

TWINSUK

PROGRAMME OF RESEARCH



VOLUNTEER INFORMATION SHEET

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VOLUNTEER INFORMATION SHEET

WHAT IS TWINSUK?

TwinsUK aims to discover the genetic and environmental causes of a wide range of conditions and to explore the differences in how we age. By using clinical and questionnaire data and samples such as DNA, we can compare similarities and differences between identical and non-identical twin pairs. These comparisons help us to estimate the importance of known, and new, genetic and environmental influences on health and wellbeing.



WHY AM I BEING INVITED TO TAKE PART IN TWINSUK?

You may take part in TwinsUK if you:

- Are a twin and both you and your co-twin want to join
- Were born in and/or are resident in the UK
- Are of any age, although most of our studies at present are for 18+
- Are identical or non-identical
- Are same sex twins or mixed sex twins



With your permission, we may also invite family members and household members to take part in TwinsUK so that we can further investigate how genetics and the environment affect health.

This leaflet gives details about what taking part involves.

WHERE WILL THE STUDY TAKE PLACE?

The research will take place either at the Department of Twin Research (DTR) at St Thomas' Hospital in London, or at home if you are taking part in a postal study or questionnaire. Occasionally we may invite you to take part in research at a partner centre elsewhere in the UK or during a home visit. If you are travelling to a clinic visit, we will reimburse public transport fares and petrol mileage up to £80. For fares over this, please contact our team first so we can help with making arrangements.



WHAT DOES TAKING PART IN TWINSUK INVOLVE?

TwinsUK is a longitudinal (ongoing) study, and you will typically be invited to take part in routine longitudinal visits every three to four years. Depending on your age, zygosity (whether you are identical or non-identical twins), previous involvement in research, clinical history or test findings, we may also invite you to participate in substudies involving research visits, postal studies and/or questionnaires. These may take place at the same time as your longitudinal visit or on a separate occasion. Research visits usually take around 3-4 hours. Participation in postal studies and questionnaire usually takes less than 1 hour.

Taking part in TwinsUK may involve some or all of the following:

1



Completing questionnaires

2



Having clinical assessments and tests, such as physical measurements, fitness tests, skin assessments, dental and oral assessments, allergy testing, eye tests, hearing tests, taste tests, and other sensory tests, for example temperature

3



Donating biological samples such as blood (for DNA and other parts of the blood), hair, nail, stool, semen, saliva and tissues (biopsies)

4



Taking psychological tests and tests to understand brain function

5



Having clinical scans such as MRI and DXA (to measure bone density), ultrasounds, EEGs, photographs and fingerprints taken, and other related tests

6



Using smart clinical devices or mobile phone apps to record, monitor and track health measures, diet, sleep, mood, movement, location and exercise to name a few

7



Taking part in focus groups or interviews

8



Environmental samples such as drinking water, soil, or dust

9



Linkage to your health, education and environmental records

We may also invite volunteers to take part in studies that involve lifestyle and/or dietary changes, including dietary supplements, probiotics, following a specified or standardised diet, or other changes that do not involve medicinal products.

We may also invite you to have a photograph or video taken to help with our publicity, for which we will ask your permission.

We will take most of these tests and samples when you attend a clinic visit, however we may ask you to collect some samples or information at home.

We will store your samples and data in the TwinsUK BioBank. For existing TwinsUK members, your previously donated samples and data will continue to be stored in the TwinsUK BioBank.

DO I HAVE TO TAKE PART IN TWINSUK?

No, you can choose whether you want to take part in TwinsUK or not.

If you do decide to join TwinsUK, you will be invited to take part in routine, longitudinal clinic visits and other studies. You can choose whether you want to take part in these visits and studies. To help you decide, we will provide information about the research tests and what they involve either over the telephone, in an information pack or in an email, through a substudy information sheet.

You can decide to take part in all of the tests on offer, some of the tests on offer or none of the tests. You can make this choice at any time. If you choose to take part in some or all of the tests, we will ask you to sign a consent form to show that you have given your permission.

DO I NEED TO DO ANYTHING TO PREPARE FOR A RESEARCH VISIT?

If you are coming in for a visit, we will give you full instructions if you need to fast overnight or if you need to provide biological samples or questionnaires ahead of the visit. Please continue to take any regular medication, as you would normally do, preferably with water only. If you have diabetes, please do not fast and inform us of this before your visit. In your pre-visit pack you will also be advised on the best clothes to wear.



WILL I BE GIVEN ANY MEDICATION AT THE VISIT?

Depending on the tests you are doing, we may give you medication such as eye drops or a local anaesthetic (numbing medicine), similar to that used at the dentist, prior to a biopsy. We only use approved medications and do not ask volunteers to use any investigational medicines in any part of our study.

LINKING TO YOUR DATA

Data about us is collected when we interact with different organisations. Data linkage enables TwinsUK to accurately and confidentially collect information from your official records without disturbing TwinsUK members.

We will ask your permission to request additional information about you through linkage to your health, education and environmental records held by official organisations and government bodies.



This has a number of benefits for both TwinsUK members and researchers:

- Some may find it difficult to take part in projects at TwinsUK. Data linkage is an easier, effortless way to be involved in vital research.
- Even if you have been very active in TwinsUK and attended many visits, there may still be some 'gaps' of information in what we know about you. Data linkage can help fill these and create a bigger picture so that we can accurately carry out our research.
- Some of the most important information about us is not something we necessarily know or remember. Data linkage helps to collect this information. For example, the precise type and dose of antibiotics you may have been given in the past.

We will securely share identifiers such as your name, date of birth and NHS number with official organisations that hold your records. They will then provide us with the linked data. The data is imported into our database with any information that could directly identify you removed. The data is linked with your current TwinsUK pseudonymised data using a unique, de-identified number.

If you take part in TwinsUK, you will need to indicate on your consent form which, if any, types of data you would be happy for us to link to. We will always respect your decision, and you may contact us at any time to change which of your data we link to.

For more information about the types of data we link to and how, please read more here:
<https://twinsuk.ac.uk/about-us/further-information-about-data-linkage/>

The UK Longitudinal Linkage Collaboration

During the COVID-19 pandemic, TwinsUK united with other cohorts in the UK to pool together our data in order to advance COVID-19 research, through the UK Longitudinal Linkage Collaboration. The data is held securely at the University of Swansea and managed by the University of Bristol.

Now, the UK LLC is expanding to allow researchers to study research questions beyond COVID-19. The UK LLC will hold research data that cohorts choose to share on their participants and link to health, environmental, education and administrative records depending on each study's permissions. TwinsUK will share some of our data sets with the UK LLC, and allow the UK LLC to link to participants' health, education and environmental records according to your preferences as indicated on your TwinsUK consent form. All participants' data held in the UK LLC will be de-identified at all stages, meaning that researchers and the UK LLC staff cannot identify anyone from the 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. The TwinsUK Resource Executive Committee will review every request to use TwinsUK data and only allow access to bona fide researchers carrying out health research for the public good, as described below in 'What will happen to my data and samples?'.

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

WHAT ARE THE ADVANTAGES OF TAKING PART?

Your involvement will contribute towards the advancement of health research. You can find out more about our research findings through our website news stories [HERE](#).

For some studies, including the longitudinal clinic visit, you will receive a set of clinically useful results that you can take to your GP, which may help identify health conditions (see Test results below).

TEST RESULTS

The tests we use are purely for research purposes, and so your visit to the DTR is not like a health check with your doctor. However, some of our research tests can be used to identify health problems. We will send the results of these tests to you in a report within 6 to 8 weeks of your visit. If you would like to discuss what your results mean for your health, we will recommend you speak with your GP and share a copy of your results letter with them. We will not send your routine results to your GP directly. For some studies, we may contact you and your GP if there are incidental findings that require further attention.

Some of the tests we do are useful for research but currently have no clear medical meaning, for example microbiome testing. This means that neither we, nor a GP, can interpret the results reliably. Other tests, such as the genetic tests, are carried out in a research laboratory rather than a clinical laboratory and therefore cannot be used to diagnose health-related issues. We will therefore not tell you the results of any of these tests.

WHAT ARE THE DISADVANTAGES OR RISKS OF TAKING PART?

You should not experience any serious side effects whilst taking part in TwinsUK studies. However, you may experience the following minor side effects, depending on which tests you take:

- You may feel slight discomfort when giving a blood sample.
- You may feel slight discomfort when having a cannula inserted. There is also a small risk of infection and tenderness.
- Some sensory tests may leave a small temporary area of reddening on the skin.
- The bone mineral density scan (DXA scan) delivers a very small dose of radiation – less than the amount we are exposed to in our daily lives. If you are pregnant, or think you might be, you should let us know, as we will not ask you to do this scan.
- If you have volunteered to have a biopsy, it will probably leave a small scar. There is also a small risk that you will experience some bleeding, tenderness and a possible risk of infection.

- If you have volunteered to have a biopsy, there is a risk of a reaction to the local anaesthetic used to numb the area. Research staff will be fully trained to manage this, and you should not take part in a biopsy if you are allergic to anaesthetics.
- Some specialised procedures will involve an extra consultation with qualified research staff to make sure that you are fully aware of any risks before deciding to go ahead.

There are also risks related to data privacy and security. More information about how we protect against these risks is available in the sections 'Your data and confidentiality' and 'What happens to my data and samples' below.

HOW WILL YOU CONTACT ME?

We may contact you through a variety of methods such as telephone, email and letter, depending on your permissions, and social media. We will post updates on our social media channels and send you regular newsletters and emails to update you of further developments and studies within the DTR.



HOW WILL YOU USE INFORMATION ABOUT ME?

We will need to use information from you, and if you agree, from your medical, education and environmental records for this research project. This information will include you:

- Name
- Contact details
- Address details
- NHS number

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

King's College London is the sponsor of this research. King's College London is responsible for looking after your information. We will share your information related to this research project with the following types of organisations:

- Universities and research organisations: we may share your research data and samples with a code number, to enable health and wellbeing research
- Commercial companies: we may share your research data and samples with a code number, to enable health and wellbeing research
- Service providers, such as lab and postal services: we may need to share your name and address details as well as your research data and samples, to ensure they can carry out their services

We will keep all information about you safe and secure by:

- Storing your data and samples in the TwinsUK BioBank (IRAS ID: 341962), in accordance with the UK General Data Protection Regulation 2018, Data Protection Act 2018 and Human Tissue Act 2004

- Strictly controlling and reviewing all requests for data and sample sharing through our management committee, the TwinsUK Resource Executive Committee (TREC). TREC will only approve requests from legitimate researchers working on good quality health and wellbeing research, for the public good
- Only sharing the minimum amount of information necessary for the approved researcher to answer their specific research questions.
- Only sharing your data and samples linked to your unique code number and your birth month and year with approved researchers, so that you cannot be personally identified.
- Having additional restrictions and contracts in place with researchers at commercial companies (who only make up a small number of requests). You can indicate whether or not you would like to share your research data with commercial companies on the TwinsUK consent form
- Treating it as a potential criminal offence to misuse data, including trying to re-identify someone without permission
- Having contracts in place with service providers.



INTERNATIONAL TRANSFERS

We may share or provide access to data about you outside the UK for research related purposes to:

- Research collaborations
- Data and sample sharing requests from researchers based at organisations outside the UK
- Service provision, for example lab services for sample processing outside the UK

If this happens, we will only share the data that is needed. We will also make sure you can't be identified from the data that is shared where possible. This may not be possible under certain circumstances - for instance, if you have a rare illness, it may still be possible to identify you. If your data is shared outside the UK, it will be with the following sorts of organisations:

- Universities and research organisations: we may share your research data and samples with a code number, to enable health and wellbeing research
- Commercial companies: we may share your research data and samples with a code number, to enable health and wellbeing research
- Service providers, such as lab and postal services: we may need to share your name and address details as well as your research data and samples, to ensure they can carry out their services

We will make sure your data is protected. Anyone who accesses your data outside the UK must do what we tell them so that your data has a similar level of protection as it does under UK law. We will make sure your data is safe outside the UK by doing the following:

- We will only send data and samples outside the UK after careful review by TREC
- Some of the countries your data will be shared with have an adequacy decision in place. This means that we know their laws offer a similar level of protection to data protection laws in the UK
- We use specific contracts approved for use in the UK which give personal data the same level of protection it has in the UK. For further details visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/international-transfers/>

- We do not allow those who access your data outside the UK to use it for anything other than what our written contract with them says
- We need other organisations to have appropriate security measures to protect your data which are consistent with the data security and confidentiality obligations we have. This includes having appropriate measures to protect your data against accidental loss and unauthorised access, use, changes or sharing
- We have procedures in place to deal with any suspected personal data breach. We will tell you and applicable regulators when there has been a breach of your personal data when this is legally required. For further details about UK breach reporting rules visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/report-a-breach>

HOW WILL YOU USE INFORMATION ABOUT ME AFTER TWINSUK ENDS?

Once we have finished our research within TwinsUK, we will keep the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. TwinsUK is a longitudinal study, and we will keep your TwinsUK data for as long as we have ethical approval. In the event of TwinsUK ending, the study data will then be fully anonymised and securely archived or destroyed.

WHAT ARE MY CHOICES ABOUT HOW MY INFORMATION IS USED?

- You can stop being part of TwinsUK at any time, without giving a reason, and we will keep information about you that we already have unless you ask us not to
- If you choose to stop taking part in TwinsUK, we would like to continue collecting information about your health from NHS records, and from your education and environmental records. If you do not want this to happen, tell us and we will stop
- You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this
- If you agree to take part in TwinsUK, you will have the option to take part in future research using your data saved from TwinsUK

WHERE CAN I FIND OUT MORE ABOUT HOW MY INFORMATION IS USED?

You can find out more about how we use your information, including the specific mechanism used by us when transferring your personal data out of the UK by:

- Reading this leaflet <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/>
- Reading our Privacy Notice on our website (www.twinsuk.ac.uk)
- Asking one of the research team
- Sending an email to twinsuk@kcl.ac.uk
- Ringing us on 020 7848 4444
- Contacting the King's College London Information Compliance team and Data Protection Officer on info-compliance@kcl.ac.uk

WHO ORGANISES AND FUNDS TWINSUK?

The study is organised by the Department of Twin Research, King's College London (KCL), based at St Thomas' Hospital in London. The Head of Department is Professor Claire Steves. The main funding bodies currently supporting the DTR and TwinsUK include the Wellcome Trust, the Medical Research Council and the Chronic Disease Research Foundation (CDRF).



KCL sometimes has contracts with commercial organisations. These organisations are allowed to access, view and use the TwinsUK database; access is controlled and monitored, and data are de-identified. The contracts with these organisations may lead to income or profit to KCL. The Vice President of KCL (Finance) will determine how this income is used.

KCL will never sell any of the samples or data you donate. When we share your samples or research data with research collaborators after review and approval by TREC, we may charge them a fee in order to cover the cost of collecting, storing and sharing the samples and data. We may charge researchers at commercial companies higher fees than academic researchers. These fees will support further research at TwinsUK. If we share data or samples with commercial organisations, we will have strict agreements (contracts) in place with them. Agreements with commercial organisations may mean that other organisations might not be able to use TwinsUK BioBank data in some situations. Agreements might also limit the ability of KCL to profit from our research findings, except when the commercial organisation that holds the contract is involved.

WHO HAS REVIEWED AND APPROVED THE RESEARCH?

The TwinsUK Programme of Research was reviewed and approved by NHS North West - Liverpool Central Research Ethics Committee (REC reference 24/NW/0107).

TwinsUK BioBank approval was renewed by NHS North West - Liverpool Central Research Ethics Committee (REC reference 24/NW/0106, IRAS ID: 341962; previously under REC reference 19/NW/0187 IRAS ID 258513).

Earlier, TwinsUK main ethics was reviewed and approved by the St Thomas' Hospital Research Ethics Committee (REC reference EC04/015), and by Guy's and St Thomas' NHS Foundation Trust Research and Development (R&D) in 2012.

We also have a Volunteer Advisory Panel (VAP) consisting of a minimum of 24 members of TwinsUK, who review and offer advice on our research programme.

CAN I LEAVE TWINSUK?

You are free to change the way you interact with TwinsUK at any time without giving any reason, and without your future involvement with the DTR, medical care or legal rights being affected.

If you still want to be contactable by us in the future, hear news from TwinsUK and maybe become involved again at a later date, you can tell us that you want to change your status to News and Information only. You are also free to withdraw from TwinsUK at any time without giving any reason, or affecting your rights. Withdrawal means that we will no longer keep your personal details or be able to contact you about news or events involving the registry.

If you would like to change status to News and Information only, or withdraw completely, please use the contact details at the end of this information sheet to let us know.

If you choose to withdraw, you can choose what you want us to do about records linkage and your stored data and samples. You will be asked to confirm your selection from the following options:

Stored samples:	I am happy for TwinsUK to continue storing and using my samples	OR	I would like TwinsUK to destroy my samples
Stored research data:	I am happy for TwinsUK to continue storing and using my research data	OR	I would like TwinsUK to destroy my research data
Linked health, education and environmental data	I am happy for TwinsUK to continue linking to my health, education and environmental records	OR	I would like TwinsUK to stop linking to my health, education and environmental records

If you ask us to destroy your data and samples, we will do our best to remove these as far as possible from our TwinsUK BioBank. Please note it will not be possible to remove data from existing and published analyses. It will also not be possible to confirm the destruction of data and samples sent outside TwinsUK, although these are governed by strict agreements about how long they can be used.

WHO CAN I CONTACT FOR FURTHER INFORMATION?

If you have any questions or concerns, please contact the TwinsUK admin team on the details below.



020 7848 4444



twinsuk@kcl.ac.uk



Department of Twin Research
St Thomas' Hospital Campus
4th Floor South Wing D Block
Westminster Bridge Road
London
SE1 7EH

WHO CAN I CONTACT IF I WANT TO MAKE A COMPLAINT?

Please contact the TwinsUK admin team using the contact details above.

If your complaint is not resolved and you wish to escalate the complaint, you can do this by writing to Clinical Director of TwinsUK Professor Claire Steves, using the department address above. You can also make a complaint through the Guy's and St Thomas' Patients Advice and Liaison Service (PALS) on 020 7188 8801, pals@gstt.nhs.uk. The PALS team are based in the main entrance on the ground floor at St Thomas' Hospital and on the ground floor at Guy's Hospital in the Tower Wing.



Thank you for taking the time to read this information sheet