



Privacy Notice for The Irish Longitudinal Study on Ageing (TILDA)

Introduction

This is a statement of Trinity College Dublin (the "University" and/ "We "or "us") for the Irish Longitudinal Study on Ageing (TILDA), in connection with the processing of your personal data and the steps taken by the University as a data controller to safeguard your rights as a research participant under data protection legislation, (specifically but not limited to, the EU General Data Protection Regulation ("GDPR") and Data Protection Acts 1988-2018) .

We fully respect your right to privacy and actively seek to protect your privacy rights. Any personal information which you share with us will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection legislation.

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.
- Your rights under data protection legislation

How we collect and use your personal data

The data we collect will only be used by the University in accordance with the purposes outlined in this privacy notice. We collect information from participants over long periods of time. Each data collection "wave" occurs every 2 years. We will collect your data in the following manner:

- Computer Assisted Personal Interview (CAPI) – a trained interviewer will visit you in your home and complete an interview with you. The information collected will be entered directly into the interviewer's computer. They will also ask you to complete some physical tests and some written cognitive tests.
- Computer Assisted Telephone Interview (CATI) – a trained interviewer will conduct a telephone interview with you. The information collected will be entered directly into the interviewer's computer.
- Self-completion questionnaire (SCQ) – the interviewer will leave a booklet with you for you to complete in your own time. Alternatively, this may be sent via the post to you. We ask that you return the completed booklet to us in the stamped addressed envelope provided.

- During the interview, you will be assigned a unique TILDA identifier made up of five numbers and letters. This identifier is used instead of your name and other contact details to maintain the confidentiality of the information you provide.
- Health assessment – at every second or third wave of data collection, you will be invited to take part in a centre-based or a home-based health assessment delivered by a trained research nurse. This could include assessments of cardiovascular function, cognitive function, mobility, bone health, sensory function, anthropometry, physical activity monitoring, oral health assessments, brain magnetic resonance imaging (MRI) and blood and hair and sample collection. You may also be asked to take a saliva or stool sample and return to us in the post.

The data collected by TILDA will be shared with the following areas of the University:

- Research IT provide IT server storage and support for TILDA; all data is stored here. [wave 1-6]. Backup servers store information for a 4-year period. These backup servers have an overwrite function which automatically overwrites older files with new files. However, personal details (names, addresses) are stored on separate servers managed by TILDA. The Research IT server also hosts the TILDA biobank dataset which is powered by Sample Information Tracking System (SITS) software from Procuero Ltd.

The samples collected by TILDA will be shared with the following areas of the University.

- Blood samples taken during your health assessment are sent to the Trinity Translational Medicine Institute (TTMI) on the St James's Hospital campus to be processed into smaller samples. These are then sent to one of two secure freezer storage facilities, either at TTMI or on the Trinity College Dublin campus. The samples are sent to two different storage locations to prevent loss of all samples due to unforeseen events such as fire. Each sample is labelled with a unique TILDA identifier. Data that confirms consent to collect, test and store blood samples, the number and type of sample stored, date and time the sample was collected and location of each sample in the TILDA biobank is also stored.
- Stool and saliva samples posted back to TILDA during wave 6 are sent to the Trinity Translational Medicine Institute (TTMI) on the St James's Hospital campus to be processed into smaller samples. These are then stored long term at a secure freezer storage facility at TTMI. The samples you return will initially be labelled with your name and first line of your address, however these labels will be removed when they are received at TTMI and the samples will be re-labelled with a unique TILDA identifier. Data that confirms consent to collect, test and store stool and saliva samples, the number and type of sample stored, date and time the sample was collected and location of each sample in the TILDA biobank is also stored.

The purpose and legal basis for processing your personal data.

The personal data we collect from you will only be processed for the specific and lawful purposes as outlined in this Privacy Statement. The University will ensure that your data is processed fairly

and lawfully in keeping with the principles of data protection as set out in Article 6 (1) (E) and Article 9 (2) (J) of the GDPR.

Specifically, your personal data may be processed for any or all of the following purposes:

Category	Purpose for processing personal data	Personal Data
Participant Contact Information	Used to contact participants to take part in TILDA	name, home address, phone number, email address
Administration	Keeping Internal records of data collection	Unique TILDA identifier Unique Coded number that matches individuals to their data collected
Participant cognitive status	Used to determine cognitive health status	10-minute test of cognitive function
Participant Socio-economic Status	To study the impact of socio-economic factors on ageing	Economic dimension (pensions, employment, living standards), health aspects (physical, mental, service needs and usage) and the social domain (contact with friends and kin, formal and informal care, social participation).
Participant Social Status	To study the impact of social factors on ageing	Social data: relationship quality, sexuality, loneliness, adversity exposure (stress, childhood poverty/ abuse).
Participant Health Status	To study the gradual impact of ageing on health	cardiovascular function, cognitive function, mobility, bone health, sensory function, anthropometry, physical activity monitoring, oral health assessments, brain magnetic resonance imaging (MRI)
Participant Sample Collection	For future scientific research on impact on ageing on DNA	blood samples, hair samples, saliva and stool samples
Primary Care Reimbursement Service (PCRS) Linkage	For research on medication prescription uptake, costings of medications provision,	Medication History, prescriptions, dosage, costs

General Practitioner (GP) linkage	For cross referencing self-report outcomes with historical health records	Health Records, electronic GP records, assessment results
TILDA Hotdesk	For public access to TILDA datasets for scientific research	Participant coded data
TILDA Remote Hotdesk (SeRP)	For public remote access to TILDA datasets for scientific research	Participant coded data

How we store and secure personal data

Any data we collect from you will be stored confidentially and securely as required by The University [Research Data Management Policy](#) and [Data Protection Policy](#). The University is committed to ensuring all accesses to, uses of, and processing of TILDA data is performed in a secure manner.

We also store a subset of data in the Irish Social Science Data Archive (ISSDA) located at University College Dublin (<https://www.ucd.ie/issda/>). The Irish Social Science Data Archive (ISSDA) is Ireland's leading centre for data preservation and dissemination. International researchers and educators from within and outside the European Economic Area can apply to access the data for teaching and research purposes. No directly identifiable data is shared. For more information see: <https://www.ucd.ie/issda/data/tilda/>

Furthermore, at each wave of our study, we conduct a Data Protection Impact Assessment to identify and mitigate any risks associated with our research activities. This process ensures that we comply with obligations under the GDPR and mitigate any risks of participant confidentiality.

Details of Third Parties with Whom we Share Personal Data

We only share your data with third party service providers where necessary for the purposes of processing outlined in this Privacy Statement. In accordance with Article 28 GDPR, when we share your data with third parties the service provider will ensure that the data is processed according to our specific instructions and that the same standards of confidentiality and security are maintained.

The following table details the third parties with whom your personal data is shared together with the purposes for the sharing:

Third-party Processor	Purpose for sharing
Ipsos B&A (merger of Ipsos and B&A)	Fieldwork partners that TILDA work with. Ipsos B&A provide interviewers who visit you in your home to conduct the participant interviews
Seefin DM	Utilised to enter the information provided in the self-completed questionnaire (SCQ) for computer-based analysis

Kefron	Utilised to enter the information provided in the self-completed questionnaire (SCQ) for computer-based analysis.
General Practitioner	If you give us permission, your GP will receive results of selected health assessment tests (height, weight, blood pressure, heel bone ultrasound, visual acuity, hearing, mobility, grip strength, blood cholesterol, full blood count)
Custodian	Printing of fieldwork documents, newsletters and Christmas cards for respondents.
Iron Mountain	Provide long-term secure storage in a locked facility for study documentation e.g. consent forms, SCQs, etc.
DGD Shredding	provide confidential shredding of paper copies of study materials.
Cyclone Shredding	Confidential Shredding: Cyclone – confidential shredding of study material [Wave 1-6]
An Post	Provide the postal orders that we send you as a token of appreciation after you complete an interview. We provide a list of participant names to An Post so that your name can be printed on the postal order. We do not provide any other information to An Post. This list is only used for this purpose and is deleted after use.
Dx Limited	Transport courier services to collect and deliver blood samples nationwide.
Tekenable (previously Greenfinch)	develop software for Health Centre appointments, data collection and home assessment data collection and biological samples data collection [Wave 6 only].
ISSDA UCD	The Irish Social Science Data Archive based in University College Dublin. The aim of the data sharing initiative is to facilitate the University in carrying out the objectives of the Approved Research Study and to allow ISSDA to carry out its functions.
CodeFirst Ireland Limited (previously Eirsoft)	developed software for Health Centre appointments and data collection [Wave 3 only].
Crimson Tide	provided server for home assessment data collection and biological samples data collection [Wave 3 only].
Central Pathology Laboratory. St. James's Hospital. IRELAND	During the health assessment, you are invited to provide blood and hair samples. Blood samples are collected using your unique study ID number and delivered to the lab at Trinity Translational Medicine Institute (TTMI) at the St James's Hospital campus by a contracted courier. Once the samples are received by the TTMI lab, they are processed for cholesterol testing, full blood count and long-term storage for future research on ageing.
CAMI St. James's Hospital IRELAND	The Centre for Advanced Medical Imaging (CAMI) at St. James' Hospital in Dublin collect brain MRI data obtained during the health assessment and then store it as they have the necessary software to do so. As the scans take place in a hospital facility, TILDA are required to provide your name and address (with your permission) to CAMI, and your MRI scan is linked to a unique hospital identifier, not your unique TILDA study ID. As noted in the information sheet, we will

	contact your GP if something is detected on your MRI scan which requires further clinical assessment.
TILDA Hotdesk	<p>TILDA operates a secure 'Hotdesk' facility at its offices, where approved researchers from external universities and hospitals can access the TILDA research dataset. Access is subject to a formal approval process that includes, approval from the TILDA Management Committee, completion of data protection training and agreeing to the terms of a Data Use Contract. All computers are set up so that data cannot be copied or removed from the premises. Researchers can only produce aggregate files which contain high level statistics.</p> <p>To support researchers who are unable to travel to the TILDA offices, we are introducing TILDA VISTA (Virtual Infrastructure Supporting TILDA Data Access), a remote secure access solution delivered via a Trusted Research Environment (TRE). A Trusted Research Environment (TRE) is a secure digital platform designed to enable safe access, analysis, and sharing of sensitive data in line with GDPR requirements. The TILDA VISTA servers are hosted by Swansea University in the United Kingdom (UK) and adhere to robust data protection and security standards.</p> <p>For more information see: Accessing the Data - The Irish Longitudinal Study on Ageing (TILDA) - Trinity College Dublin</p>

How long we retain your data.

Due to the longitudinal nature of TILDA, we inform you in our information leaflet that the retention period for the research data collected is indefinite. In practice, the data will be retained for the duration of study funding cycles with review at each funding renewal cycle.

Your rights under data protection legislation

You have the following rights over the way we use your personal data. However, there are some limitations to these rights. These are outlined below.

Right of Access

You have the right to request a copy of the information we retain and can request this easily and at reasonable intervals.

If you would like to make a data access request, please write to the Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2 or email dataprotection@tcd.ie providing as much specific information as possible about your request. Please also send a photocopy of your proof of identity and address with your request. This is to ensure that we only disclose information about personal data to you, as the data subject.

All data requests will be processed in accordance with TCD's Data Access Request Policy. <https://www.tcd.ie/dataprotection/yourrights>

Right to Rectification

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

Right to Restriction of Processing

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

- You are contesting the accuracy of it.
- It was used unlawfully.
- We need to prevent the erasure of the contact details in order to comply with legal obligations.
- You have objected to the use of your personal data and wish to restrict the use until a legal basis for continued use has been verified.

Right to object

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

- We have processed your data based on a legitimate interest or for the exercise of the public tasks of the University if you believe the processing to be disproportionate or unfair to you.
- We have processed the personal data for scientific or historical research purposes or statistical purposes unless the processing is necessary for the performance of a task carried out for reasons of public interest.

Right to Erasure

You have the right to request that your information is deleted at any stage. There are however some limitations to this right that may apply in certain circumstances.

- If any process is underway, it will continue to completion e.g. if you request your data is deleted after blood samples are taken during the health assessment, immediate analysis of the blood samples and feedback to the you and your GP (if permission is given) will still take place. Similarly, if you request your data is deleted after completing a brain MRI for example, the scan will still be analysed and feedback provided in cases where further assessment is recommended. If you request that your information is erased, then we will not be in a position to provide any results to you from our assessments.
- Similarly, if an ECG recording is obtained during the health assessment, some results of this may be returned to you in the future. Analysis of this ECG recording is used to

identify an irregular heart rhythm (atrial fibrillation) which is an important risk factor for stroke. Analysis is a manual and lengthy process as ECG data is complex. This analysis can be a lengthy process and can take up to 5 years as two independent medical staff must review these files before TILDA can report on them. As this is a condition that can be managed effectively with medication, if we have your consent to contact your GP, we will inform them of the diagnosis. If we do not have your consent to contact your GP, we will inform you. If you have requested that we delete your information, we will be unable to contact you or your GP with these results.

It may also not be possible to erase data from TILDA when:

- The data have already been shared with a collaborator and cannot be retrieved as this would impact the research results.
- The results from a research study have already been published, in submission with a journal, or are just about to be published.
- Research datasets have been deposited in a publicly accessible database.
- Analysis has been conducted and withdrawal may impact the statistical validity of the results.
- Data have to be retained for safety and regulatory purposes.
- Personal data and results have been irrevocably anonymized, preventing them from being identified for removal.

Due to the large volume and complexity of data collected by TILDA, as well as the resources needed to process deletions, personal data will be deleted at specific intervals. Deletions will occur every 6 months, in March and September, following your request for data deletion.

Changes to this Privacy Notice

We regularly review and, where necessary, update our privacy notice. If we plan to use personal data for a new research project linked to health, lifestyle and ageing we will update our privacy notice and communicate the changes to individuals via the TILDA website and TILDA Annual Newsletter.

Cookies

We use information gathered from cookies to help improve your experience of our website. Some cookies are essential so you can move around the website and use its features. Our website also contains third party cookies which are listed in our Cookie Register (situated at the bottom of the www.tcd.ie website page). You can refuse or consent to third party cookies when you first visit our website or by following the guidelines in our [Cookie Policy](#).

Further Information

If you have any questions or are thinking about adjusting your participation in the study, we are happy to support you. You can reach the TILDA team at (01) 896 2509 or email tilda@tcd.ie to discuss your options. As a TILDA participant, you are free to step back at any time, whether that means skipping a single wave or withdrawing from the study altogether. We're here to support your decision and answer any questions you may have.

Please note that your data will be retained for the duration of the funding cycle unless you request its deletion.

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 Trinity College Data Protection Officer:

Data Protection Officer
Secretary's Office,
Trinity College Dublin,
Dublin 2,
Ireland.
dataprotection@tcd.ie

If you are not satisfied with the information we have provided to you in relation to the processing of your data or you wish to raise a query with the Data Protection Commission, please contact the Commission at <https://forms.dataprotection.ie/contact>

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