
Privacy Notice

Who are we?

The Department of Twin Research (DTR) at King's College London is a research department within the School of Life Sciences. The DTR collects, stores and uses personal information (any information which relates to or may identify an individual) about certain groups of people with whom we interact to perform medical research under the banner of the TwinsUK registry. King's College London (KCL) is one of the top 25 universities in the world and the fourth oldest university in England. The DTR has been conducting cutting-edge health related research for over 25 years.

KCL is the 'data controller' as defined in the Data Protection Act (the organisation who determines why and how personal data are processed). The DTR complies with the requirements of the European General Data Protection Regulations (GDPR) and the Data Protection Act (2018) regarding the collection, processing, storage and disclosure of personal information and special categories of data.

The KCL Core Privacy Notice information can be found here: <https://www.kcl.ac.uk/terms/privacy>. This privacy notice is in addition to the KCL one and explains how we use data that you share with us.

Who is this document for?

- Participants of the TwinsUK cohort
- Visitors to our website
- People using or posting information on our social media channels
- Researchers

Why are we processing your personal information?

This privacy notice tells you what to expect when the DTR collects personal information. We are performing a longitudinal cohort study, collecting similar types of data over time. Data is collected by regular questionnaires and analysis of donated biological samples from the cohort of over 12,500 twins. We may from time to time receive other complimentary data from sources such as health or environmental records. We work very hard to ensure that these data are as accurate as possible and to remove the risk that any individual may be personally identified from the data. We share these "de-identified" data with bona fide researchers anywhere in the world, to conduct health-related research working towards the KCL vision of making the world a better place.

What information does the Privacy Notice apply to?

- Information provided when visiting our website
- Information posted on social media
- Participants who:
 - Register on the TwinsUK cohort with names and contact information
 - Phone, email or text us

- Provide questionnaire responses
- Book & attend clinic visit appointments
- Update their contact details
- Provide consent forms or other written information
- Allow us to collect test information at visit in clinic or home
- Provide bio-samples
- Allow us to collect data from routine official records (e.g. NHS and other health records; school, college and university education records; economic records; environmental, census and other similar data)
- Researchers completing an online proposal form
- Researchers completing a data transfer agreement or material transfer agreement

It also applies to the way we handle, process and store your information and communicate with you.

Where applicable, further information on your privacy, confidentiality and anonymity is provided when we ask you to take part in clinical visits or to complete questionnaires.

Responsibilities

All DTR personnel who work with the data have some responsibility for ensuring data is collected, stored and handled appropriately.

Each DTR staff member handling personal data must ensure that it is handled and processed in line with the KCL and DTR Data Protection Policy and Data Protection principles.

- The only people able to access data covered by this policy should be those who need it for their work
- Data should not be shared informally
- KCL provides training to all employees to help them understand their responsibilities when handling data
- Employees should keep data secure by taking sensible precautions and following guidelines
- Strong passwords must be used, and they should never be shared
- Personal identifiable data should not be disclosed to unauthorised people, either within the Department, the University or externally
- Data should be regularly reviewed and updated if it is found to be out of date or if it is no longer required. It should be deleted and disposed of securely.
- Employees should request help from their manager if they are unsure about any aspect of data protection.

What is the legal basis for collecting and processing the information?

Our legal basis:

The DTR's mission statement is: *Twin research for a healthy future - Researching the link between our genes, the environment, and common diseases.*

Our legal basis for using your information, under GDPR and the Data Protection Act 2018, is:

- 1) performance of a task carried out in the public interest (Article 6(1)(e) in the GDPR); and, where special categories of data are involved:
- 2) scientific or historical research purposes or statistical purposes (Article 9(2)(j) in accordance with Article 89(1)).

In order to conduct our research effectively, we will collect and store “personal information” and “special categories of data”. The GDPR defines the latter as information about an individual’s race; ethnic origin; politics; religion; trade union membership; genetics; biometrics (where used for identification purposes); health; sex life; or sexual orientation.

This legal basis within GDPR and the Data Protection Act 2018 is separate to, and in addition to, our seeking consent to take part in the research process, which we use to help ensure our research is ethical and complies with other applicable laws.

We will never disclose your “personal information” to third parties unless we are under a duty to disclose or share these data to comply with any legal obligation, or in order to enforce or apply our terms of use and other agreements.

For more information and definitions, see: <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data/>

Privacy Notice for participants of the TwinsUK cohort

Our commitment to you

Taking part in the TwinsUK cohort is voluntary and you are free to withdraw at any time without providing a reason. You may be offered the choice to take part or not in research projects. We will never share your **personal** information with researchers and data that we share for research purposes is identified only by an ID number. This process is referred to as “pseudonymisation”.

We do not perform research with the primary aim of commercial gain - our research aims to benefit society. Requests for data and proposals for collaboration go through our Data Access Committee (comprising senior management staff with relevant knowledge across a broad range of areas) and are checked to have a valid scientific aim and to meet ethical standards.

Communicating with us

When you phone, email or text us we will verify your identity and ensure that you are a study participant before proceeding. We record all communications (description, date/time and method) in our database. Being a twin cohort, we regularly communicate with multiple members of the same family at the same time. With that in mind, we are extra vigilant not to divulge an individual’s personal details, information and communications with other family members.

Completing online or postal questionnaires

Paper questionnaires are identified by an ID Number only and will not contain easily identifiable information. Online questionnaires are administered using a secure encrypted interface and will either be anonymous or use an encrypted web link. We use a secure web-based application, called REDCap, for building, distributing and managing online surveys and data collection forms. The REDCap servers that we use are housed within King’s College secure Data Centres and behind a secure firewall.

When you login to REDCap, our website will collect standard internet login information and details of visitor behaviour patterns to help us understand how people are accessing different parts of the questionnaire. We will also use this information to decide if you have completed your questionnaire and may then contact you to remind you to complete your questionnaire if you have not already done so.

On the rare occasion when it is required by a particular research project, we may collect personally

identifiable information. In these cases, we will make it clear why we are collecting this and explain what we intend to do with it and how it will be safeguarded. You will always be given the choice not to answer these types of questions.

How we will use your personal details

Your personal details such as contact information etc. are treated as highly confidential and only a very few key personnel may have access to them. Your personal details will not be shared with researchers. They may be shared with certain select third parties providing service work for us. At the time of this document update we have non-disclosure agreements with the following companies (this list is not exhaustive and can change at any time):

- Iron Mountain (for long-term storage of questionnaires)
- Abacus Data & Mailing (for printing and collating large mailings)

We only share your personal details with these third parties under strict conditions set out in a legally binding data processing agreement. This offers assurances about the use, access and security of any personal data disclosed and does not allow any onward disclosure or sale of personal data by the third party. We use Royal Mail for posting questionnaires, invitations to take part and other correspondence.

Some research projects need information based on locations - such as where you live/work. We never share specific postcodes with any researchers. Rather we use the first 4 alphanumeric characters of the postcode to allow aggregation of information near where you live/work - such as levels of air pollution near your home, or crime rates in your neighbourhood.

How we will use your research data

We only collect your data with permission, for example by asking you to take part in a study, attend a clinic visit or complete a questionnaire. Once we have collected it, it will be stored securely and confidentially. We de-identify research data so that individuals cannot be identified from it. We will then provide this information to researchers on request that have been approved by the Data Access Committee. This process is described in detail here:

https://twinsuk.ac.uk/wp-content/uploads/2022/12/DTR_DataAccessPolicy_2022V1.pdf

A list of approved research projects is available on request.

Collecting data from routine official records

Where we have permission, the DTR may identify and take a copy of parts of official records such as those held by the NHS, the education system and other government information centres. We call this way of collecting information, 'data linkage'. Before we start linking to records, we will write to you explaining how this works and give you the opportunity to opt out. We accept your right to decide that you don't want the DTR to access your records, and if you feel this way it is important that you tell us.

Data linkage is a one-way flow of information only. We do not provide the organisations who keep your records with any information that you have provided to the DTR via questionnaires and/or clinic visits.

Therefore, collection of information by the DTR will not affect the services you receive from government departments in any way. To make sure we identify your records accurately we will use your personal details (e.g. name, address, date of birth, NHS ID) to make an accurate link to the equivalent information in the official records but again, these personal identifiers are not made available to researchers.

You can request from us and review the relevant documents that give more details on why we need these data, how we collect them and highlight the benefits of data linkage to the scientific community.

UK Longitudinal Linkage Collaboration (UKLLC)

The DTR (TwinsUK) is one of many longitudinal research studies contributing to the Longitudinal Health & Wellbeing National Core Study (LH&W NCS). This has been designed by the UK's top scientists to allow longitudinal studies - such as TwinsUK - to fully contribute to the national research programme and policy development.

To achieve this, the LH&W NCS has established the UK Longitudinal Linkage Collaboration (UK LLC). This is a secure research server, run by the University of Bristol (Data Controller) and supported by the University of Swansea (Data Processor for the University of Bristol). Following a consultation with our TwinsUK Volunteer Advisory Panel, we contribute some of our datasets to the UK LLC and allow the UK LLC to link to participants' education records as well as health and environmental records, according to your preferences as indicated on your TwinsUK consent form or earlier data linkage decision form. To establish the linkage to health and wellbeing and other records we provide a list of your personal identifiers (name, NHS ID, address) to the NHS Wales Informatics Service only. They will never see your study data. This NHS organisation will send identifiers to the groups conducting the linkages:

- The UK NHS authorities who share records with researchers (including NHS Digital in England, Public Health Scotland/eDRIS/National Records of Scotland in Scotland, SAIL databank in Wales, NHS Northern Ireland Business Development Organisation in NI);
- The UK statistical agencies (including the Office for National Statistics in England and Wales, eDRIS/National Records of Scotland in Scotland, Northern Ireland Statistics & Research Agency in NI);
- The University of Leicester will receive address data only to link this to precise location and then map information about this place (such as air pollution, noise data, services and the amount of greenspace around the property).

The data is stored on secure servers controlled by the University of Bristol (the servers are located and run by the University of Swansea). The UK LLC will make available a full list of researchers using the UK LLC data and the purpose for this, which can be obtained by emailing project-ukllc@bristol.ac.uk. The UK Data Protection Act 2018 provides individuals with rights over how their data are used. The UK LLC and the DTR support these rights.

All participants' data held in the UK LLC will be de-identified at all stages, meaning that research teams, as always, will never be able to identify whose data they are working on and we make sure that all the principles of the DTR are upheld.

The TwinsUK Resource Executive Committee (TREC) remains the Data Controller for your data. Researchers can apply to use any of the data held in the UK LLC. TwinsUK will retain complete control over who accesses TwinsUK data. TREC will review every request to use TwinsUK data and only allow access to bona fide researchers carrying out health research for the public good.

You may check and update your linkage preferences by contacting our team using the details below.

Due to logistical constraints, your linkage preferences will apply to both TwinsUK's ability to link to your records as well as the UK LLC. For example, if you agree to health and education records linkage, both

TwinsUK and the UK LLC will be able to link to your health and education records. If you set your preferences to not allow linkage to your environmental records, neither TwinsUK nor the UK LLC will be able to link to your environmental records.

If you have opted out of allowing your health data to be used for research or planning through your GP surgery or online, then even if you decide to agree to health linkage, we will not be able to do so. You can find out more about the National Opt-out and set your permissions here: <https://digital.nhs.uk/services/national-data-opt-out>

More information about the UK LLC is available on their website: <https://ukllc.ac.uk/>

Who we share data with?

Over the years twin volunteers have helped the DTR become an extremely data-rich scientific resource for the research community. Researchers working at universities, government departments, charities and other research organisations across the world may apply to access research data. Each application is assessed by the TwinsUK Resource Executive Committee (TREC), who decide whether the researcher is legitimate, if the data requested is needed to conduct the research, and if the research project can be conducted in line with the commitments we have made to you.

We only share data in a way that guarantees the confidentiality of your identity.

Privacy Notice for visitors to our website

We will collect standard internet log information and details of visitor behaviour patterns. These are collected to help us monitor the usage to see what is popular and what is not, to help improve the website. We do not make any attempt to find out the identities of those visiting our website. If we decide to collect or associate personal information at any point on the website, we will be open and transparent and inform visitors about it. Please see the separate document on our cookies policy.

[Privacy Notice for people using or posting information on our social media channels](#) The DTR has a social media presence to keep the members of our cohort informed and to publicise the work we do. At the latest review of this document, we maintain presence on Twitter, Instagram, Facebook and YouTube. Any information posted voluntarily on these channels is covered by the terms and conditions of the respective site and is in the public domain. Please be aware that you have a responsibility to ensure that information you post on our social media sites is within the bounds of the law.

The DTR will not use data gleaned from social media for research purposes without asking your permission. We will not attempt to use social media to collect your personal details. Social media is to only be used as a communication tool between us and you.

Privacy Notice for Researchers

We hold your name, institution name and contact details plus any application forms for any data and bio-samples that you have ever sent to us on an internally accessible secure database. We use this data for historical cross-checking purposes and to inform our funders of our data-sharing activity. We will use this information, so we can communicate with you about your proposal. We may also collect your personal details on several supporting documents related to your proposal. These may include data access agreements, data transfer agreements, material transfer agreements, confidentiality agreements or data user responsibilities agreements. We may also collect your personal details when you submit a manuscript for review.

We will also use the contact information to perform annual audits and to inform you of your obligations regarding our data and to receive data back from you where appropriate. Your name and institution name may be used in reports to our funders regarding activity based around the data we share with you.

The accuracy of your information is important to us. Please let us know if any of your details change or you move institutions.

We will not use your information for any other purpose and we will never sell your personal information to other organisations.

What are your rights?

By law, you have certain rights over your personal information:

- To receive a copy of your information
- To ask us to correct any errors
- To delete it once we no longer need it
- To ask us to stop using your information in a certain way
- To ask for certain information in a portable, electronic format
- To object to certain uses of your information (for example, marketing and automatic profiling or decision making)

For more information about this please contact us at twinsuk@kcl.ac.uk.

To make a request to us for any personal information we may hold on you, please see the document "Request for personal information". If we do hold information about you, we will give you a description of it; tell you why we are holding it; tell you who it could be disclosed to; and let you have a copy of the information.

How long do we keep your information for?

King's College London's [Records and Data Retention Schedule](#) stipulates how long relevant records are kept. The TwinsUK cohort within the DTR is a longitudinal study and as such the data and records belonging to the DTR, King's College London will be kept in perpetuity for the lifetime of the study.

[How to complain?](#)

The DTR is part of King's College London, who is the Data Controller for the information directly collected by the DTR.

The DTR aims to meet the highest standards when collecting and using personal information. We encourage people to tell us if they think that our collection or use of information is unfair, misleading or inappropriate. We would also welcome any suggestions for improving the way we handle your personal details. Please get in touch with us via email: twinsuk@kcl.ac.uk

If you would like to complain about our handling of your data, contact the University's Data Protection Officer by:

- email - info-compliance@kcl.ac.uk
- post - Information Compliance team, King's College London, Room 5.20
JCMB, 57 Waterloo Road, London SE1 8WA

[About this privacy notice](#)

This is version 1.5 of the privacy notice reviewed in December 2024