



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.

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. [Please note during 2022, all CAPI interviews will now be a CATI style interview due to COVID-19]

- 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. A special SCQ which focuses primarily on COVID-19 has also been conducted in 2021.
- 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 including blood pressure and an ECG, cognitive function, mobility, grip strength, heel bone ultrasound , sensory function including vision and hearing tests and retinal photographs, anthropometry (Height, weight, waist and hip circumference) , physical activity monitoring, oral health assessments, brain magnetic resonance imaging (MRI). A selection of biological samples is collected during each health assessment. These may include blood (full blood count and cholesterol), hair, stool or saliva samples. The information leaflet you receive about the study will describe which samples we plan to collect at each health assessment wave. You can choose to provide biological samples or not at each health assessment wave. [Please note during 2022, there will be no vision (including retinal photography) or hearing tests conducted. During 2022, there will be no MRI tests conducted.]

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 reformatted to preserve your anonymity. These datasets are accessible through established data repositories.

The data collected in archived datasets will be shared with the following areas of the University:

- Research IT provide a location for TILDA's data server and therefore, much of the data is stored and backed-up there. However, personal details (names, addresses) are stored on 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 Procuco 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. This information is stored on the TILDA TCD secure servers.
- 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. This information is stored on the TILDA TCD secure servers.

The purpose and legal basis for collecting 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 participants want to discuss any aspect of the study or their involvement including withdrawal.
- Once a withdrawal request is received, TILDA management will contact the participant to clarify and fully understand whether the participant wishes to withdraw permanently from the study, or to pause or skip for a particular wave while remaining in the following waves of the study.
- When a participant wishes to permanently withdraw from the study, they will be asked if they are happy for TILDA to retain the information collected to date for continued use. If the participant does not agree to their information being retained for continued use then TILDA will delete the information that would identify the participant and continue processing the data anonymously.
- If the participant requests to withdraw from the study and agrees for the continued use of their information, then the information collected to date will continue to be used for the TILDA study, and no further contact will be made.
- If the participant requests to pause or skip a particular wave, their data will continue to be held within the study. No contact will be made with the participant for this particular wave of data collection. However, TILDA will contact the participant at the next wave of data collection.

- 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 personally identifiable data (name, address, phone number etc.) if they wish for the data to be erased from TILDA databases. However, 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, and as any removal of data is likely to seriously impair the achievement of the objectives of the study we will be relying on the derogation under **Article 17(3)(d) GDPR** to continue to process existing data. It is important to note that if an individual's personally identifiable data is erased then they will not be identifiable from the remaining data held on file.

Certain information in the contact database must be retained for the following reasons:

- If a TILDA participant passes away, a family member or friend are invited to complete an end-of-life interview about the final few months of the participant's life. TILDA also 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 therefore, it is in the public interest to be able to collect it. Information in the contact dataset is required to do this. However, when an End-of-Life interview and linkage with the General Registry Office is complete, an individual's contact details will be deleted if requested. At this stage, the data will be fully anonymised.
- If a participant withdraws their consent to participate in the current wave of data collection, any process that is underway will continue to completion e.g. if a participant withdraws after blood samples are taken during the health assessment, immediate analysis of the blood samples and feedback to the participants and their GP (if permission is given) will still take place. Similarly, if a participant withdraws after completing a brain MRI, the scan will still be analysed and feedback provided in cases where further assessment is recommended. Contact details must be retained to allow this process to be completed and participants to be contacted.
- If a participant permanently withdraws from future waves of data collection, they will be asked if they consent for TILDA to continue using any blood, DNA, hair, stool or saliva samples which were previously provided. If a participant agrees, research using these samples will continue, in line with consent previously provided. If a participant wishes to have their samples destroyed, TILDA will do so, thus preventing any future processing. However, if a sample is currently being processed, the process will be completed before the sample can be destroyed. If a participant agrees, data generated from the biological samples prior to the request to withdraw consent will be retained. This data provides important population reference values for biological risk factors for age-related health outcomes and it is in the public interest to collect and retain this information.
- An ECG recording is obtained during the health assessment. Subsequent analysis of this ECG recording is used to identify an irregular heart rhythm (atrial fibrillation) which is an

important risk factor for stroke. As this is a condition that can be managed effectively with medication, the participants' GPs or the participants themselves (if consent to GP contact is not provided) are informed of the diagnosis. Analysis is a manual and lengthy process which can take up to 5 years, therefore contact details will be retained to allow this process to be completed.

Certain information in the raw dataset must be retained for the following reasons:

- The raw datasets must be available to allow replication studies which aim to replicate and validate the findings of earlier research. This is in keeping with best practice in research as set out by the FAIR Principles (Findable, Accessible, Interoperable and Re-usable) for data management. If the data of all participants who withdraw are deleted, it will be very difficult to replicate the findings of published research as the datasets will not be comparable. A reduction in participant numbers also reduces the research potential of the dataset.

Certain information in the research dataset must be retained for the following reasons:

- The research datasets must be retained as TILDA provides a comprehensive and accurate picture of the health, social and economic situation of older persons in Ireland. The information collected is invaluable for government and non-government organisations, policy-makers, clinicians and researchers. Deleting specific individuals' data from the research datasets would be detrimental to these aims.

Data storage and security

Any data we collect from you will be stored confidentially and securely as required by the TCD Information Systems Security Policy and the TCD Data Protection Policy. Trinity College Dublin is committed to ensuring all accesses to, uses of, and processing of TILDA 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 annually.

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.

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.

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

Details of third parties with whom we share personal data

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

- Behaviour & Attitudes Limited (B&A) are the fieldwork partners that TILDA work with. B&A provide the social interviewers who visit participants in their homes 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.

- Seefin Data Management and Kefron 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.
- During the health assessment, you will be invited to provide some biological samples such as blood, hair, stool and saliva samples. This will be discussed with you in greater detail during the health assessment. You may agree or not agree to provide such samples. Blood samples are collected 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. Hair samples are stored in TILDA offices. Saliva and stool samples are usually transported through standard post as these samples are taken at home.
- Once the blood samples are received by the TTMI lab, they are processed for cholesterol testing, full blood count and long-term storage. One sample from each participant, who has provided written informed consent, is sent for immediate analysis of blood cholesterol levels and full blood count at the Central Pathology Laboratory at St. James's Hospital. The remaining blood samples are archived in long-term freezer storage at -80°C according to the written informed consent provided by each participant. 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 your GP (if you give permission for this). TILDA do not provide personal information (names, addresses) or other information provided by you during the interview, SCQ or health assessment to either the TTMI lab or the Central Pathology Laboratory at St. James's Hospital; instead the blood sample is labelled with a unique identifier. Information stored in the Procu SITS system is for TILDA use only. Only nominated TILDA personnel and nominated TTMI lab personnel have access to the TILDA biobank samples and dataset.
- Depending on the timing and focus of subsequent research, additional samples (blood, hair or stool) are sent to various laboratories for analysis. For each sample, the unique TILDA identifiers will be randomly and anonymously recoded to generate unique study specific identifiers so that we can link the information back to the rest of your data. TILDA may provide a small number of other variables with the samples (e.g. age group, gender), however personal data (e.g. your name, contact details, medical card number, job title) is never provided. The laboratories then return a file containing the unique study identifier and the results of the analysis. Any remaining blood, hair or stool samples are returned to TILDA or destroyed under instruction by TILDA. Information provided to these laboratories is only used for the purposes specified above.
- Retinal photographs collected during the health assessment have been transferred to collaborators for analysis. TILDA provide the unique TILDA identifier only but do not provide any personal or other information to these collaborators. An individual cannot be

identified by looking at the photo. Once analysed, collaborators return the scans and the derived information to TILDA. Information provided is only used for the purposes specified above. [Please note during 2022, there will be no vision or hearing tests conducted. This includes retinal photographs]

- Your General Practitioner will receive results of selected health assessment tests should you consent to this. We will not provide any other information to your GP without your permission. These results may include (height, weight, blood pressure, heel bone ultrasound, visual acuity, hearing, mobility, grip strength, blood cholesterol, full blood count). 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).
- 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) but your scan is linked to a unique hospital identifier, not your TILDA identifier. TILDA also do not provide any other information provided by you during the interview, SCQ or health assessment. As noted in the information sheet you receive at each data collection wave, we will contact your GP, (proving you consent to this) if something is detected on your scan which requires further clinical assessment. Sometimes, CAMI transfer a limited number (up to 5) MRI scans to collaborators to facilitate discussions about analysis. These scans contain the hospital identifier (a number) only. An individual cannot be identified by looking at the scan and no other data is provided with these scans. Scans provided to collaborators are only used for the purposes specified above. [Please note MRI scans will not be conducted during 2022]
- In Wave 3, participants provided details of all addresses that they lived at through their lifetimes. 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. Data provided to Maynooth University Social Sciences Institute 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 obtained during the CAPI, SCQ and health assessment is provided. Information provided to Maynooth University Social Sciences Institute are only used for the purposes specified above.
- 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 (name, address, age, sex) who have passed away or who are no longer in the study to the GRO for cross-reference with their records. This information is transferred securely and is only used for this purpose.

- 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.
- 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.
- Tekenable Ltd. (formally Greenfinch) are a software company who TILDA work with to build our data capture software used during our Health Assessment. This software is built specifically for TILDA to use. We do not share any personal data with Tekenable. Tekenable do not have any access to the data we collect. Tekenable cannot access the information we collect during health assessments.
- Iron Mountain Inc. provide long-term secure storage in a locked facility for study documentation e.g. consent forms, SCQs, etc. The documents stored here will include a participant's name or their unique TILDA ID number but not both, therefore research data provided a participant cannot be linked to their name using these documents.
- Cyclone Shredding and DGD Shredding provide confidential shredding of paper copies of study materials.
- TILDA operate a secure 'hot desk' facility in the TILDA offices where researchers from various universities and hospitals (see www.tilda.ie for full list) access the research datasets subject to approval from the TILDA Management Committee. All researchers undergo data protection training and 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, etc) is available.
- TILDA share data with researchers based in other universities and hospitals, nationally and internationally for research on ageing. TILDA use non-identifiable information for research on ageing under strictly controlled conditions and with legal agreements in place. TILDA do not share any identifiable or individual level information with collaborating researchers. Data shared with collaborators is pseudonymised and uses a TILDA ID rather than any identifiable information. These third parties include;
 - The Irish Social Science Data Archive (ISSDA) at University College Dublin
 - Economic and Social Research Institute (ESRI)
 - Smurfit Institute of Genetics
 - Maynooth University
 - Dundalk Institute of Technology
 - National University of Ireland, Galway

- Royal College of Surgeons in Ireland
- University College Cork
- Waterford Institute of Technology
- Health Service Executive
- St. James's Hospital
- St. Vincent's Hospital
- Tallaght Hospital
- Our Lady's Hospice and Care Services
- Royal Victoria Eye and Ear Hospital, Dublin
- Queen's University Belfast
- Lancaster University, UK
- University of East Anglia, UK
- University of Birmingham, UK
- University of Nottingham, UK
- Complutense University of Madrid, Spain
- Dresden University of Technology, Germany
- Italian Institute for Genomic Medicine, Italy
- Imperial College of Science, Technology and Medicine, London
- University College London, UK
- University of Florida, USA

Data Protection Training

All TILDA staff complete 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.

Researchers accessing the research datasets on the TILDA premises must complete data protection training and sign a Data Use Contract prior to access being provided.

What are your rights?

You have the following rights over the way we use personal contact details such as your name, address, phone number and email address (personal contact details).

However, please note that these rights will not apply to any coded data being used for research purposes, as this study is a longitudinal study which relies on large amounts of data to be effective. Therefore TILDA must retain coded data obtained during this research as it is necessary for the achievement of this study, which is in the public interest.

Right of Access

You have the right to request a copy of the personal contact details we retain and can request this easily and at reasonable intervals. Additionally, you have the right to request a copy of the research data collected on you during your participation in TILDA.

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 Data Subject Rights Request Procedure.

Rectification

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

Erasure

You have the right to request that your personal contact details be deleted if we no longer have any justification for retaining them.

Withdrawal from the Study

You have the right to withdraw from current and/or future waves of the study. If you would like to withdraw from the study, please contact TILDA on (01) 896 2509 or tilda@tcd.ie.

All TILDA printed materials contain contact details for the study, should participants want to discuss any aspect of the study or their involvement including withdrawal.

Once a withdrawal request is received, TILDA management will contact the participant to confirm if they wish to skip a wave of data collection or if they want to withdraw completely from the study. If participants express a wish to withdraw permanently, they are asked if they are happy for TILDA to retain the information collected to date for continued use. This discussion is documented, and TILDA mark those participants as withdrawn in our study contact database so they will not be contacted again in the future. Participants who withdraw from TILDA are asked if they are agreeable for TILDA to retain their data for continued processing. If yes, these participants will not be approached in any future waves, but their data will remain part of the TILDA dataset.

However, any process that is currently underway will continue to completion. If you agree, all existing data will be retained to maintain the quality of the TILDA datasets which are in the public interest. If you do not agree, TILDA can delete your personal contact details and therefore make the data we retain truly anonymous.

If you agree, 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 you do not agree, TILDA can delete your personal contact details and therefore make the data we retain truly anonymous.

Restriction

You have the right to restrict the use of your contact details if:

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

Changes to the 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.

Contact

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 make a complaint to the Data Protection Commission, please contact the DPC via their website contact form: <https://forms.dataprotection.ie/contact>.

Date: February 2022