

Treatment preferences in rheumatoid arthritis prevention

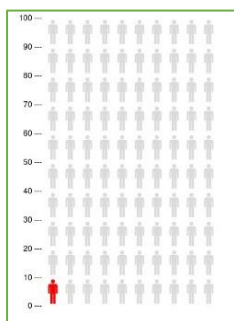


Why is this important to read?

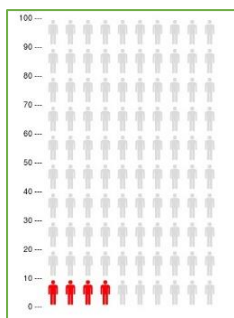


This a summary of the results of a survey we conducted to find out how people at risk of developing rheumatoid arthritis feel about preventive treatments. It tells you why we did the research, how we did the research, the main findings and implications as well as how you can find out more.

Rheumatoid arthritis (RA) is a long term condition that mainly affects the joints, it causes pain, swelling, stiffness and often also causes fatigue. If patients are not treated the joints can suffer permanent damage, which can lead to disability. Having RA may further lead to other conditions such as inflammation of other areas of the body including in the lungs, heart and eyes. Treatment of RA is usually required in the long term and is associated with potentially serious side effects.



RA is fairly common. Out of every 100 members of the general public, one person will develop RA as illustrated by the single red figure in this picture. The 99 uncoloured figures represent people who will not develop rheumatoid arthritis.



However, some people are at an increased risk of developing RA. For example, first degree relatives (FDRs) of RA patients have a slightly higher risk. Out of every 100 people who have a parent or sibling with RA, four will develop RA at some point in their life, as illustrated by the four red figures in this picture. The 96 uncoloured

figures represent people with a parent or sibling with RA who will not develop it. There is a lot of interest in the idea of treating people who are at an increased risk of RA *before* the diagnosis of RA, to reduce their risk of developing this serious condition. Several trials of preventive treatments like this have been completed or are currently ongoing.

But would a person who is at risk of RA want to take a preventive treatment? It is important to understand what kinds of treatment would be preferred by people who are at risk of RA. If we can find out which features of treatments are valued and which are disliked, this information can focus the development of preventive treatments on those treatments that are acceptable to people at risk of RA.



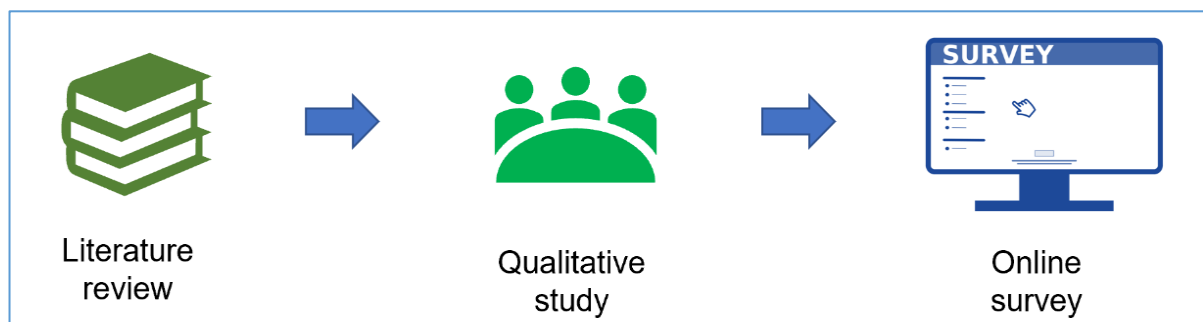
Studies of treatment preferences look at the importance people place in different features (*'attributes'*) of a treatment when they make choices about whether or not to take a treatment, or when they chose between different treatments. These features include things like side-effects, effectiveness, and how the treatment is taken. These studies also look at the extent to which people make trade-offs between these treatment features. How would you weigh up the risk of serious but rare side-effects such as cancer with the benefit of a significant reduction in your chance of developing RA? In addition, preference studies can look at the extent to which preferences for a treatment vary across different people (*'preference heterogeneity'*).

There are several ways to do research on treatment preferences. Thus, in addition to studying the preferences of people at risk of RA for preventive treatments, our study also compared two different procedures to study treatment preferences to inform future studies like this.

How did we do this research?



This research was conducted in several phases. The research team gathered information on treatment features important for RA treatment choices through a review of results of previous RA treatment preference studies (*'literature review'*). They also spoke to groups of people to identify factors that would be most important to first degree relatives and the general population if they were making a decision about whether to take preventative treatment for RA (*'qualitative study'*). The results from literature review and the qualitative study were then used to guide the design of a study to assess people's preferences for preventive RA treatment which took the form of an *online survey*.

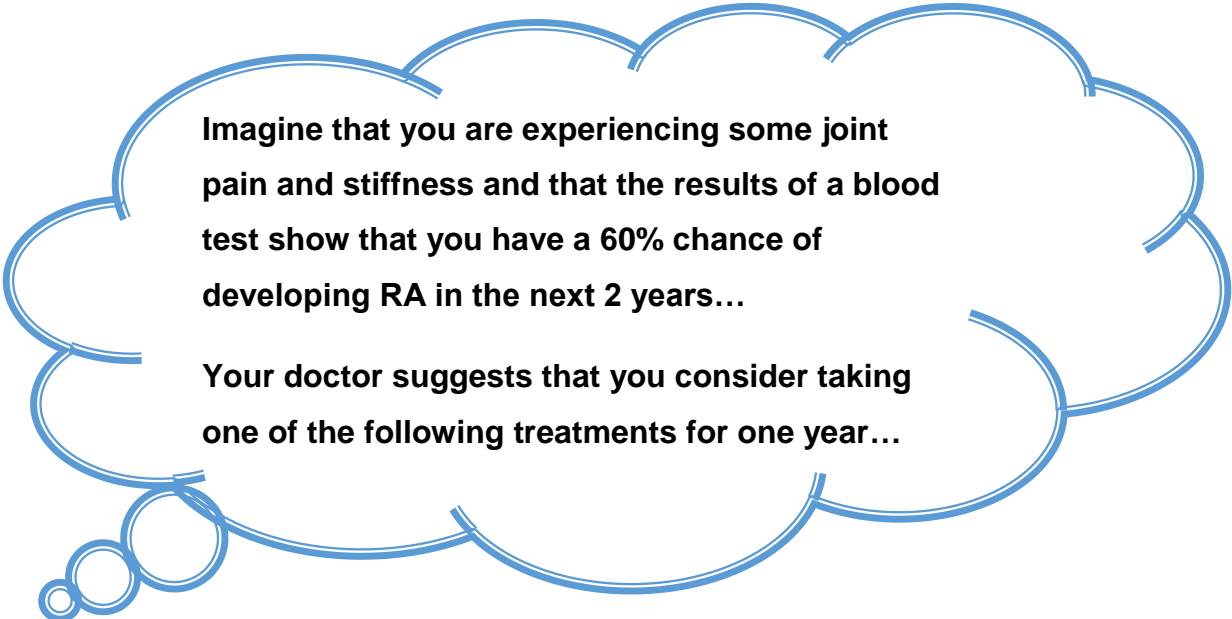


The information gathered from the literature review, the qualitative study and further consultation with rheumatologists and patient research partners resulted in the inclusion of six treatment features (*attributes*) in the survey, which are described in the table on page 4. The levels refer to the ways that a particular attribute can vary across different treatments. For example, the way you take the medication could be as a tablet, via an injection or a drip in the vein.

Overview of possible treatment features

Treatment features	Levels
Chance of developing RA reduced from 60% to	10%; 20%; 30%; 40%
How the treatment is taken	A shallow injection under the skin A drip into the vein One or two tablets
How often the medication needs to be taken	Daily Weekly Monthly Every 6 months
Chance of mild side effects (e.g. low level of constant nausea)	2%; 5%; 10%
Chance of a serious infection due to the treatment (e.g. pneumonia)	0%; 1%; 5%
Chance of a serious side effect that is potentially irreversible (e.g. blood cancer)	1 in 100,000 people 20 in 100,000 people 100 in 100,000 people

Participants were asked to imagine the following scenario:



Imagine that you are experiencing some joint pain and stiffness and that the results of a blood test show that you have a 60% chance of developing RA in the next 2 years...

Your doctor suggests that you consider taking one of the following treatments for one year...

They were then asked to make a number of choices between different types of treatment, or they could choose not to take any treatment.

The survey included two different sets of treatment choice tasks (*preference elicitation exercises*): Discrete Choice Experiment and Probabilistic Threshold Technique respectively. An example choice task is given below.




Example choice task:

Your doctor suggests that you consider taking one of the following treatments for one year.

In this case, would you prefer treatment A, treatment B or no treatment?

	Treatment A	Treatment B	No Treatment
Chance of developing RA is reduced from 60% to	20% (20 in 100 people)	10% (10 in 100 people)	60% (60 in 100 people)
How the treatment is taken	A drip into the vein	One or two tablets	-
How often the medication has to be taken	Monthly	Weekly	-
Chance of mild side effects	5% (5 in 100 people)	2% (2 in 100 people)	None (0 in 100 people)
Chance of a serious infection due to treatment	5% (5 in 100 people)	1% (1 in 100 people)	None (0 in 100 people)
Chance of a serious side effect	0.1% (100 in 100,000 people)	0.001% (1 in 100,000 people)	None (0 in 100,000 people)
I would prefer:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>




In addition to completing a series of choice tasks like the one above, participants also answered questions to assess personal characteristics such as age, gender, employment status, attitudes towards taking medication in general, how well they usually someone understand written health information (health literacy) and numerical information (numeracy), and their beliefs about RA. Participants were also asked to rate what they perceived their own risk of developing RA to be.

The survey was conducted in three different countries, namely the UK , Germany  and Romania  and in two different populations, namely first degree




relatives (FDRs) of individuals with RA and members of the general public recruited through online survey panels in each of the respective countries.




What did we find out?



Participant numbers	 UK	 Germany	 Romania
FDRs	289	67	
General public	982	984	993

The main findings can be summarized as follows:

- ★ Both first degree relatives of RA patients (FDRs) and participants from the general public preferred a treatment with:
 - increasing effectiveness (the greater the reduction in chance of RA the better),
 - a pill over an injection or drip,
 - lower frequencies of administration over higher frequencies
 - a lower chance of serious infections, serious side effects and mild side effects over higher chances of these side effects
- ★ Effectiveness (i.e. reduction in chance of developing RA down from 60%) was the most important factor influencing people's treatment decision choices for both FDRs and the general public.
- ★ There were some differences between the general public and the FDRs in the importance ratings for the other treatment features. For FDRs, serious side effects was the most important attribute after effectiveness whereas for members of the general public the way the treatment was administered was more important.
- ★ For the general population it was also possible to look at differences between countries. Although effectiveness had the most impact on treatment choice for the general population across all three countries, some differences were found:
 - Method of administration was second most important feature for British  and Romanian  participants but was less important for the Germans 

- The chance of 'serious infection' and 'serious side effects' were more important factors impacting treatment choice for Romanians  than they were for the British  and German  participants.
- ★ For both the FDRs and members of the general public treatment preferences differed significantly across individuals.
 - In the FDRs the only factor that we measured that partially explains this is the 'perceived chance of developing RA'. Participants who thought they were at high risk of RA assigned less importance to the side effects than those who perceived themselves to be at low risk.
 - For the general public, the country the participant came from helped explain differences in treatment preferences (see also country differences described above) as did health literacy, numeracy and the individual's perceived risk of developing RA. Again higher perceived risk of RA results in lower importance assigned to any of the side effects.
- ★ Finally, some differences were found between the two different methods of measuring preferences in particular for mild side effects.

What can we learn from this?



The discussions with members of the public and FDRs in the qualitative study were very important for the development of an online preference study with relevant treatment features, as were additional discussions with our panel of patient research partners, clinical colleagues and preference research experts.

The findings from the online survey show that effective preventive treatments for RA are acceptable to members of the general public and first degree relatives who have been asked to assume a 60% chance of developing RA. However, the importance of other treatment features differed somewhat across countries and across populations (FDRs vs General population).

Some differences were found between the two different types of choice task which need to be further investigated. Treatment preference studies normally only include one type of choice task and the method that has more accurate findings, and most importantly, is the easiest for participants to complete, should be considered for use in future treatment preference studies.



Implications

These findings are helpful for the design of future trials of preventive treatment for RA. It tells those companies which are developing or approving a treatment, what is the most acceptable way for the treatment to be taken and also the amount of side effects that individuals people would be willing to accept in exchange for highly effective treatment. The findings will also contribute to the development of informational resources which can be used to support decision making by those at risk of developing RA who might be considering taking part in a trial of a preventive treatment, or taking a treatment in future. Finally, these findings show the necessity of carrying out preference studies within the country and the population of interest.

Where can I find out more information about this study?



The RA case study described in this summary is part of a series of case studies conducted within the IMI PREFER project (<https://www.imi-prefer.eu/>). PREFER looks at how and when it is best to perform and include patient preferences in decision making during the medical product life cycle.

The study protocol has recently been published as a journal article.

This paper gives detailed information about how the research was conducted and is freely available: <https://bmjopen.bmj.com/content/11/4/e045851>

Who were the study investigators?



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|--|---|
| ★ Karim Raza, University of Birmingham, UK | ★ Christine Radawski, Eli Lilly and Company, USA |
| ★ Marie Falahee, University of Birmingham, UK. | ★ Matthias Englbrecht, University of Erlangen, Germany |
| ★ Gwenda Simons, University of Birmingham, UK | ★ Larissa Valor-Méndez, University of Erlangen, Germany |
| ★ Rachael DiSantostefano, Janssen R&D, USA | ★ Karin Schölin Bywall, Uppsala University, Sweden |
| ★ Jorien Veldwijk, Erasmus University, Netherlands | ★ Ulrik Kihlbom, Uppsala University, Sweden |
- ★ **Patient research partners:** Margot Bakkers; Tom Esterine; Eva C. Johansson; Ursula Ploss; Di Skingle; Sabine Stolper; Susan Thomas; Ruth Williams.

Please contact m.falahee@birmingham.ac.uk or g.simons@bham.ac.uk for more information on this report.

prefer.

PATIENT PREFERENCES

Want to know more? Go the PREFER project's website: www.imi-prefer.eu

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