

The background of the slide is a vibrant orange color. Scattered across this background are numerous white, round pills, some of which are slightly out of focus, creating a sense of depth. The pills are positioned at various angles and heights, some appearing to be floating or falling. A dark grey rectangular box is centered on the page, containing the main title and subtitle in white text.

# Preventing RA

What treatments do people at risk of rheumatoid arthritis prefer?

prefer.

# Treatment preferences in RA prevention

***Rheumatoid arthritis, often referred to as RA, is a long-term condition that mainly affects the joints. RA causes pain, swelling, stiffness and often fatigue. If patients are not treated, their joints can suffer permanent damage, which can lead to disability. Having RA can also lead to other conditions, for example inflammation in other parts of the body like the lungs, heart or eyes. Most patients need long-term treatment with medicines that come with the risk of side effects that can be serious.***

RA is fairly common and affects one out of 100 individuals. Some of us are at an increased risk of developing RA. For example, if you have a parent or sibling with RA (first-degree relative), your risk increases fourfold.

There is a lot of interest in the idea of treating people who are at an increased risk of RA before they are diagnosed with RA, reducing their risk of developing this serious condition. Several completed and ongoing clinical trials test various preventive treatments.

But would a person who is at risk of RA actually want to take a preventive treatment? Studies of treatment preferences look at the importance people place in different features ('attributes') of a treatment. These features include things like side effects, effectiveness, and how the treatment is taken (for example if it is a pill or injection).

***We asked participants which features of preventive treatments they value and which features they dislike. We also wanted to know how much value a person gives the different risks and benefits of a particular treatment, and how they balance between them.***

We further investigated if there is a difference between preferences of first-degree relatives and members of the general public. First-degree relatives already have a slightly increased risk of developing RA and might have more experience with RA through their relative. Finally, we looked at differences between countries and looked at factors that might affect preferences, such as age and a person's personal perception of their risk of developing RA.

## Who answered our questions?

In this study, 350 first degree relatives of RA patients and 3000 members of the general public were asked to imagine that they had a 60% risk of developing RA in the next 2 years before being asked to make treatment choices.

Participants came from the United Kingdom, Germany and Romania. More females took part than males, which reflects the patient population for RA.

# What did we find out?

- ***Effectiveness (in this case represented by the reduction in chance of developing RA down from 60%) was the most important factor influencing people's treatment decision choices for both first-degree relatives of RA patients and the general public across countries.***
- For first-degree relatives, avoiding serious side effects was the most important treatment feature after effectiveness, but for members of the general public, the way the treatment was administered was more important.
- Both first-degree relatives and participants from the general public preferred treatments 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, and treatments with a lower chance of serious infections, serious side effects and mild side effects.
- For both the first degree relatives and members of the general public treatment preferences differed across individuals. For the first-degree relatives, 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 as did health literacy, numeracy and the individual's perceived risk of developing RA. Again higher perceived risk of RA resulted in lower importance assigned to any of the side effects.

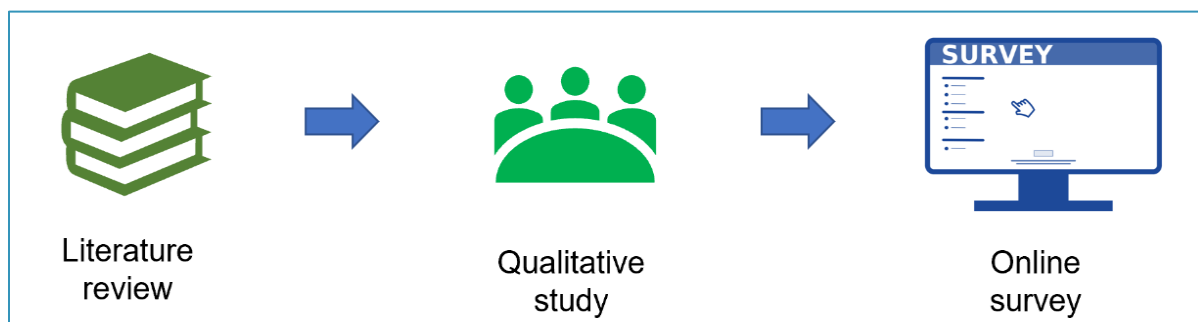
# Why is this research important?

These findings are helpful for the design of future trials of preventive treatment for RA. It tells the 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 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 the future. Finally, these findings show the necessity of carrying out preference studies within the country and the population of interest.

## How we did the research (methodology)

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 in a so-called '*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 in a '*qualitative study*'. The results from the 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 that 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 treatment choice tasks that were included in the survey.



### Example of a 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 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.

# Want to know more about the study?

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:

Falahee M, Simons G, DiSantostefano RL, et al. [Treatment preferences for preventive interventions for rheumatoid arthritis: protocol of a mixed methods case study for the Innovative Medicines Initiative PREFER project](#), BMJ Open 2021;11:e045851. DOI: 10.1136/bmjopen-2020-045851

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## Who were the study investigators?

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- ★ Matthias Englbrecht, University of Erlangen, Germany
- ★ Larissa Valor-Méndez, University of Erlangen, Germany
- ★ Karin Schölin Bywall, Uppsala University, Sweden
- ★ 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.

## About this study

**Data Privacy and Ethics Approval:** This study was conducted in accordance with General Privacy Regulation (EU) 2016/679 (GDPR). This study was approved by the London-Hampstead Research Ethics Committee (19/LO/0407) and the Health Research Authority (HRA) in the UK and the Ethics Committee of the Friedrich-Alexander-Universität Erlangen-Nürnberg (92\_17 B) in Germany.



# prefer.

## PATIENT PREFERENCES

Want to know more? Go the PREFER project's website: [www.imi-prefer.eu](http://www.imi-prefer.eu)

The Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (PREFER) project has received funding from the [Innovative Medicines Initiative 2](#) Joint Undertaking under grant agreement No 115966. This Joint Undertaking receives support from the European Union's [Horizon 2020](#) research and innovation programme and the European Federation of Pharmaceutical Industries and Associations ([EFPIA](#)). This report and its contents reflects the PREFER project's view and not the view of IMI, the European Union or EFPIA



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