



# IT POLICY

September 2022

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GIST Cancer UK

[admin@gistcancer.org.uk](mailto:admin@gistcancer.org.uk)

[www.gistcancer.org.uk](http://www.gistcancer.org.uk)

Registered Charity Number: 1129219

# GCUK IT Policy<sup>1</sup>

## Policy

The GCUK community includes patients, carers, health care practitioners as well as the charities trustees, staff and volunteers. Having an effective IT infrastructure is essential to the successful operation of the charity and in meeting the needs of its community.

It is GCUK Policy to use readily available and accessible IT applications to support the GCUK community, calling on external specialist suppliers only where there is a clear need. GCUK will work with its community to promote the effective use of technology in supporting its aims, providing support and guidance when necessary.

GCUK adheres to the legal requirements of GDPR both in the UK and EU with respect to an individual's data privacy and data protection.

## Definitions

**Information technology (IT)** – the use of computers to create, process, store, retrieve, and exchange electronic data and information.

**Application** - a computer program designed to carry out a specific task.

## Objectives

GCUK aims to use IT to:

- Provide information to the GCUK community on GIST and its treatment.
- Enable the GCUK community to share experiences of living with cancer.
- Respond confidentially to individual queries.
- Support patient meetings and specialist PAWS-GIST clinics
- Support fundraising and related activities.
- Promote the needs of GIST cancer patients beyond the GIST community.
- Support the effective operation of the Board and the trustees in discharging their duties.

In so doing it will ensure that it meets legal and other requirements, for example, in respect of the use of personal data.

## Data Privacy & Data Protection

In order to build up our understanding of GIST, keeping patients, carers and medical professionals up to date with new information in relation to GIST/GIST Cancer UK (GCUK) and help administer our Patient meetings, it is helpful to keep a record of all those who contact GCUK so that we have a way to make contact when there is relevant news.

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<sup>1</sup> This policy includes associated procedures and current use made of different technologies. These are incorporated into one document to ensure that there is a single point of reference for the current use of IT software and systems.

The European GDPR (General Data Protection Regulations) and the UK equivalent regulations apply to the storage and processing of personal data and 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. Once a GDPR consent form has been signed (electronically or wet signature), the form is archived and relevant information added to the database. At a minimum we hold full name and some means of contact (i.e. at least one of: telephone number, email address, postal address). We will also record brief details of a patient's GIST and mode of treatment if provided.

We will only use this information for legitimate purposes (e.g: inviting to patient meetings, alerting patients to relevant clinical trials etc) and will never share with third parties without explicit consent. We will hold this information indefinitely, and update the information as required, unless explicitly asked to remove the data (consent withdrawal or on request of the individual).

As per provisions of the Data Protection Act, GCUK will provide any data we hold about an individual on request via telephone or email. GCUK will also anonymize an individual's data records held in the Database on request or on consent withdrawal.

The GCUK SQL database is secured via password protection and only available to approved users. Database storage is on Microsoft Azure platform and accessed via Microsoft Access application. No versions of the database will be stored on local machines to minimise any risk of data breach.

In the event of a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data, GCUK shall promptly assess the risk to people's rights and freedoms and if appropriate report this breach to the ICO ([ICO website](https://ico.org.uk/)).

## Responsibilities

GCUK will identify a designated lead and associated IT Support team who will take responsibility for ensuring that it has in place effective systems that meet sectoral good practice, for providing access to systems for those who need it and for associated training and development.

The IT Support team will utilise additional IT services where there is a specialist need. The current additional such services are listed in Appendix C and may be amended as circumstances change to ensure a cost effective and efficient delivery or to meet changing needs through notification to the Board.

The Board will ensure that it meets its legal requirements in terms of data protection and that its IT systems are appropriately secure. Information will only be held where it is essential for the effective operation of GCUK and details will be removed on request from individuals. A current list of the information routinely held is provided in Appendix B.

The Board will keep under continuous review the use made of IT to ensure that it continues to use technologies that are effective in meeting its objectives and that it has appropriate and sufficient licenses.

## Procedures

GCUK utilises IT in a range of ways to support its activities as indicated in Appendix A. This may be amended as the needs of the community change and develop through notification to the Board.

IT support covers Office 365 accounts and core Microsoft applications (primarily: Outlook, Calendar, SharePoint, Teams, Access (including Database) and Forms (for trustees), Listserv email issues (for all registered users), Helpline telephony service (for all users).

All trustees, volunteers, and other associates can request support with IT related issues, with a member of the IT Support team providing remote and/or onsite resolution within a reasonable timeframe.

GCUK will provide documented IT Support Process for the following services:

- Office 365 accounts and applications for trustees.
- Helpline telephone service
- Listserv site and email list (to facilitate online patient/carer discussion forum)

IT Support ([ITS@glistcancer.org.uk](mailto:ITS@glistcancer.org.uk)) can be contacted to provide support on designated services and may be able to provide support for additional relevant services depending on their nature.

Any service enhancement suggestions or new service proposals should be addressed to [ITS@glistcancer.org.uk](mailto:ITS@glistcancer.org.uk) for review in the first instance.

## Appendix A: List of IT services

GCUK currently operates the following services which require some IT capability:

- Office 365 accounts and applications for trustees.
- Helpline telephone service
- Listserv site and email list (to facilitate online patient/carer discussion forum)
- Facebook pages (social media)
- Twitter pages (social media)
- Instagram (social media)
- YouTube channel (social media)
- Websites (GCUK & PAWS-GIST clinic)
- Regional patient meetings may be video recorded.
- PAWS-GIST clinics use a PAWS-GIST Mailchimp template.
- GIST training video for GP's
- GIST patient literature is made available online

## Appendix B: List of information held

GCUK currently holds the following information:

- patients and their carers who have registered.
- hospital contacts (who request GCUK literature for their hospitals).
- contact details for clinicians and allied health professionals.
- contact details for fundraisers and supporters.
- contact details for pharma and other companies with an interest in GIST Cancer.
- GDPR consent forms for data privacy of individuals.
- PAWS-GIST information in a branded format
- A GCUK branded mail chimp template (e used for a newsletter or other communications such as patient meetings).
- Spreadsheet of fundraisers held on the GCUK SharePoint (this also records when the event is, needed for social media posts and certificates after, links to online pages, if a fundraising pack has been sent, and if we have permission to post on social media).
- A list of trustees since the formation of the charity with their contact details.
- A list of volunteers with contact details.
- A list of suppliers to the charity.
- Expense claims from trustees, patients and carers.
- A password protected Excel file of the online payment platforms used by the charity and relevant access credentials (user names/passwords).
- Documents to describe how the GCUK trustees and volunteers interact in order to deliver the charity service i.e. Who does what (organogram), procedures when someone registers with GCUK, fundraising and financial

## Appendix C: List of current external providers

### **Words and People – Website & Social media Agency**

Support the GCUK & PAWS-GIST websites, and email domains in addition to the old GIST Supportuk.com domain. They have also designed and support the GCUK & PAWS-GIST mail chimp platforms as well as introducing GCUK to other helpful IT support service providers.

#### **Andrew Fall**

[andrew@wordsandpeople.co.uk](mailto:andrew@wordsandpeople.co.uk)

Tel: 07540 841286

<https://www.wordsandpeople.co.uk/>

### **Spectrum IT support**

#### **Nigel Dowse**

[info@spectrumitsupport.co.uk](mailto:info@spectrumitsupport.co.uk)

Telephone: 01438 833 671

Mobile: 07773 445 997

[www.spectrumitsupport.co.uk](http://www.spectrumitsupport.co.uk)

### **Crystal Clear Systems Limited - Business Systems and Data Specialist**

#### **David Hardstaff**

[david@hardstaff.biz](mailto:david@hardstaff.biz)

Office: 01438 832724

Mobile: 07722 605545

Website: [www.crystalclear.systems](http://www.crystalclear.systems)

### **TxRx Communications Ltd – Helpline / telephony support**

#### **Tim Robinson**

[tim@txrxcomms.co.uk](mailto:tim@txrxcomms.co.uk)

+44 1256 810630

<https://www1.txrxcomms.co.uk/>

### **Imotion - Patient meeting and remote video recording**

#### **Dishad**

[dishad@imotion.com](mailto:dishad@imotion.com)

+44 (0)845 838 2682

[www.imotion.com](http://www.imotion.com)