

PRIVACY NOTICE

Scientific Education Support believes in the value of partnering with communities to create innovative educational initiatives which give rise to empowered communities, stronger networks, and greater collaboration opportunities.

Scientific Education Support is committed to respecting the privacy of all our stakeholders and those of our partners.

Scientific Education Support (SES) Ltd. is the data controller responsible for your personal data (referred to as “SES”, “we”, “us” or “our” in this privacy notice) and this Privacy Notice explains who we are, how we collect, share and use your personal data, and how you can exercise your privacy rights.

Contact Us

If you have any questions about this privacy notice, the use of your personal information, or wish to request to exercise any of your rights please contact our **Data Protection Officer** using the following details:

By email:

sesdpo@kazient.co.uk

By post:

Data Protection Officer
3 AC Court
Thames Ditton
Surrey
KT7 0SR
UK

EU Representative

You can contact our **EU Representative** by using the following details:

By email:

seseurep@kazient.eu

By post:

Scientific Education Support EU REP c/o Kazient Privacy Experts
28 St Peter's Road
Phibsboro
Dublin 7
D07 CF53
Ireland

Personal Data We Collect From You

We only collect your personal data when you participate in our survey.

The categories of information we collect from you include:

- demographic information
- MDS disease history and current status
- treatment and support received for MDS disease
- mental health and wellbeing information
- information about your quality of life
- your access to care
- technical information such as your IP address

Note: We do not collect your contact details.

Lawful Basis of Processing

Data Protection laws only permit us to process personal data where we have a valid legal basis to do so.

We process personal data where we have one of the following legal basis:

- for the performance of a contract
- where you consent to it

Purposes of Processing

We collect, use and share Aggregated Data for research purposes only.

Your response will be combined with the responses gathered from other survey participants. This will then be aggregated and analysed as part of a group.

We do not use any of the information you provide for direct marketing or other non-research activities.

Personal Data Collected From Other Sources

We do not receive any personal data about you from third parties or public sources.

We ask Charities and other organisations to share our survey with their members, supporters, and service users.

Sharing Your Personal Data

We will not share your personal data with any third party.

We will only share anonymised data with third parties in a generic form.

Transfer of Your Personal Data Outside The UK and EU

Your personal data will be processed outside of the UK and EU by trusted service providers.

We require third parties to keep your personal data confidential and secure.

We ensure that suitable protection is maintained at all times by ensuring that appropriate safeguards are in place such as Standard Contractual Clauses.

Retaining Your Personal Data

We only keep personal data for as long as necessary.

Sometimes we are required to retain your personal information for longer than our initial purposes to meet our legal or regulatory obligations and for the exercise and/or defence of any legal claims.

Profiling

We do not engage in any profiling activities with your personal data.

Automated Decision Making

We do not use any automated processes to make decisions about you that may produce legal or significant effects concerning you.

Your Data Subject Rights

You have rights in relation to the personal data we process about you.

These rights are not absolute and may be subject to various exceptions and limitations.

You can request to exercise your rights by contacting us. The contact details can be found near the top of this privacy notice.

Your rights:

Right to be informed: We are obliged to provide clear and transparent information about our processing activities of your personal data.

Request access to your personal data (commonly known as a “data subject access request”): You have the right to understand what personal data we hold about you and why.

Request correction of the personal data: If you believe that we hold inaccurate or incomplete personal data, you have the right to request us to rectify or correct your personal data.

Request erasure of your personal data: You may ask us to delete or remove personal data where there is no good reason for us to continue to process it. Please note, however, that we may not always be able to comply with your request of erasure for specific legal reasons

Request restriction of processing of your personal data: You may ask us to stop processing your personal data. We will still hold the data but will not process it any further. You may exercise the right to restrict processing when one of the following conditions applies:

- the accuracy of the personal data is contested
- processing of the personal data is unlawful
- we no longer need the personal data for processing but the personal data is required for part of a legal process
- the right to object has been exercised and processing is restricted pending a decision on the status of the processing

Right to Withdraw Consent: You may withdraw consent at any time if we are relying on your consent to process your personal data.

This won't affect any processing already carried out before you withdraw your consent or processing under other grounds.

Right to object: You have the right to object to our processing of your data where:

- processing is based on legitimate interest
- processing is for the purpose of direct marketing

We may need specific information from you to help us confirm your identity.

Making a Data Protection Complaint

If you have any concerns about the use of your personal data or the way we handle your requests relating to your rights, you can raise a complaint directly with us by using the contact details provided in this notice.

If you are not satisfied with the way we handle your complaint, you are entitled to raise a complaint directly with the Information Commissioner's Office (ICO) if you are in the UK or your local Supervisory Authority if you are in the EU.