

RAIRDA Survey 2024

The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) have partnered with Ipsos to conduct a survey to find out what patients think about the quality of their care, guidance and treatment for their Rare Autoimmune Rheumatic Disease (RAIRD). The aim of the survey is to provide valuable insights into what is working well about patients' experience of care, areas for improvement, and aims to shape the way services are provided in the future.

The survey will include questions relating to what is good about the care provided and how it can be improved. By participating, you can contribute to how services are delivered in future. You will be able to take part from April to May 2024.

What does it involve?

We would like you to take part in an online survey that should take approximately 10 minutes to complete. The survey will include questions on your experience for your RAIRD condition, information about you, and other related questions.

Where will this take place?

The survey is online, and you can complete it at a time or place convenient to you. The survey can be accessed by using the camera on your smart phone to scan the QR Code below:



Or by clicking on this link: <https://ipsos.uk/RAIRDAsurvey2024>

If you have technical issues accessing the survey or would like to take part via a telephone interview, please contact 0800 1510990, or email UK-RAIRDASurvey2024@ipsos.com

How often will you have to take part, and for how long?

You will be asked to complete a one-off survey that will take approximately 10 minutes.

Do you have to take part?

No, your participation is voluntary. If you decide to take part in the survey after reading this Participant Information Sheet, you can still decide to withdraw at any time without giving a reason. To safeguard your rights, we will use the minimum personally identifiable information possible. You can download and save a copy of this document for your records.

What are the possible risks or disadvantages of taking part?

We do not foresee any risks associated with taking part in this research.

What are the possible benefits of taking part?

The information collected will provide vital information to RAIRDA to identify what's working well and what can be improved. It helps to identify inequalities in experience too, as the results can be analysed across different groups of people.

Will anyone be able to connect you with what is recorded and reported?

No, you will not be identifiable in any data Ipsos shares with RAIRDA nor in any published results.

Who will have access to the data?

The data is being collected by Ipsos UK. All data will be treated in confidence and held securely in line with the Data Protection Act 2018 (GDPR) and comply with Ipsos UK guidance on the collection and storage of data. All data will be stored securely by Ipsos UK, Principle Consulting and RAIRDA. Nothing you tell us will be used or shared in a way that can identify you personally.

What will happen to the information when this study is over?

Ipsos will only retain your data in a way that can identify you for as long as is necessary to support the evaluation project and findings. The responses from the survey will be securely deleted from Ipsos' systems once the study and any quality control checks are complete; this is usually carried out within three months of project close.

What will happen to the results of this study?

Results will be written up by the research team at Ipsos UK and form a report which will be shared with the team at RAIRDA alongside full data tables. No personally identifiable data will be published in any of the findings.