**TeamUp for Dementia Research**

**Terms and Conditions of Use**

**Introduction**

TeamUp for Dementia Research (TUDR) is a service provided by The Alzheimer Society of Ireland (ASI) in collaboration with The Dementia Research Network Ireland. It has been developed to make it easy for people to register their interest in taking part in dementia-related research. People with dementia and their families provide personal information about themselves which is then used to match them with suitable dementia research studies.

In agreeing to these Terms and Conditions of Use outlined below, you are undertaking to ensure the protection and security of all data transferred from TUDR for the purposes of your research and to process all such data in accordance with prevailing data protection legislation and the below conditions.

The ASI reserves the right to alter or update these Terms and Conditions of Use at any time. The date of issue of this version can be found at the bottom of each page.

**Minimum Requirements**

To be eligible for recruitment support through TUDR, the minimum requirements must be met. These include;

1. The Researcher must fill out a TeamUp for Dementia Research Application Form detailing relevant study information.
2. The researcher must provide proof of ethical approval for their study from a relevant Research Ethics Committee(s) in the Republic of Ireland.
3. The Research team/Researcher must accept, sign, and return these Terms & Conditions of Use to The ASI.
4. Use of TUDR must have potential to benefit the research study i.e. The ASI reserves the right to be confident that use of the TUDR service would provide significant benefit to the study being conducted.

**Acceptable Use**

Specific queries can be made through the contact information listed at the end of this document.

In agreeing to these Terms and Conditions, you are undertaking to ensure the protection and security of all data transferred to you from The ASI TUDR service and to process this data in accordance with the following conditions:

1. You are responsible for enrolling participants in your research study, and for ensuring that any members of TUDR who take part in their research study have capacity to consent to taking part in that study, and to obtain their explicit consent.
2. All information and documentation transferred from TUDR should be treated with the strictest confidence at all times and managed in line with prevailing data protection legislation.
3. You are expected to implement an appropriate level of information security good practice at all times e.g. robust by industry standard IT systems, choosing secure passwords, not sharing data with people who are not authorised to see it, keeping any paper documents secure.
4. Data transferred from TUDR should only be used for the purposes of contacting potential research participants in relation to the specific research study applied for and no other purpose.
5. Any data transferred by ASI must be securely destroyed should a TUDR member choose not to take part in your research study.
6. You must make contact with TUDR members within five working days of receiving their information.

The ASI endeavours to ensure that all information on TUDR is accurate and available in a timely manner. If you encounter inaccurate information, please inform ASI using the contact details below. We endeavour to assist each study that meets the requirements with their participant recruitment, but we cannot guarantee this will always be possible.

The ASI reserves the right not to support a research study through TUDR.

**Consent**

Each member of TUDR gives their explicit consent to be part of the database and have their data shared with research teams carrying out dementia-related studies. This consent is verified with the database members a minimum of once per year. However, research teams can never assume that this means an individual has the capacity to subsequently provide their explicit consent to taking part in any particular research project. Therefore, it is imperative that consent is carefully obtained before the person participates in any research. If you have any concerns about a particular person’s ability to give valid consent, you must inform The ASI.

If an individual withdraws their explicit consent to be part of TUDR and The ASI has recently transmitted their data to your research team (meaning there is a reasonable chance that individual may not already have been enrolled by the research project) then The ASI will contact you to inform you that the individual’s data must not be further processed and should be securely destroyed as they have withdrawn their explicit consent for this data sharing.

**Breaches of Terms & Conditions**

Any breaches of data within a project in relation to data protection law must be risk assessed and reported to the Data Protection Commission if required.

The research team carrying out the study undertakes to promptly inform The ASI of any decision that results in the DPC exercising its corrective powers under the Data Protection Act against the research team/their employer (s.127); issuing any administrative fine against the research team/their employer (s.141); commencing any formal investigation into the research team/their employer (s.137). The ASI will also be swiftly notified if any member of a research team or contractor is charged under s.144 or s.145 for the unauthorised disclosure of relevant personal data.

The ASI will request feedback on TUDR from research teams. There will also be a continuous feedback process with members of the TUDR. Should a pattern of negative feedback arise, The ASI reserves the right to not engage with particular institutions or companies in relation to the TUDR service.

**Further information**

For queries, please contact:

Cíara O’Reilly

The Alzheimer Society of Ireland

National Office

Temple Road

Blackrock

County Dublin

E-mail: TeamUp@alzheimer.ie

Phone: 085 870 9671

*I accept the TeamUp for Dementia Research Terms and Conditions of Use and have authority to sign on behalf of my research project.*

Signed:

Print Name:

Role:

Research Project:

Institution/company:

Date: