

**Title and research team:** The impact of multi-component support groups for those living with rare dementias. ESRC-NIHR Dementia Research Initiative. £4,431.885.00. 1<sup>st</sup> January 2019-31<sup>st</sup> December 2023. (PI Sebastian Crutch, UCL; Co-Is Paul Camic, UCL, Roberta Mackee-Jackson, UCL; Mary Pat Sullivan, Nipissing University, Joshua Stott UCL, Gill Windle Bangor University lead; Rhiannon Tudor Edwards, Bangor University, Zoe Hoare, Bangor University).

**Summary:** We will carry out the first major study of the value of support groups for people living with or caring for someone with a rare form of dementia. We will be looking at the benefits of meeting other people living with a similar condition, and sharing practical and emotional support.

We will do this with the help of over 1000 members of the Rare Dementia Support network ([www.raredementiasupport.org](http://www.raredementiasupport.org)) and address the following areas of activity:

- 1) WS1 [Retrospective Cohort Study]. Understanding the problems faced and care received through a retrospective cohort study of >1000 current and historical members to create the first mapping of abilities, challenges, care needs, care events, and health and care resource use (including informal/familial care) in the rarer dementias across all stages of dementia.
- 2) WS2 [Theoretical development]. Identifying the ‘active ingredients’ of support groups through theoretical development. Mixed-methods including (i) literature review using the principles of realist synthesis; (ii) situational analysis and focussed ethnographic work involving a sub-sampling of members; (iii) analysis of WS1 interview dataset; and (iv) iterative construction of general Theory of Change (ToC) and nested sub-theories.
- 3) WS3 [Measures]. Optimising and innovating measure selection and development We will review existing relevant concepts and measures iteratively as WS2 theory develops and, where possible, draw on existing conceptualisations (e.g. for ‘social connectedness’, the distinction between individual connectedness [e.g. PLWD-carer relationships] and ‘overall’ social connectedness [e.g. carer and support group]). We will identify a primary measure of effect (e.g. DEMQOL, Smith et al., 2007) to enable exploratory cost effectiveness. We will develop and test a resilience outcome measure suitable for different forms of dementia.
- 4) WS4 [Prospective longitudinal cohort study]. Evaluating the impact and pathways to impact of multi-component support groups on new members through a prospective longitudinal cohort study. Methods: Mixed methods to evaluate how membership and degree of involvement are associated with primary (e.g. QoL, connectedness, coping, knowledge of condition, knowledge and use of appropriate services, stigma; to be agreed, informed by WSs13) and secondary (e.g. resilience, stigma, mental health) outcomes at 6-monthly intervals.
- 5) WS5 [Intervention development]. Theory-driven design and feasibility testing of a new, online multicomponent support intervention.
- 6) WS6 [Economic analysis]. Investigating cost effectiveness through economic analysis
- 7) Embedded case studies in rural Wales and Canada will explore the context (e.g. the environment/neighbourhood) which may support or exacerbate the experience of living with dementia.
- 8) PhD studentships