



Dementia Analytics Research User Group (DARUG) - A model for meaningful stakeholder engagement in dementia research

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Dementia Analytics Research User Group (DARUG) - A Model for meaningful stakeholder engagement in dementia research

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Abstract Text:

Background: The importance of involving stakeholders in research is widely recognised but few studies provide details to implementation in practice. The use of real-time technology involving patients, carers and professionals in project design, monitoring, delivery and reporting could maximise contribution. Stakeholder engagement was included as part of a Dementia Analytics Research User Group project which applied machine learning to the Trinity-Ulster-Department of Agriculture (TUDA) data set, identifying clinical and lifestyle factors associated with cognitive health in 5000 community-dwelling older Irish adults.

Method: An innovative model for engagement (ENGAGE) was used¹ - a methodological and technology platform, that gains insight into group thinking and consensus. Developed by Ulster University, this produces a report in real time for sharing to all stakeholders, thus ensuring active involvement in defining the research question. Using a Personal and Public Involvement (PPI) approach, representatives from patient and carer groups (including TUDA participants), charities (e.g., Alzheimer's UK), as well as professionals, were invited to attend one of three scoping events. Each event commenced with an overview by the project team of the value of data analytics and initial data analysis. The PPI groups were then invited to answer specific questions relating to risk factors for dementia and were asked to articulate their expectations on the potential outcomes from the project. These responses were analysed using ENGAGE and word clouds generated for discussion to help refine the project going forward.

Results: Participants (n=87) Lifestyle, Genetics, Stress and were the dominant emerging themes for risk factors of dementia. Prevention, Help and Information/ Research emerged as strong themes, with the mind maps showing stimulus, understanding and awareness as key outputs of this project. The outcomes of this engagement model were utilised to successfully inform the subsequent data analytics portion of the study².

Conclusion: The model performed well, capturing discussions in real time. Feedback was positive and helped to focus and inform the research team's thinking. What was not so successful was the longer-term inclusion in the project, with engagement through remote channels tending to drift over time, somewhat exacerbated by COVID 19 restrictions. The team aim to follow up on this aspect.

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