

# GDPR Notice and Consent

Friendsourcing Ireland

Draft 3

July 15th 2019

## Notification/Consent for Collection and Use of Data – Friendsourcing Ireland

This research project is a collaboration between Care Alliance Ireland, Indiana University and The Alzheimer Society of Ireland.

This notice relates to your participation in an applied research project called Friendsourcing Ireland.

This research will collect data about you that can identify you, referred to as special category personal data. The General Data Protection Regulation (“GDPR”) requires researchers to provide this Notice to you when we collect and use Study Data about people who are located in a member state of the EU or is in the EEA that belongs to the European Union or in the European Economic Area.

We will obtain and create Study Data directly from you and from your participation in a closed Facebook group so we can properly conduct this research.

The Data controllers for this research are Care Alliance Ireland and Indiana University.

Contact details;

Care Alliance Ireland  
Coleraine House  
Coleraine Street  
Dublin 7  
Republic of Ireland

Indiana University  
TBA

[info@carealliance.ie](mailto:info@carealliance.ie)

TBA

01 874 7776

TBA

Both data controllers have signed a cross border transfer agreement for personal data to be transferred to the US plus a joint controller agreement required in accordance with Article 26 of GDPR.

The Research Team will collect and use the following types of Study Data for this research:

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- Contact Information (including your name, phone number, Facebook name, and e-mail address)
- Personal Health information (one question rating your own health)
- Demographic questions (such as your ethnicity, age, gender, marital status, education, and employment)
- Use of the Internet and in particular your use of Facebook
- Details of your caring role (Including health information about the person with dementia that you care for)

Through an online piece of software called Qualtrics, you will be invited to enter data about you and the person you care for. This will help us decide if you meet requirements to be in this applied research project. You will also be invited to complete a similar shorter questionnaire after eight weeks. This will also help us measure any impact the intervention may have.

The project will make extensive use of online and cloud storage systems including Qualtrics, a well-established tool we use to support with project eligibility screening and with managing a pre and post intervention questionnaire. We also are using Facebook as an online platform to facilitate the support groups and to secure participants friends comments to questions posed. We will be using a bespoke App that will automatically collate all the comments made to the questions posted as part of the eight week intervention. We will also be using Indiana University's own servers to store and analyse the group discussions.

We have signed contracts in place with these data processors whom are GDPR compliant.

While in each of these online platforms there remains a level of privacy risk, we believe that the overall risk of a data breach is low to medium and any likely impact minimal.

This research will keep your data for three years after this project ends and will then be deleted from all databases and servers.

The following categories of individuals may receive Study Data collected or created about you:

- Members of the project team from Care Alliance Ireland (2 persons), and Indiana University (4 persons) so they can properly conduct the research.
- Indiana University (School of Social Work) will oversee the research to make sure it is conducted correctly and to protect your safety and rights

One person from the Alzheimer Society of Ireland (ASI) will be involved in the research and specifically in the recruitment of participants and in the online Facebook support group moderation. The ASI representative will not have access to any other of your personal data other than what you choose to share when you interact in the Facebook group.

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The research team will transfer your data to our research collaborators in the United States (Indiana University, School of Social Work). The United States does not have the same laws to protect your data as States in the EU/EEA. However, the research team is committed to protecting the confidentiality of your data.

We will be processing your data on the basis of explicit consent received.

Additional information about the protections we will use is included in the main explicit consent document that you will be invited to review and agree to before we process any of your data.

The GDPR gives you the following rights;

1. The right to be informed
2. The right of access
3. The right to rectification
4. The right to erasure
5. The right to restrict processing
6. The right to data portability
7. The right to object
8. Rights in relation to automated decision making and profiling.

Specifically in relation to your data, you have the right to:

- Access, correct or withdraw your data;
- Restrict the types of activities the research team can do with your data
- Object to using your data for specific types of activities
- Withdraw your consent to use your data for the purposes outlined in the consent form and in this document

For more information about your data rights visit [www.dataprotection.ie](http://www.dataprotection.ie)

You have the right to make a complaint to the Data Protection Commission

### Contact Details:

21 Fitzwilliam Square South  
Dublin 2  
D02 RD28  
Ireland

[0761 104 800](tel:0761104800)  
[057 868 4800](tel:0578684800)

## GDPR Notice and Consent

09:15 - 17:30 hrs (17:15 Friday)

General Details of how to contact the data Protection Commission ;

<https://www.dataprotection.ie/en/contact/how-contact-us>

Webform: <https://forms.dataprotection.ie/contact>

To exercise any of your above rights you may contact Liam O'Sullivan, Care Alliance Ireland;  
Phone at 087 207 3265 or by email [ndo@carealliance.ie](mailto:ndo@carealliance.ie) if you have:

- Questions about this Notice
- Complaints about the use of your Data
- If you want to make a request relating to the rights listed above.

Please click one of the boxes below to indicate whether you understand and agree with the contents of this notice.

I understand the contents of this notice (Tick Box Here)