

Privacy notice

The purpose of this Privacy Notice is to explain to you, our participants, how we collect share and use the personal information about you which forms the RKD Biobank resource. We are required to provide the information set out below in accordance with the Irish Health Research Regulations.

Fundamentally, we should like to assure you that we will only process, store and use your data in a manner that is consistent with the basis on which you joined RKD Biobank (as described in the information leaflet and consent [form](#)). This Privacy Notice sets out the types of data we have collected from you and how and by whom that data is used. It also sets out the lawful basis on which we process your data, your rights as a data subject and your rights to withdraw from RKD Biobank.

We would also emphasise that wherever possible your data is de-identified such that direct and indirect identifies are removed. We only use identifiable data where necessary: for example when we contact you with a participant newsletter or to advise you about a clinical trial we feel may be of interest to you.

Useful links

[Participant Information leaflet and Consent Form](#)

[Data privacy impact assessment](#)

[Withdrawal form](#)

[The types of data RKD Biobank processes](#)

What personal information does RKD Biobank collect?

RKD Biobank collects personal information about you from two sources (1) directly from you and (2) through linkage to your health records. These are explained in more detail below:

Data collected directly from you

Initial Collection

When you were recruited to join RKD Biobank you will have visited an RKD Biobank research clinic and provided some data about yourself - this will have included measures such as your weight, height and biological samples such as blood and urine. Any identifiable data obtained at recruitment is held separately on a separate log to which only the relevant research nurse and site investigator have access.

Ongoing collection

Following the original recruitment RKD Biobank has continued to collect more data on a periodic basis, such as:

- data collected when participants attend a study clinic or hospital
- data collected through participants completing online questionnaires
- data collected from assays performed on the samples you provided

Data generation

With the data and samples that you provide us we can generate further data to enhance our database, particularly from undertaking assays of the samples. This includes, by way of example, biomarkers - which include common biomarkers, such as cholesterol, infectious disease markers, proteomic and metabolomic markers - and genetic data (ranging from genotype to exome sequence to whole genome sequence). All assay work is conducted in a manner whereby the participant remains de-identified.

Further, all our approved researchers are also obliged to return the results which underpin their research at the end of their research project. In turn these results are made available for other researchers to access.

Who does RKD Biobank share my data with?

Access to your data is strictly limited to:

- the study site/hospital where you are seen for your clinical care;
- Approved researchers whose research project has been approved under our Access Procedures, which means that the researcher has to be a bona fide researcher and enter into a bilateral agreement with TCD. If you would like more information about the approved research projects which have access to RKD Biobank data, please click the link below.

[View approved research](#)

RKD Biobank's lawful basis for processing your data

A legal requirement of the RKD Biobank is that we tell you about the legal basis on which we will process your personal data.

As RKD Biobank is a research project, consent was sought from all participants for their participation in the Biobank. Through the information leaflet and [consent form](#) RKD Biobank set out to explain the basis of such participation and a summary of the scope to which participant data would be used by RKD Biobank and the research community.

The legal basis under which we process your data is:

- Article 6(1)(e) - Public Interest and
- Article 9(2)(j) Scientific Research.

Explicit consent is sought as an appropriate safeguard to rights of the data subject as mandated by the Health Research Regulations.

Your Data Protection Rights

Pursuant to the Health Research Regulations individuals have a number of rights:

Rights to be forgotten, erasure and withdrawal: these rights are covered by your ability to withdraw from RKD Biobank at any time for any reason (although we should add that we very much hope that you choose not to exercise that right so that your data can continue to be

used to help researchers study the causes, prevention and treatment of many different diseases).

Participants have the right to contact, at any time, the RKD's data protection authority – the Irish Data Protection Commission - if they have any concerns about RKD Biobank's use of personal data and/or RKD Biobank's approach to data protection and the Health Research Regulations.

Protecting your data

RKD Biobank and its appointed data processors store your data securely and to the highest industry and professional standards. Before RKD Biobank provides data to researchers, we first remove all the personal identifiers so that individual participants cannot easily be identified. In addition, your data are only provided to researchers on the execution of a legal agreement prohibiting the researcher from trying to identify a participant.

Only a very limited number of people working in the RKD Biobank centres have access to participants' data with the personal identifiers (which is necessary in order to allow us to interact with you and add more information about each participant as it becomes available). These individuals are subject to strict confidentiality provisions and are required to undertake regular data security training.

Retention of data

RKD Biobank will store participants' data for as long as it has a legitimate interest in doing so. The RKD Biobank project is a long-term study and participants' data will be kept for the duration of the project. However, should a participant wish to leave RKD Biobank they can do so at any time.

International Data Transfers and industry engagement

Our objective is to set up and manage a major research resource for health-related research that is in the public interest. We aim to understand the causes of rare autoimmune diseases, develop precision medicine technologies, and provide the foundation for development of novel therapies. Engagement with international collaborators is an essential part of this journey; sometimes these collaborators are in the non-academic (industry) domain. Our engagement with them is always defined using a formal bilateral agreement that determines what they are allowed to do with the samples and data, ensuring that they are used to further the public interest mission of RKD Biobank. RKD Biobank's main computer storage is located in Trinity College. Approved researchers and RKD Biobank's other third-party service providers operate around the world. This means that your data may be processed in these countries. Nevertheless, we take the appropriate safeguards to ensure that your personal information will remain protected in accordance with this Privacy Notice. Such safeguards include mechanisms approved by the Health Research Regulations such as Standard Contractual Clauses and data transfers to countries covered by an "adequacy decision".

Data Protection Officer

Trinity College has a research Data Protection Officer ("DPO") who can be contacted with any questions or concerns relating to RKD Biobank's approach to data protection and the Health Research Regulations. Please write to the DPO using researchDPO@tcd.ie or via post: Trinity College Dublin, College Green, Dublin D02 PN40.

Withdrawal from RKD Biobank

You are free to withdraw at any time from the study without giving us a reason. You are welcome to discuss concerns with us at any time, and the various options you have for withdrawal.

Participants can withdraw at one of two levels:

No further access

This means that RKD Biobank would no longer contact the participant or obtain further information from health records in the future, but still has permission to use the information and samples provided previously. You need to contact RKD Biobank by phoning 01 896 4810, email us at rkdbiobank@tcd.ie, or you can send us a letter at the address on this page to request a Withdrawal Form.

No further use

In addition to no longer contacting the participant or obtaining further information, any information and samples collected previously would no longer be available to researchers. RKD Biobank would destroy samples (although it may not be possible to trace all distributed sample remnants) and would only hold information for archival audit purposes. Such a withdrawal would prevent information about the participant from contributing to further research, but it would not be possible to remove data from research that had already taken place. You need to contact RKD Biobank by phoning 01 896 4810, email us at rkdbiobank@tcd.ie, or you can send us a letter at the address on this page to request a Withdrawal Form.

RKD Biobank contact details

If you want to contact RKD Biobank you can do so as follows:

Email; rkdbiobank@tcd.ie

Phone: +353 1 896 4810

You can write to RKD Biobank at:

Rare Kidney Disease Registry and Biobank,

Trinity Health Kidney Centre,

Office 2.13 / Lab 1.06,

Trinity Translational Medicine Institute,

St James' Hospital,

Dublin 8,

D08 W9RT,

Ireland.

You can also contact the RKD Biobank DPO at any time using the contact details set out in the DPO box above.