



CRF Privacy Notice

Introduction

We are the Wellcome - HRB Clinical Research Facility at St James's Hospital (the "CRF"), a department of Trinity College Dublin, the University of Dublin at College Green, Dublin 2, Ireland (the "University").

This privacy notice sets out the basis on which any personal data we collect from you, or that you provide to us, will be processed by us. Please read the following carefully to understand our practices regarding your personal data and the steps taken by us to protect your personal data and your right to privacy.

The CRF and the University fully respect your right to privacy and actively seek to preserve the privacy rights of individuals who share information with the CRF and the University. Any personal information that you voluntarily provide to us will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection legislation, including the General Data Protection Regulation (EU) 2016/679 and the Data Protection Act 2018 ("**Data Protection Legislation**"). Under Data Protection Legislation, the University is the "data controller" of personal data that you provide to us.

The privacy notice explains the following:

- How we collect and use your personal data;
- The purpose and legal basis for collecting your personal data;
- How we store and secure personal data;
- Details of third parties with whom we share personal data; and
- Your rights under Data Protection Legislation.

If you have any queries or complaints in relation to the use of your personal data you can contact the Data Protection Officer for the University as follows:

Data Protection Officer
Secretary's Office, Trinity College Dublin,
Dublin 2, Ireland.

dataprotection@tcd.ie

Who does this privacy notice apply to?

This privacy notice applies to anyone that has provided personal information to the CRF as part of a service agreement, registering interest in service provision or as part of public or patient involvement in research conducted in the CRF.

Please note that this privacy notice does not apply to data collected as part of a research study. Participants in research studies at the CRF should refer to the information that will be provided to them by the study team.

How we collect your personal data?

The data we collect from you will be used by the CRF only in accordance with the purposes outlined in this privacy notice. We collect personal data from you when you have registered with the CRF, via website forms, application forms and documents, sign-in logs, email and phone enquiries.

The purpose and legal basis for collecting your data

We will collect your data in the following manner for the purposes and for the legal bases as set out below:

Who we collect data from?	Purpose for processing personal data	Description	Legal basis for processing
Participants attending the CRF	Participant bookings and attendance for study visits.	<p>We collect data regarding attendance in the CRF for study visits. We will only ever ask you to disclose as much personal information as is necessary for confirming and booking participant visits in the CRF and logging patient attendance on the St James's Hospital patient attendance/registration system.</p> <p>When Participants attend the CRF, we will collect the following information: name, MRN, date of birth, address and study number to confirm your attendance at the CRF.</p> <p>All participants attending the CRF must be registered on the St James's Hospital patient attendance/ registration system. For participants who are not already registered in St James's Hospital, we will collect the following additional information: gender and next-of-kin</p>	Necessary for the performance of a contract

		<p>(name and contact details). Data will be collected on a patient registration form.</p> <p>The data which we collect at this point is necessary for administration and patient safety in the CRF.</p>	
Interested parties visiting the CRF	Records of attendance to the CRF.	Interested parties visiting the CRF will include the following: researchers, research collaborators, health professionals, service providers, sponsor representatives and representatives of regulatory bodies. The CRF will collect the following information from interested parties visiting the CRF: date and time of visit, purpose of visit and visitor name. Where you are provided with a temporary swipe access card, we will also collect your phone number. This is for security and for health and safety reasons.	Legitimate interests of the CRF
Researchers and health professionals accessing CRF services	<p>Assessing applications for services or support that are submitted to the CRF.</p> <p>Carrying out our obligations arising from contracts entered into between researchers and the CRF.</p>	<p>We collect data when a researcher applies to us for provision of our services/ facilities to support a research study, study feasibility or research grant application.</p> <p>Generating reports, as part of our agreement with grant funders and to demonstrate use of funding, on support and services provided by the CRF.</p> <p>The type of information you may provide includes your curricula vitae (CV), work experience, professional qualifications, specialisations, board certification, educational background and contact data (your name, address, e-mail address and phone number). CVs should include information relevant to your employment history and education (degrees obtained, places worked, positions held, relevant awards, and so forth). We ask that you do not disclose sensitive personal information (e.g. medical information, ethnic origin,</p>	Legitimate interests of the CRF

		religion, philosophical or political beliefs, and financial data) in your application.	
Members of the Patient Advocacy Group	To contact Patient Advocacy Group members when involvement opportunities arise or to send information about the group's activities to members.	The type of information you may provide will include contact details (name, email, phone number, address – as per your expressed preference of being contacted) and a note about the kinds of patient and public involvement activities that interest you. This may include information about any health conditions you have or are interested in learning about.	Legitimate interests of the CRF
Event attendees or members of public applying to attend events	Course or event administration and to allow us to tailor training events to the needs of attendees and to liaise with you about future events.	If you attend a course or event that is run/hosted/facilitated by the CRF we will ask you to provide personal information including current job, professional qualification, specialisations and contact details.	Legitimate Interests of the CRF
Sponsor representatives or service providers	To allow us to liaise with you.	The type of information you may provide includes your current job title and contact data (your name, e-mail address and phone number).	Necessary for the performance of a contract
Collaborators or peer network participants	Administration and liaising with collaborators or peer network participants about projects.	The type of information you may provide includes your current job title, professional qualifications, work experience, specialisations and contact data (your name, e-mail address and phone number).	Legitimate Interests of the CRF
Website users	To allow us to improve the service we deliver and to improve the security of your interaction with the website. To allow us to make suggestions and recommendations to you and other users about services that may interest you or them.	We will collect information on your IP address, operating system and browser type where this is available. This information is logged automatically by the web server.	Legitimate interests of the CRF

Who do we share your data within the University?

Your data may be shared with the following areas of the University where compatible with its primary purpose:

- Trinity Research and Innovation Office: we will share data received from researchers or health professional for the purposes of putting in place contracts between the researcher and the CRF;
- Estates and Facilities; and
- Financial Services Division for the purposes of issuing purchase orders and invoices for services provided.

How we store and secure your data

Any data we collect from you will be stored confidentially and securely as required by the University Information Security Policy. The University is committed to ensuring all access, use of, and processing of University data is performed in a secure manner.

In keeping with the data protection principles we will only store your data for as long as is necessary and in accordance with our Records Management Policy and Records Retention Schedule. For the purposes described here we will store your data for the following periods:

1. Applications or consultations to the CRF for support/services will be stored for up to 5 years after cessation of service/support;
2. Data provided from service providers to support service provision as part of a Clinical Trial or Clinical Investigation will be retained in accordance with the approved archiving period as per applicable legislation to demonstrate that the trial/ investigation has been conducted in accordance with legal and regulatory requirements;
3. Data provided in relation to training course attendance will be stored for 5 years to conform with CPD accreditation and financial reporting requirements; and
4. Data provided in relation to your role on a peer network or as a collaborator will be retained for up to 5 years after cessation of your role.

When we store your personal data on our systems the data will be stored either on the CRF premises or on secure IT platforms hosted by the University within the European Economic Area (EEA), which is also subject to European data protection requirements.

We may store or share your data outside of the EEA when using cloud services for the secure storage of data. Some cloud services providers store data in international data centres e.g. the US. The University will only use services that are compliant with the European Data Protection Regulation and which satisfy the conditions for processing personal data outside the EEA.

Who might we share your data with?

We will share your data with third parties only where necessary for purposes of the processing outlined here and where there is a legal basis to do so. We will share your data with the following third parties:

- On occasion, we may work with external organisations to deliver courses/ events, this includes but is not limited to external speakers, event leads, venues and caterers. Relevant information will be shared where essential and appropriate for course/event delivery;
- We may provide contact details for investigators to study Sponsors as part of feasibility review;
- St James's Hospital for the purposes of registering new patients and logging attendance on the St James's Hospital patient attendance system;
- Government agencies such as the Revenue Commissioners, Data Protection Commissioner, or other agencies for the detection, investigation or prosecution of offences to enable them to perform their function;
- The Health Products Regulatory Authorities, European Medicines Agency or other regulatory bodies in performance of their duties where research falls within their remit;
- Research ethics committees, where you have requested our services in relation to regulatory support for research ethics applications;
- IT back-up providers;
- Shredding/ archiving companies contracted to the University; and
- Auditors (including financial and sponsor audits)

When we share your data with the third parties outlined here both the CRF and the University will ensure that the data is only processed according to our specific instructions and that the same standards of confidentiality and security are maintained. Once the processing of the data is complete any third parties with whom data was shared will be required to return the data to the University save where they are required to retain it by law.

What are your rights?

You have the following rights over the way we process your personal data:

Right of Access

You have the right to request a copy of the personal data we are processing about you and to exercise that right easily and at reasonable intervals.

Withdraw Consent

You have the right to withdraw your consent where that is the legal basis of for processing your personal information.

Rectify

You have the right to have inaccuracies in personal data that we hold about you rectified.

Erase

You have the right to have your personal data deleted where we no longer have any justification for retaining it subject to exemptions such as the use of anonymised data for scientific research.

Object

You have the right to object to the processing of personal data if:

- We have processed your data on the basis of public interest or in order to pursue a legitimate interest if you believe the processing to be disproportionate or unfair.
- The personal data was processed for the purposes of direct marketing or profiling related to direct marketing.
- We have processed the personal data for scientific or historical purposes or statistical purposes unless the processing is necessary for the performance of a task carried out in the public interest.

Restrict Processing

You have the right to restrict the processing of your personal data if:

- You are contesting the accuracy of the data.
- The Personal data was processed unlawfully.
- You need to prevent the erasure of the personal data in order to comply with legal obligations.
- You have objected to the processing of the personal data and wish to restrict the processing until a legal basis for continued processing has been verified.

Portable Format

Where it is technically feasible you have the right to have a readily accessible machine-readable copy of your data transferred or moved to another data controller where we are processing your data based on your consent and if that processing is carried out by automated means.

Contact

If you have any queries relating to the processing of your personal data for the purposes outlined above or you wish to make a request in relation to your rights you can contact:

The Data Protection Officer, Trinity College Dublin at dataprotection@tcd.ie

If you wish to make a complaint or escalate an issue relating to your rights you can contact the Data Protection Officer at dataprotection@tcd.ie .

Finally if you are not satisfied with the information we have provided to you in relation to the processing of your data, you can also make a complaint to the Data Protection Commissioner via the link in their website [Making a Complaint to the DPC.](#)

Changes to this privacy notice

We reserve the right to update this privacy notice at any time and will provide you with a new privacy notice when we make substantial updates to this privacy notice.