

SarcoidosisUK Research Participants' Data Protection and Privacy Policy

About the Policy

If you take part in our SarcoidosisUK Research, we are fully committed to protecting your privacy. To understand how your personal information will be treated, please read the following policy.

The terms of this policy may change to reflect the changing activities and services of the charity. Please check it from time to time. We last updated the policy in July 2023.

If you have any queries about this policy please contact us: SarcoidosisUK, 214 China Works, 100 Black Prince Road, London, SE1 7SJ.

This policy is informed by the Data Protection Act with help from the ICO and Helplines Partnership. It has been written in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act.

See the *SarcoidosisUK Data Protection and Privacy Policy* for more general information about how we treat any personal information and data not involved with SarcoidosisUK Research.

This policy explains:

- What we mean by 'SarcoidosisUK Research'
- What information we collect for research purposes
- Why we collect information for research purposes
- How we collect information for research purposes
- How we use your information
- Who we share your information with
- How we protect your information
- How long we keep your information
- Your rights
- Further information and contacts



Data Protection and Privacy Policy

What do we mean by 'SarcoidosisUK Research'?

SarcoidosisUK Research means any research which is authored, conducted and promoted by SarcoidosisUK, either alone or in partnership with external academic or research bodies (our Trusted Research Partners). SarcoidosisUK Research may be conducted either online or in print, but is generally administered through our website at <https://surveys.sarcoidosisuk.org/>. It may include the following:

- Surveys and questionnaires
- Health status measures and other consultation assessment tools
- Patient reported experience measures (PREM)

This policy does not cover participants involved in research found through external links on the SarcoidosisUK website, for example NHS clinical trials or European Lung Foundation surveys.

If you are unsure and would like to find out if you are participating in SarcoidosisUK Research, please contact the SarcoidosisUK member of staff named below.

What information do we collect?

There are two main types of information we may collect - Personal and Sensitive. Any other information is covered by the separate *SarcoidosisUK Data Protection and Privacy Policy*. SarcoidosisUK only collect information necessary for that specific and intended research purpose.

Personal Information: SarcoidosisUK does not collect information identifying you personally unless that information is voluntarily disclosed. The personal information we collect may include your name, date of birth, email address, IP address (internet protocol address), postal address or telephone number and certain demographic details such as age and ethnicity.

Sensitive Information: In conducting our research, we may also need to collect personal information recognised by data protection law as sensitive, in particular information about your health. We will only collect sensitive information when there is a clear reason to do so. If you have chosen to take part in a research project and subsequently decide that you do not want to share sensitive information, you may end your participation at any time. For more information see 'Your Rights', below.

Why do we collect your information?

Our research is conducted for a variety of reasons with the overarching goal to understand more about sarcoidosis, how it affects sarcoidosis patients and ultimately to find a cure for the disease.

Personal: SarcoidosisUK uses the personal information we collect about you to help better administer and further our research programme. SarcoidosisUK or our trusted research partners may need to contact you to discuss your answers or the results of the research.

Sensitive: SarcoidosisUK uses the sensitive information we collect to further our research and learn more about sarcoidosis and how it affects patients. The information about health that you provide may be very useful in answering a wide range of important questions relating to our research.

How do we collect personal and sensitive information?

You share your information with SarcoidosisUK when you participate in research online through our website or by filling out a paper form.

How do we use your information?

We use your personal and sensitive information to further our research programme.

Personal information could be used to:

- communicate with you about the research you have participated in
- provide you with results from research you have participated in
- discuss with you results from research you have participated in
- give information and advice, if requested by you.

Sensitive information could be used to:

- provide you with more information about your sarcoidosis and how it is affecting you
- provide your medical team with more information about your sarcoidosis and how it is affecting you
- understand more about your sarcoidosis
- understand more about sarcoidosis and SarcoidosisUK
- form part of a database that may be used for specific research and development purposes.

Lawful Basis

SarcoidosisUK collects and processes data under the following lawful basis as set out in Article 6 of the General Data Protection Regulations (GDPR).

Our lawful basis for processing personal data is legitimate interest.

Consent: the data subject has given consent to the processing of his or her personal data for one or more specific purposes.

Legitimate interests: the processing is necessary for SarcoidosisUK's legitimate interests or the legitimate interests of a third party unless there is a good reason to protect the individual's personal data which overrides those legitimate interests.

Who do we share your information with (personal and sensitive)?

We will only share your personal and sensitive information within SarcoidosisUK, with your medical team and in some cases with our trusted research partners. Each trusted research partner will be clearly named and available to all participants taking part in that respective research project.

We will ask for informed consent before sharing information with your medical team or research partners. This includes your spoken consent directly to your medical team.

We will not disclose any information identifying you personally to any other third parties, except with your prior explicit permission or where required by law.

For more information see the *SarcoidosisUK Safeguarding Policy*.

We reserve the right to share personal information with our financial and legal advisers to protect our legal rights.

How do we protect your information (personal and sensitive)?

When we collect your information, we use strict procedures and security features to prevent unauthorised access. We also take appropriate measures to make sure the information disclosed to us is:

- kept secure, accurate and up-to-date and
- kept only for as long as it's needed for the purposes for which it was intended.

While do our best to protect your personal information, we cannot guarantee the security of any information you post, email or transmit by other means to us. You do so at your own risk.

How long do we keep your information (personal and sensitive)?

We regularly review how long we hold your information. We are legally required to hold some types of information to fulfil our statutory obligations. We will hold your personal and sensitive information on our systems for as long as necessary for the intended purpose – this may be up to many years if you have consented to be part of a longitudinal study. If you asked us not to contact you again we would hold a record of that indefinitely. Where your information is no longer required we will dispose of it in a secure manner.

SarcoidosisUK stores information in line with Article 5(1)(e) of GDPR.

Research Partners Disclaimer

SarcoidosisUK is not responsible for any third-party content or privacy practices accessible through our trusted research partners unrelated to the SarcoidosisUK Research in which you may be participating. We do not necessarily endorse the services, content or otherwise opinions of these partners.

Your Rights

You have the following rights in relation to your personal and sensitive information.

If you are thinking about or participating in any SarcoidosisUK Research Project, at any time, you have the right to:

- stop participating and sharing your information- no prior notice or reason is needed
- cancel or modify your information by contacting the SarcoidosisUK office (info@sarcoidosisuk.org)
- ask for a copy of the personal information we hold about you and for us to correct any inaccuracies
- request us to erase your personal information; to restrict our processing of your personal information, or to object to our processing of your personal information

If you want to exercise these rights, please email info@sarcoidosisuk.org. Depending on the request, it may be necessary to send copies of 2 separate identification documents such as a passport, driving licence, or utility bill. The first should give photo identification and the second confirm your address. Please also give information about the nature of your contact with us, to help us locate your records. Alternatively, you can send the documents by post to: SarcoidosisUK, 214 China Works, 100 Black Prince Road, London, SE1 7SJ.

We will respond within 30 days, once we receive your written request and copies of your identification documents.

We reserve the right to charge an administration fee for excessive or manifestly unfounded requests.

Further Information and Contacts

Other Related SarcoidosisUK Policies

- *SarcoidosisUK Data Protection and Privacy Policy*
- *SarcoidosisUK Information Standards Policy*
- *SarcoidosisUK Safeguarding Policy*
- *SarcoidosisUK Nurse Helpline Service Standards* (including Confidentiality and Data Protection Policy, Safeguarding Policy and Information Standards Policy)

For more information about this Policy please contact:

Leo Casimo
214 China Works
100 Black Prince Road
London
SE1 7SJ

info@sarcoidosisuk.org
020 3389 7221

The Data Protection Regulator:

You can get more information and advice about data protection or reporting a concern about data protection from:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
SK9 5AF

Helpline: 0303 123 1113
From outside the UK: +44 1625 545 745
ico.org.uk