



## THE ALZHEIMER SOCIETY of IRELAND

### Data Protection 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 (CHY 7868).

**What do we do:** The ASI works within communities nationwide providing dementia related services such as day care, home care, respite, social clubs, dementia advisors and a national helpline. The ASI also advocates for the rights and needs of all people living with dementia and their carers or families. We process 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 privacy statement [here](#) on our main charity website.

**Research at The ASI:** 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 we collect:** When individuals sign up for TeamUp For Dementia Research ASI Research collects the following data: 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 processes names and contact details for relevant researchers and academics.

**How 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.

**Our legal grounds for processing:** In each instance that ASI processes personal data and for the wider purpose of organising the TeamUp For Dementia Research database, e.g. processing the data of researchers or academics, it is reliant on one of the following legal grounds set out in Articles 6 GDPR.

- Legal Basis Legitimate interests *(It is in the interests of ASI to efficiently and effectively provide opportunities to participate in research to people with dementia and their families)*
- Necessary for execution of a contract
- Data made public by the individual
- Compliance with a legal obligation

In each instance that ASI processes personal data and/or special category personal data for the direct purpose of administering the TeamUp For Dementia Research database e.g. processing the data of individuals who sign up to the database, it is reliant on one of the following legal grounds set out in Articles 6 & 9 GDPR.

- Consent (can be withdrawn at any time)
- Explicit consent (can be withdrawn at any time)
- Vital Interests

**Who we share data with:** The ASI shares your data only with GDPR compliant and contracted data processors. ASI Research utilises the digital survey software, Qualtrics, to distribute a secure form to facilitate digital sign-ups to TeamUp For Dementia Research. To read the Qualtrics Security Statement Click [HERE](#). ASI Research utilises Salesforce to securely store and further process the relevant data. To read the Salesforce Privacy Statement click [HERE](#). ASI Research will distribute an optional newsletter to members of TeamUp For Dementia Research via email using email marketing software dotdigital. To read the dotdigital Privacy Policy click [HERE](#).

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, we may, in certain circumstances, report this to the ASI Safeguarding Officer for possible further steps.

**Where we keep data:** Salesforce, contracted by The ASI, hold TeamUp for Dementia personal data in digital form in secure data centres inside the EU/EEA.

**Ensuring privacy:** Internal ASI access to TeamUp For Dementia Research data is strictly restricted to the relevant ASI Research Team. 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 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).

**How long we retain your data:** The ASI will retain personal data and special category personal data for as long as a valid 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. Should you wish to be removed from the database, The ASI will remove all of your personal data from Salesforce and any email correspondence with you will be deleted. You will be removed from any TeamUp For Dementia Research Communications. In the event that a TeamUp For Dementia Research member becomes uncontactable and it is not possible to verify consent after 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.

**Your rights relating to your data:** Individuals have rights over their personal data under EU and Irish Data Protection law. In summary your rights are: Right to be informed; Right of access; 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. If you believe your data privacy rights have been infringed you have the right to make a complaint to the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, D02 RD28, email: [info@dataprotection.ie](mailto:info@dataprotection.ie).

**Contact the ASI Data Protection Officer:** The ASI is committed to helping individuals exercise their data protection rights. **Address:** DPO, ASI National Office, Temple Road, Blackrock, Co. Dublin. **Email:** [dataprotection@alzheimer.ie](mailto:dataprotection@alzheimer.ie)

*We will update this data protection statement from time to time. Any updates will be made available and, where appropriate, notified to you.*