Care Alliance Ireland

'Guiding support for family carers'

**Feedback received from The Data Protection Commission regarding Friendsourcing Project.**

**23rd August 2019**

With regard to your DPIA we remind you that it is the responsibility of data controller(s) to ensure their processing adheres to the legal obligations placed upon them by GDPR, the Data Protection Act 2018 and any other amendment/statutory instrument

Based on the information you have provided we do not concur with your assessment that the proposed processing has sufficiently identified and mitigated the risks to data subjects, directly and indirectly identifiable. We note that you do not provide a legal basis found in Article 6 and a condition in Article 9 that is required for processing special category data. 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 SI. It is unclear how you will secure the explicit consent of 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.

Your references to the due diligence you have performed do not set out any specific action(s) on your behalf to do so. 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 is 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.

We note that you reject the Alzheimer's Society DPO assertions around the robustness of your assessment of risk either without offering evidence of any mitigatory measure to combat her concerns. We also note that you have not explicitly stated who the data controllers of the research are. Given that you intend to transfer data outside of the EU you should familiarise yourself with the following:

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

We would be in broad agreement with the comments raised by the Alzheimer's Society DPO and would suggest that these should be addressed more substantially, in conjunction with our comments and observations on the draft DPIA.

We suggest you revisit your DPIA in light of the above comments. A DPIA is intended to be a living document that is updated throughout the lifecycle of the project as risks emerge.

HRB Guidance on informed consent: https://www.hrb.ie/fileadmin/1._Non-plugin_related_files/RSF_files/GDPR_guidance_for_researchers/Health_Research_Information_Principles.pdf

We trust this information facilitates your query, if you have any further specific questions we are happy to engage further with you on this matter.

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