

## **Including best practices and the voices of experience in developing post-diagnostic dementia support guidelines for people with an intellectual disability**

**Lead Institution:** Trinity College Dublin

**Principal Investigator:** Prof Mary McCarron

People with an Intellectual Disability are at greater risk of developing dementia than the general population. In particular, those with Down syndrome are the world's largest group with a genetic risk for Alzheimer's disease.

Prof McCarron and her colleagues will work with researchers, clinicians, services and people with Intellectual Disabilities to provide recommendations and guidelines on how best to provide post-diagnostic dementia supports to people with an Intellectual Disability and their families.

**ASI Role:** Co-funder through the HRB-HRCI Joint Funding Scheme 2020

## **SMART Dementia Care Project**

**Lead Institution:** Technological University of Dublin

**Principal Investigator:** Dr. Julie Doyle

This project, funded by Science Foundation Ireland's Frontiers of the Future programme and in collaboration with Technological University of Dublin will develop a new digital toolkit that will support someone living with dementia, together with their formal and informal carers, to self-manage their care.

**ASI Role:** Collaborator, PPI

## **Virtual Cognitive Stimulation Therapy (vCST): A pilot mixed methods study to evaluate the outcomes of vCST in clinical settings in Ireland,**

**Lead Institution:** National University of Ireland, Galway

**Principal Investigator:** Dr Orla Dolan

This proposal uses two approaches. A single blind RCT will be used to answer the question of whether the transfer of the manualised CST programme to a virtual format achieves similar clinical outcomes in the area of cognition, quality of life, communication, behaviour, activities of daily living and mood for individuals living with dementia. Secondly, a qualitative study will use online focus groups with individuals living with dementia and their carer's/family members to elicit their views on vCST. Qualitative interviews with staff who deliver vCST will be completed. Public and Patient Involvement is included with all aspects of the research.

**ASI Role:** Community Partner, PPI

## **Diversifying dementia service delivery in Ireland: Developing consensus-based recommendations for the future needs of older LGBTQI+ adults.**

**Lead Institution: National University of Ireland, Galway**

**Principal Investigator: Dr Sinead Hynes**

This research collaboration aims to identify the future needs that older LGBTQI+ people and their care partners living in Ireland face in relation to dementia care service delivery. The primary objective is to complete an in-depth needs assessment of older LGBTQI+ people's care needs through a consensus process. We will share recommendations with relevant parties to help inform service provision.

Secondary aims are (a) to develop links between ASI and LGBTQI+ organisations in Ireland (b) to increase diversity of PPI collaborators at ASI and (c) to develop research collaborations that support future funding applications specific to research in LGBTQI+ dementia interventions.

**ASI Role:** Community Partner

## **SENSE-Cog Care: A feasibility study of hearing and vision support to improve quality of life in care home residents with dementia**

**Lead Institution: Trinity College Dublin**

**Principal Investigator: Prof Iracema Leroi**

Over 90% of Nursing Home residents with dementia have significant hearing and vision problems that are frequently undetected or under-corrected. Also, the sensory environment (noise, bad lighting) in many nursing homes may contribute to poor sensory-cognitive functioning. Poor sensory function can worsen quality of life for residents with dementia by making communication more difficult and increasing confusion and challenging behaviour. Thus, hearing and vision care for Residents with Dementia in nursing homes is a critical unmet need.

This is a 'sensory support intervention' involving: training staff to detect sensory problems and communicate better with residents; ensuring residents have access to good hearing and vision care (hearing aids, glasses); improving the sensory environment of the home (e.g. lighting, noise reduction).

**ASI Role:** PPI Coordinator, Collaborator

## **Dementia Trials Ireland**

**Lead Institution: Trinity College Dublin**

**Principal Investigator: Prof Iracema Leroi**

Ensuring preparedness for delivering clinical trials. The aim of this initiative is to develop a nation-wide network of professionals and the public, who share the common goal of increasing the number and quality of dementia trials in Ireland. This will be done by linking individuals and teams together to develop and carry out new dementia trials. It will involve training young professionals and educating our health workforce to safely perform trials. It will actively seek out private companies and international partners to test out new treatments (medications and devices) in

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Ireland. By doing this, by 2026, we hope to have tripled the number of dementia trials available for people in Ireland.

**ASI Role:** Collaborator

### **Developing Patient & Public Voice Programme at the Global Brain Health Institute, Trinity College Dublin and University of California San Francisco**

A two-year development project to work with a Patient and Public Voice (PPV) panel for the two sites (TCD and UCSF) of GBHI, fully aligned with GBHI's learning and research goals. Including PPV in the Global Brain Health Institute (GBHI) fellowship experience will foster the GBHI values of equity and promote person-centred research and practice.

**ASI Role:** Partner

### **Investigating COVID-19-related loneliness and social isolation in carers of people with brain health challenges in Ireland.**

**Lead Institution:** Trinity College Dublin

**Principal Investigator:** Prof Iracema Leroi

This project seeks to look at the impact of loneliness and social isolation among carers of people with dementia and other brain health challenges.

**ASI Role:** Secondary Community Partner (after Family Carers Ireland)