

## ASI Privacy Statement - TeamUp For Dementia Research



**Who are we?** The Alzheimer Society of Ireland (ASI) is a company limited by guarantee and a registered charity in the Republic of Ireland (Registered charity number 20018238).

**What do we do?** ASI works within communities across the country providing dementia related services such as day care, day care at home, home care, social clubs, Alzheimer cafés, dementia advisors, community engagement and a national helpline. The ASI also advocates for the rights and needs of all people living with dementia and their carers or families. ASI processes personal data (identifying information) and special category personal data (more sensitive data such as health information) to carry out this work. ASI is committed to adhering to data protection legislation and you can find the ASI Main Privacy Statement in the footer of our charity's website.

**How does ASI Research processes data?** The ASI is also engaged in a research participation initiative called TeamUp For Dementia Research. This statement gives details on how we use data during and after signing up individuals for the TeamUp For Dementia Research database. ASI Research also processes the personal data of researchers, academics etc. in order to carry out this work.

**What personal data do we collect?** When individuals chose to sign up for TeamUp For Dementia Research they provide the following data to ASI: name, date of birth, address, email, contact number, living situation, caring situation, ethnicity and health information (e.g. dementia diagnosis information). Health information and ethnicity represent special category personal data (i.e. potentially more sensitive data). ASI Research also collects names and contact details for relevant researchers and academics.

**How do we use data for TeamUp For Dementia Research?** We process data for the purpose of organising and administering the Team Up for Dementia database. This includes exchanging information with relevant researchers and academics, checking if a person is eligible to take part in research studies, sending research newsletters and communicating with individuals about opportunities to take part in research.

**What are our grounds for processing?** In each instance that ASI processes your personal data and/or special category personal data it is reliant on one of the following legal grounds depending upon how or why you are interacting with us. Under GDPR there are six distinct legal basis for the processing of personal data (Art. 6) and a further ten distinct legal basis for the processing of special category personal data e.g. more sensitive information such as health (Art. 9). ASI decides which legal basis is most suitable to align with each act of processing as set out below:

### Purpose

Management of research initiatives

### Legal basis

Consent (can be withdrawn at any time) (Art.6)  
Necessary for execution of a contract (Art.6)  
Legitimate interests (Art.6)

- *It is in the interests of ASI to conduct research with ASI service-related data to formulate evidence-based policies. It is in the interests of ASI to collaborate with select external academic researchers, although research participant data is not shared with ASI.*

Data made public by the individual (Art 6)

Compliance with a legal obligation (Art.6)

Administration of TUDR database

Explicit consent (can be withdrawn at any time) (Art. 9)

Vital Interests (Art. 9)

**How long do we retain your data?** For the specific purpose of managing the TeamUp For Dementia database, ASI Research will retain personal data and special category personal data for as long as a valid explicit consent to process that data is in place. The ASI will verify an individual continues to consent to being a part of TeamUp For Dementia Research each time direct contact is made with the database participant and at a minimum this contact will be made once every 12 months. Please note that you can request to be removed from the database at any time. To remove an individual ASI Research will securely delete all of your personal data from the CRM system and all email correspondence with you. You will also be automatically removed from TeamUp For Dementia Research communications contact list unless you wish to provide a new consent to continue to receive TUDF communications. In the event that a TeamUp For Dementia Research member becomes uncontactable and it is not possible to verify consent once every 12 months, that members data will be removed from the database after three attempts over four weeks to contact them. ASI Research will retain the personal data of researchers, academics etc. for as long as is deemed necessary.

**Where do we keep your data?** Sector leader service providers have been contracted and ASI data, in digital form, is stored in data centres in Ireland. All back up servers are located inside the EU. ASI IT oversee key security and usage procedures and policies relating to information security and devise clear instructions for staff. ASI Research utilises the digital survey software, Qualtrics, to distribute a secure form to facilitate digital sign-ups to TeamUp For Dementia Research. ASI Research utilises Salesforce to securely store and further process the relevant data. ASI Research will distribute an optional newsletter to members of TeamUp For Dementia Research via email using email marketing software Dotdigital.

**How does your process ensure privacy?** We collect the data of database participants using two Qualtrics digital forms meaning contact information and health data are not directly linked. Within 48 hours of completing the forms all personal data is removed from Qualtrics and only re-matched to the individual when inputted to Salesforce. Individuals can sign up for TeamUp For Dementia Research over the phone with a member of The ASI Research Team if they would prefer to not use digital online forms (i.e. Qualtrics).

**Do we share your data?** TeamUp For Dementia Research data is strictly restricted to the relevant ASI Research Team. The data is not shared within ASI or with external researchers without a valid explicit consent in place. ASI contracts third party service providers to manage and store personal data. These situations are managed by data processor agreements which contain clear contractual safeguards for individuals. It is important to note as a charity representing vulnerable individuals the ASI has a duty of care to persons with dementia and carers. If the safety or health of a member of TeamUp For Dementia Research, or a person with dementia, is believed to be compromised or in danger, ASI Research may, in certain circumstances, report this to the ASI Safeguarding Officer or otherwise share your personal data to ensure your safety.

**What are your rights?** Individuals have rights over their personal data under EU and Irish Data Protection law. These rights are not absolute, and qualifications or restrictions can apply. The most exercised right by individuals is the right of access. This is the making of a request by a data subject, which gives them the right to obtain – subject to certain restrictions provided for under the GDPR and the DPA 2018 – access to, and copies of, their own personal data, and other relevant information, free of charge and in an accessible form. A data controller must ensure that individuals whose data they are processing are facilitated in lodging access requests. A data controller must provide a response to an access request in a certain manner and within a certain time.

In summary, the rights that can be exercised by data subjects under data protection law also include: the right to be informed; right to rectification; right to be forgotten / erasure; right to restrict processing; right to object; right not to be subject to automated decision making and/or profiling; right to portability and the right to withdraw consent at any time. ASI is committed to helping individuals exercise their rights over their own data. Please contact the ASI DPO as set out below to exercise any of these rights or for further information. If you believe your data privacy rights have been infringed by ASI, you have the right to make a complaint to the Data Protection Commission using the contact details below. It may also be possible to seek compensation through the courts.

**How can you contact the ASI Data Protection Officer?** You can contact the ASI DPO by email: [dataprotection@alzheimer.ie](mailto:dataprotection@alzheimer.ie) or by post: DPO, Alzheimer Society of Ireland, National Office, Temple Road, Blackrock, Co. Dublin, A94 N8Y0. Telephone: (01) 2073800

You can contact the Irish data protection regulator, the Data Protection Commission by webform on its website [www.dataprotection.ie](http://www.dataprotection.ie) by email: [info@dataprotection.ie](mailto:info@dataprotection.ie) or by post: 21 Fitzwilliam Square South, Dublin 2, D02 RD28 and Canal House, Station Road, Portarlinton, Co. Laois, R32 AP23. Telephone (01) 765 01 00 / 1800 437 737

*ASI updates this main Privacy Statement periodically. Updates will be made available and, where appropriate, notified to you. Privacy Notice dated: October 2024*