Trinity College Dublin
The University of Dublin

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Privacy Notice for the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)

Introduction

This notice outlines the practices of The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) regarding the use of any personal data you share with us as a research participant.

The Intellectual Disability study (IDS-TILDA) is hosted by the Trinity Centre for Ageing and Intellectual Disability (TCAID) in Trinity College Dublin, The University of Dublin (the "University") of College Green, Dublin 2, Ireland.

IDS-TILDA is a long-term study supported by the Department of Health and funded by the Health Research Board. Its main objective is to understand the health and wellbeing for people with an intellectual disability aged 40 and over.

This study is the first of its kind in Europe, and the only study able to directly compare the ageing of people with an intellectual disability with the general ageing population (information collected by the Irish Longitudinal Study on Ageing) (TILDA).

Information collected by IDS-TILDA will help to inform health and social care policies for people with an intellectual disability. It provides a comprehensive and accurate picture of the health, social and economic situation of older persons with an intellectual disability in Ireland.

Longitudinal studies such as IDS-TILDA require large amounts of data over long periods of time to achieve their purpose. The information that all IDS-TILDA participants have provided since it began over 13 years ago, have contributed to this invaluable data resource.

IDS-TILDA fully respects your right to privacy and actively seeks to protect your privacy rights.

Any personal information which you share with IDS-TILDA will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection laws.

The privacy notice seeks to explain the following:

- How we collect and use your personal data
- How we store and secure your personal data
- The purpose and legal basis for collecting your personal data
- Your rights
- Details of third parties with whom we share your personal data

How we collect and use your personal data

IDS-TILDA collects information directly from you as a research participant to provide evidence to address the inequalities and health disparities for people with intellectual disability as they age.

All information collected by us is only used for research.

We will store all information collected (detailed below) for five years' post completion of IDS-TILDA to allow for publication. IDS-TILDA Is currently funded until December 2024, but we hope that we will receive more funding to continue post 2024, for the valuable research we carry out.

We collect personal data from research participant with an intellectual disability in the following ways:

Pre-Interview Questionnaire (PIQ)-

We post you the PIQ which you can complete in your own time either by yourself (with or without support) or by a proxy on your behalf.

You return the completed PIQ in the stamped addressed envelope provided or the field researcher collects it at the time of interview.

In the PIQ, we ask you information about things like - how you spend your free time, the health services you use, the medications you take, your sources of income, your living circumstances and the level of support (if any) that you need.

Computer Assisted Participant Interview (CAPI)-

After the PIQ is completed, a trained interviewer will arrange to carry out the CAPI interview with you. The interviewer will discuss with you how you want the interview to take place. If you wish, the interviewer can call to your home/place of your choice and conduct the interview with you in person/and or your proxy, or if you prefer, the interview can take place on the telephone, or online either on Teams or Zoom.

The information collected during the interview is directly entered into the interviewer's secure and encrypted computer.

In the interview, we will ask you, for example, about activities you do every day, your health and wellbeing, your friends, your family, your interests and hobbies, your work, your home and how you got on during COVID.

Objective Health Assessment (also known as the Health Fair) –

We will invite you to take part in a health assessment delivered by a trained research nurse with experience in working with people with an intellectual disability.

The nurse will assess things like - oral health, mid upper arm circumference, blood pressure, repeated chair stand test, quantitative ultrasound test, foot assessment, calf measure, timed up and go test, balance assessment, activity measurement application, hand grip strength

test, waist to hip ratio, cognitive assessment, height, weight, nutrition assessment, and a two (2)-minute step assessment.

The nurse manually records all information from each assessment and this information is later entered into secure computers.

Linkage with the Primary Care Reimbursement Service (PCRS)

We will ask for your consent to use your Drug Payment Scheme or medical card number and/or Long-Term Illness number to link to information held by the PCRS in the HSE. If you are unable to give this information on your own, you can ask someone (for example a family member, guardian, key worker or advocate) to help you give this information.

The PCRS is responsible for making payments to healthcare professionals, such as GPs, dentists and pharmacists, for the free or reduced costs services they provide to the public.

The PCRS contains detailed information on any medicines you may have received - for example, it includes the exact name of the medicine, the strength and dosage and the cost of the medicine.

If you agree, the medical card number and/or Drug Payment Scheme/Long Term Illness number you provide us with will be securely shared with the HSE PCRS to obtain this information, to help us explore further the costs associated with healthcare as you age and if current policies around medication usage, reimbursement schemes and treatment schemes are fit for purpose. The HSE PCRS will undertake a consent documentation verification process which will involve requesting a random selection of completed participant consent forms to verify consent.

Linkage with General Registry Office (GRO)
In order to understand and confirm the cause of death of your relative/friend/client's life we, link with the GRO death registration records.

We collect information from carers of research participants in the following ways:

- **The Carers Study-**
  This study hopes to improve experiences of family members caring for people with an intellectual disability. We invite you as a family carer, to share your experiences of caring for your family member.

  We ask you to self-complete a paper-based questionnaire. We will ask you questions about the supports you provide, your role as a carer and the services required by the person you care/support.

- **The End-of-Life study-**
  This study explores important end of life issues for older people with intellectual disabilities and their carers.

  We invite consenting carers/support persons of IDS-TILDA participants who passed away whilst they were an IDS-TILDA participant to take part.

We collect information about how your relative/friend/client's life may have changed in the time before their death. We will focus on their health, social and care situation in this time and the quality of support provided to them during the last stages of their life.

We can do this by phone or in person. The interview is conducted by a trained researcher and will be audio-recorded and later transcribed.

How we store and secure your personal data

We are committed to ensuring all accesses to, and use of, IDS-TILDA data is performed in a secure manner.

IDS-TILDA 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.

All IDS-TILDA team members receive an induction presentation and must complete data protection training delivered by the University. Any researchers accessing the IDS-TILDA research datasets must complete data protection training and sign a Data User Agreement prior to access being provided.

All information we collect is stored confidentially and securely as is required by the University Information Systems Security Policy and the TCD Data Protection Policy. The University's IT Services provides a secure location for IDS-TILDA datasets on the Network Attached Storage (NAS) which stores and backs-up the data, with round-the-clock availability. NAS data storage folders can only be accessed by the approved TCD employees from any TCD computer connected securely to the Trinity network.

Description of the datasets IDS-TILDA holds

The list of datasets is described below:

- **Contact database -** this information contains contact details for the participant and the family member/support staff (shared with us by the participant) such as name, address, phone number, email address and the IDS-TILDA identifier personal identification number (PIN). This is a unique alphanumeric identifier made up of 5 numbers and one alphabet used to maintain confidentiality.

  This information is necessary to stay in contact with the participants and their family member/support staff if necessary.

  This is stored on the secure IDS-TILDA server and can only be accessed by the Project Manager/and the Principal Investigator of the study.

- **Master dataset** – this is the master dataset which contains all the data (including recordings and transcripts) which we collect for the IDS-TILDA study including contact information, medical information, information collected from the PIQ, CAPI and health

assessments, and all studies we conduct such as the Carers study, and End of Life study.

This data is stored on the secure IDS-TILDA server and can only be accessed by restricted IDS-TILDA employees who need access to this information.

- **Coded research datasets -** information from the Master dataset with directly identifiable information removed (for example - no medical card number or contact details). This dataset uses a unique IDS-TILDA Identifier instead of your name to identify you.

  This dataset is stored on the secure IDS-TILDA server. This is the information which is accessible for research purposes.

- **Archived datasets -** we replace the unique IDS-TILDA identifier with a different code. We also remove, some values, in order to mask your identity. No link is kept between the IDS-TILDA PIN and the different identifier. The datasets undergo a rigorous checking process to ensure that all identifiable information is removed before the datasets are archived. These datasets are shared with secure established data repositories such as the Irish Social Science Data Archive (ISSDA). See section below – Details of third parties with whom we share personal data.

The purpose and legal basis for collecting data

We only collect the information necessary for research purposes to identify the principal influences on successful ageing in persons with an intellectual disability, to determine if they are the same or different from the influences for the general population in Ireland.

We hope that research conducted by IDS-TILDA will improve outcomes for those ageing with an intellectual disability. (Article 6, 1, e and 9,2, J of the GDPR).

We also ask for your consent to ensure that you are informed as to the use of information you provide to us.

For those participants unable to give informed consent independently we have received a consent declaration from the Health Research Consent Declaration Committee which only grants such declarations where the research has a substantial public interest. This declaration is valid until October 2026 and is subject to an annual review process.

On recruitment we provide you, as a potential research participant, with a Study Letter, Participant Information Leaflet and a Consent form. We provide separate information leaflets for the CAPI interview, Health Fair, Carer's study and End of Life study. All of this information is intended to help you to understand what we do with the information you provide.

You can contact IDS-TILDA using the contact details below if you have any questions or would like to discuss anything you do not understand in more detail.

Withdrawal of consent

- You can request withdrawal from the study at any stage. All IDS-TILDA printed materials contain contact details for the study if you want to discuss withdrawal.
- If you wish to withdraw from the study, the IDS-TILDA Project Manager will contact you to discuss if you wish to withdraw permanently from the study, or to pause or skip for a period of time, but still remain on the contact list for possible future involvement.

What are your rights?

You have certain rights under the law in relation to your personal data which IDS-TILDA holds, unless the request would make it impossible for IDS-TILDA to reach the objectives of its research in line with Article 89 of the GDPR. For example, if we are about to publish information in a study, we may not be able to remove information you have provided from that study.

If you wish to exercise any of the rights below, please contact the project manager directly.

Contact Details: Margaret Haigh at phone: 01- 896 3186/3187 or Email: haighm@tcd.ie.

Right of Access

You have the right to request a copy of any personal data about you which IDS-TILDA holds.

Rectification

If you believe any information, we hold about you is inaccurate, you will be given the opportunity to review this information. Alternatively, participants/proxies can inform the field worker of incorrect information.

Objection

You may object to our use of your personal data for research purposes. You can contact us and let us know why you object to this use, and we will discuss this with you.

Restriction

You have the right to request restriction to the use of your personal data if -

- You are contesting the accuracy of it;
- You believe it was used unlawfully;
- You have objected to our use of your personal data and we are investigating the outcome of your objection;
- You need to prevent the erasure of it in order to comply with legal obligations;

Erasure or right to be forgotten

We do not rely on your consent as our lawful basis to use personal data collected. The information collected is invaluable for government and non-government organisations, policymakers, clinicians and researchers. We therefore rely on Article 6,1, e and 9,2, J of the GDPR as noted above.

However, if you wish to request erasure of your information, we will consider this request.

Deleting your personal data from the research datasets might be detrimental to the aims of IDS-TILDA, so we will review each request in light of the wider public interest of retaining the information. If we determine that the information cannot be erased, as it would impact the objectives of IDS-TILDA, we will notify you of our decision within one month of your request.

Please note that requesting erasure of your information does not affect the lawfulness of our use of that information, before or after that request.

Please remember that if we erase your data, this means that we will remove any identifiers, and therefore there will be no way of linking any information back to you, and all data protection rights (such as access to the information) will cease to apply .

Details of third parties with whom we share personal data

IDS-TILDA shares limited information with third parties for research purposes.

- **Archived datasets**
  We share, subject to an agreement, the information contained within the archive data set, with ISSDA located at University College Dublin.

  ISSDA is Ireland's leading centre for data preservation and dissemination, ensuring wide access to a number of Irish datasets (https://www.ucd.ie/issda/). International researchers and educators from within and outside the EEA can apply to access the data for teaching and research purposes and are subject to an approval process.
  No information which could identify you directly is shared with ISSDA. Please see archived dataset above for further information.

- **Linkage with the Primary Care Reimbursement Service (PCRS).**
  As noted above, if you agree, we will contact the PCRS to obtain information on any medicines you may have received – this information includes, for example, the exact name of the medicine, the strength and dosage and the cost of the medicine.

  The PCRS will undertake a consent documentation verification process which will involve requesting a random selection of completed participant consent forms to verify consent. We may therefore share your consent form with the PCRS to evidence your consent to this sharing. IDS-TILDA will not share any other information you have given us with the PCRS

- **Linkage with the General Registry Office (GRO)**
  Mortality information is an important outcome in a longitudinal study on ageing. When a participant passes away, IDS-TILDA obtains information from the death registration records at the GRO. To do this, IDS-TILDA provides details of participants (name, address, date of birth/death) 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.

IDS-TILDA Service Providers

IDS-TILDA uses some service providers who need to access limited personal data. We always put agreements in place prior to any sharing with third parties to ensure that data is only used for the specific purpose specified and is not retained unnecessarily. The list of service providers is listed below and is updated on a regular basis.

Behaviour & Attitudes (B&A)-

We use B&A to conduct interviews for us. We provide them with some information about you, if you have taken part in a previous interview or questionnaire, so that you do not have to repeat information we already know about you. For example, the interviewer might say "*Last time we interviewed you, you told us that you had asthma. Do you still have asthma?'* rather than asking 'Do you have asthma?' each time they interview you.

Once the information is shared with us, B&A deletes it from their systems. B&A are supported by an IT solutions management company, IT Force and a data storage company, Kefron File Stores.

Audiotrans Ltd-

We use Audiotrans Ltd. to transcribe audio recordings such as the end-of-life interview for us. They delete the audio file once the transcription process is finalised.

DHL Express (Ireland) Limited-

We use DHL Express (Ireland) Limited to ensure secure delivery of IDS-TILDA data, such as the PIQ and the Carers' study questionnaire etc.

Custodian-

We use Custodian for the purpose of printing envelope labels. This list is only used for this purpose and is deleted after use.

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 IDS-TILDA website before starting any new processing. We will never use your data for a purpose outside of the consent you have given.

Contact

Any queries relating to the processing of personal data for the purposes outlined above or requests in relation to participant rights can be directed to the Trinity College Data Protection Officer:

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

Queries can also be directed to:

Professor Mary McCarron
Principal Investigator, IDS-TILDA
mccarrm@tcd.ie

Or:

Ms Margaret Haigh
Project Manager, IDS-TILDA
01 – 896 3187
haighm@tcd.ie

If you are not satisfied with the information We have provided regarding the processing of your personal data, or you wish to raise a concern with the Data Protection Commissioner (DPC), please contact the DPC via their website contact form: https://forms.dataprotection.ie/contact

Date: September 2022