

# EVALUATION OF THE NATIONAL DEMENTIA STRATEGY

Final Report  
November 2019

Ipsos MORI  
University College Cork



Ipsos MORI





# PREFACE

The National Dementia Office commissioned Ipsos MORI in partnership with University College Cork (UCC) to undertake an evaluation of the Irish National Dementia Strategy and the National Implementation Plan. The aim of the evaluation was to understand the impact of the six priority actions set out under the plan on the lives of People Living with Dementia, their caregivers and staff in the statutory and Not for Profit sector who provide services.

The evaluation team took an inclusive approach and sought to engage with a wide range of individuals including health and social care professionals, as well as People Living with Dementia and their caregivers. In doing so the team completed one-to-one interviews and focus groups with 35 individuals and received 838 responses to online and hard copy surveys.

The findings highlighted that whilst the level of awareness of the needs of people living with dementia had increased since the implementation of the strategy many of those who participated in the strategy were relatively unaware of the impact of the priority actions set out in the Strategy upon those living in the community.

This report is aimed towards all of those who wish to know more about the impact of the strategy so far and where further action is required including, Not for Profit Organisations, People Living with Dementia and their Caregivers.

## Acknowledgements

The authors would like to express their gratitude to a number of people and organisations who supported the development and completion of this evaluation. Firstly, thanks to those individuals who are living with dementia and their caregivers who provided their time and gave their opinions so freely, as well as the staff and volunteers from third sector organisations including Alzheimer's Society of Ireland who invested their time and shared their knowledge and insights throughout.

We also wish to acknowledge the crucial role that staff from the Department of Health and the National Dementia Office in providing guidance throughout the project and for supporting access to health and social care staff.

## Evaluation Steering Group

Anna de Suin, National Dementia Office (NDO)  
Mairead Creed, Department of Health (DOH)  
Dr. Maurice O'Connell, NDS Monitoring Group  
Dr. Emer Begley, National Dementia Office (NDO)  
Mary Manning NDO  
Dr. Tom Andrews, UCC  
Dr. Laura O'Philbin, UCC

## List of contributors

Dr Irene Hartigan, UCC  
Dr Karen Clarke, Ipsos MORI  
Dr Nicola Cornally, UCC  
Ms Fiona Rooney, Ipsos MORI  
Professor Jonathan Drennan, UCC  
Professor Corina Naughton, UCC  
Dr Catherine Buckley, UCC  
Dr Rónán O'Caoimh, MUH/UCC  
Dr Kieran Walsh, MUH  
Professor Kevin Brazil, QUB  
Professor Alice Coffey, UL  
Dr Niamh O'Regan, McMaster Canada

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# GLOSSARY

<b>AP</b>	The Atlantic Philanthropies
<b>ASI</b>	Alzheimer's Society of Ireland
<b>CHO</b>	Community Health Organisation
<b>CNS</b>	Clinical Nurse Specialist
<b>CPD</b>	Continuing Professional Development
<b>CSO</b>	Central Statistics Office
<b>DA</b>	Dementia Adviser
<b>DoH</b>	Department of Health
<b>EOI</b>	Expression of Interest
<b>GDPR</b>	General Data Protection Regulations
<b>GP</b>	General Practitioner
<b>HSCP</b>	Health and Social Care Professional
<b>HSE</b>	Health Service Executive
<b>IHCP</b>	Intensive Homecare Package
<b>IT</b>	Information Technology
<b>NDO</b>	National Dementia Office
<b>NDS</b>	National Dementia Strategy
<b>NDSIP</b>	National Dementia Strategy Implementation Plan
<b>NfP</b>	Not for Profit (organisation)
<b>OCED</b>	Organisation for Economic Co-operation and Development
<b>OT</b>	Occupational Therapist
<b>PHN</b>	Public Health Nurse
<b>PLwD</b>	Person/People Living with Dementia
<b>TCD</b>	Trinity College Dublin
<b>TD</b>	Teachtaí Dála (Member of the Irish Parliament)
<b>UCC</b>	University College Cork
<b>USA</b>	United States of America
<b>UT</b>	Understand Together

# EVALUATION OF THE NATIONAL DEMENTIA STRATEGY

## SUMMARY

### Introduction

There are an estimated 55,000 people in Ireland living with dementia and this is expected to double (to 115,000) within 20 years.<sup>1</sup> A National Dementia Strategy (NDS) was highlighted as a key policy goal in the 2011 National Programme for Government. The first Irish NDS was then launched in December 2014. Atlantic Philanthropies invested €12.5 million in the implementation of the NDS, which was matched by a further €15 million by the Department of Health. The NDS was based on the need for an effective and structured response to dementia, it also brings Ireland in line with other jurisdictions and enables international comparisons. The Irish NDS seeks to progress the dual and overarching principles of personhood and citizenship, thus enabling people with dementia to maintain their identity and dignity and by recognising that they remain valued, independent citizens along with their carers. Eight principles served as the foundation of the NDS, informing the full range of health and social care services provided to people

with dementia, their families and carers. The strategy identifies 14 Priority Actions and 21 additional Actions which are grouped under six Action Areas, namely:

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

Implementation of the NDS began in 2015 and initially focused on those actions that could be prioritised with funding from the Health Service Executive, Department of Health and Atlantic Philanthropies. All but one action outlined in the Strategy are now being implemented,<sup>2</sup> albeit at different stages of development. The role of the National Dementia Office within the Health Service Executive is to oversee and lead the implementation of the NDS by working in partnership and collaboration with key

stakeholders (such as the Department of Health, relevant voluntary and community groups and other parts of the Health Service Executive).

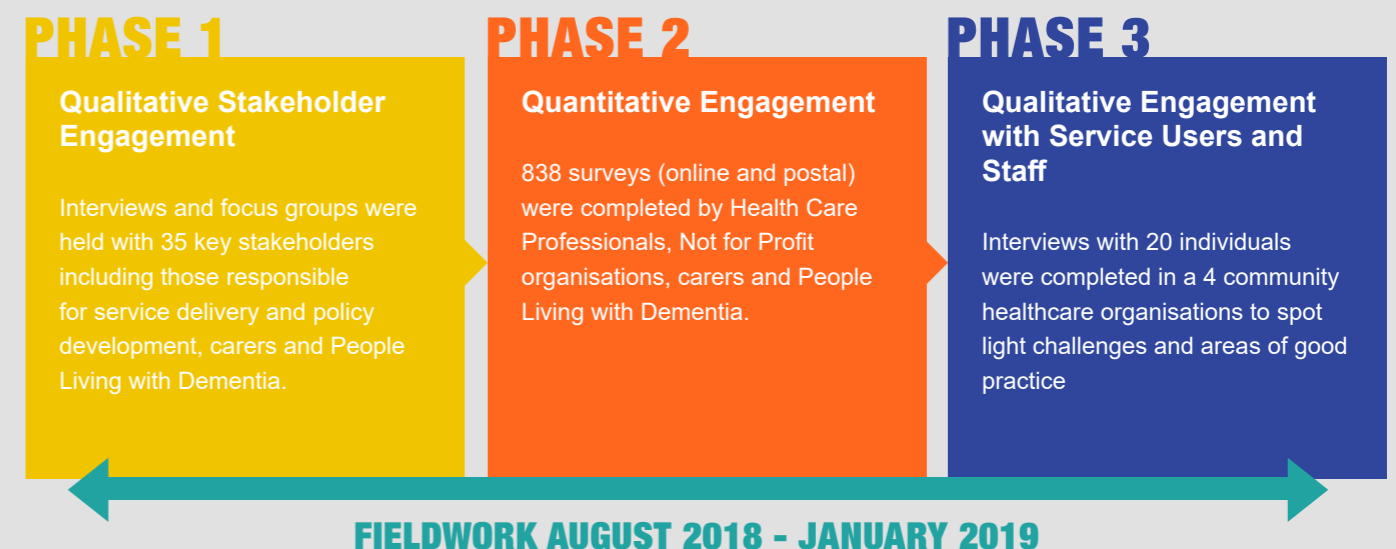
### Evaluation Objectives and Methodology

As part of the Memorandum of Understanding with the Atlantic Philanthropies, Department of Health and the Health Service Executive, funding was allocated for an external, independent evaluation of the NDS. Following a national tender competition, the Health Service Executive commissioned Ipsos MORI in partnership with University College Cork to undertake an independent evaluation of

the NDS and National Dementia Strategy Implementation Plan. A mixed methodology was applied which involved three main phases of primary data collection as summarised in Figure 1.

In addition to these three phases of primary data collection, a review of national and international literature relating to the development and implementation of dementia strategies was also completed. This was done to understand how dementia strategies were developed and prioritised in other countries and what lessons there could be for the implementation of the Irish NDS.

Figure 1 Phases of data collection



<sup>1</sup> Mid-term Review of the Implementation of the National Dementia Strategy. Department of Health (2018).  
<sup>2</sup> The action on maximisation of the implementation of the national policy on restraint has not yet progressed.



## Summary of key findings

The findings from each phase of data collection were triangulated to provide an understanding of the NDS from multiple perspectives. The overall findings are reported within the context of what is currently known. It is recognised that other external and internal evaluation reports are emerging and the evaluation team drew on available reports to inform the final synthesis of the evaluation data.<sup>3</sup>

The following paragraphs provide an overview of the key findings as they relate to the Strategy's six Priority Action Areas.

### Priority Action Area 1

#### Better Awareness and Understanding

A key objective for this Priority Action Area is to increase public awareness and understanding of dementia. All of those who contributed to the evaluation highlighted the importance of increasing awareness and understanding of dementia, especially in local communities. One of the key activities delivered under this priority Action Area is the Understand Together programme which was launched as a public awareness campaign in 2017 and currently has a primary focus on community activation. Findings from each phase of the data collection process suggest

that it is the most salient output of the Strategy's implementation, with both service users and carers referring to the campaign when asked about the NDS (even if they had not heard of the NDS).

The mid-term review of the NDS noted relatively high levels of use of the UnderstandTogether.ie website (e.g. 90,000 hits in 2017/18 and 7,000 Facebook likes). However, findings from this evaluation noted that over one third of stakeholders regarded the level of understanding of dementia amongst the media and politicians as poor. Conversely, Health and Social Care Professionals rated their own understanding of dementia as good to excellent. While the results were largely positive, some people living with dementia participating in the evaluation felt that dementia awareness is still relatively poor in parts of Ireland and that there were mixed attitudes towards dementia in their local communities.

### Priority Action Area 2

#### Timely Diagnosis and Intervention

A key objective for this priority Action Area relates to putting in place structures and care pathways to optimise people's journeys through the health and social care system. This evaluation found that the majority of Health and Social Care Professionals and

carers considered timely diagnosis and intervention as highly important. Feedback from carers in phases two and three of the data collection also highlighted that there is a lack of awareness of what services and supports are available for people living with dementia in local communities following a diagnosis. Under the NDS, €1.2 million funding was allocated to University College Cork for the PREPARED project (the Primary Care Education, Pathways and Research in Dementia) to upskill GPs and Primary Care Teams in the assessment, diagnosis, and care for people living with dementia. It has not yet been possible to understand the impact of PREPARED, as the independent evaluation report was not available at the time of publication.

Findings from our evaluation highlighted that the knowledge and care provided by GPs and/or consultants had a significant bearing on how a diagnosis of dementia was disclosed and the degree to which people living with dementia and their carers were able to access follow-up support and information. It was clear that the ability to obtain information from local professionals was very valuable to those who had received it. Clinicians who actively sought out services on the person's behalf were mentioned as having a significantly positive impact on assisting the PLwD to navigate health and social care systems.

Information sources during dementia diagnosis disclosure and post diagnosis are central to the person living with dementia's experience and requires an integrated post-diagnostic model of both clinical and social care so that the person can seek information or engage with services when they are ready and on terms that meet both their clinical and personal needs. Findings collated during this evaluation suggest that there is a need for structured pathways to follow after a diagnosis of dementia is given. Carers and people living with dementia want adequate information on the likely trajectory, what the future holds, and information on the services available to them.

Navigating the various elements of the health and social care system can be difficult and the need for someone in the community to co-ordinate care and/or refer and signpost to other services was stressed by those who participated in the evaluation. An evaluation of the Alzheimer Society of Ireland's Dementia Advisor Service highlighted the importance of a dedicated person to contact directly when a diagnosis is made to offer advice and signpost people living with dementia and their carers to support services.

Findings from all phases of the evaluation highlighted that carers and people living with dementia regard well-informed primary

<sup>3</sup> For example, this included the Evaluation of the PREPARED project and the Evaluation of the Dementia Adviser Service.

care teams as critical and that it is important to receive information about supports and services from GPs and/or Primary Care Teams. Dormant account funding has been secured to support dementia post-diagnostics interventions, as part of the National Dementia Office's national dementia post-diagnostic project, 18 grants worth up to €25,000 each were made available to Health and Social Care Professionals working in a range of settings to deliver post-diagnostic supports. The grant scheme is being independently evaluated and preliminary findings will be available towards the end of 2019.

### Priority Action Area 3

#### Integrated services, support and care for people with dementia and their carers

One of the key objectives of this Action Area is the better co-ordination, integration and seamless transitions between primary, secondary, mental health, community care, acute, long-term and palliative care services.

This evaluation found that there was a high level of agreement across all data collection phases that integrated services supports and care is the most important Priority Action Area for people living with dementia. However, there was also evidence to suggest that access to dementia care and support

services is inconsistent across Ireland. Almost half of the carers who participated in the evaluation reported difficulties in accessing sufficient supports and services. Carers reported a lack of signposting to existing services and those in rural areas reported difficulties in accessing services even when they were made aware of them.

A lack of dementia accessible transport was identified as a key issue in phases one and two of data collection. The pressing need for joined-up care across sectors and the further development of dementia-specific services were recurring themes in all phases of data collection, with discussions around homecare supports dominating the minds of most stakeholders. Feedback from stakeholders emphasised the need for a dementia care pathway that sets out the roles and responsibilities of various agencies and care providers at each stage of the patients' journey.

One of the most significant projects delivered under the NDS was the Dementia Intensive Homecare Packages (Dementia IHCP). The Dementia IHCPs were introduced to test the feasibility of delivering a high level of flexible and personalised support to people with complex needs to enable them to remain at home and/or to facilitate timely discharge from hospital. Over 300 people living with dementia received packages under the testing concept project and they continue to be rolled out across the country.

Preliminary findings from the evaluation of Intensive Homecare Packages noted that the processes of working with carers and people living with dementia to develop personalised packages increased the quality of care provided and maximised the resources used, which in turn led to improved hospital discharge and avoidance. Those who participated in this evaluation and were also aware of the Dementia-Intensive Homecare Packages, highlighted that IHCPs were invaluable and should be made available across Ireland.

Participants in all phases of the evaluation also noted the importance of dementia accessible environments in acute care settings and public facilities. Acute hospitals can be distressing and disorientating for a person living with dementia and are often associated with a decline in cognitive ability and levels of functioning. Evaluation participants emphasised the need to shift towards dementia accessible care environments and improve training of all healthcare staff. The NDO supported the development of design guidelines (Dementia Friendly Hospitals from a Universal Design Approach, 2018<sup>4</sup>) to help inform

national policy and support staff to create environments that improve the experience of people living with dementia and their carers when accessing acute services.

### Priority Action Area 4

#### Training and Education

The aim of this Priority Action Area is to encourage and facilitate the provision of dementia specific training to relevant occupations and professional groups. As highlighted in a review of the literature, training, education and continuing professional development (CPD) are essential components of improving care for people living with dementia.<sup>5</sup> Both Health and Social Care Professionals and carers who responded to the survey ranked training and education as the third most important Priority Action Area.

Almost half (45%) of people living with dementia who responded to the survey stated that education is the most important priority area. Whilst around half of survey respondents noted that they had received dementia specific training and/or

<sup>4</sup> This project was led by Trinity College Dublin and funded by the Health Research Board and supported by the National Dementia Office.

<sup>5</sup> E.g. see Lillo Crespo, Manuel & Riquelme, Jorge & Macrae, Rhoda & Abreu, Wilson & Hanson, Elizabeth & Holmerova, Iva & Martínez, María José & Ferrer-Cascales, Rosario & Tolson, Debbie. (2018). Experiences of advanced dementia care in seven European countries: implications for educating the workforce. *Global Health Action*. 11. 10.1080/16549716.2018.1478686.

<sup>4</sup> Priority Action 3.7 notes that the HSE 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 pathways to be developed and implemented on a local level in acute hospital.



education, 80% of Health and Social Care Professionals and staff from Not for Profit organisations also reported that they would like more training. Health and Social Care Professionals noted that the most significant barriers to receiving further training was the lack of time and the availability of programmes that met their training requirements.

## **Priority Action Area 5**

### Research and Information Systems

Accurate and timely data drives changes, therefore the inclusion of a Priority Area focusing on research and information is central to reporting the outcomes and impacts of activities supported through the NDS. However, findings from this evaluation highlighted that research and information had a low ranking for the evaluation participants. The use of big data and supporting information technology is required to provide better integrated care to people living with dementia and will support research to potentially improve dementia care (Hofmann-Apitius 2015).

In Ireland, the wider implementation of the Single Assessment Tool (SAT) (beyond pilot stages) and integration with existing systems and planned electronic health records will assist with this nationally. In addition, the development of a National

Dementia Registry and better recording and coding of hospital data is crucial to research. Evaluation participants highlighted that e-health initiatives and post-diagnostic support are interrelated. Therefore, the absence of a dementia registry makes it difficult to mobilise and prepare services and supports.

However, the National Dementia Office supported the completion of a feasibility study and awarded funding to Dublin City University (DCU) to develop a model for a dementia registry in Ireland. This work is expected to be completed in 2020.

## **Priority Action Area 6**

### Leadership

The leadership and co-ordination that the National Dementia Office have provided to the NDS has been clear and their work has been visible and wide reaching. The governance structure of the NDO is key to continuing the roll out of the strategy as its values and objectives reflect those of other organisations working to improve dementia care in Ireland.

Feedback provided via surveys, focus groups and interviews highlighted concern regarding the lack of ring-fenced Government funding for the NDS going forward. Stakeholders believed that this has the potential to de-

prioritise dementia care operationally and politically. Dementia care needs to be supported (financially or, through integration of services) if it is to have a lasting and life-changing impact for people with dementia and their families.

## **Conclusion**

A total of €27.5 million programme funding was invested in dementia in Ireland from 2014 to 2017. This funding gave the development of dementia care increased priority and impetus. The full impact of this investment in Ireland will not be known for some time. Many of the programmes that were funded under the strategy are at an early stage and only a small number of them have completed internal or external evaluations. The Priority Actions were key to the implementation of the strategy and reconfiguring existing resources is central to delivery of a cost neutral strategy.

The NDS Implementation Plan is not time bound therefore it remains to be seen if we will witness an implementation time lag. Also, its implementation is further complicated as there is a lack of commitment to further funding, and as a result there is potential for dementia care to be de-prioritised operationally and politically. There are, however, clear and executive management structures within the Health Service

Executive to provide leadership at a system level for the continued implementation of the Strategy. In Ireland, various voluntary organisations have done tremendous advocacy work for people living with dementia and their carers; such foundations and components of commonality between and among organisations are essential to supporting people living with dementia to remain valued, independent citizens.

# CHAPTER 1

## Background to the Strategy

### Introduction

Dementia is best understood as an interplay between neurological impairment and psychosocial factors (Kitwood, 1998). It is a progressive condition leading to decline in multiple areas of function including: decline in memory, reasoning, communication skills and in the ability to carry out daily activities. While treatment and intervention are strived to prevent or slow the trajectory of cognitive decline, there is increasing recognition of the need to focus on managing symptoms.

It is estimated that there are over 9.9 million new cases of dementia each year worldwide, implying one new case every 3.2 seconds (Alzheimer's Disease International, 2015). Dementia care is now centre stage internationally and has already been identified as an emerging public health priority (Alzheimer's Disease International, 2018). In Ireland, the number of people living with dementia (PLWDError! Bookmark not defined.) is expected to treble in the next 30 years rising to 157,883 cases by 2046 (O'Shea et al, 2017). Hence the development of an NDS was highlighted as a key policy goal under the 2011 National Programme for Government. The Irish

government gave a commitment in 2010 to develop and implement a strategy which was based on research findings and collating estimates of current and future prevalence rates, costs and service provision. It also reviewed models of local and international best practice placing an emphasis on those which are person-centred and where the individual is treated as a full citizen with accompanying rights (Cahill et al. 2012). Recommendations from the first national audit of dementia care in Ireland's acute hospital (INAD, 2014) were also included in the National Dementia Strategy (NDS).

Late in 2014, Ireland launched the Irish NDS which was based on the need for an effective, structured, response to dementia. This also aligned Ireland with other jurisdictions which allows international comparisons to be made. Key messages from International National Dementia Strategies are outlined in the next section to help understand dementia priorities in other countries.

### Ireland's National Dementia Strategy (NDS)

Ireland's NDS has been widely welcomed by groups across Ireland and by organisations such as Alzheimer Europe. A total of €27.5 million programme funding was allocated in 2014. Atlantic Philanthropies (AP) invested €12.5 million to the implementation of the strategy, which was matched by funding of €15 million from the Department of Health (DoH)/Health Service Executive (HSE). The investors collaboratively developed the National Dementia Strategy Implementation Plan (NDSIP) which allocated this funding to address key Priority Actions within the strategy.

It was advocated that Dementia policy, service delivery and development should be guided by the principles of chronic disease management as set out in the Policy Framework for the Management of Chronic Diseases (HSE, 2008).

Additional principles specific to the NDS include refocusing of current service delivery to address the needs of people with dementia and their carers in a way that is responsive and flexible.

The four projects funded under the NDSIP were:

- 1 Development and implementation of a public awareness campaign (Understand Together);**
- 2 Development and facilitation of education and resource materials for GPs and Primary Care Teams (PREPARED);**
- 3 The establishment of the National Dementia Office (NDO); and**
- 4 Testing the concept of Dementia Intensive Homecare Packages.**

## Key Principles

The NDS sets out eight guiding principles, they are:

- 1 Appropriate account should be taken of dementia in the development and implementation of existing and future health policies.
- 2 The approach of the Age Friendly Cities and Counties Programme and the Healthy Communities/Cities Programme, which is to enable people with dementia to live well as valued citizens should be supported and encouraged, including through representation for people with dementia on Older People's Councils, the establishment of which has been committed to in the Programme for Government.
- 3 Regular assessments of palliative care need should be conducted by staff providing care to people with dementia. Staff should have the training in the principles of palliative care to assess palliative care need, and referral should be made to specialist palliative care services to support care provision where required. People with dementia should be supported to be cared for in the place of their choice, as far as is possible, including at the end of life.
- 4 Those who provide services/care or who interact with people with dementia, including healthcare professionals, clerical and administrative staff, volunteers and staff of external organisations, should be appropriately trained and regularly updated in dealing and communicating with those with dementia. All communications with, or material relevant to, people with dementia should have content and format that maximises accessibility and ease of understanding.
- 5 People with dementia should be supported to retain skills as much as possible.
- 6 Available resources should be deployed on the basis of need and as effectively as possible to provide services for all people with dementia, including those with early-onset dementia and/or an intellectual disability, and should be delivered in a culturally appropriate way.
- 7 An integrated partnership approach should be taken to the planning, development, delivery, evaluation and monitoring of services for people with dementia, with the inclusion of all stakeholders from the public (i.e. local authorities and other state agencies, health and social services), private and voluntary sectors.

- 8 Clinical effectiveness as a key component of safe, quality care is an underpinning principle of the National Dementia Strategy. A clinical effectiveness approach incorporating national and international best evidence will promote the delivery of integrated dementia care that is current, effective and consistent.

## NDS Implementation Structures

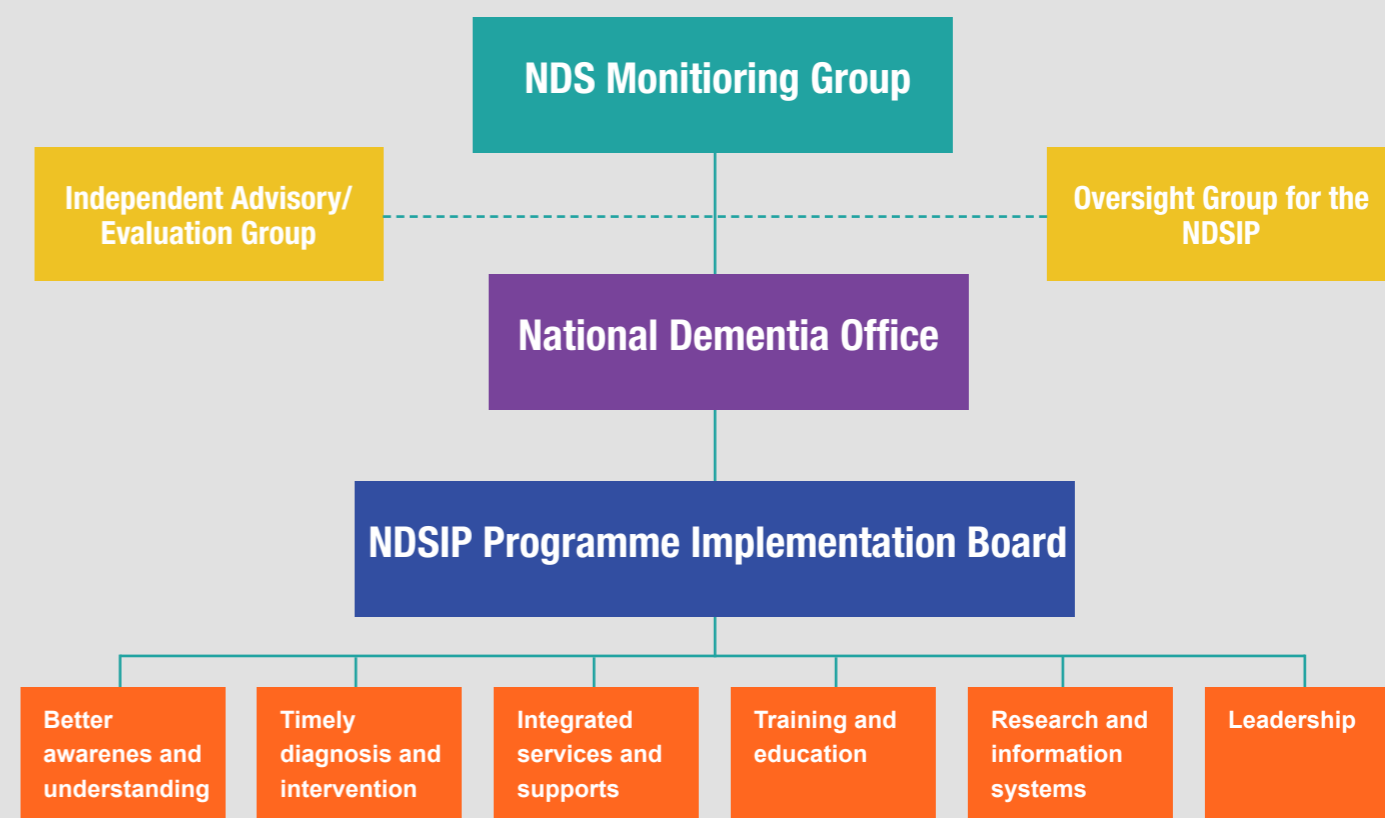
The strategy identifies 14 Priority Actions and 21 Additional Actions which are grouped under the 6 Action Areas. The priority actions are considered to be key to the implementation of the strategy and were originally intended to be implemented within

existing resources or by reconfiguring resources as it was necessary for the Strategy to be cost neutral. The implementation of the NDS began in 2015 and initially focused on actions that could be prioritised with funding from HSE and AP. As set out in the following diagram (Figure 1.2) the implementation of the strategy is overseen by the NDS Monitoring Group.

The Monitoring Group is a multi-agency, multi-disciplinary group, which is chaired by the DoH and includes academic, clinical experts and voluntary organisations, a person living with dementia and a family carer, in addition to senior representatives from the DoH and the HSE. The role of the

Figure 1.1 National Dementia Strategy Implementation Governance

Source HSE (2018)





NDS Monitoring Group is to monitor the implementation of the strategy and to allow experts to input into its roll-out. An Oversight Group, chaired by the DoH and including representatives from the HSE and the AP, oversees the implementation of the NDSIP.

## The National Dementia Office

The National Dementia Office (NDO) was established in 2015 in response to one of the priority actions of the NDS with the HSE committing €1.5 million in funding to support the establishment of the NDO which became fully operational in 2017. To complete the governance structure the National Dementia Strategy Implementation Board was established and brings together project leads for each of the different work streams within the NDSIP. The many representatives within this board facilitates information sharing and integration of priority actions areas. This Implementation Plan was published in 2017 and describes the NDSIP programme, purpose, scope and terms of references. It also provides a summary of key deliverables for each work stream and who is responsible for the implementation task and a key performance indicator traffic light system is used to communicate the status of the project.

The NDO is key to progressing the NDS. The vision of the NDO is very much underpinned

by the guiding principles of the NDS, that of personhood and citizenship.

In order to achieve this vision, the NDO:

- **Oversee and lead the implementation of the NDS;**
- **Work in partnership and collaboration with key stakeholders;**
- **Integrate different elements of the strategy into the wider health and social care system;**
- **Develop the required evidence base, test concepts and support innovation; and**
- **Inform policy and strategic direction.**

The NDO operates at a strategic level within the HSE and is involved in influencing the health service planning at both a national and local operational level. The NDO works with the DoH ensuring that best practice and research findings in dementia care influence strategy and policy at a national level.

Although the office is not directly responsible for service provision, it does engage with health and social care professionals who are in direct service provision as well as at a senior management level.

The key role of the NDO is to build relationships with key stakeholders, including PLwD and their families and to maximise individual work by promoting collaboration. Members of the office formally meet and consult with the Irish Dementia Working Group and the Dementia Carers campaign

network. Within the health services, the NDO are building links with colleagues working across community, primary, acute and long-term care, as well as colleagues in the intellectual disability (ID) services to integrate dementia care within existing programmes; for example, the integrated care programme for older persons (ICPOP), the Chronic Disease Management Framework, Sláintecare and the broader health and social care system.

The NDO also work with a range of voluntary and not-for-profit organisations in Ireland. The largest of these organisations is the Alzheimer Society of Ireland (ASI).

The NDO works to ensure that a coherent and holistic approach is adopted to the implementation of the NDS. The NDO have established a number of different projects and work together with a variety of health and social care professionals (HSCPs) to build a comprehensive dementia services for the island of Ireland. For example, the public awareness campaign, Understand Together, which is led by HSE communications in partnership with the Alzheimer Society of Ireland and Genio and supported by the NDO and HSE Health and Well-Being. Other examples include the Dementia Diagnostic and Post-diagnostic Projects, the establishment of a network of Memory Technology Resource Rooms in the community, the delivery of community based post-diagnostic supports and psycho-

educational programmes, training and education programmes.

The NDO work with a range of research organisations and institutions to promote the transfer of knowledge generated from research into policy and practice. Finally, listening to the voices of people with dementia and their families, is an integral part to ensuring the work of the NDO is meeting needs. There are many challenges associated with managing the care of PLwD, in acute care or in the community, including healthcare professional-specific and patient-specific challenges. These were highlighted by Ireland's NDS (2014) as Priority Action Areas, many of which are closely connected (see Table 1.1). The current state of these Action Areas in national (Irish) and international settings are reported in the Mid-Term Review of the Implementation of the NDS published in 2018.



**Table 1.1** Summary of the Priority Action Areas under Ireland’s National Dementia Strategy

<b>1. Better awareness and understanding</b>	
1.1	Better Awareness and Understanding: a) Provide a better understanding of dementia b) Reduce the stigma that can associated with dementia c) Target populations, particularly at risk including people with an intellectual disability d) 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 Activity Plan which will encourage the population to be more physically active.
1.2	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 the frontline public services, as part of the Health-Promoting Health Service Executive Initiative.
<b>2. Timely diagnosis and intervention</b>	
2.1	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.
2.2	The following material will be developed and made available to GPs: a) Dementia specific material to broaden skills base; b) Guidance on national and local pathways to investigation and diagnosis; c) Information about health and social supports available in the local community.
2.3	The HSE 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.
2.4	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.

2.5	The HSE 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.
2.6	The Health Service Executive will implement the National Consent Policy (Health Service Executive – May 2013).
2.7	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.
2.8	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.
2.9	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>3. Integrated services, supports and care for people with dementia and their carers</b>	
3.1	The HSE will critically review health and personal social services for people with dementia to: a. Identify gaps in existing provision; and b. Prioritise areas for action in accordance resources availability, with priority being given to the most urgent deficits that can be addressed either within or, by reconfiguring existing resources.
3.2	The HSE will consider how best to configure resources currently invested in 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 to improve the supports available for carers.
3.3	The HSE will evaluate the potential of assistive technology to provide flexible support both to carers and to people with dementia.

3.4	In line with health promoting health service model, the HSE 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.
3.5	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.
3.6	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.
3.7	The HSE will develop and implement a dementia and delirium care pathway, which could be fitted into existing acute, rehabilitative, care of older people, stroke, mental health, palliative care and end-of-life pathways to be developed and implemented on a local level in each acute hospital.
3.8	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.
3.9	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.
3.10	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.
3.11	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.
3.12	The Health Service Executive will work to maximise the implementation of the national policy on restraint: Towards a Restraint Free Environment in Nursing Homes.

3.13	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.
3.14	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>4. Training and Education</b>	
4.1	The HSE 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 staff of nursing homes
4.2	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>5. Research and Information Systems</b>	
5.1	The Health Service Executive will ensure that data from the Single Assessment Tool (SAT) is factored into research to inform dementia care in Ireland.
5.2	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.
5.3	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>6. Leadership</b>	
6.1	Clear, overall responsibility for dementia will be assigned to a person at senior management level within the HSE.



6.2	The Clinical Strategy and Programmes Division of the HSE will establish a Workstream on Dementia Care as 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 HSE Directorates
6.3	Within primary care services, a named key worker will be appointed to play a key role in co-ordinating each patient's care promoting continuity and ensuring that the patient knows who to access for information and advice.
6.4	Clear and effective management structures will be established within the HSE to provide leadership at a system level for the implementation of the Strategy.
6.5	The DoH and the HSE 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.

## Summary

The NDS was launched in 2014 with total funding of €27.5 million provided by both AP and the DoH. The NDO was then established in 2015 to drive forward the implementation of the strategy. A multi-agency, multi-disciplinary monitoring group was also established to monitoring the implementation of the strategy and to allow for expert in-put.

As part of the Memorandum of Understanding (MoU) with the AP, DOH and the HSE for the implementation of the NDS, funding was allocated for an external evaluation of the NDS. Following a national tender competition, the HSE commissioned a consortium of Ipsos MORI and the University College Cork (UCC) to undertake an evaluation of the NDS and the NDSIP.

# CHAPTER 2

## Terms of Reference and Methodology

The purpose of this chapter is to outline the methods used to capture the learning from the impact of the NDS and the outcomes from the three investment priority actions activities. Efforts were made to evaluate the NDS on three levels 1) whole system level, 2) programme evaluation level and; 3) project level. There are a number of interventions both simple and complex that are part of the NDS, therefore, a mixed-method design was adopted to explore the interventions and hypotheses were generated to inform the evaluation process.

The overall aim of this evaluation report is to provide a description of the NDS from the perspective of key stakeholders.

### Terms of Reference

The overarching objectives of the evaluation, as set out in the terms of reference, are to understand the impact of the NDS and the NDS Implementation Plan, as well as an:

- **Assessment of how the NDS/NDSIP was implemented and the processes used;**
- **Assessment of improvements in the dementia care systems;**
- **Assessment of the extent to which the NDS programme and project activities**

**impacted on people with dementia, their families and carers;**

- **Assessment of strategic dementia policy impacts and outcomes for providers;**
- **Assessment of the level of engagement and effectiveness of internal and external partnerships;**
- **Assessment of whether the NDS and NDSIP have increased availability of dementia care services and opportunities to access a range of supports;**
- **Assessment of the reach of the NDS and the number of people who engage in the NDS interventions;**
- **Evidence and data on the degree to which the objectives of both the programme and individual projects were met and the extent to which achievements are sustainable; and**
- **Assessment of incentives and barriers encountered, including lessons on what worked well and what did not work.**

### Methodology

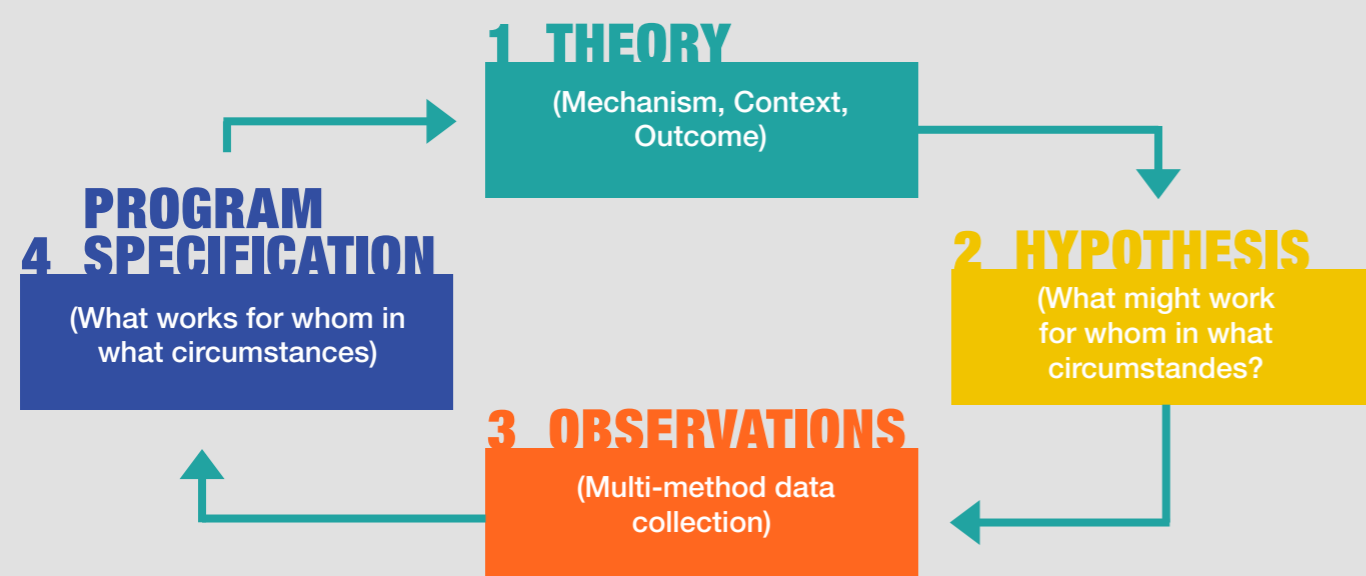
Very soon after appointment the evaluation team undertook an evaluability assessment of the NDSIP. Following this it was agreed with the Evaluation Steering Group that it was too early in the process to complete a credible evaluation of the NDSIP. Therefore, the focus of the evaluation should be on the NDS itself.

The methodology applied to this evaluation was a Realist Evaluation Framework. This involved four stages of work to identify and examine the mechanisms (M) that allowed the strategy to be implemented, the conditions and context (C) in which the strategy operates in the outcomes (O) that have emerged so far, as summarised in the table below. The evaluation team then undertook a theory building exercise to examine the goals and guiding principles of the NDS. The evaluation team worked closely with the steering group and other key stakeholders to access relevant reports and communications to determine what outcomes have emerged to date and who the outcomes were intended for. This was followed by a process of deconstructing the project objectives. A traditional project management model of initiate, define and explore helped to structure and simplify the project procedures into a series of logical work packages.

The realist cycle, as outlined in figure 2.1 facilitated the identification and examination of the interwoven activities of the NDS that developed simultaneously and across different levels in society. The evaluation also explored the mechanisms that allowed the interventions of the NDS to develop and the conditions or contexts in which they operated.

The evaluation fieldwork was conducted over 12 months, (between January 2018 and January 2019) and involved three distinct phases of data collection (see Table 2.1). Ethical approval for all phases was granted by the Social Research Ethics Committee at UCC. Confidentiality and anonymity were paramount during all phases of data collection and reporting.

**Figure 2.1** Realistic Cycles



**Table 2.1** Key activities in each phase of the data collection

Summary of Phase 1-3 Data Collection Methods			
1	Phase 1: Stakeholder Engagement. Qualitative Cycle	2	Phase 2: Self-completion of surveys (online and postal). Quantitative Cycle
3	Phase 3: Service Users and Staff Experiences. Qualitative Inquiry	4	Interviews and focus groups were held with 35 key stakeholders from Executive or Service User Level.
5	Those on the Executive Level (n=18) were involved in the development, monitoring, oversight, or implementation of the NDS and NDSIP, and includes PLwD.	7	Surveys were completed by: <ul style="list-style-type: none"> <li>• Health and Social Care Professionals (n=634)</li> <li>• Not for Profit organisations that provide services to people living with dementia and their carers (n=16)</li> <li>• People with living with dementia (n=6)</li> <li>• Informal carers/ family members of people with dementia (n=177)</li> </ul>
6	Stakeholders on the Service User Level (n=17) are individuals that the NDS and NDSIP are intended to impact upon (i.e. PLwD and their caregivers).	8	Participants were recruited from Four Community Health Organisation areas based on the following criteria:
		9	(i) Geographical location
		10	(ii) Number of respondents in the area
		11	(iii) The spread of disciplines amongst health and social care professionals
		12	Interviews were held with participants (n=20) both lay and professional to capture the experiences of people living and working with people with dementia.
Fieldwork: August 2018 to January 2019			



## Evaluation of NDS Supported Initiatives

Many innovative and unique projects have been developed in Ireland since the strategy was published, some of which were funded directly from the strategy, whilst others used the Irish NDS as a launch pad to establish good practice within the HSE or, the voluntary sector. Given the significant reach and influence of the NDS it is very difficult to identify and measure the merits of all of these projects. Projects that were funded through the original AP/HSE investment had an evaluation in-built and therefore additional evaluation of their outcomes is outside the scope of this evaluation. These interventions/projects are at different stages of implementation and evaluation, but all indicate high levels of acceptability and feasibility to deliver. However, ascertaining the sustainability and scalability of all these interventions is ongoing. The Mid-Term Review of the implementation (DoH, 2018) illustrates the progress against each of the 35 actions set out in the NDS and identifies where more activity is required. The work of the National Dementia Office is fundamental to further progressing the implementation of the strategy.

From evaluation data available it is evident that, so far tremendous progress has been made, particularly in the implementation of funded actions. The implementation of other

actions has been gradual. An example of this is the Dementia Adviser Service (DA service); an additional action of the Priority Action Area 'Timely Diagnosis and Intervention' in the NDS, the Health Service Executive is to consider the provision of this service. The DA service was initially piloted in Dublin and Cork in 2013 and by 2015 a total of eight DAs were in post. A recent evaluation of the service (Coffey et al., 2018) used a 360 degree, mixed methods approach with feedback from key stakeholders which highlighted the importance of this service. The evolution of the DA service is in line with international experience (see Chapter 3). A recommendation from the evaluation states that it is important that the DA Service has legitimacy within formal services to access supports and provide an integrated holistic model of care. The HSE has now funded this service since 2016. The longer term plan and strategic direction of the service remains unknown. The following table (2.2) provides an overview of the evaluation data that is available for the AP/HSE funded projects.

## Limitations of the Evaluation

There are a number of limitations to this evaluation. Firstly, it was difficult to recruit PLwD unless they were formally part of an advocacy group or organisation. Secondly, for phase two, participants self-selected to complete the questionnaire. Despite a number of reminder e-mails distributed by the HSE and an extended period for participants to complete the survey, the response rate remained low for key HSCPs. Also for PLwD and their carers, the ASI distributed the survey to its members therefore caution needs to be exercised with the generalisation of the results. There was an overwhelming response to the expressions of interest in phase 3 however there were project constraints that hindered further exploration of the cases. Whilst the team have made every attempt to ensure that the information contained in this review is as comprehensive as is possible, other external evaluations were not complete at the time of completing this study so the true impact of the strategy remains to be observed.





**Table 2.2** Overview of NDS projects funded through AP/HSE investment

Name	Aim/Scope	Activity
Evaluation of Intensive homecare package (IHCP) 2014	To examine the feasibility and effectiveness of IHCPs in providing care for older people with complex needs at home.	Support the HSE in the development of a suite of indicators for IHCPs and related data collection tool and provide on-going data analysis and reporting of IHCPs. This included a particular focus on dementia-IHCPs. This is reported in Report 1: Supporting Older People with Complex Needs at Home: Evaluation of the HSE Intensive Homecare Package Initiative-Context, Recipients and Costs (Keogh et al 2018).
Evaluation of Intensive homecare package (IHCP) 2014	To determine the outcomes and practical implementation of IHCPs, with a focus on user satisfaction and quality of life.	Design, manage and undertake an in depth study of a sample of dementia-IHCPs to evaluate their effectiveness and how well they are working. This work is reported in Report 2: Supporting older people with complex needs at home: What works for people with complex needs at home: What works for people with dementia? (Keogh et al 2018).

### Main Findings & Challenges

Over the first 3 years of the IHCP initiative, 505 people were supported to remain at home, often for significant periods of time. This included almost 300 people with dementia. Estimates of the likely duration of IHCPs were calculated from the outset and after 12 months about half of all packages remained active and after 24 months this reduced to almost a quarter. It is evident that IHCPs can keep people at home for significant periods of time both in urban and rural settings, for those with high dependency levels, for people with little or no family and for people who were at the end of life. The main component of all IHCPs was hours of care provided by home helps and homecare workers. The number of hours provided by dementia IHCPs ranged from 6-168 hours per week with a mean of 39 hours per week provided. IHCP recipients with dementia received significantly fewer hours per week than non-dementia recipients. The average weekly cost was €925 for dementia-IHCPs. The importance of a family care system can't be underestimated and the provision of flexible, responsive and reliable support is key for family carers.

This initiative demonstrated that the delivery of IHCP was effective at maintaining people with dementia at home for an average of 42 weeks. The majority of carers and people with dementia were satisfied or very satisfied with their package. The quality of life of carers was also maintained with the package for the majority. The packages worked well for families when homecare workers were well trained and a personalised approach to care was evident. The estimated weekly average cost of homecare per person with dementia was €1,124 per week. The average weekly cost of long stay care in residential settings ranges from €1,526 in public facilities to €909 in private nursing home outside Dublin and €1,149 in private nursing home in Dublin. Informal care and private care combined account for 47% of overall costs for people with dementia living in a community setting. A striking finding was the strong family commitment to caring. The input from families is substantial and is not replaced by the IHCP.

Name	Aim/Scope	Activity
Evaluation of Intensive homecare package (IHCP) 2014	To identify the challenges and enablers for undertaking personalised care by testing the concept within real environments of care delivery	Support the HSE in the implementation of personalise dementia IHCPs. Genio Programme Managers have been working collaboratively with multidisciplinary groups in eight sites, to promote a personalised response to homecare for people with dementia, by creating and testing enhanced pathways for delivery.  This work is still underway at the time of this publication/report, partial results are reported in Report 3: Developing Integrated Personalised Supports for People with Dementia. (Howard et al 2019)
Primary Care Education, Pathways and Research of Dementia (PREPARED)	To support GPs to assess, diagnose and help manage people with dementia in the community.	A broad strand of work focused on designing, developing and delivering a range of dementia educational programmes and guidance and resource materials. <ul style="list-style-type: none"> <li>• Peer-facilitated dementia workshops for general practitioners</li> <li>• Interprofessional dementia workshops for primary care teams</li> <li>• Develop a dementia website for primary care based health professionals <a href="http://www.dementiaphways.ie">www.dementiaphways.ie</a></li> <li>• ICGP e-learning dementia module</li> <li>• UCC university accredited 12-week blended learning course</li> <li>• Audit tools – iPCRN and ICGP</li> <li>• Dementia reference Guide for the ICGP</li> </ul>

Main Findings & Challenges
<p>The personalised approach to care delivery was tested and demonstrated the potential for cost effective outcomes that are quality driven and facilitate the avoidance of premature entry to long term care. Despite the significant challenges in the implementation, the national roll out of dementia specific IHCP was broadly welcomed by staff. Adopting a personalised approach to care for people with dementia helped give equal weight to the psychosocial needs of the person with dementia not just the physical care needs.</p> <p>Staff reported that when they engaged with families, built a relationship of trust and co-designed supports it helped strengthen the homecare service. There was a demand for more local forums that would work towards integrating services and adapting personalised supports and local community connection. The process of personalising packages was central to saving costs and maximising resources rather than having a standard pre-determined format such as a 30 minute or 1 hour allocation of support to provide personal care at set intervals during the day.</p>
<p>The evaluation of the IT/web based resources was demonstrated to 190 general practitioners in 36 workshops nationwide. All of the general practitioners surveyed felt that <a href="http://dementiaphways.ie">dementiaphways.ie</a> was a useful resource for them.</p> <p>Self-reported improved knowledge and confidence in dementia care. Small-group peer facilitation was well-received by GPs as an education model. Feasible and acceptable model of education delivery to GPs</p> <p>The total number of GPs/workshops run by PREPARED up to the end of March 2019 in either practice-based small group sessions or at ICGP small group sessions was 94 workshops, 610 attendees. Challenges to bring about behaviour and practice change relate to current workloads, absence of a chronic disease programme for dementia and absence of functioning primary care teams nationally. Misperceptions and knowledge deficits identified in relation to BPSD and advanced care planning. An external evaluation of the report is ongoing and wider roll out and sustainability was considered e.g. for GPs, by engaging with the ICGP and some of their CME small group tutors to make the PREPARED material available to them, and by working with the NDO on the roll out of the PCT/interdisciplinary programme nationwide through educational networks and interested individuals. Further follow-up is required to evaluate any impact on clinical practice or outcomes for PLWD and carers.</p>

Name	Aim/Scope	Activity
Understand Together (UT) a campaign led by HSE (Health and Wellbeing Directorate), working with The Alzheimer Society of Ireland and Genio.	The campaign seeks to build on the wide range of dementia specific programmes and initiatives already in place around Ireland. The aim is to draw together the people and organisations to create a national movement to help support those living with dementia and their loved ones.	Survey public knowledge and understanding of dementia. This survey informed the development of a national understand together campaign which aimed to educate the general public about dementia
Understand Together (UT) a campaign led by HSE (Health and Wellbeing Directorate), working with The Alzheimer Society of Ireland and Genio.	The campaign seeks to build on the wide range of dementia specific programmes and initiatives already in place around Ireland. The aim is to draw together the people and organisations to create a national movement to help support those living with dementia and their loved ones.	Assess general population's understanding and attitudes to dementia  Establish awareness of the UT campaign  Multimedia campaign (TV, radio, newspaper)

Main Findings & Challenges
<ul style="list-style-type: none"> <li>• Survey of public knowledge and understanding of dementia (n=1,217) [2017].</li> <li>• 52% knew someone with dementia, 39% were aware of early signs and 46% believed they could reduce their risk of dementia.</li> <li>• Knowing someone with dementia was associated with greater insight into dementia.</li> <li>• 1 in 3 or 1 in 5 did not know specific modifiable factors (hypertension, diet smoking, alcohol and exercise)</li> <li>• Over high levels of confusion about the relationship between dementia and ageing, and knowledge of risk and protective factors for dementia is very poor.</li> <li>• In essence prior to the campaign the general public are confused about the relationship between dementia and ageing, and knowledge of risk and protective factors for dementia is very poor.</li> </ul> <p>While not dissimilar to those reported internationally, the findings present a challenge to those tasked with promoting behaviour change and interventions to delay or prevent the onset of dementia.</p>
<p>Survey conducted with general population (n=1,003) [2017] via computer assisted telephone interviews. 32% spontaneously aware of campaign. TV=89% most effective medium, 59% report some impact (mainly on intentions), 50% likely to delay seeking early diagnosis and intervention. Overall positive impact, more emphatic views towards PLwD. Increased awareness of risk reduction. Low levels of active engagement with PLwD and families (9-12%). 50% likely to delay getting an early diagnosis. 25% report stigma associated with dementia. 52% knew someone with dementia, 39% were aware of early signs. 46% believed they could reduce their risk of dementia. 1 in 3 or 1 in 5 did not know specific modifiable factors (hypertension, diet smoking, alcohol and exercise). Over high levels of confusion about the relationship between dementia and ageing, and knowledge of risk and protective factors for dementia is very poor. Need for public education campaign with emphasis on dementia risk reduction.</p>



# CHAPTER 3

## International National Dementia Strategies

### Introduction

In addition to the three phases of primary data collection a review of national and international literature was completed. This focused on the development and implementation of dementia strategies and was done to understand how dementia strategies were developed and prioritised in other countries.

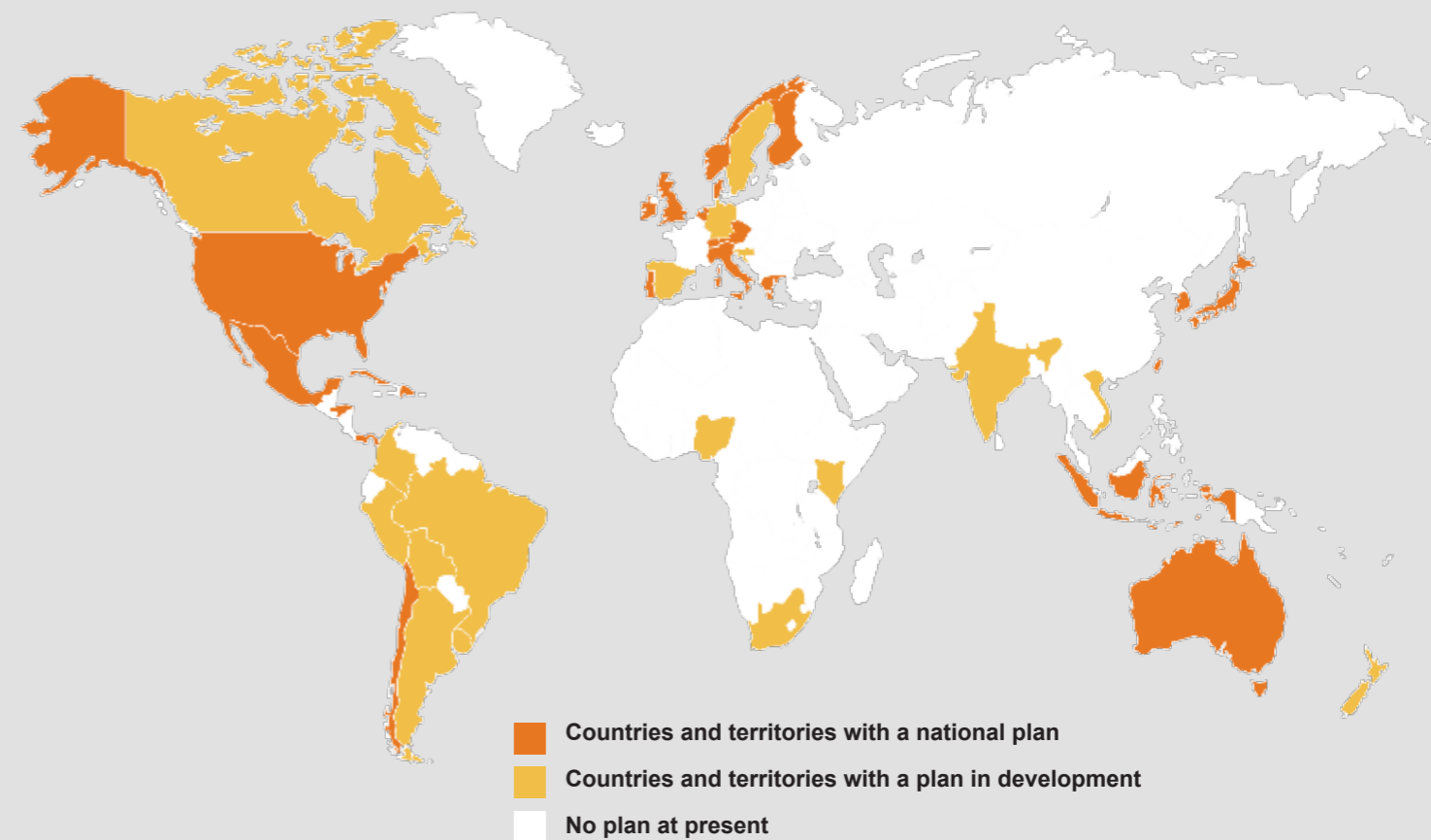
Over recent years several countries have produced a National Dementia Strategies or guidelines which have already begun to change the way dementia care is perceived and managed. Whilst, there is debate about how effective these programmes are in delivering truly patient-centred care in dementia, a national strategy can provide best-practice, goal directed guidelines that summarise key principles and priorities to structure and inform the full range of health and social care services for PLWD, their families and carers. It also acts as a road map for professionals to support the integration of systems by increasing awareness, early diagnosis, intervention and the development of enhanced care pathways.

Dementia Strategies are positive; they generate extra resources for the sector and are designed to engender changes in public attitudes (Cahill, O' Shea & Pierce, 2012).

Population ageing has been a driver both nationally and internationally to develop a NDS. International data from Alzheimer's Disease International show that as of 2017, 32 countries and territories across five continents have adopted national dementia plan (<https://www.alz.co.uk/dementia-plans>). Data from Alzheimer's Disease International (2018) highlights countries across the world that have a NDS in place see Figure 3.1. Outside the European Union (EU) there are strategic plans already in place in such countries as Australia, Canada and the United States of America (USA). Across many of these international examples, there are common themes, for example, the inclusion of the individual with dementia in decision-making.

Figure 3.1 The Status of National Dementia Strategies Internationally

Countries with plans on dementia or in development in 2018



(Source Alzheimer's Disease International, 2018)

### Key Messages from the International Literature

**A review was undertaken to explore evaluations of components or programmes emanating from National Dementia Strategies or, plans internationally and are discussed below.**

**Table 3.1 Summary of Priority Areas in other National Strategies**

Priority Area	Number of Countries	Strategy or Key Action
Increasing awareness of dementia	18 Countries	Education of families and community, awareness campaigns, create dementia-friendly communities.
Reducing the stigma of dementia	6 Countries	Awareness campaigns, annual events for World Alzheimer's day.
Identifying support services	14 Countries	Support networks for caregivers, telephone help-lines, creation of websites, Czech Republic planned to provide financial support to caregivers. Many countries appointed a professional to support patients through the disease journey and some also prioritised support for specific groups including younger persons with dementia, those with behavioural problems, or with learning disability. Post-diagnostic support and access to day programs were also included in some of the NDSs.
Improving the quality of care	29 Countries	MDT care, improving access to care and services. Some countries planned to develop clinical guidelines and pathways to standardise care. Plans to improve dementia care in the acute hospital through specialised co-ordinators and / or teams appears frequently also (Ireland mentioned). Individual NDSs include plans to improve access to end-of-life care, standardise the approach to driving assessment in persons with dementia, develop 24-hour care services, and / or conduct home visits for older adults to help prevent dementia.

(Source Chow et al. 2018)

Improving training and education for HSCPs	16 countries	Included incorporating geriatrics training in undergraduate and graduate curricula, increasing the number of dementia specialists, revision courses for HSCPs, development of clinical and research scholarships and upskilling general practitioners (Ireland mentioned).
Promoting research	17 countries	Areas for research and hosting dementia research summits.
Funding	13 countries	Specified funding but only 6 gave figures (inc. Ireland)
Implementation	16 countries	Implementation plans -only two had well-structured and detailed plans (Cuba and Finland). 5 countries specified how the NDS would be reviewed and monitored.

### Priority Areas Internationally

*Chow et al. (2018)* reviewed the 29 existing NDSs in 2018 with a view to aiding the development of the Canadian NDS. They summarised each NDS including the years the NDS has been active, framework conditions, key actions, involvement of stakeholders, funding and implementation plans. Although each NDS varied, there were several common major priorities as summarised in the previous table.

Similarity, *Edick et al (2017)* identified that the most common themes across Strategies were improving diagnosis and assessment; increasing access to care; and education of the workforce with the former two themes evident in all 22 strategies (16 countries

and 6 Canadian provinces) and the latter in all but one. Additional areas of priority demonstrate certain elements do not transcend all strategies for example human rights, legal matters, residential care, and technology (Alzheimer's Europe, 2018).

Public awareness, improved understanding and acceptance of dementia were seen as key components of all strategies reviewed. In a review of 15 European and 9 global policy documents on dementia, *Wright and O'Connor (2018)* found that raising awareness and reducing stigma were key themes. A further review of 29 national strategies by *Chow et al. (2018)* found that increased awareness of dementia reduced stigma.

An evaluation of the Australian National Dementia Quality Care Initiative by *Westera et al (2014)* reported that consumers had the capacity to drive effective knowledge translation in relation to dementia and recommended the maintenance of consumers in the translation process. They further found that balancing the perspective of people with dementia and carers in priority setting for future projects would on the success of the NQDCI. The initiative also demonstrated to the broader aged care sector that service users (consumers) have the capacity to drive effective knowledge translation (*Westera et al., 2014*).

The review of the literature identified the need for an integrated approach to training along with further investment in research, training and education for staff. For example, *Chow et al. (2018)* noted that 16 National Strategies have prioritised education and training for HSCPs.

*Clarke et al. (2014)* evaluated Dementia Advisors (DAs) and Peer Support Networks across 40 demonstration sites in the UK. They found that in successful services, the function of DAs and PSNs incorporated filling gaps in existing services as well as assisting with transitions between services and providing information, advice and interpersonal support on an individualised basis.

*Fortinsky and Downs (2014)* highlight that much of the focus of NDSs is on preventing or delaying transitions rather than facilitating or improving the transition experience. They also note that most strategies focus on providing care within a particular setting rather than on transitions of care. The level of specifics in the actions plans for addressing transitions varies widely between the strategies. Most strategies refer to a dementia care coordinator or advisor but do not outline which transitional points in the dementia journey that they have responsibility to facilitate. Most strategies do not make it clear to patients and caregivers how services can be accessed at transition points. Few strategies consider evidence-based approaches to improve transitions.

Themes identified by the *Alzheimer Strategy Overview Committee in Canada (2013)* include the need for an increased emphasis on prevention and risk reduction along with the need for early recognition, initial assessment and diagnosis in a strengthened primary care. These authors also recommended the development of medical specialist resources and caregiver information and support; recognition of caregiver contribution; workplace flexibility and financial assistance for carers; assistance with system navigation; increased access to services for people with dementia and further training and education for health and social services staff (*Alzheimer Strategy*

*Overview Committee, 2014*).

Similar findings were reported by *Martel Consulting in Ontario (2015)* with additional need identified for system integration and co-ordinated pathways of care. They recommended that support was needed for dementia as a chronic condition and activities and attitudes to 'live well' with dementia, with better access to a continuum of dementia care. A dearth of official data and of care services particularly for people in late stages of dementia and a lack of trained specialists and staff at all levels were identified by *Alzheimer's Bulgaria (2015)*. This report called for an integrated approach along with investment in education and training. Investment in further research, training and education for workforces was also recommended by *Wright and O'Connor (2018)* in their review of European and global policy documents on dementia and by *Lillo-Crespo et al. (2017)* and *Chow et al. (2018)*.

## International Methods of Evaluation

It is interesting to note that very few countries have evaluated the effectiveness of their Dementia Strategies. Furthermore, it is difficult to compare the effectiveness of the different strategies internationally, as different countries have unique levels of access to a universal healthcare system (*Chow et al.,*

*2018*). The literature review also considered what methods were used in other countries to evaluate national strategies. The majority of those who have implemented any form of evaluation used consultative processes and/or a comprehensive review of published dementia strategies and relevant literature and/ or survey methods.

The *Alzheimer Strategy Overview Committee of Canada, (2013)* reported the use of an extensive review, a gap analysis and focused stakeholder consultations with caregivers and care/service providers to provide a roadmap that outlined gaps and strategic opportunities for the future strategy.

In Australia the *Health Ministers Advisory Council (2015)* reported using an extensive national consultation process with all stakeholders (PLwD, carers and service providers) to develop a new National Framework for Action on Dementia that would build on the achievements of the previous strategy. In the *UK Wright and O'Connor (2018)* used an adaptation of the PESTEL framework for business analysis to conduct a review of 15 European and nine global policy documents. *Alzheimer's Bulgaria (2015)* used two quantitative studies, six round table discussions (not detailed) along with a review of official policy documents to conduct their review of their NDS. In a similar review, a national survey with people with dementia and their families was conducted by the *Norwegian Ministry of*



*Health (2015)*. A mixed methods approach and an evaluation framework on three levels of evaluation (consumers, providers and the system) was employed by *Westera, Thompson and Morris (2014)* to evaluate Alzheimer's Australia National Quality Dementia Care Initiative.

## Summary of papers reporting on programmes pre and post launch of National Dementia Strategies Internationally

There were no papers sourced that specifically sought to evaluate dementia services, supports and care pre and post the launch of a national dementia strategy, however a number of documents were found that reported impact following the implementation of a programme(s) emanating directly from a strategy.

*Jack-Waugh et al. (2018)* assessed the educational impact of the dementia champions programme in Scotland. A repeated measure design (pre and post programme) using a self-complete questionnaire of attitudes towards people with dementia; self-efficacy and knowledge of dementia was completed by healthcare staff. Data was collated from four cohorts (n=524) across four years (2014–2017). The Dementia Champions programme was

delivered via blended learning; over an eight month period. The findings indicated that the programme had a measurable positive impact on participants, regarding their knowledge of dementia, approaches to dementia and confidence in their ability to achieve the learning outcomes.

The prescription of antipsychotics after the introduction of an NDS has mixed findings. *Szcepura et al (2016)* conducted a retrospective analysis of rates of antipsychotic prescribing in 616 Long-Term Care (LTC) institutions following the launch of the NDS in England and Wales. The rates of antipsychotic prescribing was compared between the 1st of January 2009 (pre-launch) and 31st December 2012 (4 years post-launch). There was no significant difference in prevalence of anti-psychotic prescribing between the two time points, nor in agent type or duration of prescription. However, *Donegan et al., (2017)* reported a large reduction in overall antipsychotic drug prescription in dementia, from 22.1% in 2005 to 11.4% by 2015 in the UK. Within acute hospitals in the UK there was a 51.8% reduction in the use of antipsychotic medications for hospitalized patients with dementia in England and Wales from 2008 to 2011.

*Mukadam et al., (2014)* used nationally available data to estimate diagnostic rates and treatment of dementia before and after

launch of the English NDS. The NDS for England was launched in 2009, but similar strategies were published for Scotland in June 2010 and Wales in February 2011. Data was extracted from five national databases and trends over time in rates of dementia diagnoses were examined. Findings showed that dementia diagnosis rate was lower prior to launch of the NDS and increased significantly after it was launched. The number of anti-dementia prescriptions and the cost of anti-dementia drugs relative to total Primary Care Trust prescribing costs increased significantly after 2009. The launch of the NDS was associated with a significant increase in dementia diagnosis rates and prescriptions of anti-dementia drugs. Furthermore a memory clinic survey found that the number of people using memory services was 1.5 times higher in 2010/2011 than in 2008/2009.

*Menon and Lerner (2011)* reported on the positive impact of dementia strategies. Specifically, they sought to examine the impact of NDS and Social Care Institute for Excellence and/or National Institute for Health and Clinical Excellence (UK) on frequency of cognitive screening instrument use reported in referrals (n = 306). There was an increase in the number of GP referrals over the study period but the proportion of dementia diagnoses fell and the frequency of cognitive screening instrument use was unchanged.

## Conclusion

A National Dementia Strategy is a comprehensive government plan, developed in collaboration with multiple stakeholders, to provide appropriate care for people with dementia and may also provide education and resources to the general public on how best to prevent the onset of dementia (Chow, 2018). It is typically tailored to the unique needs of the population served. Common priorities for NDSs include raising awareness of the disease, addressing stigma, mapping existing support services, epidemiological study of the numbers of persons with dementia, reviewing and improving care quality, and reviewing the availability of and access to diagnostic services.

Our review revealed few evaluations exist of National Dementia Strategies. Of those that were available for review, the methods of evaluation were variable but most included wide consultation with stakeholders using a mix of methods. Results show that there are some benefits reported from National Dementia Strategies including greater public awareness of dementia, enabling the creation of dementia friendly communities, promoting prevention of dementia and allowing for early referral and assessment. However, the evaluations also highlighted that there are continuing needs in relation to the understanding of dementia, access to co-ordinated care pathways and support

and services for people with dementia and their caregivers. All papers reviewed in this modified multivocal review globally recommend increased focus on prevention, risk reduction, early diagnosis, adequate resources, education and training for staff and increased support for persons with dementia and their caregivers related to need.

**Table 3.2** Summary of Key Messages from the Literature

Recommendations and improvements for future dementia care and strategies/plans	
1	Attention needs to be given to prevention, particularly in relation to the risk factors for dementia and lifestyle choices (O’Shea et al, 2017; Alzheimer Strategy Overview Committee in Canada, 2013)
2	The Norwegian National Dementia plan by the Ministry of Health and Social Care (2014), found that lack of awareness was not specifically identified as an area for improvement however it continued one of the key priorities identified along with prevention, knowledge and competence
3	Investment in further research, training and education for workforces is required (Lillo-Crespo et al 2017; Chow et al, 2018; Wright and O’Connor 2018; Alzheimer Strategy Overview Committee, 2014).
4	The need for innovative approaches to diagnosis and support in a strengthened primary care (Koch and Iliffe, 2011), recognition of caregiver contribution; workplace flexibility and financial assistance for carers; assistance with system navigation; increased access to services for people with dementia (Alzheimer Strategy Overview Committee, 2014)
5	To identify dementia challenges and policy gap implications broader sources of information frames of reference were advised as a potential for enabling bolder and radically better dementia care models (Wright and O’Connor 2018)

6	Clear responsibilities in relation to national leadership and the involvement of people with dementia (Merkle, 2016).
7	Effective National Dementia Strategies require financial resources and the inclusion of specific milestones and a pre-determined evaluation (Chow et al., 2018).
8	Each country to continue to conduct their own research, consultation and priority setting when developing a national dementia strategy and future plans (Edick, 2017).
9	Recognise dementia as a chronic disease and be mindful of multimorbidity rather than focusing specifically on one condition. Support should be available in both the disability care and aged care systems (Australian Government, Department of Social Services, 2015).
10	Balancing the perspective of people with dementia and carers in priority setting for future projects (Westera et al, 2014)
11	Need to address the domain “prognostication and timely recognition of dying” and spiritual caregiving (Nakanishi et al, 2015).
12	Focus of NDSs is on preventing or delaying transitions, however it should be on facilitating or improving the transition experience (Fortinsky and Downs, 2014).

# CHAPTER 4

## Phase 1 Qualitative Engagement

### Introduction

This section provides details of the key themes and findings that were identified in the individual interviews and focus groups that were held with 35 key stakeholders related to the NDS. Participants were stakeholders from groups that were deemed to be on an Executive or Service User Level. Those on the Executive Level are/were involved in the development, monitoring, oversight, or implementation of the NDS and NDSIP, and includes PLwD. Stakeholders on the Service User Level are individuals that the NDS and NDSIP are intended to impact

upon (i.e. PLwD and their caregivers). Table 4.1 details the main themes and sub-themes that emerged from the discussions.

Within this theme, five sub-themes were identified:

- (i) Development of the NDS and NDSIP**
- (ii) Content of the NDS and NDSIP**
- (iii) Barriers to Implementation**
- (iv) Implementation Enablers, and**
- (v) Internal and External Partnerships**

**Table 4.1** Themes from Phase one data collection

Theme	Subtheme
Development & Implementation of the NDS and NDSIP	Development of the NDS and NDSIP
	Content of the NDS and NDSIP
	Barriers to Implementation
	Implementation Enablers
	Internal and External Partnerships
Perspectives on Local Services	Local Community Service Provision
	Accessing services and accessing information
	Homecare
Awareness & Understanding of Dementia	The Understand Together Campaign
	Community awareness and understanding

Theme	Subtheme
Dementia Diagnoses & Healthcare	Diagnosis and GP visits
	Education and Primary care
	The need for more training
Future Considerations	The International Landscape
	Political Engagement with Dementia
	Perceived impact of the NDS and NDSIP
	Sustainability
	Where to next?

### Development and Implementation of the NDS and NDSIP

Participants on the Executive Level had more views on the development and implementation of the NDS than Service User Level participants.

During the interviews participants described how the NDS was developed. They recounted that in 2011, following years of extensive lobbying from research professionals, charitable organisations, and advocacy groups, the incoming government committed to developing a Dementia Strategy. The DoH led the development of the Strategy but given that Ireland was in the depths of a recession, the NDS had been intended to be a no-cost strategy with no commitment to the provision of additional resources or finances for implementing it.

“ *It was really progressive to have a National Dementia Strategy the fall line was that there wasn't any money for it -- not only for that, but for any other development really, to be honest with you.* (Executive Level participant)

Almost all participants noted that around the same time, AP proposed to invest a significant sum of money to implement the NDS (i.e. the NDSIP), if the investment was matched by the DoH. The DoH allocated €15 million, representing a combined investment with AP of over €27 million. Therefore, it was widely acknowledged by the participants that the large funding commitment by AP was a key driver behind the NDSIP, particularly as there was no funding allocated to implementing the NDS originally. The majority felt that without AP, no funding would have been allocated to the implementation of the NDS, making it a significant driver in the development of the NDSIP.



## Content of the NDS and NDSIP

A small number of participants expressed views about the content of the NDS. Although overall they believed that the NDS was relatively good it was agreed that several of the 35 Actions important over time and some became less important as the NDS developed and the context in which the Strategy was implemented changed. One participant mentioned how a large research review<sup>6</sup>, commissioned by AP, informed the development of the National Dementia Strategy. This, in addition to consultative processes with stakeholders in the area (e.g. research professionals, DoH, registered charities, advocacy groups etc.), helped to inform the NDS and NDSIP. There was general agreement among participants on both levels that when developing the NDS and the NDSIP was that the fundamental essence of living well in community for as long as possible is critical.

*“ I mean it certainly reflects changing healthcare needs, the greater numbers of people with dementia and the focus on care in the community and keeping people well as long as possible. And I think also the emphasis on more of a social care model rather than a health based model [is important].  
(Executive Level participant)*

Aside from the actual programmes outlined in the NDSIP, participants in one Executive Level focus group felt strongly that the requirements for those implementing the projects are quite rigid, and there is little room for creativity or development. They felt this was due to objectives being decided before the projects were fully planned in detail. A small minority of participants in another focus group also mentioned this rigidity and felt it could potentially be a hindrance in planning and carrying out the research projects for those assigned to do so.

*“ There was quite a prescriptive implementation plan that in effect, I think they tried to set performance management parameters way ahead before perhaps the nascent projects had actually established what they were going to do and how they were going to do it.  
(Executive Level participant)*

## Barriers to Implementation

Participants on the Executive Level were asked what they considered to be barriers in the implementation of the aims of the NDS and NDSIP. All participants cited finance/funding, while a significant minority discussed how dementia services and care

in Ireland are coming from a low base. In addition, several participants felt that dementia is not prioritised within the HSE and wider government and this causes delays in implementation.

Several issues relating to funding and finance as a barrier to implementation of the NDS and NDSIP were discussed. Since the original €27.5 million was allocated to the NDSIP, over €4.6 million additional funding was acquired through the DoH Dormant Account fund and €3 million awarded by the HSE to continue the provision of dementia specific Dementia Intensive Homecare Packages (Dementia IHCPs). In the Budget 2019 announcement, there was no mention of dementia-specific funding despite significant lobbying by the ASI, and 1,274 letters sent by members of the public to Teachtaí Dála (TDs) around the country. Participants noted that they hoped that dementia-specific funding will be secured in the HSE's National Service Plan 2019 through further lobbying efforts<sup>7,8</sup>.

A small number of Executive Level participants noted that the NDO, which is responsible for driving the implementation of the NDS, does not have a specific allocated budget which is a sizeable barrier to implementation. While some new projects

(e.g. Dementia Diagnostic Project, Dementia Registry Project) have been financed through dormant accounts funding, this is not sustainable and often has time constraints attached to it.

*“ To try and get anything off the ground without funding is hard. And... the dormant accounts funding, hasn't made, it a lot easier to get things moving. Because the difficulty with dormant account funding is that, it's time restricted to 12 months or to two years -- so, it's not a sustainable mechanism for long term funding of any projects. So, I would say it [funding] is a big challenge.  
(Executive Level participant)*

Participants from the Executive Level also noted that prior to the publication and implementation of the NDS, dementia services in Ireland were critically underdeveloped and under-resourced. This, coupled with the ageing population, creates additional need for services meaning even significant investment can result in a limited observable impact. This has implications both for the implementation of the NDS, and the impact felt by PLWD and caregivers 'on the ground'. One Executive Level participant noted:

<sup>7</sup> The Alzheimer Society of Ireland (October, 2018). The Alzheimer Society of Ireland frustrated with lack of dedicated Dementia Fund in Budget 2019. Press Release ([http://www.alzheimer.ie/getattachment/About-Us/News-and-Media/Press-Releases/Budget\\_2019\\_PR\\_Final.pdf.aspx](http://www.alzheimer.ie/getattachment/About-Us/News-and-Media/Press-Releases/Budget_2019_PR_Final.pdf.aspx))

<sup>8</sup> The HSE National Service Plan 2019, was published after the focus groups and interviews took place. The Plan does note that the NDS will continue to be implemented via the NDO.

“ *Despite the fact that we are only out of recession the health budget is under severe pressure. . . And we have this ageing population, so a lot of the increases that there have been and there has been significant increases in the older people’s budget, but a lot of those increases are just swallowed up by basically standing still by trying to cope with the numbers of older people needing services.*

(Executive Level participant)

Participants discussed how dementia is one of several competing health problems in Ireland that requires significant funding and government attention. Many participants had the viewpoint that dementia is not a priority in the current Government or the HSE. Some participants acknowledged that while dementia was a priority for them, other people have different health priorities and that these require attention too.

## Implementation Enablers

Executive Level participants were also asked about factors they feel enable or facilitate the implementation of the National Dementia Strategy. According to participants, the key facilitators of implementation are goodwill, the establishment of the NDO, and the legacy of AP.

Willingness and empathy among Irish people (e.g. the public, service providers, and health and social care professionals) was a commonly cited enabler among participants on both levels. There was the impression that the public is very receptive to the idea of improving life for people with dementia and caregivers as perhaps it is something most people have been touched by in some way.

Participants also noted that they believed service providers and health/social care professionals generally desire positive change and are keen to communicate and collaborate in a collective effort to improve services and supports for people with dementia and caregivers. An additional consequence is that practitioners are also happier when the system is working better and this was noted to increase job satisfaction. This, in itself, fosters good will.

Similarly, some Executive Level participants noted that those involved in the development and implementation of the NDS and NDSIP are passionate about improving life for people with dementia in Ireland, with several giving up their time freely to contribute to this.

“ *When you’re asking about things that were encouraging, you are always struck by the extent in which practitioners themselves are so much happier when the system is working better. You know, that there’s more job satisfaction. . . .so, I think there is tremendous goodwill there. . .*

(Executive Level participant)

They also conveyed that the establishment of the National Dementia Office and quality of the staff there was another key enabler in implementing the Action Areas of the NDS and NDSIP. This was mentioned in most interviews and focus groups on the Executive Level. As the NDO was set up to drive implementation and provide leadership at an HSE level, it is fitting that several participants felt this was the catalyst for activity and implementation to gain momentum. One participant commented that they did not see real progress until the NDO was fully established and staffed<sup>9</sup>.

While AP is hailed as a key driver in the development of the NDS and NDSIP, Executive Level participants felt that the previous work and funding that existed prior to the AP NDS grant has also contributed significantly to the implementation of the NDS. AP had been actively funding dementia services, supports, and initiatives in Ireland

since 2004. Between 2012 and 2015 alone, AP invested €10 million (and leveraged an additional €6 million from the HSE) on individual projects that would later support the NDS. Examples include the promotion of dementia friendly communities, gearing up ASI services in political and policy advocacy, development of End of Life Care models with the Irish Hospice Foundation, and up skilling frontline workers through the Dementia Skills Elevator programme<sup>10</sup>.

Three participants noted that AP mobilised those who wanted change through research, support, and funding. This is consistent with the 2017 report on the impact of AP mentioned above (O’Shea and Carney, 2017) which suggests AP has contributed to a shift from older biological models or care to a person-centred biopsychosocial approach. Therefore, when the NDS and NDSIP were in development and launched, there was a mobilised community, some resources, and pockets of good practice that could be utilised to support this.

<sup>9</sup> The National Dementia Office was established in 2014, but was not fully staffed until the second half of 2017.

<sup>10</sup> O’Shea, E., & Carney, P., (2017) Paying Dividends: A Report on The Atlantic Philanthropies Investment in Dementia in Ireland.

“ *But core, key strategic funding enabled enough critical mass of people, because I think that’s what we need. We need the critical mass of researchers and educators, as well as the core healthcare system, to support us. Because you know, it’s not just silos within healthcare; it’s also really linking with resources within colleges and things, you know. So, I think, yeah, they [AP] definitely primed that.* (Executive Level participant)

*I would say even outside of the strategy, Atlantic Philanthropies, I mean you couldn’t talk about dementia in Ireland without talking about them.* (Executive Level participant)

## Internal and External Partnerships

There were several groups involved in the development and initial implementation of NDS, each with specific roles and terms of reference. Feedback from participants highlighted positive communication and collaboration between AP, the Irish Government, the HSE and other key stakeholders (e.g. research professionals, advocacy groups, and not for profit organisations) which was a significant factor in getting key initiatives off the ground.

In relation to more recent progress and

implementation of the NDS and NDSIP, approximately half of Executive Level participants felt that there is a lack of meaningful communication between the various groups that were established as part of the strategy’s governance structures (such as the monitoring group and the implementation group). Participants discussed how communication between the groups took on a standardised ‘reporting’ format, whereby they report on specific activities or programmes of work, rather than an open dialogue or discussions. They felt that this led to missed opportunities in terms of collaboration and sharing learning and advice which would have added more value to both groups.

Many stakeholders felt that they have expertise and experience to provide a more meaningful contribution they were not provided with the opportunity to do so.

“ *There was no advisory capacity of either board [the monitoring and the implementation group], so there’s no advice asked for on how could this be done better? Or it wasn’t solicited, it wasn’t asked for.* (Executive Level participant)

*Nobody ever sought any advice from the committees [implementation or monitoring].* (Executive level participant)

One participant noted that steps are being taken to improve communication and dialogue between stakeholders, beginning with the preparation of a paper, which will outline how issues and problems will be discussed and resolved in the future, with greater inclusion of stakeholder groups. This was also noted in the Midterm Review of the Implementation of the *National Dementia Strategy* (DoH, 2018).

## Summary of key points from ‘Development and Implementation of the NDS and NDSIP

The NDS was developed through the programme for Government (2011 – 2016) after years of extensive lobbying. The development of the NDSIP was initiated by AP who are considered a key driving force, of both of the NDS and the NDSIP. AP committed to providing significant funding for the NDSIP if it was matched by the Department of Health, in addition to commissioning a large research review to contribute to the development of the NDS. It was evident from participant testimony that the main barriers to implementing the NDS and NDSIP include a lack of finance/funding, dementia care and services in Ireland coming from a low base, and a lack of prioritisation of dementia within the HSE

and wider government due to competing priorities. Meanwhile, key implementation enablers include the legacy of AP, the establishment and existence of the NDO to drive implementation, and the goodwill of the public, health/social care professionals, and stakeholders involved in the NDS and NDSIP. Feedback from Executive Level participants suggests that whilst there was communication between various stakeholder groups however there is a greater need for more collaborative work and discussion.

## Perspectives on Local Services

On the Service User Level, participants with dementia and informal caregivers provided feedback on their experiences accessing and using services and supports in their local community. Three sub-themes

- (i) **Local Community Service Provision,**
- (ii) **Accessing Information and Accessing Services and**
- (iii) **Homecare were identified.**

## Local Community Service Provision

Participants with dementia and caregivers noted that the number and type of services available to them and number of hours that care can be accessed differed depending on whether they lived in urban or rural areas.



Community service entitlement and provision is an important aspect of the social care and community care model, as it enables PLwD to live longer in their community. In fact, in a report by the Organisation for Economic Co-operation and Development (OECD, 2018) Ireland featured strongly in terms of local and ad-hoc initiatives bridging the gap for services where none are available.

This is aligned with a social care model, which is considered more cost effective than long-term care (DoH, 2015) in addition to enabling PLwD to live in their community, which is typically their preferred option. A minority noted that they have access to community services such as Singing for the Brain (a social singing club), a day centre, and a Dementia Adviser. Of the services that participants discussed, many are part-funded by the HSE though were not necessarily for people with dementia exclusively. One participant spoke of how she cannot reach any services (either dementia or, non-dementia specific) as she has no way to transport herself to them.

Although most participants have limited access to services, they really value them and are very grateful for any services they use. Some services are considered a life-line to the person. Several participants with dementia also discussed how attending one service can lead to wider access to other services as they learn about what

else is available in the area from others. Furthermore, they felt a sense of belonging when they attended these services, both dementia-specific and non-dementia specific. Some participants also have access to a Dementia Adviser, provided through the ASI. Those participants (both PLwD and caregivers) who have access to a Dementia Adviser consider them a 'godsend' and again, are very grateful for them.

Currently, not all counties are covered by the Dementia Adviser (DA) Service, although a recent independent evaluation demonstrated its importance and recommended that there should be at least one per county (*Coffey, et al. 2018*)<sup>11</sup>.

However, participants with early-onset dementia felt strongly that there needs to be more age-appropriate services as they feel most HSE funded services are oriented towards older adults. Participants discussed how keeping physically, socially, and mentally active was very important to them, but most felt that local services do not fulfil these needs. One person also mentioned how attending dementia-specific services for older adults may be upsetting or distressing for those with early onset dementia.

Participants commented that services do not have to be dementia-specific, just dementia-accessible. Some currently attend non-dementia specific services in their area, but

they were in the minority of people with early onset dementia that we spoke to.

## Accessing services and Information

A key frustration discussed by most caregivers of PLwD related to accessing services and information. Firstly, they felt that identifying services and entitlements available to them is very difficult due to a lack of information. Secondly, they felt that services are disjointed and it is frustrating and stressful to navigate them. All caregiver participants noted that information and signposting to the supports and services available to PLwD and caregivers is the key to improving life for both groups. In terms of integrated services, the majority of caregiver participants referred to the idea of a 'one-stop-shop', whereby there should be one source of information and coordination of medical and social supports. One participant noted that their Public Health Nurse, was particularly knowledgeable and dedicated and they were very grateful for the service she provides.

Representatives from the NDO noted that in the Mid Term Review of the Implementation of the NDS, it is reported that some funding from Dormant Accounts fund is now earmarked for the development of an

information portal for health and social care professionals, as part of the Post Diagnostic Support Pathway Project.

Most participants believed that there are inequalities in access to dementia services and supports across Ireland. This was particularly salient in relation to community services and dementia-specific homecare packages. PLwD and caregivers felt there is no reason or logic to deciding on service entitlement and that there is too much variation between counties, and even between different areas in the same county. The views expressed by participants were consistent with the findings of an NDO 2017 report on dementia-specific and voluntary services, which found that there was large variance across the country in terms of service availability. For example, in CHO Area 4, only 7 of the 40 recorded dementia-specific services are based in Kerry while the remaining 33 are located in Cork<sup>12</sup>. This report also found that no county in Ireland has an acceptable level of dementia support. Furthermore, a review of memory clinics in Ireland (*Gibb and Begley, 2017*) identified inequitable geographic spread of these clinics, with over 50% of counties having no memory clinic in place. In addition, it found that the memory clinics vary in the type of service they provide and their composition.

<sup>11</sup> Since this fieldwork was completed, the Irish Government has announced funding for ten additional Dementia Advisers in the 2020 budget.

<sup>12</sup> It should also be noted, that as highlighted in the Mapping report, that the authors were relying on responses from local areas to build a detailed understanding of local resources and that in some areas data was missing.

“  
*Like, you should be entitled just as much, but unfortunately, there's so much need in the local community; they can't do that. So, it's unfair, and that's probably why we're trying to roll out the equality; that every county gets the same, and everyone gets the same. On an individual basis as opposed to a county basis.*  
(Executive Level participant)

## Homecare

Service User Level Participants discussed enhanced dementia-specific IHCPs, particularly in interviews and focus groups with family caregivers. These packages were rolled out as part of the NDSIP with €20.5 million allocated. Some participants, particularly on the Executive Level, felt that this is one of the most effective outputs of the NDSIP as IHCPs have a significant impact on the families who are in receipt of them. In fact, two Executive Level participants felt that only those in receipt of these packages might feel an impact of the NDS and NDSIP. While there is agreement among most participants that there are not enough IHCPs, it is also acknowledged that they would not exist, at any level, without the NDS.

All caregiver participants felt that there is no clear logic to allocating homecare packages and are disappointed with the level of support they are entitled to.

One participant who was in receipt of an IHCP said that they had to fight hard for it and believed that this is something that not everyone would have the time or willpower to do. Those who were trying to access homecare hours felt that no clear information about the number of homecare packages available, and that any information is difficult to obtain.

## Summary of Key Points from 'Perspectives on Local Services'

Participants on the Service User Level were particularly engaged in this element of the focus groups. Their feedback suggested that there is an inequitable distribution of services across Ireland, but that any services that are accessed (e.g. Alzheimer Café, Singing Groups, Social Clubs) are genuinely valued by PLWD. Several participants, particularly caregivers, refer to needing a one-stop shop whereby information and service coordination is combined within one contact or source as navigating services is currently very challenging. Dementia-Specific Intensive Homecare Packages were considered as one of the most valuable contributions of the NDS and NDSIP by Executive participants, but Service User Level participants noted that they did not have enough information on entitlement to these services and how to access them.

## Awareness & Understanding of Dementia

Promoting awareness and understanding of dementia is a Priority Action Area in the NDS, and a funded work stream in the NDSIP. For the most part discussions around awareness and understanding of dementia was emerged organically and unprompted. Two sub-themes were identified:

- (i) **The Understand Together Campaign and**
- (ii) **Impact of Community Awareness and Understanding.**

## The Understand Together Campaign

The Dementia Understand Together Campaign is a national campaign aimed at raising public awareness of dementia and reducing stigma, which initially received €2.7 million in funding through the NDSIP. As part of the campaign, several social media, print, radio, and television adverts have been broadcasted. In addition, the Understand Together website ([www.understandtogether.ie](http://www.understandtogether.ie)) also includes a service directory. When Service User Level participants were asked about their awareness of the NDS, the media campaign was the first thing they mentioned. The majority were aware of the media campaign but not the National Dementia Strategy. To some extent this is to be expected, given the nature of the

campaign which aims to create impactful and memorable advertisements in relation to dementia. The majority of participants noted that it has reached most people 'on the ground' relative to the other Action Areas of the NDS and the NDSIP, though they spoke almost exclusively about the advertising campaign rather than the website. Participants suggested that the awareness campaign is the most obvious output of the NDS and the NDSIP so far.

Service User Level participants believed it has had a positive impact on community attitudes and is creating conversation and a degree of awareness about dementia (anecdotally). This feedback from the participants is consistent with the independent national survey of the Understand Together Campaign in 2018 (KICK, 2018) which found that awareness and understanding of dementia has improved a small amount compared to the benchmark levels in 2016. According to the survey data, 59% of those who recalled the campaign believed they were impacted to take some positive action. A minority of Executive Level participants noted that a great deal more work is necessary to raise awareness and promote understanding of dementia, and the Understand Together Campaign represents a 'small step'. In addition to the initial funding (€2.7 million), the public awareness campaign has received an additional €0.5 million from HSE Health and Wellbeing to strengthen the rollout of the campaign.

“ *I think the general public have noticed the campaign and I think that, there is more awareness about dementia generally. But how that actually transfers into a more dementia friendly community, well it's just a baby step along the way... It's just opening a door, it's a baby step towards making Ireland a more dementia friendly place.*

(Executive Level participant)

## Impact of Community Awareness and Understanding

Some participants with dementia felt that dementia awareness is still relatively poor in parts of Ireland and there are mixed attitudes towards dementia in their local communities. They spoke of how these attitudes, both positive and negative, significantly impact them in their day-to-day life and how they feel within their community. For example, some participants with dementia felt that others avoid them or their diagnosis is not taken seriously. Most positive examples related to how people in their community 'looked out' for them, which helps with peace of mind both for the person and their caregiver.

Some participants also felt that people working with the public should receive training in dementia and that local

businesses should take steps to become more dementia accessible and support PLwD to go about their daily lives. This type of training and awareness has been implemented to some extent pre the NDS through the Dementia Skills Elevator Programme and Dementia Champions initiative. This programme is now incorporated into a community activation element of the Understand Together campaign, and the resources from this are available and promoted through the Understand Together Website.

This Community Activation work is continuing at least until the end of 2019 and further funding is being sought to continue this into 2020.

“ *I don't think it's badness in people. I think it's even just a lack of understanding and therefore they become dismissive, or they pull back and that's extremely hurtful.*

(Service User Level participant)

## Summary of Key Points from Awareness & Understanding of Dementia

Overall, it was clear that the Dementia Awareness Campaign (Understand Together) is considered the most salient output of the NDS and NDSIP so far, particularly to participants on the Service User Level. Among Executive Level participants,

there was a sense that the Understand Together Campaign represents one small step to promoting positive awareness and understanding, and there is much more to be carried out. This is important because from speaking to participants with dementia, it was evident that community attitudes to dementia have a significant impact on the person living with dementia and how they feel within their community.

## Dementia Diagnoses and Healthcare

Participants were asked their views on dementia diagnoses and healthcare for PLwD. Within this theme, there are three subthemes relating to participant perspectives or experiences of

- (i) **Diagnosis and GP visits,**
- (ii) **Education in Primary Care and**
- (iii) **The Need for More Training.**

### Diagnosis and GP visits

Among participants with dementia, the experience of receiving their diagnosis varied greatly. The knowledge and care provided by their respective GPs or consultants had a significant bearing on their experience of both receiving a dementia diagnosis and accessing follow up support and information.

It was clear that the ability to obtain information from local professionals was very valuable to those who had received it. When the GP or consultant took time to explain and reassure the person with dementia, it had a significantly positive impact on them. Doctors who actively seek out services on the person's behalf were mentioned as having a positive impact but where the doctor was less active or not forthright with the diagnosis, this had a negative impact. Overall, the manner in which the doctor communicated to and advocated, or not, for the person with dementia greatly affected them.

## Education in Primary Care

The PREPARED (Primary Care Education, Pathways and Research of Dementia) program was a national research and service development initiative focused on primary care. It received €1.2 million through the NDSIP to develop resources to upskill GPs in relation to assessment, diagnosis, and care for PLwD, and empower them by clear, accessible dementia care pathways.

A minority of participants on the Executive Level discussed the PREPARED Programme, this topic arose naturally without prompting. Participants noted that the impact of PREPARED is difficult to measure (particularly because of the lack



of a dementia registry) and is affected by other factors such as the availability of post-diagnostic services (i.e. having somewhere to refer the person to after giving a dementia diagnosis). They also felt that the structure of the NDSIP in relation to PREPARED focused largely on quantitative outcomes (e.g. the number of people trained, number of leaflets distributed) and that important impacts and learnings from the initiative were not being captured such as upskilling, research, and development of education.

There were also concerns about the sustainability and legacy of this programme as it was funded until the end of 2018.

“ *One of the other problems is that the focus for an implementation plan like that quite often comes down to being very quantitative. How many GPs have been trained? How many people ...?* ”

*How many leaflets have been printed and sent out? How many people have attended the course? And actually it missed the whole bigger picture which was the development of the course...*

*Performance and management of the course, evaluation of it and the research work, the publications; none of that could really be captured and it was sort of like left almost to saying, “They got 1.2 million and have trained x number of GPs”, and it’s just so crude that it doesn’t capture the bigger up-skilling, research, education, development.*

(Executive Level participant)

## The Need for More Training

A minority of Executive Level participants discussed training and education for those who provide health and social care for PLwD. These participants felt very strongly that dementia-specific training and education for health and social care workers is inadequate, particularly those who provide formal homecare support. This means they may not be equipped to treat or care for PLwD satisfactorily, despite wanting to. They felt that dementia-specific training and education needs to be a key priority if any progress is to be made in improving the quality of services and supports. Similar to comments about the impact of GPs in the above, good practice within health and social care settings has a very significant impact on PLwD and caregivers.

“ *Our carers are leaving the service like the raindrops falling down, and yet there is no sustainable training for carers, across the whole sector... how can you expect a carer to go into somebody’s home with dementia and understand how to support and enable that person, involve them, do with rather than for them, active participation, not passive recipient.* ”  
(Executive Level participant).

NDO and DoH representatives noted that the Mid-Term Review of the Implementation of the National Dementia Strategy notes that a research team at Dublin City University have developed and piloted a dementia education programme for homecare workers. In 2018, Dormant Account funding was secured to fund its roll-out and 50 facilitators have been upskilled to deliver this two-day education programme to date. The delivery of the programme will be facilitated at CHO level, which will be rolled out nationally in early 2019.

## Summary of key points from ‘Dementia Diagnoses and Healthcare’

In terms of dementia diagnoses and GP visits, it was clear from speaking to Service User Level participants that dementia-specific knowledge, care, and the ability to signpost to services (or not) had a significant

impact on their experience of receiving a diagnosis and their life post-diagnosis. Executive participants discussed the PREPARED program and noted concern regarding the difficulty in measuring the true impact, and future sustainability of the learnings from the program.

A synthesis report of the PREPARED project will be published in 2020, providing a set of conclusions and recommendations from the project. Whilst (as noted in the following chapter) there are a wide range of dementia training programmes currently available participants believed that sustainable dementia-specific training should be embedded into training and education in all health and social care sectors. There was a perception among most participants that health and social care staff are not adequately equipped to provide person centred care to PLwD and that more training is required.

## Future Considerations

This theme refers to the overall state of dementia care in Ireland, including international comparisons. Within this theme there are three subthemes

- (i) **The International Landscape,**
- (ii) **Political Engagement with Dementia and**
- (iii) **Perceived Impact.**

## The International Landscape

### Dementia is a global issue that is being tackled in different ways all over the world.

To date, 32 countries and territories have adopted a plan or strategy on dementia (ADI, 2018). Executive participants were asked how they felt Ireland compared to other countries in relation to dementia care and services. Participants generally agreed that previously Ireland was considered to lag behind other European countries but is now 'catching up' and is somewhere "in the middle" with a "good deal more ground to cover". As discussed throughout this chapter, the content of the NDS is considered reasonably good, but the implementation of it is an issue. Participants had mixed views about how well Ireland is performing in relation to various actions compared to other countries. In the 2017 OCED report mentioned earlier, Ireland was recognised for its efforts in developing guidelines in areas such as improving the suitability of care facilities and dementia accessible design.

When asked about Ireland's particular strengths in relation to improving life for PLwD, participants noted several factors. These included the integration of health and social care services at HSE level, the existence of an NDO, and strong elements of

palliative care permeating the whole strategy. Similarly, as discussed previously in this section, the goodwill of Irish people was also regarded as a key strength.

[It's the structure of the] Irish Health Service that makes it easier to improve dementia care which is the fact that health and social care is integrated in Ireland and that's not the case in a lot of other countries but they would have a health department and a health service and then separately they'd have social care like in the UK social care it's delivered by local authorities. And just those structural barriers make it a bit harder whereas in Ireland social care which includes older people's care is integrated into the overall health service (Executive Level participant).

Executive participants were also asked to consider where Ireland is falling behind compared to other countries. Responses include e-health and post-diagnostic support. In some ways e-health and post diagnostic support are interrelated. Not having a dementia registry makes it difficult to mobilise and prepare services and supports as the level/number of required services is not fully known. However, in the OCED (2017) report, Ireland was recognised as one of four countries where improving data for dementia is recognised as a key policy in a national action and strategic plan.

As noted in the Mid-term Review of the

Implementation of the NDS<sup>13</sup>, dormant accounts funding was allocated to research into the development of a National Dementia Registry and preliminary work has been carried out on improving hospital recording and coding of primary and secondary dementia diagnoses through the Hospital In-Patient Enquiry action.

Participants commented.

*"... We talk about 55,000 [PLwD]; it's an absolutely rubbish number. It's probably three times that, because we don't have a register [dementia registry]. (Service User Level participant)*  
*We don't have an eHealth system. We don't have a unique health identifier. I mean we're so behind, so in the dark ages and that is such a barrier to a good health system. But a generic barrier obviously. (Executive Level participant)*

### Political Engagement with Dementia

A significant portion of all participants felt frustrated and disappointed as they believed that there is a lack of engagement from the Irish Government with dementia and that it is not a priority. Some cited the NDS being intended as a 'no cost strategy' before

Atlantic Philanthropies committed significant funding. Participants also noted that there was no further funding for dementia in the Budget 2019 announcement, and there has been a lack of further significant funding since the NDSIP commitment (with the exception of a commitment to Intensive homecare packages and dormant accounts funding being awarded to progress certain actions).

Furthermore, two participants with dementia expressed their disappointment that Ireland was the last EU Member State to ratify the United Nations Convention on the Rights of Persons with Disabilities (in March 2018) which was adopted by the UN in 2006. They also noted that Ireland was not represented at the World Health Organisation's first Ministerial Conference on Global Action against Dementia, (2015), just months after the NDS was launched<sup>14</sup>:

*"That [Ireland was not represented at the WHO Ministerial Conference in 2015], spoke volumes about what was thought about people with dementia in Ireland. I just thought, "Three months after it's put out there, is it really a priority? Are we really a priority? (Service User Level participant).*

<sup>13</sup> Mid-Term Review of the Implementation of the National Dementia Strategy. Department of Health (2018)

<sup>14</sup> The Department of Health is a member of the working group of European Governmental Experts on Dementia, previously organised by the European Commission and now by Alzheimer's Europe. Minister of State for Mental Health and Older People, Jim Daly, T.D., recently attended the 3rd Dementia Forum X meeting hosted by Sweden (2018), participating in a panel discussion on innovation in dementia.



“ ... but the problem is that the Department of Health and HSE don't seem to care about my rights. They're not interested in my rights, they're not interested in my rights as a person. (Service User Level participant).

A small number of Executive Level participants mentioned that they believe the NDS was a box ticking exercise as it is no longer included in the Program for Government. They noted that while there was government commitment at the time of the NDS and NDSIP, that seems to have waned lately. In addition, obtaining ministerial access to discuss dementia in Ireland is difficult and demonstrates lack of political will and interest.

Executive Level participants noted: *And we haven't seen dementia in a Programme for Government since then [2011-2016] and I think there was a commitment with the Fine Gael Labour government at that time around dementia. I think now that the strategy, it's seen as, well, that box is ticked a little bit.*

*Like, Wales can come out and say that they've a new strategy, and €10 million a year is going to be put aside for it. And, we're fighting to get a meeting with a minister for the last six months.*

*Don't think there's any political will for strategy mark two as far as I can see. There doesn't seem to be any hope of us having ever another strategy.... what we're seeing is a lack of interest.*

## Perceived impact of the NDS and NDSIP

Participants were also asked about their perception of the overall impact of the NDS and NDSIP. Most felt that a multitude of positive work had been completed and that steps are being taken to implement the Action Areas of the NDS and the NDSIP, but progress is slow. Two primary reasons were noted for this slow progress, delays in the NDO being fully staffed and limited funding. According to the Mid Term Review of the Implementation of the NDS, whilst substantial work has been completed on 15 Action Areas in the NDS, only preliminary work has been completed in 17 Action Areas. Two actions have been completed (Implementation of the National Consent Policy and Responsibility for Dementia at HSE level), while one has been delayed (Implementation of the National Policy on Restraint).

Most participants believed that while positive progress has been made in relation to the implementation of the NDS, this work is not yet reaching PLwD and caregivers 'on the ground' and making a tangible

impact on their lives (except for those who have received Intensive Homecare Packages). Service User Level participants acknowledged and are grateful for the hard work of those attempting to implement to the NDS and the individual projects but, felt disappointed with the lack of impact they have felt in their own lives.

Participants noted:

“ *It's kind of not fair to say nothing is happening, and I only know this because of being part of the working group, so I can only imagine people out there in the greater society wondering, "Are we just a lost cause?" So, because of what I had been on and seen through, I know there is work going on, you know, and I do know there are very genuine people who are working.* (Service User Level participant)

“ *People with dementia and the working group who are representing people with dementia have been very outspoken and saying there's been just ... there's just no change for us. There's no difference.* (Executive Level participant)

However, several Executive Level participants mentioned that it is still too early to feel an impact from the projects initiated through the NDS and NDSIP, and a minority

believed that the current evaluation was commissioned too early. They felt that we should not expect to see a large impact at this stage, as these first four years of the NDS and NDSIP have been foundations to greater change and work in the future. These participants acknowledged that implementing whole systems changes with a wide range of stakeholders involved can be challenging and can take time.

A small number of participants felt strongly that implementation of the NDS is moving too slowly. This is reflected in the Mid Term Review of the Implementation of the National Dementia Strategy, which states that a good deal of preparatory work is required to ensure that the development of services and supports is 'evidence based and can integrate seamlessly with existing services'.

Furthermore, work on implementing the Action Areas is planned to continue well into 2019. Participants agreed that the existence of an NDS did help to secure vital funding and resources and has resulted in leadership at HSE level through the National Dementia Office.

Executive participants' comments included: *What you are trying to do was to move the system a step forward. But that's all we've done. You know we've moved a step forward. We haven't solved the issue, and so, the key issue is... is there enough now*



*internal dynamism in the system to keep really engaging and trying to move a further step forward, and so I would say, from our perspective, it's a very good start. It's very promising.*

*We'll have delivered... on the commitments that were made and... there has been significant additional investment that went in and...it wouldn't have happened if there hadn't been a strategy. And it would never have been one of the priorities within all of the things that need to be done in the HSE. So it [the strategy] drove that response and demanded that response.*

## Sustainability

**In terms of sustainability, one Executive Level participant mentioned that Dementia IHCPs are now part of what the HSE does so they'll continue into the future.**

Dementia IHCPs have been externally evaluated which adds key insight into how they are developed and delivered. However, several Executive Level participants expressed concern regarding the sustainability of the other initiatives

within the NDS and NDSIP. Approximately half of participants on this level felt that sustainability was not fully considered in the development of the NDSIP and are uncertain about how learnings and outputs from the initiatives will develop and grow without continued funding and resources. There are several key projects detailed in the NDSIP which have specific targets and outputs within an allotted period. Participants noted that there was a lack of clarity on whether these projects will continue beyond the stated timescales.

Similarly, a number of actions within the NDS have been funded through (one-off) dormant accounts, which by their nature is not conducive to sustainability. So far, the Actions Areas have typically been supported with short-term funding, but maintenance and sustainability require long-term investment. However, those who are applying for dormant accounts funding to progress Action Areas of the NDS are asked to consider and propose plans for establishing sustainability within the proposals e.g. Post-Diagnostic Grant Scheme. One participant commented on how the government ring-fenced money for mental health services over an extended period, and how doing this within dementia might facilitate planning ahead which would help to ensure sustainability.

Executive Level participants noted:  
*We see that we've been awarded money*

*for a certain amount of time to deliver certain objectives and when we deliver that objective, or the date comes up then the project is finished; and the only legacy that we're going to be able to leave will be the publications and the resources and all the rest of it.*

*But I suppose this was a sustainability issue. So dormant account funding can be used; it's more like a once off for innovation projects but it doesn't recur so what do you do then when you have these developed?*

## Where to Next?

Participants were asked about what they would like to see happen in the future in relation to the NDS now that all of the actions set out in the strategy are underway and substantial work has been completed on almost half. A small number of Executive Level participants felt that there should be a continued attempt to meet the aims of the current strategy before developing future strategies or plans. Other participants (both Executive and Service User Level) suggested that Action Areas have fluctuating levels of importance over time and a future NDS or plan should be flexible and continually evolving to meet needs, depending on the social and economic climate in Ireland.

The idea of creating long-term adaptable plans rather than dementia strategies is growing across Europe and the rest of the world, with several countries having recently adopted long-term plans (e.g. *Wales Dementia Action Plan 2018-2022, Slovenia National Plan 2016-2020, Denmark Action Plan 2017-2025*).

There was general agreement among participants on the Executive Level about the need for an adaptable, 'living' plan that can evolve over time, rather than developing a second National Dementia Strategy. However, there is concern that the government and political climate do not bode well for future iterations of the NDS and NDSIP, given political engagement discussed earlier in this section which is now more challenging without the financial support of AP.

*“ We should be revisiting these things on a five-year cycle and saying... how did we do, and how do you ratchet up again? Now, there's an inertia around that, and it's never five years, you know; seven years or ten years or whatever. But refreshing these strategies and having them be as living documents and implementation [is] difficult, but I think it's essential.*

*(Executive Level Participant)*

## Summary of key points from 'Future Considerations'

In the interviews and focus groups, participants highlighted specific areas where they believed that Ireland was both ahead (e.g. existence of NDO, palliative care) and behind (e.g. e-health, social health) other countries in relation to dementia. Therefore, overall there was a sense that Ireland was considered to be somewhere 'in the middle' and this has been recognised in an OCED report.

Both Executive and Service User Level participants expressed disappointment and frustration with the level of political engagement with dementia in Ireland. Most participants feel that dementia is not a priority within the HSE and wider Government, and that political interest has waned since the NDS and NDSIP were launched. Whilst it was acknowledged that significant amounts of work have been delivered under the strategy, there was general agreement among participants that the NDS was not yet having an impact 'on the ground' i.e. impacting PLWD and their caregivers. Most Service User Level participants said they couldn't really feel any change or difference. There is frustration at the progress of implementation, but participants acknowledge and are aware that hard work is happening to improve things. Among several Executive Level participants,

there was a sense that we should not necessarily expect to see a large impact yet as a good deal of research and preparatory work is required first.

Participants also expressed concern regarding the uncertainty around the sustainability of NDS/NDSIP funded programmes and projects, with the exception of dementia-intensive homecare packages which the HSE has committed to funding. Although there is some concern regarding a lack of political will in relation to dementia, most Executive Level participants agreed that a long-term, adaptable, and evolving plan for dementia is more appropriate than a second NDS.

## Summary of Key findings from the focus groups and interviews

As detailed above, those who participated in the focus groups and one-to-one interviews had a detailed understanding of dementia and dementia services and policy in Ireland. General themes from the discussions included:

Previously in Ireland, dementia services and infrastructure were critically under-developed, but extensive lobbying followed by considerable support from AP (both in priming infrastructure and funding) has

brought about a from the classic medical model, to a more social and person-centred model of care.

Overall, the implementation of the NDS is progressing and a significant amount of work has been completed. Whilst PLWD and caregivers noted that they have felt a very limited impact so far, Executive Level participants noted that often policies that involve a wide range of stakeholders (often with competing priorities) can take time to have an impact at a local level.

## Priority Action Area 1 Better Awareness and Understanding

The Understand Together media campaign appears to be the most salient output of the strategy, with several Service User Level participants immediately referring to it when asked about the NDS, even if they did not know what the NDS was. This is important because attitudes of local communities had a significant effect on participants with dementia.

Most participants noted that a more social model of care is desired, whereby PLWD have access to considerably more dementia accessible services and activities (services that are not specifically for people with living dementia, but are adapted to be accessible for PLWD) within their community that are

age appropriate and accessible. Access to services is inequitable across Ireland (depending on geographic location) and it is evident that participants with dementia have access to relatively few services in their localities. However, they were very grateful for those they did have.

## Priority Action Area 4 Training and Education

The knowledge of HSCPs had a significant impact on participants with dementia and their caregivers, particularly GPs. More training for HSCPs across the board is desired.

## Priority Action Area 5 Research and Information Systems

Participants noted a lack of a dementia registry and that it makes it difficult to understand the level of services and supports that are required. The development of a dementia registry is noted as an action under Priority Action 5 in the NDS. A feasibility study (*Hopper, et al., 2016*) into establishing a register noted that whilst there are several challenges associated with this, a register would provide information that improves dementia-related policy and decision making in Ireland, improves the care provided to PLWD and would support research.

## Priority Action Area 6

### Leadership

Executive Level participants noted that they would like better communication and open collaboration between stakeholder groups involved in the NDS and NDSIP.

Participants noted that information is vital to PLwD and caregivers, and ideally this should be provided by one point of contact. The importance of access to information and having a single point of contact is also highlighted under Priority Action 6 of the NDS it notes that key worker roles should be established. A working group have been convened to gather evidence on what this role should entail, how they should be positioned in the health and social care system and to draft a job description for the key worker role.

Participants noted that leadership is crucial with driving forward the National Dementia Strategy, and the NDO is considered integral to the implementation and completion of various Action Areas.

Funding was regarded as the most critical issue. Participants also expressed disappointment with political engagement in relation to dementia and felt that it is not a priority in Ireland.

Participants appeared to prefer the idea of a long term, adaptable 'plan' rather than a second NDS because a plan infers action. Participants noted that at times they felt that the strategy was too rigid and inflexible and that a plan would be more flexible and adaptable to changes in circumstances.

Now that AP have stopped funding dementia in Ireland, it is more important than ever to have sustainable dementia-specific funding allocated to the NDO to drive implementation, and political engagement so that the future can be considered in the face of an ageing population.

## CHAPTER 5

### Phase 2 Survey Findings

#### Introduction

This section sets out the key findings from surveys that were distributed under Phase 2 of the research methodology, the surveys were issued to:

- **HSCPs**
- **Not for Profit (NfP) organisations that provide services to people living with dementia and their carers**
- **PLwD; and**
- **Informal carers/ family carers of PLwD.**

#### Health and Social Care Professionals' Survey Findings

A total of 634 staff within the HSE completed the online survey, 87% of whom were female and 13% were male. Responses were received from a wide range of clinical and administrative professional staff as summarised in Table 5.1.

A wide variety of professionals responded to the survey, reflecting the range of staff involved in the diagnosis and care for PLwD. The largest proportion of responses were from nurses, in total 187 (29%) of

respondents reported that they were either a PHN, Registered General Nurse, Community Registered General Nurse, a Clinical Nurse Specialist or, a Director of Nursing. This is broadly consistent with the proportion of nursing staff within the Public Health Service (32%<sup>15</sup>). There was also good representation from Allied Health Professionals with a total of 119 responses (19%) from OTs, Physiotherapists and Speech and Language Therapists. Only ten GPs completed the survey (1.6%).

A significant proportion of respondents (28%) defined their occupation as other; this included roles such as:

- **Administrative or corporate roles;**
- **Staff in dementia specific clinical programmes, e.g. memory clinics;**
- **Academics or, research staff; and**
- **Hostels, day centres and community hospitals/nursing units.**

15 <https://health.gov.ie/wp-content/uploads/2018/12/KT2018-Figure-5-2.png>



**Table 5.1 Occupation of Healthcare Professionals who responded to the survey**

Occupation	%	Occupation	%
Registered General Nurse	11.0	Healthcare worker undefined	2.8
Occupational Therapist	8.4	Psychologist	1.9
Director of Nursing	6.9	Community Registered General Nurse	1.7
Clinical Nurse Specialist	5.8	GP	1.6
Physiotherapist	5.4	Consultant	1.6
Speech & Language Therapist	4.9	Healthcare assistant	1.1
Social Worker	4.7	Practice Nurse Service	0.6
Corporate	3.5	Neurologist	0.3
Public Health Nurse	3.3	Area Medical Officer	0.2
Geriatrician	3.3	Pharmacist	0.2
Psychiatrist	2.8	Dietician	0.2

Base = 634

## Location of Respondents

Respondents were asked to indicate which county they worked in. All areas of the country were represented by HSCP survey, responses were received for all counties and therefore all Community Health Organisation (CHO) areas, as summarised below. As some counties are split across CHOs, it is not possible to present findings by CHO.

As would be expected, the more densely populated areas of Ireland had the greatest number of responses with Dublin, Galway, and Cork accounting for 43% of all responses.

**Table 5.2 Location of HSCPs**

County	%	County	%
Carlow	0.7	Longford	0.3
Cavan	2.5	Louth	4.2
Clare	1.2	Mayo	4.5
Cork	10.9	Meath	1.0
Donegal	4.9	Monaghan	0.5
Dublin	22.2	Offaly	2.5
Galway	9.6	Roscommon	1.3
Kerry	3.5	Sligo	3.7
Kildare	1.5	Tipperary	4.0
Kilkenny	2.7	Waterford	2.0
Laois	2.9	Westmeath	2.4
Leitrim	1.5	Wexford	2.0
Limerick	6.2	Wicklow	1.2

Base = 595

## Health and Social Care Professionals' Key Findings

HSCPs were asked, how often do you encounter PLWD? Just over half (52%) of respondents had daily contact with PLWD, a further quarter (26%) had at least weekly contact. Overall, the majority of those who completed the survey had frequent contact with PLWD; other respondents noted

less frequent contact or, indirect contact, e.g. through providing training for staff or caregivers.

**Table 5.3** How often do you encounter people living with dementia?

Frequency of contact	%
Daily	52.0
Weekly	26.3
Monthly	11.0
Other (please specify)	1.2
Less often than monthly	5.0
No direct contact	4.5

Base = 581

The following table sets out how frequently each issue was ranked 1,2 or 3. The HSCP respondents, ranked Integrated Services, Supports and Care as the most important priority action under the NDS, with the vast majority of respondents ranking it as 1,2 or 3. Timely diagnosis and intervention was also regarded as important with almost half (45%) of respondents ranking it as the first most important action area. Research and Information systems were regarded as the least important priority area by respondents, with less than one quarter (24%) of respondents giving it any ranking.

**Table 5.4** How would you rank the Priority Action Areas of the Dementia Strategy?

Action Area	% of respondents			
	Any rank (1st, 2nd, 3rd)	1st	2nd	3rd
Better awareness & understanding	52.6	22.2	12.6	17.8
Timely diagnosis & intervention	82.1	44.9	23.1	14.1
Integrated services, supports & care	87.7	40.5	28.8	18.4
Training & education	58.9	14.4	18.9	25.6
Research & information systems	24.3	9.7	5.6	9.0
Leadership	40.0	14.6	10.8	14.6

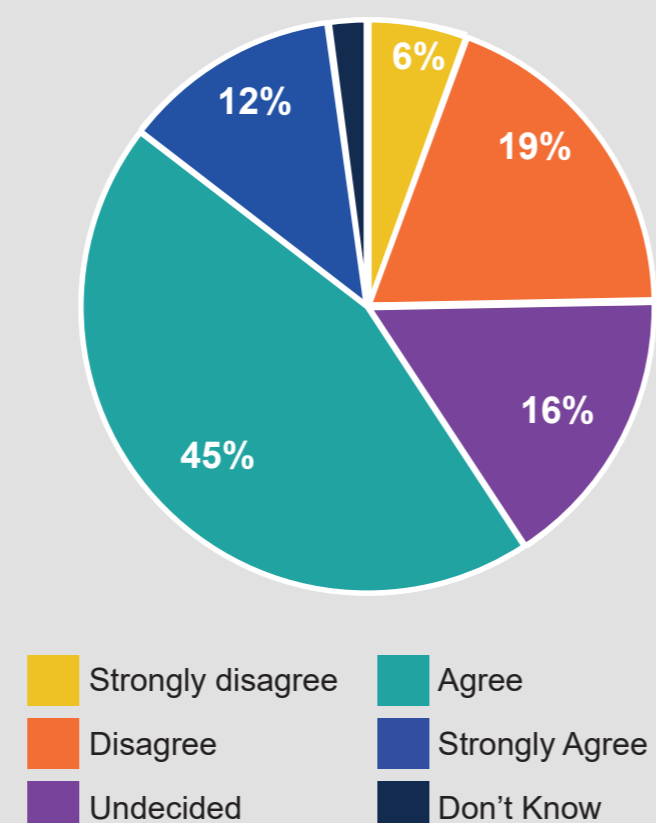
Base = 555

## Awareness and Understanding of the strategy

Whilst the majority (83%) of respondents had heard of the National Dementia Strategy, the extent to which respondents understood the strategy was much more varied.

Just over half of respondents (57%) agreed or strongly agreed that they understood the NDS, compared to the 83% who were aware of it. A quarter (25%) of respondents disagreed or strongly disagreed, with this statement. Only one third (31%) reported that their workplace had been in contact with the NDO. Reasons for contacting the NDO included, advice (29%) and training (28%). Respondents were asked to rank the top 3 most important priority Action Areas of the National Dementia Strategy.

**Figure 5.1** I have a good understanding of the National Dementia Strategy



Base = 481

Respondents were also provided with the opportunity to provide details of other areas that they thought should be a priority area for dementia in Ireland. Half of the respondents (49%) provided a response; analysis of the qualitative responses provided showed a number of key themes:

Homecare, awareness, training and creating dementia accessible environments, nutrition and legal/finance.

### Homecare (39%)

“ Additional support should be provided to allow families to continue to care for people with dementia at home. This includes greater access to respite care and support in the home.

### Sharing information and raising awareness of services that already exist in the community (11%)

“ There should be a central resource for accessing services for our dementia patients that would provide advice and information re resources available.

### Better awareness and care of patients with dementia in Acute Hospitals (10%)

“ There should be... better information provided to them in relation to services available in their area and who to contact.

## Staff training / making staff training more accessible (9%)

“ *Run Dementia Champion course specific to nurses, doctors and management. All of these should support modules on the ground and in the classroom.* ”

## Nutrition, a small proportion of respondents (3%)

Noted that patients with dementia should get dietary advice on how to eat well to minimise/ reduce the progression of dementia. None of the respondents referred to the Nutrition and Dementia booklet that was supported by NDO. [https://www.indi.ie/images/Dementia\\_Booklet.pdf](https://www.indi.ie/images/Dementia_Booklet.pdf).

## Creating dementia accessible environments

A small proportion of respondents (9%) noted that steps should be taken to make a wide range of public places (including health and social care facilities) accessible to PLWD<sup>16</sup>.

“ *The lack of properly designed and staffed units for demented patients in hospital is a major deficiency. Every large hospital should have an appropriate area for patients with dementia who often have concurrent delirium from acute illness.* ”

<sup>16</sup> Guidance and publications on creating dementia friendly environment are available of the Understand Together website: <http://www.understandtogether.ie/news-and-events/news/dementia-friendly-hospital-guidelines-from-a-universal-design-approach.html>

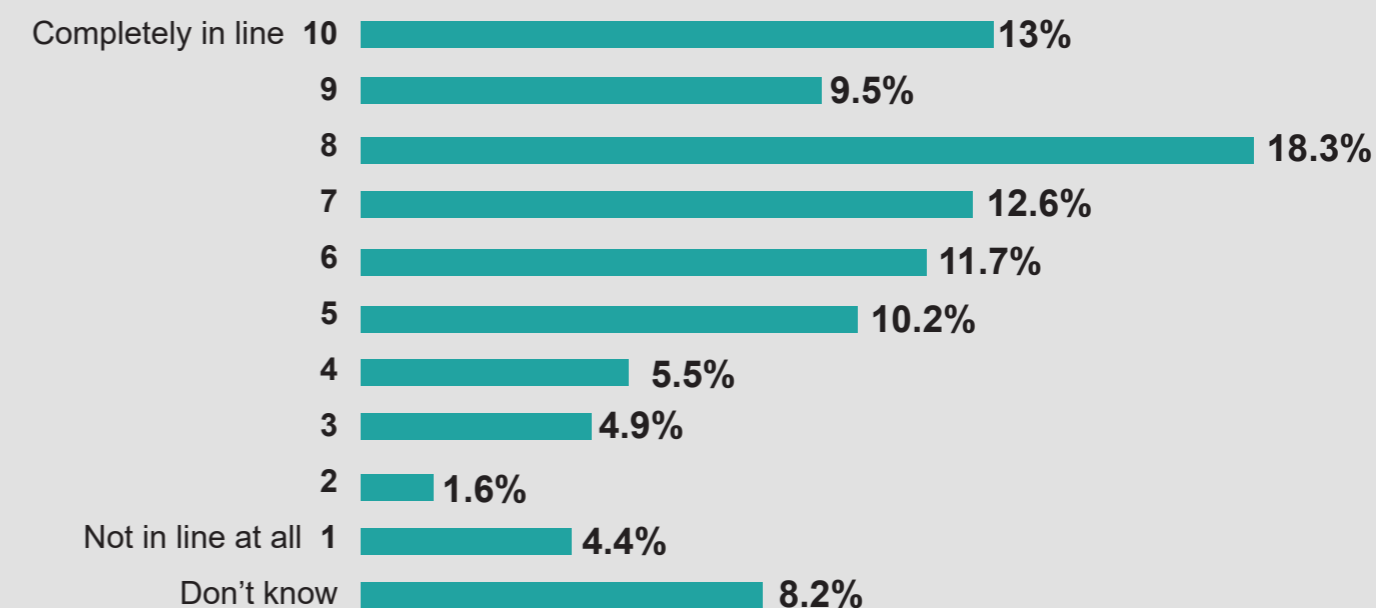
## Legal and/or financial advice

A small proportion of respondents (4%) noted that they would like greater guidance or, support relating to legal and/or financial advice for PLWD.

“ *Advice re: legal issues when GPs are dealing with patients who may no longer be able to make informed decisions about their own care.* ”

Respondents were also asked to what extent the six Priority Areas within the NDS are in line with their work priorities. The majority of respondents believed that the priorities of their work were in line with the six Priority Areas of the NDS, with over half (53%) of respondents rating the alignment as a seven or more (with 10 being completely in line).

Figure 5.2 To what extent are the NDS Priorities in line with your work priorities



Base = 547

Respondents were asked if additional resources were made available in their workplace to help implement actions within the NDS. Almost one quarter (24%) said that additional resources had been made available, whilst almost half said they had not (46%); the remaining 30% did not know. This is consistent with the way in which the actions under the strategy have been funded. Almost all (94%) of the respondents who stated that additional resources had been made available to implement actions of the NDS provided further details about what those resources were. A thematic analysis of the responses showed, that staff training as the most frequently cited additional resource, followed by additional resources and equipment (e.g. dementia friendly signage).

Of those respondents that noted that additional resources were not made available 79% of respondents provided details of what additional resources might be needed. A thematic analysis of responses revealed that training for staff and carers was the most frequently cited resource that was made available (34%), followed by the provision of additional staff (14%), additional dementia specialist staff (12%) and homecare or, support for informal carers.

The most commonly cited additional need was for dementia specific training, with one third of respondents noting that further training was required. A small proportion (less than 10%) of these respondents also noted that training should be provided for carers.



**Table 5.5** Additional Resources provided as a result of the NDS Location of HSCPs

Additional resources provided	% of responses
Training	40.0
Resources & equipment	18.3
New Technology	17.5
Additional staff time	15.0
Additional Homecare services	10.8
Awareness raising	10.0
Other	7.5

Base = 120

Comments relating the additional resources that are required included:

“ *Mandatory bespoke training for all of the public and health and social care professionals.*

*Increased support from Home Help Staff ... to keep Dementia patients at home as long as safe and fair etc to relatives... ageing spouses etc.*

*Environmental improvements such as suitable colour & type of flooring, rooms, wall colours, signage & Bathrooms to allow specialised area of ward for people with dementia.*

*Homecare packages to facilitate more home discharges. - Training on dementia-related behaviours that challenge. - Dementia friendly ward environments in the acute hospital.*

Respondents were asked about the level of understanding of the needs of PLwD amongst themselves, the public political leaders, the media and HSCPs generally. Over 80% of the Healthcare professionals rated their own understanding of the needs of PLwD as good or excellent.

**Table 5.6** Additional Resources required to implement the NDS

Resources Required	% of respondents
Training for staff & carers	33.8
More staff	14.4
Dementia specialist staff	11.8
Homecare / support for carers	10.8
Equipment / Resources	7.7
Dementia Friendly / Accessible Environments	6.7
Day / social activities	4.1
More information (provided to staff & carers)	3.6
Awareness Raising	3.1
Dementia specialist units	3.1
Support for more research	2.6

Base = 195

**Table 5.7** How would you rate your understanding of the need of people living with dementia

Rating	%
Poor	1.7
Fair	2.5
Average	14.9
Good	48.3
Excellent	32.2
Don't know	0.4

However, respondents rated the level of understanding among other groups such as general public and political leaders as poor to fair. This compares to half of respondents (51.4%) noting that other HSCPs have a good or excellent understanding of dementia. Notably, this is compared to the 80% of HSCP respondents who rated their own understanding as good or excellent.

Base = 522

**Table 5.8** How you rate the understanding of dementia among...

Rating	General Public	Political Leaders	Media	Health & Social Care Professionals	Total %
Poor	26.5	35.9	20.2	3.1	21.4
Fair	41.8	32.1	37.6	10	30.4
Average	27.3	22.6	29.6	34.5	28.5
Good	3.3	4.2	8.6	44.9	15.3
Excellent	2.0	0.0	1.0	6.5	1.9
Don't know	1.0	5.2	3.1	1	2.5

Base = 521

Whilst two fifths (42%) of respondents believed that there was no stigma about PLwD among staff, half (50%) of respondents reported some degree of stigma (i.e. among some, most or, all staff). This is surprising as we would expect HSCPs to be the most knowledgeable about dementia.

**Table 5.9** To what extent do you think there are negative associations about people who are living with dementia among staff

	%
Not at all	42.1
Among some staff	42.2
Among most staff	7.7
Among all staff	0.2
Don't know	4.6
Not applicable	3.1

Base = 519

**Table 5.10** I am aware of the National Consent Policy, the Assisted Decision-Making Capacity Bill and the Single Assessment Tool

I am aware of...	General Public	Political Leaders	Media	Health & Social Care Professionals	Total %
Poor	26.5	35.9	20.2	3.1	21.4
Fair	41.8	32.1	37.6	10	30.4
Average	27.3	22.6	29.6	34.5	28.5
Good	3.3	4.2	8.6	44.9	15.3
Excellent	2.0	0.0	1.0	6.5	1.9
Don't know	1.0	5.2	3.1	1	2.5

Base = 508

Respondents were then asked to what extent they agreed with a series of statements relating to various policies and services relating to dementia. Most respondents agreed or strongly agreed that they were aware of the National Consent Policy, the Assisted Decision-Making Capacity Bill and the Single Assessment Tool (SAT). Respondents were most aware of the Assisted Decision-Making Capacity Bill (85%), followed by the National Consent Policy (77%).

The National Consent Policy and the Assisted Decision-Making Capacity Bill are directly relevant to people living with dementia and their carers, and the Single Assessment Tool relates to all individuals aged 65 or over who are looking for support

under the Nursing Home Support Scheme or, Home Support Services. Respondents appeared to be least aware of the SAT with just over one half (55%) agreeing or, strongly agreeing that they had heard of the tool, a further quarter (26%) disagreed or strongly disagreed.

Respondents were asked the extent to which they agreed with other statements relating to the policies and services for PLwD.

Around half of the respondents (49%) disagreed or strongly disagreed that there were clear pathways and protocols (46%) designed specifically for service users with dementia.



**Table 5.11** Awareness of issues relating to dementia

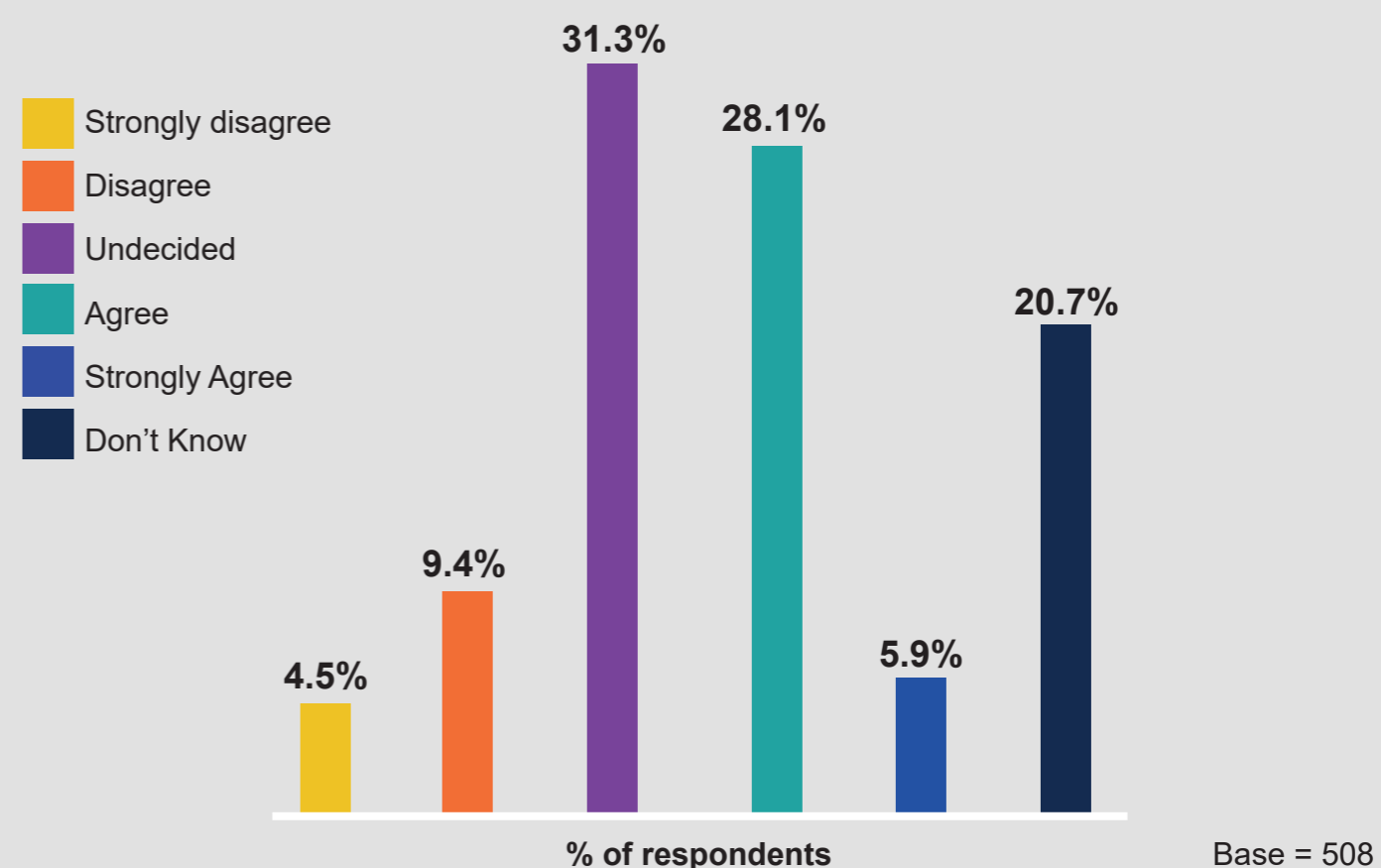
	Strongly disagree	Disagree	Undecided	Agree	Strongly agree	Don't Know
I am aware of issues surrounding people with intellectual disability who have dementia %	4.1	16.7	13.2	41.7	22.1	1.8
In the last 3 years hospitals have taken measures to ensure better recordings of dementia diagnosis %	4.3	15.4	29.9	20.7	5.3	24.4
There are clear pathways designed specifically for services users who have dementia %	13.8	35.4	22.2	14.4	4.5	9.6
There are clear protocols designed specifically for services users who have dementia %	13	33.3	23.6	16.9	3.1	10
I am aware of end-of-life care services for people with dementia %	7.9	16.1	13.2	37	20.5	5.3

Base = 508

The majority of respondents (64%) agreed or strongly agreed that they were aware of the issues surrounding people with intellectual disability who have dementia. Around half of the respondents (58%) agreed or strongly agreed that they were aware of end-of-life

care services for PLwD, around a quarter (24%) disagreeing or strongly disagreeing that there were aware of end of life services. A third of respondents (34%) agreed or strongly agreed that the NDS is integrated in wider governmental policies and strategies.

**Figure 5.3** Percentage of respondents who agreed that the NDS is integrated into wider government policy & objectives



This compares to just over half (52%) of those who didn't know (21%) or were undecided.

Respondents were asked to what extent they agreed with a number of statements relating to formal and informal services for PLwD in their local area. The responses suggest that the level of awareness between formal and informal services in local areas is reasonably similar with around two thirds of respondents reporting that they agreed or strongly agreed that they were aware of formal (69%) and informal services (63%). The majority of respondents agreed that they can signpost to both formal and informal services. Just

over half of respondents (58%) agreed (or strongly agreed) that they can signpost to informal services and over two-thirds (68%) of respondents agreed (or strongly agreed) that they can signpost to formal services.

Furthermore, the majority of respondents (82%) agreed that HSCPs should be responsible for signposting to informal, local community supports and services.



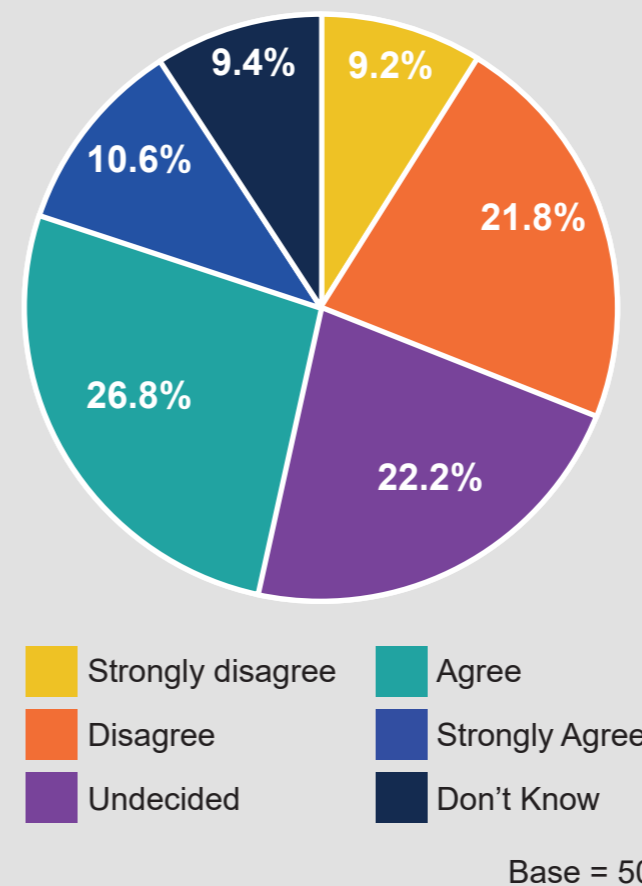
**Table 5.12** Percentage of respondents agreeing to statements on services and supports for people with dementia in the local area

	% of Respondents					
	Strongly disagree	Disagree	Undecided	Agree	Strongly agree	Don't Know
I know what informal services/supports are available to people with Dementia in the local area	13	49.8	11.8	18	3.6	3.2
I can signpost informal services/supports are available to people with Dementia in the local area	12.6	45.6	13.8	2	4.4	3.6
I know what formal services/supports are available to people with Dementia in the local area	18.2	50.8	12.6	10.8	4.4	3.2
I can signpost formal services/supports are available to people with Dementia in the local area	17.8	50.6	13.6	10.6	5	2.4

Base = 500

Respondents were asked if services and support in the area where they work had grown as a result of the NDS; only one third (36%) feel that services have grown. It is interesting to note that 22% are undecided, this perhaps indicates that respondents feel that it is too early to tell the impact of the NDS.

**Figure 5.4** Over the last 3 years dementia related supports & services in the area that I work have grown



It is interesting to note that around one third (32%) of HSCP respondents didn't know or were undecided if dementia supports and services had grown in their area over the last three years. This is comparable with the 37% of respondents who agree or, strongly agreed that supports had grown.

To understand what areas of support in the community that HSCPs regarded as most important respondents were asked to rank from 1 to 3 what they regarded the most important, as set out below.

**Table 5.13** Ranking of areas of support need by people with dementia in the community

Areas of Support	% of respondents			
	Any rank (1st, 2nd, 3rd)	1st	2nd	3rd
Homecare support	80.9	53.4	19.1	8.4
Education for PWD / care partner	62.2	26.0	18.7	17.5
Planning for the future	53.9	17.1	16.7	20.1
Information	46.3	17.5	14.9	13.9
Therapeutic Intervention	44.3	12.7	17.5	14.1
Social Activities	43.2	12.2	14.3	16.7

Base = 498



Most respondents (53%) ranked Homecare support (e.g. home help) as the most important area of support for PLwD.

Education for the person with dementia or, their care partner was ranked as the second most needed area of support, with 26% of respondents ranking it number 1 and 62% of respondents giving it a 1,2 or, 3 ranking. Respondents were least likely to rank social activities as important with only 12% of respondents ranking them as most important and 43% of respondents giving it any ranking.

Respondents were provided with the opportunity to provide further details on other areas of support that they think may be needed by PLwD in the community. Almost half of respondents (46%) noted other areas of support, a thematic analysis of responses revealed that their additional support needs centred around more help /care for PLwD in their own home and respite for carers to allow them to continue providing care at home and access to social activities.

### Respite Care (22.8%)

Respondents gave various examples of respite ranging from specialist overnight care, to a sitting service for a few hours to allow the carer to do other things.

“ *Night time respite in the home funded by HSE or to provide reduced rates.* ”

**Table 5.14** Other suggested areas of additional support

Other areas of support	%
Respite Care	22.8
Social Activities	22.8
Homecare / Home Help	22.4
Carer Support	14.3
Greater awareness / info	8.5
Transport	6.1
Better linking of services	3.7
Access to dementia specialist staff	1.7

Base = 519

*Block home help hours so carers can get respite at home. Increased number of respite beds.*

*Carer support/respite, sitting services; to avoid carer burn-out.*

### Social Activities (22.8%)

The need for better access to existing, local, social activities or the provision of dementia specific activities was also noted by almost one quarter of respondents.

“ *Group session in the community to stimulate social interaction* ”

*Need more access to community resources/social activities and therapeutic activities.*

*Dementia friendly day centres could offer cognitive stimulation therapy , reminiscence etc , provide a social outlet and provide formal carers with free time from their role.*

### Integration / Linking of services (3.7%)

It is also of note that a small proportion of respondents noted that they believed that services should be better linked, this included formal to formal services, and formal to informal services. Improved linkages with different service providers are consistent with the aims and objectives of the strategy.

“ *There would be a benefit in a dementia coordinator role that would work at working on and motivating community support and linking with the formal service providers.* ”

*There needs to be increased integration between hospital and community.*

*A priority for people living with dementia is to remain (where possible) within their own homes and within their own communities. This requires an integrated health & social care response to dementia care and the changing needs of these people and their families and carers.*



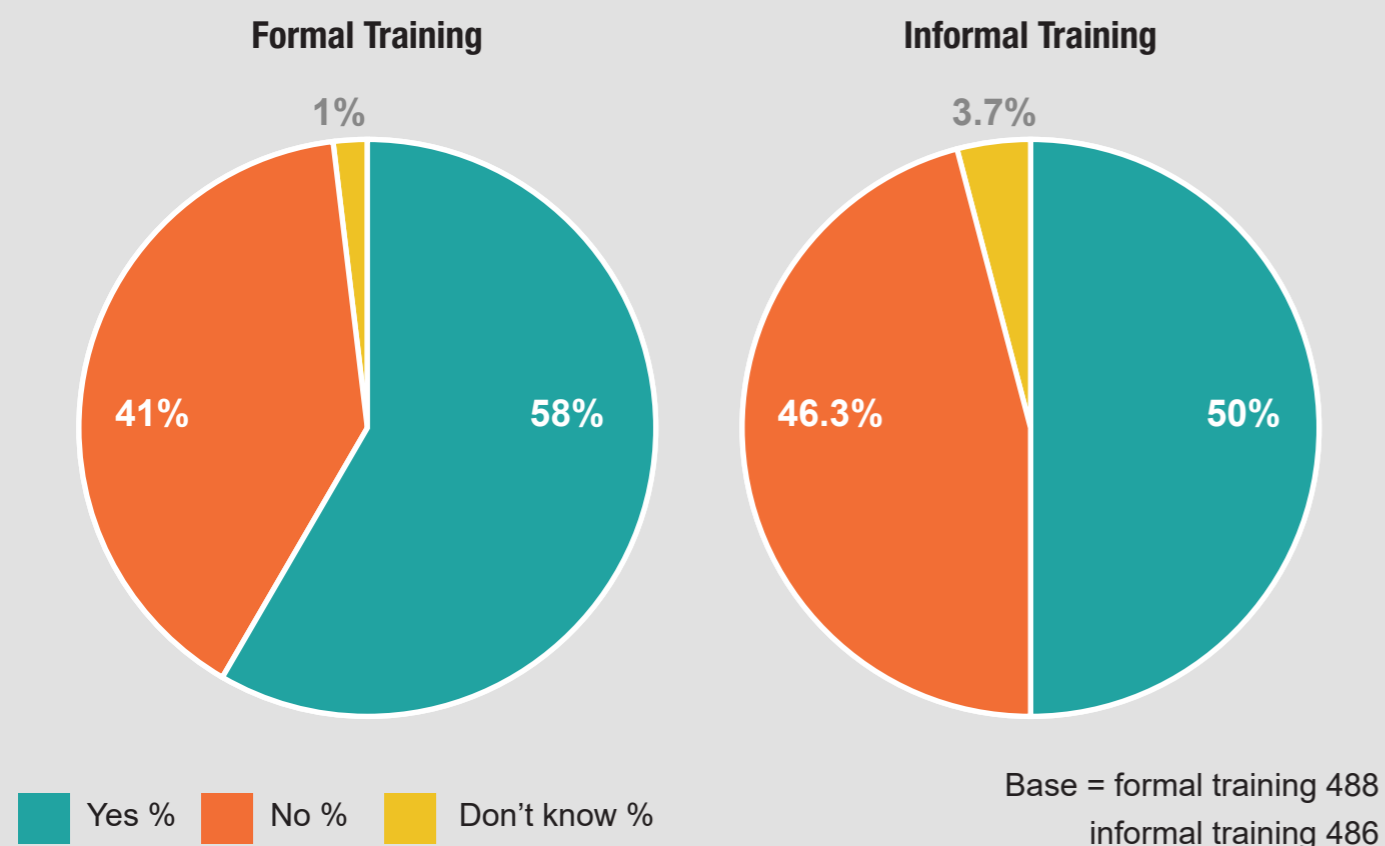


## Training and Education

Respondents were asked a series of questions regarding any dementia specific training or education that they may have received, the results are summarised below. Over half (58%) of respondents noted that they had received formal training and half had received informal training. These categories are not mutually exclusive and respondents may have received both types of training.

Respondents noted a wide range of courses from professional, academic courses (e.g. Master's, Degrees and Diplomas) to attendances at specialist conferences.

Figure 5.5 Have you had training



## Formal Training

The list of courses provided above suggests that there is a wide range of training courses available to HSCPs that are relevant to dementia. Almost one third (29%) noted that they had attended Dementia Awareness Training / Dementia Care training. Almost one tenth had also attended the Dementia Champion training. Other training courses, each noted by less than 3% of respondents included:

- **University College Cork Dementia in Primary Care**
- **Dementia uncovered**
- **Behaviour that challenges**
- **SAT course**
- **FETAC course**

Table 5.15 Formal Training courses attended

Training course	%
Dementia Awareness Training / Dementia Care training	28.7
Dementia Awareness Training / Dementia Care training	9.7
2/3-day National Dementia course	9.3
Post Grad Certificate/Diplomas in Dementia	9.0
MSc in Dementia / Masters (other courses with dementia)	6.2
Conference / seminar attendance / Specialist talks	6.2
Profession Specific Training (e.g. SpR, Mental Health Nurse)	5.5
Enhancing and Enabling Well-Being for Person with Dementia	5.0
Online training course / MOOC	5.0
Degree course	4.3
In-house training	3.1
Higher Specialist Training	3.1
Other	45.0

Base = 360

## Informal Training

Respondents provided a description of informal education and training they had received, as with the formal training, this also varied greatly from in-house training (12%) and workshops (10%) to reading relevant books, journals etc, (11%).

## Additional Training Requirements

Around half of respondents had received either formal or, informal training but there was clearly an appetite for further training. Over three quarters of respondents (79%) noted that they would like more training or education in dementia care, whilst two thirds (66%) noted that they require more training. The majority (80%) of respondents



who had noted that they had received formal or informal training stated that they would like more training. The desire for more training was evident among all professional groups, the highest being 89% of Community Registered General Nurses but, particularly among Community Registered General Nurses (89%).

Almost three quarters of respondents would like further training in communication techniques (71%) and care strategies (70%). Over half of respondents also noted that they would like more training in assessment (60%) and end-of-life care (56%).

**Table 5.16** Areas for further training

Area	%
Communication Strategies	71.1
Care Strategies	69.7
Support Services in your area	62.1
Assessment	59.7
End of life care	56.3
Other	9.7

Base = 380

A range of other types of training were also noted, albeit to a lesser degree, these included:

- **UTherapies (e.g. evidence-based therapies, cognitive stimulation etc);**
- **Carers support;**
- **Physical and social activities.**

Further analysis undertaken to identify any potential differences in those who would like more training in dementia care revealed no significant differences. For example, of those respondents who noted that they would like more training, 64% recorded that they had previously completed formal training and 70% had not. In addition, there were no significant differences in respondents wanting more training based on the county where they currently worked; for example, 79% of respondents in Dublin would like more training, as would 82% of respondents from Donegal. This also suggests that there is no significant difference between those who work in urban or rural areas.

Respondents believed there were several barriers to accessing dementia specific training. Lack of availability of suitable training courses was the most frequently ranked barrier by over three quarters of respondents (76.9%) followed by having the time to attend training. Lack of motivation to attend training was least likely to be cited as a barrier with less than one fifth (17%) respondents ranking this as either 1, 2 or 3.

However, lack of time and opportunities were also thought to be significant barriers by over half of respondents.

**Table 5.17** Ranking of barriers to training

Barrier	% of respondents			
	Any rank (1st, 2nd, 3rd)	1st	2nd	3rd
Availability of suitable training programmes	76.9	34.7	29.5	12.7
Time (e.g. too busy to attend)	55.5	27.7	11.9	16.0
Lack of opportunities	53.6	21	17.3	15.4
Location of training	50.3	12.7	14.8	22.9
Finance (e.g. courses are expensive)	46.9	13.3	16.6	17.0
Lack of motivation	16.8	3.1	4.0	9.8

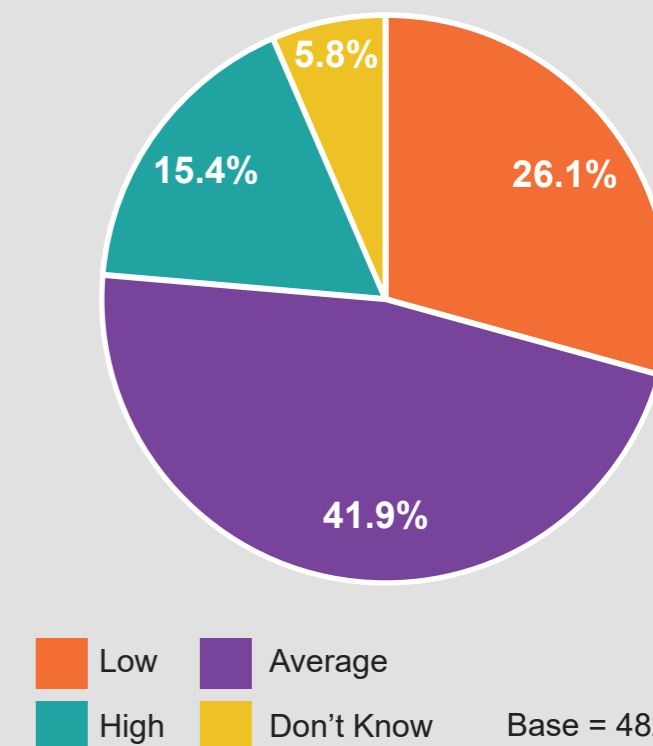
Base = 481

## Organisational Support

Respondents tended to rate level of organisational support they received in caring for PLWD from their own organisation as quite low, less than half (42%) reported it as average and around one quarter (26%) reported it as low.

Almost one third (29%) of respondents provided additional comments about the level of support they received in caring for PLWD in their organisation. An analysis of these qualitative comments identified several common themes, such as:

**Figure 5.6** How would you rank the level of organisational support over the last 3 years?



**Lack of staff or resources:**

“ [my] Organisation does not appear resourced to meet the growing number of people with ID (intellectual disabilities) and dementia.

Nurses are not given the resources or freedom to develop strategies to help or improve the care of patients in the hospital.

**Acute hospitals care:**

“ There is no support from physicians in local Hospitals to care for people with dementia

Accessing inpatient hospital care in a crisis is an issue.

Care for people with dementia is not a priority of the acute medicine programme/ hospital groups.

Basic training needs to be given to all hospital staff.

**Impact of the National Dementia Strategy**

There were very mixed views among HSCPs regarding the impact of the NDS, for example over half (54%) of respondents were undecided or didn't know if the NDS had improved the quality of life of PLwD in Ireland. Furthermore, almost half (48%) of HSCPs were undecided or didn't know if the NDS had made it easier to support the needs of people with dementia in their role.

Although HSCPs were largely undecided about the impact of the NDS, just under half (46.1%) of HSCPs did agree or strongly agree that the NDS has been a worthwhile investment and one third (35.8%) agreed that the NDS has improved the quality of life for PLwD in Ireland.

In addition to their opinion on the impact of the NDS, almost one quarter (23%) of HSCPs provided further comments on the strategy and the needs of PLwD in Ireland. A thematic analysis of the additional comments is summarised below.

**Support for carers and PLwD in the community:**

almost one fifth (18%) of respondents who provided additional comments noted that there is a need to increase the support for PLwD (and their carers) to allow them to remain at home as long as possible.

“ [it is] Important to assist families to keep their loved ones in the community by providing more home help respite and day care facilities.

**Local implementation of the National Strategy is difficult:**

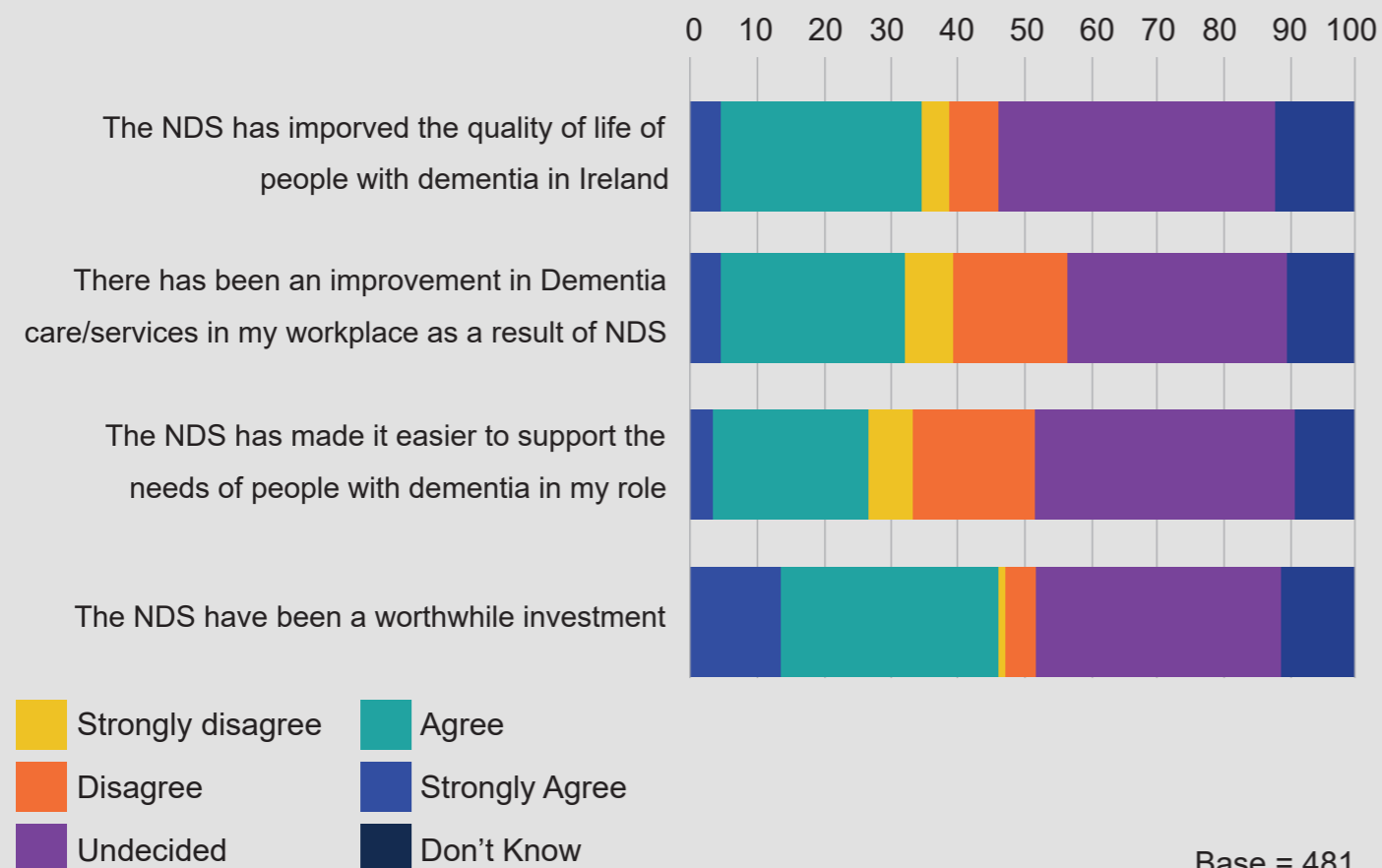
One tenth (9%) of respondents noted that whilst the NDS itself is welcome, implementation of the actions and objectives in local areas is much more difficult. For example:

“ The dementia strategy is brilliant but its implementation at the ground level needs more polishing.

**Raising awareness:** Respondents (14%) noted, not only the need to raise awareness of dementia (and associated issues) across local communities and professional groupings but also to make carers aware of local services and supports that may be available to them.

“ Keep generating the awareness and supporting training. Ensure training extends to the community.

**Figure 5.7** How would you rank the level of organisational support over the last 3 years?





## Not for Profit Organisations Key Findings

Responses were received from 16 Not for Profit Organisations (NfPs) who provide support or services for PLwD and/or their carers in Ireland.

The majority (56%) of responding organisations provide advocacy for PLwD (and/or carers), a significant proportion of organisations also noted they undertake research (38%) and education (25%). Almost one third (31%) of organisations noted that they provide 'other' services this included other support services (13% of all organisations) and arts and culture (19% of all organisations). Three quarters (75%) of those who completed the survey for the NfPs described themselves as being in a management role, the remaining 25% described their role as Teaching, Administrator, Healthcare or Analyst.

To understand the size of the responding organisations and the number of people using the service, respondents were asked to indicate the number of PLwD that use their service annually. Around one third (34%) of respondents were from organisations that support 100 or more PLwD annually.

Base = 15

**Table 5.18 Purpose of Not for Profit Organisations**

Purpose	%
Advocacy	56.3
Research	37.5
Education	25.0
Information	25.0
Home Support	6.3
Activities/companionship	6.3
Medical	6.3
Other	31.3

NB: Some organisations identified with more than one purpose. Base = 16

**Table 5.19 Approximately how many people with dementia use your service annually**

	%
0-50	13.4
51-100	6.7
100-200	6.7
200-300	13.4
4,000	6.7
10,000	6.7
Don't Know	25.0
N/A	18.8

One third of the NfP respondents provided information on the extent to which their organisation receives, and almost one third (31%) of those who responded noted that their organisation received state funding for dementia supports and services.

## Overview of Key Findings of the Not for Profit's Survey

The majority of respondents (80%) indicated that they had heard of the NDS. Almost half (47%) agreed that they had a good understanding, however one third disagreed. Given that these NfP organisation exist to support or, to provide services to PLwD/their carers it is somewhat surprising that nearly half (46%) disagreed or, were undecided that they had a good understanding of the NDS.

**Table 5.20 Level of understanding of the NDS**

As an organisation we have a good understanding of the NDS...	%
Strongly Disagree	0.0
Disagree	33.3
Undecided	13.3
Somewhat Agree	6.7
Agree	46.7
Strongly Agree	0.0

Base = 15

Respondents were then asked to indicate if their organisation had received any funding as a result of the NDS. Only one third of NfPs noted if they had received state funding or not. The majority of those that did (60%) noted that they had received funding as a result of the NDS. One organisation noted that they received funding for telephone calls and another that they were funded, to deliver an arts programme. Eleven respondents chose not to answer this question.

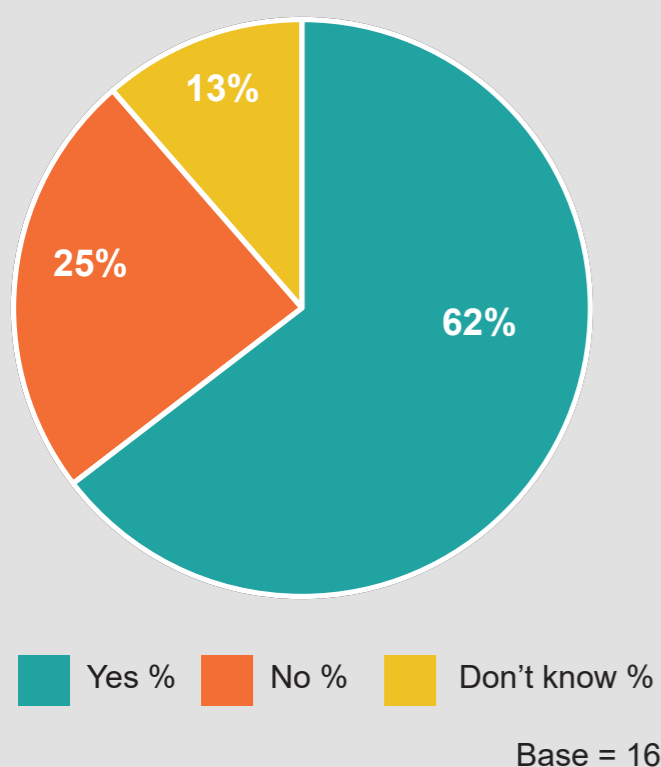




## Contact with the NDO

The majority (63%), of NfPs had reported that their organisation had been in touch with the National Dementia Office (NDO). This is a much higher proportion than the HSCP respondents (31%).

**Figure 5.8** Has your organisation ever been in touch with the National Dementia Office?



The main reasons for contacting the NDO was research (60%) and advice (30%). Some respondents provided details on the 'other' reasons for contacting the NDO they included requesting details on the interim report and information on collaboration.

**Table 5.21** Reason for being in touch with the NDO

Reason	%
Research	60
Advice	30
Funding	20
Training	20
Other	50

Base = 10

## Importance of the NDS Priority Areas

Respondents were asked to rank the six Priority Action Areas of the NDS in order of importance. Almost half (46%) of the respondents ranked Joined-up services and better supports as the most important priority Action Area. Better Awareness and Understanding was ranked as the 2nd most important Priority Area. The Research and Information Systems Priority was regarded by the NfP organisations as the least most important Action Area.

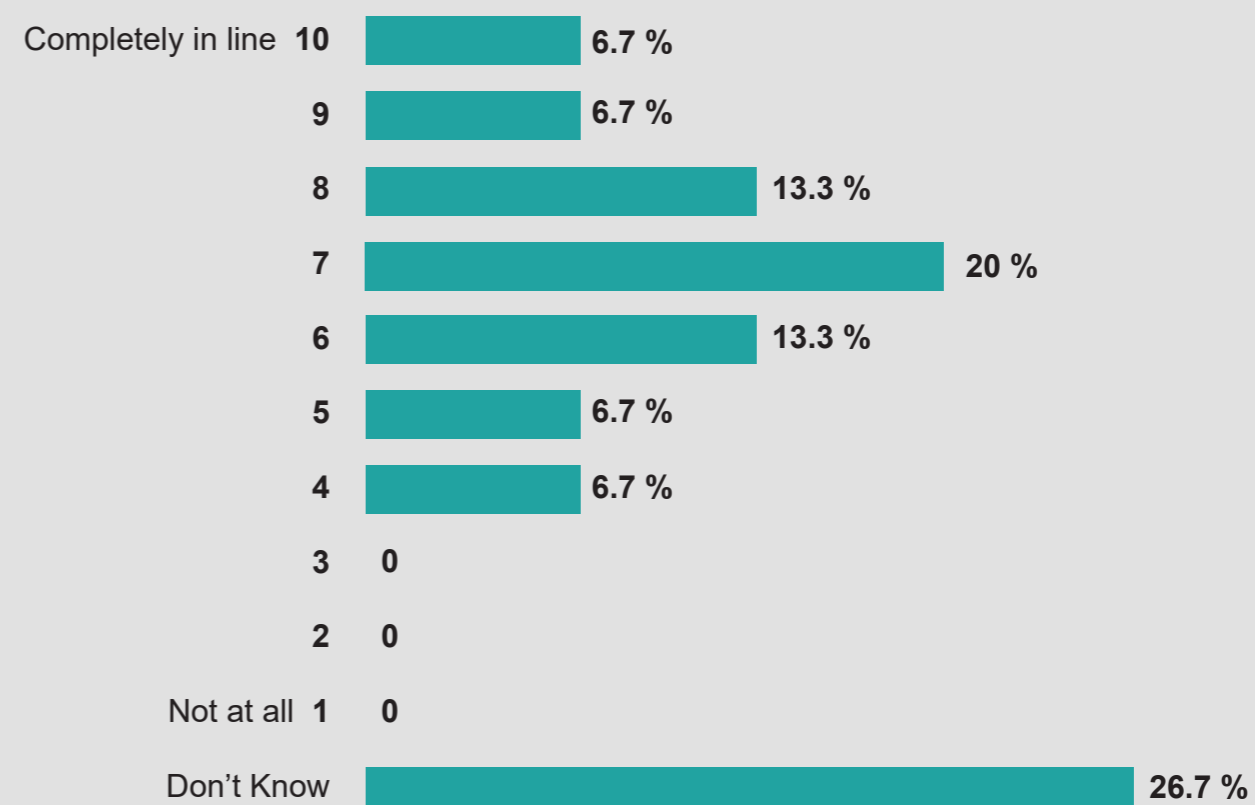
Respondents were also asked to what extent the priority areas within the NDS are in line with the priorities of their work. None of the respondents noted that the NDS priorities were not in line with the priorities of their work.

**Table 5.22** Ranking of the NDS Priority Action Areas

Priority Action Area	% of respondents			
	Any rank (1st, 2nd, 3rd)	1st	2nd	3rd
Better awareness & Understanding	81.0	36.4	18.2	27.3
Timely diagnosis & early intervention	54.6	27.3	27.3	0
Joined-up services and better supports	91.0	45.5	18.2	27.3
Training for healthcare staff & education for caregivers	36.4	9.1	18.2	9.1
Research & Information Systems	9.1	9.1	0	0
Leadership	27.3	9.1	0	18.2

Base = 11

**Figure 5.9** Extent to which the priority areas of the NDS are in line with the priorities of your work



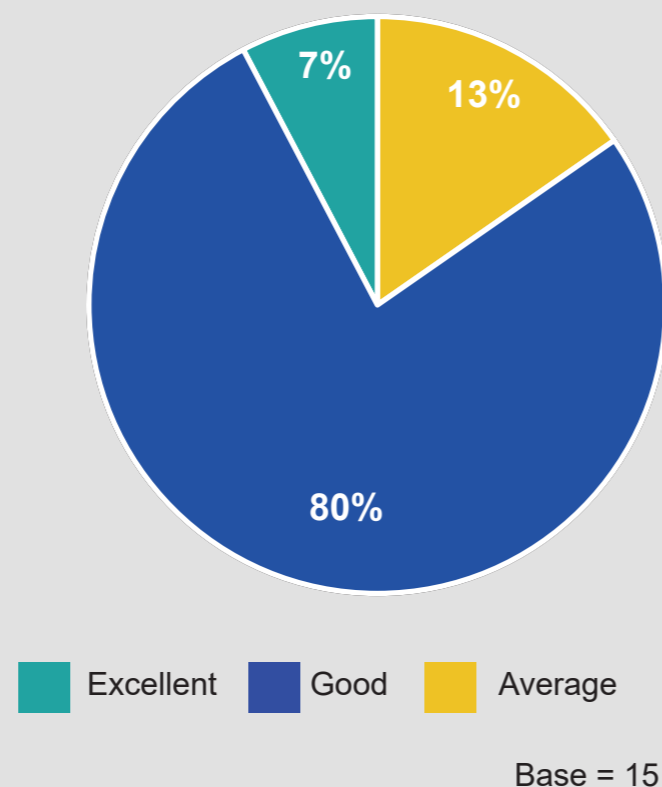
Base = 15

Respondents were also asked to rate their understanding of PLwD. The majority of respondents (87%) rated their own understanding of the needs of PLwD as good or excellent, with the remaining 13% stating average. None of the NfPs rated their understanding as 'Poor' or, 'Fair'.

NfP organisations tended to rank their understanding of the needs of people with dementia much higher than that of others (i.e. the general public, political leaders, etc.).

Respondents tended to rate the level of understanding among others much lower than themselves, with just over half (53%) of NfPs rating HSCPs as good or, excellent, compared to 87% rating their own understanding as good or excellent.

**Figure 5.10** How would you rate your understanding of the needs of people with dementia



Respondents tended to rate the level of understanding among others much lower than themselves, with just over half (53%) of NfPs rating HSCPs as good or, excellent, compared to 87% rating their own understanding as good or excellent.

It is also interesting to note that only HSCPs were rated by the NfPs as good or, excellent. NfPs were more likely to rate the level of understanding amongst political leaders and the media as poor (33% and 27%). One fifth (20%) of NfPs also stated that didn't know the level of understanding of dementia among political leaders. No respondents rated the level of understanding among the general public, political leaders or the media as good or, excellent.

NfP respondents believed stigma and negative associations about PLwD exists within their organisation to varying degrees.

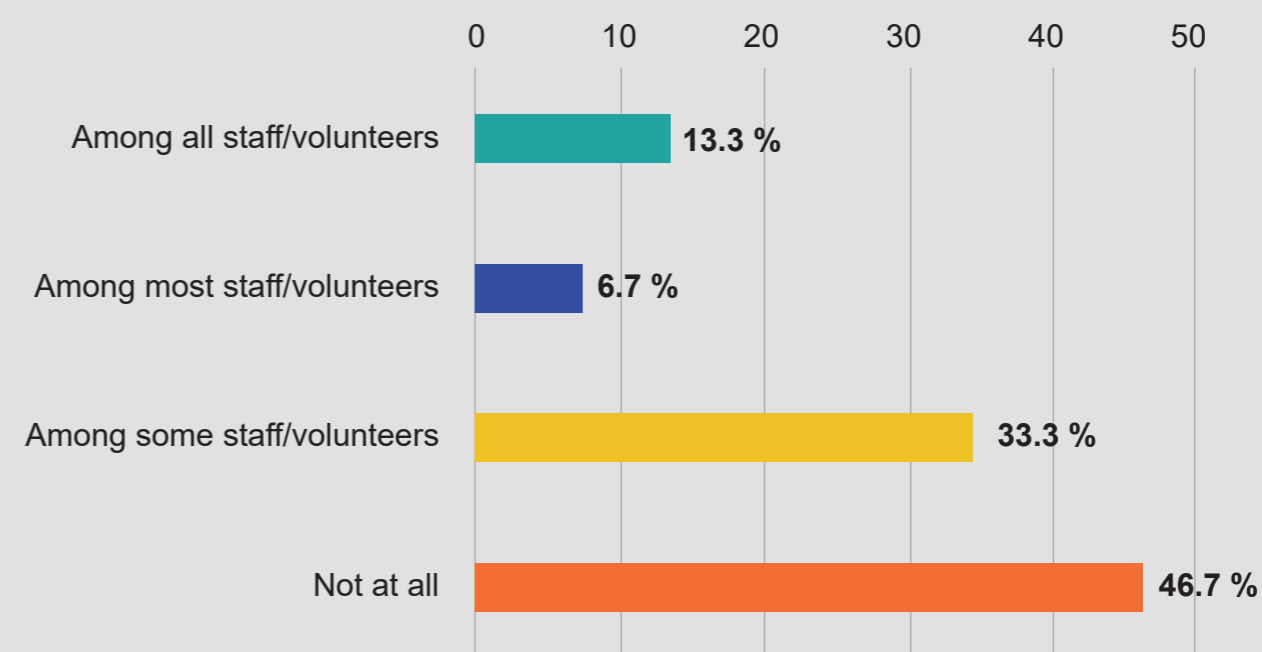
Almost half (46.7%) of respondents stated that there was no stigma about people living with dementia in their organisation. Just over one tenth (13.3%) believed that was stigma among all staff or volunteers.

**Table 5.23** How would you rate the level of understanding of dementia in others

Rating	% of respondents			
	General Public	Political Leaders	Media	Health & Social Care Professionals
Excellent	0	0	0	13.3
Good	0	0	0	40
Average	26.7	26.7	20	26.7
Fair	26.7	20	46.7	0
Poor	40	33.3	26.7	13.3
Don't Know	6.7	20	6.7	6.7

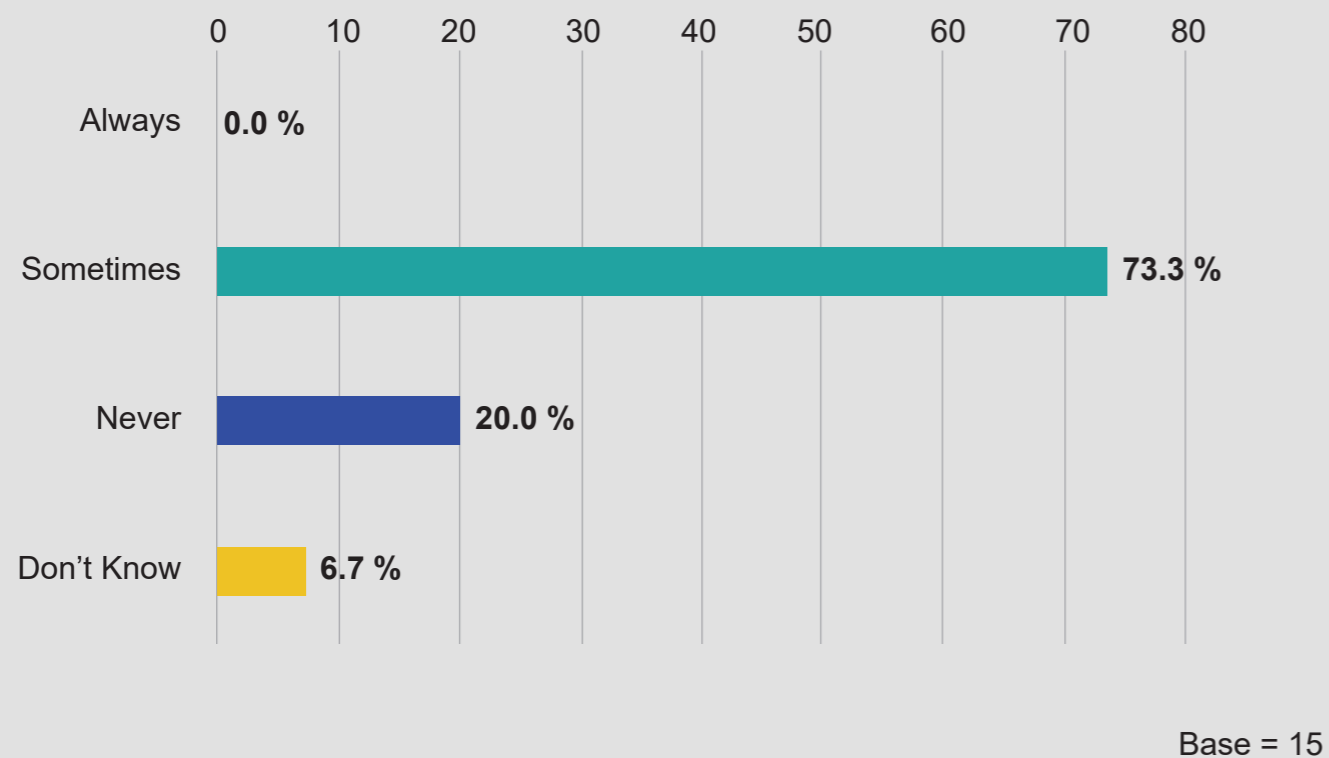
Base = 15

**Figure 5.11** Within your organisation do you think there are negative associations (i.e. stigma) about people who are living with dementia



Base = 15

**Figure 5.12** Do health and social care services work together to communicate the care needs of people with dementia?



## Community Services

In relation to community services and integrated supports, respondents were asked, if, in their opinion do health and social care services work together to communicate the care needs of PLwD?

Almost three quarters (73%) of respondents believed that health and social care services sometimes worked together to communicate the care needs of PLwD. It is interesting that no NfPs thought that Health and Social Care services always work together to communicate the needs of people PLwD. One fifth of respondents (20%) believed

that they never worked together and no respondents believed that health and social care services always work together. There was a clear 50/50 split among respondents on whether they agreed that there was adequate support, communication and signposting to informal supports and services in local areas. Half (50%) of NfPs agreed that the NDS is integrated in wider government policies and objectives, whilst the other half did not know. Similarly half (50%) of NfPs, agreed that the number of dementia supports or services in the local area had grown, whilst the other half did not know.

Respondents were then asked their views on dementia supports and services at a regional level, responses are summarised below.

- **The number of dementia supports or services in the region has grown**
- There are adequate informal dementia supports in the region's community
- **Signposting to our organisation's services by HSCPs has increased**
- There is good integration between informal and healthcare services for people with dementia
- **There is good communication between informal and healthcare services for people with dementia**
- The NDS is integrated into wider government policy and objectives (e.g. National Aging Strategy).

None of the NfP respondents agreed with the above statements. For each statement 50% of NfPs disagreed or did not know. This indicates that respondents did not see any regional growth in services for PLwD, compared to the 50% of HSCP respondents who agreed that there was growth in services at a local level. It is possible that respondents are aware of services, integration and communication at a local level but have less awareness of developments regionally. It is also interesting to note that whilst 50% of respondents who answered the question relating to local services, agreed that the NDS is integrated

into wider government policy and objectives, none of the respondents who answered the question relating to regional services agreed.

Respondents had more mixed views about services and supports at a National level. Whilst almost two thirds (64%) of respondents disagreed that there is good integration between informal services and healthcare services and that there is good communication between the two, around half of the respondents agreed that the number of support services has grown (55%) and that signposting has increased (46%).

The most frequently ranked required area of support was Homecare, with 81.8% of respondents ranking it 1, 2 or 3. The second most frequently cited need was Education for PLwD and their carers, with 73% of respondents giving it a rank of 1, 2 or 3. Planning for the future and Information services were regarded by respondents as equally important with 46% respondents ranking them as 1,2 or,3.



**Table 5.24** National Supports and Services

To what extent do you agree with the following statements?...	% of respondents			
	Agree	Somewhat agree	Disagree	Don't Know
The number of dementia supports or services in Ireland has grown	54.6	0	36.4	9.1
There are adequate informal dementia supports in Ireland	9.1	9.1	54.6	27.3
Signposting to our organisation's services by health and social care providers has increased	45.5	9.1	27.3	18.2
There is good integration between informal and healthcare services for people with dementia	18.2	0	63.6	18.2
There is good communication between informal and healthcare services for people with dementia	9.1	0	63.6	27.3
The NDS is integrated into wider government policy and objectives (e.g. National Aging Strategy)	18.2	9.1	27.3	45.5

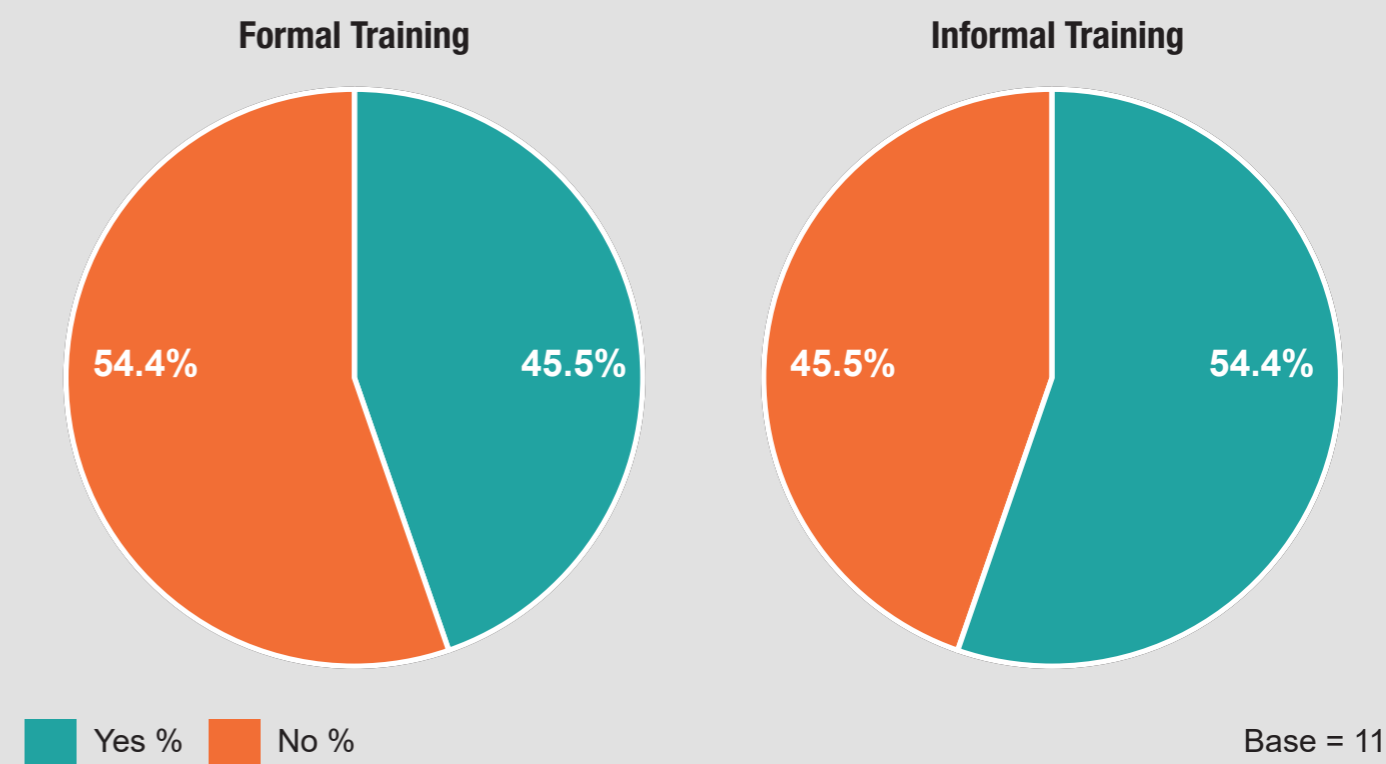
Base = 11

**Table 5.25** Ranking of most needed areas of support for people with dementia in the community

Ranking	% of respondents			
	Any rank (1st, 2nd, 3rd)	1st	2nd	3rd
Homecare support (e.g. home help)	81.8	63.6	18.2	0
Education for the with dementia/care partner)	72.8	27.3	27.3	18.2
Information (e.g. on managing dementia, local services)	45.5	18.2	9.1	18.2
Planning for the future (e.g. legal or, financial assistance)	45.5	0	18.2	27.3
Social Activities	36.4	9.1	27.3	0
Therapeutic interventions (e.g. Cognitive stimulation)	27.3	0	18.2	9.1

Base = 11

**Figure 5.13** Formal and Informal training in dementia care



## Training and Education

NfPs noted that they had received a mix of formal and informal training in dementia care, as summarised above.

Almost half (46%) of respondents had received formal training in dementia care compared to the 58% of HSCP respondents who noted that they had received formal training. Just over half (55%) of NfP respondents had received informal training, which is similar to the HSCP respondents. A small number of respondents provided details on what training they had received, this included:

- **Dementia Champions (Dublin College University);**
- MSc Gerontological Nursing;
- **SONAS (Dementia and the Arts); and**
- On the job training in care centres.

The majority (80%) of respondents suggested that they would like more training in caring for PLwD which is similar to the 79% of HSCPs who noted that they would like more training.

**Table 5.26** Impact of the NDS on your organisation

In my opinion the National Dementia Strategy has:	% of respondents					
	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Don't Know
Easier for my organisation to support local needs of people with dementia / caregivers	6.7	26.7	26.7	20	6.7	13.3
Led to increased availability of my organisation's services/support to people with dementia/caregivers	6.7	26.7	26.7	13.3	6.7	20
Led to increased capacity in my organisation	0	26.7	20	26.7	6.7	20
Improved the number of people that my organisation can reach	0	26.7	33.3	20	6.7	13.3

Base = 15

## Impacts of the NDS

NfP respondents had mixed views on the impacts of the NDS on their organisation, with a very small proportion agreeing or disagreeing strongly with any of the impacts.

However, one third of respondents (33%) agreed that the NDS has led to increased availability of services and supports and increased capacity within their own organisation. This compares to the 50% of respondents that agreed that the number of dementia services in their area had increased. However, between a fifth and one third were undecided about the impact of the NDS on their organisation, Moreover,

a fifth (20%) of organisations did not know if the NDS has led to their organisation having increased availability of services/supports for PLwD/carers or increased capacity.

Almost two thirds of respondents (60%) agreed or strongly agreed that the NDS has improved the quality of life for PLwD in Ireland. Around half of respondents (47%) also agreed or strongly agreed that the NDS has made it easier to support PLwD and that the NDS has been a worthwhile investment. However, there was some ambivalence regarding the NDS with almost one third of respondents who didn't know or, were undecided if it was a worthwhile investment.

**Table 5.27** Impacts of the NDS on services and people with dementia

To what extent do you agree with the following...	% of respondents					
	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Don't Know
There has been improved collaboration between my organisation and the HSE as a result of the NDS	40	6.7	6.7	40	0	6.7
The NDS has improved the quality of life of people with dementia in Ireland	6.7	53.3	6.7	20	0	13.3
The NDS has made it easier for my organisation to support people with dementia	6.7	40	13.3	26.7	0	13.3
The NDS has improved the reach of informal dementia services	0	33.3	20	26.7	0	20
The NDS has been a worthwhile investment	0	20	6.7	33.3	13.3	26.7

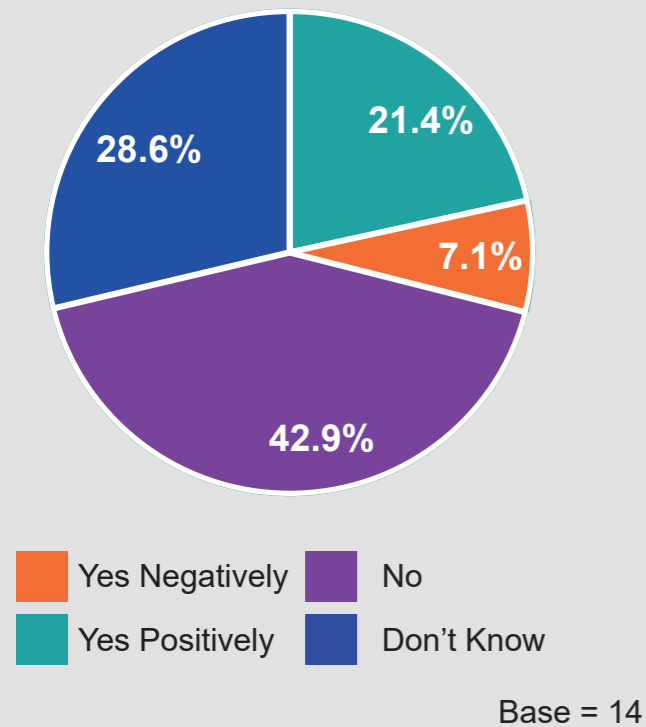
Base = 15

## Organisational Change due to the NDS

In conclusion to the survey of NfP respondents were asked if their organisation had changed as a result of the NDS, as summarised on previous page. Overall, there were varying degrees of organisational change which was directly attributed to the NDS.

The most frequent response (42.9%) from NfPs was that their organisation had not changed as a result of the NDS. Just over a quarter (29%) believed that their organisation had changed positively. A small number of respondents provided additional details of these and there was a sense that there was an increased understand of PLwD and that new services were being developed:

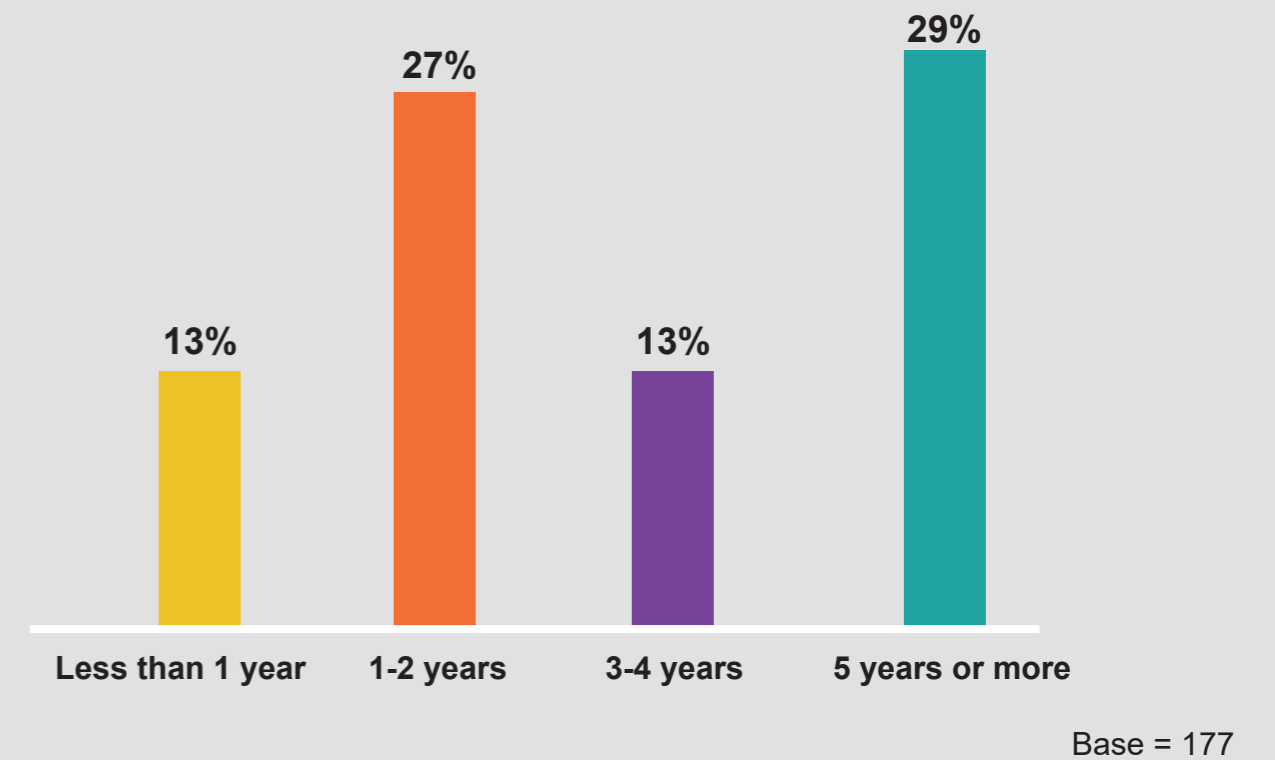
**Figure 5.14** Has your organisation changed as a result of the NDS?



majority were female (88%), 11% were male, and 1% of respondents defined themselves as other. The majority (54%) of respondents were aged 51 year or older.

The length of time that respondents had been caring for a PLwD varied. Almost one third (29%) had been caring for five years or more. Just over one quarter (27%) have been caring for 1 – 2 years, while a smaller proportion have been caring for less than 1 year (13%) or, 3-4 years (13%).

**Figure 5.16** How long have you been caring for a person with dementia



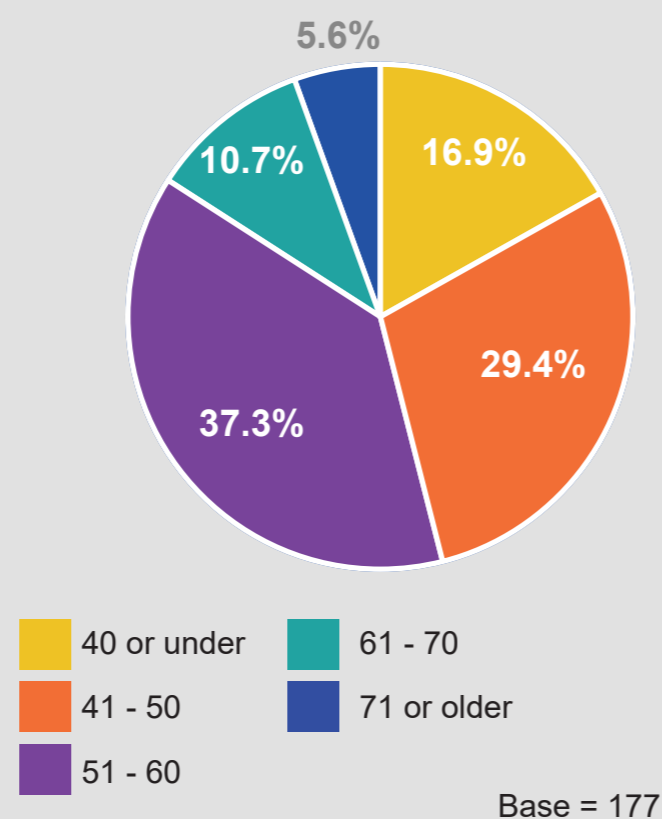
“*There is a greater understanding of dementia and people are more compassionate towards people with dementia and their family carers.*”

*We are developing small pieces of work that we can deliver to carers and also people living with dementia.*

### Carers' Survey Key Findings

The carers' survey was distributed in hard copy (via local support groups) and via social media. It covered the same broad themes as the both the HSCP and NfP surveys. In total 177 carers completed the survey of these the

**Figure 5.15** Age groups of respondents



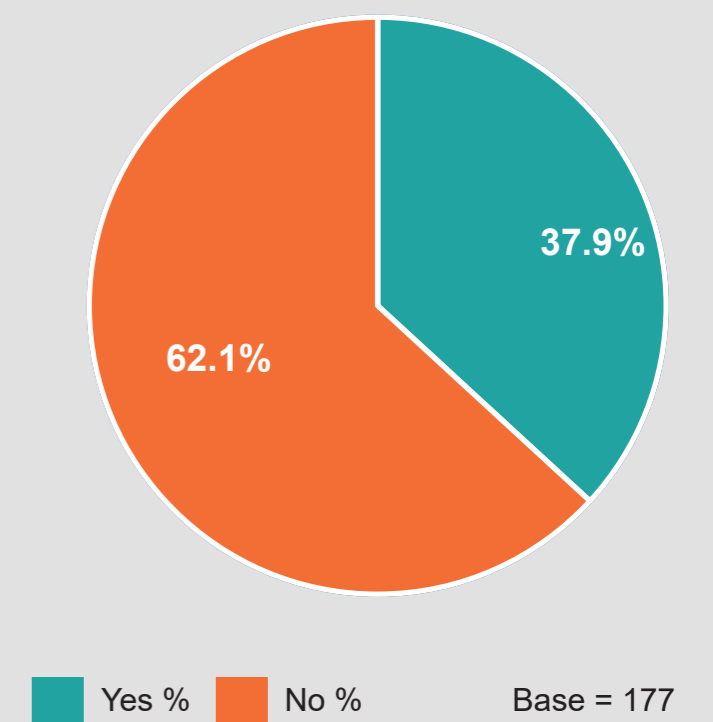
### Awareness and understanding of the Strategy

Just over one third (38%) of respondents had heard of the strategy. During phase one of the qualitative research of this evaluation the service user level participants also had a low level of awareness of the strategy.

Carers identified the NDS Priority Action Areas that were most important to them.

Joined-up (Integrated) services was most frequently ranked as the most important action area for carers with almost half (45.5%) of carers ranking it as number one. This was also ranked as the most important

**Figure 5.17** Have you heard of the National Dementia Strategy





**Table 5.28 Rank the Priority Action Areas that are important to you**

Priority Action Area	% of respondents			
	Any rank (1st, 2nd, 3rd)	1st	2nd	3rd
Better awareness & Understanding	45.5	15.8	12.7	17.0
Timely diagnosis & early intervention	76.3	42.4	23.6	10.3
Joined-up services and better supports	87.3	46.1	30.3	10.9
Training for healthcare staff & education for caregivers	56.3	13.3	14.5	28.5
Research & Information Systems	16.4	4.8	5.5	6.1
Leadership	36.4	7.3	11.5	15.6

priority Action Area by both HSCPs and NfP (with 87% and 91% respectively ranking it first, second or, third).

Timely diagnosis and early intervention was also ranked as important, with 42% ranking it 1st, it also ranked as 1,2 or, 3 by 76% of respondents. Research and information services and Leadership were given the lowest priority by carers. This is similar to the rankings provided by HSCPs and NfPs who also gave Research and Information Systems and Leadership the lowest priority.

### Sources of Information

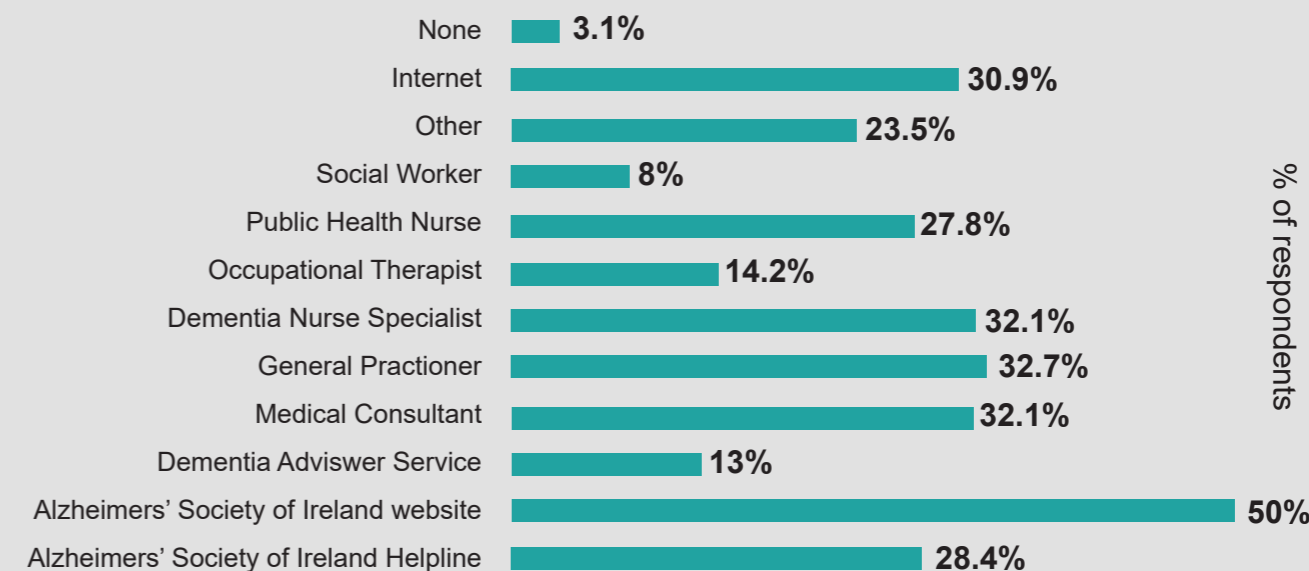
Carers used a myriad of sources to garner information on dementia. The top three most frequently cited sources of information

were, the ASI website, GPs and Consultants/ Dementia Nurse Specialists.

Half (50%) of carers noted that they sourced information from the ASI website. Further sources of information tended to be from the medical profession with around one third noting that they had also received information from GPs (32%), Dementia Nurse Specialist (32%) and Medical Consultants (32%). Just under one third (30%) of respondents noted that they used other websites such as:

- **Google searches (14%)**
- **Alzheimer's' UK (3%)**
- **Other Dementia websites and forums (3%)**
- **Local Alzheimer's' support groups**
- **Media, i.e. newspapers, magazines or, TV**
- **Friends, colleagues or, relatives; and**
- **Understand Together website**

**Figure 5.18 Sources of Information**



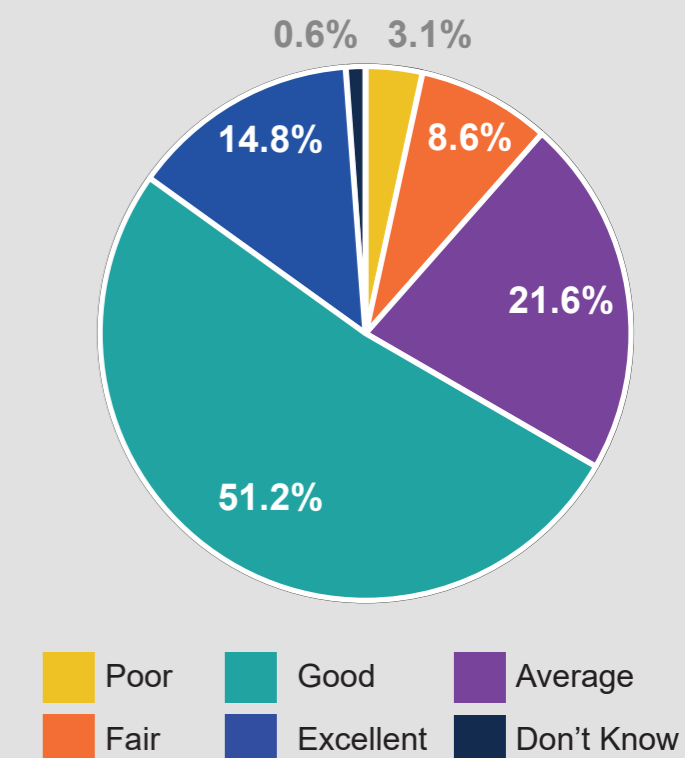
Base = 162

Whilst the Understand Together website was not included as a specific option in the survey a small proportion of respondents who provided details of 'other' or 'internet' sources of information noted the Understand Together website.

A very small proportion of carers (3%) had no sources of information. It is also interesting that a very small percentage of respondents referred to the TV as a source of information.

Whilst television advertising was a key element of the Understand Together awareness campaign the television campaign was intended to raise awareness as opposed to providing information.

**Figure 5.19 How would you rate your understanding of the needs of people with dementia**



Base = 162

**Table 5.29** How would you rate the understanding of dementia among other groups

% of respondents	Poor	Fair	Average	Good	Excellent	Don't Know
General Public	42	35.8	14.8	6.2	0	1.2
Political Leaders	49.4	29	9.9	2.5	0	9.3
Media	17.3	37	27.8	12.3	0.6	4.9
Health & Social Care Professionals	7.4	19.1	35.8	29	8	0.6
Members of my community	21.6	36.4	32.7	6.2	0.6	2.5
My family	11.1	21	25.3	33.3	9.2	0
My friends	15.4	27.2	31.5	22.2	3.1	0.6

Base = 162

Two thirds of respondents (66%) rated their understanding of the needs of PLwD as good or, excellent. A very small percentage of respondents (12%) rated their understanding as fair or poor. This contrasts with the one third of HSCPs (32.2%) who rated their understanding as good or, excellent or, the 6.7% of NfPs.

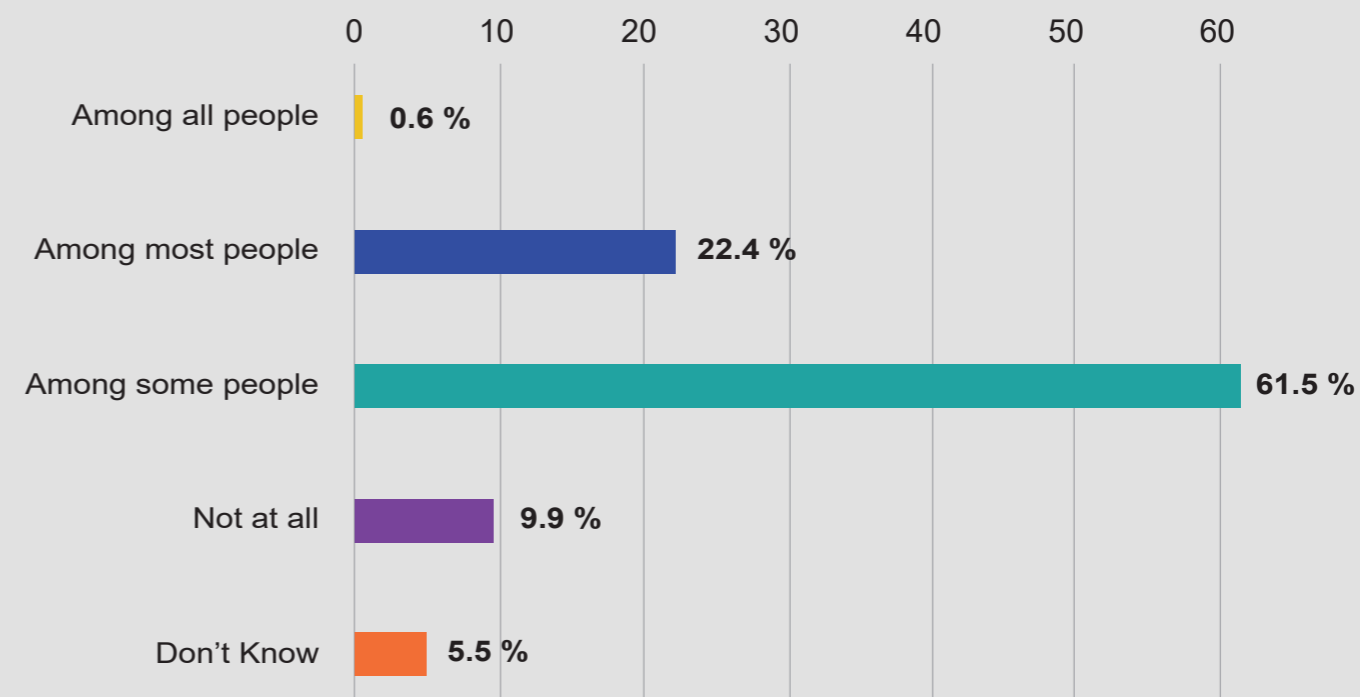
Carers regarded the level of understanding of dementia among other groups as variable.

Almost half of carers regarded the level of understanding of dementia among the general public (42%) and political leaders (49.4%) as particularly poor. HSCPs and members of the family were most likely to be rated as good or excellent at 37% and 43% respectively. This is consistent with

the 51% of HSCPs who rated the level of understanding amongst other professionals as good or, excellent. The ratings given to other groups by carers contrasts with the two thirds (66%) of carers who rated their own understanding of dementia as good or excellent. The majority (80%) of HSCPs also rated their own understanding as good or excellent.

Carers were asked their views about negative associations in their community regarding PLwD and the majority (62%) believed that there were negative associations among some people. This compares with HSCPs, where 42% believed that there were negative associations with dementia among staff.

**Figure 5.20** Within your community, do you think there are negative associations (i.e. stigma) about people who are living with dementia.

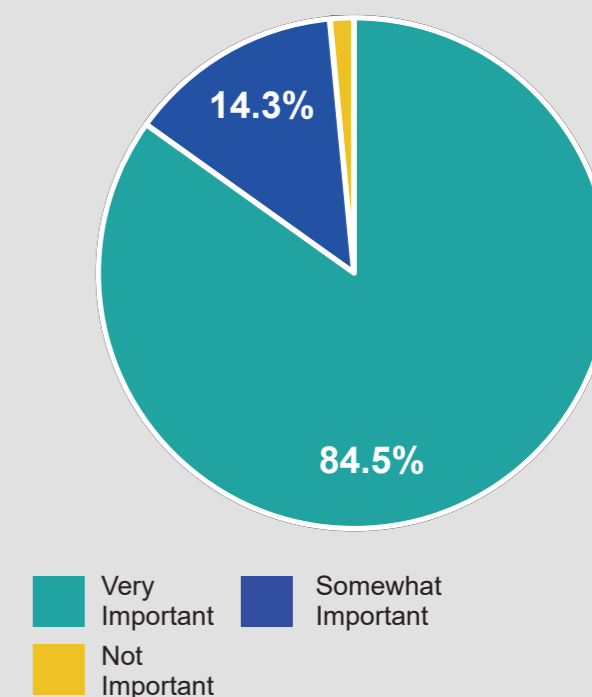


Base = 161

Very few carers (10%) believed that there were no negative associations about people who are living with dementia in their community. Respondents were then asked a series of questions relating to the Priority Action Areas within the NDS, the first of which relates to the importance of early diagnosis.

Almost all (99%) carers stated that an early diagnosis of dementia is important. Carers also provided further details on how to improve the experience of someone who has been given a diagnosis of dementia. Almost all respondents (85%) provided some feedback on this, a thematic analysis of these qualitative responses identified four main themes:

**Figure 5.21** How important is it to receive an early diagnosis of dementia



Base = 161

**Support:** Over on third (36%) of carers noted that the person with dementia and their family should receive support after diagnosis, including being referred/signposted to support in the community;

**Family involvement:** Almost one third (30%) of carers noted that the family should be involved in the communication of the diagnosis and receive support throughout the care planning process;

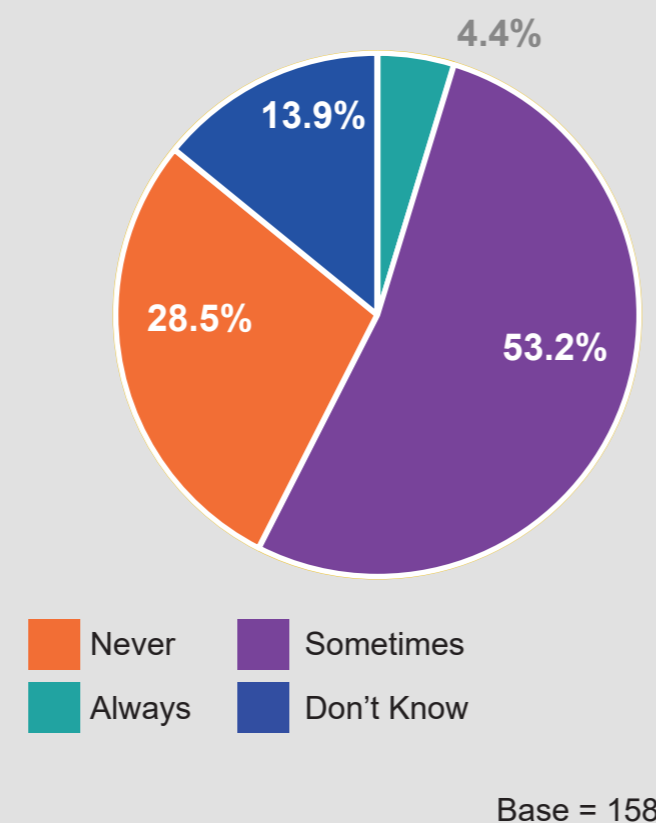
**Care plans:** Almost one quarter (23%) of carers noted that following diagnosis plans should be made to care for and support the person as their condition deteriorates and 7% thought that Life Planning should be part of the care plan. Carers felt that following a life changing diagnosis such as dementia, patients should receive support (or be signposted to) for appropriate planning, such as power of attorney, will writing and financial planning; and

**Communication:** 23% of carers regarded communication as a key issue, both that the diagnosis should be communicated with kindness and dignity and that health care staff should also communicate with patients and their families what services and supports are available to them.

Informal carers had relatively mixed views on the extent to which health and social care services worked together. Most carers (53.2%) thought that they sometimes worked together, whereas as some carers (28.5%) thought that they never worked together.

Only 4.4% of carers thought that they always worked together.

**Figure 5.22** In your opinion do health and social services work together to provide care to your relative with dementia?



Carers had varying opinions regarding the services that the person they care for has access to.

Just over half of carers (51.3%) disagreed that the person they care for has access to local services for socialising, furthermore, almost three quarters (71%) disagreed that the person they care has access to local services for socialising. In addition to this more than half of carers (55%) disagreed that they had access to respite care.

**Table 5.30** To what extent do you agree with the following statements?

% of respondents	Agree	Somewhat agree	Disagree	Don't Know
The person I am caring for has/uses dementia services/supports in the local community	35.9	16.7	46.2	1.3
The number of local dementia services has grown in the last three years	10.3	21.2	28.2	40.4
The person I am caring for has access to local services for socialising	19.2	23.7	51.3	5.8
The person I am caring for has access to help with day to day living	21.8	34	37.8	6.4
The person I am caring for continues to have the opportunity to develop new interests and new social networks	5.8	17.9	71.2	5.1
As a caregiver, I have enough access to local dementia services and supports	9.6	34.6	50.6	5.1
I have access to respite care when I need it, along with other services that support me to help care for my friend/relative	11.5	25	54.4	9

Base = 156

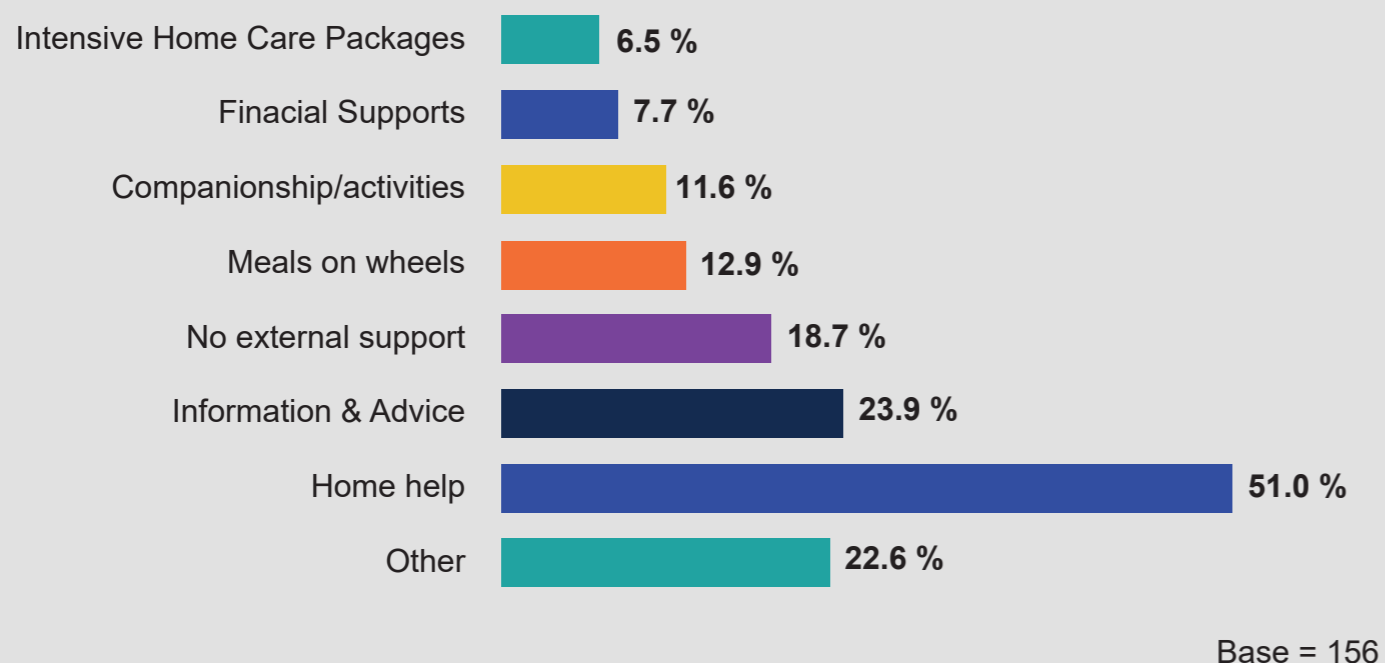
The need for better access to respite care was also raised as a key issue by many informal carers in response to other questions in the survey.

Carers were also asked if they agreed that services for PLwD in their local area had grown in the last three years. Responses were very mixed, with around one in three (28%) disagreed and a further third (31.5%) agreeing or somewhat agreeing. However, a significant proportion (40.4%) did not know if their local dementia services had grown in

the last three years. To some extent it would appear that carers/the person they care for receive a mix of supports and services.



**Figure 5.23** What external supports do you/ the person you care for receive?



The most frequently received support was home help (51%). Almost one quarter of carers (24%) received information and advice, whilst around one fifth (19%) received no external supports. Other responses included:

- Limited homecare (4%);
- Day care (4%); and
- Respite (1%).

The informal carers subsequently ranked the top 3 areas of support which they believe is needed by people living with dementia in the community.

Over half (57%) of carers ranked homecare support as the most important area of support for PLwD, with the majority (80%) of carers ranking it as 1st,2nd or, 3rd. Non-

medical interventions and help for planning for the future were ranked as the 2nd and 3rd most important areas of support.

- **A small number of respondents (26%), provided information on informal, community-based services that are available to PLwD that they were aware of. The most frequently cited services were: Alzheimer's / Dementia Cafes;**
- Day care centre; and
- **Local support groups.**

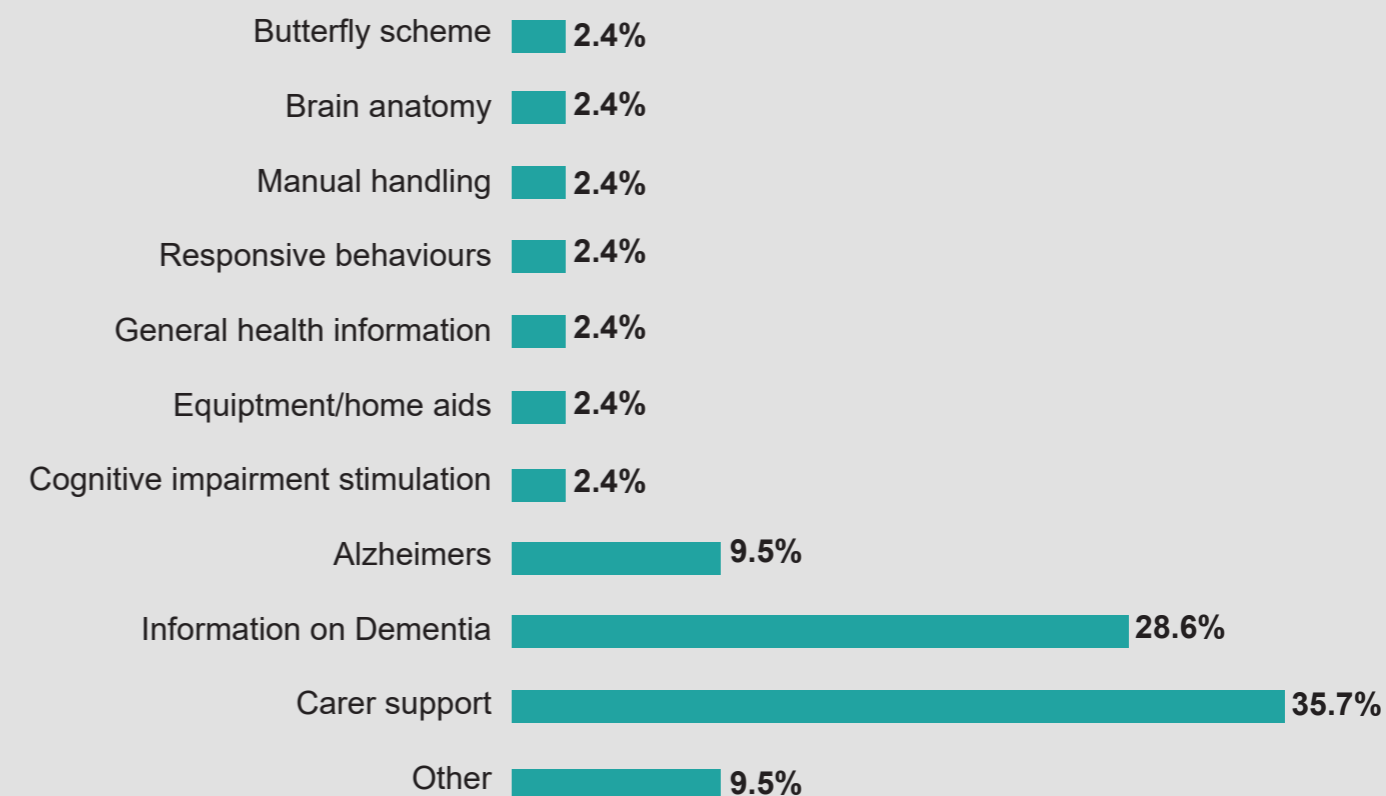
Carers were asked a series of questions about dementia specific education they may have received. Only one third (33%) had received dementia education within the last three years. The most frequent training or, education received was carer support and information on dementia and Alzheimer's.

**Table 5.31** Areas of support required by people with dementia

Priority Action Area	% of respondents			
	Any rank (1st, 2nd, 3rd)	1st	2nd	3rd
Homecare support	79.6	57.2	15.8	6.6
Non-medical interventions	59.2	23	21.1	15.1
Help with planning for the future	51.3	13.2	24.3	13.8
Information	48.7	14.5	12.5	21.7
Social activities	44.7	9.9	15.1	19.7
Education for me and relative/friend with dementia	41.4	15.1	9.9	16.4

Base = 165

**Figure 5.24** Focus of dementia specific education received



Base = 135

Almost half (49%) of carers had received face-to-face training, one quarter (26%) had received training online or, via Facebook and 13% had received training in a classroom or lecture format. The remaining 12% received training via group sessions, booklets or, public meetings/talks by professionals. The most frequently cited training provider was the ASI (34%), followed by HSE (13%) various hospitals (13%) such as Tallaght and St James' and the internet/online training (8%). Other providers included Universities, Dementia Care Groups and a Dementia Advisor.

Carers were then asked to what extent they agreed with statements relating to advice and information and the NDS.

Just over half (52%) of respondents disagreed that the NDS has improved their

quality of life and furthermore, around one third (37%) of carers disagreed that the NDS had improved the quality of life for the person that they care for. However, the majority (57%) agreed or, somewhat agree that they had enough information and advice to help the person they care for make decisions. These responses contrast with those from NfP, 60% of whom agreed that the NDS had improved the lives of PLwD. Interestingly, over a third (34.7%) didn't know if the NDS has improved the quality of life for the person they care for and a quarter didn't know if it had enhanced their own quality of life. Clearly if there has been an impact from the NDS it less obvious to some than others.

**Table 5.32** To what extent do you agree with the following...

% of respondents	Disagree	Somewhat agree	Agree	Don't Know
I have enough information & advice to help the person I am caring for to make decisions about managing their dementia	36.7	38.1	18.4	6.8
The NDS has improved the quality of life for the person I care for	36.7	21.8	6.8	34.7
The NDS has improved my quality of life as someone who cares for a person with dementia	52.4	17	3.4	27.2

Base = 147

## People Living with Dementia Survey Key Findings

Eleven PLwD completed hard copy surveys, of which nine were female and two were male. Six (55%) were under 65 years of age and five (45%) were over. All of whom had been diagnosed with dementia for at least three years.

### Awareness of the NDS

Seven respondents (64%) of PLwD had heard of the NDS. PLwD felt that all six Priority Action Areas were important, only one PLwD ranked Priority 4: Training for healthcare staff and more education for me/family/friends and Priority 5: Leadership, as 'Somewhat important'.

**Table 5.33** Thematic Analysis of what is important to you to improve life for people with dementia

Themes	%
Access to appropriate support at home	36
Access to age appropriate support (self & carer)	27
Education of the general public & health care staff	18
Access to social activities	18

Base = 11

PLwD were asked "What is important to you to improve life for people with dementia?". A thematic analysis of responses identified key themes, as summarised in the previous table.

Having access to appropriate support at home was the most important issue for PLwD to improve their life (36.0%), this is consistent with the views expressed by the respondents to the HSCPs, NfPs and carers. Access to appropriate support services for those with early onset dementia and younger carers was important to PLwD.

Following on from this, respondents were asked, what sources have you received information from about dementia?

**Table 5.34** Sources of Information

Sources of support	%
Alzheimer's Society of Ireland	54.5
Dementia Advisory Service	63.6
Medical Consultant/GP	100
Internet	18.2
Public Health Nurse	36.4
Other PWD	18.2
Social Worker	9.1
Other	18.2

Base = 11

**Table 5.35** In your opinion do the following groups understand dementia?

% of respondents	Yes	No	Don't Know
General Public	18.2	36.4	45.5
Political Leaders	0.0	9.1	90.9
Media	9.1	36.4	54.5
Health & Social Care Professionals	63.6	0.0	36.4
Members of my community	27.3	36.4	36.4
My family	81.8	0.0	18.2
My friends	63.6	9.1	27.3

Base = 11

All respondents noted that they get information from their GP or medical consultant. Almost two thirds of respondents also noted that they had used the Dementia Advisory Service.

PLwD were asked about the extent to which other groups understood dementia.

PLwD were most likely to say that their family, friends and HSCPs understood dementia. overall, PLwD believed that the general public and the media did not understand dementia. There was also mixed feedback regarding members of the community. It is also notable the high proportion of PLwD who did not know if the political leaders, the media or, the general public understood dementia.

Almost three quarters (73%) of PLwD agreed

or somewhat agreed that they have access to local supports.

Almost all PLwD (82%) agreed or somewhat agreed that they feel safe and supported in their own home and community. Around half of respondents (55%) agreed or somewhat agreed that the number of local dementia supports has grown in the last three years. This is comparable to the 50% of NfP organisations who also stated that local dementia services have grown in the last three years. It is also interesting to note that around one third of PLwD (36.4%) did not know if the number of supports in their local area had grown or, if they had access to local services to help with day-to-day living.

**Table 5.36** Community Services and Integrated supports

% of respondents	Disagree	Somewhat agree	Agree	Don't Know
I have used dementia services/supports in my local community	27.3	54.5	0.0	18.2
The number of local dementia supports/ services has grown in the last 3 years	9.1	0.0	54.5	36.4
I have access to local services for socialising	18.2	27.3	45.5	9.1
I have access to local services for help with my day-to-day living	27.3	9.1	27.3	36.4
I continue to have the opportunity to develop new interests and meet others	27.3	18.2	45.5	9.1
I have support that helps me live my life	18.2	9.1	63.6	9.1
I feel safe and supported in my home & in my community, which includes shops, sporting & cultural activities	9.1	27.3	54.5	9.1

Base = 11

**Table 5.37** Impact of the National Dementia Strategy

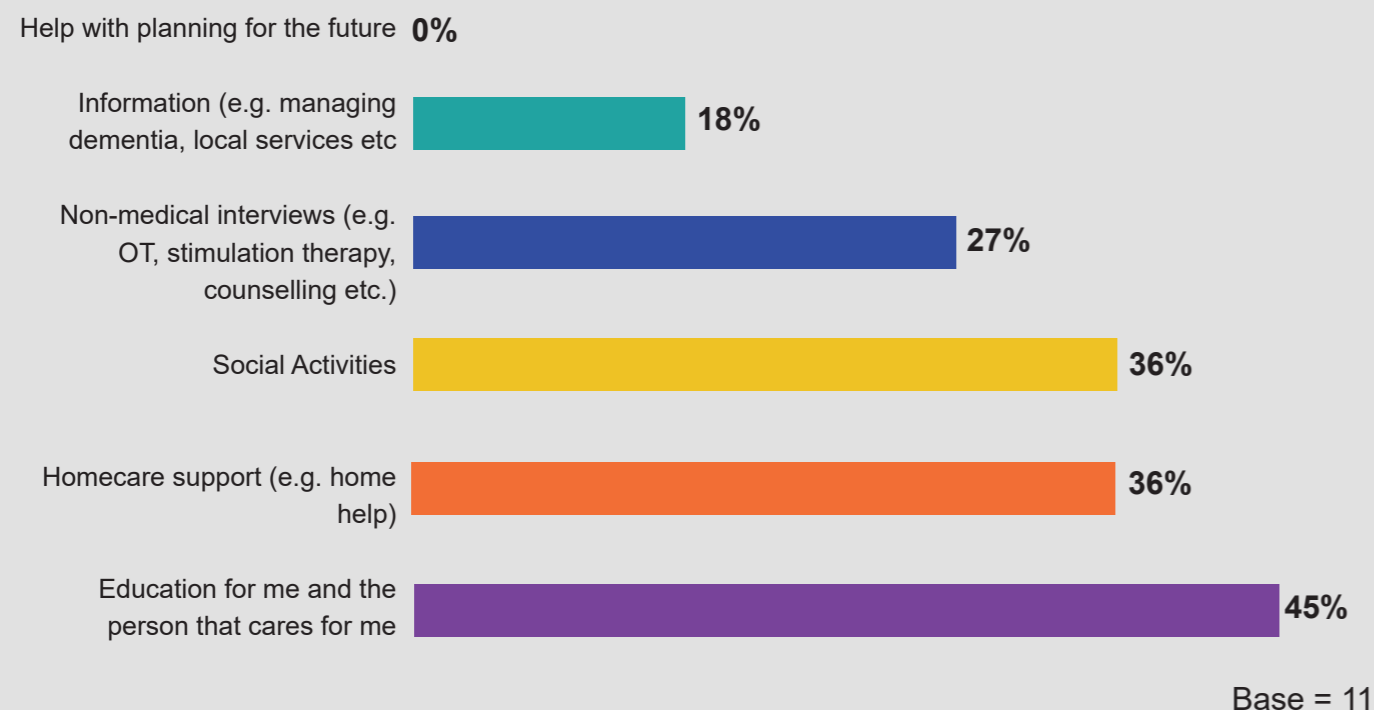
% of respondents	Disagree	Somewhat agree	Agree	Don't Know
I have enough information and advice to make decisions about managing my dementia now and in the future	0	36	56	9
The NDS has improved my life	18	0	64	18

Base = 11

PLwD were most likely to indicate that education for them and their carer is the most important area of support (45%).



**Figure 5.25** Top three most important areas of support



Homecare and social activities were the next most commonly cited required support (36%). This is consistent with the findings from the carers and NfP survey, where 82% of NfPs noted that homecare for PLwD is important and 72% noted that Education for people living with dementia and their carers was important. Similarly, 54% of HSCPs ranked Homecare support as the most important source of support and education for PLwD and their carers.

The majority of PLwD agreed that the NDS had improved their life (64%). Over half (56%) of PLwD also agreed that they had enough information to make decisions about managing their future.

### Summary of key findings from all surveys

An analysis of the surveys identified a number of common themes and issues across each of the four responding groups. There was a high level of agreement across all survey groups relating to the prioritisation of the six Action Areas within the strategy.

HSCPs, NfP organisations and carers all agreed that the integrated (joined-up) services and supports was the most important Priority Action Areas.

This was closely followed by the need for timely diagnosis and intervention, which was ranked second by all three groups. All key findings are summarised in the table below.

**Table 5.38** Summary of key findings

Priority Areas	Health and Social Care Professionals	Not for Profit organisations	Carers	PLwD
<b>Key Findings</b>	Joined-up services and supports ranked as the most important Priority across all four groups of respondents			
<b>Impact of NDS</b>	37% agreed or, strongly agreed that dementia supports and services in Ireland had grown over the last three years.  36% agreed or strongly agreed that the NDS has improved the quality of life for PLwD in Ireland.	55% agreed that dementia supports and services in Ireland had grown over the last three years.  60% agreed or strongly agreed that the NDS has improved the quality of life for PLwD in Ireland.	31% agreed or, somewhat agreed that dementia supports and services had grown over the last three years.  29% agreed or, somewhat agreed that the NDS had improved the quality of life for people living with dementia.	55% agreed that dementia supports and services had grown over the last three years.  64% agreed that the NDS had improved their life
<b>Education and Training</b>	58% had formal dementia training  79% would like more training	46% had formal dementia training  80% would like more training	33% had received dementia education	45% indicated that education is the most important area of support.
<b>Awareness</b>	57% Agreed that they had a good understanding of the NDS  81% rated their understanding of the needs of PLwD as good or excellent	53% Agreed that they had a good understanding of the NDS  87% rated their understanding of the needs of PLwD as good or excellent.	38% had heard of the NDS  66% rated their understanding of the needs of PLwD as good	64% had heard of the NDS
<b>Areas of need</b>	81% agreed that Homecare support was the most important area of need.	82% agreed that Homecare support was the most important area of need.	80% agreed that Homecare support was the most important area of need.	36% agreed that Homecare support was the most important area of need.

# CHAPTER 6

## Phase 3 Qualitative Inquiry Service Users and Staff Experiences

### Introduction

Phase three of the primary data collection sought to gain an understanding of the dementia services, from the perspectives of staff and service users, residing in four CHOs. This phase spotlights good practice and unearths issues that transcend those living with dementia and working with people with dementia. The overall purpose of this phase is to learn more about the extent to which people feel the NDS/NDSIP impacted 'on the ground' as well as empowering people with dementia and those in their support networks to contribute and have a voice in this national evaluation.

As part of the quantitative phase of the evaluation (Phase 2), those who completed the questionnaire were invited to return an Expression of Interest (EOI) form, to participate in Phase 3. Of the 688 people who completed the questionnaire, 155 also completed and submitted an EOI form. Of these, 43 were from PLwD or caregivers, and 112 were HSCPs. Those who returned an EOI form were contacted using the details provided by e-mail or phone and were requested to provide the name of the townland where the person lives (people

with dementia, caregivers) or works (HSCP), and if they would be willing to speak with a research team member over the following two to three weeks. Ascertaining the name of the townland was to inform the mapping exercise to ensure a national geographical spread. A total of 68 participants responded to this follow up correspondence; 43 of these were HSCPs and 25 were PLwD and/or their caregivers.

The following criteria informed the selection of participants:

- (i) **Geographical location (to achieve a wide geographical spread across Ireland);**
- (ii) Number of respondents in the area
- (iii) **The spread of disciplines amongst health and social care providers**
- (iv) The level of resource provision in the specific counties in which participants live/work to include both resource intensive and resource limited areas. This was informed using several resources including (but not limited to)
  - a. **Dementia Policy Paper**
  - b. [Dementia Mapping Report](#)
  - c. **HSE Website**
  - d. [A Guide to Memory Clinics in Ireland; 4th Edition.](#)

After selecting four CHO areas, the evaluation team aimed to recruit five participants per area (one to two service users and three to four HSCPs), using the above criteria. In some cases, the service user suggested potential HSCPs or people working in the community to contact. These individuals were also invited to take part in the research.

We attempted to contact participants a maximum of two times. If a response was not received or the person declined, another participant was contacted until five participants per CHO Area were recruited.

Participants who took part were living and/or working in the following areas:

- **CHO 1: Donegal, Sligo, Leitrim, Cavan, Monaghan;**
- CHO 2: Galway, Roscommon, Mayo;
- **CHO 4: Kerry, Cork; and**
- CHO 6: Wicklow, Dun Laoghaire, Dublin South East.

In total, 20 participants were interviewed, 5 per CHO area. Those represented included; administrator, Advanced Nurse Practitioner, Clinical Nurse Manager, Clinical Nurse Specialist, Dementia specific NfP employee, Dementia Project Coordinator, Director of Nursing, Geriatrician, GP, Informal caregivers, OT, Old Age Psychiatrist, PLwD and a Priest.

The findings from these qualitative interviews were analysed using content analysis and are presented in terms of two overarching themes reflective of the interview guide:

- **Challenges; and**
- [Facilitators, Services and Initiatives.](#)

Subsequent to this new and emerging themes are presented and discussed.

### Challenges

According to all participants, working and supporting PLwD can be challenging due to the lack of services and variation of services across sectors and regions. One challenge mentioned is the inequity felt among staff regarding the distribution of services, in particular home help and social supports. This causes undue stress on staff when family report that their neighbour received 'huge support' and they are 'fighting' to get the very basic hours for their parent. Furthermore, some services are reported as being supported by a Clinical Nurse Specialist, but others are not.

Rural isolation is very prominent in some areas and many feel that while there are great services and resources available in the larger towns, some of these facilities could be over 40 miles away from people that need to access them. This issue is further

compounded by the lack of public transport. There were mixed views from participants on the level of awareness within the broader community, with some stating that there is a lack of understanding among shop keepers and others in the community. However, some participants reported that once training was offered it was welcomed and availed of.

While certain services do exist, an informal care giver reported that some people are afraid to access them and over burden an already limited and often stretched resource:

“ *The dementia advisor is supposed to be good. But, I haven't made contact with her yet and I'm thinking well if there's only one nurse for Donegal she's not going to be, you know, the support's going to be minimum.* ”

A lack of community awareness of dementia was raised, particularly in rural areas. A community member highlighted the point that some people are lacking in basic dementia information. A lack of awareness may mean that others involved are not fully informed when discussing issues (for example a PLwD was advised that he should not be out walking alone). Furthermore, a lack of knowledge about the actual diagnosis might mean that people working in the community (e.g. a Priest) are not able to provide information about community-based supports and service because they are not aware of the specific problem. Also, people in

the community do not necessarily have any experience in dementia or access to training, for example, a priest in the community stated he would look up information on the internet to ensure he is informed but, thought that training should be provided to people like him in the community.

“ *Like everyone else in the community...we wouldn't be ...experts in any way... so I think [if] the Alzheimer's society...were in touch with people like me [a Priest]...maybe educate us a little bit more about it...all kinds of groups could be made ...aware of the issue in the community.* ”

The NDO newsletter was described as a great resource; however, it is electronic and many people with dementia do not have access to emails or to a reliable internet connection. Recent figures from the Eurostat show that 50 per cent of people in Ireland aged between 65 and 74 have never been online. This lack of access to ICT also affects staff who cannot provide information to people in real-time as they also do not have access to online services:

“ *There's a community hospital and they, their staff don't actually have emails or access to ICT which is pretty amazing, but pretty shocking in this day and age... but I mean that, that's a huge gap in their ability to access information.* ”

Interviewees reported very long waiting lists for referred services, such as specialists or to attend day care, with some people waiting months or even years for a formal diagnosis. GP referral is described as improving but the waiting lists were described as very long with only a very limited number of Geriatricians and Psychiatry of Older Age services available in certain geographical areas.

“ *I think that that's a huge deficit for people because they really do not know what's out there and some of them know bits and pieces and they know through this work and our talking to people, but there's no kind of package for people with dementia to access, services and supports* ”

Services relating to homecare were described by some participants as challenging with 'a massive gap' in what is required by PLwD; examples included the provision of homecare for personal hygiene needs being available for only 30 minutes per day. Day care was described as being under-resourced due to operating for only two days per week. There was also a reported lack of facilities that are purpose-built and owned by the health service; examples provided by participants included day care centres are essentially borrowed community rooms, for example one care giver noted:

“ *they're not good. I just know from talking to people, you know, that if they only got a few hours, you know, I mean there's great talk about homecare packages and intensive homecare packages .....But I know in my experience people just don't have them...or some people might only have half an hour for personal care...that's no good really for a person with dementia...'* ”

It was also reported that there is limited funding for homecare and that there is very low awareness among participants that we spoke to, of the HSE dementia specific IHCPs. Caregivers who availed of homecare reported that they had to fight hard for it or, could only access it privately. They also cited both positive and negative experiences with homecare assistants and feel there is too much variation in the training provided to staff and the quality of service. One care giver noted:

“ *We eventually after a bit of pushing got five hours sanctioned from the HSE about two months ago and we've somebody coming in an hour a day but again I actually questioned... what real training they've had in dementia care and indeed what training these companies have had in dementia care.* ”



One carer noted that that did not know how to access dementia specific IHCPs.

“ *I don't know where the dementia specific ones [Homecare Assistants] are...and that's being completely truthful about that...I haven't seen them.* ”

HSCPs interviewed discussed the tensions between privacy and choice of diagnosis disclosure (i.e. telling others in the community and receiving extra help and therefore potentially facing stigma). These tensions were highlighted as being stronger in rural areas.

Many interviewees reported a fragmented healthcare system. When it comes to people with dementia, there was a perception of the poor integration of services and the availability of post-diagnostic follow up was reported as being very scarce. One HSCP commented that acute care services are siloed from community and homecare:

“ *She's just very lost and went home and no follow-up at all in relation to what the family would need and what her husband and carer would need and what information they should have to make life easier for them. Once a diagnosis is given in acute care there are no leaflets to give out to say this is who you need to contact. The family are left with trying to source everything.* ”

Furthermore, participants reported lack of joined-up working practices across organisations due to existing practices; in addition, data privacy policies, such as the General Data Protection Regulations (GDPR), restricted the voluntary sector in discussing client information with HSE services, despite providing complex care arrangements. There was a reported separation of services between the voluntary sector and the public sector. It was highlighted that, even though they are providing care for the same individuals, the voluntary sector reported that they feel they are 'not included as part of the care team for these people' (Referring to multi-disciplinary team meetings, community team meetings, reports from allied health care professional assessments (i.e. OTs, Speech and Language Therapists etc.)).

The design of acute care facilities was also highlighted as a growing concern for staff who work in these environments. HSCP participants reported that daily they see people struggling with basic things such as signage in the Out-Patient Department or families becoming distressed because of lack of trained staff to support their loved one while in hospital. Staff working in acute care stated that there is a lack of recognition of dementia specific needs in some facilities. One HSE staff member noted:

“ *our hospitals are not built for dementia patients, particularly outpatients where people with dementia frequent.* ”

“ *Having a dementia specific A&E... well signposted and appropriate contrast of colour etc... maybe not every ward in the hospital, but I think care of the elderly wards and maybe wards with a higher concentration of patients with dementia, e.g. orthopaedic ward could be another one. Also, having the information leaflets available to create awareness.* ”

An acute general hospital admission can be a confusing and often frightening place for someone who has a diagnosis of dementia. The stress of an unfamiliar environment and the constant challenge the person with dementia faces in understanding what is happening can be overwhelming. Evidence suggests that care delivery and outcomes of hospital admission are poorer for people with dementia than for those without.

The inpatient acute hospital environment was described as very difficult for both HSCPs and carers. On some occasions when a formal diagnosis of dementia is not documented this can be particularly challenging for HSCPs.

Participants reported an apparent lack of recognition of dementia specific needs

in acute care. The design of the ward environment is not conducive to people with dementia. Staff are addressing the recommendations set out in the NDS (2014) and the Dementia Friendly Hospitals Design Guidelines (2018) through small projects so that the ward environment is dementia accessible from admission to discharge. However, it is hard to change the structure of the wards when so many factors are beyond the control of staff. As one care giver noted:

“ *There are elements to the ward that could be better, like having the nurses' station in the middle and safe walking spaces for patients. ...have a dayroom for families and carers.* ”

The Emergency Department or Acute Medical Unit were highlighted as a concern (in two of the areas covered by the interviews) as this environment can be overwhelming for a person with dementia and their carer. By its very nature, the emergency department can be stressful due to excessive noise and lack of orientation between different areas of the emergency department e.g. reception area, triage, waiting area, designated bays and toilets. This can be distressing and disorientating for people with dementia and their carers, one HSCP noted:

“ We don’t have a specialized area in the emergency department, really for somebody with Dementia coming into Hospital you want to try and make that as streamlined as possible.

A Clinical Nurse Specialist (CNS) in gerontology was highlighted as an immediate requirement to coordinate care for people with dementia who present to the emergency department. This is a dedicated person to organise the clinical pathway, speak with carers and advise on non-acute issues. Overall, nursing staff levels and the lack of a CNS in gerontology were a cause for concern as care delivery was perceived as fragmented. One care giver noted:

“ I think probably the big things, yeah, would be maybe around nursing, staffing and just I think we haven’t really set up systems of care for dementia and the hospital. Ideally there would be a planned admission, like we are getting CT done this afternoon. We are getting whatever done tomorrow morning to try and get them through their admission in a seamless coordinated way. So, like if you did have a CNS in Gerontology at least there would be two people trained to coordinate that pathway through Hospital.

One carer described her frustrations with regard to the disjointed care when trying to

alleviate symptoms for her mother and how a CNS or dementia specific HSCP would have been an important resource:

“ I suppose we were trucking for about nine months, before we eventually found the right medication, and actually calmed her down. But her body kept resisting all the medication. So, it would be perfect for two days; I’d say, “Oh my God. Yes,” and then, shortly after that, it was gone again, and we’re looking for another review on it. It was hard. But I just found, like, you had to go back to the GP, or you had to go back to somebody. There was no dementia nurse there, so you couldn’t just ring them and say, “Look. Can you come up and tell me what am I going to do?” That’s what I found; that there was ... like, it’s fine putting them in a day centre; but sure they won’t take them in a day centre if they’re cross. You have to find the right balance, and I found that there was nobody that you could turn to. There was just ... it was yourself.

Those interviewed feel that stronger and clearer links and pathways are needed stating that it is too complex and challenging for caregivers and PLwD to navigate dementia-related services across all sectors, as care givers noted:

“ I certainly think a single point of contact (is needed), so a one-stop shop.

“ There could be a lot of different people all working on that but we’re not working together as a unit as such? We’re fragmented.

Overall, the expansion of services and capacity building is needed to avoid hospital admission for PLwD. There is a shortage of homecare packages and home help hours. Respite in both cases was offered but not availed of because in one case it was deemed not necessary and the other case it was challenging as the person with dementia had complex issues that the carer felt would be difficult to manage unless the provider knew the person with dementia. Where it did exist, homecare was described as non-flexible and not person centred.

Often societal views and stigma about dementia can act as a barrier to the delivery of dignified care. The Understand Together campaign sought to increase people’s awareness, understanding and attitudes around dementia however the full impact of the campaign remains to be observed especially for those at the later stages of dementia. One care giver noted:

“ There definitely is still a lot of stigma and a lot of taboo around diagnosis of dementia, and I’m meeting carers who wouldn’t like to be going out in public with their loved one, in case they get an unexpected reaction or an unexpected

response. I do think, in this area, there has been a change... because the momentum, over a number of years now, that ... between businesses, schools and social groups and volunteer groups, and there’s been so many information evenings and the GPs and primary care team are so heavily involved there .... But definitely the uncertainty that comes with a diagnosis of dementia still has a fear factor attached to it.

While community services for those with moderate stage dementia are generally available and accessible, some participants felt that there is a paucity of services for people in the early and advanced stages of dementia. Participants also felt that, social activities and groups are also lacking for people living with early-onset dementia, some care givers noted:

“ But we do need some, you need to really be looking at early stage diagnosis and the appropriate supports that we can give to people in the early stages. You know people moving into the middle stages, the likes of the day service, the Living Well with Dementia, the exercises, the walking group, all of that, they work you know they do work and people who are still independent but might just need the smallest support to remain part of their community, you feel they don’t have those services, those services do not exist.



Care givers commented that physically accessing services can also be a barrier. They reported that their parents with dementia attended and enjoyed some local services (e.g. social clubs) but now they can no longer attend due to limited mobility.

One mentioned how she would love if some services (e.g. arts & crafts) could come to the person's house as it was something he enjoyed very much when he could attend in the local community.

In the experience of participants, there was also a wide variation in the quality and organisation of healthcare professionals they encountered (e.g. GPs, consultants), and in many cases caregivers chose to attend different practices upon advice of their friends who had a better experience. One care giver noted:

*“ The GP is a lovely gentleman but the GP practice...they're not up to date, they're not organised, you know stuff goes in there and unless you go chasing it, you're at an end to nothing so I think it's really the whole health service really just needs to step up.*

*“ And then the GP, I don't know, we didn't get an awful lot of information from the GP. Going into the [Memory Clinic] once a year, you know, do the memory tests and there was no follow up, there was nothing – just 'see you next year'. And that was very hard.*

In acute settings, it was said that low staffing levels makes it difficult for staff to find the time to make use of training and education in acute settings. According to HSCP interviewed more optimal staffing levels are desired so that staff can take part in training and education, and then have more time to implement learnings with people with dementia and their caregivers.

*“ I mean, usually the only barriers to staff attending training would be...staff shortages...and that's why delivering it in an accessible way is really important.*

In addition, a HSCP reported that staff turnover can be a barrier to training and education having an impact. They feel that sustainable and ongoing training, education and awareness is needed across Ireland.

*“ Like ongoing training is always good for the quality of the staff because we have a huge turnover of staff but then that is not unique to where I work – across the board in healthcare.*

Although public residential care facilities receive HSE-provided information and resources relating to dementia, one participant commented how this not the case for private sector facilities.

## Facilitators, Services and Initiatives

### Facilitators

Of those interviewed, all stated that the services that do exist are 'wonderful' and the staff and volunteers are to be highly commended for the work they do.

However, it is evident that the number of services needs to increase to meet the existing and growing needs of people with dementia. Particular services highlighted as lacking in some areas included; dementia in-home respite and dementia case management.

Services such as day care and nursing homes that host coffee mornings were lauded and are highly used in certain communities. Those that provided a bus service to and from these services were deemed 'excellent'.

Public Health Nurses (PHNs) were regarded as a fantastic resource with participants noting that they supported families and people with dementia and had superior knowledge of all sectors and services that

could be accessed to assist people with dementia to live longer and better at home. Nurse education centres were also mentioned as a facilitator to providing better care as they ran a number of training sessions for all nurses regardless of healthcare service and these programmes were provided freely through the NDO and as a direct result of the NDS.

The NDS itself was described as having an impact with particular reference to service planning, and while this may be at an embryonic stage in some sectors, it was felt that the NDS and the NDSIP provided a blue print for managers to bring together social workers, Occupational Therapists (OTs), PHNs and other members of the multidisciplinary team.

Local and National Alzheimer's ambassadors were also seen as great facilitators by interviewees to destigmatising dementia in rural areas and a catalyst to opening conversations. Furthermore, the visibility of Alzheimer's café and awareness campaigns facilitated by the Dementia Advisors (DAs) was described as making living with dementia something that is more accepted and understood in local communities. Participants discussed the dementia advisor service (self-referral possible). This was described as well equipped, offering support, information and signposting. It can commence at the early stages (day to day



living well) and as the possible information relating to future issues (legal issues etc.). A HSCP described those staff with a special interest in Dementia as key to improving services for people with dementia.

“ *We are quite lucky in our area because we have an Occupational Therapist, who, her pure remit is Dementia care.* ”

“ *The dementia advisor has a huge geographical area to cover, so, yeah, with particular complex cases, it would be a case of picking up the phone and ringing her to pick her brains and get some advice. But there isn't a formalised partnership, other than we're all sitting on the same dementia services group for Cork and Kerry. I think a goal of that group would be that there would be a more harmonised delivery of services, but I understand, at the moment, that's not happening.* ”

## Services

Psychiatry of Older Age Teams and Consultant Geriatricians were described as invaluable, but acknowledgement was made that they were over stretched and under resourced. Multi-disciplinary teams with an interest in dementia attached to acute care also made it easier to support people with

dementia, often leading to a more seamless experience for the patient when navigating the services. But these were described as isolated healthcare teams rather than standard practice.

Dementia awareness online training for people working in shops and public services was seen as a great resource, as were the memory technology resource rooms.

The HSCPs reported that people are presenting at an earlier stage of dementia development, (which they believe is due to the awareness campaigns) and this helps with forward planning. Initiatives such as the “COGS”<sup>17</sup> club aims to provide a service for people living with early stage dementia. HSCPs reported using peer to peer support (formal and informal) and found this helpful for them when trying to develop the scope of their role. There has also been an improvement noted in GP identification of memory issues, and subsequent referral to specialist care (this may be related to NDS projects such as PREPARED).

Hospital based initiatives, such as the Butterfly scheme, was discussed by one participant as a means to create an environment within the hospital setting that is dementia accessible.

Day care, homecare were all described as ‘great’. Likewise, the DA and related services were described as ‘helpful’.

Other voluntary services were described by HSCPs as helpful, this allowed carers time for other responsibilities, such services included Day Centres and sitting services. However, the availability of these services varied across areas with some areas better resourced than others;

“ *We also have a sitting service through one of the Carer's Agencies locally which is run by volunteers, or it's a voluntary service, it is something you pay for, but a very nominal amount, I think it's like a hundred euros a year.* ”

## Initiatives

The majority of HSCP interviewees had engaged in various education and training to inform their practice.

“ *From the training and education point of view, there's nearly 2,000 home help or healthcare support assistants, in the Cork/Kerry area, that are HSE. Over the next two years, there's a plan that 400 of those will receive training. I believe that St. Luke's, here in Cork, are also going to be delivering training as well to groups of up to 20 at a time.* ”

This education initiative refers to the ‘homecare worker education programme’, which the NDO are governing the roll out. In addition, resources available from Understand Together website also help create educational awareness, one HSCP noted:

“ *I would routinely hand out bags of Understand Together badges to all members of the group and hand out the information leaflets about Understand Together. It helps in some way with the roll out of the National Dementia Strategy.* ”

Social media such as ASI Facebook pages, the Understand Together site and other local resources were described as ‘brilliant’ and were viewed as providing so much useful information regarding supports, services and upcoming events. These resources are used by staff, family and PLWD. A HSCP also mentioned that a local helpline was could be useful in the future as many people in rural settings use their landline phone as the primary mode of communication.

The Dementia Champions training programme provided by Dublin City University targets Health and Social Care Professionals, this module is blended learning (online and face to face), running over 12 weeks with 6 half days contact time. This programme is aimed at changing care cultures, broadening dementia awareness

<sup>17</sup> The COGS club is a service designed to help people newly diagnosed with dementia to improve their memory and overall mental function.

and improving standards of care and support for people with dementia. One HSCP had completed this module which was free for HSE staff.

*“ I have completed DCU Dementia Champion's Course. So that was quite interesting in terms of looking at dementia a different way. I think it is geared towards community.*

HSCP participants noted that they thought the NDO was a key resource to support educational initiatives as well as to engage with HSCPs who are in direct service provision. The opportunity to link in with the NDO was described by HSCP as beneficial. The NDS itself was described as having a specific impact on service planning and while this may be at an early stage in some sectors, it was felt that the NDS and the NDSIP provided a blue print for managers to bring together social workers, OTs, PHNs and other members of the multidisciplinary team

According to some participants, local communities welcomed and supported new services and service development efforts warmly. For example, one caregiver describes a local church that provides a room free of charge on a weekly basis for groups to meet in. There are also funded services such as Living Well with Dementia which was often cited as being extremely positive for the area by participants.

*“ I know the 'Living Well with Dementia' group did have a fabulous homecare project that was dementia specific you know and it was absolutely brilliant.*

Participants who were caregivers of PLWD felt that local communities were generally very supportive, but more training and awareness is needed, particularly with public facing groups (e.g. banks, post office etc.). According to participants, neighbours often 'look out' for the person living with dementia, highlighting the need to tell people. However, one person had a situation where her relative with dementia was taken advantage of (financially) and cautioned against making the information about a dementia diagnosis too public.

In the acute setting, some hospitals benefitted from education and training programmes (Level 1) for health and social care professionals who practice there (multi-disciplinary). It was reported by participants that accessible training and information make it easier for staff to support people with dementia in this setting. A key facilitating factor was that some of this training is provided on the ward, and available online through staff intranet.

The HSCP participants noted that they are more aware of dementia and feel happier to support somebody with dementia as a result of this training.

Participants reported a “very strong sense of community partnership” in local areas and initiatives such as a memory groups in small rural villages helps to support this. As part of the Cork/Kerry operational plan the key priorities aim to address the limited resources e.g. to continue the development of integrated care services in conjunction with acute hospitals focusing on improving service pathways specifically in dementia and also to progress home support governance work. The recent appointment of an Advanced Nurse Practitioner candidate will help integrate care services. Other service improvements at the local general hospital were also welcomed, as one HSCP noted:

*“ They have a dementia nurse there now. There are plans to open a six-bedded ward, especially for dementia patients, where they can avoid A&E; they can go up to the ward. They will be assessed there for pain or whatever their symptoms, overall my experience was good in KGH we were seen fairly quick”.*

Also, there are plans to increase the number of dementia support workers for the wider Kinsale/Bandon in the area.

*“ So far, I know the feedback is anecdotal, but dementia support workers have been very well received, both from*

*service users and from carers, as well. We have been looking at the kind of numbers that we expect to be dealing with, and we've used the Euro code; figures in order to profile the numbers we expect to be dealing with, across network 13, and when you correct for people that are expected to be within residential care, we're coming out with a number of 372 people, across network 13, living with dementia in the community. So, I suppose when we cover the whole of network 13, and we see the type of demands that's been ... that we're dealing with ... the type of home support hours that there is a requirement for ... I think that should better equip us to be able to start looking at what resources will be needed for other networks, outside of network 13.”*

Despite a number of gaps existing's in the availability and provision of appropriate dementia services, HSCP are aware of future strategic plans by the government and HSE. Action plans are identified within the Mid-Term Review of the implementation of the National Dementia Strategy. Also, the Sláintecare ten-year programme provides a roadmap for service redesign and supporting infrastructure to develop health and social care services.

**Table 6.1** Key Messages from those interviewed

	Summary of Key Messages from participants (N=5)
Challenges	<p>Some rural areas are under resourced and public transport for people with dementia and their families is described as insufficient.</p> <p>Perceived lack of integration and collaboration between services, particularly post diagnosis leading to an inefficient use of the services that are available.</p> <ul style="list-style-type: none"> <li>• Homecare is described as inflexible and non-person centred; this leads to issues in providing quality care in the person with dementia’s own home. More funding towards home/day and social care would be valued.</li> <li>• Some acute care settings are not designed to meet the needs of people with Dementia.</li> <li>• Lack of multi-disciplinary central location for older adults with dementia was reported</li> <li>• Very little flexibility around budgets (to afford staff in the service greater decision-making ability)</li> <li>• Lack of appropriate hospital design can be overwhelming and disorientating for PLwD and their carers</li> <li>• The quality of homecare was described, by those interviewed, as challenging as it was not always carried out with dignity and respect</li> <li>• Lack of recruitment and retention of HCA/Support workers and HSCPs with an interest and awareness in dementia was described by participants</li> <li>• Lack of integrated coordinate care and dementia specific pathways with significant geographical variation was reported.</li> <li>• There is large staff turnover and often low staffing levels across the healthcare sector in Ireland, which is a challenge for providing a sustainable impact of training.</li> <li>• Within the acute setting, participants felt that awareness of the NDS itself is relatively low it has perhaps been forgotten to some extent.</li> </ul>

	Summary of Key Messages from participants (N=5)
Facilitators & Services	<p>Health and Social Services that are available are excellent but there is a perception that there are not enough healthcare specialists in dementia to cover the population.</p> <p>Neighbours and community are very important in rural settings</p> <p>Resources and services described as excellent include;</p> <ul style="list-style-type: none"> <li>• Understand Together website (understandtogether.ie)</li> <li>• ASI Facebook page</li> <li>• Public Health Nurse</li> <li>• Local and National Alzheimer’s Ambassadors</li> <li>• The National Dementia Office</li> <li>• The National Dementia Strategy</li> <li>• Nurse Education Centres</li> <li>• Day Care and local Nursing Homes.</li> <li>• Hospital initiatives such as the Butterfly Scheme</li> <li>• COGs club</li> <li>• Improved GP care noted perhaps as a result of PREPARED project</li> <li>• Befriending service</li> <li>• Alzheimer’s café</li> <li>• Carer support group</li> <li>• Caregiver training which provides psychoeducation.</li> <li>• Dedicated HSCPs with dementia specific interest enhance care delivery</li> <li>• Voluntary initiatives are crucial for families e.g. sitting service.</li> </ul> <p>Other initiatives that were in existence prior to the development of the NDS and have informed service planning e.g. Dementia Advisor, Crystal Project, Memory Resource Room, etc. are valuable and should be expanded/upscaled.</p> <p>The quality of education and training in dementia for community workers is streamlined in conjunction with the NDO.</p> <ul style="list-style-type: none"> <li>• According to participants, a well-resourced Dementia Adviser service is available for those with moderate stage dementia but less so for those in early and advanced stages, and those with early onset dementia</li> <li>• The NDS (through Understand Together) has increased awareness and raises the standards so that dementia will be prioritised, which has had a positive effect.</li> <li>• Ongoing, and accessible training (e.g. through online learning modules, on wards) in acute settings appears to have had a positive effect on the confidence and capability of staff to care for PLwD</li> <li>• Both NDS-funded projects such as Memory Technology Resource Rooms and non NDS-funded initiatives such as the Living Well with Dementia Initiative were mentioned as having a positive impact.</li> </ul>



Figure 6.1



## Emerging Themes

Emerging findings from the 20 interviews resulted in a number of themes for consideration; urban/rural dichotomy, fragmented health and social services, issues around lack of preparedness of acute services to meet the needs of people with dementia; examples of good practices/ services initiatives; and training and education across all sectors.

### Urban/Rural Dichotomy

Across the CHO areas there was an urban and rural mix of participants. Living in a rural area presented significant challenges. The most recent figures from the Central Statistics Office (CSO) indicate that the

island of Ireland is becoming more urban with the concentration of people in cities and large towns. Consequently, rural depopulation is occurring and comparison of CSO figures, from year to year, report a decrease in overall population but a rise in the elderly population in rural areas. This can lead to isolation and gaps in caring as younger family members migrate to large towns and cities. Thus, this influences the delivery and availability of services. Recent evidence demonstrates the additional barriers faced by carers of people with dementia in rural areas (Ruggiano et al. 2018). Similar barriers emerged for all CHOs in that large distances from health care providers and/or limited numbers of health care providers were reported. This can further exacerbate caregiver burden.

However, local community supports and especially the strategic reconfiguration of resources towards community-based care has been shown to be important in shaping opportunities at home (Kuluski et al., 2012, O'Shea et al, 2017).

Broadly speaking there is an apparent inequity regarding the distribution of services and this is further amplified in the rural/urban divide. The backbone of the community and the core reasons that a PLwD is able to stay at home appears to be voluntariness and good will of family, friends and neighbours. Where a concealment of a diagnosis exists or, a person is isolated from services and the community, premature placement into long-term care occurs. It is of note that, while greater services exist in urban areas, people may still feel isolated due to an inability to afford transport to and from the service. Sitting services were mentioned across a number of areas and were described as essential to reducing burnout among family carers. A local helpline was suggested to meet the needs of those in that catchment area. Bus services were also seen as essential in rural locations. In-home dementia specific social activities were highlighted as an initiative that could help to support those with significant co-morbidities and those at a more advanced stage where day care services were less able to meet their social needs.

## Fragmented Health and Social Services

Fragmentation can occur across and between health and social professionals and this is related to poor communication channels and lack of dementia specific care pathways. Fragmentation and lack of continuity can also occur as a result of isolating a care episode (e.g. person admitted for a fall to an Emergency Department and is discharged post investigation and treatment).

Interviewees across all the CHOs noted there is a need to improve the integration of services and collaboration among Health and Social Care Professionals. This appears to be more evident in the initial post-diagnostic phase where follow up is described as 'poor'; not until a crisis does occur the person with dementia re-engage with acute services. Where good integration exists, it is often the result of a very proactive family and good primary care professionals with a specialist interest in dementia such as the GP and PHNs. This type of integration, at present, is lacking in the systematic implementation of clinical guidelines or pathways of care. Gage et al. (2013) refer to the fragmented approach to dementia care between acute care and long-term care. This was also alluded to by those interviewed but more emphasis was placed on the disconnect between acute and community, where a lack

of continuity of care dominated discussions. There is evidence to suggest that dementia case managers are cost effective and provide care continuity, advice and support for persons with dementia and their family, through all stages of the disease (Minkman et al. 2009). It is acknowledged by the NDO 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 an effort to address this issue, a Dementia Key Worker Working Group was established by the NDO in November 2017.

A priority action within the NDSIP is to ensure information on how to access services is routinely given. The dementia advisors have played a key role in the provision of information, however within some of the CHOs, the fact that some services were not self-referral, restricted access and delayed engagement with services of potential benefit. This issue is further compounded by inadequate numbers of dementia specialists in the area.

Inflexible and inadequate homecare hours were common challenges mentioned. Allocation of homecare is described as nonperson-centred and provider availability/preference is placed above the needs of the person with dementia. It has been

reported that people are on long waiting lists for homecare and in fact many transition to long-term care as a result of the delay. According to Banerjee et al., (2003) people with a resident-carer were 20 times less likely to transition to long-term care. Extensive resources have been injected into homecare packages as part of the NDSIP and by the first quarter of 2018, 309 people had received dementia intensive homecare packages as part of the Genio programme.

## Acute Care Preparedness

Issues regarding acute care were highlighted by participants, these related to lack of dementia specific staff, poor general awareness of the needs of people with dementia and hospital buildings devoid of dementia accessible design features. Empirical research continues to reflect on a consistent interrelationship between the patient, hospital environment and improved health outcomes (Robinson et al. 2015). Despite concerns regarding the layout and design of hospital environments, there is little evidence to determine the use of Evidence Based Design<sup>18</sup> in healthcare settings.

National and international research confirms that an admission to an acute hospital can be distressing and disorientating for a person with dementia and is often associated with

decline in cognitive ability and levels of functioning around activities of daily living (Cunningham, 2006; Covinsky et al., 2011). Irish data for PLwD highlighted that many have long hospital stays (Economic and Social Research Institute 2009) and frequent out-patient appointments yet a shift in culture of care and Evidence Based Design for people with dementia is sporadic and locally driven. Simple things such as signage were described by some participants to be low cost yet effective initiatives; for example, in OPDs and the ED. TrinityHaus (2017)<sup>19</sup> have developed a Dementia Friendly Hospital Design Audit Tool to help staff to identify areas that require improvements and are an excellent starting point when coupled with the 'Dementia Inclusive Design for Acute Hospitals from a Universal Design Perspective' guidelines (2018). This publication is a very welcome addition; the audit tool is currently being piloted which will support the implementation of the guidelines.

According to the mid-term review of the NDSIP, 25% of acute general hospitals will have a CNS in dementia care in post by the end of 2018. In 2017, three new Dementia CNSs were appointed; however, without further investment these roles will remain limited and only exist where local management have prioritised dementia and championed change in their service. The CNS role encompasses comprehensive

assessment and the provision of psychological and emotional support to people with dementia and their families/carers throughout their disease trajectory; thus, becoming a single contact point in acute services. The role would also ensure that dementia pathways in acute hospitals are implemented and that staff are educated and knowledgeable about the distinct and varied needs of people with dementia. Initiatives such as the Butterfly scheme were highlighted by some participants as having a positive impact on acute services and acted as a catalyst for awareness raising; however, this was seen as only one part of a much larger picture. It was clear that firm plans with financial commitment need to be deployed to acute services to tackle the current issues and ensure that services and staff are prepared and equipped to meet the needs of people with dementia. Furthermore, it was felt that only level one hospitals were the focus of dementia specific initiatives while smaller more rural hospitals were neglected, and often these are the types of acute care facilities that interact most with people with dementia and their families.

18 "Evidence-Based Design (EBD) is the process of basing decisions about the built environment on credible research to achieve the best possible outcomes." <https://www.healthdesign.org/>

19 <https://trinityhaus.tcd.ie/dementiafriendlyhospitals/>

## Good Practice/Dementia Specific Services

All 20 interviewees alluded to or explicitly mentioned initiatives within their CHO area that were having a real and positive impact. Some of these included the Memory Technology Resource Room, Living Well with Dementia, K-Cord and the Crystal Project. The thrust of these initiatives was to develop new services and supports for people affected by dementia and overall this appears to have been achieved. Day care services were also described as very welcome resources; however, a recurring theme was the fact that waiting lists for access existed and activities were not meeting the needs of those with early onset or those with advancing disease.

Initiatives such as Living Well with Dementia have embedded into the community and are effecting change, however this level of concentrated dementia specific activities and supports was not consistently or evenly distributed across CHO areas. Other services were specific to health care delivery and targeted at long-term care, for example, outreach services in the CHO 6 area that provided mobile x-rays resulted in people with dementia avoiding acute hospital admission.

Non-doctor referral services were described as most effective and accessible- an

example includes the dementia advisor. Their role and function within the community was unanimously described as essential by both carers and health and social care professionals. However, some people were very conscious that only one dementia advisor was covering a large geographical area and were reluctant to access their service with the fear of burdening an already stretched resource. This is a significant issue as it could lead to delayed access to essential information or planning services which could prevent crisis engagement with acute care at a later point.

## Training and Education

Training and education was raised throughout all the interviews and consistently the Understand Together project was described as an excellent initiative that was frequently accessed and referred to by staff and carers alike. Participants also noted that information should be posted out to HSCPs and PLWD in rural areas, particularly in areas where there is no or limited broadband access, as people in these areas could experience specific barriers to accessing information. Furthermore, one private nursing home did not appear to be accessing the training provided by HSEland or Understand Together and felt isolated from publicly available resources. While the NDSIP has created an emphasis on GP

education and training in long term care, the acute services again were highlighted as a group of HSCP that needed training but had challenges accessing courses due to lack of cover. Release of staff to attend non-mandatory training sessions is a major barrier to up skilling front line staff. Without training staff do not feel competent to meet the needs of people with dementia and this can result in increased stigma and lack of dignified care.

The provision of education and training opportunities for HSCPs, carers and PLWD is part of the HSE commitment to enable HSCPs to meet the needs of PLWD in a person-centred and compassionate way. Given the proliferation of training available, the NDO offer programme governance to ensure the delivery of accessible high-quality Homecare Worker Education Programme. There are a wide range of educational programmes available nationally, at different learning levels. These programmes can be accessed by health and social care staff and also by individuals who are caring for people in the community; a list of programmes is available on the Understand Together website.

## Conclusion

Findings demonstrate that good practice exists and new initiatives are beginning to have impact but, many are embryonic and thus there is hesitance among staff and carers to commend these changes until systematic implementation occurs coupled with strategic investment in services and staff aimed at long term sustainability (e.g. homecare packages, Dementia CNS, Dementia Advisors, Community based Case Managers/Dementia Key Workers and Specialist Consultants). The focus also needs to shift marginally to acute care regardless of 'level' and an emphasis on integrating dementia specific pathways needs an accelerated roll out. This phase has highlighted a number of important issues for consideration and plays a key role in informing the evaluation of the NDS and the NDSIP, particularly in terms of determining where impact is being felt.

However, there are limitations to the qualitative approach and representation in each CHO area. Hence, the conclusions that can be drawn from the data given the size and scope of services being provided in each CHO area is limited and needs to be interpreted with caution. The findings from this phase will be discussed further in the next chapter within the context of phase one and two and other NDS supported programme evaluations.



# CHAPTER 7

## Conclusions

### Introduction

The key findings from the three phases of research have been triangulated to understand the impact of the NDS to date. A realistic evaluation approach, using mixed quantitative and qualitative methodologies, was used to identify relevant contextual issues and capture the realities of dementia in Ireland from multiple stakeholders. Overall, the findings recommend that the NDS is a mechanism for improving the social care and supports for PLwD and their carers in Ireland and strives for optimum service delivery by highly trained health and social care providers.

The following provides an overview of these key findings which focused on understanding the views and opinions of key stakeholders (PLwD, informal caregivers, healthcare professionals, and not-for-profit groups), who are end-users of services, programmes and campaigns developed under the umbrella of the NDS. Interviews with a range of these stakeholders emphasised that prior to the implementation of the NDS, dementia services and infrastructure were critically under-developed in Ireland. This evaluation also focused on the impact and reach of the NDS and the NDSIP in Ireland.

From the outset, the NDS recognised that it was important to capture the learning and to identify effective practice, therefore evaluation was integral to each of the projects funded through the original HSE and AP investment. However, as described in Chapter 2, to date, not all of these evaluations have concluded. Hence, where possible, evaluation reports or reviews are referred to in an effort to provide a comprehensive range of evidence as to the effectiveness of the six priority actions identified in the NDS.

It is clear that the introduction of the NDS in 2014 was timely and that the support from AP (both in priming infrastructure and funding) was central to bringing about a change in the scale and range of dementia services in Ireland, particularly those with a focus on person-centred models of care. This is reflected by the positive views of many of the stakeholders participating in this evaluation. Thus, this evaluation identifies both the strengths of work completed so far and areas that could be improved to fully realise the goals of the NDS.

### Priority Action Area 1

#### Better Awareness and Understanding

A key objective for this Priority Action Area relates to increase public awareness and understanding of dementia. A review of the international literature highlighted the importance of raising awareness of dementia (e.g. see Merkle (2016), Chow et al (2018) or, Wright and O'Connor (2018)), in order to increase understanding and to reduce the stigma of dementia. All key stakeholders who were engaged at each stage of the evaluation noted the importance of creating a better understanding and awareness of dementia at all levels but especially in local communities. One of the key activities under this Priority Action Area was the Understand Together programme which was launched as a public awareness campaign for dementia. Findings from our survey and interviews of Health and Social Care Professionals, Not for Profit Organisations, PLwD and their carers suggests that it is the most salient output of the strategy in this Priority Action Area, with both service users and carers referring to it when asked about the NDS (even if they had not heard of the NDS). Whilst the mid-term evaluation noted relatively high levels of use of the UnderstandTogether.ie website (e.g. 90,000 hits in 2017/18) and 7,000 Facebook likes, findings from this evaluation noted that a sizeable number of stakeholders regarded the level of understanding of dementia

amongst the media and politicians as poor but good to excellent among HSCPs. When asked if this should be a priority area in the future almost half of the HSCPs would not rank it in their top 3, this is most likely testament to the fact that there has been such progress in this area and its impact is tangible on the ground. Fortunately, the vast majority of respondents (84%) believed that there was little or, no stigma associated with dementia amongst healthcare staff. These findings are also consistent with the 2016 and 2018 surveys that were conducted as part of the Understand Together campaign which found that there was an increase in the number of people who stated that they had a reasonable understanding of dementia (increasing from 24% in 2016 and 33% in 2018)<sup>20</sup>. Furthermore, an analysis of the survey data showed a positive association between awareness of the Understand Together campaign and views on the benefits of early diagnosis and seeking help (Hickey, 2019).

While the results were largely positive, some PLwD participating in this evaluation felt that dementia awareness is still relatively poor in parts of Ireland and that there were mixed attitudes towards dementia in their local communities. They spoke of how these attitudes, both positive and negative, significantly impact them in their day-to-day life and how they feel within their community.

<sup>20</sup> <https://www.understandtogether.ie/understand-together-campaign/>

For example, some PLwD felt that others avoid them or that their diagnosis is not taken seriously.

This ongoing stigma was echoed by HSCPs who discussed the tensions between privacy and choice, and diagnosis disclosure (i.e. telling others in the community and receiving extra help and or/facing stigma). These tensions appeared to them to be stronger in rural areas. Enabling resources in reducing stigma and increasing acceptance was the work undertaken by local and national Alzheimer's ambassadors. These were described as great facilitators to de-stigmatising dementia in rural areas and a catalyst to opening conversations. Furthermore, the visibility of the network of Alzheimer's cafés and local and regional awareness campaigns facilitated by the DAs were described as making living with dementia something that is more accepted and understood in local communities. A movement towards dementia accessible communities was mentioned by some participants in phase 1 of the primary data collection but there was a perception that this would take significant lobbying of local politicians and community leaders to achieve. Under the Understand Together campaign the Dementia Community Champions was launched which encourages and supports people to work with their local community to make their local area more dementia inclusive. There are also 40 national partners

who are engaged in the community activation aspect of the campaign. Since, the interviews and focus groups were completed for this evaluation €90,000 from Dormant Accounts funding was awarded to fund a post of Dementia Community Activation Coordinator. This post has been co-managed by the HSE and the ASI under a unique partnership. The Dementia Community Activation Coordinator is working with national organisations and key community stakeholders to support the development of dementia inclusive communities across Ireland. The role of the Co-ordinator is to grow the number of champions and people within communities to take action to create sustainable dementia inclusive communities.

## Priority Action Area 2

### Timely Diagnosis and Intervention

The key outcomes for this Priority Action Area relates to diagnosis, how and when the diagnosis is arrived at and post diagnostic supports for PLwD and their families. The requirement for better service integration also emerged as an outcome in this Action Area but this is addressed specifically under Priority Action 3. The mixed methods approach to gathering data from all stakeholders highlighted not only the importance of timely diagnosis but also indicated that PLwD needed access to appropriate information and services. Since

the launch of the NDS, access to information after individuals receive the life-changing diagnosis of dementia is now more available. Several initiatives and interventions have emanated from the programmes developed under the NDS, although respondents described variations locally and regionally.

### Diagnosis of Dementia

The primary research conducted for this evaluation highlighted considerable differences in how the diagnosis of dementia is made and communicated across Ireland. Ideally, diagnosis should be based on a multi-disciplinary assessment taking into account the results of investigations, using cognitive screening tools as an adjunct. However, challenges exist for physicians given the nature of dementia and availability of resources. Cognitive impairment is a heterogeneous disorder and presents in a heterogeneous fashion. Difficulties associated with dementia can range from memory, language, and behaviour that leads to impairments in activities of daily living (Robison et al., 2015). Therefore symptoms, especially in the early stages, can be concealed for fear of stigma and for other reasons. The primary data collection highlighted that HSCPs often felt challenged when a formal diagnosis of dementia is not documented. In addition to this staff and carers identified the tensions between respecting the PLwD's privacy and diagnosis disclosure. Therefore, the choices regarding

maintaining privacy and diagnosis disclosure has implications for access to post diagnostic supports.

Given that evidence suggests that dementia may, in some cases, be preventable (Prince et al., 2014; Matthews et al., 2013) there is now more focus on earlier diagnosis and intervention prior to the onset of functional impairment (Prince et al 2011). Where dementia is present, early diagnosis may still have benefit allowing prompt and appropriate initiation of care and treatment. In particular, it allows the physician to differentiate between normal ageing, mild cognitive impairment without dementia and early dementia. This evaluation found that HSCPs considered that while timely diagnosis and intervention was fundamental (ranked by 82% HSCPs as highly important), they reported that the post-diagnostic dementia pathway is not clear. This implies that there is a mismatch between the priority attached to it and the support and other structures around it in order to deliver this in a meaningful way. Timely diagnosis and early intervention was also ranked as highly important by carers (76%), furthermore, 85% of carers reported that early diagnosis was very important. However, further feedback from carers highlighted a lack of awareness with regard to what supports are available in local communities following a diagnosis, with just over half (56%) of carers agreeing that they have access to the information they

require. Carers elaborated on the how the diagnosis should be disclosed, emphasising that kindness and dignity should be central to this communication process.

Since the NDS was published, €1.2 million funding was allocated to establishing the PREPARED project (the Primary Care Education, Pathways and Research in Dementia) to upskill GPs in relation to assessment, diagnosis, and care for PLwD. The impact of PREPARED is difficult to measure, particularly because of the lack of a dementia registry, and is affected by other factors such as the availability of a formal post-diagnostic services (i.e. having somewhere to refer the person to after giving a dementia diagnosis). The independent PREPARED evaluation report was not available at the time of this evaluation however, various aspects of PREPARED have been reported in a number of peer reviewed publications, much of this data focuses on quantitative outcomes (e.g. the number of people trained, number of leaflets distributed) therefore owing to the nature of the PREPARED project, it was not possible to establish the direct impact of PREPARED for PLwD and their carers. However, findings from our evaluation did highlight that the knowledge and care provided by GPs or consultants had a significant bearing on how a diagnosis of dementia was disclosed and the degree to which they were able to access follow-up support and information. It

was clear that the ability to obtain information from local professionals was very valuable for to those who had received it. Doctors who actively sought out services on the person's behalf were mentioned as having a significant impact on their journey. This process of identifying local services is now made easier with the access to Dementia Specific Services in the Community: Mapping Public and Voluntary Services (2017) report undertaken by the NDO and ASI. This work also informed the service finder tool on the Understand Together website.

A recent literature review on Dementia Diagnostic Services (2018) highlighted that a timely diagnosis must be flexible and integrated across all levels of care. This was not evident in our evaluation, the majority of respondents commented on the difficulties encountered during diagnosis disclosure and opportunities for flexible diagnostic support was absent. Equal access to community resources to support people in their homes was lacking. The NICE-SCIE Guidelines 42 recommend that PLwD should be informed about care e.g. creating a will, an enduring power of attorney, advanced care directives or home supports. When a diagnosis is made, depending upon the stage of progression and the extent to which a patient or their family accept the diagnosis support needs are many and varied. The post diagnostic stage is not time bound and given the amount of information to be

communicated, this period needs to be considered by HSCP in line with the persons immediate needs as well as mid to long term needs. In an attempt to communicate timely diagnosis and post-diagnostic information to individuals concerned about memory 'A guide to Memory Clinics in Ireland'<sup>21</sup> was made available to health service professionals, family members and individuals. This was first published in 2010 and now supported by the NDO, is in its fourth edition, providing comprehensive information on timely diagnosis of a dementia, though based on this evaluation HSCPs did not mention it specifically'.

### Post Diagnostic Support and Information

Information sources during dementia disclosure and post diagnosis are central to the PLwD's experience and requires an integrated post-diagnostic model of clinical and social care so that the person can seek information or engage with services when they are ready and on terms that meet both their clinical and personal needs. Qualitative feedback collated during this evaluation suggests that there is a need for structured pathways to follow after a diagnosis of dementia is given. Carers want adequate information on the likely trajectory and what the future holds, and information on the services available to them. A Post Diagnostic Support Pathway

Project was established under Priority Action Area 2, which aims to improve the quality of life for PLwD and family carers following a diagnosis of dementia by developing a model and approach to post-diagnostic care and support. The NDO are supporting the development of 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.

Feedback provided via the surveys from informal carers and PLwD highlighted that well informed primary care teams are critical to post diagnostic pathways, as 33% of carers and 100% of PLwD reported that they received information and signposting from GPs. Significant investment has been devoted to the NDO's national dementia post-diagnostic support project, as 18 grants worth up to €25,000 were made available to HSCPs working in a range of settings to deliver post-diagnostic supports. The scheme aims to improve access to support for PLwD after their diagnosis. The funded interventions include: cognitive rehabilitation, cognitive stimulation therapies and/or dementia psycho-education programmes. The scheme was funded by Dormant Accounts through the Department of Health. The grant scheme is currently undergoing

21 <http://dementia.ie/images/uploads/site-images/MemoryClinic.pdf>



independent evaluation and preliminary findings will be available towards the end of 2019. Also connected to the NDO's Dementia Post-diagnostic Support Project is the "The Next Steps (2019)" guidance document which provides guidance for HSCPs on the development and delivery of post-diagnostic psycho-education programmes for PLwD and their carers.

Other examples of post-diagnostic support, supported through the NDO, is the development of a National Alzheimer Café Coordinator who will work over 15 months to support the roll-out of a national model for Alzheimer Café's in Ireland; supporting existing café's and working with communities of interest on the establishment of new cafes and the development of an on-line information portal for health and social care professionals. Other projects and initiatives underway include the Dementia Diagnostic Project and the establishment of a network of Memory Technology Resource Rooms in the community. The NDO is currently working with a range of research organisations and institutions to promote timely diagnosis and post-diagnostic support initiative. It must be noted that key stakeholders communicated concerns regarding the sustainability of funding for many of these interventions. Stakeholders commented on how the government should ring-fenced money over an extended period of time for Post Diagnostic Support. A

review of memory clinics carried out by the NDO and Dementia Services Information Development Centre (DSIDC, 2017) noted that there is considerable variability in the structure, availability and function of memory clinics across the country. The planned development of a diagnostic and post-diagnostic framework by the NDO should address the some of this variability.

Primary research conducted for this evaluation also highlighted the need for Dementia specialists and 'key workers' who are knowledgeable on the care and support needs of PLwD following a diagnosis. The need for post diagnosis support in Ireland has been highlighted previously, for example, O'Shea et al. (2017) noted that "Diagnosis should be followed by immediate access to a named and trained contact person who will: support and empower the individual; help that person maintain a level of independence and autonomy; avert future problems; and provide ongoing information and advice to their carer. This contact person should be embedded in the care system, has the credibility and authority to act as an agent for the person with dementia within a well-defined geographical area and have the necessary skills and training to interact with family carers and formal providers of care". The NDS also notes need to develop a 'key worker', it also highlights the challenges associated with this, such as identifying the most appropriate model to deliver the service

under and financing the roles. Evaluation participants noted that where the service was available, the Dementia Adviser was found to be important in this regard, a dedicated person to directly contact was reported as instrumental when a diagnosis is made to offer advice and signpost to other services.

Survey respondents provided mixed views on whether or not the NDS has improved the quality of life for people living with dementia, as just over one third of carers (39%) and Health and Social Care professionals (36%) agreed and two thirds of PLwD (64%) and NfPs (60%) agreed that the NDS has improved the quality of life for PLwD.

### Priority Action Area 3

#### Integrated services, support and care for people with dementia and their carers.

This evaluation consistently found high levels of agreement that integrated services supports and care, was the most important Priority Action Area for PLwD. However, less than half (44%) of carers agreed that they had access to sufficient supports and services.

Throughout the interviews and focus groups the pressing need for joined-up care across sectors and the development of dementia

specific services were recurring themes with discussions around homecare supports dominating the minds of most stakeholders.

#### Homecare Supports

A common theme was the belief amongst respondents that the provision of timely and effective support at home can reduce hospital admissions and transition to long-term care. This evaluation also found that the provision of additional, person-centred support in the home and/or local community was vital to allowing PLwD to stay at home for as long as possible. However, it should be noted that for many carers and PLwD that this also included being provided with access to or, information on, existing local community initiatives and supports, in addition to HSE-funded home help. Respondents gave various examples of respite ranging from specialist overnight care, to a sitting service for a few hours to allow the carer to do other things. According to Banerjee et al., (2003) people with resident-carer were 20 times less likely to transition to long-term care. Extensive resources have been injected into homecare packages as part of the NDS<sup>22</sup> and by the end of March 2019, 443 people had received dementia intensive homecare packages. Investing in homecare packages and respite care facilitates PLwD to continue living in their own homes and communities for as long as possible. Further roll out is needed and allocation across

22 €22.1 million funding was provided by Atlantic Philanthropies, Health Service Executive and the Department of Health.

and within CHOs needs to be a transparent process. There were undertones of a lack of confidence in homecare allocation and this will continue until a more robust statutory scheme is developed and deployed nationally. There has also been a call to action on in-home respite from carers involved in this evaluation. "Homecare support is the main support the person with dementia and their carer need in order for the person with dementia to be able to stay at home for as long as possible". The majority of all survey respondents ranked homecare support as highly important, the majority of HSCP respondents (53%) ranked homecare support (e.g. home help) as the most important area of support for PLwD. The most frequently ranked required area of support among NfP was also homecare, with 82% of respondents ranking it 1, 2 or, 3. This view is also reflected in the literature, which highlights that access and choice is central to good person-centred care for PLwD (Fazio et al., 2018). From this evaluation it is evident that homecare is a key area for future development and while there has been substantial development and learning through the pilot sites involved in the Personalised Home Support Initiative much more needs to happen and across a more diverse geographic spread. The DoH is currently engaged in the development of a new statutory scheme for the financing and regulation of homecare services; this will provide much needed guidance and

decision-making framework regarding the allocation of homecare services for people in a sustained, equitable and financially viable way. A planned realist review of the benefits of intensive homecare packages for PLwD is planned and will provide additional information to show the effect of such supports (Keogh et al., 2018).

### Community Services and Integration

The provision of information and access to services is a key element of this Priority Action Area. According to survey responses almost 55% of NfP respondents and 37% of HSCP respondents agreed that the number of dementia supports or services in Ireland has grown since the NDS was published in 2014. A number of elements were identified as working well in the community and these specifically related to DAs, GPs with dementia training, PHN, and day care. However, continually across each phase of the evaluation, participants noted that staffing resources were scarce which could deter people from seeking help as they did not want burden what they perceived as over-stretched service. Self-referral to dementia specific services is something that worked well for carers of PLwD. However, there was concern amongst some focus group participants and survey respondents that access to referral-based services across Ireland may be inequitable, with people in rural areas having greater difficulties

accessing services, which was often compounded by lack of public transport. It is of note that transport issues were not limited to rural areas; for example, some people in urban areas noted that there were numerous services available to them but, taxis and public transport were costly and this acted as a barrier to accessing such services.

In terms of the integration of services, the majority of carers referred to the idea of a 'one-stop-shop', whereby there should be one source of information and coordination of medical and social supports. Almost two thirds (64%) of NfPs disagreed that there is good integration between informal services and healthcare services, whilst 57% of carers reported that health and social services always or sometimes work together to provide services. There is evidence to suggest that community-based dementia case managers are cost-effective and provide care continuity, advice and support for persons with dementia and their family, through all stages of the disease (Minkman et al. 2019). Dementia pathways and care coordinated by a dementia specialist are some of the ways overcoming the lack of integration and fragmented communication between professional care providers. These issues will be discussed further in the next section.

### Dementia Care in Acute Settings

Another important issue identified within the evaluation was the impact of the NDS on understanding and addressing the needs of PLwD in acute care settings (e.g. Accident and Emergency Departments). While understanding in the community appears to have improved over recent years, there is a clear message that understanding the needs and planning for the needs of PLwD when they enter acute secondary care (hospital) services is underdeveloped and under resourced. Admission to a general hospital can be confusing and often frightening for someone who has dementia, particularly given their increased vulnerability to adverse events, including prolonged length of stay and delirium (Fogg et al., 2018). The stress of an unfamiliar environment and the constant challenge the PLwD faces in understanding what is happening can be overwhelming. National and international research confirms that an admission to an acute hospital can be distressing and disorientating for a person with dementia and is often associated with decline in cognitive ability and levels of functioning around activities of daily living (Cunningham, 2006; Covinsky et al., 2011). Irish data reflects this with the recommendations from the Irish National Audit of Dementia (INAD) emphasising the need to shift towards dementia accessible care environments and training of healthcare staff. Schemes such as the Butterfly scheme dementia awareness

programme in acute care, developed in the UK and recently introduced in Ireland, seek to support PLwD to receive more appropriate care while in hospital. Another UK initiative is John's campaign which gives carers greater ability to support a person with dementia while in hospital. The Swiss Dementia Strategy has also focused on dementia care in acute care and with a specific focus on infrastructure, treatment and interface management. A more focused approach to improving dementia awareness and understanding among all levels of staff in acute care is required in Ireland and this is particularly evident among those interviewed as part of phase 3. Priority Action 3.9 of the NDS notes that hospitals will be required to ensure that PLwD have a specific pathway through Emergency Departments and Acute Medical Units that is appropriate to their sensory and psychological needs. The Genio project developed and tested dementia specific pathways in three demonstrator acute hospital sites<sup>23</sup>, which included raising staff awareness and training as well as environmental changes and linkages to community services. Preliminary evaluation findings noted that the experience of PLwD had improved across all three sites.

Very progressive work and outputs have taken place in relation to supporting the needs of PLwD in hospitals, specifically regarding evidence-based design.

TrinityHaus (TCD) were awarded funding by the Health Research Board (HRB) with a focus on design of dementia accessible hospitals in Ireland. The production of the 'Dementia Friendly Hospitals from a Universal Design Approach' is a welcome move however; given the costly and complex nature of redesign and refurbishment a national approach supported by HSE Estates has yet to take hold. Simple and cheap initiatives were highlighted by some of the participants in this evaluation and these related to signage in Accident and Emergency and Older Peoples' wards. There was a perception among evaluation participants that any changes to date in infrastructure within acute hospitals were sporadic and locally driven. Almost half of the HSCPs who responded to the survey reported that no additional resources were made available to support a dementia accessible hospital. For a person-centred approach to dementia care to take place in acute care, optimum evidence-based design and resources must co-exist.

### Dementia Pathways

As noted in the mid-term review of the Implementation of the NDS, the development of a dementia and delirium care pathway are underway, in Ireland. Clear clinical pathways and guidelines and improved transitions between care streams are mentioned in most

EU Dementia Strategies (Alzheimer Europe, 2018); however, real impact on the ground in terms of a joined-up approach appears to be limited. The findings of this evaluation noted that over 50% of respondents disagree that there is good communication between informal and healthcare services for PLwD in Ireland. Around half of the HSCP respondents (49%) disagreed or strongly disagreed that there were clear pathways and protocols (46%) designed specifically for service users with dementia. This suggests that further work is needed to improve communication between acute and primary care services.

Fortinsky and Downs (2014) highlight that much of the focus of dementia strategies internationally is on preventing or delaying transitions rather than facilitating or improving the transition experience. They also note that most strategies focus on providing care within a particular setting rather than on transitions of care. The level of specifics in the actions plans for addressing transitions varies widely between the strategies. Most strategies refer to a dementia care coordinator or advisor but do not outline which transitional points in the dementia journey that they are responsibility for. Most strategies do not make it clear to patients and caregivers how services can be accessed at transition points. Few strategies consider evidence-based approaches to improve transitions. However, the Swiss

strategy has committed to developing services in the community and ensuring crisis teams are in place to negate unnecessary hospitalisation (Alzheimer's Europe, 2018) improve care transitions when necessary.

The NDS itself was described by respondents in this evaluation as having an impact with particular reference to service planning, and while this may be at an embryonic stage in some sectors it was felt that the NDS and the NDSIP provided a blue print for managers to develop integrated healthcare teams comprising of complementary staff with different skillsets such as social workers, OT, PHN etc. Multi-disciplinary teams with an interest in dementia attached to acute care also made it easier to support PLwD, often leading to a more seamless experience for the patient when navigating the services. But these were described by participants as isolated healthcare teams rather than standard practice. According to the mid-term review of the NDSIP there is a commitment to develop the role of the CNS and the ANP in dementia. In 2017, three Dementia CNS's were in post, however devoid of a budget these roles will remain sparse and only exist where local management have prioritised dementia and championed for change in their service. The CNS roles encompasses comprehensive assessment and the provision of psychological and emotional support to PLwD and their families/carers throughout

23 <https://www.genio.ie/meeting-the-challenges/dementia/transition-between-hospital-and-the-community>



their disease trajectory, becoming a single contact point in acute services. The role would also ensure that dementia pathways in acute hospitals are implemented and that staff are educated and knowledgeable about the distinct and varied needs of PLwD. The NDO is currently working with the Office of Nursing and Midwifery Service Director (ONMSD) in progressing this action. Roles such as community-based case managers and CNS/ANP in dementia in acute care should have a major impact on the quality and flow of communication between services and sectors and improve the transition experience for PLwD and their family/carers.

## Priority Action Area 4

### Training and Education

Training and education are fundamental components of improving care for PLwD. A recent systematic review recommended that specialised dementia education programmes should be relevant to participants' role and experience, involve active face-to-face participation, focus on practice-based learning with theory and support learning in clinical practice (Surr et al., 2017). This is reinforced by Alzheimer Europe who advocate for improvements in the knowledge, skills and training of health professionals across all healthcare disciplines as a central component of delivering high quality care and support

to PLwD in Europe (Alzheimer Europe Yearbook 2018). In line with European recommendations, various institutions and organisations in Ireland have engaged in a variety of methods including continuous professional development such as the Royal College of Physicians of Ireland and the Irish College of General Practitioners and the creation of nation-wide posts to enhance education and training for example clinical nurse specialists in dementia whose role incorporates the education of HSCPs. The Irish strategy outlined in the NDS focuses on engaging with professionals and academic organisations to develop the provision of dementia-specific training, professional peer-led support, education for GPs and nursing home staff. The challenges associated with interdisciplinary training across health and social care are numerous, though the scope is wider, thereby creating opportunities for disciplinary cross fertilisation.

### Education provision

A number of international reports advocate for investment in dementia education and training (Wright and O'Connor 2018; Lillo-Crespo et al., 2017; Chow et al, 2018). In Ireland, the Dementia Educational Needs Analysis (ENA) 2014 provided assessment of the information, education and training needs of PLwD, their care-giving network, and healthcare system. The Dementia Hub Ireland website, launched in 2017, documents the innovation that is helping to

transform dementia care, policy and practice in Ireland. Significant investment in a number of educational projects that address issues as diverse as philosophy, understanding, education, skills and training, care practice, public policy and other initiatives are now more available since the launch of the NDS (<http://dementiahubireland.ie>).

In this evaluation, education was valued by all respondents and ranked as the 3rd most important area of support by HSCPs and carers. This evaluation demonstrated that accessible training and information made it easier for staff to support PLwD. The majority of respondents had received education and training, however they reported that they would like more. Respondents indicated the types of education and training received. Training ranged from professional, academic courses (e.g. Master's degrees, Degrees and Diplomas) to attendances at specialist conferences. Other courses noted included Dementia Uncovered, Dementia Awareness Training, behaviours that challenge, Single Assessment Test course and Further Education and Training Awards Council (FETAC) course. The list of courses provided in this evaluation suggests that there is a wide range of training courses available relevant to dementia in Ireland from in-house training to blended learning courses e.g. the elevator project and the Dementia Champion project.

### Educational Needs

This evaluation revealed that most respondents had additional education / training needs. The majority (80%) of HSCPs and respondents working in NfP organisations reported that they would like more training. Community-based staff stated a clear need for further education and training, especially Community-Registered General Nurses. Similarly, while hospital-based staff reported having received training to different levels, most reported that more training would be beneficial. This is in keeping with recent surveys of HSCPs at different levels, which indicate that while self-reported knowledge among medical and nursing staff in hospitals is good, this is not true at all levels with more training for healthcare assistants and other non-specialised staff recommended (Flattery et al., 2017). Further measures suggested by respondents included the need for training in communication techniques, care strategies, assessment and end of life care. Of concern, many HSCPs stated that without training they do not feel competent to meet the needs of PLwD and this could reduce the standard of care provided and potentially result in increased stigma.

Education programmes can be difficult to deliver given the complexity of dementia and the spectrum of topics to inform care, therefore the availability of educational resources, guidance documents, booklets

etc is crucial. International research on the feasibility and effectiveness for dementia training in various primary care settings revealed continued pragmatic challenges (e.g. lack of access, time and skills in using them, Aminzadeh et al, 2012). Similar findings were reported in our evaluation with many in the acute services in particular reporting barriers to staff attending training e.g. staff shortages and turnover.

It is evident that programmes currently in place are having an impact on knowledge deficits. In this evaluation, education on timely diagnosis and integrated services were reported as a priority area for HSCPs. Prior to the NDS, less than 20% of nurses had dementia training (De Siún and Manning, 2010), while in this sample over 58% reported having received some training. The Alzheimer's Europe Carer's Survey (2018)<sup>24</sup> reported that significant number of carers felt that many HSCPs lacked awareness and education about dementia and this impacted on the disclosure of dementia. Similar findings were reported in our evaluation with carers highlighting that training should be mandatory for all staff providing care for PLWD. As previously mentioned information on relevant aspects of care, recommended by NICE-SCIE Guidelines 42 such as advance care planning, legal rights and driving need to be addressed.

Key stakeholders discussed the PREPARED programme and it was evident that sustainable dementia-specific training should be embedded into training and education in all health and social care sectors. Emerging findings from PREPARED suggest that health care staff are not adequately equipped to provide person-centred care to PLWD and that more training is required. Equally, an international Dementia Diagnostic Services review (2018), reported a lack knowledge with regard to support services available for PLWD/caregivers and this presents a considerable barrier to managing the broader quality of life and psychosocial needs for PLWD and their carers. One potential way of overcoming this barrier is to develop guidelines targeting primary care in more explicit terms (Dementia Diagnostic Services, 2018). The PREPARED project is an excellent model for this, which developed interventions at practice level including peer-led support and at national level for GPs and Primary care teams to support the needs of HSCPs.

## Priority Action Area 5

### Research and Information Systems

Data drives change and the inclusion of a Priority Action Area on research and information is central to reporting outcomes. However, in this evaluation the 'Research and Information Systems' Action Area had a low priority among respondents, for example only 24% of the HSCPs who responded to the survey ranked it 1st, 2nd or 3rd in order of importance. However, research and evaluation has been fundamental to the implementation of the NDS and the various programmes that are being implemented under it. For this evaluation, participants who engaged in phase 1, were also involved with the strategy at a policy level. These respondents believed that it is too early to see a significant impact of the NDS on the ground and there is much to be learnt from the preparatory work (research) involved in developing many of the supported interventions.

For example, research has been core to the development of the PREPARED project and the Intensive Homecare Programme. Since the introduction of the NDS, Single Assessment Tool training programme and implementation of the Single Assessment Tool has occurred in three hospitals. The Single Assessment Tool, based on the InterRAI instrument, is particularly useful in PLWD in assisting in confirming a diagnosis

and assessing care levels and can be used across the continuum of care and stages of the disease (Foebel et al., 2013). It is currently being used at different levels in the healthcare system, most prominently to inform decision making process for members of the Local Placement Forum who make a determination on the suitability of individuals including PLWD to enter into long term (nursing) care based on the older persons wishes and assessed need. Continuity and integration of care between acute and community sectors will be facilitated and promoted through the implementation of the Single Assessment Tool. Similarly, the Swiss strategy identified the need for national data on the structure of care services and their uptake, to inform long term management, care planning and care services (The Alzheimer Europe Yearbook, 2018).

The use of big data and supporting information technology is required to provide better integrated care to PLWD and will support research to potentially improve dementia care (Hofmann-Apitius 2015). In Ireland, the wider implementation of the SAT (beyond pilot stages) and integration with existing systems and planned electronic health records will assist with this nationally. In addition, the development of a National Dementia Registry and better recording and coding of hospital data is crucial to research. From this evaluation, executive participants reported that e-health initiatives

<sup>24</sup> <https://www.alzheimer-europe.org/Publications/E-Shop/Carers-report/European-Carers-Report-2018>

and post diagnostic support are interrelated. Therefore, the absence of a dementia registry makes it difficult to mobilise and prepare services and supports. In 2018 Dublin City University (DCU) were awarded funding from the NDO to develop a model for a dementia registry for Ireland. This work is ongoing and will be completed in the summer 2020. The project is overseen by a national multi-stakeholder steering group. Funding for the project was provided by Dormant Accounts through the Department of Health. The project is identifying existing dementia related data sources, taking learnings from existing patient registries in Ireland and existing dementia registries internationally. The project team also have a special interest group of people with dementia and family carers and are working with experts across legal, ethical, health economics, IT and clinical fields to support the design of the registry model.

However, it remains unknown what delays might be encountered for the dementia registry given the implications associated with the Health Information and Patient Safety Bill. Preliminary work has been carried out on improving hospital recording and coding of primary and secondary dementia diagnoses through the Hospital In-Patient Enquiry action. However, until it is possible to measure and comment on epidemiological data, the true outcomes of the Irish strategy will become more evident.

## Priority Action Area 6

### Leadership

Leadership was a priority Action Area that was regarded a less important by those who engaged with this evaluation, particularly in Phase 2 (surveys with health and social care professionals, carers, PLwD and NfP organisations). While the reasons for this are unclear, it is likely that those who participated in the surveys did not have sight of actions that are taking place under this priority. Executive level participants from Phase 1 of the data collection noted that they would like better communication and open collaboration between stakeholder groups involved in the NDS and NDSIP. Clear responsibility for the implementation is crucial to provide the best outcomes and policy makers must provide positive leadership. Participants were less likely to indicate that politicians had a good understanding of dementia and the needs of carers as a result of the NDS. Evidence suggests that leaders should be active role models, provide and extoll a clear vision and include and empower staff in the professional development process (Rokstad et al., 2015). Participants noted that leadership is crucial to drive forward the NDS, and the NDO is considered integral to the implementation and completion of various Action Areas.

According to the mid-term review much progress has been made in planning for and demonstrating leadership at a

national level. Crucially a representative from the NDO sits on the steering group for the Integrated Programme for Older People and on the working group for the Clinical Care Programme for Older People. Furthermore, a Clinical Lead with the NDO was appointed with the remit of supporting the implementation of actions associated with dementia care across care divisions. The NDSIP has plans to progress the appointment of key case workers to co-ordinate the care of a person with dementia (previously discussed under Priority Action Area 3). This leadership role will support a seamless transition through services and signpost the person with dementia and their family to appropriate and timely services.

A number of countries are already moving towards a second dementia strategy however from data collected to support this evaluation there appears to be more of a desire to see a long term, adaptable 'plan' rather than a second strategy. The difficulty with the Irish strategy is that it is 'open-ended'- the lack of a time bounded strategy makes it difficult to detail when effect has taken place or when the strategy should be updated. This is also further complicated where there is a lack of commitment to funding, thus making the process of achieving significant change difficult (Alzheimer's Europe, 2018).

## Conclusion

A total of €27.5 million programme funding was invested in dementia in Ireland from 2014 to 2017. This funding gave the development of dementia care increased priority and impetus. The full impact of this investment in Ireland will not be known for some time. Many of the programmes that were funded under the strategy are at an early stage and only a small number of them have completed internal or external evaluations. The priority actions were key to the implementation of the strategy and reconfiguring existing resources is central to delivery of a cost neutral strategy. The NDS Implementation Plan is not time bound therefore it remains to be seen if we will witness an implementation time lag. Also, its implementation is further complicated as there is a lack of commitment to further funding, and as a result there is potential for dementia care to be de-prioritised operationally and politically. There are, however, clear and executive management structures within the Health Service Executive to provide leadership at a system level for the continued implementation of the Strategy. In Ireland, various voluntary organisations have done tremendous advocacy work for people living with dementia and their carers; such foundations and components of commonality between and among organisations are essential to achieving goals of care.



# APPENDIX 1

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# For more information

Ipsos MORI  
Carroll House  
463A Ormeau Road  
Belfast

Phone: +44 (1)28 9050 0800

[www.ipsos-mori.com](http://www.ipsos-mori.com)

<http://twitter.com/IpsosMORI>

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