MANCHESTER 1824
The University of Manchester

British Society for Rheumatology

Rheumatoid Arthritis Register

Your views on your illness, treatment and general health and how this impacts on your life

We are interested in your views about your illness, treatment and general health. We know that people may respond differently to the same treatment for a number of reasons. We are particularly interested in seeing if these differences can be explained by how a person perceives their illness and treatment.

This booklet contains a series of questionnaires.
Please try to answer every question in the booklet.
There are no right or wrong answers.

If you have any questions or queries about this booklet, please contact:

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The illness you are being treated for in the Rheumatology Department is "your illness" we refer to throughout this booklet

QUESTIONNAIRE A: Your views about your illness

Here are a number of symptoms that you may or may not have experienced.

A1 Please tick in either the "Yes" or "No" box as to whether you have experienced any of the symptoms listed **SINCE your illness** and if so whether you believe the symptom to be related to **your illness** or not.

	SINCE my illness		RELATED to my illness	
	Yes	No	Yes	No
Pain	☐	☐	☐	☐
Sore Throat	☐	☐	☐	☐
Nausea	☐	☐	☐	☐
Breathlessness	☐	☐	☐	☐
Weight Loss	☐	☐	☐	☐
Fatigue	☐	☐	☐	☐
Stiff Joints	☐	☐	☐	☐
Sore Eyes	☐	☐	☐	☐
Wheeziness	☐	☐	☐	☐
Headaches	☐	☐	☐	☐
Upset Stomach	☐	☐	☐	☐
Sleep Difficulties	☐	☐	☐	☐
Dizziness	☐	☐	☐	☐
Loss of Strength	☐	☐	☐	☐

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
A2	My illness will last a short time	☐	☐	☐	☐	☐
A3	My illness is likely to be permanent rather than temporary	☐	☐	☐	☐	☐
A4	My illness will last for a long time	☐	☐	☐	☐	☐
A5	This illness will pass quickly	☐	☐	☐	☐	☐
A6	I expect to have this illness for the rest of my life	☐	☐	☐	☐	☐

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
A7	My illness is a serious condition	☐	☐	☐	☐	☐
A8	My illness has major consequences on my life	☐	☐	☐	☐	☐
A9	My illness does not have much effect on my life	☐	☐	☐	☐	☐
A10	My illness strongly affects the way others see me	☐	☐	☐	☐	☐
A11	My illness has serious financial consequences	☐	☐	☐	☐	☐
A12	My illness causes difficulties for those who are close to me	☐	☐	☐	☐	☐
A13	There is a lot which I can do to control my symptoms	☐	☐	☐	☐	☐
A14	What I do can determine whether my illness gets better or worse	☐	☐	☐	☐	☐
A15	The course of my illness depends on me	☐	☐	☐	☐	☐
A16	Nothing I do will affect my illness	☐	☐	☐	☐	☐
A17	I have the power to influence my illness	☐	☐	☐	☐	☐
A18	My actions will have no affect on the outcome of my illness	☐	☐	☐	☐	☐
A19	My illness will improve in time	☐	☐	☐	☐	☐
A20	There is very little that can be done to improve my illness	☐	☐	☐	☐	☐
A21	My treatment will be effective in curing my illness	☐	☐	☐	☐	☐
A22	Negative effects of my illness can be prevented/avoided by my treatment	☐	☐	☐	☐	☐
A23	My treatment can control my illness	☐	☐	☐	☐	☐
A24	There is nothing which can help my condition	☐	☐	☐	☐	☐
A25	The symptoms of my condition are puzzling to me	☐	☐	☐	☐	☐
A26	My illness is a mystery to me	☐	☐	☐	☐	☐
A27	I don't understand my illness	☐	☐	☐	☐	☐
A28	My illness doesn't make any sense to me	☐	☐	☐	☐	☐
A29	I have a clear picture or understanding of my condition	☐	☐	☐	☐	☐
A30	The symptoms of my illness change a great deal from day to day	☐	☐	☐	☐	☐
A31	My symptoms come and go in cycles	☐	☐	☐	☐	☐

QUESTIONNAIRE A: Your views about your illness (continued)

		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
A32	My illness is very unpredictable	☐	☐	☐	☐	☐
A33	I go through cycles in which my illness gets better and worse	☐	☐	☐	☐	☐
A34	I get depressed when I think about my illness	☐	☐	☐	☐	☐
A35	When I think about my illness I get upset	☐	☐	☐	☐	☐
A36	My illness makes me feel angry	☐	☐	☐	☐	☐
A37	My illness does not worry me	☐	☐	☐	☐	☐
A38	Having this illness makes me feel anxious	☐	☐	☐	☐	☐
A39	My RA makes me feel afraid	☐	☐	☐	☐	☐

QUESTIONNAIRE B: How you cope with your illness

We are interested in your own personal views of how you cope with your current illness.
Here are some different statements that people have made describing how they personally cope with their illness. For each statement, please could you indicate how often you adopt the particular approach.

		Not used	Used a little	Used somewhat	Used a great deal
B1	I diverted attention away from my arthritis by thinking about other things or engaging in some activity	☐	☐	☐	☐
B2	I tried to see my arthritis in a different light that made it more bearable	☐	☐	☐	☐
B3	I thought about solutions to handle my arthritis	☐	☐	☐	☐
B4	I gathered information	☐	☐	☐	☐
B5	I actually did something to handle my arthritis	☐	☐	☐	☐
B6	I expressed emotions to my arthritis to reduce tension, anxiety or frustration	☐	☐	☐	☐
B7	I accepted the fact that the arthritis was there, but that nothing could be done	☐	☐	☐	☐
B8	I sought or found emotional support from loved ones or friends	☐	☐	☐	☐
B9	I sought help or advice from professionals	☐	☐	☐	☐
B10	I did something with the explicit intention of relaxing	☐	☐	☐	☐
B11	I sought or found spiritual comfort	☐	☐	☐	☐

QUESTIONNAIRE C : How you have felt in the PAST WEEK

We are interested in how you have been feeling recently.

Read each item and tick the relevant box to the reply that comes closest to how you have been feeling in the **PAST WEEK**. Your immediate response to each item will probably be more accurate than a long thought out response.

C1 I feel tense or 'wound up'

Most of the time	☐	From time to time, occasionally	☐
A lot of the time	☐	Not at all	☐

C2 I still enjoy the things I used to enjoy

Definitely as much	☐	Only a little	☐
Not quite as much	☐	Hardly at all	☐

C3 I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly	☐	A little, but it doesn't worry me	☐
Yes, but not too badly	☐	Not at all	☐

C4 I can laugh and see the funny side of things

As much as I always could	☐	Definitely not so much now	☐
Not quite as much now	☐	Not at all	☐

C5 Worrying thoughts go through my mind

A great deal of the time	☐	From time to time, but not too often	☐
A lot of the time	☐	Only occasionally	☐

C6 I feel cheerful

Not at all	☐	Sometimes	☐
Not too often	☐	Most of the time	☐

C7 I can sit at ease and feel relaxed

Definitely	☐	Not often	☐
Usually	☐	Not at all	☐

QUESTIONNAIRE C: How you have felt in the PAST WEEK (continued)

C8 I feel as if I am slowed down

- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

C9 I get a sort of frightened feeling like 'butterflies' in the stomach

- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

C10 I have lost interest in my appearance

- Definitely ☐
- I don't take as much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

C11 I feel restless as I have to be on the move

- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

C12 I look forward with enjoyment to things

- As much as I ever did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

C13 I get sudden feelings of panic

- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

C14 I can enjoy a good book or radio or TV programme

- Often ☐
- Sometimes ☐
- Not often ☐
- Very seldom ☐

QUESTIONNAIRE A: Your views about your rheumatoid arthritis

Your rheumatoid arthritis is "your illness" we refer to in this questionnaire

For the following questions, please circle the number that best corresponds to your views:

A1 How much does your illness affect your life?

0 1 2 3 4 5 6 7 8 9 10

no affect at all — severely affects my life

A2 How long do you think your illness will continue?

0 1 2 3 4 5 6 7 8 9 10

a very short time — forever

A3 How much control do you feel you have over your illness?

0 1 2 3 4 5 6 7 8 9 10

absolutely no control — extreme amount of control

A4 How much do you think your treatment can help your illness?

0 1 2 3 4 5 6 7 8 9 10

not at all — extremely helpful

A5 How much do you experience symptoms from your illness?

0 1 2 3 4 5 6 7 8 9 10

no symptoms at all — many severe symptoms

A6 How concerned are you about your illness?

0 1 2 3 4 5 6 7 8 9 10

not at all concerned — extremely concerned

A7 How well do you feel you understand your illness?

0 1 2 3 4 5 6 7 8 9 10

don't understand at all — understand very clearly

A8 How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0 1 2 3 4 5 6 7 8 9 10

not at all affected emotionally — extremely affected emotionally

A9 Please list in rank-order the three most important factors that you believe caused your illness. *The most important causes for me:-*

1. _____

2. _____

3. _____

QUESTIONNAIRE B: Your views about your medication (I)

It is possible that you sometimes do not take your arthritis medication or that you yourself decided to change your dose because of various reasons (not because your rheumatologist told you to stop taking or to change the dose).

We would like to know for each of the following statements if it never, rarely, sometimes, often or very often happened in the last 6 months.

During the last six months	Never	Rarely	Sometimes	Often	Very often
B1 I altered the dose of my arthritis medication	❍	❍	❍	❍	❍
B2 I forgot to use my arthritis medication	❍	❍	❍	❍	❍
B3 I stopped taking my arthritis medication for a while	❍	❍	❍	❍	❍
B4 I decided to miss out on a dose of my arthritis medication	❍	❍	❍	❍	❍
B5 I took less arthritis medication than instructed	❍	❍	❍	❍	❍

QUESTIONNAIRE ~~D~~C: Your views about your medication ~~(I)~~ (II)

Here you will find a list of statements made by patients with a rheumatic disease.

Please indicate for each statement how far you agree by ticking the appropriate box that reflects your opinion best. It is important you complete all the items listed.

	Don't agree at all	Don't agree	Agree	Agree very much
~~D~~C1 If the rheumatologists tells me to take the medicines, I do so	☐	☐	☐	☐
~~D~~C2 I take my anti-rheumatic medicines because I then have fewer problems	☐	☐	☐	☐
~~D~~C3 I definitely don't dare to miss my anti-rheumatic medications	☐	☐	☐	☐
~~D~~C4 If I can help myself with alternative therapies, I prefer that to what my rheumatologist prescribes	☐	☐	☐	☐
~~D~~C5 My medicines are always stored in the same place, and that's why I don't forget them	☐	☐	☐	☐

QUESTIONNAIRE C: Your views about your medication (II) (continued)

		Don't agree at all	Don't agree	Agree	Agree very much
~~D~~C6	I take my medicines because I have complete confidence in my rheumatologist	☐	☐	☐	☐
~~D~~C7	The most important reason to take my anti-rheumatic medicines is that I can still do what I want to do	☐	☐	☐	☐
~~D~~C8	I don't like to take medicines. If I can do without them, I will	☐	☐	☐	☐
~~D~~C9	When I am on holiday, it sometimes happens that I don't take my medicines/miss my appointment for my medicines	☐	☐	☐	☐
~~D~~C10	I take my anti-rheumatic drugs, for otherwise what's the point of consulting a rheumatologist?	☐	☐	☐	☐
~~D~~C11	I don't expect miracles from my anti-rheumatic medicines	☐	☐	☐	☐
~~D~~C12	If you can't stand the medicines you might say: "throw it away, no matter what"	☐	☐	☐	☐
~~D~~C13	If I don't take my anti-rheumatic medicines regularly, the inflammation returns	☐	☐	☐	☐
~~D~~C14	If I don't take my anti-rheumatic medicines, my body warns me	☐	☐	☐	☐
~~D~~C15	My health goes above anything else and if I have to take medicines to keep well, I will	☐	☐	☐	☐
~~D~~C16	I use a dose organiser or some other way to remember my medicines	☐	☐	☐	☐
~~D~~C17	What the doctor tells me, I hang on to	☐	☐	☐	☐
~~D~~C18	If I don't take my anti-rheumatic medicines, I have more complaints	☐	☐	☐	☐
~~D~~C19	It happens every now and then, I go out for the weekend and then I don't take my medicines/miss my appointment for my medicines	☐	☐	☐	☐

QUESTIONNAIRE ~~E~~D: Your views about your medication ~~(II)~~ (III)

We would like to ask you about your personal views about ~~your~~ medicines prescribed ~~to~~ for you.

These are statements other people have made about their medicines.

~~Please indicate for each statement how far you agree by ticking the appropriate box that reflects your opinion best. It is important you complete all the items listed.~~

Please indicate the extent to which you agree or disagree with them by ticking the appropriate box.

There are no right or wrong answers. We are interested in your personal views.

		Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
~~E~~D1	My health, at present, depends on my anti-rheumatic medicines	☐	☐	☐	☐	☐
~~E~~D2	Having to take anti-rheumatic medicines worries me	☐	☐	☐	☐	☐
~~E~~D3	My life would be impossible without anti-rheumatic medicines	☐	☐	☐	☐	☐
~~E~~D4	Without my anti-rheumatic medicines I would be very ill	☐	☐	☐	☐	☐
~~E~~D5	I sometimes worry about long-term effects of my anti-rheumatic medicines	☐	☐	☐	☐	☐
~~E~~D6	My anti-rheumatic medicines are a mystery to me	☐	☐	☐	☐	☐
~~E~~D7	My health in the future will depend on my anti-rheumatic medicines	☐	☐	☐	☐	☐
~~E~~D8	My anti-rheumatic medicines disrupt my life	☐	☐	☐	☐	☐
~~E~~D9	I sometimes worry about becoming too dependent on my anti-rheumatic medicines	☐	☐	☐	☐	☐
~~E~~D10	My anti-rheumatic medicines protect me from becoming worse	☐	☐	☐	☐	☐

We would like to thank you

for completing this booklet of questionnaires.

Your contribution is much appreciated.

Please return the completed booklet in the pre-paid envelope provided.
You do not need to use a stamp.

British Society for Rheumatology

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