

GCUK: Privacy Policy

Policy

This Policy specifies the types of personal information that the charity collects and the ways in which it will be used.

Objectives

This policy:

- Explains what information we collect on trustees, patients, carers and others associated with the charity's work.
- How the charity uses the personal information it collects
- How the charity ensures personal information is securely held
- The rights that individuals have to know the information the charity holds on them
- Explains how to raise issues or concerns

Definitions

Representatives means all those where the nature of their work for the charity, whether paid or unpaid, is regular and structured. This includes trustees, paid staff, Helpline volunteers, and consultants or equivalents.

Beneficiaries means all those who benefit from, engage with, or come into contact with GCUK. It includes patients, carers, family or friends who engage with the charity.

Trustee means a member of the GCUK Board of Trustees.

Volunteer means someone who supports the work of the charity, without being paid, and where the nature of the work is unstructured, ad hoc or intermittent.

Responsibilities

The Board has overall responsibility for determining and reviewing the Privacy Policy.

All those who utilise personal information on behalf of GCUK must abide by the policy.

GCUK's Secretary is responsible for monitoring compliance with relevant legislation in relation to personal information.

Procedures

When do we collect information?

GIST Cancer UK (GCUK) collects personal information through its website, when people become a representative, make a donation, or communicate with us by email, phone or post.

What personal information do we collect?

General Information:

- Name and postal address
- Additional contact details including email address, telephone number(s), and social media identities if beneficiaries opt to provide them;
- Information about our services which you beneficiaries use, such as attendance at GCUK events and meetings with GCUK Trustees or donations;
- Your communication preferences;
- Information about computer/ mobile devices and visits to and use of our website, including, for example, IP addresses and geographical location;
- Any other personal information beneficiaries choose to share with us.

Why do we collect information?

GCUK collects information in order to build up our understanding of GIST, keep patients' carers and medical professionals up-to-date with new information and help administer our activities such as patient meetings.

Permission Required

The European GDPR (General Data Protection Regulations) apply to the storage and processing of personal data, and they contain provisions with which GCUK must legally comply. One of the GDPR regulations requires us to have explicit permission from each person who is registered with us to hold their personal data.

Special categories of data

The UK General Data Protection Regulation (GDPR) recognises certain categories of personal information as sensitive, and therefore requiring more protection. These categories of data include information about your health, ethnicity and political opinions.

In certain situations, GCUK may collect and/or use special categories of data (for example in order to make adjustments for any disabilities or dietary requirements beneficiaries may have when attending events or to provide audio/video versions of our Patient/Carer meetings and quarterly newsletters for doing so and where the GDPR allows us to do so. We will seek explicit consent to use such data.

How we use personal information

GCUK may use your personal information:

- a. to provide you with services, products or information that you have requested;
- b. to provide access to online services;
- c. to provide updates about our work, services, activities, publications or products
- d. to invite you to GCUK events we feel that you might be interested in;
- e. to process your donations;
- f. to answer your questions/ requests and communicate with you in general;
- g. to further our charitable aim in general, including for fundraising activities and asking for volunteer support;
- h. to analyse and improve our work, services, activities, products or information (including our website) or for our internal records;
- i. to audit and/or administer our accounts;
- j. to include your contribution in Patient Stories area of our website if you contact us with content;
- k. to satisfy legal obligations which are binding on us, for example in relation to law enforcement requests or due diligence checks before accepting major donations;
- l. for the prevention of fraud or misuse of service; and
- m. for the establishment, defence or enforcement of legal claims.

Lawful processing

We are required to rely on one or more lawful grounds to collect and use the personal information that we have outlined above. We consider the grounds listed below to be relevant:

Consent: Where you have provided your consent for our use of your personal information in a certain way, for example where we ask for your consent to send you a newsletter.

Legal obligation: Where the processing of your personal information is necessary for us to comply with a legal obligation to which we are subject.

Contractual relationship: Where it is necessary for us to process your personal information to perform a contract to which you are a party (or to take steps at your request prior to entering a contract), for example GCUK. relies on this ground to fulfil requests for literature or fundraising merchandising.

Legitimate interests: We rely on this basis where applicable law allows us to collect and use personal information for our legitimate interests and the use of your personal information is fair, balanced, and does not unduly impact your rights. For instance, it is in our legitimate interest to promote the aims and objectives of GCUK and to use the personal data of members to do so.

Patient Database

GCUK operates a private online patient & carer discussion forum. This has operated since the charity started in 2009. Through time many thousands of GIST patients and carers have shared information and helped and supported each other to manage individual situations related to GIST, in a private, specialist patient community. We encourage open discussion on all topics that are relevant to GIST and ask that members observe commonly accepted standards of etiquette and act responsibly and courteously when interacting with other members of our GIST forum.

Patients and carers who join our forum can email the group to ask questions, exchange information and discuss any issues related to GIST. It is a safe and secure place to meet and learn from others who have experience of similar situations.

When you contribute to the forum discussion, your email address will be visible to all participants.

Advice given

As stated in the disclaimer on our website www.glistcancer.org.uk/disclaimer-notice advice given on the Forum, Helpline or in other contexts is that of patients and carers. Any opinions expressed are those of the author and do not necessarily represent the official view of GCUK. Medical advice should always be sought from those responsible for your treatment.

Do we share your personal information?

GCUK will not sell, rent or lease your personal information to others.

We use the database to send out the quarterly newsletter. From time to time, we may use external third-party providers such as SurveyMonkey, to facilitate our surveys. The information you provide is sent directly to SurveyMonkey.

If you become a Supporter, your transaction will be processed by Just Giving <https://www.justgiving.com/glistcanceruk> and their privacy policy can be found at: at <https://www.justgiving.com/about/info/privacy-policy/privacy-policy-v30>

We reserve the right to disclose your personal information to third parties in the following circumstances:

- a. when you provide your personal information in our contact form, the form may be forwarded to the appropriate trustee or representative, to accommodate your request;
- b. for auditing purposes e.g., finance audits where we employ chartered accountants;
- c. if we are under any legal or regulatory obligation to do so; and
- d. in connection with any legal proceedings or prospective legal proceedings, to establish, exercise or defend our legal rights.

International Data Transfers

As we occasionally use third parties to process personal information, it is possible that personal GCUK Privacy Policy V1

information we collect from you will be transferred to and stored in a location outside the UK.

Please note that certain countries outside of the UK have a lower standard of protection for personal information, including lower security protections. Where your personal information is transferred, stored, and/or otherwise processed outside the UK in a country that does not offer an equivalent standard of protection to the UK, we will take all reasonable steps necessary to ensure that the recipient implements appropriate safeguards designed to protect your personal information. If you have any questions about the transfer of your personal information, please contact us.

GCUK Trustees may sometimes conduct online surveys to assist with our campaigns.

Our third-party provider, SurveyMonkey, stores your personal data on servers in the United States. They will only use it for the purpose of facilitating the survey. SurveyMonkey is certified under the Privacy Shield.

When you sign up for one of our online newsletters, GCUK stores your email address (and, if you provide it, your name) on servers in the United Kingdom. They will only use it for the purpose of sending you the newsletter you have subscribed to. You can easily unsubscribe from any newsletter by clicking on the “unsubscribe” link provided at the end of the email, or send an email to admin@glistcancer.org.uk

If you decide to comment on GCUK content, our third-party provider, LSOFT will store your name, email address and IP address on servers in the United States. They will only use your data for the purpose of providing the commenting functionality on LISTSERVE. LSOFT is certified under the Privacy Shield.

Securing your personal information

GCUK will take all reasonable technical and organisational precautions to prevent the loss, misuse or alteration of your personal information. We restrict access to those who have a need to know, and we train representatives in handling the information securely. GCUK will store all the personal information you provide on secure servers.

How long do we keep your personal information?

Unless still required in connection with the purpose for which it was collected and/or processed, we will generally remove your personal information from our records six years after the date that it was collected. For instance, if you cancel your GCUK membership, we will usually delete your personal data from our records 6 years after your cancellation.

However, before this date: (i) if your personal information is no longer required in connection with such purpose(s); (ii) we are no longer lawfully entitled to process it; or (iii) you validly exercise your rights to remove your records.

Your rights and preferences

GCUK may contact you by post, telephone, email, social media or other electronic means depending on the communication preferences you have previously indicated.

Where we rely on your consent to use your personal information, you have the right to withdraw your consent at any time.

When we use your personal information, you have the right to:

- a. Ask us for confirmation of what personal information we hold about you, and to request a copy of that information. If we are satisfied that you have a legal entitlement to see this personal information, and we can confirm your identity, we will provide you with this personal information.
- b. Request that we delete the personal information we hold about you, as far as we are legally required to do so.
- c. Ask that we correct any personal information that we hold about you which you believe to be inaccurate.
- d. Object to the processing of your personal information where we: (i) process based on the legitimate interest's ground; (ii) use the personal information for direct marketing; or (iii) use the personal information for statistical purposes.
- e. Ask for the provision of your personal information in a machine-readable format to either yourself or a third party, provided that the personal information

in question has been provided to us by you, and is being processed by us: (i) in reliance on your consent; or (ii) because it is necessary for the performance of a contract to which you are party; and in either instance, we are processing it using automated means.

- f. Ask for processing of your personal information to be restricted if there is disagreement about its accuracy or legitimate usage.

At any point, you can request to unsubscribe from any GCUK newsletters you have subscribed to or remove your personal information from the database by contacting us via secretary@glistcancer.org.uk .

Please note that where you ask us to delete your personal information, we will maintain a skeleton record comprising your name and contact details to ensure that we do not inadvertently contact you in the future. We may also need to retain some financial records for statutory purposes, for example Gift Aid.

Please note that you also have the right to lodge a complaint with the Information Commissioner's Office at www.ico.org.uk/concerns

Updating this privacy notice

GCUK may update this privacy notice by posting a new version on this website. If we update this privacy notice in a way that significantly changes how we use your personal information, we will bring these changes to your attention. Otherwise, we would recommend that you periodically review this privacy notice to be aware of any other revisions.

How to contact us

You can contact the Secretary if you have any questions about this privacy policy or our treatment of your personal information or if you wish to change your preferences:

Email: secretary@glistcancer.org.uk

Reference points

Guidance produced by the Charity Commission

Version Control - Approval and Review

Policy owner: Mark Atlay GCUK Secretary

Version No	Approved By	Approval Date	Main Changes	Review Period
1.0	Board	9 th July 24		At least annually