

Invitation letter

Young people living with rheumatic conditions

University of Oxford PhD researcher Julia Salafranca Gomez – funded by Reuben College

We invite you to participate in the first activity of the *Young People living with Rheumatic conditions (YPR)* program, which aims to create a space for young people living with rheumatic conditions.

You are not required to be involved, and you can withdraw your involvement at any point. Before you decide, we would like you to understand why this activity is being done and your involvement. We are therefore providing you with the following information. Please take time to read it carefully and discuss it with others if you wish. Please contact ppie@kennedy.ox.ac.uk with any questions you may have.

Purpose of the activity

This activity aims to involve and engage young people living with rheumatic diseases and involve them in research. Studies demonstrate the benefit of patient involvement in research. Young researchers in the field of rheumatic diseases will be attending this event. Thus, their involvement will provide a patient perspective that shapes their research. Furthermore, it can also serve as a space for the young people living with a rheumatic condition to socialize and get to know each other.

This initiative offers you an opportunity to express your concerns and priorities to researchers. Furthermore, it will be an enjoyable experience, as we will spend one hour doing an activity chosen by the participants.

What we would like you to do

Firstly, you need to register your interest via the form <https://oxford.onlinesurveys.ac.uk/young-people-living-with-rheumatic-conditions>.

The questionnaire includes questions about your age, gender, and rheumatic condition. You don't have to answer these questions if you don't want to, but we aim to recruit young people and match their condition to a researcher in that field. Moreover, it will ask you about the type of activity you want to carry out and your availability. We also want to register your interest in participating in other engagement and involvement activities. With your consent, your contact data will be collected to contact you for the activity or other initiatives you have expressed an interest in.



A two and a half hour activity will be set up in May/June 2022 in Oxford with a group of people with a rheumatic disease and researchers to share their experiences, opinions on current research, and concerns. The group will be composed of a maximum of nine people, with four to five people with a rheumatic condition, and up to four researchers. The activity will have two parts; during the first hour, we will do a fun activity, to promote team building between the participants. We will then have a discussion in small groups of people with a rheumatic condition and the researchers (one and half hours). Then you will be asked to evaluate the activity through an online questionnaire.

After the activity, we will ask you to complete a payment request form that includes your bank details and national insurance number (or nationality if you are not a UK resident) to enable us to pay you for your involvement.

Do I have to take part?

It is up to you to decide whether or not to take part. Using the registration form, you can consent to us contacting you for the activity or other engagement or involvement initiatives. Registering with the form doesn't mean you have to participate in the activity, and your participation can be withdrawn at any point.

Expenses and payment

You will be paid £65 for your participation in the activity (rate of £26/hour). This will be transferred to you after you have completed the post-activity questionnaire. Moreover, reasonable expenses can be covered, such as travel or carer costs.

What are the possible benefits of taking part?

- Contributing to research. By expressing your opinions, priorities, and concerns, you will directly shape the research.
- Establishing relationships with other young people living with rheumatic conditions.
- Learning about the current research being carried out in rheumatology.
- Some fun! This experience aims to be enjoyable for all the participants.
- An opportunity to shape the collaboration between patients and researchers in the Oxford Research into Inflammatory Arthritis Centre (RACE) program.

Confidentiality

Any information collected will be maintained confidentially, and access will be restricted to people responsible for the initiative. Your name will not be disclosed, nor will details of your answers be given to anyone. Your responses to the evaluation questionnaire may be included in a report, but these will be completely anonymous.

What will happen after the activity?

After the activity, an online anonymous evaluation questionnaire will be sent to you to complete. The questionnaire will also register your interest in future engagement and/or involvement initiatives.

Payment will be made to you via bank transfer.

A report with the results of the initiative will be carried out. This will include information about the group and the evaluation. All information will be anonymized.

Contact information

Contact us at ppie@kennedy.ox.ac.uk

