



**FRIENDSOURCING**

Online intervention for family carers  
of people with dementia

## Friendsourcing Ireland Project

### Data Protection Impact Assessment (DPIA)

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#### Step 1: Identify the need for a DPIA

Explain briefly what the project aims to achieve and what type of processing it involves. You may find it useful to refer or link to other documents, such as a project proposal. Summarise why you identified the need for a DPIA

There are over 60,000 people caring for someone with dementia in Ireland. The vast majority of people with dementia are cared for at home by family members/carers.

Many dementia family carers, due significantly to their caring roles, may find it difficult or indeed impossible to partake in the more traditional forms of carer support – for example face to face peer support groups, face to face training etc. Being able to take part in virtual/online support groups provides many thousands of family carers in Ireland the opportunity to benefit from such interactions. However, providing evidence-based methods of online support has been hindered by

limited resources for technology development as well as possible health and social care practitioner reluctance.

Consequently, investigators must innovate to adapt and repurpose technologies (including social media platforms that were developed originally for non-psychosocial intervention purposes). One example of this research is a pilot research study of dementia carers by US investigators that are members of our project team, that demonstrated through the use of Facebook considerable potential to support with stress and burden reduction as well as improved quality of life. Using Facebook again this project will investigate the further capacity of the intervention for adapting and harnessing Facebook to achieve social good for Irish dementia caregivers using a model of online support called Friendsourcing. We propose to deliver this model through a time limited online moderated peer support intervention that seeks to improve the self-reported quality of life of caregiver participants. The importance of this online caregiver support intervention is that here is a positive association between family carer quality of life and the Person with Dementia (PWD) quality of life. Gitlin and Hodgson (2015) found caregiver quality of life contributes to PwD slowing disease progression which can delay entry residential care which is associated with increased morbidity. It is also explicit Irish government policy to support care at home and to delay unnecessary entry to long term care.

This investigation will use qualitative and quantitative data to compare small online caregiver groups' changes in social support, caregiving burden, and caregiver stress following participation in the Friendsourcing intervention – with a view to increasing the size, availability, speed and effectiveness of online support. We will explore the effect of the Friendsourcing intervention on types of support developed through closed Facebook groups operating over an 8 week period.

Discussions will take place in four separate and consecutive closed groups, run over 8 week periods. The online text discussions will be manually copied by the research team, for later analysis. A bespoke Facebook App will also collate the shares made and the comments posted in response to agreed carer related questions that emanate from the closed group (See the two flow charts in Appendix I)

The questions will be posted on a FB page managed by the project lead (Care Alliance Ireland). Each group of 20 participants in the four closed groups will be invited to comment and or repost the questions – which are likely then to appear initially in their friends FB feeds and then beyond. (Note that a comprehensive set of documents including ; GDPR Notification and Consent; a separate Informed Consent Statement, a Screening Questionnaire and other project related material has been created, in part for, a submission to the Indiana University (IU) Internal Review Board (IRB, also known as a Research Ethics Committee) (Protocol Number 19027773321). The application was approved on 23<sup>rd</sup> May 2019. The material supplied based largely on the 2016-2017 intervention previously approved by the IRB in IU. Modifications have been made that reduce the amount of data collected. In addition, the sharing of questions will require participants to actively share each question/post rather than this being done automatically by the app which investigators used for their earlier research.

#### **Need for DPIA.**

Our considered assessment is that any deliberate data processing being undertaken as part of this project presents minimal risk to the privacy and safety of participants. The previous 2016 US based investigation was judged by Indiana University IRB to present minimal risk to participants and no data breaches were reported in this earlier trial.

However, we are proceeding with a full DPIA for the following reasons;

This project uses the Facebook platform as an integral part of its operations. We are aware that a number of statutory investigations by the data protection regulator (DPC) are underway in relation to Facebook. This raises concerns in general. We believe there exists a level of risk, both reputational and other types of risk, by simply being involved with a project that utilises Facebook.

On the other hand our screening process only allows regular Facebook users to take part. As such, we can reasonably argue that such eligible participants (Family Carers) have knowingly signed up to Facebook's terms and conditions.

There is also a risk that relates to the public sharing of the private health information by family carers of people with dementia, and specifically the risk of the sharing of personal data of such people with dementia.

In commenting on and or sharing these public posts, as detailed above, it is likely that participant's friends, and other Facebook users, will become aware (if they are not already) that their friends are involved in caring for a relative with dementia. This raises a level of concern about undermining the person with dementia's right to privacy, and specifically as it pertains to their 'special category personal data'. People with dementia are rightly classified as vulnerable individuals. A risk to these individuals is the loss of control over their own special category personal data.

We have decided that best practice is to secure the explicit consent of the person with dementia for the participation of the person who cares for them in this project. We have set in place a multi-faceted approach to securing this consent. The Alzheimer Society of Ireland are considered to have particular expertise in this regard.

We are aware of the challenges of securing the explicit consent of people with dementia, particular those where their condition is at an advanced stage. Whilst we have not yet agreed on a detailed protocol in relation to how we will seek such consent; we will be guided by the 2015 Assisted Decision Making Capacity Act. We will also be guided by the position paper adopted by the Alzheimer Society of Ireland. <https://alzheimer.ie/wp-content/uploads/2018/12/ASI-Position-Assisted-Decision-Making-Capacity-Act-2015.pdf>

In particular we will be mindful of the four key principles;

A presumption of capacity; -

Where capacity is in question, a functional or task approach to capacity must be taken;

There is to be no intervention unless necessary in individual circumstance and any intervener must choose least restrictive alternative;

Will and preferences and beliefs and values of the person must be central to all decision making.

We are also cognisant of the need to use a functional based approach. (p's 7 and 8 of the position paper) and to seek guidance for those more experienced in this area.

There is always concern around consenting vulnerable adults, particularly those who have dementia as capacity to consent may decline over time as levels of cognitive impairment progress. However, the Assisted Decision Making (Capacity) Act 2015, advises that it cannot be assumed that a person lacks capacity to consent in the first instance.

However, we are also cognisant of the fact that some people with dementia, particularly advanced dementia, may not be in a position to provide informed consent. Should a power of attorney be in place, then this may enable such consent to be given. However, we are acutely aware of the possible conflicts of interest that may exist in a situation whereby the family carer also has power of attorney.

To withdraw consent, the person with dementia can contact the project assistant by phone, e-mail or post. The details of this person will be given to the PwD and available on the project website.

The reason we are seeking PwD consent is that the private health information of the (PwD) is likely to be discussed by the project participants as part of the closed Facebook group. Furthermore, the material risk is that the health condition of individuals with dementia will be made (more) public following the posting of questions on FB and their subsequent sharing/comments.

We believe that the real value of this proposed approach - namely of the moderator facilitating participants to identify the individuals with dementia (for example 'my mother', 'my husband' ) is that the closed group discussions can be more authentic – in that participants will be free to refer to the person they are caring for by name, rather than being asked to avoid identification which may be experienced by the participants as contrived and artificial. As such, the whole experience will be more genuine and require less 'forced anonymisation' by the participants.

Reluctantly, we have decided that should it not be possible to secure such explicit consent from people with dementia, that these potential participants (ie family carers) will not be facilitated to take part in this project. We are aware that this will exclude participation for some family carers.

As a further protection, will be make it explicit to family carer participants that there remains a risk to the privacy of the person with dementia. This will be done as part of the recruitment process and will include the ability to withdraw at any stage of the recruitment or 8 week intervention stage. We will also advise them of the tight moderation protocols we will have in place should a breach of privacy occur. These include a daily review of posts. It will also include an agreed set of protocols that reflect best practice in NGO online moderation, that is consistent with data protection and other regulations; this includes clear posting guidelines, respectful comments, use of profanities as well as moderation and guidelines around protecting privacy. We will detail the consequences for breaches of rules.

#### **Need for Consultation with DPC**

The envisaged processing will involve potentially some indirect processing of the special category data of vulnerable individuals, namely people with dementia. Although we do not believe that

mitigating actions cannot address any high risk that could be posed to these individuals (meaning no residual high risk is indicated by this DPIA) nevertheless this project wishes to ensure it is not mistaken in this regard. We therefore wish to refer this DPIA to the Supervisory Authority in accordance with Recital 84 GDPR. The as yet outstanding Regulations set out in s.84 (9) DPA 2018 means we also wish to refer for clarity.

## Step 2: Describe the processing

**Describe the nature of the processing:** How will you collect, use, store and delete the data? What is the source of the data? Will you be sharing data with anyone? You might find it useful to refer to a flow diagram or another way of describing data flows. What types of processing identified as likely high risk are involved?

The project will make extensive use of online and cloud storage systems including Qualtrics, a well-established tool we use to support with a GDPR Fair processing notice, to manage project eligibility screening and with managing a pre and post intervention questionnaire.

We have also undertaken a level of due diligence in respect of Qualtrics compliance with GDPR and have independently established that Qualtrics is EU-US Privacy Shield Certified

We have been advised by Qualtrics that data is deleted 90 days after it is deleted by the customer.

Comments generated from the FB posts will be analysed through Dedoose software to generate thematic analysis. This data will be stored in IU secure servers and will be destroyed by IU within 3 years. We have also undertaken a level of due diligence in respect of Dedoose's compliance with GDPR and Dedoose report to be EU-US Privacy Shield Certified (Ref; <https://www.dedoose.com/about/security> )

Dedoose claims the following “ keeps a backup of all data for restoration purposes for a period of 2 years. This data backup is encrypted using AES256. A user can delete their project from Dedoose at any time and we can remove that data permanently from our backups by a certified written request if needed.”

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 developed by Indiana University 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.

In spite of our attempts, we have not been able to fully understand or clarify how FB uses data nor get a full understanding of it's data retention policy. We however understand that posts made (that the app will capture) will not be normally deleted unless done so by the FB user or if their account is deleted. Ref: [https://www.facebook.com/full\\_data\\_use\\_policy](https://www.facebook.com/full_data_use_policy)

As the data processing by the project on FB is limited to comments on a closed group owner by the project (Care Alliance Ireland) as well as comments made on posts posted by Care Alliance Ireland – the project has the power to delete all such comments and data. This will be done by

Care Alliance Ireland within three years or sooner than that if not required to deliver on the objectives of the project. We understand that this will result in the deletion of such data from FB's servers. Furthermore, IU, the owner of the bespoke App is committed to deleting all data on the app within three years.

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

This data will be shared between the research team – which comprises of Indiana University (4 people), and Care Alliance Ireland ( 2 people)

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

There are two sources of data for this project. The first is pre and post survey data completed by the caregiver through Qualtrics in which they are requested to answer some demographic questions and to report their experiences with caregiving burden, stress, and forms of support they receive.

The second source of data are the posts and comments made in a closed Facebook support group and the posts and comments made on a public-facing page which shares emotional and informational support questions that the closed Facebook support group decides they would like to share publicly. This data is collected manually by the researchers as well as by the bespoke Facebook app.

Following the posting of a specific question: public shares and comments are captured by the App along with the date, time, and name of person by an app for the purpose of automating the manual process of copying and pasting. Shares and comments are stored in a secure database behind the Indiana University firewall that is password protected. No other personal information or data is captured. The data is stored for the purpose of analysing content to determine the nature and extent of emotional and information support that caregivers obtain through the intervention. All data will be deleted from all servers/databases of Indiana University and Care Alliance Ireland within 3 years.

To operate successfully, the project will be required to process a level of personal data; initially during family carer participant recruitment and specifically the name ( ); FB name, email address, and phone number. Screening/Inclusion/Exclusion questions for participation of family carers include two that relate to health status (specific exclusion criteria are recent psychiatric hospitalisation and recent suicide attempt) A yes response to these two questions will be deemed to make the potential participant ineligible for participation. They will be directed to suitable support organisations and their data will be deleted immediately other than recording their ineligibility.

The pre and post intervention surveys also include questions that could be considered 'personal data'.

Potential participants will be invited via a Qualtrics link, to review the screening/eligibility criteria, and then invited to read the GDPR Fair Processing Notice. They are then invited to read the Explicit Consent document – and accept it. In reading and ticking the ‘I agree’ section, they are deemed to be providing explicit consent. They are then invited to complete some demographic questions and survey instruments relating stress, carer burden etc.

Therefore, family carer participants will be required to provide explicit consent in relation to the above data.

Data collection will only proceed when a joint controller agreement has been signed by the joint controllers, namely Care Alliance Ireland and Indiana University.

The IRB (in IU) acts to ensure researchers have been trained in Human Subject Research Protection and that the research meets all criterion set forth to minimize risk and protect the privacy of participants and the confidentiality of their data. Explicit consent notifies them of the purpose of the research, describes its procedures, benefits, risks, and how privacy protections are managed. Importantly, the IRB assesses the scientific validity of studies and determines whether benefits outweigh risks. We have assessed that we have a lawful basis in processing personal data of the family carer participants and the person with dementia being cared for – under the basis of explicit consent.

The transfer of personal data from the EU to controllers and processors located outside the EU in third countries should not undermine the level of protection of the individuals concerned. We are endeavouring to ensure that transfers of data between project partners are done in full compliance with Chapter V of the General Data Protection Regulation, the “GDPR”.

We have reviewed the Data Protection Commissioners guidelines on this issue.

<https://www.dataprotection.ie/sites/default/files/uploads/2019-06/190611%20Transfers%20of%20Personal%20Data%20to%20Third%20Countries%20or%20International%20Organisations.pdf>

The remaining section of Step 2 of our DPIA (below) focusses specifically on ‘data processing’ where potentially personal data of a person with dementia may be posted by Facebook users.

While it is not the intention of the project, we do believe that there is a risk that outside of the closed Facebook group, that a level of additional personal data of a person with dementia will be created/shared by the participants themselves, their FB network and other FB users and subsequently captured as part of the operations/data collection of the project.

Clearly, as the FB posts are shared and commented on, there remains a real risk that other people with dementia’s private health condition may be shared without their consent. (for example a friend may respond by saying in a comment – ‘I have some idea of what it may be like for you, I am caring for my dad with dementia’)

It is not practicable for each person who wishes to comment on the post to secure consent from someone with dementia for them to comment publicly on the PwD’s individual health condition. As alluded to earlier, each of the eight post’s will be accompanied by a link that sets out clearly that any comments should not identify the private health condition of other people and the actions we will take to delete such data

The researchers, to support with thematic analysis and to measure the efficacy of the intervention will collect the following data;

1)The comments/discussions in four closed groups of 20 family carers and a moderator ( assessed as being minimal risk)

Full transcripts of the closed group activity will be collated along with the date, time, and name of person replying.

In addition, to support with thematic analysis and to measure the efficacy of the intervention; a dedicated FB app will collect the following data;

1)The comments generated by other FB users in response to the specific questions posted by Care Alliance Ireland through its Facebook page (NationalCarersWeek), and its subsequent sharing. (assessed as being low to moderate risk in respect of the right to privacy of people with dementia)

The Indiana University research team owns the coding for the web interface to collect public comments. Only the research team has access to the interface that talks to Facebook. IU cloud storage (IU Box) accounts are password protected by the IU Single Sign –ON CAS System.

One question per week will be posted, on average, for 8 weeks.

A joint controller agreement is also in place between Indiana University and Facebook – attached below as Appendix 2

Journal articles, conference presentations and reports to funders will be prepared – but will be fully anonymised.

By its very nature, any comments made on FB (outside of closed discussion groups) are to be considered public.

Specific actions will be taken to minimise the risk of data protection breaches in respect of people with dementia. These include;

At the early stage of the closed group participants will be invited to review and agree confidentiality statements that would be similar to those signed up to in the traditional face-to-face carer support groups. In light of the electronic nature of the discussions, additional requirements around agreeing not to copy or distribute any identifiable discussion text/information from the group into other electronic formats will be required.

Participants will also be asked to watch and review a number of short videos that focus on how to manage their own and others privacy on social media platforms. We believe that this will add another layer of protection to data privacy.

Questions that are agreed for public posting will not identify any one individual in particular.

In relation to the questions posed publically, by the FB administrator/moderator, and subsequently shared by participants, there will be a statement accompanying each "Question/Post" stating that these questions are not meant to identify any one individual in particular. Furthermore. Readers will be reminded of the importance of not compromising any

individual private health information. A link will also accompany each question detailing further the project and discouraging FB users from posting material that would breach privacy and confidentiality in particular in relation to the personal data of people with dementia.

We will also put in place a reporting mechanism whereby other family carer participants can report possible either their own or others data breaches directly to the project.

Furthermore, core group family carer participants will be directed to comment on the post in the following way;

“I am involved in an applied research project that seeks to support family carers in Ireland. By commenting on this question below that I have just shared, created by a closed carer support group, you can potentially contribute to the wellbeing of family carers. Before responding to this question, please read more information on this applied research project click by clicking here. Thank-you.”

The link supplied will detail the law in relation to the right to privacy in particular as it pertains to ‘special category data’; specifically individual health information.

Should public comments appear in the thread of the ‘Question’ posts that identify any individual being cared for (either directly and or indirectly) - any such comments will be removed by one of the FB page administrators/moderators within 24 hours. In addition, the person who posted the comment will be contacted directly, asking them to modify their comment and to refrain from posting such identifying comments again and reminding them of their obligations under data protection laws.

A key part of the therapeutic potential for such groups is the hearing/reading about the ‘shared experiences’ of other participants. For this reason, the group participants will not be discouraged from discussing specific individual situations that relate to the caring of a family member with dementia. To do so would greatly undermine the potential of the group to benefit participants.

**Describe the scope of the processing:** what is the nature of the data, and does it include special category or criminal offence data? How much data will you be collecting and using? How often? How long will you keep it? How many individuals are affected? What geographical area does it cover?

The data processing will include special category data (most specifically health data) but will not include criminal offence data.

Whilst comments made on the closed group will contain personal information, participants will be advised of the reason for this data being generated, stored and how it will be used and deleted by both data controllers (Care Alliance Ireland and Indiana University) within three years. Data will be pseudonymised by both parties as soon as is possible. (Forexample a name is replaced with a unique number.)

All participants will need to demonstrate a genuine and legitimate reason to be part of the closed group (most specifically through their capacity as a family carer of someone with dementia). All participants will be screened, per inclusion/exclusion criteria, below.

The family carer participants and the person with dementia will be deemed to be fully capable of explicit consent in relation to any personal data the project collects, unless during the consent process it becomes clear that they are not in a position to provide such explicit consent. They will also have the option of accessing, correcting and erasing data on them and of opting out of the project without reason and at any time.

Inclusion criteria for participation will be as follows:

- Participant is 18 years or older and living in the Republic of Ireland.
- Participant can read, comprehend, and write in the English language.
- Participant is an unpaid caregiver of an individual with Dementia or Alzheimer's disease.
- Participant provides at least 8 hours of caregiving for the person with Dementia or Alzheimer's disease per week.
- Participant has a Facebook account.
- Participant has at least 20 friends in their Facebook social network
- Participant posts or comments on Facebook on average at least once per week for the past month.
- Participant has ready access to the Internet.
- Participant agrees to give their informed consent to participate in this research.

Exclusion criteria for participants who would otherwise qualify is as follows:

- o Participant has had a psychiatric hospitalization in the past year.
- o Participant has had a suicide attempt in the past year.

Potential participants (ie Family Carers) will be advised that for them to take part in this project, the person they care for will need to give their explicit consent.

As indicated earlier, the material risk is that the health condition of individuals with dementia will be made (more) public following the posting of questions on FB and their subsequent sharing/comments. This project is not seeking to secure or store such individual data (that is; any information about individuals with dementia), but by virtue of comments posted in the closed group and or comments made in response to a post, we may end up storing such data.

Participants will be informed about the specific risk of sharing personal data on FB and of FBs poor track record on data protection issues within the explicit consent process.

The target for participants is 80 family carers of people with dementia living in Ireland. Most but not necessarily all of the people with dementia such participants are caring for will be residing in Ireland; as caring generally requires the physical presence of the carer with/near the cared for. However, there are a number of long-distance dementia carers who share the care with others; and as such, there is a possibility that a small number of people with dementia that the 80 participants are caring for, will be living outside of Ireland. Data flows will be restricted between the geographical areas of the EU/EEA and the US.

**Describe the context of the processing:** what is the nature of your relationship with the individuals? How much control will they have? Would they expect you to use their data in this way? Do they include children or other vulnerable groups? Are there prior concerns over this type of processing or security flaws? Is it novel in any way? What is the current state of technology in this area? Are there current issues or public concern that you should factor in? Are you signed up to any approved code of conduct or certification scheme (once any have been approved)?

The project team has a level of concern in relation to Facebook's well documented security flaws. We are not in a position to fully assess the level of such flaws. Public disclosures and discussions of such flaws together with recent and ongoing commitments made by Facebook in relation to how it is doing more to minimise these risks provide a level of reassurance to the team.

The family carers who participate in the research will generally not be known individually to the project team.

The Alzheimer Society of Ireland (ASI) on behalf of the researchers, will make contact directly with family carers whom have in recent years participated in the ASI online family carer training course. The researchers will not have access to this database of family carers. The potential participants will be invited initially by email (and perhaps later by post) to participate in the online intervention. Potential participants will also be directed to a dedicated project website where a pdf of the consent form, the GDPR Fair Processing Notice, the eligibility criteria will be available as well as a completed DPIA.

As part of the recruitment process, there will be an opportunity to make direct contact with the researchers via email ([friendsourcing@carealliance.ie](mailto:friendsourcing@carealliance.ie)) and a dedicated phone number. It also provides the opportunity to go straight to the online Qualtrics link, to progress with the application for participation as detailed earlier.

Other 'paid ad' type recruitment strategies (through Facebook and elsewhere) will also be used.

In relation to the people with dementia, they will generally be family members of the family carer participants. On occasion, a friend of a neighbour will be an unpaid carer.

The risk, as alluded to earlier, is that a person with a dementia health condition may become more public, due to the posting/sharing/comment on of a FB question/post.

This intervention is novel. An earlier iteration of it was trialled in 2016, with very promising results. The PI of this project and another key actor, are both original investigators in the pilot 2016 intervention.

Many dementia carers, due significantly to their caring roles, may find it difficult or indeed impossible to partake in the more traditional forms of carer support – for example face to face peer support groups, face to face training etc. Being able to take part in this virtual support group provides many family carers the opportunity to benefit from such interactions.

The positive impact of peer-to-peer support for dementia caregivers, in decreasing isolation and increasing social support, has been documented extensively, and most recently for example by

Whitlatch, C. J., & Orsulic-Jeras, S. (2018); and in online peer support, for example by Dyer et al (2012).(Full references in Appendix 3)

Furthermore, feedback from family carers involved in previous ASI training indicates that they valued the support of other participants/peers.

Although the small sample limits the generalisability of the impact of the original 2016 intervention, a recent peer reviewed publication reported significant improvements in carer levels of burden and in perceived stress (Wilkerson et al, 2018). The Revised Scale for Caregiving Self-Efficacy, a measure of confidence regarding caring activities, showed a trend toward improved confidence. Based on participation and qualitative feedback from participants, the study found Friendsourcing to be a feasible Web-based intervention for dementia caregivers. (Friendsourcing in this instance may be described briefly as the use of online friends to support you in your caring journey)

**Describe to purposes of the processing:** what do you want to achieve? What is the intended effect on individuals? What are the benefits of the processing for you, and more broadly?

As indicated earlier, the purpose of the processing of data is to support with our understanding of the potential therapeutic impact of Friendsourcing to family carers of people with dementia.

The key intended effect of the intervention is to reduce the level of reported carer burden and stress experienced by the family carer participants.

None of the research team will be monetising this data and or monetising this app for sale.

We believe that any risks detailed above can be minimised by careful document and protocol preparation, ongoing communications, and timely and close moderation in particular of specific and scheduled post sharing/commenting.

We will carefully review each and every comment made in relation to each of the 8 questions posted as part of the first cohort of 20 family carers. Should any data protection concerns and or breaches emerge – we will carefully review the project in its entirety and make any necessary changes to improve the data protection aspects of the project.

### Part 3: Consultation process

**Consider how to consult with relevant stakeholders:** describe when and how you will seek individuals' views – or justify why it's not appropriate to do so. Who else do you need to involve within your organisation? Do you need to ask your processors to assist? Do you plan to consult information security experts, or any other experts?

The Alzheimer Society of Ireland (ASI) is the leading dementia advocacy organisation in Ireland. As such, they are considered to have the interests of people with dementia at the core of all they do. The ASI has been a key partner in this project and continues to be actively involved in the project throughout its lifetime. One member of the Dementia Carers Campaign Network has reviewed a number of the draft documents including the eligibility criteria, the consent document, the questionnaires and some draft FB recruitment posts. Her feedback was that the documents were very detailed and easy to complete. The only specific suggestion was to consider the language around the questions around self-harm.

Partners in IU include a senior Social Work practitioner/educator and a Psychiatric Gerontologist/Researcher, as well as an experienced IT staff member.

The research committee of the board of Care Alliance Ireland has approved our participation in this project. Its' members have reviewed and inputted into this draft DPIA. Another board member also has recently secured qualifications in data protection and has provided feedback. Specifically, she has communicated that she is happy with the content of the DPIA.

From an early stage of this project, we have sought the views, expertise and input from the Data Protection Officer in the ASI. This has been most helpful informing the population of the content of this DPIA.

The Indiana University GDPR working group have also been consulted extensively in preparing this DPIA and in relation to the wider data protection issues.

We have endeavoured to address issues and concerns the above representatives have raised.

#### **Step 4: Assess necessity and proportionality**

**Describe compliance and proportionality measures, in particular:** what is your lawful basis for processing? Does the processing actually achieve your purpose? Is there another way to achieve the same outcome? How will you ensure data quality and data minimisation? What information will you give individuals? How will you help to support their rights? What measures do you take to ensure processors comply? How do you safeguard any international transfers?

We believe our 'lawful basis' for processing special category data is explicit consent.

A GDPR Fair Processing Notice has been prepared for review and acceptance by potential participants.

A detailed consent form will be used as part of the screening process for family carer participation as well as for acceptance into the project. Online consent forms will be used and stored securely and available for viewing at any time.

In relation to processing data of special category data of people with dementia - any processing that may be undertaken is more incidental in nature. As detailed later in this DPIA, such data may be stored by the app on a very temporary basis .

We have not looked at alternative platforms, social media or otherwise, to deliver the hoped for outcomes. The hypothesis of this applied research project is that the use of 'friends' to support family carers through the Facebook platform is an integral part of the potential efficacy of this intervention. We are not aware of other equivalent and or as popular platforms.

The view of the Principal Investigator (PI) and the wider team is that the 'posting questions to FB friends' aspect of the intervention is a critical component and cannot reasonably or legitimately be replaced. As stated earlier, the hypothesis of the intervention is that the use of social network peers (through micro social volunteering) to support family carers is a key component of the possible efficacy of the overall intervention. The use of closed peer support groups whilst prevalent, the evidence for its efficacy is not particularly robust. Without this added part of posting questions/ micro social volunteering, the intervention is not novel, nor is it likely to be as effective in achieving the objectives of the intervention.

We have detailed earlier the type and quantity of data that will be stored in relation to the family carer participants. The risk to their personal data is considered minimal to moderate.

All seven key participants in the project have successfully completed introductory online research ethics training ( Human Research - Social/Behavioral Researchers - Level One Research in Human Behaviours/CITI training).

All seven key project participants have read the relevant GDPR resources and instructional videos as supplied by the ASI Data Protection Officer, the DPC (Irl), ICO(UK) and others.

Data sharing between the Principal Investigator in IU and project partners in Ireland (Care Alliance Ireland) will be conducted using a secure cloud based service ('Box' – using private health information (PHI) compliant security protocols).

This project has a data processing (joint controller) agreement in place between Care Alliance Ireland (based in the EU) and Indiana University (based outside the EU, in the USA). For full transparency, this agreement will be available to view on the project webpage [http://www.carealliance.ie/Friendsourcing\\_Ireland](http://www.carealliance.ie/Friendsourcing_Ireland)

No organisation wishes to be associated (either directly or indirectly) with the divulging of peoples private health information, without the explicit consent of the person in question.

Each of the three organisations involved accept there remains a minimal/ medium level of risk to the right to privacy of a small number of people with dementia. Whilst 80 people with dementia are theoretically at risk, we believe that in only a small number of these 80 will there be a real risk of their privacy being compromised. To be clear, the risk is that their dementia condition will be made more public.

We believe there needs to be a proportionate assessment of the ratio between the likelihood of risk and degree of harm to the individual; and an estimate of the potential for reward. The strong view of the project team is that the potential for reward massively outweighs the risk of harm.

This project seeks to minimise but not eliminate the risks to privacy of the person with dementia. On the other hand, it is a project that offers the real opportunity to materially improve the quality of life for a cohort of family carers of people with dementia. Disability and caring are two sides of

the same coin. In supporting the wellbeing of the family carer there is likely to be a direct positive impact on the wellbeing of the person with dementia.

The lead organisation in this project (Care Alliance Ireland) has satisfied itself as to the residual risks and that they are of an acceptable level. The Data Protection Officer in one of the partners, The Alzheimer Society of Ireland, takes a different view, as detailed later in this DPIA.

### Step 5: Identify and assess risks

Describe the source of risks and nature of potential impact on individuals. Include associated compliance and corporate risks as necessary	Likelihood of harm	Severity of harm	Overall risk
<p><b>1.</b> Personal (health) identifying information of people with dementia may be posted on FB in response to a question posted/shared and commented on as part of the project. – participants friends may post a comment like the following ; “Gosh I didn’t know that your mum has dementia. That must be really tough.”</p>	Possible/Probable	Minimal	Minimal/Medium
<p>People with dementias right to privacy, specifically in relation to their own personal health, may be compromised. Although explicit consent will be secured from the person with dementia for their family carer participation, and the risks explained, this consent will not reasonably extend to permission being given for the public naming of someone on public FB posts and their associated health condition.</p>	Remote	Minimal	Minimal/Medium
<p><b>2.</b> Personal data of core group participants</p>	Remote	Minimal	Minimal
<p><b>3.</b> Hacking/data breaches within Cloud based providers</p>	Remote	Minimal	Minimal
<p>This project utilises a number of online data storage providers including</p>			

<p>Qualtrics, Dedoose Facebook, and Indiana University's own server.</p> <p>We have reviewed the Data protection Commissioners guidelines on these risks and are confident of the mitigation measures these providers have in place to minimise risks of data breaches. For example Indiana University has demonstrated a real commitment to protecting data in having established its own GDPR working group since 2017. It also has a comprehensive set of relevant data protection/privacy policies and procedures. See <a href="https://protect.iu.edu/online-safety/privacy/index.html">https://protect.iu.edu/online-safety/privacy/index.html</a></p>			
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**Step 6: Identify measures to reduce risks**

<b>Identify additional measures you could take to reduce or eliminate risks identified as medium or high risk in step 5</b>				
<b>Risk</b>	<b>Options to reduce or eliminate risk</b>	<b>Effect on risk</b>	<b>Residual risk</b>	<b>Measure approved</b>
<p>Private health information of a person with dementia will be posted on FB.</p>	<p>Specific instructions to distance the family carer participant from the specific question posted will be contained in the link in the post of all questions posed.</p> <p>The public use of names or other identifiable characteristics will be actively</p>	<p>Reduced</p>	<p>Medium</p>	

	<p>discouraged – and removed as necessary.</p> <p>Notifications in respect of all comments made on the questions posted will be checked at least every 24 hours by a member of the project team, and any breaches will be addressed within a further 24 hours. This may include the removing of comments.</p> <p>A Data Protection Risk Register will be established and reviewed regularly; at least after each closed group finishes. Its content will reflect any solutions or new risks which have been identified.</p>			
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**Step 7: Sign off and record outcomes**

<b>Item</b>	<b>Name/date</b>	<b>Notes</b>
Measures approved by:	Dan Bateman, PI. (IU) David Wilkerson, (IU) Liam O’Sullivan, Project Manager, (CAI) Fergus Timmons, Project Partner. (ASI)	Draft 7.1 (July 16 <sup>th</sup> 2019) Under further ongoing consideration by entire team and by ASI DPO and IU GDPR working group.
Residual risks approved by:		
DPO advice provided:	Clare Murphy ASI DPO.	

DPO advice accepted or overruled by:		
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**ASI DPO Comments 12 July 2019:**

The premise of this project is that the Alzheimer Society of Ireland will contact a portion of their database of family carers to publicise, support and invite carers to participate in the Facebook Friendsourcing Care Alliance Ireland / Indiana University project. The ASI head of external training would then be peripherally involved in the project on an ongoing basis and would receive feedback on its results.

The central issues from an ASI perspective are legal basis and data sharing. The legal basis employed by the ASI training department is largely legitimate interests (6.1.f) and the provision of health and social care (9.2.d). It has also recorded consent from certain carers who are happy to be contacted in relation to relevant events, media or research opportunities. The ASI training department says that only carers that have given this consent for further related communications will be contacted and the department wishes to contact these individuals by email. Closer examination of this pre-GDPR consent wording illustrates an absence of granularity on mode of communication which means its validity is arguably questionable under Recital 32. Postal communication should be possible.

The research department of the Alzheimer Society of Ireland recently submitted a DPIA for consideration by the regulator in relation to the establishment of a Dementia Research Database. This database would process and potentially share the information of Persons with Dementia in addition to other interested parties such as family members and carers. Under the framework of the proposed ASI DRD the Friendsourcing Facebook Care Alliance Ireland/Indiana University project would not be an acceptable project to provide research participants to. This is because the data of the participants would be transferred outside of the EU/EEA and also on the grounds that the ethical approval for the project would not be Irish based. This chimes with the demands of the Health Research Regulations 2018 which, under section 4(3), clearly sets out the legal minimum standard for ethical approval.

I am concerned about the remaining lack of detail surrounding how the legal basis of explicit consent from the Person with Dementia would be gathered and maintained. Would ASI be tasked with this? ASI is not a data controller on this project. I am unclear as to what would be the boundaries on this explicit consent in relation to closed and open groups on Facebook.

I am concerned about the projects' current lack of understanding around data subject rights. The project team must realise that reliance on explicit consent as a legal basis means the individual have overarching rights of erasure, restriction, etc. and their right to withdraw their consent at any time cannot be usurped. This thinking must be catered for and built into the design of the project.

The role of Facebook is also an unknown entity in relation to its role as a Joint Controller with Indiana University. I am unclear what assurances it has given in relation to appropriate security, data retention and the further sharing of sensitive data with unknown third parties. The current DPC investigations and ECJ court examination of this tech giant give great pause for thought.

I would differ from the project researchers in relation to my assessment of the risk to (vulnerable) individuals and would have thought that the projects' accepted likelihood that at least a small number of Persons with Dementia will lose control over their personal data (also potentially damage to reputation and revealing special category personal data) would translate into high risk to them as opposed to the low/medium risk described in this document.

I have recommended referral to the DPC under Article 36 GDPR as I believe the intrinsic nature of this project means it may be highly difficult to put in place suitable safeguards for individuals. The intense level of moderation required may be unrealistic to expect the joint controllers Care Alliance Ireland and Indiana University (and Facebook) to provide.

Consultation responses reviewed by:

All project team

**Comments from project team:**

Care Alliance Ireland respectfully do not agree with the assessment of the DPO from the Alzheimer Society of Ireland; for the following reasons;

- i) A data sharing agreement between CAI and IU as joint controllers will be in place.
- ii) Indiana University (IU) is a partner in this project and is a joint controller. The IU Internal Review Board (IU IRB) ( akin to a research ethics committee as understood in Ireland) considered and approved this research. The IU IRB is reputable and long established. It has a strong set of principles and protocols in place. See <https://research.iu.edu/policies/human-subjects-irb/index.html> We assess it is as being an acceptable research ethics committee. We therefore do not see the legal requirement for an additional ethics board based in Ireland to review the proposal.
- iii) Explicit consent will be secured from the people with dementia who are being cared for by the family carer participants. A draft outline of how this may be done is in Appendix IV.
- iv) The project team are fully aware of data subject rights and in particular their overarching rights of erasure, restriction, etc. and their right to withdraw their consent at any time. The project is being designed with this in mind.
- v) We are aware of Facebooks poor track record in regard to data protection and accept that a level of risk remains in this regard.
- vi) We are aware of the risks to vulnerable individuals loss of control of some of their personal data (ie their dementia condition). We have put safeguards in place to reduce these risks, which we believe are acceptable in the overall context of the likely low severity of harm, the small scale of the project, the potential of the intervention to materially positively impact on the wellbeing of the family carer and the iterative nature of this applied research intervention (that is we will adjust the approach based on learning for the first group of 20 family carer participants).
- vii) We contend that there is no residual high risk to the PwD. We are confident that we will secure explicit and valid consent appropriately from such PwD – in a way that they understand what they are consenting to and the inherent risks of there being some loss of control over their private health information. We are fully aware of the different levels of consent.
- viii) As reported in the 2016 project, there were no data breaches recorded and or reported by the project team.

- ix) We have detailed our commitment to intense observation and moderation of the FB posts.

Whilst we do not believe there is any residual high risk we are nonetheless referring the project to the Data Protection Commission in Ireland.

This DPIA will be kept under review by:

All project partners.  
ASI data Protection Officer  
IU GDPR Working Group

### Appendix 1 ; Flow Charts



Facebook Study -  
Participant Recruitme



FS Post-Recruitment  
3rd July.pdf

### Appendix 2 ; Joint Controller Agreement



Facebook Joint  
Controller Agreeemer

### Appendix 3: References

Dyer, E. A., Kansagara, D., McInnes, D. K., Freeman, M., & Woods, S. (2012). Mobile applications and internet-based approaches for supporting non-professional caregivers: A systematic review. VA-ESP Project #05-225. Washington (DC): Department of Veteran Affairs (US); November 2012. Retrieved from: <https://www.ncbi.nlm.nih.gov/books/NBK115102>

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Media. *Journal of Technology in Human Services*, 1-20.

Wilkerson, D. A., Brady, E., Yi, E. H., & Bateman, D. R. (2018). Friendsourcing Peer Support for Alzheimer's Caregivers Using Facebook Social Media. *Journal of Technology in Human Services*, 1-20.

### Appendix IV



Consent Form Draft 3  
July 16th 2019.pdf