Rare Dementia Support Impact Study (2019 – 2023)

The Rare Dementia Support Impact Study is a multi-site project that aims to understand what support looks like, when best to deliver it and the impact on those living with dementia, at risk of a dementia diagnosis or caring for someone.

The study is a global first, given people living with rare dementia are often underrepresented in the research literature. The study is funded by the Economic and Social Research Council and Institute for Health Research in the United Kingdom.

The study aims to:

1. Generate a theoretical explanation and evidence base demonstrating the critical role and added value of multicomponent continuous and sustainable support for people affected by rare dementias throughout and beyond the course of their dementia.
2. Develop a theoretically-informed understanding of support group membership, social connectedness, coping skills and understandings around a diagnostic condition.
3. Demonstrate the feasibility of improving access to support through innovative online services.
4. Demonstrate that multicomponent support groups provide a valuable, continuous and cost-effective means of support which can be adopted in different locations and with different dementia communities.
5. Generate new research tools (e.g., dementia-relevant resilience outcome measure) and methodologies (e.g., computational event-based modelling of care needs in the different rare dementias).

The investigator team includes:

- Sebastian Crutch, Josh Stott, Roberta McKee-Jackson and Paul Camic, Dementia Research Centre, University College London (UK)
- Mary Pat Sullivan, Faculty of Education and Professional Studies, Nipissing University (CA)
- Gill Windle, Zoe Hoare and Rhiannon Edwards, School of Medical and Health Sciences, Bangor University (UK)