UNIVERSITY OF
BIRMINGHAM

Participant Information Sheet

Title of Project:

Improving patient education for people of South Asian* origin living with rheumatoid arthritis in England

Use this link to hear in Hindi: https://youtu.be/aCOfk7BAzkg?si=eKLjptKWlxl-vDjn

Invitation paragraph

You are being invited to take part in a research study. Before you decide it is important that you understand why the research is being done and what it will involve.

What is the purpose of the study?

The doctors and nurses provide information to help patients understand their condition, manage symptoms, take medication correctly, and work with us to control their illness. We understand that in some cultures, learning about a condition and its treatment takes time. That’s why we want to check if the information we give is clear and helpful and how much this helps people understand their condition.

We are inviting people to share their experiences with us so we can improve the support we provide. In particular, we would like to hear from South Asian people, where English might be an issue to ensure our information meets their cultural needs and helps with decision-making about their health, self-care, and medication.

Why have I been invited?

You are receiving care from the rheumatology department to manage your condition. As part of your treatment, you may be taking medication and have received information about your condition. We want to make sure the information we provide during clinic appointments is clear and helpful. To do this, we would like to ask you a few questions about how well our information supports your understanding. Your feedback will help us improve the way we share information and ensure people get the support they need.

Do I have to take part?

Taking part in this study is completely your choice. If you decide to join, you can change your mind and stop at any time without giving a reason. This will not affect your care in any way—your GP and the Rheumatology team will continue to treat you as usual. If you choose to take part, you will receive this information sheet to keep. We will also ask you to sign a consent form which means to give us permission to ask you some questions.

*= people who are able to speak in Hindi, Punjabi and Urdu

What will happen to me if I take part?

If you decide to take part, the research team member will ask you to complete some questionnaires, which will take about 20 minutes. These questions will be about your experience with the information you received and your thoughts on living with your condition. Some questions will also ask basic details about you, like your age, education, and the area you live in. You will be asked to complete the first set of questions when we meet at the rheumatology department then after three months, our team will contact you again to ask similar questions about your condition and how you are managing.

If you speak Hindi, Punjabi, or Urdu, a researcher will speak with you in these languages. If you have difficulty reading, don't worry—an audio recording of the questions will be available to help you understand and answer them fully.

After we have gathered all the information from everyone, we will send you a summary in Hindi telling you what we found.

What are the possible disadvantages and risks of taking part?

The only difference is that your appointment may take a little longer—you will need to set aside about 20 minutes to complete the questionnaires with us. There are no major risks in taking part, but if you feel upset or distressed while answering the questions, we will pause and carry on only when you feel ready. If needed, you can also get support from the research team or your healthcare provider.

What are the possible benefits of taking part?

You may not get a direct benefit from taking part, but your feedback will help the Rheumatology team understand patients' experiences better in receiving information from us. This will allow us to improve how we share information when you come to clinic visits and ensure we provide the most important information to help patients manage their condition.

What will happen when this research study stops?

After we collect all the information from you, the research team will look at it closely. Your information will be safely stored at the University of Birmingham (Medical School) for at least 10 years. The reason we do this is in case we need to look at the file again. After this time, it will be securely destroyed to protect your privacy.

Will my taking part in this study be kept private?

Your information will be stored securely on a password-protected University of Birmingham computer. Any paper files will be locked in a filing cabinet at the university for 10 years. Only the research team will have access to this information. Everything you share will be kept strictly private for this project. Your details will not be shared with your rheumatologist, specialist nurse, or GP. When we look the data, your name will not be used—instead, each questionnaire will be given a number (for example "Patient 1").

In some cases, authorised individuals from the University of Birmingham, NHS, or guiding bodies may review the project files making sure everything is in line with rules and regulation.

How will we use information about you?
The University of Birmingham will keep your consent form which is your permission form and all your information private. Your details will not be shared with any other people. All files will be numbered, and only those who need to see it will have access. Your files will be assigned a code number, not your name, to keep it private. We will keep all your information safe and secure. After the study is finished, we will keep some files to check the results. Any reports we write will not show that you took part in the study.

What are your choices about how your information is used?
You can stop taking part in the study at any time, without giving a reason. But any information we've already collected about you will still be kept. We need to manage your files in a certain way to make sure the research is reliable, so we won't be able to let you see or change the information we have about you.

Where can you find out more about how your information is used?
You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to the University of Birmingham's Data Protection Officer on dataprotection@contacts.bham.ac.uk or
- by ringing us on **07904507726**.

What if there is a problem?
If you have any concerns about the project, please speak to Dr. Kanta Kumar or a member of the research team. They will do their best to answer your questions. If they cannot resolve your concern, or if you want to make a complaint, you can contact the Patient Advice and Liaison Services (PALS) team at 0800 028 4203.

What should I do now?
If you decide you would like to take part in this study, you will meet the research team, and they will take you though all the information.

Who is organising the research?
The University of Birmingham is supporting this research and is providing insurance to cover the project. The project itself is funded by a government organisation called the NIHR (National Institute for Health Research).

Who has reviewed the study?
The South Central-Oxford A Research Ethics Committee has approved the project.

Contact and Further information:
Chief Investigator: **Dr Kanta Kumar – k.kumar@bham.ac.uk**