DRNI CONNECT Issue No. 12 - October 2022



Welcome to the 12th issue of

### **DRNI CONNECT**

After a few month's absence, DRNI Connect is back!

My name is Vanessa Moore and I have taken over the role as Scientific Project Manager from Carol Rogan. I am delighted to have joined DRNI, and am looking forward to working with all of you!

In this edition of the newsletter, you will find details of our new **DRNI Early Career Researcher Registry**, as well as the new **DRNI LinkedIn** page. We report from the launch of **Dementia Trials Ireland**, and provide information about **TeamUp for Dementia Research**. Also, the **National Dementia Office** provide information about the implementation of National Clinical Guideline No 21: Appropriate Prescribing of Psychotropic Medication for Noncognitive Symptoms in People with Dementia.

As usual, you'll find information about **upcoming events, projects and our new network members**. Don't hesitate to get in touch if you have any news, projects or events that you would like to share in future bulletins!

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#### 1) DRNI Early Career Researcher Registry

In September, DRNI issued a call for Early Career Researchers (ECRs) to join our newly established ECR Registry. One of the core pillars of DRNI is supporting ECRs from basic science, clinical and social research in the dementia/neurodegeneration field. DRNI are committed to encourage networking, collaboration, and building capacity among ECRs in as far as possible.

In order to get an idea of who our ECRs are, what areas of dementia/neurodegeneration they are working in, and how we can best support their plans for the future, the DRNI ECR Registry was established. So far the response has been excellent, and we are thrilled that there is such an interest among ECRs to join.

If you want to join the ECR Registry, or if you know someone who you think would be interested, please do not hesitate to contact DRNI: info@dementianetwork.ie



27<sup>th</sup> September saw the long-awaited launch of Dementia Trials Ireland (DTI). Taking place in TCD's Naughton Institute, the launch began with a riveting performance by the Forget-Me-Nots choir and Mike Hanrahan, GBHI fellow and musician. This was followed by professor Iracema Leroi of DTI and TCD Provost Dr Linda Doyle introducing DTI and setting the importance of DTI in context. DRNI's own professor Sean Kennelly then chaired a discussion of DTI's PPI panel, before the event drew to a close.

DTI has received funding from the Health Research Board for a period of five years until 2026, to develop and expand dementia clinical trials in Ireland. The trials that are currently in place are small and DTI intends to not only expand but also include diverse types of studies, both pharmacological and non-pharmacological, suitable for all stages and subtypes of dementia. Imaging, biomarkers and neuropsychological methods will be used to assess healthy volunteers, carers, and people with dementia who take part in a trial. The aim of DTI is to improve the lives of those at risk of, or living with, dementia and that everyone has the opportunity to access clinical trials.

The launch was organised by Karen Meenan, PPI and Comms lead and supported by Lara Gibney, Network Coordinator.

For further information please visit: dementiatrials.ie









# 3) TeamUp for Dementia Research

In July 2021, The Alzheimer Society of Ireland launched its newest service TeamUp for Dementia Research in collaboration with Dementia Research Networks Ireland. This service connects people with an experience of dementia

The Members range in age from 23 to 87 and represent not just people who live close to universities or hospitals, but those from small towns and rural locations around Ireland. A recent survey of the members found 55% live in large towns / cities, 26% live in rural locations and 19% live in small towns / villages.

The service supports the research community to cast an extremely wide net during their recruitment process. Current membership stats show 63% of members identify as family caregivers / supporters, 24% identify as former family caregivers / supporters and 13% are people living with a type of dementia.

By cross-referencing researchers' inclusion criteria with the members' stated research preferences, it ensures the service runs in a streamlined manner.

TeamUp for Dementia Research is an inclusive and accessible service. We welcome people from all backgrounds. No previous research experience is required.

For further information about TeamUp for Dementia Research, click HERE.

# 4) National Dementia Office - Implementation of National Clinical Guideline No 21: Appropriate Prescribing of Psychotropic Medication for Non-cognitive Symptoms in People with Dementia

The National Clinical Guideline on "Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia" was published by the Department of Health in December 2019 to guide the appropriate use of psychotropic medication for non-cognitive symptoms being experienced by people living with dementia. The main driver for the development of the guideline was the Irish National Dementia Strategy, which stated that psychotropic drugs, in particular antipsychotics, should only be used when all other non-pharmacological interventions have first been tried and exhausted.

The National Dementia Office is now rolling out the clinical guideline through a comprehensive implementation plan. The national implementation of the guideline will improve health outcomes for people with dementia, reduce variation in practice and improve the quality of clinical decisions made by healthcare professionals.

Aims of the Implementation Programme:

- 1. Raise awareness of the risks of psychotropic medications for people with dementia, and to raise awareness of the guideline as a key resource to guide clinical decision making.
- 2. Develop a multi-component education package to support practice change and roll this out to relevant staff
- 3. Develop, pilot and disseminate an audit tool and audit manual to assess compliance to the guideline.

impact.

#### Highlights to date:

A national multi-disciplinary Steering Committee, as well as an Education Working Group, have been established with very positive engagement from both groups. A key focus of the project at present is the development of a HSeLanD module which will be launched in December. This module, called "Support pathways for people with non-cognitive symptoms of dementia" is targeted at all healthcare professionals who provide care to people with dementia across all settings. The module aims to help the learner to determine the best person-centred supports for a person with non-cognitive symptoms of dementia and to recognise the risks of unnecessarily prescribing a psychotropic medication.

As part of the implementation programme, the National Dementia Office and the HSE National Safeguarding Office hosted a webinar on non-cognitive symptoms of dementia in September entitled "A focus on non-cognitive symptoms of dementia: Promoting a culture of safety". You can watch the webinar by clicking <u>HERE</u>.

To keep up to date with the progress of the implementation programme, click <u>HERE</u>.

# 5) Invitation to participate in a focus group: peer-support and people living with Lewy Body disease

What do you wish you had known before you got diagnosed with Lewy Body Disease?

If you knew someone who just got diagnosed with Lewy Body Disease, what do you wish they'd know to increase their quality of life through the trajectory of the disease?

There are some of the questions that Dr Laura Booi, research fellow at the Centre for Dementia Research at Leeds Beckett University, is asking in her study on peer-support and people living with Lewy Body Disease.

If you are living with Lewy Body Disease, are a family member or a professional focused on Lewy Body Disease, Dr Booi is running small group conversations (one hour, between 3-6 people) online and would love to speak with you. For more information, contact laura.booi@gbhi.org or click <u>HERE</u>.



# 6) Dance exercise interventions for people living with dementia and their care partners

A PhD at TUS Midlands Athlone is studying the effects of a dance exercise intervention in people living with dementia and their care partners. The aim is to identify what would help a person with dementia stay engaged in an exercise intervention.

This four-year project will develop and implement a dance exercise intervention for people living with dementia and their care partners. Stage 1 of the project is the development of the intervention, which will be informed by both previous research and key stakeholders with a lived experience of dementia through focus groups. For this Niamh Kelly, PhD candidate and her supervisor Dr. Clare McDermott are currently looking for people living with dementia and healthcare professionals to take part.

If you are someone living with dementia or know some who is, or you are a physician, a nurse, a physiotherapist, or an occupational therapist and you are interested in participating, or to find out more, please contact Niamh Kelly:

A00301923@student.ait.ie



#### 7) Researcher In Focus: Helena Dolphin, TUH

This edition's Researcher in Focus is Dr Helena Dolphin, Research Fellow in the Department of Age-Related Healthcare at Tallaght University Hospital.

Helena took time out of her busy day to speak to us about her research - to find out more click HERE.

### 8) DRNI LinkedIn page

The DRNI Twitter account (@drnire) has now been joined by the DRNI LinkedIn page!

To follow the page, please go to <a href="https://www.linkedin.com/company/drni">https://www.linkedin.com/company/drni</a>



#### 9) Upcoming Events

• Engaging Dementia: Fostering a Dementia Inclusive Ireland

Engaging Dementia's annual conference is taking place **15-16 November** in Croke Park, Dublin as well as online. For more information please click <u>HERE</u>.

#### • Tea-Time with Lewy

The next **Tea-Time with Lewy** meeting will take place on **Thursday 24 November at 4-5 pm.** Tea-Time with Lewy is a monthly get-together for anyone affected by Lewy body disease. To register for the meeting, click on the Eventbrite link <u>HERE</u>.

December's Tea Time with Lewy will take place on Thursday 15 December 10-11 am.



• Hot Topics in Dementia webinar: TeamUp for Dementia Research

DRNI together with the Alzheimer Society of Ireland will jointly host a webinar in early December which will focus on the development of TeamUp for Dementia Research as well as Dementia Trials Ireland. More details to follow!



## 10) Welcome to our New DRNI Members

We have the great pleasure of welcoming a grand total of 20 new DRNI members in this edition of DRNI Connect!

Martina Gallagher, Speech and Language Therapist, Belfast Health & Social Care Trust

Rebecca Maher, PhD student, Trinity College Institute of Neuroscience

Niamh Kelly, PhD student, TUS Athlone

Dr Cassandra Dinius, Postdoctoral Researcher, Department of Psychology, Maynooth University

Cathal Blake, PhD student, DCU

Dr Siobhán McGettigan, PhD student, UCC

Ying Zhai, PhD student, Pharmacology and Therapeutics, NUIG

Danai Giannopoulou, Speech and Language Therapist, MSc Dementia student, TCD

Conor Lannon-Boran, PhD student, National College of Ireland Leeanne O'Hara, Research Fellow, Centre for Public Health, Queen's University Belfast

Dr Charlotte Neville, Senior research Fellow, Centre for Public Health, Queen's University Belfast

Daniela Costa, PhD student, CURAM, NUIG

Oisín Joyce, PhD student, Dept of Physiology, School of Medicine, Trinity College Dublin

Aoife Sweeney, Research Fellow, Queen's University Belfast

Rebecca Townsend, PhD student, Queen's University Belfast

Dr Calum Marr, Postdoctoral Researcher, Queen's University Belfast

Lisa Sheridan, Speech and Language Therapist, Tallaght University Hospital

Jennifer Allen, PhD student, UCD

If you are interested in becoming a member of DRNI, please email info@dementianetwork.ie

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