol, and am over weight due to the physical limitations RA brings. West Midlands.

"Perhaps a more one to one relationship with Consultant and nurse But I cannot complain as XXXX has admitted me twice when I needed and put me on prednisolone drips (\$ weeks In Hospital)."

65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Breathlessness and walking due to medication has destroyed nerve endings in feet and legs. West Midlands.

"Purpose built departments should be encouraged so that patients know where to go, have adequate waiting areas as well as treatment rooms that actually make them feel human and cared for, instead of just a number on a statistics spreadsheet." [Also listed under 'Integrated services']

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Only Osteo arthritis. Yorkshire and the Humber.

"I wish that I was treated as an individual not put on a "conveyor belt" with all others whilst attending the consultant appointments. I have specific needs as RA affects difficult people in different ways but I feel we are all treated the same way, not as individuals. If I have questions I feel there is not enough time, so just go in and listen to them and go home. This has happened to often so I have avoided going but have now experienced another flare up so have had no choice but to return to the hospital consultant." [Also filed under 'Greater length of time in the consulting room'.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. East Anglia.

5. Better doctor-patient relationship required [Continued 1]

"Improvement in the nurse practitioners so that they treated patients as individuals and didn't give consultations 'on auto pilot'"

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. East Anglia.

"That I am treated as an individual, with a life that is affected severely by the RA. More support should be available in order to improve my quality of life."

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. Osteoporosis Asthma Hiatis Hernia. East Midlands.

"Compassion and understanding in the teaching of RA to the general public from med staff"

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. Hypertension. East Midlands.

"Doctors Who Know What They Are talking About, And ones who will listen. There is never enough time within appointments" [Also filed under 'Greater length of time in the consulting room'.]

Male. 60-64. Diagnosed. 10 years or more. Cardiac. RA NOT currently stable. Greater London.

"More sympathetic consultants who explain things better! Often overworked, clinics often run late and most of the explaining is left to the (excellent) RA nurse at a later date, making for a worry filled few weeks between appointments"

Female. 35-44. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. Greater London.

"A consultant who has at least 10% empathy about the huge psychological impact the illness has on the pat."

Female. 25-34. Diagnosed. One month or more, but less than 3 months. RA NOT currently stable. epilepsi. endometriosis, asma. Greater London.

"I would like to be treated as an individual and therefore given as much information, treatment and help as possible" [Also filed under 'More information/education from medical professionals'.]

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"Doctors who LISTEN to you."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. raynauds phenomenom. North-west England.

"the consultants and their attitude to their patients."

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. i have a lung condition osteoporsis osteoarthritis diverticulus. North-west England.

"More support and more Patient led treatment. Consultants in particular should be more aware of patients need and wish's"

Female. 54-59. Diagnosed. RA NOT currently stable. 2 years or more, but less than 5 years. very severe pain, shortness of breath, high blood pressure. joints wearing out and damaged, difficulty with mobility, and not able to cope with the everyday things most people take for granted. North-west England.

"That they took more notice of the severe side effects of the drugs that are given and that more information and help was given on the severe fatigue of having RA. Having a counsellor that was also just for RA help would also be good because most counsellors don't know much about it." [Also filed under 'More information/education from medical professionals', 'and 'Other services: counselling'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Agorophobia Irritable bowel. North-west England.

"GPs and consultants are more understanding and listen."

Female. 35-44. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. South-central England.

"MAKE CONSULTANTS AWARE OF HOW THEIR STAFF TALK TO PATIENTS"

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. heart condition. South-central England.

"The attitude of consultants. More listening and proactively responding to what patients are saying they need and want. Having respect and supporting patients use of complimentary therapies if they choose. And refering patients routinely to other specialists within NHS such as physiotherapists, occupational therapists etc." [Also filed under 'Alternative therapies'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Possible sjrogren's syndrome.. South-central England.

5. Better doctor-patient relationship required [Continued 2]

"care about patients we are human beings that have had a terrifying experience and go for help, not a non caring attitude"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. asthma,depression,wczema,psrosis. South-central England.

"More interaction.between myself and specialist. Would feel more involved."

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. COPD. South-east England.

"More involment with the paitent"

Male. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. lung scarring. South-east England.

"Things that i would change would be 1) That the Dr's and Consulant's listen to the person that has RA then things might be better"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. South-east England.

"More empathy and understanding of people generally"

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. Diverticulitis Sliding Hyiatas Hernia. South-east England.

"THAT PEOPLE LISTEN TO WHAT YOU ARE TELLING THEM LIKE THEY ARE INTERESTED IN YOU AS A PERSON AND THAT THEY WANT TO HELP YOU."

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. ALLERGY TO ASPIRIN – SALICYLIC ACID ALLERGY TO INSECT BITES HAY FEVER REACTIVE HYPOGLYCEMIA LEFT LEG SHORTER THAN RIGHT LEUKODERMA KYPHOSIS MIGRAINES OSTEOARTHRITIS PHOTOPHOBIA RAYNAUDS DISEASE RHEUMATOID ARTHRITIS SJOGRENS SYNDROME – (SHURGRE. South-east England.

"Some of the consultants took time just giving lecture on the sickness not right medicine on right time."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. South-west England.

"listen to patient"

Female. 16 to 24. Diagnosed. 10 years or more. RA NOT currently stable. fibromyalgia, psoriasis, depression. West Midlands.

"Please let consultants and nurses listen to patients and at least give them option of choice and they should not mention cost after all its not the fault of the patient having RA so do not blame them" [Also filed under 'Access to the best medication/choice of treatment'.]

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. West Midlands.

"GPS were more understanding"

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. eczema. West Midlands.

"Checklist for person presenting to RA specialist detailing physical exam/x -rays/treatment plan/services available etc., etc., etc. This would be very easy to formulate but it would need the commitment from the health professionals to understand and use (no doubt this would be the main stumbling block - they aren't really interested). If this was organised then it would be more difficult to people to slip through the net regarding services, would give better information as to what is available (and when in the course of treatment), would benefit hospital stats and would, best of all, would probably make the patient feel as if someone was interested in them as a whole person not just as someone with RA to give drugs to." [Also filed under 'Integrated services'.]

Female. 45-54. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. Waiting on appointment with neurology as possible additional problem. Also just had bone density scan and one marker fine, the other not so good but not as far along as osteoporosis. Yorkshire and the Humber.

"More treatment for the patient as an individual rather than having to follow a set path of medication and care for all. Everyone has different needs and each person is different in the way they are able to deal with their RA." [Also filed under 'Being treated holistically'.]

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Hypothyroidism Osteoarthritis in knees. Yorkshire and the Humber.

"Improved communication skills for doctors"

Female. 45-54. 10 years or more. Greater London.

6. Access to a dedicated nurse specialist

Some respondents request a consultation with a specialist nurse.

Others wish for a specialist nurse to be reliably available by telephone.

Another sub-theme is that access should be especially speedy when a patient has a 'flare up'.

"Maybe assigned a nurse that I could speak to when needed, instead of having to wait months to see specialist"

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. High Blood Pressure over active thyroid. East Anglia.

"Provision of a RA nurse or a GP trained in symptoms of RA to provide help and support directly after diagnosis. Having a knowledgeable local point of contact with more accessibility than a consultant would make a world of difference in dealing with the anxiety of the diagnosis and would allow people having trouble seeing their consultants an additional source of support. If I could change TWO things, I'd make a uniform, medically-motivated waiting list limit across the NHS in all of the UK. Knowing your symptoms match RA, reading that permanent joint damage can take place in the first six months, and being told to wait half a year for a consultant is extremely distressing."

Female. 25-34. Diagnosed. A year or more, but less than 2 years. RA currently stable. East Midlands.

"Having access to a RA nurse - I rang the Rheu Dept of my hospital asking where I was on the list for an injection for my flared up knee (already waited 12wks, & was told "there are people worse than you" . Since I had been put on the list the pain had become much worse. Eventually I had the injection 18 weeks after being put on list. I felt guilty that I had rung up to find out."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Nerve pain after back operation to remove tumour from spine. East Midlands.

"Every Rheumatology Department of every hospital should have a Specialist RA Nurse team."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Greater London.

"To have access to a specialist nurse."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-east England.

"No post code lotteries e.g. RH nurse specialists for everyone"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. depression believe is linked to RA. East Anglia.

"I looked at Arthritis forums etc. on the internet to obtain information and support about RA when I was first diagnosed. But this was a minefield and it is no substitution for having a one to one meeting with a knowledgeable person (similar to a Macmillan Nurse). I realise that they could not give you an incite into the future but they could give you a general idea of what could happen and some support which would definitely have helped me during what was one of the worst year of my life. And I am sure would help others in a similar situation."

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. Was treated for Cervical Cancer and am currently in remission. North-west England.

"quicker access when a flare up occurs I have a number for an SOS nurse but by time they can get an appt it is easing of so I dont bother any more"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. High Blood pressure. North-west England.

"Specialist nurses that ring you back straight away and not one week later when having a flare up."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. Hormonal Migranes. North-west England.

"More Rheumatology Specialist nurses so that they were easily contactable and available for help and support."

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Thyroid condition Heart palpitations. South-central England.

"Provide more rheumatology nurse specialists. GP's and Rheumatologists have insufficient time to go into detail, but the specialist nurse is more accessible and can provide more time for each patient, providing support and information in a more relaxed manner."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-east England.

6. Access to a dedicated nurse specialist [Continued 1]

"Providing access to a RA nurse or clinic to enable quick and easy information/help with my RA if/when needed."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. South-east England.

"More autonomy for rheumatoid nurse specialists."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Hypothyroidism, factor V Leiden heterozygote clotting condition, and cardiac arrhythmias. East Anglia.

"Build up the RA nurse specialist role and provide online advice and access to rheumatology teams in local hospitals."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. Fibromyalgia Irritable bowel syndrome. Greater London.

"Having rheumatoid nurses available at all hospitals as well as a support group."

Female. 65-74. Diagnosed. 10 years or more. RA currently stable. South-east England.

"an appointed RA nurse who is approachable for telephone advice and support, rather than having to waste consultant's precious time."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Fibromyalgia symptoms, asthma and migraines. South-east England.

"More staff and more information given to patients. At the moment should I suffer from a flare, I would have to contact my consultant's secretary and probably leave a message on her voicemail. They then might get back to me or call me in, but only on a Tuesday or a Thursday because that's when the one specialist nurse is in. This is simply not good enough."

Female. 45-54. Diagnosed. 6 months or more, but less than a year. RA currently stable. South-east England.

"Specialist rheumatology nurses should be made available to all RA sufferers."

Female. 65-74. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

"Greater availability of specialist nurses"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. Underactive thyroid, vitiligo. South-west England.

"to have more access and contact with the RA specialist nurse"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. underactive thyroid. South-west England.

"To be able to access a specialist nurse"

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Asthma. South-west England.

"Some kind of home visit so they can assess if you need any immediate help. I am lucky that my parents only live a 15 minute drive away, and they were a enormous help with my children . I don't know how I would have coped otherwise."

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. i am now anaemic due to RA. South-west England.

"Increased numbers of trained RA nurses to give adequate time to number of RA patients in area."

Male. 45-54. Diagnosed. 10 years or more. RA currently stable. Suffered SVT in November 2007, but completely resolved following surgery in December 2007. Yorkshire and the Humber.

"more access to specialist nurses."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. underactive thyroid pernicious anaemia. Yorkshire and the Humber.

"I would like to see my specialist nurse more often. She knows me and is very helpful when I see her."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Some osteo arthritis and fibromyalgia. Yorkshire and the Humber.

"easier access to specialist help even if it was email or phone to a RA nurse to answer questions that arise after RA appointments"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. osteo arthritis/reynards/ sjorgorns disease/gilberts disease. Yorkshire and the Humber.

"Easy access to GP based RA trained nurses for general advice." [Also filed under 'Care should be based at primary-care level'.]

Male. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. spondylosis. East Anglia.

6. Access to a dedicated nurse specialist [Continued 2]

"Direct access to the nurses that can help when a flare up takes place at present it is a one day a week clinic which no direct contact outside of there opening hrs."

Male. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. East Midlands.

"More specialist nurses that could see you on a walk in basis, because time you get to see gp/consult and blood tests done, that phase could and normally has passed with a lot of pain and uncertainty on patients part"

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. kidney infections. Greater London.

"you need a help line to the hospital when you are having a flare up,so that you can be seen by a special nurse at that time instead of having to wait in agony and also the new drugs that are available" [Also filed under 'Other services: helpline'.]

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Right Hip replaycement,waiting for a left hip replaycement. North-west England.

"I have been unable to speak to the Rheumatoid Nurse in my area and I feel that I would have benefitted from this service, I telephoned her helpline on 1st December and am still awaiting a response, so in desperation have been to my GP"

Female. 65-74. Diagnosed. One month or more, but less than 3 months. RA NOT currently stable. South-east England.

"During a recent flare-up I did try to contact my RA specialist nurse for advice but received a recording saying that if I was experiencing a flare-up that I should consult my GP."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Diabetes, depression, high blood pressure, IBS. South-west England.

"implementation of a specialist nurse service at my local hospital so that there is a point of contact when problems arise. telephone support 24 hrs a day or access via answerphone."

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. residual mobility problems following road traffic accident. South-west England.

"A Rheumatology Nurse Specialist at the hospital who I could email and phone who worked full time. A lot of the stress has been caused by waiting to found out what is the latest side effect and to get the appropriate treatment."

Male. 54-59. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Pulmonary Fibrosis. Yorkshire and the Humber.

"Having a more open approach to being able to contact my consultant although the specialist nurse is very good.She has given advice about contacting the GP to get certain tests done before next appointment with the consultant which should speed up next course of action. Every step seems to take forever." [Also filed under 'Faster and easier access to secondary care'.]

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Yorkshire and the Humber.

7. More frequent consultations

"More frequent consultations with specialist nurse, OT and physio."

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Osteo arthritis, Ulcerative Colitis. East Anglia.

"After the initial diagnosis and care don't leave patients out on a limb, we need follow up, advise, more thought"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Psoriasis-leg ulcer. East Anglia.

"More regular appointments as I feel a year between appointments is too long and often feel that I only have a short time and that there is no one to listen to me even though I am not in flare up I may still feel rough."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. East Midlands.

"Regular reviews by consultant"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Greater London.

"more frequent appointments and liaison with nurse"

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. diabetes and osteoarthritis knee replacement now neuropathic pain. Greater London.

"More frequent appointments with hospital specialist."

Female. 65-74. Diagnosed. 6 months or more, but less than a year. RA currently stable. diabetes type 2. North-east England.

"More regular consultations with RA specialist at the hospital until fully under control. Easier access to physiotherapy advice."

Male. 65-74. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-central England.

"More frequent appointments at the rheumatology clinic, mainly for reassurance."

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Hypothyroidism. South-east England

"Less time between appointments. the consultants says see you in 6 months but the appointments are usually 8 or 9 months apart. Due to workload."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Diabetes, Asthma, Raised Blood pressure. South-west England.

"More communication with the patient. For example follow up appointments and perhaps an annual visit to the consultant"

Male. 60-64. Diagnosed. 10 years or more. RA currently stable. South-west England.

"seeing the consultant more often."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. feet are disformed and twisted but overall MUCH better than last year NO PAIN!!!. South-west England.

"That the RA Specialist were not under so much pressure."

Female. 65-74. Diagnosed. 10 years or more. RA currently stable. South-west England.

"To be able to see the main RA Consultant more often and not pushed on to registrars."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. Type 1 Diabetes, heart murmur, retinopathy, neuropathy, nephropathy. South-west England.

"To give patients regular appointments assigned by the specialist rather than changing and lengthening the time. emergency help/ walking in clinic in a rheumatology dept"

Female. 65-74. Diagnosed. 10 years or more. RA currently stable. High Blood Pressure. Yorkshire and the Humber.

"random blood tests without having to wait for appointments"

Male. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. East Anglia.

"More frequent appointments with Rheumatology department until RA settles down."

Female. 35-44. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. Carpal Tunnel Syndrome. East Anglia.

"Consultations with RA Specialist should be more often than once a year. Assessment of DMARD effectiveness could be better monitored. It has taken two years to be assessed for treatment with Anti-TNF Drugs not yet approved."

Male. 65-74. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. East Anglia.

7. More frequent consultations [Continued]

"More frequent appointments so that RA can be better assessed."

Male. 65-74. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Deafness in right ear. East Anglia.

"Some consultants should see their patients more frequently and not every 3 months if the RA is active."

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Greater London.

"More frequent allocation of NHS consultant appointments so that changes in best available medication (including biologicals) can be done quickly to relieve RA symptoms/flare-ups and so prevent permanent joint damage." [Also filed under 'Medication to be changed more quickly if it does not appear to be working'.]

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Greater London.

"The offer of more effective drugs and greater frequency of consultant appointments as the damage which can occur within 6 months can be quite considerable and irreversible." [Also filed under 'Access to the best medication/choice of treatment'.]

Male. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. North-east England.

"Faster transfer to other medication if the current one fails and more frequent consultations with RA staff, as before January 2008 I personally was on 9 monthly appointments and only saw consultant once in 5 years, uniformity in treatments throughout the UK would be better" [Also filed under 'A consistent national approach to treatment and care' and 'Medication to be changed more quickly if it does not appear to be working'.]

Male. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. 1 Auto immune haemolytic anaemia, 2 COPD, 3 enlarged heart, 4 osteoarthritis, osteoporosis, dislocated spinal discs. North-west England.

"An appointment system where you could see an RA specialist more frequently than nine months."

Male. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Severe fracture of Tib & Fib in skiing accident Feb 2006, problems with healing resulting in hospitalisation. fracture healed mid 2008. South-central England.

"I would like the appointments with the consultant to be 3 monthly when they say that is what is needed. Especially when newly diagnosed and the medication is being amended at each visit. I know from regular blood test results and my physical well being that my medication could still be improved but it is now 4 months since my last visit when the consultant said I want to see you in 12 weeks." Also filed under 'Faster and easier access to secondary care'.]

Female. 54-59. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. Type 2 diabetes. South-central England.

"More frequent check-ups say on a three monthly basis. Any new treatment could then commence more promptly and hopefully with greater effect. To date no treatment has worked for me and I am in constant pain both day and night." [Also filed under 'Medication to be changed more quickly if it does not appear to be working'.]

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. osteoarthritis and brochiectasis. South-central England.

"when first diagnosed to have more support and help from the nhs, and not be left with just 6 monthly checks, and feeling that you are alone as it is very depressing."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. South-east England.

"more contact from RA specialists"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. I also have osteoarthritis, IBS and I have had bowel cancer approx 10 years ago. South-west England.

"to see the consultants more often"

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. West Midlands.

"see the consultant more than twice a year."

Female. 25-34. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. West Midlands.

"Seeing rheumatologist at least every 12 months"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. The RA is NOT currently stable. North-west England.

"Shorter appointment interval so that I can see the Rheumatologist in the hospital more often."

Female. 25-34. 2 years or more, but less than 5 years. West Midlands.

8. Other services: counselling

"More psychological help. There is never anyone to talk to about how it's impacting on you personally. Appointments are always very quick and just focus on physical symptoms. More empathy from professionals about what it's like to live with RA."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. East Anglia.

"I was in my middle 20's when I diagnosed and would have certainly liked some counselling and support offered at a very difficult. As I was so young at the time it did have a huge impact at that time. I would have definitely used the service."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. East Midlands.

"Addressing the emotional aspect of R.A. I have learned that the healthcare professionals intervention is based solely on scientific results. When my specialist nurse consults with me I tell her what is happening and add, "Wait for the blood results". I have become quite good at predicting blood result outcomes. I don't think emotional conditions are so easily measured may be that is why clinicians are less interested in them. I have learned that a mood change indicates the presence of inflammation, though articles suggest that inflammation causes depression. Either way I feel I would have benefited from emotional support, not through medication and in turn my family would have benefited. There seems to be no reference at all to the impact of R.A. on families."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. Asthma and eczema. Greater London.

"I think the main change I would make is more emotional support for people with RA, medication is one thing but the effect RA has emotionally on a person and their family and friends is not addressed as widely on the NHS as I feel it should be. More information on where to get help socially, financial and counselling would be great"

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. East Anglia.

"I think more could be done for the mental state of a patient such as been offered access to support groups or counseling so patients don't feel left alone. There are lots of good treatments for the physical condition but nothing for the mental state. You need to help yourself in regards to this."

Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. My knees are damaged so was unable to walk unaided until I was treated with Anti-TNF. I now have a limp so can't walk too far or run. Greater London.

"more drop in facilities for help when it is needed especially psychological help"

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. under active thyroid. North-east England.

"More use of programmes like Expert Patient Programme. A buddying scheme for patient newly diagnose to speak someone living with RA for many years to make them realise that it is not the end of their world"

Female. 60-64. Diagnosed. RA is currently stable. Neuropathy, Divericulitis. North-west England.

"A 'buddie system' for those who have recently been diagnosed."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. osteoporosis high blood pressure. South-west England.

"Stress Management courses for those with RA on the NHS."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Asthma; Diabetes. South-central England.

"More psychological support for people with RA."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Asthma Hypothyroidism. South-central England.

"No-one is interested in the psychological aspects of RA, how it affects everything you do? even when you may not be in pain!"

Female. 25-34. Diagnosed. A year or more, but less than 2 years. RA currently stable. Carpal tunnel syndrome in both hands. Sciatica. South-central England.

"More psychological support and benefits for those not just physically impaired."

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. West Midlands.

"Emotional support at the time of diagnosis. I was devastated when diagnosed because I thought my condition would just deteriorate and I would be disabled for the rest of my life (I had been very fit and active)."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Coeliac's Disease Osteopenia. Yorkshire and the Humber.

8. Other services: counselling [Continued 1]

"access to mediator/counsellors who can assist with the major unexpected issues associated with autoimmune diseases - ie employment/housing/family"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. sacro-illitis - crohnes disease - raynauds disease - gynae prolapses - carpal tunnel syndrome. East Anglia.

"More access to counselling services."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. East Midlands.

"When people are first diagnosed with having arthritis it is a life changing diagnosis. I feel it would be helpful if counselling was offered."

Female. 16 to 24. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Diagnosed with boderline personality disorder and dpression. East Midlands.

"Better support emotionally- was very depressed and bewildered at diagnosis - nobody to help you with the emotions and this side of the illness."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Greater London.

"initially some kind of cousselling as this is a hard journey and sometimes you do feel totally inadequate and it can be a very depressing disease..."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. i have cervical spondylosis and also nodules on my thyroid. Greater London.

"Haveing someone to talk to would have been brilliant when i was first diagnosed , and when I am feeling down and in a lot of pain , the hospital nurses and doctors are always to busy to listen .And I feel like i am putting them out if I ring to see if i can have an injection to help , they dont ring me back till the end of the day or even the nect day , it's always on answer phone and you just feel neglected.and alone ." [Also filed under 'Faster and easier access to secondary care' .]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Ashma ,and diverticular disease. North-east England.

"If i could change anything, it would be to have more emotional support with dealing with all the life changes & also more financial advice. Also more information about what can be done & options available." [Also filed under 'Other financial assistance' .]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Fibromyalgia, IBS. North-west England.

"That they took more notice of the severe side effects of the drugs that are given and that more information and help was given on the severe fatigue of having RA. Having a counsellor that was also just for RA help would also be good because most counsellors don't know much about it." [Also filed under 'More information/education from medical professionals' , and 'Better doctor-patient relationship required' .]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Agorophobia Irritable bowel. North-west England.

"I think it would be nice to have someone stationed at the hospital on the RA department who actually had RA, that you could go and talk to them becuase i dont know anybody else my age that has RA, or even anyone else that has it regardless of age."

Female. 16 to 24. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. South-east England.

"I believe that when first diagnosed, you should be given the opportunity to discuss it with someone e.g. a counsellor or fellow RA patient. Each RA department in a hospital should have a support group to help newly diagnosed patients."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. South-east England.

"I have had RA for 31years and experienced depression linked to pain and disability. It would have helped if depression and treatments/therapies were included in consultations" [Also filed under 'Respondents diagnosed before current medication was available' .]

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. Depression. South-east England.

"when first diagnosed - offer counselling as its a major change and something which really affects your whole life so coming to terms with it was difficult"

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. South-west England.

8. Other services: counselling [Continued 2]

"counselling should be offered at the point of diagnosis."

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Raynauds Syndrome. West Midlands.

"Social/emotional support - at present, I have never been able to have this sort of support. This is vital to me because my specialist and surgeon have told me they are doing all they can with drugs etc. I simply have to learn to live with the fact that I will never get better - only worse - which is hard to cope with, therefore, I am in desperate need of support (someone who specialises in RA and can help me on a one to one basis on my daily life)."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. Bulemia, Obesity, Depression. Yorkshire and the Humber.

"More advice, support and assistance in dealing with the emotional strain RA places on people, especially those who are dealing with RA whilst at work and dealing with the demands of everyday life e.g raising a family. Local support groups are often attended by people of a much greater age range and one to one counselling would be a great benefit."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Under active thyroid gland.

"With patients' consent, I would have found it very helpful to be put in touch (eg via consultants) with other RA patients with similar conditions - to be able to compare symptoms/treatments. Also if potential drawbacks to a particular medication were being explained it would have been helpful to have been able talk to someone who had decided to proceed with it." [Also filed under 'More self-help/patient support groups'.]

Male. 54-59. 2 years or more, but less than 5 years. South-east England.

9. Better access to biological drugs [Closely linked to 'Access to the best medication/choice of treatment']

"Increased access to Anti-TNF therapies for other RA sufferers"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Type 1 Diabetes. Greater London.

"More people eligible for 'biologic' drugs, such as humira, which has been a real life-saver for me"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. East Anglia.

"not have just one chance at a biologic! that idea is totally absurd! People are in pain!"

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. East Midlands.

"End any suggestion of a postcode lottery for the biologicals."

Female. 35-44. Diagnosed. 3 months or more, but less than 6 months. RA currently stable. autoimmune hypothyroiditis. Greater London.

"For newly diagnosed patients if compatible the first drug treatment they should be offered is the new biologics."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Osteoporosis and Clinical Depression. North-west England.

"I would allow access to biological drugs as a first, rather than last option, so that treatment can begin before joints have been irreparably damaged."

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-central England.

"If diagnosed with RA, to receive the biological drugs more quickly and not have to try out the DMARDS first. If the biological drugs had been available to me earlier I believe I would not have had to stop working. I think they work two ways, Firstly less overall cost to the NHS by not having to have all the operations and treatments and hospital admissions etc and secondly a better quality of life to the patients."

Male. 60-64. Diagnosed. 10 years or more. RA currently stable. Ulcerative Colitis. South-central England.

"embrol and other biologics offered earlier"

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-east England.

"Provision of more funding for the more expensive and effective drugs [such as anti TNF] to be made available to more patients at an earlier stage - so as to prevent pain and disability before the disease has had time to make an impact on patients lives."

Male. 54-59. Diagnosed. 10 years or more. RA currently stable. North-east England.

"That all RA patients should be given the opportunity to try biologics so that their RA can be treated aggressively in the early years to avoid the longer term joint damage."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. Disability due to partial deafness and hip problems. I walk with a cane and cannot stand too long or walk too far. South-west England.

"Access to biologic therapies, for those who qualify, without delay and issues of cost."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Duodenal and peptic ulcers as a result of NSAIDs and systemic lupus erythematosus Osteoporosis. West Midlands.

"NICE do NOT change the rules on the prescription of more than one drug within the biological drug group (eg etanercept)"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. West Midlands.

"I had to go on to an injection method trial and allow myself to flair up just so that I could have a DAS score of above 5.1 and could then go on Enbrel. I was still trying to work and look after a baby. This is ridiculous when I wasn't currently in flair up." [Also filed under 'Employment issues'.]

Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-west England.

"Earlier treatment with biological drugs as the earlier they are prescribed the more effective they are."

Male. 65-74. Diagnosed. 10 years or more. RA currently stable. High cholesterol and blood pressure (controlled). Yorkshire and the Humber.

"make all aware of criteria for front line drugs. Consultant provides unbiased information re front line drugs eg humira, instead of scare tactics."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. IBS. South-east England.

9. Better access to biological drugs [Continued]

"The prescription of anti TNF drugs, because I have now had three DMARDs and in other parts of the country people get biological drugs after two DMARDs have been found to be unsuccessful. In fact, make that four DMARDs as I have had both oral and sub cut methotrexate. Currently on leflunamide, this drug is as good as anything, but has unacceptable side effects at times." [Also filed under 'Medication to be changed more quickly if it does not appear to be working'.]

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. North-east England.

"Easier access to biological drugs, I had to wait 10 months for permission by the PCT to start on Enbrel after other medication had failed to control the disease. By which time I was in terrible pain and my joint damage has increased substantially. Even now I have been warned that I may only be allowed the drug for 6 months as it is so expensive!"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. multi nodule goitre - migraine. South-east England.

"Move onto biologic drugs to improve the rest of my life (have had RA for 20yrs and i am 66)"

Male. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. South-east England.

"Not bound by cost enabling all people who would benefit from biological drus to receive them"

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Fibromyalgia. West Midlands.

"to be offered anti tna instead of being told they are expensive"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. angina and blocked arteries. West Midlands.

"offer all RA patients anti tnf i struggled for 14 months in terrible and flare up unable to work which was crippling me finacially then when i started my Humira treatment i was back at work within 6 weeks RA under cotrol earning againand paying taxes" [Also filed under 'Employment issues'.]

Male. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Glaucoma High blood pressure. West Midlands.

"treatment earlier, when will tocilizumab be available in Britain."

Male. 65-74. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Hypertension, diabetes, Vascular problems. South-east England.

"FUNDING and doing away with need to try DMARDs and fail before moving on to Anti TFs my consultant admits that due to severe nature of my RA i was always a candidate for anti TNFS but i wasted 18 months- lost my job and have knackered my hands while going throughthe hoops- again differentiate between sudden severe types and slow onset PLEASE" [Also filed under 'Employment issues'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. i hve Adult Onset stiils a rare auto immune disease- which in addition to RA gives me some organ trouble. South-east England.

"The discrimination of who is 'entitled' to receive anti-tnf drugs. By the time you are entitled to receive them, the damage is already done!"

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"The long waiting time before you are put onto something like Humira. From the time my consultant decided I needed to have this drug I had to wait over 9 months before the funding was approved and I started treatment. Had I received this earlier, I may have avoided having to have surgery on my foot and neck which is on the horizon for 2009."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Greater London.

"A qucker way of getting anti-tnf - I had to be assessed over a period of nearly two months - this resulted in sick leave and made carrying on a normal family life difficult."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-west England.

"I think that the "wonder" drugs such as Humira should be available to everyone with RA. I have had to go through a criteria of this drug and that drug before I qualified. The Humira has helped and I do feel better so why did I have to wait so long?"

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. West Midlands.

"quicker access to biological therapies"

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. sjorgen syndrome fibromyalgia. West Midlands.

10. Better communication among medical professionals [A similar category to 'Integrated services']

"Combined care by all consultants and GPs should be more effective."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Kidney failure. Greater London.

"communication systems between gp and hospital have been appalling which has caused totally unnecessary stress and wasted lots of my time. I have had to change hospitals, in order to facilitate communication of blood tests and continuity in my prescriptions. i finally have a mutually convenient system at my gp surgery but it was a hard fought battle and took years to achieve"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. hypertension. Greater London.

"My only comment is that the pathology lab appears out of the loop. This may also be the case with other professionals. My hospital consultant wants monthly blood tests and my GP also wants to see the results. My GP says he is responsible for prescribing medicines and my day to day care. My consultant says that the GP cannot prescribe the medicine without his authority. It seems beyond the capability of the blood laboratory to automatically copy the results to both doctors. So when I receive the blood test forms from both doctors, I tear up one set and write on the other set COPY TO....and highlight it with a marker pen. It does not always work and then I get grief from one or the other for missing a blood test and they eventually chase the laboratory but it can be well after the event by then."

Male. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Slight blood pressure. Greater London.

"We need much better liaison between hospitals and GPs. This communication is poor to non-existent in my area."

Female. 75 or older. Diagnosed. Less than a month. RA currently stable. North-west England.

"Communication between Patients, Consultants and GPs. There is a lack of this at present and I have had to find so much out by myself."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Fibromyalgia, Asthma, Emphysema, Stomach and bowel problem. South-central England.

"I would like the GP's and the consultants to be more communicative with each other and I would also like to see patients being treated as individuals rather than just another moaning old arthritic, not all people with RA are old! I would also like to see some clarification regarding medication, the stress involved in getting the GP to prescribe the drugs which my consultant has recommended has actually caused a flareup."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Asthma. South-east England.

"That once diagnosed with a critical illness your NHS file is marked and when ever you attend hospital A & E or GP or any other appointment you are treated jointly with your Rheumatologist. If you have an immune problem condition then it will and does effect every part of your health and so this needs to be taken into consideration when you are ill at any time, it is more than possible that any illness is due to medication or the RA itself."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. High Blood Pressure and Fibromyalgia due to RA. South-east England.

"Better communication between GP, rheumatologist and me. Perhaps email could be used more to save costs?"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

"more awareness and more access between gp and rheumatologist. My GP has no involvement with the care of my RA I always wait for my appointment with rheumatologist. I get more information and help from NRAS charity"

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-east England.

"For all Rheumatologists GP's ,Surgeons and other Health Care providers involved with an RA patient to work as a team."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. osteoporosis, asthma, gastric reflux. South-west England.

"Better communication between services and for the services to be what the NHS direct site tells me i should be getting."

Female. 35-44. Diagnosed. 6 months or more, but less than a year. RA currently stable. Hypothyroidism. Yorkshire and the Humber.

10. Better communication among medical professionals [Continued 1]

"During the time I consulted with the Hospital and consultants there was no follow up or co-ordination between the different branches of the health service"

Male. 45-54. Diagnosed. 10 years or more. RA currently stable. Psoriasis. Yorkshire and the Humber.

"all areas to work together so we dont have to beg for services such as rheumatologist, physio, poditrist, dietician, occupation therapist etc., for general nurses to know about RA and how to help us when admitted on a normal ward"

Female. 25-34. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. recurrent miscarriages, livedo reticularis. East Anglia.

"For local GP and Rheumy communicate better - I find I am telling each one what is going on - tricky!! But they are both good and both listen to me!"

Female. 35-44. Diagnosed. One month or more, but less than 3 months. RA NOT currently stable. East Anglia.

"That the GP and the RA Drs have to communicate with each other at all times. I think my care would be better then."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. I also have Thyroid disease. East Midlands.

"That GPs and specialists at the hospital worked together more as I've found that when I've been put on new medication I can never get a repeat as my GP wont give it to me because the specialist at the hospital has not sent the details of new treatment. This is very frustrating as no one tells you what to do."

Female. 16 to 24. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Greater London.

"Have the hospital and the GP on the same computer system. At present a backlog at the hospital means I have to make an appointment to see my GP so that their notes are up-to-date! Daft!"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Greater London.

"GP & hospital contact.....things are often lost between them, it would be better if they could work together more and all letters should be copied to the pateint so that we are kept up to date with our treatment and conditionthey did this when i was pregnant so I don't see why it wouldn't work for RA services"

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. North-east England.

"communication between various departments so people get seen by anyone that may be able to offer assistance."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. over pronation of feet, under active thyroid. North-west England.

"More communication between different departments in the hospital and the doctors. A better understanding of how the patient feels to be passed from pillar to post."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. South-central England.

"AS I LIVE ON 3 COUNTY BOARDERS . COMMUNICATIONS BETWEEN THE DIFFERENT HOSPITALS & GP PRACTISE DOES NOT HAPPEN.eg.BLOOD TEST RESULTS FROM HOSPITAL TO GP DO NOT ARRIVE."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Hard of Hearing. South-east England.

"More connection between the hospital RA clinic and my GP, to enable quick treatment of flare ups, and also understanding of medication and other illness issues ie chest infections."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Asthma. South-east England.

"better communication between hospital deparments"

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. under active thyroid psoriasis - not active at present. South-east England.

"GP SERVICES TO WORK MORE CLOSELY WITH HOSPITAL SPECIALIST"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. West Midlands.

"A co-ordinated approach between GP and RA consultant"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. West Midlands.

"Better GP understanding and liason between themselves and the rheumatologists."

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. fibromyalgia, hypertension, depression. West Midlands.

10. Better communication among medical professionals [Continued 2]

"Its got to be dealing with a flare There is a real lack of joined up thinking in this area. It tends to work like this We phone the hospital help line (useful this service for medicine enquiries) They send us to the GP (ok) He comes out (he has to the wife can't get to him thats the problem) (ok) He rings the help line and talks to another doctor They arrange a plan (ok) If the plan does not inc going to the hosp we are not going to improve just get worse. We know this its happened consistently for years. Getting into the hosp is the hiccup. In the last couple of years my wife was twice carried into the hospital on a stretcher and that means in pain and totally imobile. Incidentally I got the hard words of the consultant." [Also filed under 'Faster and easier access to secondary care'.]

I am an informal carer for someone with RA. Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. The RA is NOT currently stable. North-east England.

"That my GP and Consultant worked as a team and talked to each other. There seems to be a void between the 2 x professionals which interferes with patient care"

I am an informal carer for someone with RA. Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. The RA is NOT currently stable. West Midlands.

11. Integrated services [A similar category to 'Better communication among medical professionals']

"To have integrated services available in one unit s"

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. high blood pressure. Greater London.

"have one person to arrange and help provide info on all aspect of ra eg chiropodit exercise classes ,ra associations ect"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. North-west England.

"Local support group for people with ra. All ra services on one site eg; all clinics and services together. In the same way as breast clinics etc. In the trust i use rheumatology seems to be a 'cinderella' service, compared to other specialities."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Asthma, irritable bowel syndrome. North-west England.

"Group sessions run by the NHS which would provide support, exercise, information etc. on a regular basis. My nearest support group is over 40 miles away."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Thyroid - on thyroxine. On medication for an unstable bladder and high cholesterol. South-east England.

"Small dedicated teams.Doctor/ nurse."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Type 1 insulin diebeties Colon problems due to long term steroid use. South-east England.

"A PROPPER WARD FOR RA IN HOSPITAL AS THIS HAS NOT ALWAYS BEEN THE CASE"

Male. 54-59. Diagnosed. 10 years or more. RA currently stable. kidney stones.thyroid, inflamation of lining of stomach. South-west England.

"More of a universal change, but if the NHS could work like a unified entity instead of a bunch of mismanaged, disparate organisations, that'd be a big help."

Male. 16 to 24. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Ankylosing spondylitis. South-west England.

"Return to rheumatology units with dedicated staff/facilities - a one stop shop."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-west England.

"That RA patients are seen by all members of the RA team ie RA specialist Nurses/physios/orthotists/ podiatrists etc at initial referral and on a regular or on patient request basis"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. West Midlands.

"Purpose built departments should be encouraged so that patients know where to go, have adequate waiting areas as well as treatment rooms that actually make them feel human and cared for, instead of just a number on a statistics spreadsheet." [Also listed under 'Better doctor-patient relationship required']

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Only Osteo arthritis. Yorkshire and the Humber.

"a more effective system at hospital where you get seen by many different professionals under 1 roof- like a one stop shop. the current system means waiting for each individual OPA for physio, consultant, orthotics, blood tests, scanning, xrays. with fatigue being a major component in many peole with RA and impact on ability to work etc.. it can be tough making arrangements to get to each OPA and can be costly for travel, parking etc. specialist centres i think is what i am saying would improve the patient experience."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. East Anglia.

"A one stop shop in my hospital where I could receive advice about living with RA, treatments, Occupational Therapy Physiotherapy etc." [Also filed under 'More information/education from medical professionals' .]

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. Bronciectasis Primary Immune Deficiency. East Anglia.

"Designated facility for one stop treatment or advice" [Also filed under 'More information/education from medical professionals' .]

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. East Anglia.

"More aggressive, early intervention. Joint Clinics held with Endocrinologist / Fertility Consultants."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Hypothyroidism. East Midlands.

11. Integrated services [Continued 1]

"Complete care, although note that the shock of the diagnosis can lead to denial...but being able to see a choropidist and a physio and a RA nurse all in one place and clinic, like is being proposed for elderly people sounds great! Maybe, if it could be co-ordinated to work properly this could mean no waiting in between and certainly less time away from work." [Also filed under 'Alternative therapies' and 'Employment issues'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Sjorgens syndrome as a secondary. RA has lead to disability. North-east England.

"An integrated RA team with nurses, physios,etc.."

Male. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"I would have all the multi disciplinary teams working much more closely together - this would provide a much more consistent service to the patient."

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. underactive thyroid,nodules on the lungs and high cholestrol. North-west England.

"If all the relevant services took a joined up approach, eg. if my rheumatology specialist nurse thinks I need a blue badge, who are social services to say no, sorry, you're not ill enough for that. The off hand way I was dealt with was very upsetting indeed."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. diabetes, high blood pressure. North-west England.

"One team.. specialist doctor, nurse & GP that follow up, know me and care about my personal situation and also realise that although I may not fulfill the criteria for the new drugs that a I have two children under 5 they would improve the life for all 3 of us!" [Also filed under 'Access to the best medication/choice of treatment'.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. Fibromyalgia. South-central England.

"The ability to have tests in any medical facility to allow me to carry on travelling for work and leisure and not be tied to local monitoring." [Also filed under 'Employment issues'.]

Male. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Mild asthma. South-east England.

"I had to wait 4 months for consultant appointment by which tme my symptoms were well controlled by GP with steroids and NSAISs. I had to reduce steroids to bring symptoms back to enable consultant to make diagnosis - that was horrible as they were worse than originally."

Female. 60-64. Diagnosed. One month or more, but less than 3 months. RA NOT currently stable. South-east England.

"Proper rheumatology units with beds for respite care and admission for tests and assessment to save all the travelling up and down. Sorry but here's a second one - regular enforced education for ALL nurses, GPs and personnel on how to help people with RA." [Also filed under 'GPs should be more knowledgeable about RA'.]

Female. 75 or older. Diagnosed. 10 years or more. RA NOT currently stable. Atrial fibrillation Rheumatoid lung Sjogren's syndrome (all complications). South-west England.

"Support - there needs to be far better support with a multi agency/specialist co-ordination of services." [Also filed under 'Other support'.]

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Chronic fatigue, Chronic pain syndrome. South-west England.

"they all work together and have some knowledge to help manage pain while waiting to get an appointment with RA nurse"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. West Midlands.

"Fewer hoops to jump through - as a person with a long-term progressive/disabling illness you have to do more, not less, than other people to achieve the same. Systems should be more integrated - and more should be offered as a matter of course, rather than constantly having to apply for, and negotiated to receive, services. I was overwhelmed as much by paperwork etc as the effects of RA when first diagnosed."

Male. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. West Midlands.

11. Integrated services [Continued 2]

"Have each Rheumatology centre in the country equipped as a one stop shop but ALSO include a link to social services in the mix to give patients clear, simple access to benefits or support they are entitled to without a battle and interminable waiting periods." [Also filed under 'Not having to fight for treatment, care or support'.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. West Midlands.

"Checklist for person presenting to RA specialist detailing physical exam/x-rays/treatment plan/services available etc., etc., etc. This would be very easy to formulate but it would need the commitment from the health professionals to understand and use (no doubt this would be the main stumbling block - they aren't really interested). If this was organised then it would be more difficult to people to slip through the net regarding services, would give better information as to what is available (and when in the course of treatment), would benefit hospital stats and would, best of all, would probably make the patient feel as if someone was interested in them as a whole person not just as someone with RA to give drugs to." [Also filed under 'Better doctor-patient relationship required'.]

Female. 45-54. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. Waiting on appointment with neurology as possible additional problem. Also just had bone density scan and one marker fine, the other not so good but not as far along as osteoporosis. Yorkshire and the Humber.

"JOINED UP SERVICES FOR EVERYONE THROUGHOUT THE UK" [Also filed under 'A consistent national approach to treatment and care'.]

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. I have corneal dystrophy. South-east England.

12. Alternative therapies

"To know more about alternative therapies and treatments, such as those mentioned in this questionnaire."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-east England.

"Offer of complementary therapy for relaxation and well-being."

Female. 65-74. Diagnosed. 6 months or more, but less than a year. RA currently stable. diabetes type 2. North-east England.

"Access to other therapies would be great. I seem to have been offered the drug therapy side and nothing else. Hence I don't go back to my RA team very often."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-east England.

"More information about possible alternative treatments."

Male. 65-74. Diagnosed. 10 years or more. RA currently stable. North-west England.

"More alternative help. I want to manage my RA as holistically as possible, but it seems that I have to either take the medication OR try and manage it myself, my Rheumatologist is not in support of alternative methods."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Ankylosing Spondylitis, Rheumatoid vasculitis. North-west England.

"The main thing I would change in the current services for arthritis would be a vast increase in complimentary treatment."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Under active thyroid. South-east England.

"More advice on holistic treatments, ie diet and exercise and how to avoid medication."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. Recurrent iritis prior to diagnosis (no reoccurrence since diagnosis). South-east England.

"consultants / GPs working most closely with alternative and complimentary specialists. eg acupuncture - hydrotherapy etc"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. South-east England.

"Make complementary therapies (e.g. acupuncture) more readily available."

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. South-west England.

"Each patient needs ongoing support and access to free hydrotherapy, complimentary therapies etc for a continuous period."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-west England.

"Offer a wider range of options when first diagnosed, let people try alternative therapies and go down other routes before convincing them that they need strong medication and that they have either no control over or responsibility for their own bodies. I do believe that there is a glaringly obvious lack of psychological care and support when going through the journey that this disease becomes and that were people given much more of this kind of support and encouragement that they would be better able to question/cope and make decisions for themselves. Unfortunately, doctors and nurses are not adequately trained in any form of psychology/counselling so very often miss the mark unless it is one which can be hit with a drug..."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Nothing else. West Midlands.

"Information about alternative medicine. In the past when I haven't responded to the drugs I have been prescribed I have not been offered any alternatives. The medication I am on now is becoming less and less effective and I'm really worried that there will be no alternative when it stops working."

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. Yorkshire and the Humber.

"more info on natural remedies,"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. psoriasis. Yorkshire and the Humber.

"Have Serrapeptase Enzyme available for everyone instead of ridiculing it."

I am an informal carer for someone with RA. Male. 65-74. 5 years or more, but less than 10 years. The RA is currently stable. Inflamed prostate. South-west England.

12. Alternative therapies [Continued 1]

"Recognition of positive effects of drug free complimentary medicine because of the side effects and cost of drugs.Funding for research."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. myxodoema, osteo arthritis. East Anglia.

"To be offered free complementary therapies. Although it doesn't take the pain away for long, massage does provide me with temporary relief, and works on a par with medication in my opinion. With no side effects! I would love to have massage on the NHS regularly"

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Hypothyroidism. East Midlands.

"Patients should be offered other services like occupational therapy, life style and diet counselling and maybe even workshops or meetings to learn about the RA and how to live with it. The diet things I found it quite importan as some medications damage your body in many different ways."

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Greater London.

"I'm in pain most of the time, but there are no alternative therapies offered, like acupuncture, physiotherapy, massages, heat treatments, spa treatments with sulphure rich mineral hot water (like for example in Central and South East Europe and Rotorua in New Zealand) - these spas are so helpful, but I have to go abroad to use them and spend my annual leave, which is limited. Because of the work commitments, having such spa facilities in UK would be fantastic. Surely if these treatments help alleviate the pain and general symptoms of RA, some should be available on NHS, cutting the time we take off from work when having a flare up and causing some people to retire too early due to ill health, thus costing the society much more than a few spa/hydrotherapy centres would cost."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Greater London.

"Complete care, although note that the shock of the diagnosis can lead to denial...but being able to see a choropidist and a physio and a RA nurse all in one place and clinic, like is being proposed for elderly people sounds great! Maybe, if it could be co-ordinated to work properly this could mean no waiting in between and certainly less time away from work." [Also filed under 'Integrated services' and 'Employment issues'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Sjorgens syndrome as a secondary . RA has lead to disability. North-east England.

"The ancillary services that are available as outlined in this survey being made noticeably available. A leaflet outlining the different treatments that are available would be useful" [Also filed under 'More information/education (general)'.]

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. North-west England.

"The attitude of consultants. More listening and proactively responding to what patients are saying they need and want. Having respect and supporting patients use of complimentary therapies if they choose. And refering patients routinely to other specialists within NHS such as physiotherapists, occupational therapists etc." [Also filed under 'Better doctor-patient relationship required'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Possible sjrogren's syndrome.. South-central England.

"Not to see medication as the be all and end all in the treatment of RA, give ALL patients the opportunity of using physiotherapy, hydrotherapy etc. because too much emphasis is placed on age and not enough on the needs of the patient, even though I am 31, I get just as stiff as someone with RA twice my age."

Female. 25-34. Diagnosed. A year or more, but less than 2 years. PRA NOT currently stable. oly Psoriatic Arthritis, Asthma, Eczema. South-east England.

"alternative therapies eg acupuncture provided, makes a huge difference. condition affects my ability to earn which means I can't have treatment that makes a big difference.....Also help with housework etc."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. South-east England.

"Patients own choice [if known]of medication,pain relieve,including oil [hemp] for stiff swollen joints,and to be allowed to use canabis medically ,not the pharmaceutical stuff as its ingredients are nt natural ,less pharmacuticle duff drugs made and used in RA 7A treatment ,its the long term effect and damage to other body parts n functions.thanks"

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. psoriatic arthritis, severe psoriasis,[whole body covered,also scalp],very high cholestrial,menstral pain &problems, p,t,s,d[post tramatic stress disorder]. South-east England.

12. Alternative therapies [Continued 2]

"More access to services that may help, such as hydro, physio, dietician, complementary therapy, OT, massage."

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Lupus. South-east England.

"To have consultants who had more time to listen and who offered complementary therapies as well as conventional treatment" [Also filed under 'Greater length of time in the consulting room'.]

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Hypothyroidism. South-west England.

13. Better awareness of the condition: among the public [A similar category to 'More information/ education (general)']

"Increase general awareness, understanding and information"

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Hypertension. East Anglia.

"More awareness overall in society."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. Back injury. East Midlands.

"More awareness by people who do not suffer as symptoms are not always visible and one day you are able to something that another day would cause pain"

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Reynauds. North-west England.

"I would like people to realise how different RA is from osteoarthritis - but only because when I have a flareup and feel so dreadful they would understand that I'm not exaggerating the effects of it."

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-central England.

"The service is really good but it is my own difficulty in telling other people other than really close friends and family. I feel at work there is very little understanding/support. Taking time off causes me enormous worry and guilt-its awful."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Diabetes. sinus infections. South-east England.

"A greater awareness in society as a whole about the effects & impacts of RA."

Male. 45-54. Diagnosed. Less than a month. RA currently stable. High blood pressure, which is being treated with medication & responding well. South-east England.

"Raised public awareness. It is still very much an 'invisible disease' - just because I look ok it doesn't mean I am."

Female. 45-54. Diagnosed. 6 months or more, but less than a year. RA currently stable. asthma. South-east England.

"People's understanding that younger people can and do suffer with RA"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. South-east England.

"For all personnel in public services, councils, housing associations, social serv, libraries, dentists etc to have extended training on what it like for people with a disability/RA. What it like to get up in the morning and try and get yourself breakfast/ dressed with only 1 hand 'cause the other is so painful you could scream. And dinner? ha! They can never feel the pain, exhaustion, unpredictability of the disease or the dread/fear you feel when you know you're going to have a flare up. You're helpless"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Sjögren's syndrome, Raynauds and carpal tunnel in both hands. South-west England.

"I would like to see a lot more publicity about RA. the most annoying thing i find is when people say "Oh i know how you feel i get arthritis in my knee "etc. Its not just an illness that gives you joint pain. You feel really really ill and the pain is all over your body when you have a flare. . To name just one thing is very difficult because i would also like to be able to find work where it would be possible to work in such a flexible way to cope with the bad days. I can see that this is probably impossible to achieve."

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-west England.

"PA which is the main arthritis I have should also be recognised but most have never heard of this disease and yet it can effect the joints severly, sometimes more so than RA. Unfortunately because with this disease you have good and bad days people don't always understand that you have constant pain every second of the day whether it be severe constant pain or just that dull constant pain because of the meds - just because someone does not look disabled or does not complain about the pain they are always in does not mean that they do not need or want help."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. Psoriatic Arthritis and Psoriasis. West Midlands.

"More information on the symptoms so that I would have gone to the doctor earlier and been diagnosed earlier."

Female. 54-59. Diagnosed. A year or more, but less than 2 years. RA currently stable. West Midlands.

"More people should be more aware about how arthritis can hit young people - it's not limited by age."

Female. 16 to 24. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Anaemia, Osteoporosis. West Midlands.

13. Better awareness of the condition: among the public [Continued]

"Improve the level of understanding (its not just a strain) or tendonitis"

Male. 54-59. Diagnosed. A year or more, but less than 2 years. RA currently stable. Gillian Barr Syndrome. West Midlands.

"More knowledge about the condition"

Male. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. West Midlands.

"The public perception of RA so that I had more dignity and felt less like a burdon on everyone."

Male. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. East Midlands.

"Advertise, so that people are more aware of how much pain real suffers are really in. Before I became afflicted I never thought of it as a disabling disease, let alone that it life long."

Male. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Greater London.

"an understanding that we don't always look ill, but could be in a lot of pain, it is embarrassing to remind people that just because you are able to make it to work does not mean you are not having problems." [Also filed under 'Better awareness of the condition: among employers'.]

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. micro bacterium xenopi (long term non tuberculous chest infection). North-east England.

"I feel that a more integrated approach is needed that should included working with any existing or in the establishment of 'self-help' groups. Education is important as RA can affect anyone and is not just an old persons complaint and also the condition should not continue to be the butt of comedians jokes!" [Also filed under 'More self-help/patient support groups'.]

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"that because of my age people would understand, the pain i go through. and that it isn't just an elderly persons disease"

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. asthma. North-west England.

"For people to stop assuming that young people do not get RA"

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. IBS Osteoporosis Psoriasis. North-west England.

"More publicity about RA as most people think it is just aches and pains and really don't understand what is wrong with you. A more widespread understanding and higher profile for the disease would help right across the board."

Female. 45-54. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. South-central England.

"Educate people as has been done for 'Aids' - evrybody thinks you must be 'old' to have RA as they only hear the word 'arthritis'- a national campaign is needed."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. South-east England.

"It would be to be treated the same as other people with long term illnessess. Someone with diabetes I know never has pain but has everything free I have RA and am constanley in pain or unable to move around due to flare ups and people like me are forgotten."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. South-east England.

"More information available for everyone, NHS practitioners, sufferers, carers, families, friends and the general public. Much more awareness of RA is needed. Even just basic things, like people need to know that RA is not the same as OA, that disabled people may not have any visible signs of their disability and that young people can have arthritis too."

Female. 16 to 24. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. Yorkshire and the Humber.

"Just because people with RA are receiving medication, the general population beleives you are just fine. If you are not knarled, you are just fine."

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Dergenative disc diease and osteoporosias.

14. Faster referral by GPs to rheumatologists [A similar category to 'GPs should be more knowledgeable about RA' and 'Faster and easier access to secondary care'.]

"It would of helped if my GP had refered me as soon as he could instead of making be wait at least 4 months to see if the symptoms would improve"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. East Anglia.

"Quicker GP referrals - this could be helped by GP's being better informed."

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Greater London.

"my problems were only with my GP. i was suprised just how long it took from start to finish to get my diognosis"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. high blood preasure and some nerve pain. North-east England.

"Make Doctors more aware of what can be done and that referral is of paramount importance as soon as possible to get the symptoms under control and to halt the deterioration of your joints."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. depression. North-west England.

"GPs to be quicker to identify possible cases or RA and to refer sooner to RA consultants."

Male. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. High blood pressure. North-west England.

"For GP's to refer you to a specialist straight away and to be able to see the specialist quickly and not having to wait several months."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. North-west England.

"Gp's to refer immediately to a specialist if arthritic symptoms occur in a patient"

Male. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-west England.

"That G.Ps would realise there was a possibility of their patient having R.A. so sending them to a consultant quicker"

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-central England.

"more awareness for RA and quick referral to the right people asap then consistent monitoring for the patient in reliable NHS department -- this soon wont be the csae with some PCTs!"

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. lung fibrosis. South-east England.

"Improve access to treatment by improving GP knowledge"

Male. 54-59. Diagnosed. A year or more, but less than 2 years. RA currently stable. None that I am aware of. South-east England.

"get a really quick diagnosis and on to effective treatment as fast as possible! this means ALL G.P.s in the first instance being totally on the ball"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. South-east England.

"better diagnosis from GP, took too long, saw too many wrong specialists before RA specialist"

Male. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

"More rapid referral instead of "What do u expect at 80!""

Male. 75 or older. Diagnosed. One month or more, but less than 3 months. RA currently stable. Leg Ulcers Heart attack in 1986 "T=Rheumatic Fever" when a child. South-east England.

"Early access to diagnosis and treatment"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. osteoporosis high blood pressure. South-west England.

"Early diagnosis and referal by GPs."

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Lipodermatosclerosis. West Midlands.

"Quicker referrals for patients to NHS consultants/hospital clinics. - I have been very fortunate in this respect (see personal story) but this is probably not the case for everyone. Early diagnosis and treatment is clearly vital in the treatment of RA, and raising public awareness of this disease is the first step."

Female. 45-54. Diagnosed. 3 months or more, but less than 6 months. RA currently stable. West Midlands.

"Referral immediately to a consultant."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Duodenal and peptic ulcers as a result of NSAIDs and systemic lupus erythromatosis Osteoporosis. West Midlands.

14. Faster referral by GPs to rheumatologists [Continued]

"GPs to refer patients to a consultant immediately. This would slow or halt the progression of the disease."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. depression and badly damaged joints. Mobility problems. Yorkshire and the Humber.

"Quicker diagnosis from the GP. They seem to think it is often just stiffness"

Male. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Yorkshire and the Humber.

"GPs taking it seriously and referring for help instead of just saying there's nothing more they can do." [Also listed under 'GPs should be more knowledgeable about RA']

I am an informal carer for someone with RA. Female. 75 or older. 10 years or more. The RA is currently stable. angina, blood pressure problems. East Midlands.

"To have more access out of hours for people who work. ie GP appointments, Blood Test appointments, GP appointments when you have a flare - the gp recognises and puts you in for an appt asap." [Also filed under 'Employment issues' and 'Appointments scheduled more conveniently for patients'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Bronciectisis. North-west England.

"a faster referral to consultant/specialists"

Female. 35-44. Diagnosed. One month or more, but less than 3 months. RA NOT currently stable. lower back problems/ sciatica. North-west England.

"To increase GP's knowlege of RA and how it affects patients. I should have been refered at least a year ago." [Also listed under 'GPs should be more knowledgeable about RA']

Female. 60-64. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. South-central England.

"Early checking out of symptoms by a rheumatologist when RA is suspected. I was only referred when I could not walk. Methotrexate and steroids alleviated the symptoms immediately"

Female. 65-74. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. West Midlands.

"GP referral to an appropriate RA specialist"

I am an informal carer for someone with RA. Male. 45-54. Diagnosed. 10 years or more. The RA is NOT currently stable. Greater London.

"When the GP thinks it could be RA he can only refer to a consultant for medication to begin. The waiting time can be several months so the people who can afford to go privately to have the diagnosis confirmed . I know many people who do this and pay for the initial consultation and then revert to the nhs for treatment. It is wrong that the people who cannot afford to pay may have to wait a long time to see a consultant andmeanwhile their RA progresses with no treatment other than the GP's painkillers."

Male. 65-74. 5 years or more, but less than 10 years. lung fibrosis. South-west England.

15. Medication to be changed more quickly if it does not appear to be working [A similar category to 'Access to the best medication/choice of treatment', and 'Better access to biological drugs']

"Better follow up of medication and if one does not work change it quicker before permanent damage is done."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. East Anglia.

"As it takes up to 12 weeks to work you really want to be sure you can be treated quickly and effectively."

Male. 35-44. Diagnosed. 6 months or more, but less than a year. RA currently stable. East Midlands.

"The ability to chop and change between the various anti-TNF drugs and other drugs of similar status."

Female. 60-64. Diagnosed. Less than a month. RA currently stable. high blood pressure seasonal allergy - trees (birch family). Greater London.

"Make it easier to change TNF if the current one does not suit or work as effectively as it initially did"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Hashimoto's thyroiditis Discoid Lupus Auto-immune early menopause. Greater London.

"Make the more expensive therapies available much more readily to patients obviously not doing well on conventional DMARDs, anti-inflammatories, etc."

Male. 45-54. Diagnosed. 10 years or more. RA currently stable. No, apart from disabilities as a result of long term RA. South-central England.

"I would allow RA patients access to more than one anti TNF therapy if the first choice of drug doesn't work."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. South-central England.

"The waiting time between trying different drugs."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. West Midlands.

"change my medication to something with less drastic side effects."

Male. 25-34. Diagnosed. A year or more, but less than 2 years. RA currently stable. Yorkshire and the Humber.

"Continuous updating of new treatments"

Male. 65-74. Diagnosed. 10 years or more. RA currently stable. Yorkshire and the Humber.

"Completely disagree with the recent NICE decision that patients on anti TNF treatments (e.g Enbrel/ Humira/Remicade) can not switch between them."

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. Greater London.

"access to more than one anti TNF drug"

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. depression. East Anglia.

"DO NOT TAKE AWAY THE OPPORTUNITY OF CHANGING ANTI-TNF DRUGS, IF ONE BECOMES EITHER INEFFECTIVE OR DOES NOT WORK 1ST TIME AROUND."

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. East Midlands.

"More frequent allocation of NHS consultant appointments so that changes in best available medication (including biologicals) can be done quickly to relieve RA symptoms/flare-ups and so prevent permanent joint damage." [Also filed under 'More frequent consultations'.]

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Greater London.

"having set amount of times for going from one treatment to another, e.g. if methotrexate does not work after 1 year, then immediately move on to another, like anti-TNFs. i feel this could possibly prevent people's conditions becoming worse, and as quickly, if they are able to try enough different medications until they find the one that works best for them, rather than waiting for doctors to decide when it is "time for a change"."

Female. 16 to 24. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. North-east England.

"The prescription of anti TNF drugs, because I have now had three DMARDs and in other parts of the country people get biological drugs after two DMARDs have been found to be unsuccessful. In fact, make that four DMARDs as I have had both oral and sub cut methotrexate. Currently on leflunamide, this drug is as good as anything, but has unacceptable side effects at times." [Also filed under 'Better access to biological drugs'.]

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. North-east England.

15. Medication to be changed more quickly if it does not appear to be working [Continued]

"Access to the new medications/treatments as soon as possible if your current treatment does not work (NICE to be more understanding about cost effectiveness versus quality of life)."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. South-west England.

"Faster transfer to other medication if the current one fails and more frequent consultations with RA staff, as before January 2008 I personally was on 9 monthly appointments and only saw consultant once in 5 years, uniformity in treatments throughout the UK would be better" [Also filed under 'A consistent national approach to treatment and care' and 'More frequent consultations'.]

Male. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. 1 Auto immune haemolytic anaemia, 2 COPD, 3 enlarged heart, 4 osteoarthritis, osteoporosis, dislocated spinal discs. North-west England.

"More frequent check-ups say on a three monthly basis. Any new treatment could then commence more promptly and hopefully with greater effect. To date no treatment has worked for me and I am in constant pain both day and night." [Also filed under 'More frequent consultations'.]

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. osteoarthritis and bronchiectasis. South-central England.

"Speed the timing up of changes in medication, it can take months for approval and funding. More damage is done waiting for new meds."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Scleritis. South-east England.

"Ability to try more than one anti TNF if the first one does not work ."

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. Ulcerative colitis, asthma, polio late effects. South-west England.

"Quicker treatment, and when a drug doesn't work try something else sooner. If this had been done the damage to my joints could well be a lot less and it would have saved the NHS the costs of surgery."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. South-west England.

"Very concerned about the one choice of treatment rather than able to try up to 3 treatments as my current treatment of methotrexate does not seem to be working."

Female. 54-59. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. asthma and underactive thyroid. South-west England.

16. A consistent national approach to treatment and care

"no postcode lottery for provision of drugs and NICE to provide anti tnf therapy for all people who need it" [Also filed under 'Access to the best medication/choice of treatment'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. North-west England.

"More availability of latest drugs.No post code lottery!" [Also filed under 'Access to the best medication/choice of treatment'.]

Female. 45-54. Diagnosed. 6 months or more, but less than a year. RA currently stable. North-west England.

"Having consistent national approach to treatment and care of RA - I'm hoping the forthcoming NICE clinical guidelines will help to address this (but only if healthcare professionals actually implement the guidance!)"

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. East Anglia.

"Have standardised treatment across the UK."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. North-west England.

"Make care the same nationally. My experiences have highlighted the vast differences between the services. Whether this is because I was young when I was diagnosed (19) and am a student, making my treatment more difficult anyway, I do not know, but, whatever the reason, a nationalised standard of care is essential to improving the lives of those with RA."

Female. 16 to 24. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. recurrent psychotic depression. South-central England.

"In my NHS district, nothing but I suspect treatment is not the same nationally and I would dearly like current services for me to be consistent throughout the country"

Female. 54-59. Diagnosed. A year or more, but less than 2 years. RA currently stable. West Midlands.

"Continuity of care across the NHS system. I have moved local authority areas twice since being diagnosed and the standard of care in different NHS areas varies widely. I have also had problems with getting notes transferred from one doctor to another and several of my notes have gone missing over the years. RAs in the different areas have different approaches to dealing with RA. For example I have moved from an RA who was very hands on and who I saw every two or three months to one who as long as my blood test results are clear is happy to see me every nine months."

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. West Midlands.

"The same treatment should be available regardless of where you live."

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Yorkshire and the Humber.

"That everyone could enjoy the same standard of treatment, I feel very lucky. As my treatment at previous health authority was dreadful and mainly because nobody cared."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. gastritis. Greater London.

"Faster transfer to other medication if the current one fails and more frequent consultations with RA staff, as before January 2008 I personally was on 9 monthly appointments and only saw consultant once in 5 years, uniformity in treatments throughout the UK would be better" [Also filed under 'More frequent consultations' and 'Medication to be changed more quickly if it does not appear to be working'.]

Male. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. 1 Auto immune haemolytic anaemia, 2 COPD, 3 enlarged heart, 4 osteoarthritis, osteoporosis, dilocated spinal discs. North-west England.

"to stop the lottery system of being lucky if you get a good rheumatologist i was lucky but not everyone is and it shouldn't be down to luck."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. asthma, osteo arthritis. South-central England.

"That all forms of treatment are available to all patients wherever they live. It strikes me you have to make a fuss to get anything that helps."

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. heart problems carpal tunnel. South-east England.

"Consistent service levels across the country."

Male. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Asthma. South-east England.

16. A consistent national approach to treatment and care [Continued]

"Ensure equality of care across the NHS"

Male. 45-54. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. South-west England.

"Standardised treatment for all areas of the UK, with equal access for all to drugs, etc."

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. Mitral valve regurgitation. Hypertension. South-west England.

"Availability of all existing and new drugs to be driven by their perceived benefits and not by their cost and the age of the patient, thus eliminating the 'post code' lottery." [Also filed under 'Access to the best medication/choice of treatment'.]

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. Heart attack 13 years ago has left me with heart damage and angina. Yorkshire and the Humber.

"I would change 'postcoding' medications and allow everyone, no matter where they live to have access to the drugs if they qualify. I know they are expensive, but aren't we all entitled to a good quality of life??" [Also filed under 'Access to the best medication/choice of treatment'.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. Irritable Bowel Syndrome. Migraine. Yorkshire and the Humber.

"Funding is equal throughout the UK. I was told 05/06 the area I live spent £20,000 on DMARDS so 2 patients, while another health authority spent £700,000 & had no waiting list if you met the criteria required."

I am an informal carer for someone with RA. Male. 54-59. Diagnosed. 10 years or more. The RA is NOT currently stable. Depression, Anxiety. South-west England.

"Equal treatment without postcode lottery."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. The RA is NOT currently stable. North-west England.

"JOINED UP SERVICES FOR EVERYONE THROUGHOUT THE UK" [Also filed under 'Integrated services'.]

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. I have corneal dystrophy. South-east England.

17. Exemption from prescription charges

"It would be a massive help if people with RA were exempt from prescription charges. I require a lot of medicines which often I cannot afford because I am unemployed as a result of my arthritis. And then if I don't take my medicine because I can't afford it, I can't work and it becomes cyclical! I have also been refused incapacity benefit and income support because my condition is not deemed to meet the requirements for such benefits, despite having severe RA."

Female. 16 to 24. Diagnosed. 10 years or more. RA currently stable. East Anglia.

"I have to pay for all my medication because I am in work. I should not be penalised for being in work."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. High blood pressure. Greater London.

"We should not be paying for prescriptions as I ended up paying £20 a month with the chopping and changing of drugs from the consultant to settle my condition. R/A is an expensive condition."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. hiatus hernia I.B.S. North-east England.

"Free prescriptions. It seems unfair that I have a long-term incurable disease and have to pay for two prescription items per month - over £100 per year even with a pre-pay certificate. As a younger RA sufferer (diagnosed at 36) I will be paying for a long time to come."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. North-west England.

"prescriptions should be free"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-west England.

"We should not have to pay for them [drugs]"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Polymyalgia Rheumatica Glaucoma Osteoporosis. South-east England.

"Free prescriptions"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. South-east England.

"Make NHS prescriptions FREE"

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-west England.

"Help with prescription charges !!"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. South-west England.

"free lifetime prescriptions as thyroid patients have"

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Yorkshire and the Humber.

"Free Prescriptions for RA sufferers would be a great help."

Male. 16 to 24. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Yorkshire and the Humber.

"Allow free prescriptions for this condition. Our daughter will have this for life, its going to be an expensive future."

I am an informal carer for someone with RA. Female. 16 to 24. 5 years or more, but less than 10 years. The RA is currently stable. Asthma and allergies. South-east England.

"Not having to pay the prescription charges regularly for all the medications which I need. I do have a PPC card which I pay for from Incapacity benefit and disability allowance"

Male. 54-59. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Osteoarthritis with Lung Fibrosis. East Midlands.

"Payment for medication when others receive there's for free for other life time illnesses. I'm currently on over 15 drugs a day and have to pay for these"

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. Recurring DVTs Reanl Artery Stenosis Bouts of Septic Arthritis. Greater London.

"Free prescriptions - because it costs a fortune as you are continually popping pills."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Greater London.

"MORE HELP AND FREE MEDICATION"

Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. bronchitis asthma. North-west England.

17. Exemption from prescription charges [Continued]

"Free prescriptions as this is a chronic condition."

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. South-west England.

"for people with long term illness such as RA be given free prescriptions. because my husband works we have to pay for everything, my monthly prescriptions alone would cost around £80 if i didnt get a yearly pre-payment certificate."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. i will mention that i have great walking difficulties caused by the RA and hve had a many operations on them including staples,pins and bone grafts. I say this because most reports etc concerning RA do not take into consideration the feet, why i dont un. West Midlands.

"I would instigate free prescriptions for RA sufferers."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. West Midlands.

"That we didn't need to pay for our prescription. this is a life long disease and its reclassified we need to pay. my current repeat prescription has 7 drugs on it making it very expensive."

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. West Midlands.

18. Employment issues

"For younger patients in employment quicker access to the best drugs." [Also filed under 'Access to the best medication/choice of treatment']

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. West Midlands.

"More support meetings allocated for RA sufferers in employment. Support meetings are currently held during working hours which are difficult for employed people to attend." [Also filed under 'Appointments scheduled more conveniently for patients'.]

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. raynauds & connective tissue disease. Greater London.

"If blood tests could be taken at any doctors surgery ie those near to a place of work and not always at a hospital or own GP surgery it would make life a lot easier." [Also filed under 'Care should be based at primary-care level'.]

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. East Midlands.

"The drug funding is not cost effective. I have been unable to work for 3 years now - but am only 45. If there was access to the medication which would actually help then I could stop claiming benefits and get on with work and life." [Also filed under 'Access to the best medication/choice of treatment']

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. other autoimmune diseases - underactive thyroid premature menopause psoriasis herpes rosacea. Yorkshire and the Humber.

"I had to go on to an injection method trial and allow myself to flair up just so that I could have a DAS score of above 5.1 and could then go on Enbrel. I was still trying to work and look after a baby. This is ridiculous when I wasn't currently in flair up." [Also filed under 'Better access to biological drugs'.]

Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-west England.

"Complete care, although note that the shock of the diagnosis can lead to denial...but being able to see a choropidist and a physio and a RA nurse all in one place and clinic, like is being proposed for elderly people sounds great! Maybe, if it could be co-ordinated to work properly this could mean no waiting in btween and certainly less time away from work." [Also filed under 'Integrated services' and 'Alternative therapies'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Sjorgens syndrome as a secondary . RA has lead to disability. North-east England.

"shorter waiting lists to see a consultant. I was referred in April and did not see a Rheumatologist until Mid August by which time I was unable to work due to RA symptoms. I live in a rural area and we have a visiting consultant from another hospital in a main town, I believe this lengthens waiting list times." [Also filed under 'Faster and easier access to secondary care' and 'Better RA services in rural locations'.]

Female. 45-54. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. multiple cerebral aneurysms (three surgically treated four low risk aneurysms being monitored). High blood pressure under control with medication. North-east England.

"Not making the decision to work part time so difficult financially"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Spondalosis. North-east England.

"To have more access out of hours for people who work. ie GP appointments, Blood Test appointments, GP appointments when you have a flare - the gp recognises and puts you in for an appt asap." [Also filed under 'Appointments scheduled more conveniently for patients' and 'Faster referral by GPs to rheumatologists'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Bronciectisis. North-west England.

"The ability to have tests in any medical facility to allow me to carry on travelling for work and leisure and not be tied to local monitoring." [Also filed under 'Integrated services'.]

Male. 35-44. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Mild asthma. South-east England.

"FUNDING and doing away with need to try DMARDS and fail before moving on to Anti TFs my consultant admits that due to severe nature of my RA i was always a candidate for anti TNFS but i wasted 18 months- lost my job and have knackered my hands while going throughthe hoops- again differentitate between sudden severe types and slow onset PLEASE" [Also filed under 'Better access to biological drugs']

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. i hve Adult Onset stills a rare auto immune disease- which in addition to RA gives me some organ trouble. South-east England.

18. Employment issues [Continued]

"A fast track service for people who are working and are afraid of losing their jobs because they cannot get medical treatment quickly enough." [Also filed under 'Faster and easier access to secondary care'.]

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. ulcerative colitis - stable. West Midlands.

"hydro therapy pools to be available for all RA patients particularly in the early stages and to be available regularly thereafter. Water is the best place for exercise but many hospital pools have been closed. I AM SURE MORE PEOPLE WOULD BENEFIT AND HAVE LESS PAIN AND BE ABLE TO WORK." [Also filed under 'Other services: hydrotherapy'.]

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. Polio as a child my right arm is virtually paralysed, late effects of polio this causes more problems with my spine neck and arm. Ulcerative colitis my type of RA is apparently due to this. Asthma, South-west England.

"There should be a refined pathway to avoid the journey I went on as like I say if I had a full time job at the time I would have with no doubt had to have given up my home as I wouldn't have been able to have afforded to continue with my mortgage having been off sick for so long. I wouldn't have been able to claim any benefits either as there was no diagnosis." [Also filed under 'Other financial assistance' and 'Faster and easier access to secondary care'.]

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. West Midlands.

"offer all RA patients anti tnf I struggled for 14 months in terrible and flare up unable to work which was crippling me financially then when I started my Humira treatment I was back at work within 6 weeks RA under control earning again and paying taxes" [Also filed under 'Better access to biological drugs'.]

Male. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Glaucoma High blood pressure. West Midlands.

"easier access to hospital appointments. it would help if you are in severe pain to be able to get an injection to get you going again and back to work." [Also filed under 'Faster and easier access to secondary care'.]

Female. 54-59. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. psoriatic arthritis sjogren's syndrome collapsed back muscles hypertension underactive thyroid anxiety/depression/panic attacks. Yorkshire and the Humber.

"Honest information about all the drugs available. I believe there are drugs that could help me stay in employment for longer which I am not being offered because of the cost, which is crazy - I will end up disabled and on benefits instead of well and in work and paying taxes." [Also filed under 'Access to the best medication/choice of treatment' and 'More information/education from medical professionals'.]

I am an informal carer for someone with RA. Male. 45-54. Diagnosed. 5 years or more, but less than 10 years. The RA is NOT currently stable. diabetes. West Midlands.

19. Greater length of time in the consulting room [A similar category to 'Better doctor-patient relationship required']

"More time with consultant on follow up visits (10 minutes is not long enough"

Male. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. copd. East Anglia.

"Time for them to read the notes before hand."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. Asthma shoulder joint tendon tears. East Anglia.

"Allow patients more TIME!"

Female. 60-64. Diagnosed. A year or more, but less than 2 years. RA currently stable. East Midlands.

"just a bit of time taken to properly test and look at symptoms so maube some other people will not have to go thru what i did thank you"

Male. 45-54. Diagnosed. 3 months or more, but less than 6 months. RA currently stable. i have various other problems that are either linked or started at the same time. Greater London.

"More time from NHS for patients."

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Greater London.

"For the Rheumatologist to have more time to listen and discuss my condition"

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. High Blood Pressure, Type 2 Diabetes, Anaemia, Osteo arthritis and two years ago I had successful surgery for Bowel Cancer. North-east England.

"More time with a consultant at shorter intervals."

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Thyroid condition Heart palpitations. South-central England.

"That appointments could be made regularly for monitoring."

Female. 65-74. Diagnosed. 10 years or more. RA currently stable. South-west England.

"more time with specialists and more specialist espec ra nurse specialists"

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. get migrains. South-west England.

"I wish that I was treated as an individual not put on a "conveyor belt" with all others whilst attending the consultant appointments. I have specific needs as RA affects difficult people in different ways but I feel we are all treated the same way, not as individuals. If I have questions I feel there is not enough time, so just go in and listen to them and go home. This has happened to often so I have avoided going but have now experienced another flare up so have had no choice but to return to the hospital consultant." [Also filed under 'Better doctor-patient relationship required'.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. East Anglia.

"more time with the nurse and consultants so they can explain in more detail about your condition and also the drugs to help you"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. epilepsy asthma high blood pressure twitching bladder dry eye. East Midlands.

"Give health care professionals MORE TIME with the patient. They see you as a box to be ticked for the number of people seen that day. I understand that there are resource issues but 10 mins isn't really adequate to discuss a life changing disease."

Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. East Midlands.

"Gps should be more accessible and have more time for patients with chronic disorders such as RA. 10 minutes is just not enough."

Female. 65-74. Diagnosed. 10 years or more. RA NOT currently stable. hypertension shoulder requires replacement (due to ra) sciatica. Greater London.

"Doctors Who Know What They Are talking About, And ones who will listen. There is never enough time within appointments" [Also filed under 'Better doctor-patient relationship required'.]

Male. 60-64. Diagnosed. 10 years or more. Cardiac. RA NOT currently stable. Greater London.

"more time for discussion about the disease and lifestyle factors"

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. North-east England.

"To have consultants who had more time to listen and who offered complementary therapies as well as conventional treatment" [Also filed under 'Alternative therapies'.]

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Hypothyroidism. South-west England.

20. Continuity of care

"Always seeing the same people for appointments."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. Asthma shoulder joint tendon tears. East Anglia.

"There are lots of improvements since I started with RA 19 years ago. I am so fed up of telling the same story to different people in different departments and the amount of notes that must overlap."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Bronchiectasis and hypertension. East Midlands.

"consistency - always seeing someone who knows your case and therefore knows what your issues are both personal and directly related to your RA"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Greater London.

"Less turnover of RA doctors whom I see when not actually seen by my consultant. These are Drs who are on rotation."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. North-west England.

"I would like to see the same specialist as seeing a different one each time results in nothing being changed or new treatments being tried. I feel that boxes are just being ticked."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. North-west England.

"more permanent staff"

Male. 75 or older. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-central England.

"Consistency of nurse/consultant specialist"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. South-west England.

"Constantly changing medics. (not good for continuity for both patient and Dr)."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. hypothyroidism, fibromyalgia, IBS, patulous eustachian tube (PET). superior semi circular canal dehiscence syndrome. Yorkshire and the Humber.

"Continuity is essential for the wellbeing of Arthritis sufferers, in my opinion."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Only Osteo arthritis. Yorkshire and the Humber.

"After stopping with drug treatments I have had no follow up with any medical srvcies."

Male. 45-54. Diagnosed. 10 years or more. RA currently stable. Psoriasis. Yorkshire and the Humber.

"Contnuity and the ability for patients to have copies of all their medical notes - so that they have control and can take the relevant hand held note to appointments - often when attending appointments notes have been missed off or sent to the wrong depts especially when care is provided at different hospitals." [Also filed under 'Better record keeping'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Underactive Thyroid, Asthma, Fibromyalgia. North-east England.

"I would stop rotation of house men who only know about standard picture of RA. Each one I meet I have to start explaining my own idiosyncrasies. It is so much easier if I see the same person each time who knows me, my history and if I say I feel worse takes me seriously."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. vasculitis. South-east England.

"change the consultation period with medical professionals so that it is patient led and not appointment led. I have waited ages to see the consultant and had a progressive worsening of my joints while waiting for an apointment. and have also been feeling well enough at times NOT to have to see a doctor or for a junior doctor who doesnt know me ask a whole barrel of questions that I have already answered." [Also filed under 'Faster and easier access to secondary care'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. West Midlands.

"Continuity of care."

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Underactive Thyroid. Yorkshire and the Humber.

"Continuity of care. It's difficult I know because professionals move but it's such a nuisance to have to recount symptoms and treatment at each GP/hospital visit."

Male. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Heart murmurs; hypertension; irregular heartbeat. Yorkshire and the Humber.

21. More information/education (general, or on particular subjects)

"I would like information to be more readily available"

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. High Blood Pressure over active thyroid. East Anglia.

"More education for people on how to treat people with RA."

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. pernicious anaemia psoriasis. East Midlands.

"Being informed of all the services that i can access as after 13yrs i still only know of the hosp and GP.Didnt know about any of the other services you have mentioned in this survey."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. liver cirrosis due to taking methotrexate for my RA. Greater London.

"more understanding and infomation on excersise and any special diet i might need"

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-west England.

"More information about available recent advances in treatment. Can one with RA be totally pain free for any real length of time?"

Male. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Yorkshire and the Humber.

"Tell patients what's available more often as I have no idea of any of the help I can have apart from to see my Orthopedic Surgeon, GP and Rheumatoid Specialist."

Female. 25-34. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. Trouble walking, underwent double hip and double knee replacement surgery between March 2006 - March 2007. Constant pain in arms/elbows/shoulders. Trouble with ankles and fingers. North-east England.

"someone to talk to about help and where to get it."

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. i hav a lung condition osteoporsis osteoarthritis diverticulus. North-west England.

"The ancillary services that are available as outlined in this survey being made noticeably available. A leaflet outlining the different treatments that are available would be useful" [Also filed under 'Alternative therapies'.]

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. North-west England.

"Someone to tell you what what support there is and what you're entitled to at the point you are diagnosed. It seems that you have to know what's out there and ask for it before anyone can help you. Initially, you have no idea."

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. South-central England.

"More information about what treatments or help are available (in addition to medication)."

Female. 54-59. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. South-east England.

"More information. For example, I did not know there was such a thing as specialist rheumatology nurses until recently."

Male. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Depression/anxiety. South-east England.

"Giving more advice on other alternatives - diet, help with staying at work." [Also filed under 'More work-oriented help for people with RA'.]

Female. 25-34. Diagnosed. 10 years or more. RA NOT currently stable. Psoriasis. South-east England.

"easier access to info"

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. sjergons syndrom. South-west England.

"Access to help with benefits as I feel I have had to fight to get any money and to have had to prove I have RA to the same people on several occasions. If information about benefits and services was available from person/place, it would make life easier. I have had RA for three years and still do not really know what money/services I am entitled to and where I should go to get these." [Also filed under 'Other financial assistance'.]

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Sjorgrens Syndrome. West Midlands.

21. More information/education (general, or on particular subjects) [Continued]

"I am currently trying to get pregnant and feel there is not enough support and information provided I feel there could be alot more help and support"

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Yorkshire and the Humber.

22. Care should be based at primary-care level (particularly for reasons of patient convenience)

"Unless I need RA advice that my GP cannot answer my 3monthly appointment should be with my GP.
Reason: travel / distance"

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. East Midlands.

"If blood tests could be taken at any doctors surgery ie those near to a place of work and not always at a hospital or own GP surgery it would make life a lot easier." [Also filed under 'Employment issues'.]

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. East Midlands.

"In my case the only suggestion would be for my GP to give the steroid injections when required at my local surgery instead of a trip to the hospital."

Male. 65-74. Diagnosed. 3 months or more, but less than 6 months. RA currently stable. South-central England.

"the ability to have regular blood tests at local doctors surgery, instead of having to make the 20-mile trip to the hospital every 3 months"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. South-central England.

"the GP should be more responsible for our care instead of passing me over to the clinic all the time"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. South-east England.

"A better support network based through the GPs surgery as in diabetes treatment."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. South-east England.

"Having one individual nurse who could advise you locally maybe at my GP practice on symptom management etc on top of just the annual 5 minute appointment with my specialist and then managing on your own the rest of the time."

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. 10 years or more. Raynaud's syndrome. South-east England.

"Someone at my GPs practice I could turn to who knew how I feel. they are an excellent practice but I feel a little let down by my treatment."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Underactive thyroid gland Gastritis Acid reflux disease oesophagitis. West Midlands.

"The fact that once diagnosed the care becomes poor. The GP would be a more useful person to be able to consult as consultants are hard to see and often not very sympathetic. (as is mine!)"

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. fibromyalgia. West Midlands.

"For it to be better recognised and more help from GP surgeries"

Female. 60-64. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. depressive illness. East Anglia.

"Easy access to GP based RA trained nurses for general advice." [Also filed under 'Access to a dedicated nurse specialist'.]

Male. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. spondylosis. East Anglia.

"For my GP to offer cortisone injections when and if I do get a flare up. On two occasions my knees have been so inflamed and needing aspiration and steroid injections and in the early stages of my RA I did feel rather scared and did not know quite who to contact. When I asked my GP if he could do this he said no because the knee joints were too big."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Under active Thyroid. South-east England.

"More frequent contact with GP between consultant appointments, I frequently feel unsupported and forgotten."

Male. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Yorkshire and the Humber.

"The one thing I would change is to have a GP in every surgery that is a specialist in auto immune diseases as I think RA would be too small a field. I think this the missing link that lets me and other down a lot."

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. I have a form of Inflammatory Bowel disease that has been difficult to diagnose. Yorkshire and the Humber.

23. Other financial assistance [including Disability Living Allowance (DLA) issues]

"financial help because although my ra is a lot better i am still very limited to do any work outside of the home as i tire very easily and find it difficult to stay on my feet for long ."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-central England.

"Dissapointed with the Powers to be on benifits (The Govenment) Cannot claim Mobility allowance as i am over 65 (Ageism)"

65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Breathlessness and walking due to medication has destroyed nerve endings in feet and legs. West Midlands.

"There should be a refined pathway to avoid the journey i went on as like i say if i had a full time job at the time i would have with no doubt had to have given up my home as i wouldn't have been able to have afforded to continued with my mortgage having been off sick for so long. I wouldn't have been able to claim any benefits either as there was no diagnosis. " [Also filed under 'Employment issues' and 'Faster and easier access to secondary care'.]

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. West Midlands.

"Use expert systems for categorising reports for DLA and pension providers to speed up the system"

Male. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. psoriasis. Yorkshire and the Humber.

"Better understanding from benefits agencies about the disabling daily fluctuations in movement and pain. I have had to wait 9 months to be offered a course by the hospital on how to cope with RA. It would have been a greater benifit to have the information as soon as diagnosed."

Male. 45-54. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. Underactive thyroid, High blood pressure. East Midlands.

"If i could change anything, it would be to have more emotional support with dealing with all the life changes & also more financial advice. Also more information about what can be done & options available." [Also filed under 'Other services: counselling'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Fibromyalgia, IBS. North-west England.

"More financial help"

Male. 25-34. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. North-west England.

"A LOT MORE SUPPORT, FINANCIAL ASSISTANCE AND UNDERSTANDING OF THE CONDITION."

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Cervical Myelopathy Osteoporosis Hypertension. South-east England.

"There is no support for people who work part time with RA. Financially worse off because of the RA but there is no financial support from the government. Unfortunately, the hospital can advise but if the policy isn't in place then nothing can be done." [Also filed under 'More work-oriented help for people with RA'.]

Female. 25-34. Diagnosed. 10 years or more. RA NOT currently stable. Fibromyalgia. West Midlands.

"Access to help with benefits as I feel I have had to fight to get any money and to have had to prove I have RA to the same people on several occasions. If information about benefits and services was available from person/place, it would make life easier. I have had RA for three years and still do not really know what money/services I am entitled to and where I should go to get these." [Also filed under 'More information/education (general)'.]

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Sjorgrens Syndrome. West Midlands.

"A POSITIVE change in the DLA questionnaire."

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. fybromyalgia, hypertension, depression. West Midlands.

"Should be given automatically the high rate DLA if unable to work. The people who assess the claims do not understand the fatigue and flu like systems that can make you unable to do things even though you are virtually able to do them."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Yorkshire and the Humber.

"CAN SOMEBODY INFORM THE DEPARTMENT OF WORK AND PENSIONS THAT THEY ARE NOT MEDICALLY QUALIFIED TO MAKE DECISIONS ABOUT BENEFITS AND SHOULD LISTEN TO DOCTORS/CONSULTANTS."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. kidney disease(due to treatment for RA) IBS. Yorkshire and the Humber.

23. Other financial assistance [including Disability Living Allowance (DLA) issues] [Continued]

"HELP AND UNDERSTANDING WITH EMPLOYMENT. I SPENT YEATS AFTER DIAGNOSIS HAVING TO WORK IN A LOW PAID JOB PART TIME AS I COULD NO LONGER CONTINUE WITH MY PREVIOUS CAREER. RECENTLY I WAS MEDICALLY RETIRED FROM THIS JOB AND AM NOW LIVING IN POVERTY ON INCAPACITY BENEFIT. I AM UNABLE TO ADEQUATELY HEAT MY HOME AND AM WRITING THIS WRAPPED IN BLANKETS WITH A HOT WATER BOTTLE. IT IS TRUE THAT RA DOES NOT KILL YOU BUT CAN TAKE YOUR LIFE! ROLL ON SUMMER!" [Also filed under 'More work-oriented help for people with RA'.]

Female. 45-54. 10 years or more. BRONCHIECTASIS AND ASTHMA. South-west England.

24. Hydrotherapy

"To offer more therapies like hydro therapy and heat therapy."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. pernicious anaemia. East Anglia.

"Hydrotherapy and exercise sessions regularly."

Female. 65-74. Diagnosed. 10 years or more. RA currently stable. East Midlands.

"I would have liked hydrotherapy much earlier and would like to go more often than once a fortnight"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Crohns disease, high blood pressure. Greater London.

"More hydrotherapy pools- hydrotherapy is so relaxing, so good for feelings of well-being and pain reduction but there aren't enough of them. And the "learner'pools at leisure centres aren't the same-they aren't warm enough!"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. spinal stenosis, chloroquin retinopathy, side effects of a partial gastrectomy. Greater London.

"hydrotherapy"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. North-east England.

"There wuld be more availability of hydrotherapy."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. only hayfever!. South-east England.

"More hydrotherapy and in local area. Out of house 2 - 3 hours to have half an hour self help. I know people with RA that aew too disabled to attend self help. There get no hydrotherapy. Hydro service, once excellent, now hardly exists."

Female. 65-74. Diagnosed. 10 years or more. RA currently stable. South-west England.

"Hydrotherapy for all in proper pools with trained staff."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Lack of mobility. West Midlands.

"Hydrotherapy services available locally"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. High blood pressure High Cholestoral Clinical depression Osteoporosis. Yorkshire and the Humber.

"More access to things like Hydro therapy/use of warm water swimming pools to exercise in, more help with diet and exercise."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. East Midlands.

"I would allocate swimming as a treatment and give arthritics access to local health clubs which have heated pools, which they can access."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. joint replacements. North-west England.

"I would like to have better access to a hydrotherapy pool and I think there should be a standard set of gentle workouts or exercises tailored to each patient to keep our muscles and joints moving. I think we should be allowed to have choice of the new drugs especially if one does not work or there are bad side effects we should be able to try another one."

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. South-east England.

"hydro therapy pools to be available for all RA patitients particularly in the early stages and to be available regularly there after .Water is the best place for excercise but many many hospital pools have been closed .I AM SURE MORE PEOPLE WOULD BENIFIT AND HAVE LESS PAIN AND BE ABLE TO WORK ." [Also filed under 'Employment issues' .]

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. Polio as a child my right arm is virtually parylised , late effects of polio this causes more problems with my spine neck and arm . Ulcerative colitis my type of RA is aparently due to this .Asthma,. South-west England.

25. More work-oriented help for people with RA

"More advice on working life with RA." [Also filed under 'More information/education from medical professionals'.]

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. No other illness. North-west England.

"More occupational therapy"

Female. 54-59. Diagnosed. A year or more, but less than 2 years. RA currently stable. Depression. West Midlands.

"I really like there to be more help in supporting people back into work. I have found this very difficult to find and have not got the confidence to do it by myself as my last 3 jobs have not worked out due to the affect they had on my arthritis. Job trials were a good idea but have been discontinued."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. East Anglia.

"Help keep people like me to remain in work"

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. South-west England.

"More help for those people who stay in work as I have (part time)."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. South-west England.

"My wish to work overseas but limitations due to visits to the hospital / clinic for treatment."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Yorkshire and the Humber.

All I want is to be able to continue with my career as a teacher. However, increasingly over the last 6 years the RA has damaged my joints to the extent that most things in my daily life are now difficult to complete. Use of DMARDS earlier in my diagnosis might have prevented some of this damage." [Also filed under 'Access to the best medication'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Coeliacs. East Anglia.

"MORE PROTECTION - INCLUDEING EMPLOYMENTS RIGHTS - DDA ACT"

Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. bronchitis asthma. North-west England.

"More help and support should be given to enable people with RA to stay in employment. Employees must be forced to work with the employee and OT to achieve the best outcome for everyone. Immediate treatment should be available, not having to wait 6-8 weeks, as in my case to receive treatments to enable me to function somewhat normally." [Also filed under 'Faster and easier access to secondary care'.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"The Consultant has to view my situation from a medical perspective. I know that my symptoms will be brought under control but in the meantime while I'm searching for work it would make a huge difference if a steroid injection into knees could be made available during interview period. While I understand I cannot have steroid injections on demand it may be the difference between obtaining employment or not. I'm sure the RA will be brought under control but I am very anxious to get back into work having spent over a year at home." [Also filed under 'Access to the best medication/choice of treatment'.]

Female. 60-64. Diagnosed. 10 years or more. RA NOT currently stable. South-east England.

"Giving more advice on other alternatives - diet, help with staying at work." [Also filed under 'More information/education (general)'.]

Female. 25-34. Diagnosed. 10 years or more. RA NOT currently stable. Psoriasis. South-east England.

"There is no support for people who work part time with RA. Financially worse off because of the RA but there is no financial support from the government. Unfortunately, the hospital can advise but if the policy isn't in place then nothing can be done." [Also filed under 'Other financial assistance'.]

Female. 25-34. Diagnosed. 10 years or more. RA NOT currently stable. Fibromyalgia. West Midlands.

"HELP AND UNDERSTANDING WITH EMPLOYMENT. I SPENT YEARS AFTER DIAGNOSIS HAVING TO WORK IN A LOW PAID JOB PART TIME AS I COULD NO LONGER CONTINUE WITH MY PREVIOUS CAREER. RECENTLY I WAS MEDICALLY RETIRED FROM THIS JOB AND AM NOW LIVING IN POVERTY ON INCAPACITY BENEFIT. I AM UNABLE TO ADEQUATELY HEAT MY HOME AND AM WRITING THIS WRAPPED IN BLANKETS WITH A HOT WATER BOTTLE. IT IS TRUE THAT RA DOES NOT KILL YOU BUT CAN TAKE YOUR LIFE! ROLL ON SUMMER!" [Also filed under 'Other financial assistance'.]

Female. 45-54. 10 years or more. BRONCHIECTASIS AND ASTHMA. South-west England.

26. Multiple points

"I would like my consultant to be more understanding and give me more information on my RA, I only see my consultant every 6 months to a year and at these appointments always seemed to be rushed and I get the feeling that he does not care, therefore I do not really benefit from the appointments. I feel that my RA is just about managed but I am sure that I could benefit from other treatments that have not been offered. To be honest I feel rather disappointed in the NHS at present."

[Could be filed under 'More information/education from medical professionals', 'Better doctor-patient relationship required', 'More frequent consultations', 'Greater length of time in the consulting room', and 'Access to the best medication/choice of treatment'.]

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. East Midlands.

"A more multi disciplinary approach to my care and my ability to work. No one seems to worry about the financial implication that this condition has on personal resources. Also as the NHS does not monitor closely the attendance of their employees, this is not true of the private sector. The NHS appear to think that taking time off work is not a problem, when in fact it is and can cause hardship to sufferers."

[Could be filed under 'Integrated services', and 'Other financial assistance'.]

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-west England.

"A centre for all treatments/therapies and support (including financial support) both practical and emotional. I felt very alone and frightened having been diagnosed with Fibromyalgia, then RA and possibly Psoriasis Ankylosing Spondylitis as well. I am unsure if I have both arthritis conditions, I know I have RA, but was told treatment is the same for both so don't worry!"

[Could be filed under 'Integrated services', 'Other services: counselling', and 'More information/education from medical professionals'.]

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Diabetes Type 2 Hypertension. Yorkshire and the Humber.

"Referrals between departments and quality of administration is generally poor. Just sending a letter from one dept to another in the same hospital can take 8 weeks! The delay is not only dangerous to the patient it shows a level of inefficiency which defies belief. A new system should be identified - why can't a 10 word email suffice. Patient has problem with x joint in foot, can you examine her with a view to surgery - see attached file." Counselling should be offered to any individual diagnosed with an illness of this type, incurable, high levels of pain and likelihood of disability especially when under the age of 35. The medical profession needs to stop reaching for the antidepressants, if I'm in pain and tired it is natural for me to be a bit down in the dumps - stop offering to cover the symptoms with yet another chemical. I want to work full time, I have a very busy job and taking time out for continual appointments which always have to be in my working day is frustrating. Surely it's in the economy's best interest and therefore in the best interest of the Govt and NHS to provide early morning or evening (up to 8pm) and Saturday appointments. Every service industry has to react to the needs and wants of their customers the NHS is no different. Prescriptions also need improving. Have joined up hospital appointments so instead of me going to the hospital 10 times a year, let me go twice but spend all day being prodded and poked."

[Could be filed under 'Better communication among medical professionals', 'Other services: counselling', 'Services scheduled outside working hours', and 'Employment issues'.]

Female. 25-34. Diagnosed. 10 years or more. RA NOT currently stable. None other than reductions in mobility caused by RA.. East Anglia.

"More information ' more help with aids 'the shops that sell aids charge very high prices' free prescriptions i have spent a small fortune over the years on drugs 'more help lines for people who suffer Ra as it can cut you off from so many activities. even the family shopping can be a real hardship. More awareness that it's not only old people who suffer but young people too"

[Could be filed under 'More information/education from medical professionals', 'Exemption from prescription charges', and 'Better awareness of the condition: among the public'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. East Midlands.

26. Multiple points [Continued 1]

"HELP ! Hydro physio and occupational support are vital but not available. A consultant who knows you and is available and pills that are available including co proxamol for pain relief are also vital but not there for you. This is not cost effective as I could ahve bene a more valuable person in society if all this was available."

[Could be filed under 'Other services: hydrotherapy', 'Other services: physiotherapy', 'More work-oriented help for people with RA', 'Continuity of care', and 'Access to the best medication'.]

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. loads of allergies brought on by drugs. Two oral diseases, stomach problems due to drugs. Food allergies and problems with eating. East Midlands.

"need more drugs that help not the cheap dmards that make you feel ill, everyone with severe arthritis should have a change to give biological drugs a go not just the post code lottery we are told first line dmards stop the process of the disease getting worse thats not true i have deformatites after 12 months of the disease and i have been on 2 dmards methrexate and sulphazazine there has only been a small improvement and make consultants more excessable we ave to wait months and months to see them and every med change its another 6 months to ssee if it works"

[Could be filed under 'Better access to biological drugs', 'A consistent national approach to treatment and care', 'Faster and easier access to secondary care', 'Medication to be changed more quickly if it does not appear to be working'.]

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. blood pressure. East Midlands.

"A recognition by government and those providing care that RA affects EVERY aspect of your life, all the time, every day, and as such patients need ongoing help. The equivalent of a Macmillan nurse would be brilliant - I wish!"

[Could be filed under 'Better awareness of the condition: among the public', 'More information/education from medical professionals', 'Access to a dedicated nurse specialist'.]

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Hypothyroidism. Greater London.

"I can only add that the system should be created in such a way that patents feel there is always someone to talk to when help is needed. Also they should be informed about any news regarding the new treatments and other ways of fighting with RA than just drugs."

[Could be filed under 'Access to a dedicated nurse specialist', 'More information/education from medical professionals', 'Alternative therapies'.]

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Greater London.

"more physiotheraphy and regular exercise classes includind hydrotherapy,by experienced RA physiotherapists. A chance to meet with nurse specialists at a drop in centre. A weekly injection clinic that would take referrals from consultants and nurse specialists."

[Could be filed under 'Alternative therapies', 'Access to a dedicated nurse specialist', and 'Faster and easier access to secondary care'.]

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. West Midlands.

"Please let all patients have a fair crack at the new drugs if they are needed and all Doctors and consultants should co-ordinate more to aid the patient with problems like drug interactions etc which I personally have been badly affected by and it's very difficult. Most importantly scrap the postcode drug lottery - make drugs available to all, or to none at all."

[Could be filed under 'A consistent national approach to treatment and care', 'Better communication among medical professionals', and 'Access to the best medication/choice of treatment'.]

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. type 1 diabetes. Osteo arthritis colitis, severe tinnitus. West Midlands.

26. Multiple points [Continued 2]

"Faster appointment referral system. I don't think my hands and feet would be in such a mess if referral had been quicker. Spent months having to build up my muscles to get walking again. Also the referral to podiatrist for a second assessment was only offered after I told consultant I was having great difficulty in obtaining comfortable footwear. Even Clarks and Echo and several other footwear shops were non starters. I don't think the hospital give enough opportunity for patients to pick up medications such as methotrexate injections. Glad I don't work as it would be impossible."

[Could be filed under 'Faster and easier access to secondary care', 'Other services: podiatry', 'Other services: orthotics', and 'More patient-friendly methods of supplying prescribed drugs'.]

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Depression and Social anxiety disorder. Also Irritable bowel syndrome.

"More consultants so you are not stuck with a clinic once a week, manned telephone helplines in clinics that are available for advice during office hours. Don't pigeon hole patients we do not all feel the same way and do not all respond to drugs in the same way. But most of all listen to what they have to say, they know their bodies better than you do, Make disability living allowance easier to apply for and remember there is currently no cure for RA."

[Could be filed under 'More rheumatologists', 'Faster and easier access to secondary care', 'Better doctor-patient relationship required', and 'Other financial assistance'.]

27. More rheumatologists [A category closely linked in theme to 'Faster and easier access to secondary care']

"More rheumatologists."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Hypothyroidism, factor V Leiden heterozygote clotting condition, and cardiac arrhythmias. East Anglia.

"More consultants, as always long wait to see, in months, and consultants always tired through overwork"

Male. 54-59. Diagnosed. 10 years or more. RA currently stable. Diabetes, Depression. North-west England.

"More RA consultants waiting time to book is 6 months plus."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. South-east England.

"Train MORE Consultants, choose among the best and brightest medical graduates and train them to the highest level, sparing no expense. It would be cheaper for the State in the long run."

Female. 75 or older. Diagnosed. 10 years or more. RA currently stable. South-east England.

"The local hospital appointing a consultant full time instead of being part of a general surgical team with other responsibilities"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. high blood pressure. Yorkshire and the Humber.

"More Consultants are needed in my local Clinic as I mentioned above, that would be a big help for starters!"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. I also have Fibromyalgia. East Midlands.

"More staff in the department, so one would be more likely to access services."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Osteoporosis. North-west England.

"To ensure that adequate and consistent is available to ensure that there is a permanent, adequately staffed Rheumatology team who can advise quickly when things take a downturn."

Male. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Additional medical problems: Arachnoiditis causing Spastic Paraplegia; Epilepsy; Asthma; Sjögrens Syndrome; Blood-clotting problems; HypoThyroid; Depression. South-east England.

"More specialist staff who know what they are dealing with."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. South-east England.

"More Doctors or help for them so everyone could be seen when they need to be with out delay"

Female. 25-34. Diagnosed. 6 months or more, but less than a year. nothing wrong prior. RA NOT currently stable. South-west England.

"Increase the number of consultants."

I am an informal carer for someone with RA. Female. 65-74. Diagnosed. 10 years or more. The RA is NOT currently stable. Peripheral Vascular Disease Pneumo Fibrosis Damaged heart muscle. North-west England.

"I would like the Rheumatology department to be well staffed so that I can relax knowing that any problems will be dealt with quickly. At present I feel very much alone embarking on another form of treatment."

Female. 65-74. One month or more, but less than 3 months. South-east England.

28. More self-help/patient support groups

"Perhaps a support group within each PCT would help."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. East Anglia.

"More self help groups."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. East Anglia.

"local support group"

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. glaucoma. East Midlands.

"Every Rheumatology Department of every hospital should have a patient support group and patient 'experts' who could be at the end of a telephone for anyone newly diagnosed."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Greater London.

"more support group service"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. asthma. North-east England.

"I would definatly like the option of an organisation providing local support for patients. Where we can meet others in the same age range or situation and share experiences and tips to cope. More education for none sufferers and friends and family, empoyers etc would be a god send as i am sick of comments about it just being stiffness when i live with agony every day. Thank you for conducting this survey and letting us have a voice."

Female. 25-34. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. East Midlands.

"I feel that a more integrated approach is needed that should included working with any existing or in the establishment of 'self-help' groups. Education is important as RA can affect anyone and is not just an old persons complaint and also the condition should not continue to be the butt of comedians jokes!" [Also filed under 'Better awareness of the condition: among the public'.]

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"local support groups, i'm a member of an online forum which is very helpfull but it would be good to be able to speak face to face with others who RA or care for people with RA, especially parents as raising a family when you have RA has many differculties and support groups could offer much needed help and advice on daily life issues."

Female. 25-34. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. under active thyroid which is controlled by medication. South-east England.

"more patient support groups in my area"

Female. 45-54. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. pernicious anaemia, asthma. South-east England.

"provision of support groups specifically for my age group - there are lots of support for juvenile arthritis, and arthritis in the elderly, nothing for the 20 - 50 age range - please help"

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. lupus, epilepsy and hughes syndrome. South-east England.

"A local support group, perhaps run by the local hospital, with talks from local specialist and service providers."

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. High Blood Pressure. Yorkshire and the Humber.

"With patients' consent, I would have found it very helpful to be put in touch (eg via consultants) with other RA patients with similar conditions - to be able to compare symptoms/treatments. Also if potential drawbacks to a particular medication were being explained it would have been helpful to have been able talk to someone who had decided to proceed with it." [Also filed under 'Other services: counselling'.]

Male. 54-59. 2 years or more, but less than 5 years. South-east England.

29. Being treated holistically [A similar category to 'Better doctor-patient relationship required', 'Better communication among medical professionals', and 'Integrated services'.]

"More treatment of the whole package ie. physical and mental."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. East Anglia.

"support services to be more tailored and regular eg mind and body"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. diabetes stroke bi polar. East Anglia.

"More holistic and personal treatment - RA affects all areas of healthcare. And in Norfolk we desperately need psychological help to be available. I chair an RA patients' group, and the stories I hear would make you weep."

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Sjrogens, associated with the RA. East Anglia.

"For the hospital rheumatologist/GP to see one holistically."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Bronchiectasis and hypertension. East Midlands.

"With RA there is tendency to have other conditions as well. You may attend different hospitals with these conditions but there is no way of being able to tie everything up and treat you holistically instead of in little pieces...why isn't there a way of all hospitals/agencies having the same info and access to xrays and notes?"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Osteoporosis Pulmonary vasculitis. Greater London.

"A more wholistic approach to care with time to 'know' the patient & effects of the Ra on lifestyle"

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. gastric ulcer as a side effect of drugs SVT. Greater London.

"Care is compartmentalised too much and should be more holistic (i.e. taking into account my diagnosis of psoriatic arthritis + depression as well)."

Male. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. psoriatic arthritis + R.A. + benign prostate hypertrophy + clinical depression + asthma. Greater London.

"To be looked at as a Whole person. My spinal stenosis limits my movement, and has done for the last 15 years, but is not taken into account by my RA professionals"

Female. 54-59. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Spinal Stenosis, stress incontinence. South-central England.

"I would like to my problems with RA to be viewed holistically, so as I received a "joined up " approach to my treatment and needs."

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Asthma. Lichen planus. South-east England.

"More treatment for the patient as an individual rather than having to follow a set path of medication and care for all. Everyone has different needs and each person is different in the way they are able to deal with their RA." [Also filed under 'Better doctor-patient relationship required'.]

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Hypothyroidism Osteoarthritis in knees. Yorkshire and the Humber.

"look at the patient as a whole - as mentioned before be pro-active not re-active. better medication advice/ dietary alternatives etc" [Also filed under 'More information/education from medical professionals'.]

I am an informal carer for someone with RA. Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. The RA is NOT currently stable. Greater London.

30. Better understanding among rheumatologists of the patients' predicament

"Ensure that every hospital had a lead rheumatologist who knew what they were doing and were caring and that they worked on the premise that when a GP referred a patient to them, the GP had serious concerns."

Male. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. East Anglia.

"More training for surgeons on living with RA. (It seems to be the younger 'crop' who are less sympathetic.)"

54-59. Diagnosed. 10 years or more. RA currently stable. East Anglia.

"Consultants (both new and Old) to sit in a class with patients who have RA so they can gain more of an understanding on an emotional level."

Female. 25-34. Diagnosed. 10 years or more. RA currently stable. East Midlands.

"Doctors with more of an understanding of what arthritis is and that the pain is often hidden"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. High blood pressure and diabetes. East Midlands.

"Medical professionals having a better understanding of the seriousness of the effects of long-term pain and lack of mobility."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Hypothyroidism. Greater London.

"The attitude of rheumatologists that just because they at that moment aren't seeing what you are like at your worst, assume that, as you have had to rest and prepare yourself for your is a typical day, and that they don't see you as a whole, just as a bunch of symptoms"

Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Fibromyalgia. North-east England.

"Student doctors should be taught more thoroughly about the many varied symptoms caused by RA. My main consultant understands all my symptoms but many of his 'team' of junior doctors don't recognise many of the symptoms I show."

Male. 35-44. Diagnosed. 10 years or more. RA currently stable. Anaemia and possibly mild asthma. South-east England.

"There is a total lack of understanding and support of living with R.A within the NHS. There needs to be more education about this devastating disease to all medical professionals and the impact it has not only on a physical level but also emotionally." [Duplicated under 'GPs should be more knowledgeable about RA']

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-west England.

"Understand my condition" [Duplicated under 'GPs should be more knowledgeable about RA']

45-54. Diagnosed. 10 years or more. RA currently stable. Hayfever, Rhinitis. South-west England.

"Consultants could try to care for their patients."

I am an informal carer for someone with RA. Female. 75 or older. 10 years or more. The RA is currently stable. South-central England.

"one to one care by my consultant who hasn't a clue how much pain I suffer daily"

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. COPD. Yorkshire and the Humber.

31. Other services: helpline

"An advice service for flare-ups/ acute episodes, I don't want to always be on at my GP, he is however very very good and we have many phone consultations, especially if he has received blood test results which need addressing."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. East Anglia.

"a dedicated helpline with a specialist nurse whom can give advice and support during working hours 7 days a week"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. hypertension and hypothyroid and some possible osteoporosis. North-west England.

"Help line for specialist nurses (for flare-up, or general advice) should be available more than just 1 hour a day."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. No other illness. North-west England.

"Better support out of appointment times - I've never been given the RA nurse telephone number or told how best I can use them. Sometimes you just need to ask a simple question to gain massive reassurance!"

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. South-east England.

"Access to a hotline/support service please!"

Female. 45-54. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. Hypothyroidism secondary to treatment for Hyperthyroidism. Osteoporosis. East Anglia.

"RA helpline with sensible, sympathetic staff (not a national version through NHS Direct)"

Female. Diagnosed. 6 months or more, but less than a year. RA NOT currently stable. East Anglia.

"Ongoing support from a specialist nurse /helpline at the rheumatology clinic"

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Osteoporosis, Osteoarthritis (cervical osteophytes). Greater London.

"you need a help line to the hospital when you are having a flare up,so that you can be seen by a special nurse at that time instead of having to wait in agony and also the new drugs that are available" [Also filed under 'Access to a dedicated nurse specialist' .]

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Right Hip replacment,waiting for a left hip replacment. North-west England.

"Have a 'helpline' available for advice and support!"

Female. 65-74. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. High Blood Pressure, High Cholesterol, totally blocked left carotid artery, osteo arthritis of right knee, South-west England.

"more people on helplines to ask about symptoms and if they are related to RA"

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Yorkshire and the Humber.

32. Appointments scheduled more conveniently for patients (including outside working hours)

[A category related to 'Employment issues']

"More support meetings allocated for RA sufferers in employment. Support meetings are currently held during working hours which are difficult for employed people to attend." [Also filed under 'Employment issues'.]

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. raynauds & connective tissue disease. Greater London.

"Working patients clinics, early, late or over lunch. RA involves so much time off work with the disease anyway appointments push it over the acceptable limit."

Female. 35-44. Diagnosed. 10 years or more. RA currently stable. North-west England.

"the attitude of my RA sprcialist nurse,the appointment system cancellations whcih means have to adjust my work rota."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Menieres Have had depression. South-central England.

"Hospital staffs attitude - if they were more supportive (especially the RA nurses) i would feel more inclinde to seek help and support for them if making appointments which were at a more convient time i would get less stressed about trying to meet all my appointments."

Female. 16 to 24. Diagnosed. A year or more, but less than 2 years. RA currently stable. Yorkshire and the Humber.

"To have more access out of hours for people who work. ie GP appointments, Blood Test appointments, GP appointments when you have a flare - the gp recognises and puts you in for an appt asap." [Also filed under 'Employment issues' and 'Faster referral by GPs to rheumatologists'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Bronciectisis. North-west England.

"Now I am older it is not so relevant but managing appointments so people of around the same age come at the same time, or at least some of the same age."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. I have recently been diagnosed with Lupus and am currently seeing a doctor at St Thomas' Lupus Clinic in addition to my RA Consultant. South-east England.

"Easier access, ie opening times, parking, appointments at more worker friendly times."

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. Alopecia Hypothyroidism. South-east England.

33. Better awareness of the condition: among employers

"More awareness overall, especially among employers."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. Back injury. East Midlands.

"To ensure that employers have a better understanding of the difficulties of finding a suitable drug regime and hence allowing time for this to happen"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Ulcerative Colitis (have ileo-anal pouch) and psoriasis. West Midlands.

"Employers required to provide support or at least not be able to make conditions so difficult that RA sufferers are bullied into leaving work."

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Lipodermatosclerosis. West Midlands.

"Workplaces and all other people should be educated about its effects on peoples lives."

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. West Midlands.

"more understanding by employers"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. diabetes,high blood presure,incontinace,cracked knee cap,endiomitrosuse,, East Midlands.

"an understanding that we don't always look ill, but could be in a lot of pain, it is embarrassing to remind people that just because you are able to make it to work does not mean you are not having problems." [Also filed under 'Better awareness of the condition: among the public'.]

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. micro bacterium xenopi (long term non tuberculous chest infection). North-east England.

"I wish services at home would be increased and emplyers would listen more and understand the struggle and pain" [Also filed under 'Other support'.]

Female. 35-44. 5 years or more, but less than 10 years. I have mobility problems due to RA. East Midlands.

34. Better understanding of RA among other medical professionals

"Doctors with more of an understanding of what arthritis is and that the pain is often hidden"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. High blood pressure and diabetes. East Midlands.

"Medical professionals having a better understanding of the seriousness of the effects of long-term pain and lack of mobility."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Hypothyroidism. Greater London.

"Student doctors should be taught more thoroughly about the many varied symptoms caused by RA. My main consultant understands all my symptoms but many of his 'team' of junior doctors don't recognise many of the symptoms I show."

Male. 35-44. Diagnosed. 10 years or more. RA currently stable. Anaemia and possibly mild asthma. South-east England.

"There is a total lack of understanding and support of living with R.A within the NHS. There needs to be more education about this devastating disease to all medical professionals and the impact it has not only on a physical level but also emotionally." [Also filed under 'GPs should be more knowledgeable about RA']

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-west England.

"Understand my condition" [Duplicated under 'GPs should be more knowledgeable about RA']

45-54. Diagnosed. 10 years or more. RA currently stable. Hayfever, Rhinitis. South-west England.

"Better awareness of RA needs among other NHS staff."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Asthma Sjogren's Syndrome.

"I would like a deeper understanding of RA in other health professionals. I found this particularly lacking from junior members of staff when I had my youngest child. Having been taken into maternity unit at a weekend whilst in labour and when "my team" were on leave, the duty Dr's and midwives did not know/understand my needs and inability to do certain things - was even told by one junior dr that I had a very low pain threshold!!!"

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. High Blood Pressure, Heart Murmur. West Midlands.

35. Not having to fight for treatment, care or support [To a certain extent, this category is interchangeable with many others.]

"A pro-active support system. Applies to the area in which I live."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Hypothyroidism, factor V Leiden heterozygote clotting condition, and cardiac arrhythmias. East Anglia.

"I have been a member on the RA forum for some time now and it just amazes me that the people on there get so much support from there gp's specialist etc maybe there is a problem where i live in resorcesses but I do feel cheated some times."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. High Blood pressure. North-west England.

"A proactive service with all treatments and therapies open for easy access on the NHS."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. raised blood pressure.. South-east England.

"Sort the GPs receptionists out! They are not 'experts' in anything and shouldn't Lord it over us!!! (not all are bad though!)"

Female. 45-54. Diagnosed. One month or more, but less than 3 months. RA currently stable. West Midlands.

"Have each Rheumatology centre in the country equipped as a one stop shop (as in how XXXX Hospital operate) but ALSO include a link to social services in the mix to give patients clear, simple access to benefits or support they are entitled to without a battle and interminable waiting periods." [Also filed under 'Integrated services'.]

Female. 35-44. Diagnosed. 10 years or more. RA NOT currently stable. West Midlands.

36. Financial assistance for heating

"I strongly feel that people with RA whose condition feels worse in the cold weather should receive some help with heating (not just those on income support as now). I've had this painful condition all my life and the cost of heating is a continual worry. Please can the government do something for people such as myself whose condition is permanent for life."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. Stomach ulcer / acid reflux / irritable bowel. East Anglia.

"RA patients should get winter fuel allowance, to enable them to keep warm in cold months."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. East Anglia.

"help with heating cost."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. South-west England.

"Any one with RA will be payed to move to a warm country because it helps and in the long run it would be cheaper on the nhs. Only a suggestion lol"

Male. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Diabetic Osteoporosis. North-west England.

37. Shorter waiting times for other services

"Shorter waiting times to see physiotherapist, occupational therapist, podiatrist etc."

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. fibromyalgia, sciatica, high blood pressure, tinnitus. East Midlands.

"That departments are better inter-related. Excellent and almost instant treatment from RA dept. but when referred to another dept. eg. physio, hydrotherapy, dermatology, etc. a patient can wait up to 6 mths for an appointment which can defeat the efforts made by the RA dept."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. Underactive Thyroid. South-west England.

"quick referral to emotional and occupational therapy support services - it was over 6 months after diagnosis before appointments came through"

I am an informal carer for someone with RA. Male. 54-59. Diagnosed. 2 years or more, but less than 5 years. The RA is NOT currently stable. West Midlands.

"The system falls down when there is a need to access other departments such as orthopedic specialists or surgery- then the waiting times are far too long"

Female. 54-59. 5 years or more, but less than 10 years. Hypertension, dry eye. Diagnosed. North-west England.

38. Other services: podiatry

"More information about podiatry." [Also filed under 'More information/education from medical professionals']

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. East Anglia.

"Podiatry -because I have diabetes and don't see one for that either."

Female. 65-74. Diagnosed. 6 months or more, but less than a year. RA currently stable. diabetes type 2. North-east England.

"At present I have to pay £25 a treatment to a private podiatrist as I am unable to reach to look after my feet, I feel that should be provided by the NHS, although I can afford it at the moment the time will come when I cannot pay and I'm sure there are a lot of people in the same position."

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. Depression. South-central England.

"Access to podiatry very quickly when flare ups occur."

Female. 65-74. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Osteoarthritis. Yorkshire and the Humber.

39. Care should be based at secondary-care level

"Could I please deal with the hospitals for treatment and NOT the GPs. You are at the mercy of Office Managers at the GPs and of rules that change with the weather. It is not a happy state to be in."

Male. 60-64. Diagnosed. 6 months or more, but less than a year. RA currently stable. Osteo Arthritis and stomach acid problems (omaprezole). East Midlands.

"I would like my treatment to be exclusively administered by the RA Specialist because there have been several times that my GP has withheld my prescriptions because blood tests were not received on time. The GP is more concerned with their bureaucratic procedures than with my requirement for medication. The GP does not understand RA and should not be involved in my treatment."

Male. 60-64. Diagnosed. 10 years or more. RA currently stable. Greater London.

"I would still rather have my monitoring carried out at the hospital rather than the DMARD Clinic. All drugs should be available to everyone."

Female. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. North-east England.

40. Car parking facilities

"Car parking can be a problem when you are attending the clinic."

Male. 45-54. Diagnosed. 10 years or more. RA currently stable. North-west England.

"easy and free parking for RA patients"

Male. 65-74. Diagnosed. 10 years or more. RA currently stable. take drug for blood pressure problem. South-east England.

"Free car parking at hospitals"

Male. 60-64. Diagnosed. 10 years or more. RA currently stable. Apart from obvious joint damage, notably severe in right knee, other major problem is pulmonary fibrosis.. West Midlands.

41. Other services: orthotics

"Orthotics."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. mild asthma; gastric problems from years of NSAIDS. Yorkshire and the Humber.

"Shoes. As my feet are now misshapen I have shoes made. Why can't shoes be made like you can buy in the shops. Like soft stretchy trainers with wonderful thick spongy soles. Or slightly more fashionable styles. I came down with RA at age 40. I wanted shoes that were comfortable but didn't look as those they were made for 80 year olds."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Greater London.

"If I could change one thing, I would like easier access to the nicer splints available on the market. I have a vast range of splints I wear most of the time and they are not the most attractive accessories."

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. South-central England.

42. Other support and understanding.

"Understanding that RA has many many debilitating problems, which, can cause other problems on top of those already experienced by the patient.Help for husband/wife/children when they maybe working and still need to care for their family."

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Asthma, Food allergies, intestinal spasms. South-west England.

"Support - there needs to be far better support with a multi agency/specialist co-ordination of services." [Also filed under 'Integrated services'.]

Female. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Chronic fatigue, Chronic pain syndrome. South-west England.

"I wish services at home would be increased and emplyers would listen more and understand the struggle and pain" [Also filed under 'Better awareness of the condition: among employers'.]

Female. 35-44. 5 years or more, but less than 10 years. I have mobility problems due to RA. East Midlands.

43. Better awareness of the condition: among PCTs

"Tackle the disconnect between PCT's and humanity. They have no consideration whatsoever for what RA does to the person physically and mentally. It's all about the numbers."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. Greater London.

"PCT's to follow Consultants treatment recommendations and fund them."

I am a person with rheumatoid arthritis (RA). Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Acquired brain injury resulting in cognitive deficits, Dysphasia, Diabetes Type 1, Hypothyroidism.. North-west England.

44. Better quality of rheumatologists

"A better path to diagnosis. I was referred immediately to a rheumatologist but he didn't give me any investigations at all and just blamed my problems on flexibility of my joints. This delayed my diagnosis by nearly two years and had a profound affect on my quality of life and my ability to work."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Fibromyalgia Joint Hypermobility Secondary Sjogrens Syndrome Vertigo. South-east England.

"My RA consultant we need people who care about us and our concerns and not people who seem to hate there jobs and us"

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. deaf in left ear. East Anglia.

45. Better RA services in rural locations

"improvement of RA services through the NHS in rural areas."

Female. 45-54. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. North-east England.

"shorter waiting lists to see a consultant. I was referred in April and did not see a Rheumatologist until Mid August by which time I was unable to work due to RA symptoms. I live in a rural area and we have a visiting consultant from another hospital in a main town, I believe this lengthens waiting list times." [Also filed under 'Faster and easier access to secondary care' and 'Employment issues'.]

Female. 45-54. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. multiple cerebral aneurysms (three surgically treated four low risk aneurysms being monitored). High blood pressure under control with medication. North-east England.

46. Better record keeping

"Better monitoring of blood results. I was left to write them up myself and I don't know what they mean."

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. South-west England.

"Continuity and the ability for patients to have copies of all their medical notes - so that they have control and can take the relevant hand held note to appointments - often when attending appointments notes have been missed off or sent to the wrong depts especially when care is provided at different hospitals." [Also filed under 'Continuity of care'.]

Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. Underactive Thyroid, Asthma, Fibromyalgia. North-east England.

47. Blood tests should consider the possibility of RA, and should be early

"That the RA factor should be included in all blood tests for people suffering from joint pain and swelling."

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Non Alcoholic fatty liver disease. East Midlands.

"early blood tests so treatments could start early if GPsays its nothing to worry about people wont go back and keep moaning they SHOULD."

Female. 60-64. Diagnosed. 10 years or more. RA currently stable. osteoporosis blood pressure copd. East Midlands.

48. Financial assistance for household adaptations

"The Council to be more helpful. I could not get a grant from the council to convert my bath into a shower even though I have slipped in the bath many times. I was penalised because I am in work."
Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. High blood pressure. Greater London.

"Someone should be available to check your home and suggest and where necessary adapt for easier living. This is so basic that it would mean more people could stay out of hospital, in work and have a much better quality of life. The effort involved in just day to day living in a bad environment is very debilitating."
Female. 65-74. Diagnosed. 10 years or more. RA currently stable. I have a floppy mitral valve. I also take omeprazole to calm my stomach. South-central England.

49. More opportunity for patient self-management

"more ability for patients to be involved in their own care. would like access to blood results for example (on computer?)."
Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

"More information about the scale of seriousness, so that I can understand where I am in relation to the population of sufferers. So that I can measure for myself, how serious my condition is." [Also filed under 'More information/education from medical professionals'.]
Male. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. North-west England.

50. Working conditions that are more suitable for people with RA

"Visiting specialists who check on the employers treatment of disabled people generally and report direct to the NHS & social services. Actually this is insulting also; there are many, many things that could be changed."
Male. 45-54. Diagnosed. 10 years or more. RA currently stable. Vasculitis. South-east England.

"work i have problems at work when i take time off due to ra"
Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-west England.

51. Other services: physiotherapy

"More access to physiotherapy, because helps me with my mobility."
Male. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. osteoarthritis. South-east England.

"Access to long term physiotherapy"
Female. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. South-west England.

52. Extension of statutory sick pay

"for the NHS to allow for extra sick days not the standard 6 months full pay then 6 months half pay. Oh and we should not be paying for prescriptions as i ended up paying £20.00 a month with the chopping and changing of drugs from the consultant to settle my condition. R/A is an expensive condition."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. hiatus hernia I.B.S. North-east England.

53. Increased blood testing facilities

"With regard to regular blood tests, to avoid having to spend hours in a queue, I have to leave home at 6.20 a.m. to join the queue for a 7 a.m. start. The centre I attend only carried out 15 blood tests per day and therefore I cannot afford to go any later."

Female. 54-59. Diagnosed. 10 years or more. RA currently stable. Greater London.

54. More information for parents of affected children

"I think there should be a better way of explaining to children what is happening to them. And there should be more understanding if they are confused or do not want to undergo the treatments."

Female. 16 to 24. Diagnosed. 10 years or more. RA is currently stable. I have osteoporosis which has caused my tibia to break. South-east England.

55. More patient-friendly methods of supplying repeat prescriptions.

"Better access to prescriptions. Currently I place a repeat prescription almost every week as the 4 drugs I take every day come in different quantities and they won't allow me to order more than a week in advance of them running out. They also make regular mistakes with doses. Last week I received 5mg tablets which is double my normal dose. It's very upsetting when your mobility is restricted with RA."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

56. More research required into RA treatments during pregnancy

"I would like to see more research done on RA and pregnancy - there is very little at the moment on best drug treatment for coping with RA during pregnancy and nobody knows how safe biological drugs really are. Some research in US shows that it is safe and it is even been successfully used in treating infertility (caused by over protective immune system of the woman), but no such study exist in UK."

Female. 35-44. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. Greater London.

57. Other services: access to wheelchair

"To supply electric wheelchair sooner."

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. South-east England.

58. Other services: chiropractic

"would like access to chiropractor as part of treatment to relieve pain"

Female. 60-64. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. North-west England.

59. Other services: exercise facilities

"easier access to exercise classes."

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-central England.

60. Patient involvement in decision-making in RA services

"To have much more patient involvement in both the strategic and the routine development of services, including an involvement in the provision of information to sufferers."

Male. 54-59. Diagnosed. 10 years or more. RA currently stable. West Midlands.

61. Repriveve hospital closure plans

"Scrap the "picture of health" plans to reduce capacity at XXXXX, Sidcup; travelling to any alternative hospital is very significantly less convenient"

Male. 54-59. Diagnosed. 10 years or more. RA currently stable. osteoarthritis; back problem following slipped disc. Greater London.

62. Other

"Dont start me!!!! I cant pick one!!! Things need to be in my control - from drug delivery (all the company is interested in is making money from taxes not my needs) and the blood testing / monitoring system is appalling at XXX."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. high blood pressure. Greater London.

"Access to having fun. My RA and lack of care means that my carepackage is not enough to go out more often and have some fun"

Male. 60-64. Diagnosed. 10 years or more. RA currently stable. no but my ra has made me serverly disabled. North-east England.

"Go back to treating it as a blood disease"

Male. 75 or older. Diagnosed. 10 years or more. RA currently stable. Heart Failure. North-west England.

"Everthing"

Female. 35-44. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-east England.

"enable those who use the NHS to see the same specialist as I do by going private"

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

"If money is spent at the earlier stages of RA, it saves money in the long run."

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. East Midlands.

"more localised advertised support"

Female. 45-54. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. West Midlands.

"more help from the hospital"

Male. 45-54. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. East Anglia.

"The whole NHS."

Male. 25-34. Diagnosed. 5 years or more, but less than 10 years. RA NOT currently stable. Ankylosing spondilitis. East Midlands.

"When I was told I had the condition I was offered no support or help. I live on my own and had to cope with all the pain and disability without any help or support"

Female. 54-59. Diagnosed. Less than a month. RA NOT currently stable. East Midlands.

"Someone being interested in my welfare (apart from my wife)"

Male. 45-54. Diagnosed. 10 years or more. RA NOT currently stable. North-west England.

"Access to someone when things get very bad. Who could make an urgent appointment for you if thing are going wrong"

Female. 45-54. Diagnosed. 2 years or more, but less than 5 years. RA NOT currently stable. diabetes, ashma, throid, bechets. South-east England.

63. The ultimate goal: wellness

"I would like to be well!!!"

Female, 45-54. Diagnosed. 10 years or more. RA currently stable. systemic Lupus - with the symptoms that occur, e.g. Rayauds, joint pain, alopecia, skin problems etc. Greater London.

"Less time spent hanging about waiting for appointments! The longer I spend in hospital the more it highlights the fact that I have something wrong with me. I want to spend minimal time waiting in clinics and maximum time focussing on getting on with my life as best as possible!"

Female, 45-54. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. South-east England.

"It could be cured. To know if you can pass it on to children. Less toxic drugs..... (sorry more than one)"

Female, 25-34. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. 1 chest infection this year - otherwise good health. South-east England.

"Get on with finding a cure!"

Female, 45-54. Diagnosed. . 2 years or more, but less than 5 years. RA NOT currently stable Oainful swollen joints and tiredness.. North-west England.

"The lack of a cure."

I am an informal carer for someone with RA. Male, 45-54. Diagnosed. 10 years or more. The RA is NOT currently stable. insulin dependant Diabetes type2, hypertension,.. North-west England.

64. Respondents diagnosed before current medication was available

"Was diagnosed in 1986 and I wish that I could have gone onto TNF treatment earlier. Was not available at the time. Hence wouldn't have 'twisted' hand & feet."

Female, 60-64. Diagnosed. 10 years or more. RA currently stable. South-central England.

"I have had RA for 31years and experienced depression linked to pain and disability. It would have helped if depression and treatments/therapies were included in consultations" [Also filed under 'Other services: counselling'.]

Female, 54-59. Diagnosed. 10 years or more. RA NOT currently stable. Depression. South-east England.

65. Satisfied with existing care and services

"None really, excellent service by all staff at the hospital and at my local GP,s"

Female. 35-44. Diagnosed. A year or more, but less than 2 years. RA currently stable. South-west England.

"Nothing XXXX have an excellent team"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. I also have Psoriatic Arthritis. South-east England.

"On the whole I get good care at my hospital and I find injecting myself weekly very good hope it lasts !!!"

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. South-east England.

"I can't think of anything that would apply to me. I was very satisfied with my treatment."

Female. 54-59. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Greater London.

"Nothing."

Male. 65-74. Diagnosed. 10 years or more. RA currently stable. Angina. Greater London.

"It has been really good for me!"

Female. 25-34. Diagnosed. 2 years or more, but less than 5 years. RA currently stable. Greater London.

"I am very pleased with my current service"

Female. 45-54. Diagnosed. A year or more, but less than 2 years. RA currently stable. Ra related Back problems & operation in 2004 due to walking incorrectly before 2 x TKR in 1999 High BP related to RA drugs. Greater London.

"I'm happy with the treatment I get from the hospital. In fairness to my GP I don't bother them so at this time it would be wrong of me to complain about anything"

Female. 54-59. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. I do suffer with panic attacks. East Anglia.

"am quite happy as it is"

Female. 45-54. Diagnosed. 10 years or more. RA currently stable. underactive thyroid. Yorkshire and the Humber.

"Nothing. My support has been brilliant, and I have always been provided with great support."

Male. 60-64. Diagnosed. 5 years or more, but less than 10 years. RA currently stable. Yorkshire and the Humber.

"Very satisfied"

Male. 54-59. Diagnosed. A year or more, but less than 2 years. RA NOT currently stable. Systemic lupus erythematosus. North-west England.

"Since my correct diagnosis I have been very lucky to have an excellent rheumatology team."

Female. 45-54. Diagnosed. 3 months or more, but less than 6 months. RA NOT currently stable. West Midlands.

"I think to-day the RA services are second to none my team are fantastic and feel they all deserve a medal for putting up with me."

Female. 54-59. Diagnosed. 10 years or more. RA NOT currently stable. joints replaced are as follows: both knees full replacements, both hands MCP joints replaced x2, fused thumbs, pinned wrists, feet both MCP joints nippedx2 fused big toe's surgery again in December08. Walking very difficult, writing very poor etc. West Midlands.

