Dear Colleagues,

It gives me great pleasure to welcome you to the summer edition of the National Dementia Office (NDO) Newsletter, 2018. Once again, the newsletter provides an update regarding the on-going work of the NDO and, as you will see, we are keeping very busy. In addition to the projects featured in this edition, the NDO team continues to actively support and lead on progressing many other priority areas in collaboration with our colleagues across the dementia landscape in Ireland.

We hope you enjoy reading the NDO Newsletter. If you would like further information on any of the initiatives outlined in the newsletter or indeed would like to know about the on-going work of the office, please feel to contact us at dementia.office@hse.ie

Finally we would like to take this opportunity to thank you for your commitment and on-going support in progressing the national dementia agenda.

Mary Manning, NDO General Manager

Quick Updates

The National Dementia Office are delighted to be successful in securing Dormant Account funding to support the implementation of several projects, including the establishment of Dementia Resource Hubs in the community, the establishment of a National Intellectual Disability Diagnostic Centre and the roll-out of a dementia education programme for homecare workers. Further details on these projects will be communicated as implementation proceeds. Further information is available by contacting dementia.office@hse.ie

The ‘Moments in Time’ – Dementia: Understand Together Garden was one of the key attractions, winning a bronze award at Bloom in Dublin’s Phoenix Park over the June bank holiday weekend. The garden is on the move to a new permanent home in the Arklow Duck Pond, Nature Walk & Leisure Area and will be formally opened by Minister for Health, Simon Harris, on Friday August 10th. For more information and tips for dementia friendly garden design visit www.understandtogether.ie/Bloom

The National Dementia Office’s recent Grant Call seeking applications for the delivery of post-diagnostic support programmes and interventions received over 50 applications. These are currently being reviewed and applicants will be informed of the outcome of the competition in August 2018. A limited number of 18 grants will be awarded.

We welcome the publication of the Dementia Friendly Hospital Guidelines from a Universal Design Approach and look forward to supporting the implementation and dissemination of these guidelines across the acute hospitals. The guidelines are available at trinityhaus.tcd.ie/dementiafriendlyhospitals/downloads/Final%20Guidelines/UD-DFH-Guidelines-2018-Full-doc-lw-res-compressed-A.pdf

The National Dementia Office in collaboration with the Centre for Economic Social Research in Dementia (CESRD) are collecting information on innovative and/or good practice dementia initiatives across the country. Our aim is to share this data among others working in the field of the dementia. For more information please contact dementia.office@hse.ie

In October 2017 the Dementia: Understand Together campaign set off with a series of real life stories aired on TV and radio that shared the personal experiences of people living with dementia and their families.

The campaign now gathers momentum as it further highlights the role communities play in the lives of people with dementia and their families. We aim to inspire all people - individuals, businesses, service providers and community groups - to take actions and create dementia inclusive communities. To make a lasting, felt difference to people across Ireland, everyone will need to play their part.

At a stakeholder forum in June, representatives of national organisations and partners to the campaign shared best practice and the steps they have taken to support people with dementia and their families. They defined how through their branches and networks they can further increase awareness for dementia at a local level.

We are now calling on Community champions to take on a leadership role in bringing people together in their own communities and inspiring them to take actions. A national event in October will be a good opportunity for Community champions to link with one another and explore how to begin or progress local initiatives.

See how you can get involved as an individual, business / service provider or Community champion and the supports available to you at http://www.understandtogether.ie/get-involved/ or contact Fiona Foley, Co-ordinator of Dementia: Understand Together in Communities, at fiona.foley1@hse.ie or 086 771 4892.
In May 2018 a project, funded by Dormant Accounts via the Department of Health and the National Dementia Office, commenced to develop a model for a National Dementia Registry in Ireland. Successful registries capture data from the person's point of entry into the health system and across all subsequent interactions. The development of an appropriate model for a registry or national database will therefore support the roll-out of the National Dementia Strategy.

Building on the Dementia Registry Feasibility Analysis commissioned by the Alzheimer Society of Ireland in 2016, the current project to develop a dementia registry model requires expert input across legal, ethical, data protection and health economic information, identifying an appropriate IT platform, as well as costing and testing the approach.

Dr. Louise Hopper in Dublin City University (DCU) was successful in tendering for this project and is establishing an expert registry team in DCU that will guide the design and development of the registry model. Developing this model will move us towards reliable, accurate, valid, comprehensive and timely data which will contribute to the effective and efficient planning, operation and evaluation of health and related social services.

The National Dementia Office recently published the Dementia Needs Analysis Framework to Support Local Service Development. The framework is a mechanism to help support the development of dementia care that most appropriately meets people's need.

The framework was developed with a six step process to identify:

- The supports and services that are currently in place to support people with dementia and their family carers;
- The supports and services that fit with the needs and preferences of people with dementia and their family carers;
- Gaps in existing provision;
- The key priority areas for action.

The framework places people with dementia and their families at the centre of the process. It also provides hints and tips on how to gather and manage relevant information; it gives useful links and sign-posts to good practice examples both nationally and internationally.

The Dementia Needs Analysis framework is for anyone involved in the planning, design and delivery of services for people with dementia and/or their families/carers.

If you have any queries please contact the National Dementia Office at: dementia.office@hse.ie or on: (057) 931 8451

You can get a copy of the framework at http://www.lenus.ie/hse/handle/10147/623105 or contact dementia.office@hse.ie for a hard copy.

The Department of Health launched the Mid-Term Review of the Implementation of the National Dementia Strategy in May of this year. The report provides an overview of the work achieved to date, as well as providing detailed updates on the progress on each of the 35 actions within the National Dementia Strategy.

At the time of the report, preliminary work had been completed on 17 of these actions, with substantial work completed in a further 16 actions. One action within the strategy has been fully completed, while work on one action has not yet commenced. A lay summary is also provided to increase the accessibility of the report.


It is estimated that approximately 11 people per day are diagnosed with dementia in Ireland. People are currently diagnosed in a number of settings, including by their GP, in memory clinics, by geriatricians, psychiatrists of old age and/or neurologists.

While there is convincing evidence of the benefits of a timely diagnosis, dementia remains hugely undetected and underdiagnosed both in Ireland and internationally. A review of memory clinics in 2017 identified considerable geographic inequity in the availability of clinics, and considerable variation in the structure and function of the 24 memory clinics identified, highlighting a lack of national guidance or definition for this type of service.

In order to address these challenges, the Dementia Diagnostic Project was established in October 2017. A multidisciplinary steering group has been established to support the work of the project and a literature review has been completed by UCC to identify international best practice in dementia diagnosis. The literature review will be launched in October 2018.

As part of this project funding was sought through the Department of Health Dormant Account fund to establish a National Intellectual Disability Memory Service in conjunction with the Centre for Ageing and Intellectual Disability at Trinity College Dublin. Over €500,000 was awarded for the establishment of this service, and work will begin shortly on implementation.