



Sickle Cell and Thalassaemia Support Project

Privacy Policy

Our contact details

Sickle Cell & Thalassaemia Support Project
Paycare House
George Street
Wolverhampton
WV2 4DX

Tel: 01902 444076/77

Fax: 01902 445322

Email: info@sctsp.org.uk

Company Limited by Guarantee
Registered in England and Wales Company No. 3575079
Registered Charity No: 1077687

Main Contact: Sutinder Herian, Executive Director

Definitions of services

Sickle Cell and Thalassaemia Support Project is abbreviated to **SCTSP** as part of our corporate branding. SCTSP is a charity providing counselling and support services to families where a diagnosis via a blood test shows a person has a blood disorder or is at risk of passing on a gene, which could lead to a blood disorder in a new-born.

What information we collect

We collect information about you and your family only if it is relevant to a service you have chosen to access or you have been referred for. The information we collect is to identify you and/or a family member(s) and this includes:

- location address
- email address
- contact numbers
- gender
- date of birth
- NHS Numbers and or
- hospital numbers

We also may collect special category data which may influence your service needs. These include:

- race
- ethnic origin
- religion
- genetics
- health
- sexual orientation
- safeguarding data

How we get the information and why we collect it

Most of the information we collect comes through referrals from health visitors, doctors and the NHS National Screening Program for blood test results. We also visit people and families and hence collect information directly from you in addition to information we received when you were referred to us. Your information may be collected in several ways, including;

- on paper
- via telephone
- via email
- face-to-face
- via online form
- website cookies

Why is your information being collected?

The organisation works closely with NHS and other partners to ensure contractual and charitable provisions are available to the affected clients and their families.

Under the General Data Protection Regulation (GDPR), the lawful basis we rely on for processing this information are:

(a) Your consent is collected on NHS forms/documents with whom we collaborate or we may also collect your explicit consent. You are able to remove your consent at any time. You can do this by contacting info@sctsp.org.uk.

(b) We have a contractual obligation with you once you self-refer a family member or consent to receiving our services.

(c) We have a vital interest in the protection of vulnerable adults or children under Safeguarding regulations, as set out in chapter 2 of *Working Together to Safeguard Children; a guide to inter-agency working to safeguard and promote the welfare of children, July 2018*. Many local organisations and agencies have a duty under section 11 of the Children Act 2004 as amended by the Children and Social Work Act 2017 to ensure that they consider the need to safeguard and promote the welfare of children when carrying out their functions. Some of the services which we deliver will be our response to the agreement with NHS England and clinical commissioning groups, NHS Trusts, NHS Foundation Trusts and General Practitioners with Statutory guidance on inter-agency working.

(d) We need it to perform a public task. Any personal information we hold about you is processed for the purposes of "the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller (SCTSP) " under chapter 2, section 6 and the "provision of health or social care or treatment or the management of health of social care systems and services "

under chapter 2, section 9 of the Data Protection Act 2018. <https://www.uhb.nhs.uk/privacy-notice/patients>

We process special category data under the course of our legitimate activities with appropriate safeguards and on condition that the processing relates solely to the services of SCTSP or to persons who have regular contact with us in connection with our services and that the personal data are not disclosed outside of statutory agencies without the consent of the data subjects.

What we do with the information

We will need to process your personal information. In this context, 'processing' refers to collecting, recording, organizing, storing, sharing, using, disclosing and disseminating your information as is necessary to fulfil our contract with yourself or to comply with legal obligation.

We share your information under our contractual obligation to provide services with Local NHS Trusts in Wolverhampton, Dudley, Walsall and Birmingham Children Hospital, The National Haemoglobinopathy Reference Laboratory Oxford as well as schools. This information is shared with us so that we are able to provide counselling services to parents expecting a child or whom have recently had a child. We provide services where new individuals have been identified as having a blood disorder so as we are able to support them in the community. The information is also required for continually improving services for the future.

Some of the information is required to show how effective our services are and this is done by anonymising the information so that no one can identify a person or family from the reports we generate. This information is shared with the relevant Clinical Commissioning Groups (CCGs) in Wolverhampton, Walsall and Dudley.

No information is shared outside of the UK.

How we store your information

Your information is stored digitally on our computer server locally with off-shore back-up in the cloud. Information in the cloud is backed up in countries which comply with GDPR within the European union. We also keep paper records which are managed by our haemoglobinopathy staff and administration.

Information is currently being kept for a minimum of 2 years unless it is a record superseded by our collaborating with government services. Processing also requires us to archive information in the public interest for scientific or historical research or statistical purposes. It will be subject to appropriate safeguards, in accordance with this Regulation, for the rights and freedoms of the information subject. The Regulation is Article 89, EU GDPR, "*Safeguards and derogations relating to processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes*".

In relation to SCTSP services we adhere to the *Records Management Code of Practice for Health and Social Care 2016* which has been published by the Information Governance Alliance (IGA) for the Department of Health (DH).

<https://digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance/codes-of-practice-for-handling-information-in-health-and-care/records-management-code-of-practice-for-health-and-social-care-2016>

Your data protection rights

Under data protection law, you have rights including:

Your right of access - You have the right to ask us for copies of your personal information.

Your right to rectification - You have the right to ask us to rectify information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.

Your right to erasure - You have the right to ask us to erase your personal information in certain circumstances.

Your right to restriction of processing - You have the right to ask us to restrict the processing of your information in certain circumstances.

Your right to object to processing - You have the right to object to the processing of your personal information in certain circumstances.

Your right to data portability - You have the right to ask that we transfer the information you gave us to another organisation, or to you, in certain circumstances.

The lawful basis listed above may not apply in all circumstances. For more information on this please read the guidance on the Information Commissioner Office website <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/>

Subject Access Request

A subject access request (SAR) is simply a written request made by or on behalf of an individual for the information which he or she is entitled to ask for under section 7 of the Data Protection Act 1998 (DPA). You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you.

If you wish to make a request, please contact us at Sutinder.Herian@sctsp.org.uk, [01902 444076/77](tel:01902444076) or write to us at Sickle Cell & Thalassaemia Support Project, Paycare House, George Street, Wolverhampton, WV2 4DX.

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You can also complain to the ICO if you are unhappy with how we have used your information.

The ICO's address:

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

Helpline number: 0303 123 1113