



Rialtas na hÉireann  
Government of Ireland

# Mid-Term Review of the implementation of the National Dementia Strategy

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# List of Abbreviations

**AMNCH:** Tallaght Hospital, (the Adelaide, the Meath and the National Children’s Hospital)

**ANP:** Advanced Nurse Practitioner

**AP:** The Atlantic Philanthropies

**ASI:** Alzheimer Society of Ireland

**AT:** Assistive Technology

**CESRD:** Centre for Economic and Social Research on Dementia

**CNS:** Clinical Nurse Specialist

**DOH:** Department of Health

**DCU:** Dublin City University

**DSIDC:** Dementia Services Information and Development Centre

**ED:** Emergency Department

**GP:** General Practitioner

**HIPE:** Hospital In-Patient Enquiry

**HRB:** Health Research Board

**HSE:** Health Service Executive

**HSeLand:** Health Services e-Learning and Development Service

**ICPOP:** Integrated Care Programme for Older People

**IHCP:** Intensive Homecare Package

**INAD:** Irish National Audit of Dementia Care

**iPCRN:** Irish Primary Care Research Network

**IPU:** Irish Pharmacy Union

**MTL:** Memory Technology Library

**MTRR:** Memory Technology Resource Room

**NDO:** National Dementia Office

**NDS:** National Dementia Strategy

**NCPOP:** National Clinical Programme for Older Persons

**NGO:** Non-Governmental Organisation

**ONMSD:** Office of Nursing and Midwifery Service Director

**PCT:** Primary Care Team

**PREPARED:** Primary Care Education, Pathways and Research of Dementia

**SAT:** Single Assessment Tool

**TCD:** Trinity College Dublin

**UCC:** University College Cork

## Minister's Foreword



It is now just over three years since the Government published Ireland's first National Dementia Strategy. Those three years have seen concerted efforts by the HSE's National Dementia Office, working with the voluntary sector, to begin a process of transforming dementia services and supports so that people with dementia, together with their families and carers, can live as well as possible for as long as possible in their own homes and communities.

This review documents the considerable progress that has been made in implementing the 35 actions in the Strategy. A €27.5 million programme of investment has resulted in an information, awareness and community activation campaign, an education programme for GPs and primary care staff, and the provision of intensive homecare packages for people with dementia. Numerous other improvements have also been initiated in the areas of diagnosis, post-diagnostic supports, education and hospital pathways, to name but a few. I would like to take this opportunity to acknowledge the considerable support provided through the Atlantic Philanthropies (AP). The financial investment made by AP, matched by Government, has been critical in delivering these initiatives.

Although great progress has been made in implementing the National Dementia Strategy so far, it is clear that significant challenges remain in ensuring that people with dementia and their carers get the support they need to live as well as possible in all care settings and to die with dignity. Changes are needed in how the HSE organises and delivers its services, but equally additional investment will be needed to fill gaps in services and expand existing services to meet the needs of the rising numbers of people with dementia.

While the challenges involved in meeting the needs of people with dementia are great, it must be remembered that Ireland's national response to dementia is at an early stage of implementation. Achieving a level of service development that meets the needs of people with dementia at all stages of their journey will be a gradual process. This review contains a roadmap for the work of the National Dementia Office until mid-2019, and that roadmap will be reviewed and adapted on an ongoing basis to respond to emerging evidence around what works best to support people with dementia.

I wish to commend the National Dementia Office for the leadership it has shown on the implementation of the Strategy. I would like to thank the members of the National Dementia Strategy Monitoring Group for their expertise and continued engagement. Thanks are due to the many healthcare professionals who are leading the transformation and integration of dementia care across the health service. Finally, I want to thank the many people with dementia and their families and carers for their involvement and for showing that while dementia is life changing, there are many things that we can do, as individuals and families, in the health service and in society more broadly, to improve the experience.

**Jim Daly, T.D.**

Minister with special responsibility for Mental Health and Older People

# Lay Summary

Around 55,000 people in Ireland are living with dementia. That number is expected to double to 115,426 within twenty years and almost treble to 157,883 within thirty years. The health and social care system will need to respond with more flexible and person-centred services and supports that address the needs of the growing number of people with dementia.

The National Dementia Strategy, published in 2014, sets out a framework for the development of dementia supports and services in Ireland. The aim of the Strategy is to improve dementia care so that people with dementia can live well for as long as possible, can ultimately die with comfort and dignity, and can have services and supports delivered in the best possible way.

In 2014, The Atlantic Philanthropies agreed to invest €12.5 million to support the Strategy’s implementation. This was matched by funding of €15 million from the Department of Health and the Health Service Executive. This investment allowed for a number of key actions within the Strategy to be resourced and implemented. Additional actions within the Strategy are being implemented by (i) reconfiguring existing resources (ii) finding alternative funding streams and (iii) considering future resource allocation.

By its nature dementia is complex. People with dementia are a diverse group who will need different services and supports at different times, as shown in Figure 1 below.

**Figure 1**

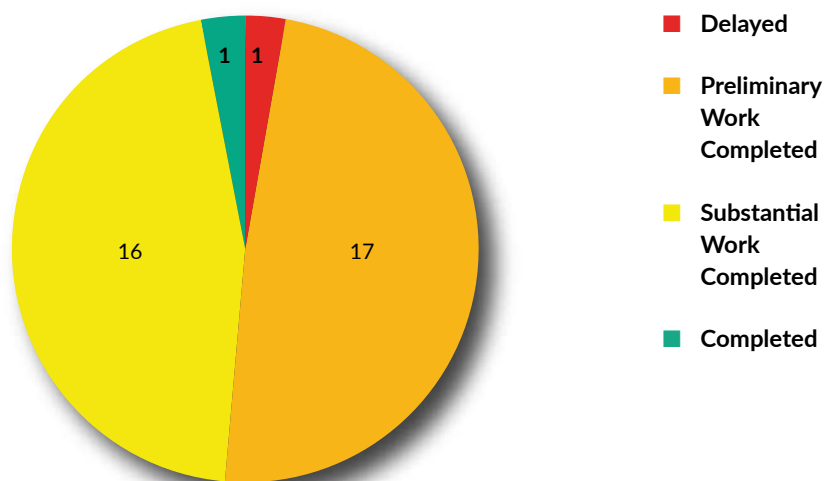


The National Dementia Strategy outlines 35 actions to improve dementia care in Ireland. These actions are grouped under the following 6 Action Areas:

- Better Awareness and Understanding
- Timely Diagnosis and Intervention
- Integrated services, supports and care for people with dementia and their carers
- Training and Education
- Research and Information Systems
- Leadership.

Progress to date on each of the 35 actions is detailed in Section 2 of this report. Figure 2 below illustrates progress achieved on each action using a traffic light system, red where work has been delayed, orange where preliminary work has been completed, yellow where substantial work has been completed to achieve an action, and green where an action has been completed.

**Figure 2: Progress on each action in the National Dementia Strategy**



**An overview of progress on work to date is described below.**

### **Funded Actions**

Good progress has been made in implementing the Strategy, particularly in relation to those actions which received funding through the original Atlantic Philanthropies, Department of Health and Health Service Executive investment. Funding was provided for:

i. *The Establishment of the National Dementia Office*

The National Dementia Office was established in 2015. The Office provides leadership around the implementation of the National Dementia Strategy. The Office monitors the funded elements of the Strategy, and drives implementation of the unfunded elements. The National Dementia Office also makes sure that all the different partners, organisations and individuals involved in implementing the Strategy are working together well.

ii. *Education and Clinical Resources for GPs and Primary Care Teams*

Education programmes have been developed for both GPs and Primary Care Teams by the PREPARED project (Primary Care Education, Pathways and Research of Dementia). To date these education programmes had been delivered to over 500 GPs, and 150 Primary Care Team members. This number will continue to rise as more workshops are scheduled for 2018. A dedicated website for primary care clinicians, [www.dementiopathways.ie](http://www.dementiopathways.ie) has also been developed. The website provides information and clinical resources for primary care providers.

iii. *Intensive Homecare Packages for People with Dementia*

Intensive Homecare Packages were introduced to provide a higher level of support to people with dementia in their own homes. To date (end February 2018) 309 people with dementia have benefitted from an Intensive Homecare Package, and 148 people are currently receiving an Intensive Home Care Package. Genio, a not-for-profit organisation, are evaluating the Intensive Homecare Packages to see if they are the best way to meet the needs of people with dementia who want to stay living in their own homes for as long as possible. Genio are also working with HSE staff around the country to support them to design and deliver this type of personalised intensive homecare.

iv. *Public Awareness Campaign*

The Dementia Understand Together campaign is a national public awareness campaign aimed at raising awareness of dementia and reducing stigma. A range of TV and radio ads have been developed as part of the campaign. Newspapers and social media have also been used to communicate key messages. The [www.understandtogether.ie](http://www.understandtogether.ie) website has been developed. This provides information on dementia and on services that are available around the country. A community activation programme is also part of the campaign. This programme will support local communities to become more dementia inclusive.

v. *External Evaluation of the National Dementia Strategy*

An international independent consortium is evaluating how the National Dementia Strategy has been implemented. The evaluation began in September 2017 and the final evaluation report will be available in January 2019.

vi. *Evaluation of the Alzheimer Society of Ireland Dementia Adviser Service*

The Alzheimer Society of Ireland provides a Dementia Adviser Service, funded by the HSE, in eight locations nationally. The service supports around 1,700 clients. University College Cork are evaluating the Dementia Adviser Service to investigate how well it works and provide recommendations on the future development of the service.

## **Non-funded actions**

As well as the work outlined above, a large number of other actions within the National Dementia Strategy are being addressed. These pieces of work were not funded through the original Atlantic Philanthropies, Department of Health and Health Service Executive investment. Some of this work has received funding from the Department of Health through the Dormant Accounts fund.

*a. Post-Diagnostic Support Pathway Project*

It is recognised that following a diagnosis, people with dementia and their families need both emotional and practical support. This project is developing a post-diagnostic support pathway that will help people receive the information and support they need, when they need it. The work is being led by the National Dementia Office and supported by a National Steering Committee. The National Dementia Office secured €640,000 from the Dormant Accounts Fund through the Department of Health to support the implementation of the pathway. The project commenced in 2017 and will continue into 2018.

*b. Dementia Diagnostic Project*

This project, which is being led by the National Dementia Office, aims to ensure people receive a timely diagnosis of dementia. Following a review of memory clinics in 2017, a National Steering Group was established to develop a diagnosis pathway for dementia in Ireland. A literature review is being done to identify best practice in diagnosis of dementia internationally.

*c. Memory Technology Resource Rooms*

Assistive technology can support people with dementia to maintain their independence, provide reassurance and reduce risk. The HSE's Services for Older Persons secured €600,000 in Dormant Accounts funding through the Department of Health to establish a Memory Technology Resource Room in each CHO area. These will provide individualised assessments and information on assistive technology devices that can support people with dementia.

*d. Mapping Dementia-Specific Community Based Services*

To support future development of services and supports for people with dementia, the National Dementia Office and the Alzheimer Society of Ireland undertook a joint project to map dementia-specific community-based services. This work was completed in 2017 and is informing the development of services locally. Information from the project is also included in an on-line service finder so people can find out what services are available in each county (see [www.understandtogether.ie](http://www.understandtogether.ie)).

*e. Dementia Registry Project*

Under the National Dementia Strategy there is a commitment to improve and increase the evidence we have on dementia in Ireland. Evidence can improve service planning and development. It can also improve outcomes for individuals. To support this, the National Dementia Office, through the Department of Health, secured Dormant Account funding of €200,000 to develop and test a model for a dementia registry. It is important that any model is workable within the Irish context. DCU have been awarded the tender and work will commence on developing an appropriate model in Q2 2018. This model will then be tested by the end of 2019.

*f. Education and Training*

Dementia-specific education is needed for people with dementia, their families, volunteers and health and social care professionals. There is a range of dementia education programmes available, many developed as part of the implementation of the National



Dementia Strategy. These include a programme for home care workers and education for communities which was developed by the Elevator Programme in Dublin City University. More education programmes are required. To support this, a review of all dementia-related education in Ireland was carried out in 2017 to identify gaps in education provision.

*g. Key Worker Role*

It is acknowledged that people with dementia and their carers need a single contact person or key worker to help co-ordinate their care, provide ongoing support and help them access the services and supports they need. In November 2017 a Dementia Key Worker Working Group was established by the National Dementia Office. The first task of this working group is to define the key worker role, identify where the key worker should sit within the existing system and determine the main duties and responsibilities of the role.

A lot of work is taking place to implement the National Dementia Strategy. Work will continue throughout 2018 and 2019 to implement all the actions within the Strategy. Much of the work to date has focused on collecting baseline information on:

- current dementia service structures
- international evidence of best practice.

The pace of implementation can be very frustrating for people living with dementia, their families and service providers, as they are still dealing with inadequate services and supports. However, this preparatory work is needed to make sure that the development of dementia services and supports meets the needs of people with dementia, is evidence based, and integrates seamlessly with existing services.

The main body of this Review sets out in detail the work being done to implement the National Dementia Strategy. It is accompanied by an Action Plan setting out the specific actions that will be undertaken over the next eighteen months by the National Dementia Office and others to further implement the Strategy. Some of the key actions in the Action Plan include:

- Continuing the public awareness campaign and rolling out the community activation programme to reduce stigma and ensure that people with dementia are included in their communities
- Ongoing delivery of Dementia Intensive Home Care Packages to approximately 120 people with dementia at any given time, and developing a process for designing and delivering personalised supports
- Developing a post-diagnostic support pathway, improving information resources and rolling out cognitive therapy programmes
- Developing a pathway for dementia diagnosis and identifying the resources needed to roll it out
- Developing a model for a National Dementia Registry and examining how data collection can be improved

- Rolling out education programmes for health and social care staff, family carers, customer facing staff and the general public, and developing new programmes
- Establishing a nationwide network of Memory Technology Resource Rooms
- Examining best practice long-term care models and developing recommendations for long-term care
- Developing and costing the role of key worker
- Developing guidance on the use of psychotropic and antipsychotic medication
- Developing recommendations for the future development of the Dementia Adviser service
- Improving dementia care in acute hospitals by developing dementia care pathways, ensuring that delirium is recognised and treated, appointing dementia nurse specialists and supporting changes to the physical environment.

Together with the development of a statutory scheme for home care, the implementation of the Assisted Decision Making (Capacity) Act and the shift towards community based supports recommended in the Sláintecare report, undertaking this work will be important stepping stones towards ensuring that people with dementia and their carers are supported throughout the health and social care system, and society more broadly, to maximise their independence and live as well as possible for as long as possible.

The Department of Health recognises that full implementation of the National Dementia Strategy will require further investment in our health and social care system. The National Dementia Office is developing the evidence base for future investment and this evidence will be used to make the case for additional resources for dementia services through the health estimates and service planning process. It must be recognised, however, that health service resources are finite and it will be difficult to obtain resources on the scale that is needed. Therefore the HSE will need to work on reconfiguring services, ensuring new and existing services are integrated where appropriate to ensure efficient use of existing resources, and ensuring that available services are directed towards those who most need them.

# Introduction

In December 2014 the first Irish National Dementia Strategy was launched. The Strategy seeks to progress the dual and overarching principles of personhood and citizenship by enabling people with dementia to maintain their identity, resilience and dignity and by recognising that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active citizens in society.

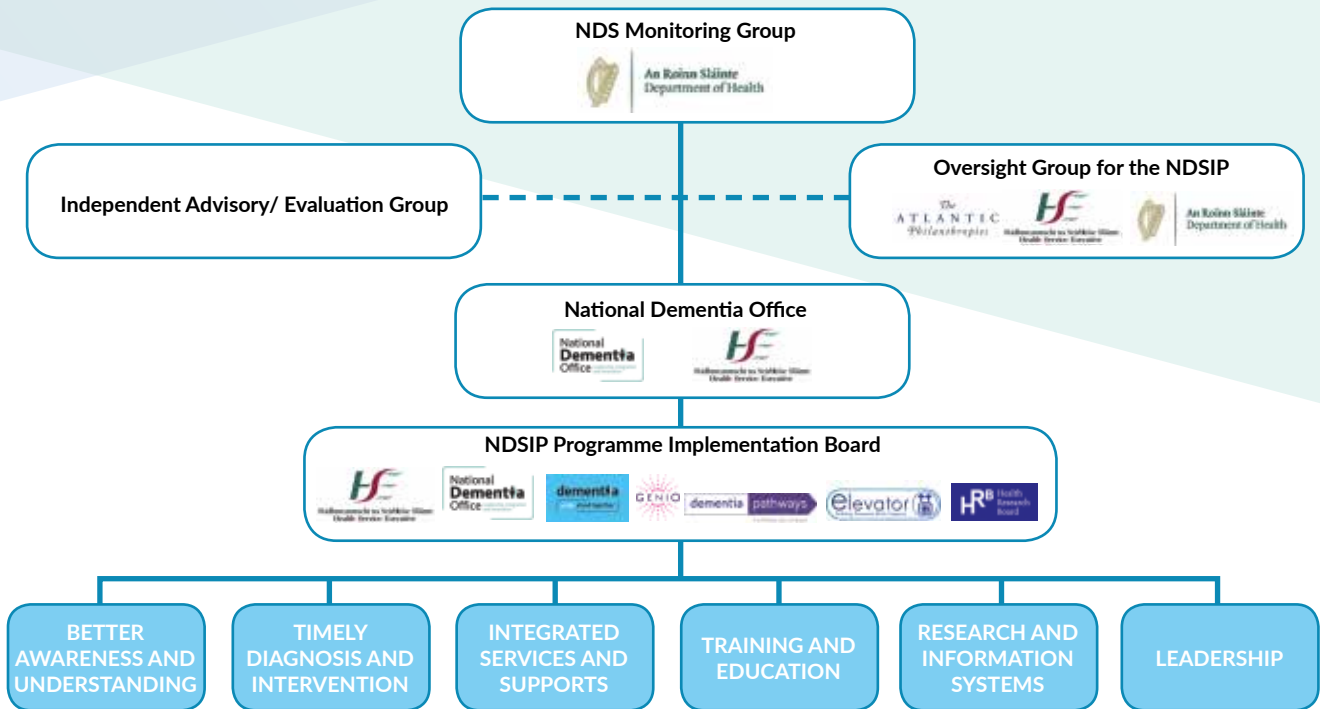
The Strategy identifies key principles to underpin and inform the full range of health and social care services provided to people with dementia, their families and carers. Recognising that a social and clinical response is required and that dementia cuts across many areas of provision, the Strategy also emphasises the need for a 'whole community response' to dementia, with health and social care services as only one part of the packages of supports that people with dementia need.

In order to translate these principles into practice, the Strategy identifies 14 Priority Actions and 21 Additional Actions (detailed in Section 2), which are grouped under the following 6 Action Areas;

- Better Awareness and Understanding
- Timely Diagnosis and Intervention
- Integrated services, supports and care for people with dementia and their carers
- Training and Education
- Research and Information Systems
- Leadership.

The priority actions are considered to be key to the implementation of the Strategy, and were originally intended to be implemented within existing resources or by reconfiguring resources as it was necessary for the Strategy to be cost neutral. In 2014, The Atlantic Philanthropies agreed to invest €12.5 million into the implementation of the Strategy, which was matched by funding of €15 million from the Department of Health/HSE. This investment allowed for a number of critical key actions to be resourced, including the development of education and resource materials for primary care, the testing of the concept of Dementia-Specific Intensive Homecare Packages, a public awareness campaign and the establishment of the National Dementia Office. Additional actions are being targeted through the reconfiguration of current resources, alternative funding streams and consideration within future resource allocation.

In 2015 an Implementation Plan for the National Dementia Strategy was developed which identifies key deliverables and some indicative timelines for each of the actions outlined in the Strategy. The National Dementia Office (NDO) was established to monitor and drive the implementation of the Strategy, and is part of the robust governance structure that oversees its implementation, as illustrated in Figure 3 opposite.

**Figure 3: Governance of the National Dementia Strategy and the National Dementia Strategy Implementation Programme**

The Monitoring Group, which is chaired by the Department of Health, is a multidisciplinary group that meets approximately 3 times per year to ensure that progress is being made and key deliverables are being met. It also functions to allow experts in the area to continuously input on the roll-out of the Strategy. The programme implementation board brings together project leads for each of the different workstreams within the National Dementia Strategy Implementation Programme, facilitating information sharing and ensuring that work being progressed to implement the Strategy does not become siloed. An Oversight Group, chaired by the Department of Health and including representatives from the HSE and the Atlantic Philanthropies, oversees the implementation of the National Dementia Strategy Implementation Programme.

As part of the Strategy's implementation, the Department of Health committed to conducting a mid-term review of progress. This review, which has been prepared by the National Dementia Office and the Department of Health, provides an overview of work completed to date and work ongoing for each of the priority actions and additional actions identified in the Strategy. The review also contains recommendations to improve the functioning of the Monitoring Group to support the Strategy's implementation (at the end of Section 1), and outlines an action plan for the work of the National Dementia Office for the period Q2 2018 – Q2 2019. It is not intended to replicate the large scale external evaluation of the impact of the National Dementia Strategy, initiated in September 2017, which will detail how the Strategy was implemented and the process overall, improvement in the dementia care system and the extent to which programmes and activities impacted on people with dementia and their families and carers. The results of the external evaluation will be available Q1 2019.

Section 1 of this review gives an overview of progress to date for both the funded and unfunded elements of the Strategy, while Section 2 provides further detail on the implementation of

each specific action. Section 3 outlines an action plan (Q2 2018 – Q2 2019) for the further implementation of the National Dementia Strategy within the resources currently available.

While a great deal of progress has been made towards implementing a range of actions in the National Dementia Strategy, there is no doubt that significant challenges remain in ensuring that people with dementia and their carers get the support they need to live as well as possible in all care settings and to die with dignity. These challenges are discussed further in the concluding remarks at the end of Section 1 of this report.

While it is outside the scope of this document to reflect fully on the evolving dementia landscape in Ireland, it must be acknowledged that a number of reports have been published since 2014 that provide new information that can inform the development of dementia care, and provide context regarding current policy and practice. One such report, ‘Developing and Implementing Dementia Policy in Ireland’ Report (CESRD, 2017) reflects on various aspects of care for people with dementia in Ireland and internationally with a view to informing future developments in dementia policy in the country. Advocacy organisations such as the Alzheimer Society of Ireland continue to identify areas for change and development through research highlighting the experiences of people with dementia and their families in Ireland. Implementing the 2014 National Dementia Strategy fully will address some of the identified needs and will drive much needed development in many areas of dementia care. However, ongoing strategic and policy development, combined with investment in changing processes and pathways will be necessary to ensure the evolving needs of people with dementia and their families are met.

Section 1:

# Overview of the Implementation of the National Dementia Strategy

## **The National Dementia Office**

The National Dementia Office (NDO) was established in 2015, but due to a delay in recruitment only became fully operational in Q1 2017. The NDO consists of a General Manager, two Senior Project Managers and a Clinical Lead (0.4 WTE). The NDO monitors and supports the implementation of the funded elements of the National Dementia Strategy, and drives the implementation of the unfunded elements of the Strategy. An overview of progress on both the funded and unfunded elements of the Strategy is outlined below, with additional detail given in Section 2.

In addition, the NDO also undertake work to ensure that all elements of the Strategy are progressed in a coherent manner, promoting a consistent approach to the development of dementia supports and services nationally. This includes focusing on improved communication around the implementation of the Strategy through the publication of newsletters, conference presentations, working with partners on networking events and meeting with key stakeholders. Traditionally dementia supports and services have developed in isolation, driven by a response to identified local need or the special interest of individuals in a particular area. The NDO are actively identifying and meeting with groups, organisations and individuals who provide and receive care to facilitate information sharing, identify gaps in service provision and work towards equitable availability and utilisation of services and supports nationally.

Currently in Ireland there is a dearth of baseline information on dementia and a lack of information systems to collect relevant data. The NDO are undertaking a number of data collection/review projects to increase our understanding and knowledge of current status. These include mapping of dementia specific community based services (in partnership with the Alzheimer Society of Ireland), a review of memory clinics, a review of dementia related education and a review of dementia information resources currently available. This work is essential to establish the evidence and information base necessary for the full implementation of the National Dementia Strategy and to inform the future development of dementia services in Ireland.

## **Funded Elements of the National Dementia Strategy**

As outlined in the introduction, funding was initially allocated through an agreement between the Department of Health, HSE and Atlantic Philanthropies to progress four specific areas of the Strategy: Primary Care, Intensive homecare packages, a public awareness campaign and the establishment of the National Dementia Office. In addition, funding was allocated to carry out an external evaluation of the impact of the implementation of the National Dementia Strategy.

### **Primary Care**

The General Practitioner (GP) is usually the first contact when concerns about thinking or memory arise. However, GPs have identified a number of difficulties with their role in the assessment, diagnosis and management of dementia. Funding of €1.2 million was awarded to the PREPARED project (Primary Care Education, Pathways and Research of Dementia), based

in UCC, to develop a suite of resources to ensure patients receive optimal, evidence-based dementia care in General Practice from GPs who are up-skilled to assess, diagnose, and care for patients with dementia and who are empowered by clear, accessible dementia care pathways. PREPARED also aims to ensure that patients receive an integrated, collaborative dementia care response from a prepared, proactive Primary Care Team (PCT).

Since 2015, a suite of resources have been developed for GPs and PCTs, based on a needs analysis, including education workshops, online tools and resources made available on [www.dementiathroughways.ie](http://www.dementiathroughways.ie) and the development of electronic clinical data and audit tools for GP practices, and a GP clinical audit guide on dementia. At the time of this review approximately 390 GPs had received dementia specific training from a GP facilitator, while approximately 235 had attended continuing medical education small group meetings on dementia. The roll-out of GP education will continue throughout 2018 through both face-to-face in practice workshops and through small group continuing medical education programmes (CME). The roll-out of the PCT workshops began in October 2017 and is being coordinated by the National Dementia Office. To date approximately 160 primary care team members have attended this workshop. A suite of discipline specific education resources is currently being developed for primary care team members.

Challenges to the full implementation of this aspect of the Strategy include difficulties with GP uptake and engagement with the available education materials and dementia register tools, and the release of Primary Care Team staff to attend the education workshops. This work is currently funded until the end of 2018, and additional resources will be needed to ensure its long term sustainability. PREPARED and the National Dementia Office are working closely to address and overcome these challenges to ensure the aims of the project are met.

### **Intensive Homecare Packages**

It is recognised that many people with dementia wish to remain living in their own homes and communities, and that flexible, person-centred services are an integral component of supporting people to remain at home. In Q4 2014 the HSE introduced Dementia Intensive Homecare Packages (Dementia-IHCPs) to test the feasibility of providing a high level of support to people with dementia with complex needs to facilitate them to remain living at home. €22.1 million was allocated to this work, of which €20.5 million was allocated for the delivery of Dementia-IHCPs from Q4 2014 – Q4 2018. €1.6 million was awarded to Genio, €440,000 to develop indicators to monitor the IHCPs and to undertake an evaluation of the effectiveness of IHCPs for people with dementia, with the remainder allocated to support the implementation of the IHCPs.

As of the end of February 2018, 309 people with dementia had benefitted from an IHCP and 148 Dementia-IHCPs were active. A data collection tool has been developed and implemented to monitor the quality and delivery of IHCPs, and a mixed-method evaluation is currently ongoing. In addition, Genio programme managers are working in eight pilot sites around the country to support the development of dementia care pathways, and to develop a process for the design



and delivery of personalised intensive homecare packages. Emerging findings highlight the passionate commitment of staff to delivering high quality care. This will require investment in the development of systems and cultures that support a more personalised approach to service design and delivery.

The HSE has committed to continuing to fund the delivery of IHCPs to people with dementia currently in receipt of a package post 2018, ensuring that approximately 120 people will continue to be in receipt of a package at any one time. The future development of this service will be informed by the results of the evaluation.

### **Public Awareness Campaign**

A total of €2.7 million was allocated by The Atlantic Philanthropies and HSE Health and Wellbeing to develop a national support campaign for people with dementia and their carers. Further funding to the value of €0.5 million has been allocated by HSE Health and Wellbeing to strengthen the roll-out of the campaign. The campaign is led by the HSE (Health and Wellbeing and National Communications) in partnership with The Alzheimer Society of Ireland (ASI) and Genio, working in collaboration with a range of partners. A Steering Group was established in June 2015 to guide the development of the national communications and information campaign. Based on extensive research, **Dementia: Understand Together** was developed and launched in October 2016.

To date the campaign has produced a range of information resources and materials, and created radio and television advertisements, PR and social media to increase awareness and understanding of dementia thereby reducing stigma. A one-stop-shop website – [www.understandtogether.ie](http://www.understandtogether.ie) – has been developed and provides general information on dementia, education, and resources available and contains a service finder that allows people to search for dementia services in their area. The campaign is supported by a network of partners from across broader society.

A comprehensive communications plan and partner engagement programme will continue to be delivered in 2018, building on the progress to date to increase knowledge and change attitudes and behaviour. A community activation platform is also being designed, building on the work of the ASI Dementia Friendly Communities and the Genio consortium work, to embed the national campaign into local communities for long term sustainability. A National Dementia Community Activation Coordinator has been appointed under a shared role between the HSE and the ASI. The Department of Health has secured €90,000 in Dormant Account funding to support this work.

### **External Evaluation of the National Dementia Strategy**

Following a national tendering process, the contract to evaluate the impact of the National Dementia Strategy was awarded to an international consortium led by Ipsos MORI in Q3 2017. The evaluation process formally commenced in September 2017. It will review and report on how the National Dementia Strategy has been implemented and the process overall; improvements

in the dementia care system from diagnosis to end of life; the extent to which the programmes and activities of the Strategy impacted on people with dementia and their families and carers; components which contributed to or hindered the implementation of the Strategy; and the extent to which the National Dementia Strategy has impacted on systems change. The external evaluation will be completed in January 2019.

### **Dementia Adviser Evaluation**

The Alzheimer Society of Ireland (ASI) provides a Dementia Adviser Service, funded by the HSE, in eight locations nationally, supporting approximately 1,700 clients. Dementia Advisers (DAs) work with people with dementia and their families and carers to provide a highly responsive and individualised information and signposting service. However, this service is not available nationally and many people with dementia cannot access a dementia adviser in their area. Under the National Dementia Strategy there is a requirement for the HSE to “consider the provision of Dementia Advisers on the basis of the experience of demonstrator sites, with an appropriate number of Advisers to be dedicated to the needs of those with early-onset dementia” (p. 23). In order to fully capture the experience of demonstrator sites and inform the future development of this service, the HSE initiated a tender process in Q2 2017 to commission an external evaluation of the service. UCC were successful in securing the tender, and the evaluation began in November 2017. The final evaluation report will be completed by Q2 2018.

### **Unfunded Elements of the National Dementia Strategy**

As outlined in the introduction, the National Dementia Strategy Implementation Programme was funded through the Atlantic Philanthropies and the HSE/Department of Health. However, many actions in the Strategy do not have specific funding allocated to them. In order to progress these actions, the National Dementia Office (NDO) is working closely with key stakeholders, and costing the implementation of specific actions where relevant. Implementation of actions with a significant resource requirement will be dependent on the future availability of funding, either through the allocation of additional resources, or by reconfiguring existing resources. Below is an overview of some of the key actions that the NDO is working on, with further details on specific actions available in Section 2 of this report.

### **Post-Diagnostic Support Pathway Project**

The National Dementia Strategy recognises that “following a diagnosis, the person with dementia will need considerable emotional and practical support. Local, well-co-ordinated support services are needed to assist people and their families to cope with the choices and dilemmas confronting them at this often distressing and challenging time” (p. 21). To address this and further the NDS’s action area ‘Timely Diagnosis and Intervention’, the NDO commenced the Dementia Post-diagnostic Support (PDS) Pathways project in June 2017.

Based on the findings from a literature review commissioned for the project and undertaken by the Centre for Economic and Social Research in Dementia (NUI, Galway), data gathered from a needs analysis and expert input from a multi-stakeholder national steering committee, a PDS framework is being developed. The National Dementia Office secured €640,000 in Dormant Account funding through the Department of Health to support the project in 2018. The funding will be used to promote and develop cognitive therapies including cognitive stimulation and cognitive rehabilitation therapies and post-diagnostic psycho-educational programmes. This will be administered through a national grant scheme. Given the integral role of information in post-diagnostic support, where people are provided with the right information at the right time and in the right way, some of the funding will focus on information provision and a small subgroup has been formed to support this work.

The complex, individualised and changing needs connected to the lived experience of dementia, which include emotional and psychological needs, will require any pathway to be flexible and personalised and this must be a consideration for the future PDS framework. The full roll-out of the pathway will also be dependent on future resources being made available.

### **Dementia Diagnostic Project**

Timely diagnosis is a crucial element of ensuring that people with dementia receive the services, care and support they need to live well with their condition. The National Dementia Strategy has a specific objective that “People receive a timely diagnosis of dementia and dementia sub-type” (p. 19). A further objective is that “[A]s much specialist expertise as possible will be available regionally to ensure appropriate investigation and timely diagnosis of dementia in primary, mental health, acute and long term care services” (p.19).

A review of memory clinics conducted by the National Dementia Office (NDO) in Q2 2017 found that memory clinics vary widely in their composition and type of service they provide. It also highlighted inequitable geographic spread of these clinics, with over 50% of counties having no memory clinic in place. A scoping exercise is currently being conducted to capture diagnostic practices in Geriatrician, Old Age Psychiatry and Neurology clinics. These findings highlight the lack of national development of dementia diagnostic services, and that services have developed in isolation. In order to address this, the Dementia Diagnostic Project was established in Q4 2017.

The project has commissioned a literature review to identify diagnostic pathways and best practice internationally and has convened an interdisciplinary steering group. The steering group will develop guidance on the establishment of standardised dementia diagnostic and assessment services nationally, and develop a national diagnostic pathway for people with dementia. The implementation of this pathway is dependent on the future availability of resources.

### **Memory Technology Resource Rooms**

Assistive Technology (AT) can support people with dementia to maintain their independence, provide reassurance and reduce risk. In 2016, HSE Services for Older People secured €300,000 in Dormant Account funding through the Department of Health to facilitate the expansion and

use of AT for people with dementia. Following a scoping exercise it was agreed to establish a Memory Technology Resource Room in each CHO area, utilising learning from the already established South Tipperary Memory Technology Library.

A standard AT equipment database was developed and a national tendering process for the purchasing of relevant equipment was completed in Q4 2017. Training on AT has been provided to 30 staff, and a Memory Technology Resource Room Network group has been established to bring together project leads from all CHO areas. The group aims to ensure standardisation in the services provided nationally, and to explore opportunities to maximise utilisation of the available resources.

A further €300,000 was secured in Dormant Account funding through the Department of Health in 2017 to recruit part time staff to establish and run the resource rooms for a time-limited period of one year. These staff will also up-skill multidisciplinary team members in the appropriate use of the MTRR resources.

### **Mapping Dementia-Specific Community Based Services**

In September 2016, the National Dementia Office and the Alzheimer Society of Ireland partnered on a project to map dementia-specific community-based services nationally. The project supports the implementation of the NDS under a commitment by the HSE to critically review health and personal social services for people with dementia to identify gaps in existing provision and prioritise areas for action in accordance with resource availability, with priority being given to the most urgent deficits that can be addressed either within or by reconfiguring existing resources.

The project, which concluded in October 2017, reports on who is doing what, where and when in relation to the delivery of dementia-specific services and is a resource to support future development and planning. In total 325 dementia-specific community-based services/supports were identified at the time of data collection. Through an ongoing NDO verification process, a further 15 services have been identified, bringing the current total of services to 340. The study provides evidence on the inequity of service provision across the country with some blackspot areas which have little in the way of dementia-specific resources. These findings provide information which will support both organisations in dementia service planning and development in a more informed and systematic way.

It's important to note that the study did not examine the quality of services, or the use of generic services by people with dementia. The project is therefore very much a baseline in which further examination of service quality and how the needs of people with dementia and family carers could be met within local contexts is required

The findings from this project have also been used to develop a service finder, which is now available on [www.understandtogether.ie](http://www.understandtogether.ie). The service finder allows people to search for dementia specific community services in their area. In addition the National Dementia Office is working with the Centre for Economic and Social Research in Dementia (CESRD) in NUI Galway on a HRB Applied Partnership Award which will include a broader audit of services people with dementia and their families use.

## **Dementia Registry Project**

An objective under the National Dementia Strategy is to improve national, regional and local estimates of current and future prevalence of dementia across all care settings (p.33). It also sets out an objective for better evidence on diagnostic rates, sub-types, and clinical outcomes for those living with the condition and for better collection of data and use of evidence to inform health and social system responses to the needs of people with dementia and their carers.

To progress this objective and build on the analysis and recommendations of the DCU/ASI feasibility analysis of a dementia registry for Ireland, funding of €200,000 was secured by the Department of Health in the 2017 Dormant Accounts Action Plan and an e-tender was issued in October 2017 for a dementia registry project. The aim of the project is to determine the most appropriate and practical design for a dementia registry; to address ethical, legal, data protection and financial considerations and test the model, assessing its efficacy and effectiveness. The tender was awarded to DCU and this 24 month project will commence in Q2 2018. The roll-out of a fully functioning National Dementia Registry will depend on future resource availability.

## **Education and Training**

Dementia-specific training and education for people with dementia, families, volunteers and health and social care professionals is an essential component in ensuring people with dementia and their families are empowered to live well with dementia, and that they receive appropriate services delivered by educated staff. A number of dementia education programmes have been developed for multiple audiences by a number of organisations, including the HSE, Alzheimer Society of Ireland, Dementia Services Information and Development Centre (DSIDC) and SONAS, and are continually delivered. However a number of gaps in education provision still exist, and the National Dementia Strategy outlines a number of actions to ensure education is developed and provided to health and social care professionals as well as people with dementia, families and carers.

In 2017 the National Dementia Office commissioned DCU to develop a dementia education programme for homecare workers. The programme was piloted in Dublin and Cork and learning from the pilots was incorporated. The programme has now been finalised and roll-out will be governed by the National Dementia Office. However the absence of dedicated funding to roll out this programme presents challenges around securing suitable facilitators to deliver the programme and release of staff to attend.

Education resources developed in DCU under the Dementia Elevator Project are currently being rolled-out to public facing services through a partnership with the Understand Together campaign. Education workshops and materials have been delivered to national transport and financial institutions and the Gardaí, while a number of local facilitators have been up-skilled as part of the community activation drive under the campaign.

In order to identify where gaps in education provision lie, the National Dementia Office recently completed a review of all dementia related education available nationally. The results of the review are currently being analysed and a final report is being drafted for Q2 2018. Initial findings

indicate a wide range of education available of variable quality, and a lack of national leadership around the development and delivery of dementia education. In addition to providing guidance on gaps in education provision, the information gathered from the review will also be used to develop an education hub on the [www.understandtogether.ie](http://www.understandtogether.ie) website.

## **Key Worker Role**

During the consultation phase for the National Dementia Strategy it was identified that people with dementia and their carers should have a designated contact person to help co-ordinate individual care plans and assist people to navigate complex care pathways and the range of services available. This need was reflected in the Strategy under the Priority Action Area of Leadership, which stated that a key worker would be appointed to coordinate each person's care.

To fully realise this action there are a number of considerations, including (i) identifying the most effective and appropriate key worker model; (ii) determining within which HSE division the role will be best placed; (iii) avoiding potential duplication with existing roles; and (iv) issues around financing. A Dementia Key Worker Working Group convened in November 2017 consisting of representatives from HSE's primary, social and integrated care as well as someone living with dementia, a voluntary sector representative and an expert academic. The first task of the working group is to define the key worker role, determine whether this should be a dementia-specific or generic role, identify where the key worker should sit within the existing system and determine the main duties and responsibilities of the role. The implementation of the dementia key worker within the health and social care system has resource implications which need to be considered at a systems level.

## **Role of the NDS Monitoring Group**

The National Dementia Strategy Monitoring Group draws its membership from various fields of expertise including health service provision and management, academia and the voluntary sector. According to its terms of reference, the role of the Group includes monitoring and assessing progress on implementing the Strategy, identifying blockages to implementation, and making recommendations on the manner in which the Strategy is implemented.

As part of the mid-term review of the National Dementia Strategy, members were asked to consider the extent to which the Monitoring Group has achieved its terms of reference and what changes are needed to the structure and functioning of the Monitoring Group in order for it to better achieve them.

Members of the Monitoring Group were of the opinion that the expertise of Monitoring Group members is not being maximised to support the implementation of the Strategy and the work of the National Dementia Office. The meetings of the Group have over-focused on relaying information and reporting, with insufficient focus on the other elements of the Group's remit, particularly discussion on future implementation or problem-solving. The Group should be used

to assist implementation and inform the process of prioritising actions for implementation in view of the finite resources available to the HSE.

Following this consultation, the Department of Health has decided to make a number of changes to the functioning of the Monitoring Group. A number of subgroups will be established to focus on specific areas of work to directly support the implementation of the Strategy. In addition, future meetings of the Monitoring Group will be used to focus in depth on specific challenges to implementation and to inform priority-setting for resources that may become available.

## Concluding Remarks

As outlined in Section 1 above, and further detailed in Section 2, a significant amount of work is currently ongoing to implement the actions of the Irish National Dementia Strategy. While there are some actions where work will commence in 2018, the vast majority of actions have been commenced. However due to the lack of reliable national data on dementia care services in Ireland, much of this work has focused on collecting baseline information on current dementia service structures, generating an evidence base for the development of services and testing concept feasibility. This work is necessary to ensure that the development of national dementia services meets the identified needs of people with dementia, their families and carers; integrates seamlessly with existing structures and systems; and is rooted in evidence-based models of care.

While this preliminary work is necessary, the pace of implementation can be frustrating for people living with dementia, their families, and service providers as they are still dealing with inadequate services and supports. It must also be acknowledged that additional funding, and/or redeployment of existing resources, will be required to move from this preparatory phase into the establishment of new dementia services and structures.

Considerable resources, both financial and staffing, will be required to implement the diagnostic and post-diagnostic supports pathways being developed by the National Dementia Office, as outlined above. Likewise, staffing resources will be needed to implement an appropriate pathway for people with dementia through acute hospitals and to provide key worker posts. Intermediate options for care other than nursing home care are required for those for whom living at home is no longer an option. These options include housing with care and sheltered housing.

A number of gaps in the availability and provision of appropriate dementia specific community services and supports were identified through the dementia-specific community-based Mapping Project outlined above. Addressing these service gaps will require a strategic approach to dementia service development at a regional level, and potentially additional resources in terms of infrastructure, funding and staffing if community-based services are to be developed in a way that meets the needs of people with dementia and their families.

One of the greatest challenges in supporting people with dementia to live well at home will be to provide adequate funding and staffing for personalised and flexible home care. While it is

estimated that one third of people with dementia reside in nursing homes, the remaining two thirds live in the community. Many also have other health conditions and, like other older people with progressive illness, disability and frailty, are likely to require increased home supports as their condition progresses and their independence reduces.

People with dementia require care to be provided in a different way to the current task-oriented approach. The responsibility of providing care in the home can be particularly high for carers of people with dementia as shown in the findings from the 2017 ASI De-Stress report. The Department of Health is working on a new statutory scheme for the financing and regulation of home care services, which will take a number of years to develop. In the meantime, existing services are being incrementally improved, though the demand for home care continues to outstrip the care available. An additional €18.25 million was allocated to home supports in budget 2018, bringing the budget for the direct provision of home support services to €408m delivering over 17m home support hours to about 50,500 people. This compares with the estimated 16.34m hours delivered to 50,000 people in 2017. In addition, 235 intensive home care packages will provide 360,000 home support hours for people with complex needs in 2018, the majority for people with dementia. The HSE has provided €3 million in 2018 to continue the personalised intensive home care packages for people with dementia that were previously funded by the Atlantic Philanthropies.

The provision of health and social care services for older people and people with dementia faces significant challenges in line with demographic projections. This challenge is recognised in the recently published Capacity Review<sup>1</sup>, which concludes that “*community-based services for older people appear to be operating at capacity both in terms of residential and home care provision*”.<sup>2</sup> It further outlines that: “*capacity requirements for home care is set to experience significant growth to 2031, with an additional 11,000 (70%) HCP, 130 (70%) IHCP, and 7.2 million (69%) HHH anticipated.*”

Capacity challenges, including staffing, to deliver home care have been highlighted in the public, voluntary and private sectors and are evident in early findings from the Genio evaluation of the Dementia-IHCPs. Issues have been highlighted around pay, working conditions and career progression. In one HSE area, it was found that 37% of people accessing generic home care had a diagnosis of dementia (O’Brien et al., 2017). As our population continues to age and the numbers with dementia continue to grow, training in dementia care will need to be an important element of the basic home care qualification for new entrants and of ongoing training for existing staff. Funding will be required to ensure sustainable roll-out of dementia education programmes to all staff who care for and support a person with dementia.

The lack of available evidence on what interventions work best in dementia service provision further hinders service development. Greater research on the most effective dementia interventions and robust evaluation of pilot projects is needed to ensure that scarce public resources are directed towards supports that lead to positive outcomes for people with dementia and their families.

<sup>1</sup> Health Service Capacity Review 2018: review of health demand and capacity requirements in Ireland to 2031

<sup>2</sup> *ibid.*, page 100



The provision of palliative care for people with dementia, whether they live at home or in nursing homes, is a challenge that is recognised in the work of the ASI, IHF and the HSE's National Clinical Programme for Palliative Care. The Department of Health has begun work on updating the existing national palliative care policy, which dates from 2001. The revised policy will include a greater focus on the development of generalist palliative care in the community, including for people with dementia.

While the challenges involved in meeting the needs of Ireland's growing population of people with dementia are great, it must be remembered that our national strategic response to dementia is at an early stage of implementation and that achieving a level of service development that meets the needs of people with dementia at all stages of their journey will be a gradual process. Integrating an awareness and knowledge of dementia into the broader health and social care system and into society more widely, is likewise a challenge that will require sustained attention if people with dementia are to be supported to live as well as possible and as independently as possible for as long as possible.

# Section 2: Implementation of Priority and Additional Actions

This section of the report provides additional detail on the current status, outputs, challenges and solutions, and future steps for each of the priority actions and additional actions identified in the National Dementia Strategy. Priority actions and additional actions are reported under the six Action Areas;

1. Better Awareness and Understanding;
2. Timely Diagnosis and Intervention;
3. Integrated Services, Support and Care for People with Dementia and their Carers;
4. Training and Education,
5. Research and Information Systems;
6. Leadership.

A traffic light system has been used to highlight where work to achieve an action has been delayed (red), where preliminary work has been completed (orange), where substantial work has been completed (yellow) and where an action has been achieved (green).

## Priority Action Area 1: Better Awareness and Understanding

### Priority Action

<b>Priority Action 1.1</b>	<p>Public awareness and health promotion measures will be implemented by the HSE in order to: -</p> <ol style="list-style-type: none"> <li>i) provide a better understanding of dementia in society generally;</li> <li>ii) reduce the stigma that can be associated with dementia;</li> <li>iii) target populations particularly at risk, including people with an intellectual disability;</li> <li>iv) support the implementation of Healthy Ireland (2013) by highlighting the modifiable lifestyle and cardiovascular risk factors which can beneficially impact on risk and time of onset of dementia, and by implementing the National Physical Activity Plan which will encourage the population to be more physically active.</li> </ol>
<b>Current Status</b>	<p>The Dementia: Understand Together campaign is led by the HSE (Health and Wellbeing and National Communications) in partnership with The Alzheimer Society of Ireland and Genio, working in collaboration with a range of partners from across the public, voluntary and community, and private sectors. A Steering Group was established in June 2015 to guide the development of the campaign and is comprised of key stakeholders including a family carer and a person with dementia. The Steering Group meets on a regular basis. A dedicated Campaign Manager was recruited to manage the campaign on a day-to-day basis.</p> <p>€2.7 million was allocated by The Atlantic Philanthropies and the HSE for the development and roll-out of the campaign. There has been significant additional funding and staffing committed by the HSE to give further momentum to this important work.</p> <p>The campaign is based on four key strands – evidence and insights; creative developments and media planning; partnership; and implementation and evaluation.</p>
<b>Outputs</b>	<p>An extensive research programme was undertaken during late 2015 and 2016, as follows:</p> <ul style="list-style-type: none"> <li>• A Literature Review was undertaken to gather a robust picture of the current situation nationally and internationally, the experience of previous initiatives and recommendations to inform next steps</li> <li>• A face-to-face survey was conducted with a nationally representative sample of 1,000 people to provide a baseline on public attitudes, knowledge and behaviour for the campaign</li> <li>• Qualitative research was carried out involving a series of focus groups with national experts, carers, people with dementia living in the community to gather further insights</li> </ul>

**Priority Action 1.1 (continued)****Outputs**  
(continued)

- Qualitative research was carried out involving a series of focus groups with national experts, carers, people with dementia living in the community to gather further insights
- Interviews were also undertaken with people with dementia in care.
- A Sounding Board event brought together 130 key stakeholders from across society to provide additional direction and guidance for the development of the campaign

The research programme informed a creative brief which led to the design and production of the Dementia: Understand Together campaign. The campaign was launched in October 2016 and is focussed on the following key messages -

1. *Any one of us can get dementia*
2. *Dementia – what it is and what it isn't*
3. *A lot of people in Ireland are affected by dementia and this is set to increase significantly*
4. *Every one of us can play a part in making life better for people with dementia – Everyone can make a difference*
5. *Dementia changes your life but you can live well with dementia*
6. *Keep your brain healthy at every age*

The following assets have been created, tested and produced for the campaign -

- Dementia: Understand Together campaign identity
- A suite of three television ads that tell the stories of real people with dementia
- Suite of four radio ads
- Outdoor adverts
- Social media campaign
- Resources and materials (posters, leaflets, stickers, badges etc.)
- “One-stop-shop” website with local service finder [www.understandtogether.ie](http://www.understandtogether.ie)
- Partner Programme with 35 partners from public sector, community and voluntary organisations, academia, professional bodies and private sector signed up to support the campaign
- PR programme of activities at regional and national level to communicate our key messages to key audiences

**Campaign Monitoring & Performance to Date**

The campaign is performing well across all key activities and there are positive indications of impact on knowledge and attitudes. A national survey of 1,000 people was conducted in February 2018 to assess the impact of the TV campaign in particular and to inform media planning in 2018. Key findings

- Recall of the TV ads is exceptionally high with almost two-thirds reporting that they had seen at least one of the ads. Six in ten of those who are aware of the campaign believe they have been impacted by it and will be more empathetic and understanding of people with dementia
- Progress is also seen in knowledge since the 2016 survey with an increase in the proportion of people who state they have a reasonable understanding of dementia and/or Alzheimer's (from 24% to 33%)
- More people believe that there are things you can do to reduce the risk of getting dementia (increase from 46% to 52%)
- There has been an increase in the proportion of people who believe that people with dementia can participate in a wide variety of activities and interests (from 40% to 52%)

The campaign website is performing very well with over 90,000 sessions since October 2017. There have been almost 4,000 uses of the Service Finder and over 6,700 document downloads.

The Understand Together Facebook page has over 7,000 page likes and there is very high engagement with messages, driving significant traffic to the website.

Almost 30,000 campaign resources have been distributed to date.

There has been strong national and regional media coverage of key messages since the launch of the campaign.

**Priority Action 1.1 (continued)**

<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>Changes in personnel had an impact on the planned timeline for development of some elements of the campaign, though the overall deliverables are not impacted</li> <li>An ongoing challenge for the campaign is reality of creating awareness of dementia, and therefore increasing demand for services when services are under-developed</li> </ul>	
<b>Future Plans</b>	Continued promotion of key messages through heavy weight presence of the Dementia: Understand Together Campaign across all media – TV, radio, social and PR.	Q1-Q4 2018
	The Partner Programme will continue to be strengthened, involving training of staff in key partner organisations and joint promotional activities. New partners will be identified and invited to join the campaign.	Q1 -Q4 2018
	A community activation platform is being designed to help embed the national campaign into local communities for longer term sustainability. A dedicated co-ordinator has been assigned to support the delivery of this work this year.	Q1-Q4 2018
	Quantitative and qualitative research programme will be undertaken to measure the impact of the campaign.	2019

**Additional Action**

<b>Additional Action 1.2</b>	The Department of Health and the Health Service Executive will consider how best to promote a better understanding of and sensitivity to dementia among staff of frontline public services, as part of the Health-Promoting Health Service Executive Initiative.	
<b>Current Status</b>	Dementia has been identified as a key policy area within the HSE’s Healthy Ireland Implementation Plans.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>Dementia specific actions have been included in all five Healthy Ireland Implementation Plans for Hospital Groups and all three CHO Plans published to date</li> <li>Dementia: Understand Together campaign materials were distributed to GP surgeries countrywide, all Acute Hospitals, Nursing Homes and Health Centres</li> <li>A range of training programmes and resources are available to staff on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a> and via HSeLanD</li> </ul>	
<b>Challenges and Solutions</b>	Release of staff for training is a challenge. Online training/blended training options which have been developed in collaboration with key partners provide more flexible options for up-skilling staff.	
<b>Future Plans</b>	All Healthy Ireland Implementation Plans will prioritise actions to support better understanding of dementia amongst staff.	Ongoing

**Priority Action Area 2: Timely Diagnosis and Intervention**

**Priority Actions**

<b>Priority Action 2.1</b>	The Health Service Executive will develop a National and Local Dementia Care Pathway to describe and clearly signpost the optimal journey through the system from initial presentation with worrying symptoms, through to diagnosis, including levels of intervention appropriate to need at any given time.	
<b>Current Status</b>	The development of a National and Local Dementia Care Pathways is being progressed through a number of on-going projects.	

Priority Action 2.1 (continued)

<b>Outputs</b>	<ul style="list-style-type: none"> <li>• PREPARED have published a GP specific dementia diagnostic pathway on the primary care resource website <a href="http://www.dementiaphways.ie">www.dementiaphways.ie</a></li> <li>• Dementia pathways have been developed in three acute hospital pilot sites as part of a Genio/ Atlantic Philanthropies funded project. Learning from these pilot sites will be rolled out to all acute hospitals as part of the work of the Clinical Lead for the National Dementia Strategy</li> <li>• The National Dementia Office has established a Post-Diagnostic Support Pathway Project which aims to improve the quality of life of people with dementia and family carers following a diagnosis of dementia by developing a model and approach to post-diagnostic care and support</li> <li>• The National Dementia Office has established a Dementia Diagnostic Pathway Project to establish a standardised approach to the assessment and diagnosis of dementia across primary, secondary and tertiary services</li> </ul>										
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• Challenges are anticipated around gaining consensus and buy in to adopt and implement the dementia pathways</li> <li>• Dementia is competing with other national priorities within the HSE that have to be implemented, and therefore is often not seen as a priority</li> <li>• There is no or very limited once-off funding to implement the different elements of the pathways</li> <li>• There is a lack of skilled practitioners to undertake elements of the pathways</li> <li>• The NDO are working with the National Clinical Care programmes to explore opportunities to progress this action</li> <li>• The NDO in consultation with stakeholders in the HSE &amp; Department of Health are exploring the possible inclusion of dementia care in the GP contract. This will allow GPs to be resourced to deliver proactive dementia care, a model that has been shown to improve diagnosis rates, improve prescribing habits and lead to better outcomes for people with dementia and their family carers</li> <li>• The NDO as part of the Implementation plans will undertake a skills/educational needs analysis to identify where there is a requirement for up skilling of practitioners and the development of suitable programmes</li> </ul>										
<b>Future Plans</b>	<table border="0"> <tr> <td data-bbox="352 1158 1286 1193">• Progress the individual projects as per project plans</td> <td data-bbox="1289 1158 1453 1193">Q 1-Q4 2018</td> </tr> <tr> <td data-bbox="352 1198 1286 1294">• Develop and get sign off at senior HSE Leadership level for the rollout and implementation of a dementia pathway across all acute hospitals Ensure that the Implementation plan is included in all operational plans for 2018</td> <td data-bbox="1289 1198 1453 1294">Q 1-Q4 2018</td> </tr> <tr> <td data-bbox="352 1299 1286 1429">• Progress the inclusion of Dementia in to the Chronic Disease management framework, thereby resourcing GPs to provide proactive evidence-based care which can lead to improved diagnosis rates, improved prescribing habits and better outcomes for people with dementia and their carers</td> <td data-bbox="1289 1299 1453 1429">Q1-Q3 2018</td> </tr> <tr> <td data-bbox="352 1433 1286 1498">• Roll-out of the PDS grant scheme to promote and develop cognitive therapies and psycho-educational programmes for people with dementia and family carers</td> <td data-bbox="1289 1433 1453 1498">Q1-Q4 2018</td> </tr> <tr> <td data-bbox="352 1503 1286 1568">• The NDO to provide guidance to HSCP on running PDS psycho-educational programmes for people with dementia</td> <td data-bbox="1289 1503 1453 1568">Q1-Q4 2018</td> </tr> </table>	• Progress the individual projects as per project plans	Q 1-Q4 2018	• Develop and get sign off at senior HSE Leadership level for the rollout and implementation of a dementia pathway across all acute hospitals Ensure that the Implementation plan is included in all operational plans for 2018	Q 1-Q4 2018	• Progress the inclusion of Dementia in to the Chronic Disease management framework, thereby resourcing GPs to provide proactive evidence-based care which can lead to improved diagnosis rates, improved prescribing habits and better outcomes for people with dementia and their carers	Q1-Q3 2018	• Roll-out of the PDS grant scheme to promote and develop cognitive therapies and psycho-educational programmes for people with dementia and family carers	Q1-Q4 2018	• The NDO to provide guidance to HSCP on running PDS psycho-educational programmes for people with dementia	Q1-Q4 2018
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<b>Priority Action 2.2</b>	<p>The following material will be developed and made available to GPs:-</p> <ol style="list-style-type: none"> <li>Dementia-specific reference material to broaden skills base;</li> <li>Guidance on national and local pathways to investigation and diagnosis;</li> <li>Information about health and social supports available in the local community</li> </ol>
<b>Current Status</b>	<p>PREPARED (Primary Care Education, Pathways and Research of Dementia) was established in May 2015 with a remit to develop resources to meet Priority Action 2.2 (i-iii). The PREPARED project office is based in UCC, and has developed a range of dementia education, guidance and information resources for GPs, as outlined below. The PREPARED project has benefitted from funding of €1.2 million from the AP/HSE/DOH National Dementia Strategy Implementation Programme</p>

Priority Action 2.2 (continued)

<b>Outputs</b>	<ul style="list-style-type: none"> <li>Learning needs assessment conducted with GPs, people with dementia and family carers to inform the content of primary care educational and training packages. Available at <a href="https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0639-8">https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0639-8</a></li> <li>Development of two 1-hour dementia workshops for GPs;                             <ul style="list-style-type: none"> <li>– Diagnosis and Post Diagnostic Support,</li> <li>– Behavioural and Psychological Symptoms of Dementia</li> </ul>                             Workshops delivered nationally by GP facilitators. As of April 2018, 228 GPs have attended workshop one and 164 GPs have attended workshop two                         </li> <li>GP workshops delivered nationally through the GP small group continuing medical education (CME) programme. Approximately 235 GPs and practice staff have received training as of April 2018</li> <li>In conjunction with the ICGP and the Dementia Elevator project, 2 online e-learning modules have been developed. A total of 494 GPs have completed the online modules at the time of this review</li> <li>UCC accredited GP Post-Graduate CPD module on dementia developed. 19 GPs completed the course in 2017/2018</li> <li>Clinical guidance and resources collated and developed, and available on the PREPARED website, <a href="http://www.dementiopathways.ie">www.dementiopathways.ie</a></li> <li>A comprehensive database and description of supports and services available in the community across the country is available on the PREPARED website, <a href="http://dementiopathways.ie">dementiopathways.ie</a></li> <li>Review and update of ICGP clinical guidance document “Dementia: Diagnosis and Management in General Practice” (Foley, T &amp; Swanwick, G: 2014), available at <a href="https://www.icgp-education.ie/dementia/resources/ICGP_QIP_DementiaJuly2014[1].pdf">https://www.icgp-education.ie/dementia/resources/ICGP_QIP_DementiaJuly2014[1].pdf</a></li> </ul>								
<b>Challenges</b>	<p>Securing the engagement of GPs and General Practice staff to undertake the training has been an ongoing challenge to fully achieving priority action 2.2. A range of incentives have been identified to encourage GPs to engage; including offering the training on-site in the GP practice at a time suitable to the GP, and accrediting the workshops for both GMS study leave and for CPD points</p> <ul style="list-style-type: none"> <li>Providing in-practice workshops free-of-charge on an on-going basis will not be sustainable without further investment, but the development of small group CME material and on-line modules will ensure GPs continue to have access to the education material</li> <li>Additional funding will be needed for the ongoing management and updating of the education resources and the website post April 2019</li> </ul>								
<b>Future Plans</b>	<table border="0"> <tr> <td>• Full suite of on-line education resources developed</td> <td>Ongoing</td> </tr> <tr> <td>• Clinical Guidance document “Dementia: Diagnosis and Management in General Practice” revised</td> <td>Q2 2018</td> </tr> <tr> <td>• Facilitation of GP Post-Graduate CPD Module on Dementia by UCC, with 20 GPs to be enrolled for 2018/19 course</td> <td>Ongoing</td> </tr> <tr> <td>• Promotion of availability of small group CME dementia resources</td> <td>Ongoing</td> </tr> </table>	• Full suite of on-line education resources developed	Ongoing	• Clinical Guidance document “Dementia: Diagnosis and Management in General Practice” revised	Q2 2018	• Facilitation of GP Post-Graduate CPD Module on Dementia by UCC, with 20 GPs to be enrolled for 2018/19 course	Ongoing	• Promotion of availability of small group CME dementia resources	Ongoing
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• Promotion of availability of small group CME dementia resources	Ongoing								

<b>Priority Action 2.3</b>	The Health Service Executive will develop guidance material on the appropriate management of medication for people with dementia, and in particular on psychotropic medication management, and make arrangements for this material to be made available in all relevant settings, including nursing homes.
<b>Current Status</b>	A national interdisciplinary steering group has been convened to bring together key stakeholders necessary to develop “Clinical Guidelines for the Appropriate Prescribing of Psychotropic Medication in People with Dementia”. The Steering committee is co-chaired by Dr Suzanne Timmons, Clinical Lead for Dementia with the National Dementia Office and Professor Stephen Byrne, Head of the School of Pharmacy, UCC.
<b>Outputs</b>	<ul style="list-style-type: none"> <li>National Steering Group convened.</li> <li>Draft project plan developed.</li> </ul>
<b>Challenges and Solutions</b>	The national steering group has been convened to ensure there is consensus and engagement with all key stakeholders.

Priority Action 2.3 (continued)

<b>Future Plans</b>	<ul style="list-style-type: none"> <li>The Steering group will develop evidence based guidelines for health care professionals to guide the use of psychotropic medications in people with dementia. Psychotropic medications include antidepressants, benzodiazepines, anticonvulsants (when not used to control seizures), and antipsychotics. Of these, antipsychotics are a particular focus of the planned guidelines</li> </ul>	Q4 2018
	<ul style="list-style-type: none"> <li>The steering group will also develop simple guidance notes for healthcare professionals on medication use in dementia in general, focussing on the need for regular review and prioritisation of medications to avoid excessive medication burden</li> </ul>	Q3 2018
	<ul style="list-style-type: none"> <li>The guidelines will be submitted to the National Clinical Effectiveness Committee to be implemented as National Clinical Guidelines</li> </ul>	Ongoing
	<ul style="list-style-type: none"> <li>The steering group will also develop an associated psychotropic medication audit tool and education/training materials in parallel with development of guidelines</li> </ul>	Q4 2018

<b>Priority Action 2.4</b>	Modifiable lifestyle risk factors, such as tobacco and alcohol use and physical inactivity, should be actively managed as part of the care plan for people with dementia.	
<b>Current Status</b>	Information on modifiable risk factors and reference to the Hello Brain resources ( <a href="http://www.hellobrain.eu/en">www.hellobrain.eu/en</a> ) are available on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a> and are included in the education resources developed through the PREPARED project for Primary Care Teams. Work underway for the post-diagnostic pathway projects will also address information available on modifiable lifestyle risk factors.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>Information resources on brain health and modifiable risk factors available on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> <li>Modifiable risk factors addressed in the education resources developed for Primary Care Teams through the PREPARED project</li> <li>A review of information resources currently being undertaken to identify gaps in information provision</li> </ul>	
<b>Challenges</b>	<ul style="list-style-type: none"> <li>It has been necessary to ensure that all information and messaging around modifiable risk factors is in keeping with emerging evidence on same. Current evidence is based on group data, with little robust evidence on individual risk. All information developed is cognisant of the complexity of this area</li> </ul>	
<b>Future Plans</b>	<p>Complete a review of information resources</p> <ul style="list-style-type: none"> <li>Address the information needs of people with dementia and family carers on modifiable risk factors as part of the development of a suite of information resources through the Post-diagnostic Support Pathway Project</li> <li>There is also potential to include brain health and risk reduction in the development of post-diagnostic cognitive programmes as part of the same project</li> <li>Include information on modifiable risk factors in all new educational programmes being developed or reviewed and updated</li> <li>Progress with the relevant stakeholders in the HSE &amp; Department of Health the inclusion of Dementia in the Chronic Disease framework</li> </ul>	<p>Q1-Q3 2018</p> <p>Q1-Q3 2018</p> <p>Q1-Q4 2018</p> <p>Ongoing</p> <p>Q3-Q4 2018</p>

<b>Priority Action 2.5</b>	The Health Service Executive will review existing service arrangements so as to maximise the access that GPs and acute hospital clinicians have to specialist assessment and diagnosis of dementia, including Old Age Psychiatry, intellectual disability services, geriatric medicine, neurology services and memory clinics.	
<b>Current Status</b>	The National Dementia Office has established a Dementia Diagnostic Pathway Project to establish a standardised approach to the assessment and diagnosis of dementia across primary, secondary and tertiary services.	



Priority Action 2.5 (continued)

<b>Outputs</b>	<ul style="list-style-type: none"> <li>Review of Memory Clinics (HSE and HSE funded) conducted in February 2017</li> <li>National Steering Group established with representation from Old Age Psychiatry, Intellectual Disability Services, Geriatric Medicine, Neurology and Memory Clinics</li> </ul>								
<b>Challenges</b>	<ul style="list-style-type: none"> <li>Resources will be required to establish and develop memory clinics to provide an equitable timely service for the assessment and diagnosis of dementia in Ireland. Efforts will be undertaken to ensure that the potential of existing diagnostic services is maximised</li> </ul>								
<b>Future Plans</b>	<table border="0"> <tr> <td> <ul style="list-style-type: none"> <li>Conduct a literature review to identify international best practice and diagnostic pathways.</li> </ul> </td> <td>Q2 2018</td> </tr> <tr> <td> <ul style="list-style-type: none"> <li>Conduct a scoping exercise to identify current diagnostic processes and practices in Ireland</li> </ul> </td> <td>Q2-Q3 2018</td> </tr> <tr> <td> <ul style="list-style-type: none"> <li>Based on the available evidence, develop guidance on appropriate diagnostic pathways nationally, and the establishment of standardised diagnostic and assessment services, cognisant of the need to maximise current resources and services.</li> </ul> </td> <td>Q4 2018</td> </tr> <tr> <td> <ul style="list-style-type: none"> <li>Guidance and costings on additional resources necessary to implement a standard diagnostic pathway for people with dementia.</li> </ul> </td> <td>Q1 2019</td> </tr> </table>	<ul style="list-style-type: none"> <li>Conduct a literature review to identify international best practice and diagnostic pathways.</li> </ul>	Q2 2018	<ul style="list-style-type: none"> <li>Conduct a scoping exercise to identify current diagnostic processes and practices in Ireland</li> </ul>	Q2-Q3 2018	<ul style="list-style-type: none"> <li>Based on the available evidence, develop guidance on appropriate diagnostic pathways nationally, and the establishment of standardised diagnostic and assessment services, cognisant of the need to maximise current resources and services.</li> </ul>	Q4 2018	<ul style="list-style-type: none"> <li>Guidance and costings on additional resources necessary to implement a standard diagnostic pathway for people with dementia.</li> </ul>	Q1 2019
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Additional Actions

<b>Additional Action 2.6</b>	The Health Service Executive will implement the National Consent Policy (Health Service Executive – May 2013).
<b>Current Status</b>	The National Consent has been signed off and is being implemented across the HSE services. The NDO continues to support the implementation of the policy.

<b>Additional Action 2.7</b>	The Health Service Executive will promote an awareness of the Assisted Decision-Making (Capacity) Bill, when enacted, to ensure that people with dementia are supported to participate in all decisions that affect them, according to their will and preference.
<b>Current Status</b>	<p>The Assisted Decision Making (Capacity) Act 2015 is relevant to all health and social care services and is about supporting decision making and maximising a person’s capacity to make decisions. The HSE has established a National Steering Group which includes staff, service users and expert advisers. It is preparing national guidance for staff on what the Act will mean for day to day practice. The group is also preparing a training and education programme to support staff and services to use the Act in their everyday work.</p> <p>Part 8 of the Act, which has yet to be fully commenced, provides a legislative framework in Ireland confirming the validity of Advance Healthcare Directives (AHD). An AHD is a statement made by a person with capacity setting out his or her will and preferences regarding treatment decisions that may arise in the future when he or she no longer has capacity.</p> <p>Under section 91 of the Act, which was commenced on 17 October 2016, the Minister for Health established a multidisciplinary working group to prepare a detailed series of recommendations for the Director of the Decision Support Service, in relation to a code of practice for the AHD provisions. The Director will subsequently prepare a code of Practice and will submit it to the Minister for Health for approval and, with the Minister’s consent, the Director will then publish the code of practice. The preparation of the code of practice will facilitate the subsequent commencement of Part 8 of the Act, pertaining to AHDs, in its entirety. A targeted consultation on the draft Code of Practice is taking place from 6 March to 4 May 2018.</p> <p>The National Dementia Office (NDO) is promoting the principles and ethos of the Assisted Decision-Making Act across activities and projects.</p>
<b>Outputs</b>	<ul style="list-style-type: none"> <li>NDO submission on the HSE Assisted Decision-making Guide for Health and Social Care Professionals</li> <li>Issues around assisted decision-making included in the NDO submission to the Department of Health Home Care Review</li> </ul>

Additional Action (continued)

<b>Additional Action 2.8</b>	The Health Service Executive will consider the provision of Dementia Advisers on the basis of the experience of demonstrator sites, with an appropriate number of such Advisers to be dedicated to the needs of those with early-onset dementia.	
<b>Current Status</b>	As of August 2017 there are eight Dementia Adviser Services across Ireland, covering 14 counties (full or partial county coverage). Seven of these services are delivered by the Alzheimer Society of Ireland and funded through the HSE, while one is run by Community Action on Dementia in Mayo. An evaluation of the Dementia Adviser Service is commencing September 2017 to inform the future development of the Service.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• Tender process for evaluation of Dementia Adviser Service complete</li> <li>• Service Level Agreement in place with UCC for completion of evaluation</li> <li>• Dementia Adviser Evaluation working group established</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• A number of issues arose which led to a delay in the Dementia Adviser Evaluation commencing, including securing three quotes for the evaluation and challenges in securing ethical approval for data collection nationally. The National Dementia Office has worked closely with the relevant HSE departments and external ethical committees to overcome these challenges and progress this work</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>• Final report completed</li> <li>• Guidance for development of Dementia Adviser service</li> </ul>	<p>Q2 2018</p> <p>Q2 2018</p>

<b>Additional Action 2.9</b>	The Health Service Executive will examine the issues arising regarding the assessment of those with Down Syndrome and other types of intellectual disability given the early age of onset of dementia for these groups and the value of establishing a reliable baseline.	
<b>Current Status</b>	<p>Personnel from the National Dementia Office (NDO) made a site visit to a well-established assessment and diagnostic service for people with intellectual disabilities. They explored issues around screening, on-going assessment, diagnostic services, post-diagnostic support for the person, their families and other residents, and discussed challenges and opportunities for expanding this type of service to other locations. There is representation from Intellectual Disability Services on both the diagnostic and post-diagnostic support projects being led by the NDO.</p> <p>The Understand Together Campaign is currently working with Down Syndrome Ireland to develop information material on dementia and Down Syndrome, while PREPARED are in discussion with Intellectual Disability Services to develop clinical resource material for GPs and Primary Care Teams.</p>	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• Professor Mary Mc Carron (TCD) is working in partnership with PREPARED to develop appropriate resources for GPs and Primary Care Teams</li> <li>• Representatives from Intellectual Disability Services are part of the Steering Committees for both the Post-Diagnostic Support Pathway Project and the Dementia Diagnostic Project</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• Progress has been very slow in establishing a working group to progress areas for development due to competing with other high priority issues within the ID sector. However the NDO and HSE Social Care Division are developing a project plan to progress priorities within the ID sector</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>• Information and education resources on dementia and Down Syndrome to be developed as part of PREPARED and the Understand Together campaign</li> <li>• Explore options for additional project support to the NDO to progress ID Dementia specific actions identified in the NDS not addressed/progressed to date</li> <li>• Examine the evidence that the TILDA Intellectual Disability Supplement data can provide on dementia prevalence, service usage, outcomes, etc. for people with intellectual disabilities</li> </ul>	<p>Q3 2018</p> <p>Q2-Q3 2018</p> <p>Q3 2018</p>

## Priority Action Area 3: Integrated services, support and care for people with dementia and their carers

### Priority Actions

<b>Priority Action 3.1</b>	<p>The Health Service Executive will critically review health and personal social services for people with dementia to:-</p> <ul style="list-style-type: none"> <li>• identify gaps in existing provision, and</li> <li>• prioritise areas for action in accordance with resource availability, with priority being given to the most urgent deficits that can be addressed either within or by reconfiguring existing resources</li> </ul>	
<b>Current Status</b>	<p>In 2016 the National Dementia Office (NDO) and the Alzheimer Society of Ireland committed to undertake a mapping project to identify dementia-specific community based supports and services across the country. It involved (i) a rapid scoping exercise to identify the appropriate model/approach (ii) development of an on-line data collection tool (iii) establishment of a key stakeholder list e.g. identifying key knowledge holders at a local level (iv) data collection (v) analysis (vi) write-up and (vii) a process of verification. Also, as part of the project, a national advisory group was established.</p> <p>The project concluded in October 2017 and a final report has been completed. Information contained in the report is informing future service development and planning, and has been used to inform a service finder hosted on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a>.</p>	
<b>Outputs</b>	<p>Final report of the mapping project available on HSE and ASI websites</p> <ul style="list-style-type: none"> <li>• CHO specific analysis presented to key personnel in each region to progress service planning and development related to dementia specific supports and services</li> <li>• Service finder live on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a>, allowing people to search for dementia specific community services in their area</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• The project was dependent on the quality of the data that was returned from local stakeholders and as a result there may be gaps in the information provided. During meeting with each CHO area the NDO will request additional information and a national verification process of received data is being undertaken three times a year.</li> <li>• The project only addressed dementia-specific community-based services and supports. There are generic services that people with dementia and their families use which were not captured in the project. The NDO through the HRB Applied Partnership Award are working with the Centre for Economic and Social Research on Dementia (CESRD) in NUI Galway to identify dementia appropriate services. The NDO is also feeding into the HSE's wider audit of day care services and respite care to gather information on people's with dementia's use of these generic services.</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>• NDO developing needs analysis framework to support local dementia service planning and development</li> <li>• Collaboration with CESRD to identify range of dementia appropriate services available nationally</li> <li>• Verification of received data on dementia-specific services to be undertaken throughout the year and the <a href="http://www.understandtogether.ie">www.understandtogether.ie</a> on-line service finder to be updated</li> </ul>	<p>Q1-Q2 2018</p> <p>Q1-Q4 2018</p> <p>Ongoing</p>

Priority Actions (continued)

<b>Priority Action 3.2</b>	The Health Service Executive will consider how best to configure resources currently invested in home care packages and respite care so as to facilitate people with dementia to continue living in their own homes and communities for as long as possible and to improve the supports available for carers.	
<b>Current Status</b>	The HSE introduced Intensive Home Care Packages (IHCPs) in Q4 2014 to test the feasibility of providing a high level of support to people with dementia with complex needs to facilitate them to remain living at home. Funding of €22.1 million was allocated from the Atlantic Philanthropies/HSE/ Department of Health National Dementia Strategy Implementation Programme. Genio was tasked with supporting the HSE to develop indicators to monitor the IHCPs and to undertake an evaluation of the effectiveness of IHCPs for people with dementia. Initial findings & ongoing evaluation are being shared with the HSE and DOH to inform service development and review for home care	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• A suite of indicators to monitor the quality and delivery of IHCPs and a data collection tool have been developed and implemented. Data relevant to each indicator is collected and analysed routinely</li> <li>• A mixed-method multi-participant evaluation of the IHCPs is currently ongoing</li> <li>• Emerging findings from data collection tool and evaluation indicate that:             <ul style="list-style-type: none"> <li>- At the end of February 2018, 309 people with dementia have benefitted from an IHCP, with 148 currently active</li> <li>- The main reasons for packages being ceased were that the person was deceased (53%) or had been admitted to a residential care centre (40%)</li> <li>- IHCPs are being delivered to people with a range of needs, and are reaching those at a higher risk of placement in long-term care</li> <li>- IHCPs provide an average of 40 hours per week with a weekly marginal cost of €929</li> <li>- There is further scope to reconfigure dementia-IHCPs so that they are individually tailored to the assessed needs and preferences of a diverse range of people with dementia and their families</li> </ul> </li> </ul> <p>Genio programme managers are working in eight pilot sites around the country to support the development of integrated working processes that enable IHCPs to deliver flexible, personalised care to people with dementia. This work involves mapping of existing formal and community/informal assets, and mapping of the local IHCP process. In collaboration with key stakeholders a pathway is developed that incorporates a range of effective support options including in home supports, flexible non-institutional respite, and a crisis-response model. The resulting pathways are being tested and implemented locally</p>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• Additional work is needed to support the implementation of personalised IHCPs, ensuring that local pathways and processes support the delivery of flexible individualised care. Genio are currently supporting the HSE to develop local dementia care pathways and processes and guidance on delivering personalised supports in eight pilot sites to help overcome this challenge</li> <li>• The complexity of the healthcare system has presented a challenge in developing a standard reliable data collection tool for IHCPs across the country. Involving staff at local level in the development of the IHCP workbook and establishing systems for feedback on the system has helped support the return of robust data</li> <li>• While review questionnaires are a key part of the IHCP data collection tool, questionnaires have been completed by only one quarter of dementia-IHCP recipients. Workload, time constraints and the large number of key workers assigned to IHCPs around the country are some of the reasons for the difficulty in collecting this information. To address this challenge, the review questionnaire has now been included as an Appendix in the SOP</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>• Ongoing review and analysis of data from IHCP workbook</li> <li>• Learning from the development of IHCP pathways in the eight pilot sites will be disseminated to all relevant HSE personnel</li> <li>• Completion of data collection for the evaluation of the effectiveness of IHCPs and presentation of final report</li> </ul>	<p>Ongoing</p> <p>Q4 2018</p> <p>Q3 2018</p>

Priority Actions (continued)

<b>Priority Action 3.3</b>	The Health Service Executive will evaluate the potential of assistive technology to provide flexible support both to carers and to people with dementia.	
<b>Current Status</b>	In 2016 HSE Services for Older Persons, through the Department of Health, secured €300,000 from Dormant Accounts to facilitate the expansion and use of Assistive Technology (AT) for older persons, in particular people with dementia. Following a scoping exercise it was decided to replicate a model based on the South Tipperary Memory Technology Library (MTL) in each CHO area. A project manager was nominated in each CHO area and a “Memory Technology Resource Room” Network has been established, chaired by the NDO, to share learning and provide peer support nationally. In 2017 a further €300,000 was secured to recruit part-time staff to establish and run the resource rooms for a time-limited period of one year. These staff will also up-skill multidisciplinary team members in the appropriate use of the MTRR resources.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• Funding secured through Dormant Accounts</li> <li>• Scoping exercise on existing assistive technology services nationally completed</li> <li>• Project Managers nominated in each CHO Area</li> <li>• National standard Assistive Technology equipment database established.</li> <li>• National tendering process for purchasing of equipment complete in partnership with the National Procurement Office. Equipment to be delivered Q4 2017</li> <li>• Training on AT delivered to 30 staff</li> <li>• Memory Technology Resource Room Network established</li> <li>• Recruitment process for 0.4WTE MTRR staff initiated</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• Funding secured through Dormant Accounts has ensured that the MTRRs have the Assistive Technology resources required, and that the rooms have the staffing required to establish the services</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>• That 0.4WTE staff would be recruited for a one-year period to run each MTRR nationally</li> </ul>	Q1-Q2 2018

<b>Priority Action 3.4</b>	In line with the health promoting health service model, the Health Service Executive will ensure that information on how to access advocacy services, voluntary organisations and other support services is routinely given to people with dementia and their families/ carers.	
<b>Current Status</b>	In order to meet the need for a centralised point of information for people with dementia and their families, the website <a href="http://www.understandtogether.ie">www.understandtogether.ie</a> was developed by the HSE in partnership with the Alzheimer Society of Ireland and Genio. The website provides information on dementia, signposts to additional resources and hosts a service finder, which allows people to search for dementia specific services in their area. Additional information materials were developed through the Understand Together campaign and distributed nationally. The importance of advocacy and information on support services is also incorporated into the training developed for GPs and Primary Care Teams (as detailed under priority actions 2.2 and 4.1).	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• Development and launch of <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> <li>• Development and roll-out of GP and Primary Care Team education</li> <li>• Distributions of information leaflets, posters and info-graphics to GPs, Health Centres, Acute Hospitals and Residential Care Centres nationally.</li> <li>• National Dementia Office supported the revision of an information leaflet on memory clinics published by DSIDC</li> <li>• Development of on-line service finder which includes information on voluntary and community services and supports for people with dementia and their families</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• In order to ensure that the information available on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a> continues to be relevant and correct, a part-time dedicated staff resource is needed. The provision of this resource is currently being negotiated with HSE Digital and HSE Older Persons Services</li> <li>• In order to reduce confusion for the end user, it is essential that the information available on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a> does not conflict with information available on partner websites, e.g. <a href="http://www.alzheimer.ie">www.alzheimer.ie</a>, <a href="http://www.dementia.ie">www.dementia.ie</a> and <a href="http://www.dementiapathways.ie">www.dementiapathways.ie</a>. Close working relationships with all partner organisations have been established and opportunities for collaboration explored</li> </ul>	

**Priority Action 3.4 (continued)**

<b>Future Plans</b>	• NDO and CESRD to collaborate in carrying out a review of dementia good practice initiatives nationally	Q3 2018
	• Review of information available on service finder	Ongoing
	• Review and development of www.understandtogether.ie website	Ongoing
	• Continually engage with people with dementia and families to ensure the information on www.understandtogether.ie is relevant, current and sufficient	Ongoing

**Additional Actions**

<b>Additional Action 3.5</b>	Subject to overall Government priorities, the Department of Health will as soon as possible formulate proposals and timelines for the regulation of home and community care services for older people.	
<b>Current Status</b>	<p>The Department of Health is currently engaged in the development of a new statutory scheme for the financing and regulation of home care services.</p> <p>The statutory scheme for home care will introduce clear rules in relation to what services individuals are eligible for and how decisions are made on allocating services. For that reason, developing a new statutory scheme will be an important step in ensuring that the system operates in a consistent and fair manner for all those who need home care services. It will also help to improve access to the home care services that people need, in an affordable and sustainable way. The system of regulation for home care will help to ensure that the public can be confident that the services provided are of a high standard.</p> <p>The new statutory home care scheme will not be developed in isolation. It will be designed to complement and integrate effectively with other health and social care services such as long term residential care (including the Nursing Homes Support Scheme), primary and community services as well as hospital services.</p> <p>The new scheme will also be developed in the context of relevant existing policies such as the Sláintecare Report, the National Carers Strategy, the National Positive Ageing Strategy and the National Dementia Strategy, among others. Work currently underway such as the development of new community nursing services and the Task Force on Personalised Budgets in the disability sector will also be considered.</p>	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• The Department of Health commissioned the Health Research Board to undertake an evidence review of the home care systems that are in place in four other European countries. The evidence review was published on 11th April 2017 and concludes that there are several principles included in regulated home care such as standards, transparency, consultation, choice, equity, and sustainability. These principles are implemented through legislation, policy, strategy, service planning and financing</li> <li>• A public consultation on home care services was launched on 6th July 2017 and closed on 2nd October 2017. Its purpose was to allow all those who have views on this topic to have their say, including service users, their families, and healthcare workers. Approximately 2,600 submissions were received and a report of the findings of this consultation process will be published in May 2018. The findings will be used by the Department in the development of the new home care scheme</li> </ul>	
<b>Challenges and Solutions</b>	The development of a new home care scheme is a complex undertaking which will involve significant legislative, operational and financial resources. A significant amount of detailed work remains to be undertaken before final decisions are taken on the form of a home care scheme and the regulation of these services. This is required if reforms are to be successful, affordable and sustainable.	
<b>Future Plans</b>	Next steps for 2018 include:	
	• Publication of the findings of the consultation process	Q2 2018
	• Continuation of the work on the development of the new scheme	Ongoing
	• Further consultation with service users	Q4 2018

**Additional Action (continued)**

<b>Additional Action 3.6</b>	The Health Service Executive will ensure that the carer assessment component of the Single Assessment Tool (SAT) is used to enable the provision of more targeted supports to carers at an individual level and to enable better planning of services and supports for carers at a national level.	
<b>Current Status</b>	The HSE through the Single Assessment Project (SAT) is progressing the development of a Carer Needs Assessment (CNA). An international pilot (Ireland being one of the 9 countries) of a draft assessment was completed in March 2017 and data was analysed. The final Carer Needs Assessment was signed off in Q4 2017 with a view to international implementation thereafter.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• Carer Needs Assessment development incorporated into SAT Project's Atlantic Philanthropies grant application and approval</li> <li>• Family Carer Reference Group membership established with representation from: The Carers Association; Care Alliance Ireland; Caring for Carers; Crosscare and RehabCare. Overall representing a national network of over 200 Carer Groups across Ireland</li> <li>• A literature review completed and various drafts (7 in total) of the CNA were developed, with assessment questions being reviewed within the international CNA Working Group</li> <li>• CNA Scoping Exercise (2015) was conducted in Ireland and Belgium to test the assessment items prior to a large scale pilot study</li> <li>• Proceeded to international pilot in 2016</li> <li>• Royal College of Practitioners of Ireland (RCPI) Research Ethics Committee (REC) approval for piloting in Ireland</li> <li>• Carer Recruitment; Potential study participants (Carers of an Older Person) were identified through the Family Carer Reference Groups' (FCRG) respective organisations. Lists of potential carer participants were drawn up by the FCRG for each study area and combined with lists of potential carer participants from HSE service lists. A random selection of carers (n=50) and their older people care recipients (n=50) were retrieved and participants numbers attained</li> <li>• Data collection and analysis of the pilot study completed</li> <li>• Final tool signed off by member states &amp; interRAI ISD committee &amp; release as a Beta Instrument – self report or clinician assisted Carer Needs Assessment (C.N.A.) for International use Q4 2017</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• Carer needs assessment successfully completed. Roll out of the Carer Needs Assessment will be resource dependent. Meeting the needs identified through the assessment process is likely to generate additional demand for services</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>• International implementation in interRAI countries is proceeding.</li> <li>• Ireland will pilot the C.N.A in 2018 in a CHO across all care groups</li> </ul>	<p>Ongoing Q4 2018</p>

**Priority Actions**

<b>Priority Action 3.7</b>	The Health Service Executive will develop and implement a dementia and delirium care pathway, which could be fitted to existing acute, rehabilitative, care of older people, stroke, mental health, palliative care and end-of-life care pathways, to be developed and implemented on a local level in each acute hospital.	
<b>Current Status</b>	<p>A delirium algorithm has been developed for implementation in the Emergency department (ED) sector and approved by the Clinical Strategy and Programmes Division, although not yet in clinical use. A linked delirium algorithm (with training slides, practice support document and implementation plan) has been developed for acute hospital wards through the National Clinical Programme for Older People, with input from the National Dementia Office. It is awaiting approval at senior level in the HSE.</p> <p>Work has begun by the National Clinical Lead on the development of a national dementia care pathway for acute hospitals, drawing heavily on the work undertaken at the three Genio/Atlantic Philanthropies funded demonstrator sites (St James Hospital, Mercy University Hospital and Connolly Hospital) and the emerging evaluation reports.</p>	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• Delirium pathway and algorithm developed and signed off for the ED</li> <li>• Delirium pathway for acute hospital wards developed</li> <li>• Dementia pathways developed in three acute demonstrator sites</li> <li>• New delirium pathway has been incorporated into the National Dementia Education programme for acute hospitals - programme currently available across 14 hospitals with plans to expand to all acute hospitals in 2018</li> </ul>	

Priority Action 3.7 (continued)

<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>Implementation of the delirium pathway for acute hospital wards is still awaiting approval and actioning of the implementation plan. Planned discussions with National Clinical Programme for Older Persons (NCPOP)/Integrated Care Programme for Older People (ICPOP) and Acute Hospital Division to try to progress this through existing and developing acute hospital models and clinical roles</li> <li>Buy in from staff for the use of the ED delirium algorithm has been challenging due to competition with other assessment processes in ED and lack of implementation action. Incorporation into the National Dementia Education programme for acute hospitals will help inform staff of the risk of delirium and prime them for change once implementation is actioned</li> </ul>
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>Negotiation for inclusion of National Dementia Education programme for acute hospitals in acute hospital operational plans for 2018</li> <li>Develop national dementia pathway for acute hospitals</li> </ul>
	<p style="text-align: right;">Q4 2017</p> <p style="text-align: right;">Q1-Q4 2018</p>

<b>Additional Action 3.8</b>	The Health Service Executive will assign responsibility in its own facilities, and elsewhere will encourage the assignment of responsibility to, a senior clinician within each hospital to lead the development, implementation and monitoring of the pathway.	
<b>Current Status</b>	<p>A Dementia Clinical Nurse Specialist (CNS) role was developed in 2017, accompanied by a comprehensive job description which was developed by the National Dementia Office (NDO) with the aid of personnel from the Nursing and Midwifery Planning and Development Unit and expert input from a range of clinical stakeholders. While the role was developed for acute care settings, progress has been made to expand it also into an integrated role. A business case template was developed by the NDO to aid local services to make a case for additional funding to secure the financing for a CNS Dementia post. In 2017 three CNS dementia appointments were made in; Sligo Regional Hospital (integrated), The Mater Hospital and Connolly Hospital</p> <p>Advanced Nurse Practitioners (ANP) posts have recently been approved for Acute &amp; Community services. The ANP will have a significant leadership role in supporting and leading the implementation of the pathway across the care continuum.</p>	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>Comprehensive CNS job description developed</li> <li>Business case template developed</li> <li>Appointment of three CNS in Dementia</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>An ongoing challenge is that there is no allocated budget for the role and local services have to campaign for funding to secure the post in their service. In an attempt to address this, the NDO drafted a business case template that can be adapted to local contexts</li> <li>A National Nurse Lead for Dementia has taken up post in the ONMSD to work with the NDO &amp; services on the development of new Nurse specialist posts in dementia</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>The NDO to champion this role and support services in the development of new posts</li> <li>The NDO working with the Office of Nursing and Midwifery Service Director (ONMSD) in progressing new CNS roles within each of the acute hospitals, making representation to senior management with each of the Hospital Groups</li> <li>The Clinical Lead with the NDO will work closely with the Integrated Care Programme (ICPOP) and National Clinical Programme (NCPOP) teams to progress and evaluate progress in this area</li> </ul>	<p style="text-align: right;">Ongoing</p> <p style="text-align: right;">Ongoing</p> <p style="text-align: right;">Ongoing</p>

<b>Additional Action 3.9</b>	Hospitals will be required to ensure that people with dementia have a specific pathway through Emergency Departments and Acute Medical Units that is appropriate to their particular sensory and psychosocial needs.	
<b>Current Status</b>	Dementia pathways have been developed in three acute hospital pilot sites as part of a Genio/Atlantic Philanthropies funded project. Learning from these pilot sites will be rolled out to all acute hospitals as part of the work of the National Dementia Office (NDO) Clinical Lead. This work will also be informed by the Universal Design guidelines currently being developed (additional information under Priority Actions 3.10 and 3.11)	



Additional Action 3.9 (continued)

<b>Outputs</b>	<ul style="list-style-type: none"> <li>Dr. Suzanne Timmons appointed as Clinical Lead with the NDO in October 2017. Her role is to support and advise on the implementation of the actions in the NDS with particular focus on leading and developing dementia care across care divisions and relevant clinical care programmes</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>Originally the National Clinical Advisory Care Group Lead (Consultant Geriatrician) provided support to the National Dementia Office. In 2017 the HSE decided additional clinical support was needed, which led to the appointment of Dr. Timmons</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>Publication of report of the work undertaken in the three acute hospital pilot sites</li> <li>Publication of 'Dementia Friendly Hospitals from a Universal Design Approach' guidelines</li> <li>Steering committee established to roll-out dementia pathways in all general hospitals</li> </ul>	<p>Q4 2018</p> <p>Q2 2018</p> <p>Q3 2018</p>

<b>Additional Action 3.10</b>	The Health Service Executive will develop guidelines on dementia-friendly ward specification to be taken into account at the design stage of all refurbishments and new builds. Elements to be considered should include safe walking spaces and the use of colour, lighting, signage, orientation cues and space used to promote social interaction.	
<b>Current Status</b>	In 2015 Tallaght Hospital (AMNCH) and TrinityHaus (TCD) were awarded funding by the Health Research Board (HRB) as part of the Applied Research Project in Dementia programme. This project is examining key issues around the design of dementia friendly hospitals in Ireland, and will produce Dementia Friendly Hospital Design Guidelines based on the available evidence. A Design Brief for Residential Care Settings has been developed by the HSE and is available on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a>	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>Publication of "Dementia Design Brief for Residential Care" on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> <li>Steering committee established and comprehensive stakeholder engagement process completed for development of "Dementia Friendly Hospital Design Guidelines"</li> <li>Development of Dementia Friendly Hospital Website; <a href="http://trinityhaus.tcd.ie/dementiafriendlyhospitals">http://trinityhaus.tcd.ie/dementiafriendlyhospitals</a></li> <li>Literature review on international best practice completed</li> <li>Research with three acute hospital pilot sites completed</li> <li>Preliminary findings presented at national and international conferences</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>Due to the complexity and scale of many acute general hospitals, coupled with the demands on staff and the vulnerability of patients engaging with relevant staff members, patients and family members as part of the research process has been challenging. Key project members, in their role as active hospital staff, have supported the research process, which has allowed the project team gain high quality access to all parts of the hospital and to key patients, carers, and staff (including clinical, management, and technical services)</li> <li>Due to cognitive impairment and the often-complex relationships with family members / accompanying persons (which for various reasons can sometimes constrain the voice of a person with dementia), it can be difficult to obtain direct feedback regarding the needs and preferences of certain patients. This can be particularly difficult in a busy hospital setting where illness is also a consideration. Through relationships built-up with key staff members, the careful selection of participants and appropriate timing of engagement in quiet and private spaces within the hospital, the research team have been able to conduct productive and relaxed interviews with a large number of patients and family members</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>Publication of Key Research Findings Report on dementia design in acute hospitals</li> <li>Publication of Dementia Friendly Hospital Design Guidelines</li> <li>The National Dementia Office to engage with HSE estates to ensure full implementation and incorporation of "Dementia Friendly Hospital Design Guidelines" and "Dementia Design Brief for Residential Care" in all refurbishments and new builds</li> </ul>	<p>Q2 2018</p> <p>Q2 2018</p> <p>Ongoing</p>

Additional Action (continued)

<b>Additional Action 3.11</b>	Hospitals will prioritise the assessment of social and environmental supports to meet the needs of people with dementia and their carers, including appropriate access to social work support.	
<b>Current Status</b>	<p>In order to support hospitals assess environmental needs, an audit tool is being developed to support the “Dementia Friendly Hospital Design” guidelines outlined under priority action 3.10. The tool will reflect the key dementia inclusive design issues underpinning the guidelines and provide a mechanism to audit the physical hospital environment based on these design issues.</p> <p>It is anticipated that the assessment of social supports, including appropriate access to social work support, will be addressed through the work of implementing acute hospital pathways (as outlined in priority action 2.1). The National Dementia Office (NDO) is also meeting with the Irish Association of Social Workers to explore challenges and opportunities for progressing this action.</p>	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• NDO meeting with the Irish Association of Social Workers</li> <li>• Successful submission to the HSE Research Awards on Ageing for ‘Redefining and Refining Assessment of Dementia Inclusive Design of Hospital Spaces’ to further develop an environmental audit tool for acute hospitals</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>• Refining and redefining of the environmental audit tool for acute hospitals, and re-audit of ward environment in acute hospitals</li> <li>• The full 2014 Irish National Audit of Dementia Care (INAD) in Acute Hospitals will be repeated by the HSE Healthcare Audit, Quality Assurance and Verification Division</li> </ul>	<p>Q1 2018-Q3 2019</p> <p>Q2 2018-Q4 2018</p>
<b>Additional Action 3.12</b>	The Health Service Executive will work to maximise the implementation of the national policy on restraint: Towards a Restraint Free Environment in Nursing Homes.	
<b>Current Status</b>	There are a number of pending legislative streams which are impacting on the progress of same including the Assisted Decision Making Act and proposed statute on Deprivation of Liberty.	
<b>Additional Action 3.13</b>	In the exceptional circumstances where a person with dementia needs acute admission to a psychiatric unit, every effort will be made to secure placement in a suitable old age psychiatry unit.	
<b>Current Status</b>	This action will be progressed in line with the development of dementia care pathways.	
<b>Additional Action 3.14</b>	The Health Service Executive will examine a range of appropriate long-term care options to accommodate the diverse needs of people with dementia, including those with behaviours that challenge. In planning future long-term residential care, the Health Service Executive will take appropriate account of the potential of new residential models, including housing with care, for people with dementia.	
<b>Current Status</b>	<p>In order to inform the future development of appropriate long-term care options for people with dementia, the National Dementia Office are in the process of commissioning a literature review on longterm care options including alternatives to traditional residential care models and home care supports.</p> <p>As part of a cross-sectoral approach to developing new models of housing with support for older people, the HSE and the Department of Health have participated in a pilot project developed by the Dublin City Housing Working Group which also included representatives from the Department of Housing and relevant NGOs. The pilot project has been included as one of the demonstration projects in Rebuilding Ireland - Action Plan for Housing &amp; Homelessness. The development in Inchicore comprises 50-60 self-contained units which will accommodate a mix of people with varying support needs, and this could include people with dementia. It will have a team of support staff based on-site, as well as providing outreach services for people within a defined catchment area.</p>	
<b>Outputs</b>		
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• The implementation of recommendations and suggested models will be subject to future resource availability. Interdepartmental working will be essential to ensure progress in this area</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>• Literature review completed</li> <li>• The National Dementia Office to establish a Steering Group to progress implementation of recommendations</li> </ul>	<p>Q4 2018</p> <p>Q1 2019</p>

## Priority Action Area 4: Training and Education

### Priority Actions

<b>Priority Action 4.1</b>	The Health Service Executive will engage with relevant professional and academic organisations to encourage and facilitate the provision of dementia-specific training, including continuous professional development, to relevant occupational and professional groups, including peer-led support and education for GPs, and to staff of nursing homes.	
<b>Current Status</b>	The National Dementia Office are engaging with a number of professional and academic organisations to develop dementia-specific education and training programmes where needed, and to ensure the continued facilitation of established education and training programmes.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>• A review of all dementia-related training and education available in Ireland carried out Q2-Q3 2017</li> <li>• A three hour workshop developed and piloted by PREPARED for Primary Care Teams entitled 'Dementia Care in Primary Care - An Interprofessional Approach'</li> <li>• Deep dive evaluation of the 'Dementia Care in Primary Care' programme completed by DCU</li> <li>• A three day dementia education programme for homecare workers developed and piloted in conjunction with DCU</li> <li>• Continued roll-out of the two day "Enabling and Enhancing Well-Being for the Person with Dementia" for community and residential care staff.</li> <li>• "Enhancing Well-Being for the Person with Dementia in the Acute Hospital" education programmes reviewed and updated</li> <li>• Continued roll-out of the 4 hour "Enhancing Well-Being for the Person with Dementia in the Acute Hospital" to acute hospital staff</li> <li>• The current DCU/HSE module for Dementia Champions, continues to expand, building leadership in dementia care, broadening dementia awareness and improving standards of care and support for people with dementia</li> <li>• A suite of free on-line education resources developed for staff working in Transport, Financial and Retail sectors in partnership with DCU (Elevator)</li> <li>• Dementia training provided to internal trainers in key national financial, transport and retail organisations</li> <li>• Education resources developed for GPs are listed under Priority Action 2.2</li> <li>• Promotion of the on-line programme "Early Identification of Memory Problems", available free of charge on HSeLand</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>• Identification and release of suitable facilitators to deliver the suite of dementia education programmes available is an ongoing challenge</li> <li>• Release of primary care team staff to attend the "Dementia Care in Primary Care" continues to be a challenge. The NDO are working to overcome this challenge by engaging closely with Primary Care management structures within the HSE and adapting the delivery of the workshops</li> <li>• Funding to support HSE staff to complete the Dementia Champions module will no longer be available from September 2018</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>• Develop education resource hub on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> <li>• Roll-out of 'Dementia Care in Primary Care' education workshop to primary care team members nationally</li> <li>• Roll-out of dementia education programme to public and private homecare workers and managers nationally</li> <li>• Development of discipline specific education resources for primary care team members</li> <li>• Explore potential to secure additional funding to continue to support HSE staff to complete the Level 8 Dementia Champions module with DCU</li> <li>• Continue to deliver the Dementia Elevator education materials to key national organisations through the Understand Together Campaign</li> <li>• Continue to engage with relevant organisations and associations to identify and meet additional educational needs</li> </ul>	<p>Q2 2018</p> <p>Q4 2017-Q4 2018</p> <p>Q2 2018-Q4 2019</p> <p>Q2-Q4 2018</p> <p>Ongoing</p> <p>Ongoing</p> <p>Ongoing</p>

**Additional Actions**

<b>Additional Action 4.2</b>	The Health Service Executive will develop appropriate training courses for family and other informal carers in keeping with the priorities highlighted in the National Educational Needs Analysis completed by the Health Service Executive in 2009 and Dementia Skills Elevator 2014.	
<b>Current Status</b>	A number of training and education resources are currently provided for families and other informal carers through both HSE and voluntary organisations. The National Review of Dementia-Related Education has identified the range of courses currently available and will provide information on how to streamline current resources and identify gaps in current service provision. The dementia elevator on-line education programme continues to be available through <a href="http://www.understandtogether.ie">www.understandtogether.ie</a> , while these materials are also being delivered in face to face sessions by volunteers across the country.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>Final report available on National Review of Dementia Related Education</li> <li>Dementia Elevator on-line education resources available for people with dementia and carers</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>A number of education resources for families and other informal carers have been developed separately at different locations around the country in response to local need. The National Review of Dementia Related Education has helped identify a number of these stand-alone programmes and the development of an education resource hub will facilitate better communication and shared learning going forward</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>Develop an education resource hub on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> <li>Work with the Understand Together campaign to support education for families through the community activation phase of the campaign</li> </ul>	<p>Q2-Q3 2018</p> <p>Ongoing</p>

**Priority Action Area 5: Research and Information Systems****Additional Actions**

<b>Additional Action 5.1</b>	The Health Service Executive will ensure that data from the Single Assessment Tool (SAT) is factored into research to inform dementia care in Ireland.	
<b>Current Status</b>	<p>Data from the SAT is currently being collected from SAT assessments underway in both acute and community locations. Currently this is confined to 3 CHOs – CHO 2, 7 and 9. National implementation of SAT is underway across the remaining 6 CHOs. The SAT database will correspondingly expand along with national implementation which is planned for 2017-2019. As larger scale data becomes available the SAT project will be in a position to complete more in-depth analysis which can be used to inform multiple areas across services for older people, including dementia.</p> <p>The Department of Health has secured Dormant Accounts funding for the National Dementia Office (NDO) to further explore the feasibility of developing a national dementia registry for Ireland. A tender process has been initiated and the successful applicant, working with all relevant stakeholders and through expert input, will develop and test an appropriate and workable model to collect, store and manage data on people who have dementia. This model will include gathering evidence from available data sources, including the Single Assessment Tool. The SAT team are supportive of the project and will, alongside the NDO, have an oversight role in the completion of the registry project.</p>	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>National SAT pilot completed from May 2016-April 2017 in Beaumont, University Hospital Galway and Tallaght hospital</li> <li>Pilot evaluation complete and national SAT implementation underway across all 9 CHOs</li> <li>Development of a model for a dementia database/registry for Ireland</li> <li>Evidence from the testing of the model as part of the broader project</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>Implementation of SAT system and initiation of SAT assessments may take up to 6 months for any one area. The implementation of SAT and data analysis is a long term project</li> <li>Developing a robust and rigorous mechanism to collect, store and manage data on people with dementia requires expert input and its roll-out will require additional financing</li> <li>Taking a stepwise approach, the NDO is phasing the development of the database/registry, with the next phase to begin Q2 2018</li> </ul>	

**Additional Action 5.1 (continued)**

<b>Future Plans</b>	<ul style="list-style-type: none"> <li>National SAT implementation</li> <li>Tender for the registries project awarded</li> <li>Registries project begins</li> <li>Registries project completion</li> </ul>	<p>Q1 2017-Q4 2019</p> <p>Q4 2017</p> <p>Q2 2018</p> <p>Q4 2019</p>
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<b>Additional Action 5.2</b>	The Health Service Executive will take measures to ensure appropriate recording and coding of dementia in primary care and the development of practice-based dementia registers.	
<b>Current Status</b>	<p>As part of the PREPARED project (funded through the National Dementia Strategy Implementation Programme), significant work has been undertaken to develop and encourage the use of a practice-based dementia register. This has been achieved by promoting the value of coding dementia in the General Practice setting through the training and education workshops delivered under Priority Action 2.2. PREPARED has also commissioned via the iPCRN (Irish Primary Care Research Network) the development and national launch of a suite of electronic dementia practice register and clinical audit tools from the 4 accredited GP software system companies available to all GPs nationally.</p> <p>Work being undertaken as part of the Registry project (outlined in priority action 5.1) will also address the coding and recording of dementia across care settings. The HSE are considering how the data from the GP practice based registers can be mined for the dementia registry project.</p>	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>A series of articles in prominent GP publications to highlight the advantage and availability of dementia audit tools</li> <li>Development of a suite of electronic dementia practice register and clinical audit tools</li> <li>HSE tender for a dementia registry advertised</li> <li>Clinical audit guide for GPs to audit dementia care published on <a href="http://dementiapathways.ie">dementiapathways.ie</a> and ICGP website</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>Currently there are no incentives or requirements for GPs to engage with and use the practice register and audit tools developed</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>Completion of registry project.</li> </ul>	<p>Q1 2018-Q4 2019</p>

<b>Additional Action 5.3</b>	Hospitals will take measures to encourage better recording and coding of a primary or secondary diagnosis of dementia in hospital records and charts to ensure that admissions, re-admissions, lengths of stay and discharge for people with dementia are captured on HIPE (Hospital In-Patient Enquiry).	
<b>Current Status</b>	An article on Dementia and Alzheimer's featured in the September 2016 edition of the Healthcare Pricing Office's "Coding Notes" publication. The article stresses the importance of coding a principal or additional diagnosis of dementia to feed into data collection for policy development and monitoring to improve care for people. It also gives examples of how to code a diagnosis.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>Dementia feature in Healthcare Pricing Office's publication "Coding Notes", issue No. 74, September 2016.</li> </ul>	
<b>Challenges and Solutions</b>	Poor documentation of dementia in medical notes regardless of coding improvements. National dementia education initiatives, dementia pathway implementation, new nurse specialist/ANP posts, and dementia registry project can all be harnessed to raise awareness in hospitals of need for improved documentation	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>Clinical Lead with the NDO will embed need for dementia documentation in pathway implementation and related activities.</li> <li>Clinical Lead will liaise with the HPO re coding issues and best means to raise awareness</li> </ul>	<p>Q2-Q4 2018</p> <p>Q2 2019</p>

## Priority Action Area 6: Leadership

### Priority Actions

<b>Priority Action 6.1</b>	Clear overall responsibility for dementia will be assigned to a person at senior management level within the Health Service Executive.	
<b>Current Status</b>	The National Dementia Office (NDO) was established in 2015, with a full-time senior management post created to lead the work of the office. The Office is under the remit of Social Care Directorate , Head of Operational Planning and Service Improvement Older Persons	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>The NDO office is now progressing work within the NDS with a General Manager two senior Project Managers, Admin support and a part time Clinical Lead</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>Staff changes and delay in getting posts approved and in place has resulted in the NDO not being fully operational until 2017</li> </ul>	
<b>Priority Action 6.2</b>	The Clinical Strategy and Programmes Division of the Health Service Executive will establish a Workstream on Dementia Care as part of its Integrated Care Programme for Older Persons, in recognition of the complexity of the illness and the need for leadership and integration across all relevant Health Service Executive Directorates.	
<b>Current Status</b>	A representative from the National Dementia Office sits on the steering group for the Integrated Programme for Older People (ICPOP) and on the working group for the Clinical Care Programme for Older People (CCPOP). The Clinical Lead with the National Dementia Office will progress the integration of dementia into these national programmes.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>Links between the NDO, the ICPOP and NCPOP have been established.</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>Getting dementia embedded as a priority in the Clinical Programmes has been a challenge due to competing agendas (e.g. frailty, stroke)</li> <li>Challenge to have dementia included in future GP contract negotiations</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>NDO Clinical Lead will liaise with the Clinical Strategy and Programmes Division of the HSE to identify an appropriate time for the development of a clinical programme in Dementia Care within the context of their overall programme of work</li> <li>NDO to liaise with Head of Operations for both acute and community to request that dementia is included in operational plans for Hospital and Community</li> <li>Work with HSE Procurement and primary care to get Dementia on the GP contract as a priority</li> </ul>	<p>Q3 2018-Q2 2019</p> <p>Ongoing</p> <p>Ongoing</p>
<b>Priority Action 6.3</b>	Within primary care services, a named key worker will be appointed to play a key role in co-ordinating each patient's care and promoting continuity, and ensuring that the patient knows who to access for information and advice.	
<b>Current Status</b>	A working group has been established to progress this action, with a focus on drafting a job description for this role. The group includes expert representatives across primary, social and integrated care; a person living with dementia and an academic partner to ensure both experiential and academic knowledge are harnessed to inform the work. The working group will convene its first meeting in November 2017.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>Terms of reference for the working group drafted</li> <li>Analysis of existing case management type roles for dementia</li> <li>Existing job descriptions for similar roles gathered</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>The lack of current consensus on what this role should do and where it should be positioned within the health and social care system is a challenge. It's envisaged that the work of the newly established working group will address these issues</li> </ul>	

Priority Action 6.3 (continued)

<b>Future Plans</b>	<ul style="list-style-type: none"> <li>Gather evidence on existing dementia key worker/case management roles across Europe – liaising with researchers from the Actifcare project</li> </ul>	Q4 2017-Q2 2018
	<ul style="list-style-type: none"> <li>Draft job description for the key worker role</li> </ul>	
	<ul style="list-style-type: none"> <li>Consensus reached on the approach</li> </ul>	Q2 2018
	<ul style="list-style-type: none"> <li>Phased roll-out of the key worker role (resource dependent)</li> </ul>	Q3-Q4 2018

<b>Priority Action 6.4</b>	Clear and effective management structures will be established within the Health Service Executive to provide leadership at a system level for the implementation of the Strategy.	
<b>Current Status</b>	The National Dementia Office (NDO) was established in 2015 to provide leadership at a system level for the implementation of the National Dementia Strategy. The office includes a General Manager, two Senior Project Managers, a 0.4WTE Clinical Lead as well as administrative support. A dementia adviser from within the HSE Older Person Services supports the work of the NDO. The Office is under the remit of HSE Social Care Directorate, Head of Operational Planning and Service Improvement Older Persons.	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>National Dementia Office established</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>A delay in fully staffing the office and securing a clinical lead presented challenges. Office is now fully staffed</li> <li>As dementia care does not sit with any one service or area, it is necessary for the NDO to establish links with a very broad range of stakeholders</li> <li>There will be a requirement for ongoing funding in the budget allocation from the DOH to ensure that the NDO remains viable and functional</li> </ul>	

<b>Priority Action 6.5</b>	The Department of Health and the Health Service Executive will develop performance indicators to measure progress in implementing the Strategy. The Department of Health will also conduct a mid-term review of progress in 2016.	
<b>Current Status</b>	Currently progress on the implementation of the National Dementia Strategy is measured and monitored through the National Dementia Strategy Implementation Plan, which is updated every quarter. It was agreed that the National Dementia Office would draft the mid-term review for the Department of Health	
<b>Outputs</b>	<ul style="list-style-type: none"> <li>Mid-term review completed December 2017.</li> <li>National Dementia Strategy Implementation Plan developed and continuously updated.</li> </ul>	
<b>Challenges and Solutions</b>	<ul style="list-style-type: none"> <li>Due to the delay in the operationalisation of the National Dementia Office (as outlined in Additional Action 5.4), it was agreed to postpone the mid-term review until 2017.</li> </ul>	
<b>Future Plans</b>	<ul style="list-style-type: none"> <li>Department of Health and the National Dementia Office to develop KPIs for the implementation of the Strategy.</li> <li>The Department of Health and the National Dementia Office will engage with the TILDA (Irish Longitudinal Study on Ageing) team to ensure that data on dementia contributes to the evidence base on dementia prevalence and on the health, wellbeing, service need and service utilisation by people with dementia and their carers.</li> </ul>	<p>Q4 2018</p> <p>Ongoing</p>

Section 3:  
**Action Plan Q1 2018 – Q2 2019**



Action Area	Key Objectives	Responsibility	Timeframe	KPIs
<b>Public Awareness</b>	<ul style="list-style-type: none"> <li>Continue to utilise print, radio, television and social media to communicate key messages of the Dementia: Understand Together campaign</li> </ul>	Understand Together Campaign	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>Full implementation of heavy weight media and PR plan</li> <li>Build community of followers on Facebook (12,000)</li> </ul>
	<ul style="list-style-type: none"> <li>Continue to raise awareness of modifiable risk factors through PR, social media, information resources</li> </ul>	Understand Together Campaign	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>Messaging around risk factors included in PR activities</li> </ul>
	<ul style="list-style-type: none"> <li>Work with national partner organisations to secure support for community activation initiatives</li> </ul>	NDO and Understand Together Campaign	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>20 key partners have committed to programme of national and local activities and training</li> </ul>
	<ul style="list-style-type: none"> <li>Development and roll-out of community activation platform to support communities to be more inclusive and understanding of people living with dementia and their families.</li> </ul>	NDO and Understand Together Campaign	Q1 – Q2 2018 Q2 – Q4 2018	<ul style="list-style-type: none"> <li>Project plan developed</li> <li>Stakeholder event held</li> <li>75 community champions identified</li> <li>Online supports for champions and communities developed and published</li> </ul>
	<ul style="list-style-type: none"> <li>Ongoing updating and management of <a href="http://www.understandtogether.ie">www.understandtogether.ie</a>, including verification of online service finder</li> </ul>	NDO and Understand Together Campaign	Q1 2018 – 2019	<ul style="list-style-type: none"> <li>Service finder data is reviewed and updated three times per annum</li> <li>Sharing hub developed for dementia initiatives nationally</li> <li>Content is kept up to date</li> </ul>
	<ul style="list-style-type: none"> <li>Evaluate the impact of the Understand Together Campaign</li> </ul>	Understand Together Campaign	Q3 2019	<ul style="list-style-type: none"> <li>National quantitative survey and qualitative research undertaken and findings published</li> </ul>
	<ul style="list-style-type: none"> <li>Ongoing delivery of Dementia-IHCPs to approximately 120 people with dementia nationally</li> </ul>	HSE	Q1 2018 – Q2 2019	<ul style="list-style-type: none"> <li>120 people with dementia in receipt of an IHCP at any one time in 2018 and 2019</li> <li>A minimum of 300 people will have benefitted from an IHCP by the end of 2018</li> </ul>
	<ul style="list-style-type: none"> <li>Work with key stakeholders in 8 pilot sites nationally to develop a process for the design and delivery of personalised intensive homecare packages to people with dementia</li> </ul>	Genio	Q1 – Q3 2018	<ul style="list-style-type: none"> <li>Report detailing the process and outcome of integrated approaches to personalised working in 8 pilot sites</li> </ul>
<b>Intensive Homecare Packages</b>	<ul style="list-style-type: none"> <li>Final evaluation report of the effectiveness of IHCPs, including recommendations for the future development of Dementia-IHCP services</li> </ul>	Genio	Q3 2018	<ul style="list-style-type: none"> <li>Publication of evaluation report</li> <li>Publication of lay summary for study participants, public and others</li> </ul>

Action Area	Key Objectives	Responsibility	Timeframe	KPIs
Post-Diagnostic Support Pathway	<ul style="list-style-type: none"> <li>Launch literature review of post-diagnostic supports</li> </ul>	NDO and CESRD	Q1 2018	<ul style="list-style-type: none"> <li>Literature review completed and available on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> <li>Report launched 24th January 2018</li> </ul>
	<ul style="list-style-type: none"> <li>Develop a post-diagnostic support pathway that will guide a person with dementia to the supports and services appropriate for maintaining their well-being and independence after diagnosis</li> </ul>	NDO and PDS steering group	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>National Steering Group meet 3 times in 2018</li> <li>Publication of Post-Diagnostic Support Pathway Framework on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> <li>Dissemination of the framework e.g. conference presentations; incorporated into training materials</li> </ul>
	<ul style="list-style-type: none"> <li>Develop key resources to support initial implementation of the post-diagnostic support pathway</li> </ul>	NDO and relevant partners	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>Development of additional information resources for people with dementia, families, carers and health and social care professionals</li> <li>Publication of guidance document for HSCP in running PDS psycho-educational programmes</li> <li>18 sites undertaking cognitive therapies and/or PDS psycho-educational programmes funded through the NDO PDS grant scheme</li> <li>Three PDS masterclasses held</li> </ul>
Dementia Diagnostic Project	<ul style="list-style-type: none"> <li>Evaluation of post-diagnostic pathway</li> </ul>	NDO and relevant partner	Q1 2018 – Q4 2019	<ul style="list-style-type: none"> <li>Evaluation awarded to successful tender</li> <li>Production of evaluation report with relevant recommendations</li> </ul>
	<ul style="list-style-type: none"> <li>Conduct literature review to identify best practice regarding diagnosis of dementia and diagnostic pathways</li> </ul>	NDO and UCC	Q2 2018	<ul style="list-style-type: none"> <li>Literature review completed and available on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> </ul>
	<ul style="list-style-type: none"> <li>Develop dementia diagnostic pathway for Ireland across primary, secondary and tertiary services. This pathway will provide guidance on the timely assessment and diagnosis of dementia nationally</li> </ul>	NDO	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>National Steering Group meet 5 times in 2018</li> <li>Publication of Dementia Diagnostic Pathway on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> </ul>
	<ul style="list-style-type: none"> <li>Identify and cost resources needed to implement the national diagnostic pathway</li> </ul>	NDO	Q1-Q2 2019	<ul style="list-style-type: none"> <li>Report outlining potential reconfiguration of existing resources and costing for establishment of additional services to implement diagnostic pathway completed</li> </ul>

Action Area	Key Objectives	Responsibility	Timeframe	KPIs
<b>Dementia Registries Project</b>	<ul style="list-style-type: none"> <li>Develop and test an appropriate and workable model to collect, store and manage data on people who have dementia</li> </ul>	NDO and DCU	Q2 2018 – Q4 2019	<ul style="list-style-type: none"> <li>Dementia registry project tender awarded</li> <li>Establishment of National Steering Group</li> <li>Development of model for dementia registry</li> <li>Testing of dementia registry model complete</li> <li>Business case developed for broader roll-out of the registry</li> </ul>
	<ul style="list-style-type: none"> <li>Facilitate roll-out of the ‘Dementia Care in Primary Care’ education workshop nationally with key stakeholders e.g. Centres for Nurse Education.</li> </ul>	NDO	Q1 2018 – Q2 2019	<ul style="list-style-type: none"> <li>A minimum of 500 PCT members attended workshop by end 2018</li> </ul>
<b>Dementia Education</b>	<ul style="list-style-type: none"> <li>Facilitate roll-out of the “Understanding and Responding to People with Dementia” 2 day education workshop in collaboration with relevant public and private education providers nationally.</li> </ul>	NDO	Q1 2018 – Q2 2019	<ul style="list-style-type: none"> <li>25% of homecare will have undertaken the “Understanding and Responding to People with Dementia” education programme for staff delivering home care.</li> </ul>
	<ul style="list-style-type: none"> <li>Support the development of discipline specific online dementia education modules for community based health care professionals.</li> </ul>	PREPARED, DSIDC, and NDO	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>Online dementia education programmes available on DSIDC website for community based allied healthcare professionals.</li> </ul>
	<ul style="list-style-type: none"> <li>Develop the training section on the Understand Together website to reflect learning from the 2017 Education Review</li> </ul>	NDO, HSE Digital, Understand Together Campaign Team	Q2 – Q3 2018 Q2 – Q4 2018	<ul style="list-style-type: none"> <li>Training and Resources inclusive of all dementia related education available nationally</li> <li>Establish working group to identify education needs and progress findings from education review report</li> </ul>
	<ul style="list-style-type: none"> <li>Continue to facilitate face-to-face workshops to GPs nationally.</li> </ul>	PREPARED	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>300 GPs partaking in face-to-face workshops</li> </ul>
	<ul style="list-style-type: none"> <li>Further embed dementia workshop materials within the Continuing Medical Education (CME) structure.</li> </ul>	PREPARED	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>A minimum of two meetings with ICGP CME leads and tutors to encourage adoption of the dementia workshop materials at local education meetings.</li> </ul>
	<ul style="list-style-type: none"> <li>Continue to facilitate the GP Post-Graduate CPD Module on dementia in UCC</li> </ul>	PREPARED and UCC	Q3 – Q4 2018	<ul style="list-style-type: none"> <li>20 GPs enrolled for 2018/2019 programme</li> </ul>
	<ul style="list-style-type: none"> <li>Development of GP e-learning modules</li> </ul>	PREPARED and ICGP	Q2 2018	<ul style="list-style-type: none"> <li>A third e-learning module on dementia available on ICGP website.</li> </ul>

Action Area	Key Objectives	Responsibility	Timeframe	KPIs
<b>Dementia Education (continued)</b>	<ul style="list-style-type: none"> <li>Acute hospital Dementia Educational Awareness programme</li> </ul>	ONMSD, NDO	Q1 2018 – Q1 2019	<p>Educational Awareness programme available to staff in:</p> <ul style="list-style-type: none"> <li>Dublin Midlands Hospital Group -5 sites</li> <li>Ireland East Hospital Group 7 sites</li> <li>RCSI Hospital Group 4 sites</li> <li>Saolta Hospital Group 4 sites</li> <li>South west Hospital Group 6 sites</li> <li>University of limerick Hospital group 5 sites</li> </ul> <p>Total Hospitals = 29 n=42</p>
	<ul style="list-style-type: none"> <li>Meet with social care personnel across all CHOs to discuss availability and development of dementia specific community resources locally e.g. peer support groups, day centres</li> </ul>	NDO and CHO social care leads	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>5 meetings with social care contacts.</li> <li>Local needs analysis framework developed</li> <li>Individual dementia services development plans reflected in 2019 operational plans</li> </ul>
<b>Development of Community Services and Supports</b>	<ul style="list-style-type: none"> <li>Support the establishment of Memory Technology Resource Rooms (MTRRs) in each CHO and the development of a national MTRR service</li> </ul>	NDO and HSE Social Care	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>A minimum of five network meetings held in 2018</li> <li>Centralised data collection system developed and implemented</li> <li>A minimum of one MTRR established in each CHO with standardised processes and services.</li> </ul>
	<ul style="list-style-type: none"> <li>Conduct literature review to identify and cost long-term care models nationally and internationally to support people with dementia to live well, maintain quality of life and promote personhood.</li> </ul>	NDO and commissioned organisation	Q1 – Q3 2018	<ul style="list-style-type: none"> <li>Tender awarded to successful applicant</li> <li>Publication of literature review on www.understandtogether.ie</li> </ul>
<b>Long-Term Care</b>	<ul style="list-style-type: none"> <li>Develop recommendations relating to long-term care e.g. psychosocial and physical environment; on meeting the preferences and stated preferred outcomes of people with dementia; staff training and knowledge required; compliance with relevant standards/regulation and cost of different long-term care models.</li> </ul>	NDO	Q3 2018 – Q1 2019	<ul style="list-style-type: none"> <li>Outline of recommendations and costings presented to NDS Monitoring Group and Department of Health</li> </ul>

Action Area	Key Objectives	Responsibility	Timeframe	KPIs
<b>Key Worker Project</b>	<ul style="list-style-type: none"> <li>Develop job description for key worker role, based on national and international best practice evidence on having a designated contact person to help coordinate individual care plans and assist people to navigate complex care pathways.</li> </ul>	NDO, Integrated Care for Older People (HSE), ASI, IDWG, Primary Care (HSE), Older Persons Services (HSE), Genio	Q2 2018	<ul style="list-style-type: none"> <li>Key Worker working group to meet 4+ times in 2018</li> <li>Cross-country comparison of similar roles undertaken</li> <li>Consensus amongst the group of what constitutes the key worker role</li> <li>Production of key worker job description</li> </ul>
	<ul style="list-style-type: none"> <li>Cost implementation of key worker role within an Irish context.</li> </ul>	NDO	Q4 2018	<ul style="list-style-type: none"> <li>Outline of recommendations and costings presented to NDS Monitoring Group and Department of Health</li> </ul>
<b>Intellectual Disabilities</b>	<ul style="list-style-type: none"> <li>Development of a proposal for additional dedicated project support from ID services to be assigned to work with the NDO to progress development of dementia services for people with ID.</li> </ul>	NDO, Social Care Directorate HSE	Q1 2018 – Q1 2019	<ul style="list-style-type: none"> <li>Plan developed to support the additional requirement need for ID</li> <li>A working group established to progress development of an action plan to address the needs of people with ID not progressed to date</li> </ul>
	<ul style="list-style-type: none"> <li>Development of evidence based guidelines for health care professionals to guide the use of psychotropic medications, including antipsychotic medications, in people with dementia</li> </ul>	NDO ASI HSE IPU	Q1 2018 – Q4 2018	<ul style="list-style-type: none"> <li>Interdisciplinary expert group established</li> <li>Group meet 3-4 times in 2018</li> <li>Guidelines on psychotropic medication for people with dementia finalised</li> <li>Audit tool and education material developed to support use of guidelines</li> </ul>
<b>Dementia Adviser Service</b>	<ul style="list-style-type: none"> <li>Development of short guidance document on appropriate prescribing of medication for people with dementia</li> </ul>	NDO, ASI, HSE, IPU	Q1 2019	<ul style="list-style-type: none"> <li>Guidance document published</li> </ul>
	<ul style="list-style-type: none"> <li>External evaluation of the ASI Dementia Adviser Service</li> <li>Develop recommendations for future development of Dementia Adviser service</li> </ul>	NDO in conjunction with ASI and UCC  NDO	Q2 2018  Q2 2018	<ul style="list-style-type: none"> <li>Evaluation report completed</li> <li>Outline of recommendations and costings developed and presented to the Department of Health</li> </ul>

Action Area	Key Objectives	Responsibility	Timeframe	KPIs
<b>Acute Care</b>	<ul style="list-style-type: none"> <li>Support adoption of Delirium Algorithm in all acute hospitals nationally to support timely identification of delirium in the acute hospital.</li> </ul>	NDO	Ongoing	<ul style="list-style-type: none"> <li>ED Delirium algorithm approved at HSE Senior Management level in December 2015</li> <li>Acute ward Delirium algorithm awaiting senior management team review since July 2017</li> <li>Implementation group established to plan and implement national roll-out once approval given</li> </ul>
	<ul style="list-style-type: none"> <li>Develop a framework for implementation of dementia pathways in acute hospitals to ensure appropriate care and support for a person with dementia in the acute hospital.</li> </ul>	Genio, NDO	Q3 – Q4 2018 Q1 2019	<ul style="list-style-type: none"> <li>Develop framework for implementation</li> <li>Establishment of implementation group</li> </ul>
	<ul style="list-style-type: none"> <li>Support the adoption of the ‘Dementia Inclusive Design for Acute Hospitals from a Universal Design Perspective’ guidelines</li> </ul>	NDO, Trinity Haus, HSE Estates	Q2 2018	<ul style="list-style-type: none"> <li>Publication of ‘Dementia Inclusive Design for Acute Hospitals from a Universal Design Perspective’ guidelines on <a href="http://www.understandtogether.ie">www.understandtogether.ie</a></li> </ul>
	<ul style="list-style-type: none"> <li>Promote the dementia CNS role within acute hospitals to provide comprehensive physical, psychological and emotional assessment and support to people with dementia and their families/carers throughout their disease trajectory</li> </ul>	NDO, ONMSD	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>25% of acute general hospitals have dementia CNS in post by end 2018</li> </ul>
<b>Communication</b>	<ul style="list-style-type: none"> <li>Communicate regarding the work ongoing to implement the National Dementia Strategy through:                             <ul style="list-style-type: none"> <li>Presentation at one international event and four national events annually.</li> <li>Publication of bi-annual NDO newsletters</li> <li>Continued networking with strategic partners e.g. Alzheimer Society of Ireland</li> <li>Co-hosting Genio learning/sharing events x 3</li> </ul> </li> </ul>	NDO  NDO NDO NDO, Genio	Q1 – Q4 2018	<ul style="list-style-type: none"> <li>A minimum of 4 presentations nationally per annum and one international presentation.</li> <li>Publication of 2 newsletters in 2018</li> <li>Meet formally with dementia advocacy groups and organisations a minimum of twice a year.</li> <li>Co-host 3 learning events in partnership with Genio in 2018</li> </ul>



Appendix 1:  
**Membership of the National  
Dementia Strategy Monitoring  
Group**



Mr Niall Redmond (Chair)	Services for Older People, Department of Health
Dr Emer Begley	Senior Project Manager, National Dementia Office
Prof Suzanne Cahill	Adjunct Professor, School of Social Work and Social Policy, Trinity College Dublin
Ms Mairead Creed	Services for Older People, Department of Health
Ms Anna de Siún	Senior Project Manager, National Dementia Office
Mr Michael Fitzgerald	Head of Operations and Service Improvement, Services for Older People, Health Service Executive
Mr Matthew Gibb	Director, Dementia Services Information and Development Centre, St. James' Hospital
Dr John Healy	Deputy Executive Director, Genio
Ms Eilis Hession	Project Lead, Genio Living Well with Dementia
Prof Kate Irving	Lecturer in Mental Health and Nursing, DCU
Dr Sean Kennelly	Consultant Physician in Geriatric and Stroke Medicine, Tallaght Hospital
Dr Fiona Keogh	Senior Research Fellow, Centre for Economic and Social Research, NUI Galway
Ms Mary Manning	General Manager, National Dementia Office, Health Service Executive
Mr Pat McLoughlin	CEO, Alzheimer Society of Ireland
Mr Maurice O'Connell	Co-ordinator, Active Ageing Partnership
Prof Eamon O'Shea	Director, Centre for Economic and Social Research on Dementia, NUI Galway
Mr Sean Donal O'Shea	Dementia Carers Campaign Network
Ms Helen Rochford-Brennan	Chairperson, European Working Group of People with Dementia
Dr Suzanne Timmons	Clinical Lead, National Dementia Office, Health Service Executive
Mr Vincent Lacey	Secretariat, Services for Older People, Department of Health

With thanks to former members Dr Richard Aboud, Ms Celine Brosnan, Dr Caitriona Crowe, Ms Jane Forman, Ms Colette Kelleher, Mr John Linehan, Ms Sarah Mahon, Mr Gerry Martin, Mr Barry Murphy, Dr Shaun O'Keeffe and Ms Mary Sutton.



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