



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



The Irish Longitudinal
Study on Ageing

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

Introduction

This is a statement of the practices of The Irish Longitudinal Study on Ageing (TILDA), Trinity College Dublin, The University of Dublin (the "University") of College Green, Dublin 2, Ireland regarding the use of personal data shared with us for this longitudinal study and the steps taken by the University to protect your privacy.

The University fully respects your right to privacy and actively seeks to protect the privacy rights of those who share information with the University. Any personal information which you volunteer to the University will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection legislation.

TILDA is a national resource which informs national and international policy. The information we collect is used for many research projects and helps to identify national priorities and policies on issues such as health and well-being, healthcare needs, caregiving and retirement. Our research outputs have been used in a range of analytic, strategic, advisory and advocacy documents by agencies and organisations across the public, private and voluntary sectors. These results also inform clinical programmes across the Irish health system and government health and social initiatives. More recently, information from TILDA has been used to help with planning for and responding to the COVID-19 pandemic nationally and internationally.

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
- What are your rights

How we collect your personal data

The Irish Longitudinal Study on Ageing (TILDA), based in Trinity College Dublin (TCD), is a large-scale, nationally representative study of community-dwelling adults aged 50 years and over in Ireland. Since 2006, it has received funding from the Department of Health, the Atlantic Philanthropies and Irish Life plc to collect information that will provide an evidence base from which Ireland can plan health, medical, social and economic policies and practices. TILDA, in collaboration with TCD, has conducted a data protection impact assessment to identify the level

of risk associated with this social, health and economic research and to take the necessary steps to ensure participant confidentiality.

The data we collect from you will be used by the University in accordance with the purposes outlined in this privacy notice. 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 will 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.

Longitudinal studies require large amounts of data over long periods of time to achieve their purpose. The data that all TILDA participants have provided over multiple waves of data collection have contributed to this invaluable data resource.

Description of datasets TILDA hold

- **Contact database** – this contains your name, address, phone number, email address and unique TILDA identifier. This information is necessary for us to stay in contact with you at each wave. This database is stored on the secure TILDA server and can only be accessed by a limited number of TILDA staff.
- **Raw datasets** – these contain all the information provided by you during your interview including your personal information. They also contain the name, address and phone number of two people who would be able to help us track you down at the next wave if we were unable to contact you. If you gave consent for a proxy interview to take place in future, we also store the name, address and telephone number of two people who you

suggest could do the interview on your behalf. These datasets are stored on the secure TILDA server and can only be accessed by a limited number of TILDA staff.

- **Research datasets** – these include answers that you have provided to questions during the interview and SCQ, scores on tests included as part of the health assessment and results of blood, hair, saliva and stool analysis. They contain your unique TILDA identifier, but they do not contain your contact details (name, address, phone number or email address) or other personal information (medical card number, job title). These datasets are stored on the secure TILDA server and are the versions accessed for research purposes.
- **TILDA Biobank dataset** - This dataset does not contain your contact details (name, address, phone number or email address) or other personal information (age, gender, medical card number, job title, etc.) gathered from the CAPI, SCQ or health assessment. This dataset contains the unique TILDA identifier along with data that confirms consent to collect, test and store biological samples (i.e. blood, hair, saliva or stool samples), the number and type of sample stored, date and time the sample was collected and location of each sample in the TILDA biobank This dataset is stored on secure servers provided by Research IT at Trinity College Dublin and are only accessible from designated TILDA computers.
- **Archived datasets** – these include answers that you have provided to questions during the interview and SCQ, scores on tests included as part of the health assessment and results of blood and hair analysis but they do not contain your contact details (name, address, phone number or email address), other personal information (medical card number, job title) or your unique TILDA identifier. Instead, these contain a different identifier, which is generated as an additional level of data security. These datasets have fewer variables than the research datasets and some values are also removed or top-coded to preserve your anonymity. These datasets are accessible through established data repositories.

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.
- 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 Collecting and Processing Personal Data

The data we collect about you will be used to provide a comprehensive and accurate picture of the characteristics, needs and contributions of older persons in Ireland and explore factors which determine successful ageing. This will provide an invaluable data resource for those developing health, social and economic policies.

The University will ensure that your data is processed fairly and lawfully in keeping with the principles of data protection. For the purposes outlined in this privacy notice the personal data provided during your interviews, health assessments, and other analysis of biosamples, will be used for scientific research in the public interest. We will also ask for your consent as a safeguard as this is health research.

Prior to each wave and/or component of data collection, you will be provided with a Participant Information Leaflet and a Consent form (separate forms for interview, health assessment, MRI, COVID-SCQ, saliva sample, etc). If you have any further questions or would like to discuss this in more detail, you are welcome to contact TILDA using the contact details provided.

Withdrawal of Consent

You can withdraw your consent to participate at any stage. All TILDA printed materials contain contact details for the study should you wish to discuss any aspect of the study or your involvement, including withdrawal.

Your data will be retained indefinitely during the lifetime of the funding cycles unless you request to withdraw from the study. For further information on withdrawing from the study and limitations to withdrawal and erasure requests, please see the 'What are your rights?' section below (insert hyperlink).

Data Storage and Security

Any data we collect from you will be stored confidentially and securely as required by the Trinity College Dublin Information Security Policy. The University is committed to ensuring all accesses to, uses of, and processing of University-controlled data is performed in a secure manner.

Due to the longitudinal nature of TILDA, there is no specified retention period for the research data collected and therefore the data will be retained indefinitely. This shall be reviewed at each funding renewal period.

When we store your personal data on our systems the data will be stored either on the University premises or on secure IT platforms within the EEA which are also subject to European data protection requirements.

Archived Datasets - Storage and Security

We may store or share your data outside the EEA in the following circumstances:

Archived datasets (non-identifiable data) will be available through the Irish Social Science Data Archive (ISSDA) located at University College Dublin (<https://www.ucd.ie/issda/>) and the Interuniversity Consortium for Political and Social Research (ICPSR) at the University of Michigan (<https://www.icpsr.umich.edu/icpsrweb/>) for the purpose of long-term data storage and dissemination. These datasets are coded and have fewer variables than the research datasets; some values are removed, grouped together or top-coded to preserve your anonymity. Your contact details are never included in these datasets. International researchers and educators from within and outside the European Economic Area can apply to access the data for teaching and research purposes.

The Irish Social Science Data Archive (ISSDA), based at University College Dublin, is Ireland's leading centre for data preservation and dissemination, ensuring wide access to a number of Irish datasets. TILDA lodge archive datasets at ISSDA which facilitates access for researchers outside of the TILDA team to the data for research and teaching purposes. The datasets undergo a rigorous checking process to ensure that all identifiable information is removed before the datasets are archived.

The Inter-university Consortium of Political and Social Research (ICPSR), based at University of Michigan, provides leadership and training in data access, curation and analysis. TILDA lodge archive datasets at ICPSR to allow researchers outside of the TILDA team, particularly those based in the US, to access and analyse the data. The datasets undergo a rigorous checking process to ensure that all identifiable information is removed before the datasets are archived.

The Gateway to Global Ageing in the US is a digital library of survey questions and identically defined variables that allows TILDA data to be compared with population survey data on ageing obtained from several other countries (<https://g2aging.org/>). They use the archived dataset to ensure that the variables are harmonised correctly, however they do not circulate the data to other researchers.

Trinity College has Data Sharing Agreements in place with ISSDA, ICPSR and Gateway to Global Ageing.

Details of Third Parties with Whom we Share Personal Data

Researchers access to TILDA information - Hotdesk Access

TILDA operate a secure 'Hotdesk' facility in the secure TILDA offices where researchers from external universities and hospitals can access a subset of the research dataset, subject to approval from the TILDA Management Committee. All computers are set up so that data cannot be copied or removed from the premises. This is to facilitate access to data for researchers outside of the TILDA team. No personal data (names, contact details, addresses etc) is available. Researchers who are approved by TILDA and are using the Hotdesk facilities can only produce aggregate files which contain high level statistics. For example, the percentage of women aged 50-60 with heart disease in Ireland. All files are reviewed by TILDA's data team prior to dissemination of the results to ensure data is appropriate and does not contain any indirectly identifiable information. In this way, TILDA can maximise the use of the data we collect while protecting participants' confidentiality and data security. Researchers accessing the research datasets on the TILDA Hotdesk must complete data protection training and sign a Data Use Contract prior to access being provided.

The University will also share your data with third parties where necessary for purposes of the processing outlined here. Agreements are in place with all third parties to ensure that data is only used for the purposes specified and is not retained unnecessarily.

Data Collection Related Services

The below lists service providers TILDA use day to day to aid with data collection.

- Behaviour & Attitudes (B&A) are the fieldwork partners that TILDA work with. B&A provide the social interviewers who visit you in your home to conduct the participant interviews. In order to allow the interviewers contact participants, TILDA provide them with your contact details. TILDA also provide B&A with some information from previous waves so that you do not have to repeat the information you provide us at each wave e.g. this allows us to ask you 'Last time we interviewed you, you said that you smoked. Do you still smoke?' rather than asking you 'Do you smoke?' at each wave. B&A collect the information that you provide during your interview and then return this to TILDA. Information provided to B&A is only used for the purposes specified above. B&A are supported by an IT solutions management company, IT Force and a data storage company, Kefron File Stores.
- SeefinDM and Kefron Limited are data management companies who TILDA employ to enter the information provided in the SCQ for computer-based analysis. They return the hard copies of the SCQ and provide the entered data to TILDA once the task is complete. TILDA do not provide any personal information (names, addresses) to SeefinDM or Kefron Limited. Information provided to SeefinDM and Kefron Limited is only used for the purposes specified above.
- Your General Practitioner 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) if you give us permission to do so. Alternatively, you may wish to share the results of any tests you receive with your GP. Sometimes, we become aware of a serious condition when doing subsequent analysis of

health assessment data e.g. atrial fibrillation, an irregular heart rhythm that is a risk factor for stroke. If we become aware of this in later analysis, we will provide this information to your GP or you (if you have not given consent for us to contact your GP).

- An Post provides 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.
- Custodian are a printing company who print our Christmas cards, newsletters and address labels for the envelopes. We send them a list of names and addresses so that they can print these on the envelopes. We do not provide any other information to Custodian. This list is only used for this purpose and is deleted after use.
- Iron Mountain provide long-term secure storage in a locked facility for study documentation e.g. consent forms, SCQs, etc. The documents stored here include your name (on the consent form) or your unique TILDA ID number (self-complete questionnaire) but not both on the one document. The information we collect is linked to your TILDA ID number. Therefore research data such as your answers in the paper questionnaire, cannot be linked to your name in these documents.
- Cyclone and DGD Shredding provide confidential shredding of paper copies of study materials.
- Dx Limited. Transport courier services to collect and deliver blood samples nationwide.
- Tekenable (previously Greenfinch) – developed software for Health Centre appointments, data collection and home assessment data collection and biological samples data collection [Wave 6 only].
- 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].

Research Services

TILDA employ specialist service providers and specialist laboratories to conduct particular analysis on data and biosamples (blood, hair, saliva, stool), in the situation that TILDA do not have the facilities, resources or expertise to conduct such analysis inhouse. Data and Biosamples are securely transferred to a research services provider or laboratory. No personal data (names, contact details, etc) are shared in these circumstances. Legal agreements are in place with each service provider or laboratory. Data and/or biosamples are shared by secure means only. Below is a list of service providers and laboratories TILDA use for research services. Please see our publications list available on the TILDA website for journal articles and reports resulting from these processes.

Service Provider	Function
<p>Central Pathology Laboratory. St. James's Hospital. IRELAND</p>	<p>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. This courier has access to the samples for transportation purposes only but has no information about who provided the samples. TILDA track all samples to ensure that they are delivered to the TTMI lab for processing.</p> <p>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.. The Procu Sample Information Tracking System (SITS) is used to log and track all blood samples. The cholesterol and full blood count data is returned to TILDA after which it is provided to you, and in some instances also to your GP (if you give permission for this).</p> <p>Only nominated TILDA personnel and nominated TTMI lab personnel have access to the TILDA biobank samples and dataset.</p> <p>Depending on the timing and focus of subsequent research, some samples (blood, hair stool, saliva) are sent to various laboratories (listed below) for further analysis, providing the correct permissions are in place. Samples are stored using the unique study ID number only. Information provided to these laboratories is only used for the purposes specified above. Legal agreements are in place with any external laboratories.</p>
<p>CAMI St. James's Hospital IRELAND</p>	<p>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.</p>
<p>National University Ireland, Maynooth. IRELAND</p>	<p>TILDA employed the services of National University Ireland Maynooth, to map and link participants lifetime addresses to local services. Each address is assigned a geographical code which can then be linked to local services such as GP access, shops and environmental influences such as fluoridation status and air pollution. The process of assigning geocodes is very complex and is carried out by collaborators at the Maynooth University Social Sciences Institute who have this expertise. Data provided to Maynooth University include the unique TILDA identifier, history of addresses, dates that the participant lived at these addresses and details of the water supply, but no other information is sent. Information</p>

	provided to Maynooth University are only used for the purposes specified above. Contractual agreements were in place for this piece of work.
Italian Institute for Genomic Medicine (IIGM), ITALY (Within EU)	TILDA employed the services of IIGM to conduct leukocyte telomere length measurements in DNA samples from consented participant samples. Leukocyte telomere length changes over time in adults. This analysis aims to investigate the relationship of socio-economic status, childhood adversity and age-related biomarkers with leukocyte telomere length. .. This is research using DNA in line with explicit consent obtained, but not genetic testing and there is no risk that the processing will identify a single participant.
Technische Universität Dresden, GERMANY (Within EU)	TILDA employed the services of Technische Universität Dresden to analyse steroid hormone levels in consented participants hair samples. This piece of work is part of a wider project to examine the association between chronic stress exposure and health among older adults. This is not genetic testing and there is no risk that the processing will identify a single participant.
HUGE Foundation, ITALY (Within EU)	TILDA employed the services of HUGE Foundation, to conduct genome-wide methylation analyses in consented participant blood samples. Only participants who gave explicit consent and agreed to have DNA extracted and used for research on ageing will be included in this project. This work aims to understand the life course biological pathways underlying social differences in healthy ageing. This analysis does not lead to the identification of any single participant.
Central Biotechnology Services. Cardiff University UK (Outside EU)	TILDA employed the services of the Central Biotechnology Services. Cardiff University to analysis consented participant blood samples. TILDA are seeking to further understand participants health by examining various biomarkers linked to ageing. Samples were analysed by CBS Laboratory to investigate a panel of 17 biomarkers linked to ageing (inflammation, neuronal survival, oxidative stress etc). TILDA sent a very small amount of plasma sample, from participants who agreed to donate a blood sample for future research on ageing to CBI. The data generated by this analysis will help TILDA continue to investigate why some Irish adults age more positively than others and experience less disease than others. This is not genetic testing and there is no risk that the processing will identify a single participant.
Harvard Medical School USA (Outside EU)	A limited number of MRI and retinal photo files (<5) were transferred to collaborators in the US Harvard Medical School during wave 3 to assist with data analysis (quality for AMD sub classification). MRI data has an SJH MRN associated with it while retinal photos have the TILDA serial. Images were sent securely and deleted after review.
CDI Laboratories USA (Outside EU)	TILDA employed the services of CDI Laboratory to analyse plasma samples from consented participants (wave 3 samples). TILDA are seeking to further understand participants past viral exposure, in conjunction to their exposure to COVID-19. CDI Laboratories analysis provides the complete viral history of participants. This is a complex analysis and this laboratory has specialist expertise in this field, lacking within the EU. TILDA sent a very small amount of plasma samples, from participants who

	<p>agreed to donate a blood sample for future research on ageing, to CDI. The data generated by this analysis will help TILDA continue to investigate why some Irish adults experienced mild, moderate or severe COVID-19 infection and the links to prior viral exposure. This is not genetic testing and only coded/pseudonymised data was provided to CDI.</p>
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Data Linkage Studies

TILDA link participants data to official records to validate data. Please see our publications list available on the TILDA website for journal articles and reports resulting from these data linkage studies.

Shared with	Purpose
GRO Linkage	Mortality information is an important outcome in a longitudinal study on ageing. When a participant passes away, TILDA obtain information from the death registration records at the General Registry Office (GRO). To do this, TILDA provide details of participants who have passed away to the GRO for cross-reference with their records. This information is transferred securely and is only used for this purpose.
GP Linkage	Many General Practitioner (GP) practices in Ireland maintain electronic patient records which include information on GP and nurse visits, symptoms, health conditions, medications, treatments and referrals. In TILDA, we ask you about your health and wellbeing, however it is also useful for us to get information directly from administrative records such as GP practice databases as this allows us to carry out more detailed research. With your permission, TILDA will obtain information from your GP health records. TILDA will securely share your details with your GP so you can be identified on their system. Your GP will then securely share the requested information with TILDA.
PCRS Linkage	The Primary Care Reimbursement Service (PCRS) run by the HSE, provide detailed information on medicines you may have received using your medical card. PCRS information tells us the exact name of the medicine, the strength and dosage and the cost of the medicine, for example. This information helps us explore further the costs associated with healthcare as we age and if current policies around medication usage, reimbursement schemes and treatment schemes are fit for purpose. With your permission, TILDA would like to link your medical card number to the information contained in the PCRS system. TILDA will securely share your medical card number with PCRS. PCRS will then securely share the requested information with TILDA.

Research Collaborations

Nationally and internationally, we collaborate with many institutions to further our research aims and promote research datasets. Some collaborations are continuous while others may be for one specific purpose on a single occasion. Legal agreements are in place for any collaborations in which TILDA share data and/or samples. Data and/or samples will only be shared in line with the consent preferences given by TILDA participants. Please see our publications list available on the TILDA website for journal articles and reports resulting from these collaborations.

Shared with	Purpose
Waterford Institute of Technology IRELAND	TILDA collaborated with WIT to analyse serum carotenoid and antioxidant compounds in consented participant blood plasma samples. Results were securely sent by WIT to TILDA. This is not genetic testing and there is no risk that the processing will identify a single participant.
Waterford Institute of Technology IRELAND	TILDA collaborated with WIT to analyse retinal images from consented participants. Digital images of retina and associated pseudonymised information was securely shared with WIT for this research. The research was being conducted as part of the ERC funded Central Retinal Enrichment Supplementation project (CREST project: 281096) at Waterford Institute of Technology. It entailed the use of retinal photographs collected by TILDA for the purposes of training, in collaboration with Moorfields Eye Hospital (reading center), on the assessment and grading of retinal photographs for pathology. Following this training and grading of retinal images, resulting data will be securely sent to TILDA.
Technische Universität Dresden GERMANY (Within EU)	TILDA collaborated with Technische Universität to publish a journal article on reference values for steroid hormones in hair samples of consented participants.
Lund Universitet, SWEDEN (Within EU)	TILDA collaborated with Lund University to advance biomedical research in the field of cardiovascular research. This research is part of a large project called the Genetics of Postural Hemodynamics (GPH) consortium. TILDA and Lund University specifically explored “Orthostatic hypotension, cardiovascular instability and novel blood pressure-associated gene variants”. This study involved the genotyping of twelve common genetic variants (SNPs), none of which have been proven to be causal of CD or BP response (only associated). The resulting genotype data was securely returned to TILDA and used in conjunction with available TILDA phenotype data to examine the associations of novel blood pressure-associated gene variants with orthostatic hypotension. This is research using DNA in line with consent given by participants, but not genetic testing and there is no risk that the processing will identify a single participant.

University of Nottingham UK (Outside EU)	TILDA collaborated with University of Nottingham for research examining ASL-MRI analysis methodologies and how patterns of perfusion are associated with cognitive performance for the purpose of publication of scientific journal articles.
Imperial College of Science, Technology and Medicine, London UK (Outside EU)	TILDA collaborated with Imperial College London for the project LIFEPAATH- Lifecourse biological pathways underlying social differences in health ageing. The pseudonymised ISSDA dataset was securely shared with the recipient, and any newly derived variables as a result of any analysis were returned securely to TILDA.
Imperial College of Science, Technology and Medicine, London UK (Outside EU)	TILDA collaborated with Imperial College London for the publication of a journal article on the role of DNA methylation as a biological intermediary between socio-economic position and longevity.
Imperial College of Science, Technology and Medicine, London UK (Outside EU)	TILDA collaborated with Imperial College London for a project entitled “Metabolomic and omic assessment of biological ageing across the life-course (METAGE)”. The aim of this research is to develop a composite marker of biological age based on multiple metabolites by analysing plasma samples from consented participants

Funded Sub-Studies

COVID-19 SCQ Altered lives in a time of crisis	Funded by the Health Research Board. TILDA-COVID-19 SCQ study involved a self-completion questionnaire (SCQ) related to participants experience of COVID-19. Participants completed the questionnaire and posted them and the consent form back to TILDA in stamped address envelopes, as face to face engagement was not possible due to government restrictions at this time.
SABS-TILDA- Saliva Antibody Study.	Funded by the Health Research Board. TILDA-COVID-19 Antibody study included a self-completion questionnaire and accompanying saliva sample. Participants completed the questionnaire, collect the saliva sample and post them and the signed consent form back to TILDA in a stamped address envelope. Saliva samples will be stored using a special saliva sample ID and will be analysed for participants exposure to the COVID-19 virus. This is not genetic testing and there is no risk that the processing will identify a single participant.
VIRCOA- TILDA	Funded by Science Foundation Ireland. VIRCOA-TILDA: Viral and Immune Risk factors for COVID-19 in Older Adults in the TILDA study. The biological reasons why COVID-19 affects older people more is unknown, but it is likely due to failure to activate appropriate immune responses, particularly anti-viral immunity. The viruses we encounter during our

	<p>lives leave an imprint on our immune system and this “viral history” is linked to health in older people, however it has not been studied in COVID-19. Using samples TILDA, this project assessed the viral history in older adults and determine how it influences who got COVID-19, the severity of disease and how it relates to important COVID-19 risk factors. CDI will complete VirScan analysis on consented blood samples Service level agreement in place for CDI service provision only (detailed above). This is not genetic testing and there is no risk that the processing will identify a single participant.</p>
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Secondary Data Analysis Projects at Trinity College Dublin

<ul style="list-style-type: none"> • Cross national comparisons of the association between socio-economic position and allostatic load
<ul style="list-style-type: none"> • Dynamic Microsimulation Projections of ADRD in Ireland and the United States.
<ul style="list-style-type: none"> • Comparison of end-of-life experience in Ireland and Northern Ireland: evidence from two longitudinal studies of ageing
<ul style="list-style-type: none"> • Mixed methods study of the older LGBTI+ population in Ireland to identify the needs, strengths and challenges.

Research Sponsorships (No access to data or samples)

TILDA sometimes work with commercial entities in a research sponsorship relationship whereby TILDA will undertake a piece of work sponsored by the commercial entity. It is important to understand TILDA will not transfer any data to the commercial entity, they cannot access any data or samples and all reports will be made publicly available. Therefore, the public, other research teams and the commercial entity will have access to the final report at the same time. These reports will only present data in an aggregated statistical form which do not identify any one participant.

TILDA and Novartis Ireland Ltd established a sponsorship agreement in 2022 to examine levels of Lipoprotein(a) [Lp(a)] in blood samples from TILDA participants. Elevated levels of Lp(a) is risk factor for atherosclerosis and cardiovascular disease. Under the sponsorship agreement, TILDA will analyse levels of Lp(a) in blood samples drawn from TILDA participants to assess the overall prevalence of elevated Lp(a) in the Irish population. This is the first study of its kind in Ireland. As data controller, TILDA will solely control, access and analyse the data collected, and all results will be publicly available. No data will be transferred outside TILDA. TILDA believe this research will help better understand the risks for heart disease in the Irish population.

Study Collaborators (No data/sample transfers)

- Economic and Social Research Institute (ESRI)
- Smurfit Institute of Genetics

- Dundalk Institute of Technology
- National University of Ireland, Galway
- Royal College of Surgeons in Ireland
- University College Cork
- St. Vincent's Hospital
- Tallaght Hospital
- Our Lady's Hospice and Care Services
- Royal Victoria Eye and Ear Hospital, Dublin
- Lancaster University, UK
- University of East Anglia, UK
- University of Birmingham, UK
- University of Bristol, UK
- Queen's University Belfast UK
- Complutense University of Madrid, Spain
- Rasmus University Medical Center Rotterdam, Netherlands.
- University College London
- University of Helsinki, Finland

Data Protection Training

All TILDA staff complete regular data protection training delivered by TCD and by TILDA. The TCD contract of employment and the TILDA Data Management Policy, both of which are signed by the employee, provide information about the required procedures relating to data protection and confidentiality.

What are your Rights?

You have the following rights over the way we use your personal information. 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 information that we hold about you rectified.

Right to Restriction of Processing

You have the right to restrict the use of your information 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 the information and wish to restrict the use until a legal basis for continued use has been verified.

Right to Erasure

You have the right to request that your information is deleted if we no longer have any justification for retaining it.

Participants can request to exercise their right to erasure at any time and there is no obligation on participants to grant TILDA the right to retain their personal data if they wish for the data to be erased from TILDA databases.

There are however certain limitations to the erasure of previously collected data.

Limitations on erasure:

There are some limitations which apply to any request to erase information from TILDA. It may not be possible to erase your data and/or samples from TILDA when:

- The results from a study have already been published.
- Coded research datasets and results that have been disseminated in other ways, such as being deposited in a publicly accessible database, where subsequent usage could not be erased.
- Analysis has been conducted and the data erasure may impact on the statistical validity of the result. In such instances data will not be used for future research purposes, but must be retained for reproducibility of research results already analysed.
- Data may have to be retained for safety and regulatory purposes.

It should be noted that, due to the large volume and complexity of the data that TILDA collect, and the resources required to delete data, data will be deleted at periodic timepoints.

Right to Withdraw from the Study

You have the right to withdraw from future waves of the study if you so wish. If you would like to withdraw from the study, please contact TILDA on (01) 896 2509 or at tilda@tcd.ie to discuss your request with a member of the research team.

You have the right to withdraw from the study, in which case TILDA will contact you to discuss your withdrawal preferences, that is; if you wish to skip one wave or you wish to permanently withdraw. We will discuss with you what your preferences are for the already collected samples and data. You may agree to give explicit consent for TILDA to retain your data and samples for future research or you may request TILDA to erase your data and samples, noting the limitations above.

Certain information in the contact database must be retained for the following reasons, provided the participant agrees and consents to this:

- If you withdraw from the study and request your data is erased, any process that is underway will continue to completion e.g. if you withdraw 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 withdraw 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, 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. Analysis is a manual and lengthy process as ECG data is complex. This analysis can take up to 5 years, as two independent medical staff must review these files before TILDA can report on them. If you have requested that we delete your information, we will be unable to contact you or your GP with these results.
- If you withdraw from future waves of data collection, you will be asked if you consent for TILDA to continue using your biological samples (blood, DNA, hair, stool or saliva samples) and data which were previously provided up to this point of withdrawal, in line with TILDAs ethical approval.
 - If you agree, research using your samples and data will continue, in the future, in line with consent previously provided and ethical approval. This maintains the quality of the TILDA datasets which are in the public interest.
 - If you do not agree and wish to have your data and samples destroyed, TILDA will do so, thus preventing any future processing. However, there are some limitations to this as set out above.
- However, if processing of a sample is already underway (i.e. in the laboratory), the sample may only be destroyed when the process has been completed.

If you agree for TILDA to retain your information for future research, contact details will be retained to allow linkage with death registration records and completion of an End-of-Life interview on the basis of public interest.

If a TILDA participant passes away, a family member or friend are invited to complete an end-of-life interview about the final months of the participant's life. TILDA links with the death registration records at the General Registry Office to confirm cause of death. Information about the final stages of life and mortality is important in a longitudinal study on ageing and it is not widely available in Ireland, therefore, it is in the public interest to be able to collect it. Information in the contact dataset is required to do this.

Changes to this Privacy Notice

We regularly review and, where necessary, update our privacy information. If we plan to use personal data for a new purpose, we will update our privacy information and communicate the changes to individuals via the TILDA website and TILDA Annual Newsletter before starting any new processing.

Further Information

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>

Last updated: 01 March 2023