



FRIENDSOURCING

Online intervention for family carers
of people with dementia

FRIENDSOURCING IRELAND

A cautionary tale of a transatlantic collaboration on an innovative, evidence informed intervention - and a data protection minefield !

World Conference on Online Learning, Dublin, Ireland 6th November 2019



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Who are we?



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Liam O'Sullivan (ndo@carealliance.ie)

- Executive Director, Care Alliance Ireland
- Social Work professional, over 20 years working in NGO sector
- Committed to supporting family caregivers

Fergus Timmons (fergus.timmons@alzheimer.ie)

- Learning and Development Manager at The Alzheimer Society of Ireland
- Doctoral student Digital Education
- Committed to supporting education and development of informal family caregivers

Background



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- There are approximately 50,000 family carers of people with dementia in Ireland (Care Alliance Ireland, 2015, *Family Caring in Ireland*)
- Characterised by high levels of stress, isolation, frustration and emotional burden (Osaki et al 2016, The Alzheimer Society 2017)
- Care Alliance and The Alzheimer Society of Ireland already provide a range of digital supports to family carers
 - **Care Alliance:**
 - Facebook page >20,000 Followers
<https://www.facebook.com/nationalcarersweek>
 - www.familycarertraining.ie (signposting/resource portal)
 - **The Alzheimer Society of Ireland:**
 - Family carer training
 - Online and blended learning programmes (Timmons 2018)

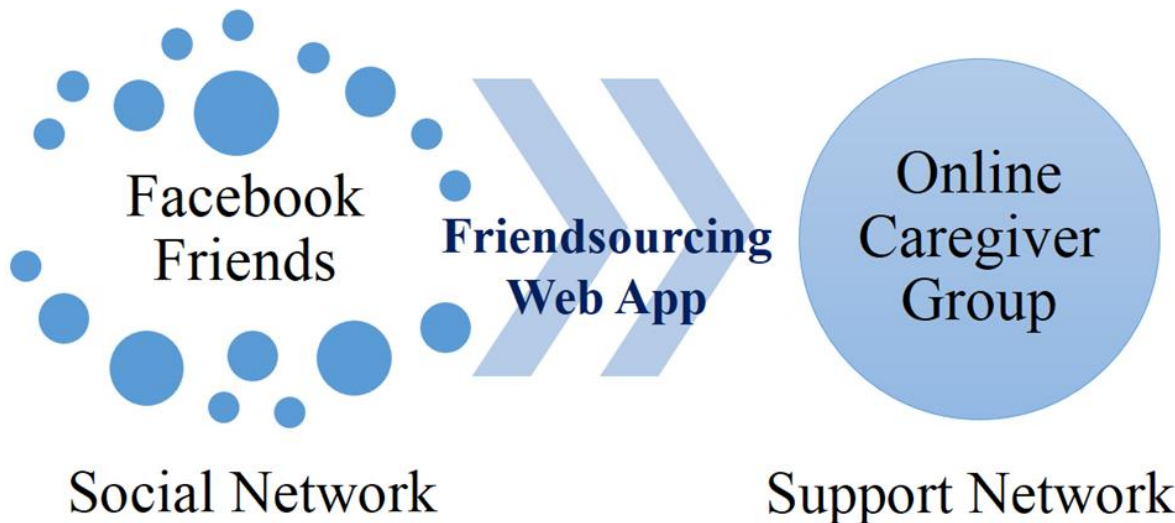
Aims and objectives



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- E-Health intervention (Sin et al 2018) using social media
- Use Facebook to ‘friendsource’ other family carers
- Collaboration with and extension of previous study at Indiana University
 - Dr. David Wilkerson dawilker@iu.edu and
 - Dr. Daniel Bateman darbate@iupui.edu
- Group cohesion, support and empathy (Wilkerson et al 2018)
- Seeking significant decreases in caregiver burden and perceived stress



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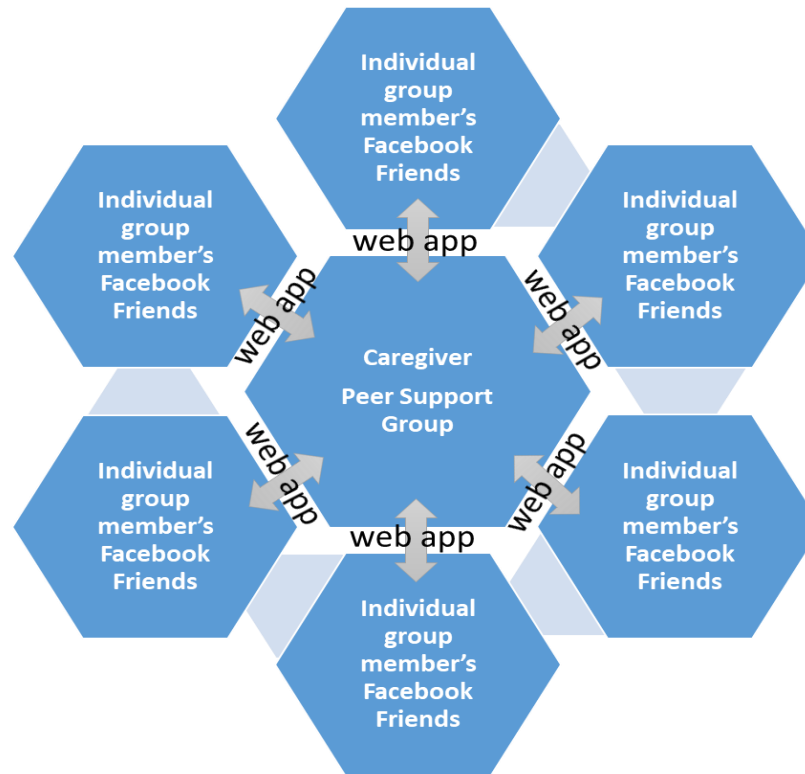
Examples of caregiver burden and perceived stress outcomes from previous study (Wilkerson 2018):

“One of the ... [Facebook friends] ... suggests to keep a journal. I started one last week and I haven’t hit it every night, but at the end of the day, I sit down and try to write my thoughts in there and think about what’s happened, think about what I could have done better or something I could have responded to better, so that’s the other thing I started—why I didn’t ever think about that myself, but that’s very helpful.”

“I had some people that I hadn’t been in touch with and I didn’t know that they had a personal experience with dementia, and they wouldn’t know that I was a caregiver, so in a way, it opens up more of a support system within your actual network of people.”

“I think [friendsourcing] has been really helpful because ... because I can actually evaluate my feelings and understand what she needs from me, and I don’t portray any of my feelings onto her, you know?”

How ?



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A small, closed group of caregivers would participate through a problem-based learning strategy. In this strategy caregivers collaborate to decide on either a information-support or emotional support question that would be sent to their Facebook Friends social networks using the intervention's web app. The web app collected responses which were shared with the group. The group then discuss answers they like best and would consider for application.

Friendsourcing Ireland



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Transatlantic partnership:

- Care Alliance Ireland (lead partner)
- School of Social Work at Indiana University, USA
- The Alzheimer Society of Ireland

- Action research to find out if a specific Facebook based social media intervention can be replicated and deployed successfully to support family carers of people with dementia in Ireland

- Funded by the Government of Ireland (through Pobal-Dormant Accounts Funds) February 2019-June 2020
 - €81k – 80% staffing (p/t staff, consulting fees to ASI/IU, app design)

Data Protection: Issues



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- Informed Consent
 - Capacity to Consent (PwD), Conflicts of Interest
- Ethics and ethical approval
 - Legitimacy of IU ethics board questioned (IRB)
- Facebook
 - Risks of data breaches – health data of third parties

(Full Details of Data Protection Impact Assessment and Data Protection Commissions feedback available at <https://www.carealliance.ie/Friendsourcing-Ireland>)

Issue 1: Consent



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Data Protection Commission (DPC) Feedback:

*“Your project involves the processing of health data for social care purposes without the explicit consent of all data subjects whose **special category personal data** will be processed during the project and as such falls under the remit of the Health Research Regulations 2018.”*

*“...people with reduced capacity whose personal data is likely to be processed as part of this research, the Decision Support Service as referenced in the ADMA is not functional at present so without this service those people who are not Wards of Court **cannot provide explicit consent.**”*

*“To include the carers who have power of attorney for people with dementia as providing explicit consent on their behalf raises a **conflict of interest** that may be best served by review by a research ethics committee in light of the Health Research Regulations requirements. Requiring the use of a witness in cases where the carer has power of attorney does not represent a mitigating action.”*

Issue 2: Ethics



DPC feedback:

“Health Research Regulations in Ireland require data controllers to ensure the timely involvement of a Research Ethics committee as identified in Section 3.1(b). It is not in line with the Health Research Regulations to use findings from the IRB in Indiana University to replace a mandatory measure prior to the initiation of processing.”

(Care Alliance Ireland disputes this interpretation!)

Issue 3: Facebook

- Elephant in the room and never specifically mentioned by Data Protection Commission (DPC)
- Scores of cases currently against FB, and DPC very wary of them.
- Project is considered both a Data Processor and Controller – Outside of EU more complicated
- Robustness of systems for data storage? (e.g. Qualtrics survey tool - US based – cloud – virtual)
- Where does the data go? (Posts/comments, Facebook contract re App)

Implications and Discussion



- Is the legitimacy of health and social care organisations to deliver online supports to family carers through Facebook, in search of a reduction in stress & burden, **seen to be of less value** than the rights of people with dementia to absolute privacy?
- Degree of Risk – Reward Ratio?
- Has Facebook any potential to ‘do good’?
- Are Research Ethics boards convened outside the EU less valid than those inside the EU? If so, why?

References



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