





Video version
of this leaflet

Medical Record Linkage at TEDS



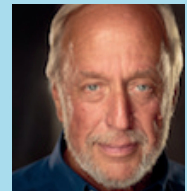
This leaflet contains important information regarding your medical data. Please read it carefully before making a decision.





Key points:

- TEDS is planning to link your medical records to your existing study data.
- You **can remain part of TEDS** even if you decide **not** to link your medical records.
-  If you **don't want us to link to your medical records** you need to **opt out** by **completing and returning the enclosed Data Linkage Opt-out Form** or contact us by phone (0800 317 029) or email (teds-project@kcl.ac.uk) by **12/01/2024**. We will send a reminder mid-way through if we don't hear from you.
-  If you choose **not to return the Data Linkage Opt-out Form**, **we will have approval to link to your records.**

If you are happy for us to use your records in our research, then you do not need to do anything. Please read this leaflet for more information.

OUR PROMISE TO YOU



-  Taking part in the research is voluntary and you are free to withdraw at any time without giving a reason.
-  You cannot be identified from published findings or datasets. We continuously strive to keep all your information confidential. We take extra care to ensure that your data is in a secure environment, and will always do so.
-  Every research project is checked to ensure that it meets the highest scientific and ethical standards. All researchers are bound by a legal data sharing agreement, to keep your data confidential.
-  All our research aims to benefit society and is never done for commercial gain. We promise to be transparent about our funders: see our website.

<https://www.teds.ac.uk/participants/tedspromise>

Thalia Eley Robert Plomin

Why is TEDS writing to me now?

TEDS is looking to the future and finding new ways to find out more about what influences physical and mental health. Data linkage, which accurately and confidentially collects information from official records, is one way to improve our research. Medical record linkage is a key research strategy for the Department of Health being undertaken in numerous studies nationally. Due to this support from the NHS, the government and research funders, medical record linkage is becoming a common aspect of research methodology for large research studies across England, Wales, Scotland and Northern Ireland.

This leaflet contains important information about our new project: **TEDS Record Linkage with NHS Primary and Secondary Care Records** (*Short title: TEDS medical record linkage*).

What are the risks of data linkage and how will TEDS minimise them?

The types of risks associated with this linked data project include data loss, data disclosure and revealing participant identities. All of these risks can be minimised through thorough staff training and process management. This will be done using the following approaches:

Minimising risk



Trusted Research Environments (TREs)

Data stored in TREs will not include your NHS ID. Medical records will be stored separately from identifiers. Data in TREs are stored and backed up in line with NHS policy.



Identifiability

Only the TEDS team and organisations who link the data can see personal identifiers, and never with your data. Researchers never see your name or address and you cannot be identified from published findings.



Researchers

Only accredited researchers working under contract will be able to request access to the data. All researchers are bound by a legal data sharing agreement to keep your data confidential.



Data Access

TEDS-Medical Records Data Access committee reviews all data requests. Researchers only access de-identified data relevant to their specific project. Every research project is checked to ensure that it meets the highest scientific and ethical standards.

Why does TEDS want to use opt-out rather than active consent (opt-in) for this?

Understanding everyone: Importantly, it will help us learn more about participants who have not always provided data to us, perhaps due to stress or health issues. These difficulties can mean some people face barriers to participating in research, meaning we have learned less from some participants than others. What we learn will be far more valuable if it applies to **everyone**, including those who have been unable to take part in research due to their circumstances. This makes the research both ethical and fair as it can benefit everyone.

Re-contact and participation: This approach allows us to contact participants with whom we have lost touch over the years, as we can contact you at the address that your GP holds for you. We know from a trial set of families we have managed to contact again that the vast majority (98%) are happy to hear from us and take part in TEDS again.

The use of opt-out methodology is seen by the NHS and our funder, the Medical Research Council, as a crucial strategy for research in the public interest.

The Health Research Authority Confidentiality Advisory Group has granted us permission to use an opt-out method (rather than collecting consent) because our research is considered to benefit the public. Some people may have asked the NHS not to share their records for research, we will fully respect this decision and the NHS will make sure your records are not shared with TEDS.

Why does TEDS want to access my medical records?

1 Increasing data: Medical record linkage will provide us with new information about our participants, giving us a more complete picture of their mental and physical health. This will allow us to look at the role of genetic and environmental influences on outcomes.

2 Increasing accuracy: Even if you have been very active in TEDS, there may still be some 'gaps' in information. Medical record linkage is a way to gain a complete picture of health across the years, helping to fill in these gaps. Some of the most important information about us is not something we necessarily know or remember. For example, the precise dose of a medication you may have been given in the past.

3 Increasing fairness: Some individuals may find it difficult to continue actively taking part in TEDS. This may result in some groups of people being excluded from research and the benefits it brings (for example, those with severe mental health difficulties). This can introduce bias to the sample and our findings. By using linked health records, we can help ensure our research is fairer and more inclusive.

4 Participant convenience: Completing frequent online questionnaires is time-consuming and can be inconvenient. Medical record linkage is an easier way to be involved in research which will allow us to obtain regular updates about your health without any extra effort from you.

Your Medical Records

How will we use information about you?

We will need to use information from your TEDS research data, and from your medical records for this research project. The identifiable information we will use to undertake the linkage and make an accurate link to your health records includes:

- Full name (held by TEDS at KCL)
- DOB (held by TEDS at KCL)
- TEDS ID (held by TEDS at KCL)
- Full current address (held by TEDS at KCL or the NHS depending how recently we've heard from you)
- Previous addresses (held by TEDS at KCL)
- NHS number (held by the NHS)



The medical record information (all held by the NHS) we would link to include:

- GP Records (details of visits, diagnoses and treatments received)
- IAPT Records (details of NHS talking therapies)
- Hospital Episode Statistics (details of visits, diagnoses and treatments received)
- Mental Health Services Data (details of mental health assessments or treatments)
- Prescription data (details of the prescriptions issued to you by your GP or other NHS care team member)
- Registers (e.g. birth, death, cancer)
- COVID-19 records (e.g. COVID-19 test results, vaccination records)



Important note. We will not be seeking any "free text"* from your medical records
*Descriptive notes that your doctor or consultant made

This information will only be used for research. **Your name and contact details will not be stored with the information from your medical records.** We have been approved by the NHS to keep your information safe and secure and we will write our reports in a way that no-one can work out that you took part in the study.

We will refresh these data on a regular basis, but you can opt out at any time **to stop further linkages.** De-identified data that has already been used by researchers cannot be recalled. There are likely to be new opportunities to connect further types of data to your TEDS records, and we will keep you up to date about new plans via the annual newsletters. We will also keep a live version of this document on our website. Any new plans will be subject to an ethical review process.

Website
live version

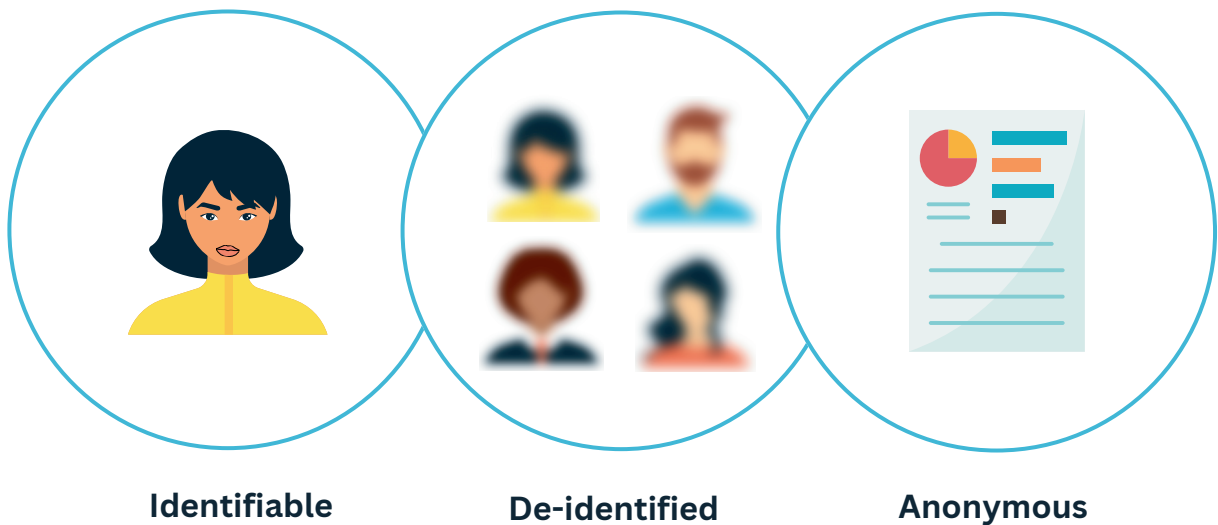


Before reading the next section, please familiarise yourself with the following terms, which describe types of data and information

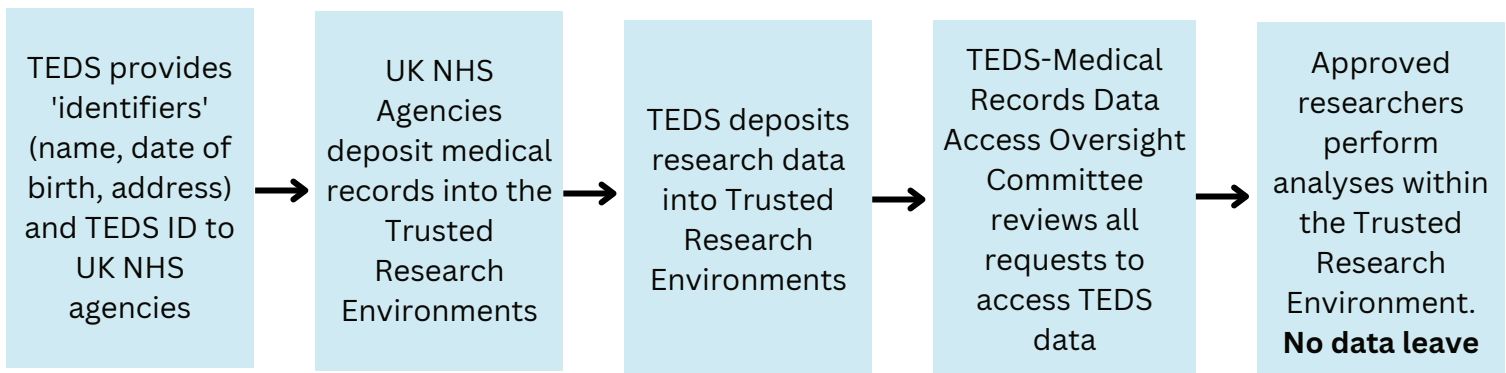
Identifiable data: Your personal information such as your name, full date of birth or address that easily and explicitly reveals your identity.

De-identified data: Data that has had any information that could identify the individual (name, address) removed. Instead, individuals are distinguished by a unique identifier (TEDS ID). This identifier is only useful to the organisation that issued it, and can only be connected back to participants' names by a small number of highly trained and trusted team members.

Anonymised data: Data in a form that does not identify individuals and where identification through its combination with other data is not possible. For example, in any publications or reports, only summary data in the form of tables or figures are provided.



Data Linkage Steps



How will data linkage work?

To identify your records, TEDS will provide your 'identifiers' (name, address, and date of birth) to UK NHS agencies that hold your health data. These NHS agencies will match your personal information to your NHS number.



If you don't opt-out, NHS agencies will remove any information that could directly identify you, and then deposit the medical records into our trusted research environments. The TEDS admin team will then deposit de-identified study data into the trusted research environments, where the medical records and study data are linked using your TEDS ID.



This de-identified data will be kept in **Trusted Research Environments (TREs)**. The NHS have decided that where medical records are used for research, this should happen in an accredited TRE. So, to access the linked data, TEDS are using relevant and highly accredited UK based TREs (run by the NHS or University sector) to bring these important safeguards and comply with NHS requirements.



The current TREs we are using are run by the NHS Clinical Data Linkage Service (CDLS) at the South London and Maudsley and the UK Longitudinal Linkage Collaboration (LLC). All research using medical records takes place within the TREs and **no data can leave these digital locations, which work a bit like a secure reading library.**



We are working with both of these TREs because they provide different opportunities and expertise. The UK Longitudinal Linkage Collaboration allows data from TEDS participants to be analysed alongside data from many other national cohorts. The South London and Maudsley Clinical Data Linkage Service is housed on the KCL Denmark Hill campus where TEDS is based, providing local expertise in medical record linkage.



Linked TEDS data will be shared with specially trained and accredited researchers. These researchers may request to access the medical record data. **All requests involving TEDS data will be reviewed by the TEDS-Medical Records Data Access Oversight Committee.** This committee comprises the TEDS project leads (Prof Robert Plomin and Prof Thalia Eley), the Data Manager, representatives of the NHS linkage team, and a TEDS participant. **All decisions are made in accordance with the TEDS Data Access and NHS policies.** Researchers will only be able to access the minimum amount of information necessary for their specific research.

TEDS is one of many longitudinal research studies in the UK. The UK Longitudinal Linkage Collaboration (UK LLC) is a UK-government funded initiative that is bringing together longitudinal research data and medical records from many UK studies into one trusted research environment. This research environment is run by the University of Bristol with secure computers at Swansea University.

By joining information from cohort studies - like TEDS - across the UK, the UK LLC increases the diversity of who can be researched. This makes research more inclusive and gives researchers larger samples to study rare conditions and understand health in more specific groups, ensuring that research is for everyone. Researchers can apply to use any of the data held in the UK LLC. Any request involving TEDS data will be reviewed by the TEDS-Medical Records Data Access Oversight Committee.



UK LLC
privacy policy



UK LLC
animation

Data storage and archiving

As TEDS is an ongoing longitudinal study, without a fixed end date, the research data will be kept for the duration of the study. If you would like to learn more about the TEDS data policy (including storage and archiving), please visit our website.



Who has reviewed and approved this research?

The KCL Research Ethics Committee has approved all waves of TEDS data collection. We comply with the UK Data Protection Act (2018), the EU General Data Protection Regulation (GDPR, 2016) and both KCL and MRC policies about the storage, processing and sharing of research data.

The Health Research Authority (ref: **22/SC/0313**) and the Confidentiality Advisory Group (CAG; ref: **22/CAG/0038**) have given us permission to link to your medical records. We have also been approved to be part of the UK Longitudinal Linkage Collaboration (UK LLC). This linkage will take place unless you opt out using the Data Linkage Opt-out Form or by getting in touch.

The function of the CAG is to provide independent advice on the use of confidential patient information in health research without consent. The Health Research Authority exists to protect and promote the interests of patients and the public in health and social care research. They make sure that research is ethically reviewed and approved.

What are my choices about how my information is used?

You can decide not to have your medical records linked and still remain part of TEDS. You can also stop being part of TEDS at any time, without giving a reason. If you make this decision, we will delete your contact details and agree not to contact you again. However, we will keep study data that we have already collected.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you, **except for your contact details.**



National opt out

You can also opt-out of all research involving medical record linkage through the national opt-out scheme. Visit the national opt-out service website for more information.

www.digital.nhs.uk/services/national-data-opt-out-programme



If you have already opted out of allowing your data to be used for this type of research through your GP surgery or online, then even if you agree to our linkage, we will not be able to do so.

Who to contact for more information?

If you have any questions or concerns, please contact the TEDS admin team with the contact details in the header, or the researchers who will do their best to answer your questions [Prof Thalia Eley, thalia.eley@kcl.ac.uk].

You can find more about how we use your information on TEDS website's medical record linkage FAQ page.



Who to contact if I want to make a complaint?

Please contact the TEDS admin team using the contact details above. If your query is not solved, you may contact the KCL Data Protection Officer whose contact details are on the KCL core privacy notice page (<https://www.kcl.ac.uk/terms/privacy>). If you remain unhappy and wish to complain formally, you can do this through the SLaM Patient Advice and Liaison Service (PALS) on 0800 731 2864, pals@slam.nhs.uk. In the event that something does go wrong, and you are harmed during the research, you may have grounds for legal action for compensation against King's College London, UK LLC and/or SLaM NHS Foundation Trust, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Thank you for taking the time to read this leaflet