



THE ALZHEIMER
SOCIETY *of* IRELAND

National
Dementia
Office

Dementia Specific Services in the Community: Mapping Public and Voluntary Services

Prepared by: The Alzheimer Society of Ireland and the National Dementia Office in the Health Service Executive

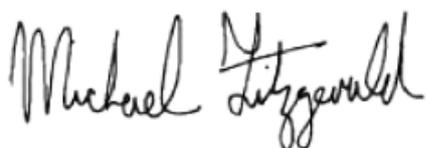


FOREWORD

The National Dementia Strategy, published in December 2014 outlines a commitment to critically review health and personal social services for people with dementia to identify gaps in existing provision and prioritise areas for action in accordance with resource availability. Our two organisations viewed this as a critical element for the successful implementation of the National Dementia Strategy which aims to improve dementia care so that people with dementia can live well for as long as possible, can ultimately die with comfort and dignity, and can have services and supports delivered in the best way possible. As a consequence we undertook a joint endeavour towards the end of 2016 to identify what dementia-specific services were available in communities across Ireland.

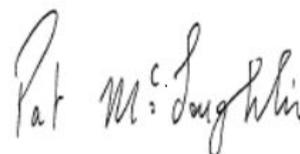
While the project did not look at the generic services which people with dementia and their families might use, or examine the quality of the identified services and supports the findings offer a valuable snapshot, telling us who is doing what, where and when in relation to the delivery of dementia-specific services and supports. They are a vital tool to support evidence-based service planning and development and offer us a baseline in which to move forward in how we address and appropriately meet the needs of people with dementia and their families, guided by the principles of the National Dementia Strategy, those of personhood and citizenship.

We would like to sincerely thank those who provided information for the project and to the staff of both organisations who were involved in compiling this report.



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CONTENTS

Executive Summary	4
1. Introduction	13
1.1 Approach	14
1.2 Methodology	15
2. Survey Results	20
2.1 Who provides dementia-specific services?	20
2.2 What dementia-specific services are available in the community?	21
2.3 Results across CHO area	23
2.4 Services Categories: Location and availability	30
3. Conclusions and Recommendations	53
Appendix 1: Survey guidance document and FAQ	57
Appendix 2: Membership of the Advisory Group	61
Appendix 3: Survey Invitation letter	62

EXECUTIVE SUMMARY

Introduction

In September 2016, the National Dementia Office (NDO), Health Service Executive (HSE) and the Alzheimer Society of Ireland (ASI) partnered on a project to map **dementia-specific¹ community-based services** nationally. The project supports the implementation of the National Dementia Strategy (NDS) under a commitment by the HSE to critically review health and personal social services for people with dementia to (i) identify gaps in existing provision, and (ii) prioritise areas for action in accordance with resource availability.

The specific aims of the project were to identify:

1. Who: Is providing dementia-specific services in each Community Health Organisation (CHO) area?
2. What: Is the nature of the dementia-specific service being provided?
3. Where: Are dementia-specific services being provided?
4. When: Are these dementia-specific services available e.g. 7 days a week, once a month etc?

A national advisory group was established (see Appendix 3 for the list of members) to provide expert knowledge and opinion on the development and roll-out of the project. Following the development of an on-line survey, key stakeholders across the HSE and the ASI were invited to participate. Data collection relates to the time period between December 2016 and March 2017.

The mapping project examined community-based dementia-specific services only and did not include generic services that people with dementia and their family carers may use. It also did not include services in residential and acute care or services provided by private providers.

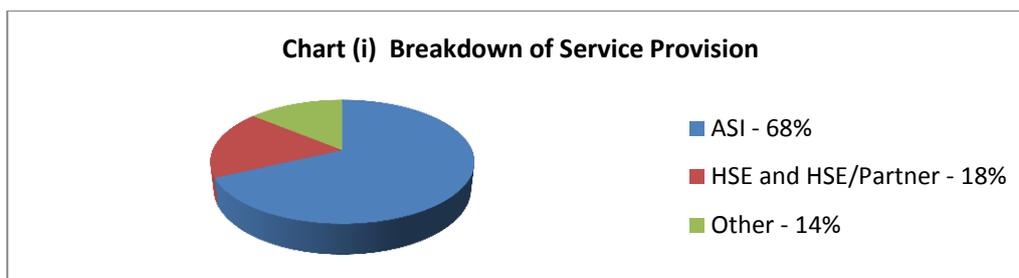
The project relied on stakeholders to self-complete. The results are therefore dependent on the quality of data received. While a verification process was undertaken to ensure the integrity of the data, there may be gaps where services/supports were not reported. In addition, the project is a baseline study and does not examine the quality or suitability of services recorded.

Quick overview of findings

Who is providing dementia-specific services?

The majority of services were provided by the Alzheimer Society of Ireland, as shown below in the pie chart below.

¹ For the purposes of this project the definition of the dementia-specific services used was “A dedicated service designed to cater exclusively for the complex needs of people with Dementia and/or their family carers”.



What services are being provided?

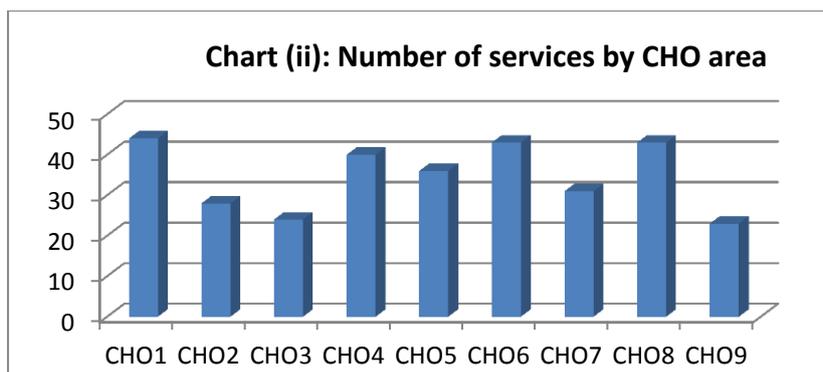
The table below shows the number of services (N=314) per service category recorded, with Day Centres (N=63) being the most common service provided.

Table (i): Number of services by service category

Service Category	Number of services
Dementia day care	63
Carer support groups	45
Dementia family carer programmes	36
Dementia-specific home care	31
Dementia friendly activities	29
Social clubs	28
ASI branches	21
Alzheimer Cafés	16
Dementia advisers	9
Dementia clinical specialists	7
Dementia cognitive therapies	7
Dementia in-home respite	6
Assistive Technology libraries	4
Case management	4
Dementia support worker programmes	3
National information services	2
People with dementia support groups	2
Dementia counselling	1
Total	314

Where are dementia-specific community services being provided?

There were recorded differences in the level of dementia community services across CHO area; ranging from 23 services in CHO9 to 44 services in CHO's 1.



When are the main dementia-specific services available?

There were also differences in the availability of services. Day centres, for example ranged from operating once a month to six days a week.

Table (ii): Availability of dementia-specific day care services

Days available	Number
6 days a week	1
5 days a week	26
4 days a week	2
3 days a week	8
2 days a week	9
1 day a week	13
Twice a month	3
Once a month	1
Total	63

There were also recorded differences in how often carer support groups met; ranging from once every two months in a number of cases to running twice a week in one case.

Table (iii): Location, number, providers, capacity and availability of carer support groups

Location	No.	Providers	Capacity	Availability
Carlow	1	ASI	15	Once a month
Cavan	2	ASI	8	Once a month
		ASI	3	Once a month
Clare	2	ASI	20	Once every two months
		ASI	10	Once a month
Cork	4	ASI	15	Once a month
		HSE (Crystal Project)	15	Twice a week
		HSE	20	Once a week
		ASI	Unlimited	Once a month
Dublin	7	HSE	20	Once a month
		ASI	20	Once a month
		ASI	15	Once a month
		ASI	10	Once a month
		ASI	10	Once a month
		ASI	4	Once a month
		ASI	4	Once a month

Galway	1	ASI	15	Once a month
Kildare	4	ASI	20	Once a month
		ASI	15	Once a month
		ASI	15	Once a month
		ASI	15	Once a month
Kilkenny	1	ASI	15	Once a month
Laois	1	ASI	15	Once a month
Limerick	1	ASI	5	Once a month
Longford	1	ASI	10	Once a month
Louth	2	ASI	20	Once a month
		ASI	15	Once a month
Mayo	2	Community Action on Dementia Mayo	35	Once a month
		Western Alzheimer's	Unlimited	Once every two months
Meath	2	ASI	15	Once a week
		ASI	8	Once a month
Monaghan	1	ASI	10	Once a month
Offaly	1	ASI	8	Once a month
Roscommon	2	Western Alzheimer's	Unlimited	Once every two months
		Family Carers Ireland	Unlimited	Once a month
Tipperary	2	ASI	15	Once a month
		ASI	10	Once a month
Waterford	1	ASI	20	Once a month
Wexford	3	Family Carers Ireland	14	Once a month
		ASI	Unlimited	Once a month
		ASI	Unlimited	Once a month
Wicklow	4	Wicklow Dementia Support	20	Once a week

Summary of Key Findings

A total of 314 dementia-specific community-based services were identified across the Republic of Ireland, provided by approximately 32 providers.

- The majority of these services (68%) were provided by the Alzheimer Society of Ireland² (ASI), followed by the HSE (18%) and other providers amounting to 14%.
- Services across the nine Community Health Organisation (CHO) areas ranged from 23 (CHO9) services to 44 (CHO1) services. The average number of services was 35.
- The largest category (20%) of services were dementia-specific day centres (N=63).
- There was a wide variance in the availability of dementia day care ranging from a 6 day a week service, to one centre opening once a month. However, the majority opened five days a week.

² 2016 Audited accounts shows HSE provided 59% funding for ASI services

<https://www.alzheimer.ie/getattachment/About-Us/Openness-and-transparency/Organisational-Structure/2016-Signed-Annual-Accounts.pdf.aspx>

- Three counties did not have any reported dementia-specific day centres – Wexford, Laois and Leitrim.
- Services targeted at family carers made up just over one quarter of services (N=81). These included dementia carer support groups (N=45) and family carer programmes (N=36).
- There were 28 social clubs reported. There was a wide variance in the number of social clubs across CHO area; ranging from 7 in CHO9 to none in CHO2.
- Services targeted specifically at people with dementia (N=25), particularly at the post-diagnostic stage, were not as readily available e.g. dementia advisers (N=9), case management (N=4), cognitive therapies (N=7), dementia-specific counselling services (N=1) and support groups for people with dementia (N=2). Other services such as Alzheimer Cafés and social clubs were also available to people with dementia.
- Alzheimer Cafés accounted for 5% of dementia specific services; with all regions, with the exception of CHO9, hosting at least one.
- Overall, there was large variance across the country in terms of service availability. For example, counties Leitrim and Laois only had three reported services; Co. Kerry only had seven of the 40 recorded dementia-specific services for CHO area 4; with the remaining 33 located in Co. Cork. This has led to a concentration of some services in some areas, and a complete absence of similar services in others. For example, there were 14 dementia friendly activities reported in CHO 6 and none in CHO 2 and CHO 1. Similarly with Dementia Advisers there were 13 counties where this service was on offer on a part-time basis with the remaining 50% of counties not having access at all to this type of service.
- The majority of the 44 dementia friendly activities reported were located in Dublin (N=15). There were 18 counties which had no reported dementia friendly activity, including: Meath, Wexford, Laois, Offaly, Westmeath, Longford, Waterford, Kerry, Clare, Tipperary, Galway, Mayo, Sligo, Leitrim, Roscommon, Donegal, Monaghan and Cavan.
- In total, seven community-based dementia specific clinical roles were identified.
- Four Assistive Technology (AT) Libraries³ were reported at the time of data collection. These were located in Carlow, Clonmel, Clonskeagh and Mallow.
- Only four dementia-specific case managers or similar posts were reported.

Conclusions and Recommendations

The findings show that there were significant gaps in service provision and inconsistency of availability of types of services by both county and CHO area. The mapping exercise and this report offers the NDO, HSE and other providers including the ASI a greater opportunity for the systematic development of new services in-line with identified local need. The findings will also assist Government in determining the locations which are most in need of developing dementia specific services.

A number of recommendations arise from the report and these are listed below.

³ Now called Memory Technology Resource Rooms (MTRR). Funding has been secured through Dormant Accounts for an MTRR in each CHO area and these are currently being established.

Recommendations:

1. Both the NDO and ASI to hold meetings with senior personnel in each CHO area to outline the findings of the report and support local service development consistent with the needs of the region and county.
2. The generation of CHO estimates on the prevalence of dementia in each area will identify potential demand for services. This should be linked to the 2016 Census data.

Findings highlight the lack of supports and interventions targeted specifically towards people with dementia and those earlier in the dementia journey, particularly in relation to post-diagnostic supports such as dementia counselling, dementia cognitive therapies, dementia information and signposting services/resources.

Recommendations:

3. The HSE, working with partners, to roll-out the NDO post-diagnostic support pathway project.
4. The development of the post-diagnostic support pathway should be used to inform CHO/HSE operational plans in relation to dementia specific services from 2019 onwards.

The low number of dementia friendly activities identified in the mapping project highlights the need for a greater community response to dementia.

Recommendation:

5. The HSE Understand Together Campaign with partners including the ASI and Genio, to use findings from the mapping project to target areas and mobilise local support where there has been little or no investment in dementia friendly activities or other services/supports within the community.

The mapping exercise shows the low number of dementia-specific clinical and case management roles in the community. Evidence of the effectiveness of these roles is available through evaluations of the Genio/HSE projects.

Recommendations:

6. The HSE to use evidence on the effectiveness of case management/coordination and specialist dementia clinical roles to inform the roll-out of these nationally.
7. The NDO to further develop clinical dementia specialist role job descriptions and support their implementation in geographical areas where there is an identified gap.
8. The NDO to progress the 'key worker' priority action as outlined in the National Dementia Strategy.
9. The NDO, in the development of such roles, will take account of the implementation of the Community Healthcare Network governance and management requirements as outlined in the Healy Report.

In order to develop and deliver a broad range of dementia services and supports, the HSE will need to work with a variety of providers, including those from the community and voluntary sector. These providers will need to be supported to evaluate and further develop their services, basing development on identified good and best practice to ensure value for money and quality of care for people with dementia and their families.

Recommendation:

10. The ASI and other community providers to work with the NDO and HSE local services, taking a cohesive and collaborative approach to identify local service need and ensure greater utilization and integration of current resources.

This mapping project has provided baseline data only. There is a requirement now to look more closely at service quality and to also scope-out the potential for other community services not readily available. Deeper analysis is required for all services which have not undergone or are not undergoing evaluation or systematic review⁴ building and identifying best social care practice.

Recommendations:

11. NDO and ASI to identify the models and approaches being used in dementia-specific day-care; examining international best practice.
12. The NDO and ASI to explore the occupancy and attendance of day services, the quality of service as well as exploring and piloting alternative day models reflecting the changing regulatory environment.
13. Through the NDO's Post-diagnostic Support Pathway project, explore the potential to examine the existing Alzheimer Café model and delivery. Identifying where providers need additional support to successfully establish or run this service/support.
14. ASI to undertake a review and examine available evidence on the effectiveness of dementia social clubs and various support groups.
15. The NDO to support the development of a national network around the Assistive Technology libraries (now called Memory Technology Resource Rooms) which will support information and knowledge sharing/transfer and quality control.
16. The NDO, ASI and other key stakeholders to work to identify and deliver appropriate home care for people with dementia – one aspect of this is the two organisations' involvement in the Centre for Economic and Social Supports in Dementia (NUI Galway) on the Applied Partnership Award titled 'Resource Allocation, Priority Setting and Consensus in Dementia Care in Ireland'.
17. Both organisations, the HSE and the ASI, to examine the appropriateness of the current dementia-specific service response by undertaking a needs-analysis to identify the preferences of people with dementia and family carers.

⁴ The ASI Dementia Adviser service is currently undergoing an independent evaluation. The ASI Cognitive Stimulation Therapy Programme underwent an evaluation in 2015. See <https://alzheimer.ie/About-Us/Research/Cognitive-Stimulation-Therapy-Evaluation.aspx>. Intensive Home Care Packages for People with Dementia are undergoing an extensive evaluation by Genio.

18. Adequate resources to undertake evaluation of services needs to be budgeted for in future NDO and HSE annual budgets.
19. NDO and ASI to examine the challenges of the geographical spread of the services, particularly the unique challenges of accessing and providing services within rural communities.

Findings from the mapping project also shed light on the current pathway of care for people with dementia and family carers in the community.

Recommendation:

20. Findings from the mapping project to inform the development of a dementia care pathway as prioritized in the National Dementia Strategy and to influence future operational budgets of HSE CHO areas.

It was evident from the data that people aged under 65 living with dementia have little or no specialist services. Also not evident in the data were community-based dementia-specific services for people with intellectual disabilities. This also warrants further investigation as respondents identified for this study may not have had this expert knowledge. They also fell mainly within social care and a further exploration of primary care responses to dementia is needed.

Recommendations:

21. Undertake a mapping exercise to identify dementia-specific services for people with intellectual disabilities.
22. A strategic approach to the needs of people aged under 65 with dementia is required – a review of their service needs to be undertaken as a first step.

As stated above, the results of this mapping project were dependent on the quality of the data provided by identified stakeholders and there may be some gaps in the data where services were not reported.

Recommendations:

23. The NDO and ASI to meet with key personnel in each CHO area to update them on the findings and to further identify services which were not captured in the mapping project.
24. The NDO to verify all services three times a year to ensure information provided in the on-line service finder remains up-to-date.
25. A mechanism for people to send amended or updated information to the NDO on dementia-specific services to be developed through www.understandtogether.ie and through the NDO newsletter.

Not everyone requires a dementia-specific service and generic services maybe a more appropriate response for many. A phase two review of services and supports for people with dementia and dementia family carers is required to identify dementia-appropriate supports/services.

Recommendations:

26. The NDO to liaise with HSE personnel on the review of generic day care and respite services.
27. The NDO to take the lead on gathering information on dementia services provided in acute and residential settings, across primary care services, Intellectual disability services and by private providers.

1. INTRODUCTION

In September 2016, the National Dementia Office (NDO), Health Service Executive (HSE) and the Alzheimer Society of Ireland (ASI) partnered on a project to map **dementia-specific⁵ community-based services** nationally. This was the first project of its kind in Ireland. The project supports the implementation of the National Dementia Strategy (NDS) as one of its six priority areas is Integrated Services, Supports and Care for People with Dementia and their Carers. Under this priority there is a commitment for the HSE to critically review health and personal social services for people with dementia to (i) identify gaps in existing provision, and (ii) prioritise areas for action in accordance with resource availability, with priority given to the most urgent deficits that can be addressed either within or by reconfiguring existing resources. The dementia-specific community-based services mapping project goes some way in addressing this action.

The mapping project involved surveying key informants from across the country on dementia-specific services available in their region, where the services were based and when they operate. The main aim of the project was to map dementia-specific community-based services and develop a baseline from which to assess these. However, it was acknowledged that people with dementia also use other community based and/or dementia appropriate services which were not included in the survey.

There were a number of significant outputs generated by the project. Foremost the findings will provide insight into dementia-specific services available at a given point in time and will inform the planning and development of future dementia-specific services in the community. Another key output is a stakeholder list of informants. This list includes HSE, ASI and other personnel working in each Community Health Organisation (CHO) area who are knowledgeable about dementia in their region.

Further to service planning, the data gathered from the mapping project has been compiled into an on-line dementia service finder. This is currently available to people with dementia, family carers, health and social care professionals and to the general public through the www.understandtogether.ie website, making access to dementia services and supports more accessible for people across the country.

To give a sense of potential demand for services the following table outlines the estimated prevalence of dementia in each county.

⁵ For the purposes of this project the definition of the dementia-specific services used was 'A dedicated service designed to cater exclusively for the complex needs of people with dementia and/or their family carers'.

Table 1: Estimated number of people living with dementia in each county

County	Population (all ages)	Number of people with dementia	% of total county
Carlow	54,612	543	0.99%
Dublin	1,273,069	12,498	0.98%
Kildare	210,312	1,453	0.69%
Kilkenny	95,419	1,057	1.11%
Laois	80,559	711	0.88%
Longford	39,000	434	1.11%
Louth	122,897	1,198	0.97%
Meath	184,135	1,400	0.76%
Offaly	76,687	790	1.03%
Westmeath	86,164	904	1.05%
Wexford	145,320	1,524	1.05%
Wicklow	136,640	1,274	0.93%
Clare	117,196	1,282	1.09%
Cork	519,032	5,425	1.05%
Kerry	145,502	1,848	1.27%
Limerick	191,809	2,013	1.05%
Tipperary Nrth	70,322	848	1.21%
Tipperary South	88,432	1,054	1.19%
Waterford	113,795	1,276	1.12%
Galway	250,653	2,683	1.07%
Leitrim	31,798	441	1.39%
Mayo	130,638	1,835	1.40%
Roscommon	64,065	893	1.39%
Sligo	65,393	857	1.31%
Cavan	73,183	851	1.16%
Monaghan	60,483	700	1.16%
Donegal	161,137	1,929	1.20%
Total	4,588,252	47,721	1.04%

(Source: Pierce, M. Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland, 2011-2046*)

These estimated are currently being updated by researchers in NUI Galway and new figures will be available in December 2017.

The following sections of the report details the methodology used for the mapping project and outlines the findings from the survey; providing data on the current service mix of dementia-specific community-based services available at a particular point in time within the nine CHO areas.

1.1 Approach

The approach taken for the project was to investigate who is doing what, where and when, in relation to the delivery of community-based dementia-specific services in Ireland. The design of the study was informed by the World Health Organization's (WHO) 4Ws approach. The 4Ws approach

was originally developed by the Inter-Agency Standing Committee (IASC), a global humanitarian body devoted to the improvement of humanitarian coordination, and the WHO to map Mental Health and Psychosocial Support (MHPSS).

The specific objectives of the project were to identify:

1. **Who:** Is providing dementia-specific services in each Community Health Organisation (CHO) area?
2. **What:** Is the nature of the dementia-specific service being provided?
3. **Where:** Are dementia-specific services being provided?
4. **When:** Are these dementia-specific services available e.g. 7 days a week, once a month etc?

A national advisory group was established to support and guide this work (see Appendix 3 for the list of members). The role of the advisory group was to provide expert knowledge and opinion on the development and roll-out of the project. The group met on five occasions during the ten month project.

1.2 Methodology

The following section outlines the methodology that was used for the mapping project, including the process of developing the on-line tool, sample identification and data collection.

1.2.1 Development of the on-line tool

A rapid review of online resources, academic journals and relevant literature was undertaken as a first step. The aim of this rapid review was to provide an overview of mapping tools used for collecting information on the availability of health and social care services and to analyse their potential for adaptation.

The rapid review found a number of Irish, European and International tools, some of which have been used extensively for comparing provision of services and for the assessment of health systems worldwide. Following the review, it was concluded that the project tool should be informed by the World Health Organisation's (WHO) Master Facility List (MFL). All other tools reviewed were too detailed in the type of data they were collecting whereas the MFL provided a basic starting point for data collection on service availability.

The WHO-MFL is a baseline data source providing a complete listing of health facilities in a country and is comprised of a set of administrative information and information that identifies each facility (signature domain). It also includes basic information on the service capacity of each facility (service domain).

WHO recommends the MFL as a prerequisite for sampling health facilities to conduct more detailed assessments of service delivery such as the Service Availability and Readiness Assessment (SARA). Linking health facility data and other core health system data (financing, human resources, and infrastructure) will be useful for administrative purposes, allowing for better analysis and synthesis of information to improve health systems reporting and planning.

Based on this rapid review of available tools, an appropriate data collection tool in the form of an on-line survey was developed modelled on the MFL. The online survey was prepared using SurveyMonkey’s Platinum Edition as it has an accessible interface for data collection.

To identify the service categories to be included in the survey, a scoping exercise was undertaken and a preliminary list of services was compiled. This list was presented to the advisory group for comment and it was subsequently updated. The final list is outlined in Table 2 below.

Table 2: List of Dementia-Specific Community-based Services Identified for the Mapping Project

Dementia Day Care	Dementia Cognitive Therapies	Dementia Social Clubs
Support Groups for People Living with Dementia	Dementia Family Carer Programmes	Dementia Carer Support Groups
Dementia Information Provision Services	Dementia Assistive Technology Libraries	Dementia In-home Respite
Dementia-specific Home Care	Dementia Clinical Specialists	Dementia Case Management
Dementia-specific Counselling Services	Alzheimer Society of Ireland Branches	Dementia Support Workers
Dementia Friendly Activities	Dementia Advisers	Alzheimer Cafés

*Descriptions of each service are provided in section 2.4 below.

As the project was mapping dementia-specific community-based service there were a number of services excluded. These included:

- Residential or acute care services such as:
 - Nursing homes and/or dementia-specific units within residential care
 - Acute, regional or community hospital services
 - Out-of home respite services
- Generic services that people with dementia may use. An enquiry into dementia appropriate services is a much bigger undertaking and will form phase two of the review of dementia services. It is also partly being addressed through the HSE review of dementia day care and respite services which is currently underway.
- Private organisations that provide dementia-specific services and are not funded by the HSE. Investigating these services requires a different methodological approach and would warrant a broader study beyond the remit of the current enquiry.

1.2.2 Pilot

The draft tool required respondents to select the range of service categories available in their catchment area. It included a reminder that the service had to be dementia-specific and that the information required for each service included a contact address, telephone number, email and website if applicable. Information was also asked on how many places (if applicable) were available for people with dementia and how many days per week or month the service operated.

Once the tool was developed it was presented to the advisory group for expert input. The advisory group was also invited to test the tool and advise on edits and/or additional questions for specific services.

The tool was then piloted with a small sample of stakeholders for accessibility and ease of use. The pilot survey took place in early November 2016 and included two HSE managers and one ASI operations manager.

Once the pilot phase was completed the tool was redrafted following feedback.

1.2.3 Sample

To ensure the maximum amount of information was captured in the survey, it was important to identify the correct people in each area to complete the survey. Possible respondents were identified by the NDO and the ASI, and an initial stakeholder list was compiled by the Project Team. This included HSE Managers of Services for Older Persons and other HSE personnel, ASI Operations Managers and other relevant ASI staff and voluntary organisations such as Family Carers Ireland. The advisory group was also asked to identify any possible respondents.

In October 2016 a letter from Michael Fitzgerald (HSE, Head of Operations and Service Improvement Services for Older People) and Pat McLoughlin (CEO of the ASI) was sent to the Chief Executive Officers in each CHO area as well as Heads of Social Care informing them of the purpose of the survey and encouraging support for participation (see appendix 3 to view a copy of this letter).

In November 2016 a further memorandum was sent to the Heads of Social Care asking them to review and update the initial stakeholder list. They were notified that the stakeholders identified would be solely responsible for completing the survey and they may nominate other stakeholders within or external to the HSE if they felt it relevant. The reviewed stakeholder list was compiled with input from the Head of Social Care in each of the nine CHO areas.

Once the stakeholder list was completed each person was contacted by the project team, where they were informed about the purpose and approach of the project. It was an opportunity also for possible respondents to ask any questions and for concerns to be addressed. The survey was then sent via an email link to each respondent. The survey link was unique to each e-mail address and as a result the project team were aware of all those who had completed the survey and information provided could be linked back to individual respondents.

Originally 35 people were identified to take part. A further 11 people were nominated to receive the survey. As a result 46 people were invited to participate.

1.2.4 Data collection

Along with the survey invite, a guidance document and Frequently Asked Questions (FAQ) sheet were circulated to support respondent's completion of the survey (see Appendix 2).

Ongoing telephone support was provided by ASI staff throughout data collection in order to answer any queries and address problems. A number of stakeholders contacted the research team via telephone and by email seeking help to complete the survey. Stakeholders who had not responded were contacted again at the end of the two week period.

Of the 46 people who received the survey, 37 completed, which was an 80.4% response rate. The project team followed up with all stakeholders who did not respond to the survey. The reasons they gave for non-participation was that they did not have any further information to add relating to their local area. All CHO areas were represented by those who completed the survey.

In terms of those who responded, the majority were HSE personnel (N=22), followed by ASI staff (N=14). A staff member from family carers Ireland also completed the survey.

In January 2017 the advisory group reviewed the initial data collected and recommended that a data verification process should be implemented to ensure the information provided was accurate. This process was undertaken in March and April 2017 when all surveys had been returned and the database of services was compiled. Every service provider was contacted to verify their relevant service data, with the NDO following-up with HSE services while the ASI verified their services and contacted all other service providers. Verification involved checking for accuracy, ensuring contact information, service type and availability were correct.

1.2.5 Research limitations

The project relied on stakeholders to self-complete the online survey and as a result information may be incomplete or inconsistent. Follow-up contact made with each stakeholder and the review of received data, as well as the verification process were important elements which sought to address this issue, however it is acknowledged that there may be gaps in the information provided. As part of ongoing service development and review, the NDO in their meetings with key senior personnel in each CHO area, will seek clarification of current services in each area. It's also important to acknowledge that information on services changes constantly and current information will need to be updated and verified regularly.

In addition, the project does not assess the quality of the service being provided as it was only collecting baseline data. Furthermore, the level of information is limited in scope as the survey was being administered to intermediate stakeholders and not the service provider directly.

Usability and Effectiveness of the tool

As the survey tool was developed for the purposes of the mapping project, the project team wanted to assess its feasibility for duplication or replication in the future. The effectiveness of the survey was investigated where respondents were asked to provide feedback on their experiences using the tool. 78.6% said that the tool was easy to use, with 14.3% responding that the tool was difficult; 7.1% had no opinion. 87.5% found the guidance document useful, 12.5% had no opinion. A high proportion (92%) were satisfied that they understood what the survey was used for and 8% were unclear.

The main aim of the project was to map dementia-specific community-based services and develop a baseline from which to assess these. However, it is acknowledged that people with dementia also use other community based and/or dementia appropriate services which were not included in the project.

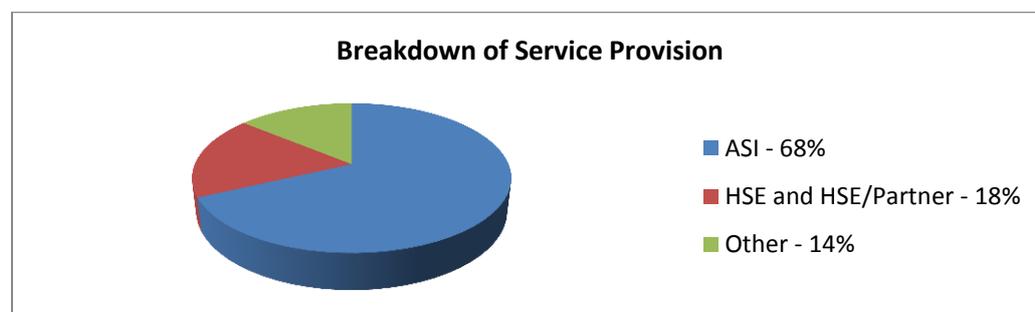
2. SURVEY RESULTS

The following section outlines the findings of the survey. These findings are largely descriptive and outline the number and extent of services in different areas. The section is structured according to the WHO's 4Ws approach, namely **who is doing what, where and when**. The first section provides information on who is providing dementia-specific services in the community. This is followed by a presentation of results relating specifically to each CHO area, highlighting the service mix in each. This is followed by a more in-depth look at each service category, where services were being provided and by whom. Information on availability and capacity is also presented. Data was collected at a given point in time, between December 2016 and March 2017, therefore service information relates to this time period only. It's important to note that services will change overtime.

2.1 Who provides dementia specific services?

The total number of services identified throughout all CHO areas was 314. Findings from the survey show that these dementia-specific community-based services were provided by a range of providers including the ASI; the HSE; Western Alzheimer's; HSE-Genio projects; Family Carers Ireland; Sonas APC; Wicklow Dementia Support; and Azure as well as other community and voluntary organisations, and art galleries who ran and facilitated dementia friendly activities in the community (see graph below for more information).

Chart 1: Breakdown of Service Provider



The majority of services were provided by the ASI (68%; N=214), followed by the HSE directly (18%; N=56) and other providers make up a smaller number (14%; N=44). It's important to note that many of the non-HSE delivered services were partly or fully funded by the HSE.

HSE/Genio projects were also identified, supported by a consortium of people in each area with various interests in dementia.

Table 3: Breakdown of other community and civic providers providing dementia-specific community-based services

Organisation	Number of services
Western Alzheimer's	9
*Azure	6
Wicklow Dementia Support	5
Community Action on Dementia in Mayo	3
Family Carers Ireland	3
**Local community groups	3
Bloomfield Care Centre	1
Clarecastle Dementia Day Care	1
Cork Old Folks Friendly Association	1
DREAM	1
Dublin City Council and the St Agnes' Community Centre for Music & Arts	1
Family Carers Ireland	1
Kilkenny Age Friendly County Programme Service Providers Forum	1
North Kerry Alzheimer's Association	1
Ryevale	1
Sonas APC	1
St. John of God's	1
St. Vincent de Paul	1
The Forget Me Nots	1
Thurles Community Social Services	1
Youghal Community Group	1
Total	44

*Azure are art programmes provided by Age and Opportunity, The Hunt Museum, Butler Gallery, The Lexicon DLR, Museum of Modern Art and Crawford Art Gallery.

** The local community groups relate to three different local groups which ran Choirs and no lead organisation was identified for these.

Western Alzheimer's provided nine dementia-specific community-based services in the West of Ireland. Wicklow Dementia Support also provided a number of services specific to Co. Wicklow. Likewise Community Action on Dementia in Mayo provided three services in Mayo.

2.2 What dementia specific services are available in the community?

The following section provides information on the type of services provided. It's important to note that the findings reflect the quality of data received from survey respondents; information was collected from each CHO area, but there may be some gaps where individual services were not identified. The NDO will seek to address this during forthcoming meetings with personnel from each of the CHO areas.

We also know that services are constantly changing and developing. For example, there will be a Memory Technology Resource Room in each CHO shortly. As stated above the results presented in this report were collected between December 2016 and March 2017 and therefore represent a

snapshot in time. In terms of the general public’s access to this information this has been facilitated with the development of an on-line service finder on www.understandtogether.ie. There will also be a mechanism for people to send information on any services that have not been captured/included and this will help to routinely update the on-line finder.

In terms of how many overall services were identified during the mapping project, table 4 provides an overview of the number of services captured in each service category (N=314).

Table 4: Number of services reported in each category

Service Category	Number of services
Dementia day care	63
Carer support groups	45
Dementia family carer programmes	36
Dementia-specific home care	31
Dementia friendly activities	29
Social clubs	28
ASI branches	21
Alzheimer Cafés	16
Dementia advisers	9
Dementia clinical specialists	7
Dementia cognitive therapies	7
Dementia in-home respite	6
Assistive Technology libraries	4
Case management	4
Dementia support worker programmes	3
National information services	2
People with dementia support groups	2
Dementia counselling	1
Total	314

The table shows that there was considerable variance across service categories, ranging from 1 to 63 services. Dementia day care was the main service reported, with 20% of all services. This was followed by a number of supports for family carers e.g. carer support groups - 14% (N=45) and dementia family carer programmes - 11% (N=36). Services directed at people living with dementia, such as dementia cognitive therapies (N=7) and people with dementia support groups (N=2) were less common.

It’s important to note that while dementia-specific home care services were included in the mapping project they relate largely to ASI regional or local operations. Generic home care is provided by the HSE and other providers, with an estimated 37% of generic Home Care Packages being utilised by people with dementia (O’Brien et al, 2017)⁶. Generic services are however, not captured in the results below.

To give further context around the provision of home care, as part of the implementation of the National Dementia Strategy, there are a limited number of Intensive Home Care Packages for people

⁶ O’Brien, I. Smuts, K. Fan, C.W. O’Sullivan, M. and Warters, A. (2017) High Prevalence of Dementia Among Community Dwelling Older People in Receipt of State Funded Home Care Packages. *Irish Journal of Psychological Medicine*. December 2017.

with dementia (Dementia-IHCP) available across the 9 CHO areas. At the end of April 2017, 217 people had received one of these packages. Table 5 outlines the most recently available figures on the delivery of these packages. This information was collated separately to the mapping project.

Table 5: Intensive home care packages for people with dementia

Area	Dementia Specific IHCPs	Approved Not Commenced	Potential Applications In Progress
West	28	8	1
South	29	3	1
DML	25	2	6
DNE	42	3	4
Total	124	16	12

2.3 Results across CHO areas

The following section provides an overview of services by CHO area, which shows the range of services delivery across each. The figure below outlines the location and composition of each CHO area.

The nine Community Healthcare Organisations are outlined below:

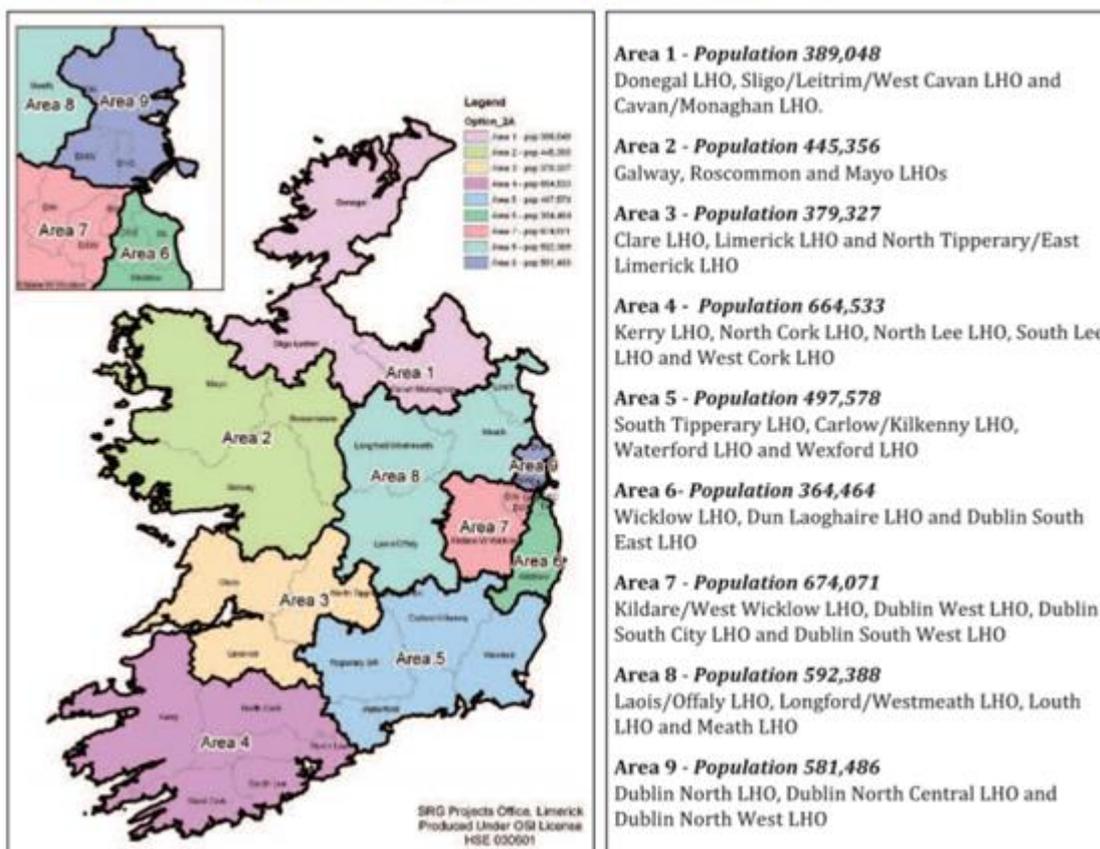
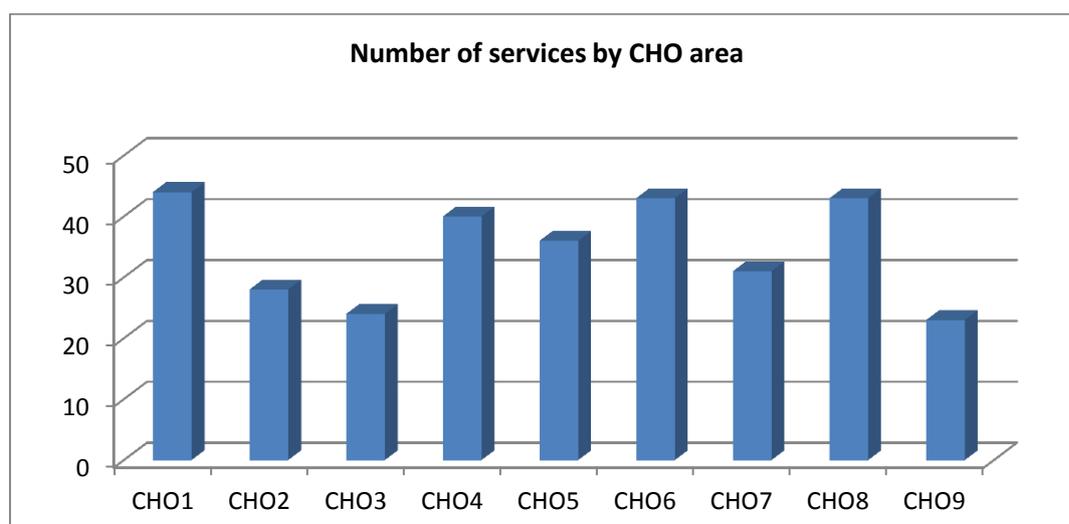


Chart 2: Dementia-specific community-based services by CHO area



Services ranged from 23 services in CHO9 to 44 in CHO1. The average number of services across regions was 35.

The following set of tables illustrates what services operated in each CHO area. These results show how many services were in each service category and highlight which services were not present.

Table 6: CHO1 (Donegal, Sligo, Leitrim, Cavan, Monaghan)

Service Category	Number
Dementia cognitive therapies	1
Dementia clinical specialist	2
Dementia advisers	2
Dementia carer support groups	3
ASI branches	4
Alzheimer Cafés	5
Dementia home care	5
Social clubs	5
Dementia family carer programmes	7
Dementia day care	10
Total	44

CHO1 had the most dementia-specific community-based services, with 44 services reported. Dementia day care were the highest (N=10), followed by dementia family carer programmes (N=7) and social clubs (N=5). However, this region did not have:

- Any dementia friendly activities reported
- An assistive technology library
- Dementia case management
- Dementia counselling
- Dementia support worker programme
- Dementia in-home respite

- People with dementia support groups

Table 7: CHO2 (Galway, Roscommon and Mayo)

Service category	Number of services
Alzheimer Café	1
Dementia clinical specialist	1
Dementia dementia cognitive therapies	1
Dementia support worker	1
Dementia adviser	2
Dementia in-home respite	2
Dementia family carer programme	3
Dementia-specific home care	4
Dementia carer support group	5
Dementia day care	8
Total	28

There were 28 services reported in CHO2. Eight dementia day care centres were reported in this area. Followed by dementia carer support groups (N=5), dementia-specific home care (N=4) and dementia family carer programmes (N=3). The following services were not reported for this region:

- ASI branches
- Assistive technology libraries
- Dementia case management
- Dementia counselling
- Dementia friendly activities
- Dementia social clubs
- People with dementia support groups

Table 8: CHO3 (Clare, Limerick, North Tipperary)

Service category	Number of services
Dementia cognitive therapies	1
Dementia adviser	1
Dementia friendly activities	1
Dementia social club	1
Dementia family carer programme	2
ASI branch	4
Carer support group	4
Dementia home care	4
Dementia day care	6
Total	24

In total there were 24 dementia-specific community-based services in CHO3. Of these dementia day care was the largest (N=6), followed by dementia-specific home care (N=4), carer supports groups (N=4) and ASI branches (N=4).

In this region the following services were not present:

- Alzheimer Café's
- Assistive technology libraries
- Dementia case management
- Dementia clinical specialist in dementia
- Dementia counselling service
- Dementia support worker
- Dementia in-home respite
- People with dementia support group

Table 9: CHO4 (Kerry, Cork)

Service Category	Number of services
ASI branch	1
AT libraries	1
Case management	1
Dementia adviser	1
Dementia support worker	1
Dementia clinical specialist	2
Dementia cognitive therapies	2
Alzheimer Café	3
Dementia friendly activities	3
Social club	3
Dementia carer support group	4
Dementia family carer programme	4
Dementia-specific home care	5
Dementia day care	9
Total	40

There were 40 services identified in CHO4. Of these dementia day care was highest (N=9), followed by home care (N=5), dementia family carer programmes (N=4) and carer support groups (N=4). All but seven of these 40 services were in Co. Cork.

The following are services which were not present in this region:

- Dementia counselling
- Dementia in-home respite
- People with dementia support groups

Table 10: CHO5 (South Tipperary, Carlow, Kilkenny, Waterford, Wexford)

Service Category	Number
Dementia clinical specialist	1
Dementia support worker	1
People with dementia support group	1
ASI branch	2
AT libraries	2
Social club	2
Dementia day care	4
Dementia friendly activities	4
Dementia-specific home care	5
Dementia carer support group	7
Dementia family carer programme	7
Total	36

The most common services in this region were dementia family carer programmes and carer supports groups, both with seven. Dementia-specific home care (N=5), dementia friendly activities (N=4) and dementia day care (N=4) followed.

There were a number of services not present in this region, including:

- Alzheimer Café's
- Dementia case management
- Dementia cognitive therapies
- Dementia adviser
- Dementia counselling
- Dementia in-home respite

Table 11: CHO6 (Wicklow, Dun Laoghaire, Dublin South East)

Service Categories	Number of services
AT libraries	1
Case management	1
Dementia clinical specialist	1
Dementia cognitive therapies	1
Dementia adviser	1
Dementia counselling	1
Dementia in-home respite	1
Alzheimer Café	2
ASI branches	2
Dementia family carer programmes	3
Dementia carer support groups	5
Dementia day care	5
Dementia social clubs	5
Dementia friendly activities	14
Total	43

In total, 43 services were identified for this region. The most common service was Dementia Friendly Activities (N=14), largely due to the Living Well with Dementia Programme operating in Dun

Laoghaire and South Dublin and a number of projects run by Wicklow Dementia Support. Other services included social clubs (N=5), dementia day care (N=5), and carer support groups (N=5). Services not present in this region included:

- Dementia support worker programme
- Dementia-specific home care
- People with dementia support groups

Table 12: CHO7 (Kildare, West Wicklow, Dublin West, Dublin South City, Dublin South West)

Service Category	Number of services
ASI branch	1
Case management	1
Dementia family carer programme	1
Dementia in-home respite	1
People with dementia support group	1
Dementia-specific home care	2
Alzheimer Café	3
Dementia friendly activities	4
Dementia social clubs	4
Dementia day care	6
Carer support group	7
Total	31

There were 31 services reported for this region. The largest was carer support groups (N=7), followed by dementia day care (N=6), social clubs (N=4) and dementia friendly activities (N=4).

Services not offered in this region included:

- Assistive technology libraries
- Dementia clinical specialist roles
- Dementia cognitive therapies
- Dementia adviser
- Dementia counselling
- Dementia support worker

Table 13: CHO8 (Laois, Offaly, Longford, Westmeath, Louth and Meath)

Service category	Number of services
Dementia case management	1
Dementia cognitive therapies	1
Dementia adviser	1
Dementia friendly activities	1
Dementia social club	1
Alzheimer Café	2
ASI branch	6
Dementia-specific home care	6
Dementia carer support group	7
Dementia family carer programme	7
Dementia day care	10
Total	43

A total of 43 services were reported in CHO 8. Dementia day care again came in the highest, with 10 centres. Also family carer and carer support groups were reported with seven services each. There was a strong presence of ASI branches with six reported.

Services not reported in this region included:

- Assistive technology libraries
- Dementia clinical specialists
- Dementia counselling
- Dementia in-home respite
- People with dementia support groups
- Dementia support worker programme

Table 14: CHO9 (Dublin North, Dublin North Central, Dublin North West)

Service Category	Number
ASI branch	1
Dementia family carer programme	1
Dementia adviser	2
Dementia friendly activities	2
Dementia-specific home care	2
Dementia carer support group	3
Dementia day care	5
Dementia social club	7
Total	23

There were 23 services reported for this region. Social clubs came in the highest (N=7), followed by dementia day care (N=5) and carer support groups (N=3).

Not present in this region were:

- Alzheimer Café's
- Assistive technology libraries
- Case management
- Dementia clinical specialists
- Dementia cognitive therapies
- Dementia counselling
- Dementia support worker programme
- Dementia in-home respite
- People with dementia support group.

2.3.1 Summary of CHO based findings

There was a wide range of services across the CHO area's, with 23 to 44 services reported. However, there was a lack of consistency of services across regions. Dementia day care was the most prevalent service in most regions. Dementia friendly activities (DFAs) had the highest number of services in one region, but this was an anomaly as DFAs were generally mid-table or lower in most regions and were not present at all in two regions e.g. CHO 1 and CHO2.

Further analysis is needed to examine county-by-county services. In some CHO regions services were concentrated in one or two counties e.g. CHO 4. A fuller picture of the local context could then be formed.

The inclusion of all service categories in the CHO analysis makes it difficult to calculate availability and capacity across regions as the services operate in different ways and caseload was not examined for a number of service categories. Capacity and availability across services is however presented below.

2.4 Services Categories: Location and availability

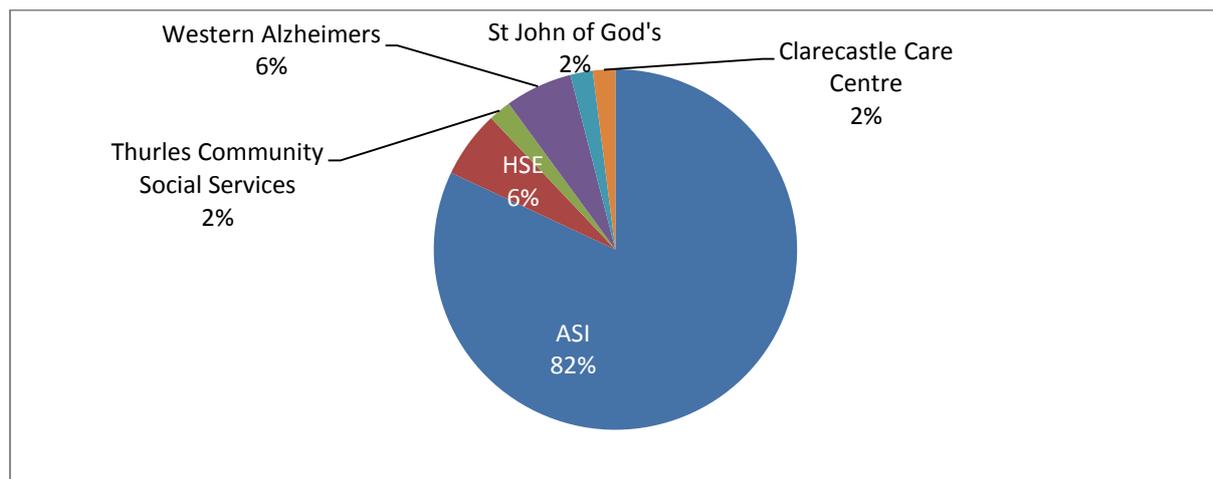
The following section gives more detail about each service category, providing details on who and where services were located and details on their availability and, where applicable, their capacity.

2.4.1 Dementia-specific day care

Described as: Dementia day care centres provide dementia-specific, person-centred care to meet the needs of the person with dementia in a welcoming and safe environment while providing support and stimulation.

By far, dementia day care centres were the most common service identified through the mapping project; making day care the most developed dementia-specific response within communities. In total 63 centres were identified. The majority of these were run by the ASI (82%), many of these partly funded through a service level agreement with the HSE e.g. Orchard Day Care Dublin, Garryowen in Limerick, Sligo daycare, etc

Chart 3: Providers of dementia-specific day-care services



There was wide variance in the availability of dementia day care services across the country, as shown in table 15.

Table 15: Availability of dementia-specific dementia day care services

Days available	Number
6 days a week	1
5 days a week	26
4 days a week	2
3 days a week	8
2 days a week	9
1 day a week	13
Twice a month	3
Once a month	1
Total	63

Services availability ranged from one day a week to once a month. In one case the service ran six days a week. The majority operated five days.

The following tables provide information on dementia day care centres by CHO area, showing the location of each by town, county and services provider. It also provides information on their capacity in terms of available places.

Table 16: Dementia day care location and availability in CHO1 (Donegal, Sligo, Leitrim, Cavan & Monaghan)

Town	Count	Availability	Capacity	Provider
Cavan	Cavan	2 days a week	12	ASI
Convoy	Donegal	1 day a week	10	HSE
Glenfin	Donegal	1 day a week	16	ASI
Glenties	Donegal	2 day a week	32	ASI
Gweedore	Donegal	2 days a week	32	ASI
Carrick	Monaghan	1 day a week	8	ASI
Monaghan	Monaghan	3 days a week	49	ASI
Sligo	Sligo	4 days a week	72	ASI
Sligo	Sligo	5 days a week	Unknown	HSE
Sligo	Sligo	Once a month	10	ASI

In total ten day centres were reported in CHO 1. Donegal had four centres, Sligo three, Monaghan two and Cavan one. Leitrim was the only county in this region with no reported dementia-specific day centre. The reported capacity (where information was provided) in this region was 241 places.

Table 17: Dementia day care location and availability in CHO2 (Galway, Roscommon & Mayo)

Town	County	Availability	Capacity	Provider
Knocknacarra	Galway	1 day a week	15	ASI
Athenry	Galway	5 days a week	20	Western Alzheimer
Galway	Galway	1 day a week	15	ASI
Galway	Galway	3 days a week	45	Western Alzheimer
Castlebar	Mayo	5 days a week	40	ASI
Claremorris	Mayo	5 days a week	10	Western Alzheimer
Castlerea	Roscommon	3 days a week	24	ASI
Roscommon	Roscommon	2 days a week	16	Western Alzheimer

The total number of dementia-specific dementia day care centres in CHO2 was eight, with Galway having four, Mayo and Roscommon with two centres each. The total capacity for this region was 185 places.

Table 18: Dementia day care location and availability in CHO3 (Clare, Limerick & North Tipperary)

Town	County	Availability	Capacity	Provider
Ennis	Clare	3 days a week	24	ASI
Clarecastle	Clare	5 days a week	20	Clarecastle Care Centre
Adare	Limerick	5 days a week	75	ASI
Limerick	Limerick	5 days a week	75	ASI
Thurles	Tipperary	2 days a week	18	Thurles Community Social Services
Ballina	Tipperary	5 days a week	35	ASI

In CHO3 there were six day centres reported; with two in Counties Clare, Limerick and Tipperary. The total capacity for this region was 247 places.

Table 19: Dementia day care location and availability in CHO4 (Cork & Kerry)

Town	County	Availability	Capacity	Provider
Bandon	Cork	1 day a week	10	ASI
Cork city	Cork	5 days a week	100	ASI
Conna	Cork	1 day a week	10	ASI
Skibbereen	Cork	1 day a week	10	ASI
Fermoy	Cork	1 day a week	10	ASI
Kinsale	Cork	2 days a week	12	HSE
Midleton	Cork	1 day a week	10	ASI
Mallow	Cork	5 days a week	80	ASI
Tralee	Kerry	5 days a week	60	ASI

In this region there were nine day centres reported. Eight in Co. Cork and one in Kerry. Capacity for this region was 302 places.

Table 20: Dementia day care location and availability in CHO5 (South Tipperary, Carlow, Kilkenny, Waterford & Wexford)

Town	County	Availability	Capacity	Provider
Carlow town	Carlow	5 days a week	60	ASI
Kilkenny city	Kilkenny	5 days a week	60	ASI
Clonmel	Tipperary	5 days a week	80	ASI
Waterford City	Waterford	5 days a week	80	ASI

In this region there were four day centres reported. One in each of counties Carlow, Kilkenny, Tipperary and Waterford. Total capacity was 280 places.

Wexford was the only county in this region where there was no reported dementia-specific day centre.

Table 21: Dementia day care location and availability in CHO6 (Wicklow, Dun Laoghaire, Dublin South East)

Town	County	Availability	Capacity	Provider
Merrion Road	Dublin	5 days a week	90	ASI
Shankill	Dublin	3 days a week	20	St John of God's
Blackrock	Dublin	5 days a week	100	ASI
Rathdrum	Wicklow	3 days a week	36	ASI
Bray	Wicklow	2 days a week	24	ASI

In CHO6 there were five day centres reported. Three in Dublin and two in Wicklow. Total capacity for this region was 270 places.

Table 22: Dementia day care location and availability in CHO7 (Kildare, West Wicklow, Dublin West, Dublin South City, Dublin South West)

Town	County	Availability	Capacity	Provider
Rathfarnham	Dublin	2 days a week	32	ASI
Crumlin	Dublin	5 days a week	100	ASI
Drimnagh	Dublin	5 days a week	100	ASI
Tallaght	Dublin	5 days a week	60	ASI
Maynooth	Kildare	Twice a month	10	ASI
Monasterevin	Kildare	3 days a week	48	ASI

In this region there were six day centres. The majority in Dublin (N=4) and two in Kildare. The total capacity for this region was 350 places.

Table 23: Dementia day care location and availability in CHO8 (Laois, Offaly, Westmeath, Louth & Meath)

Town	County	Availability	Capacity	Provider
Longford town	Longford	1 day a week	9	ASI
Carlingford	Louth	1 day a week	10	ASI
Drogheda	Louth	5 days a week	60	ASI
Dundalk	Louth	5 days a week	75	ASI
Oldcastle	Meath	2 days a week	10	ASI
Navan	Meath	6 days a week	95	ASI
Birr	Offaly	3 days a week	18	ASI
Tullamore	Offaly	Twice a month	6	ASI
Mullingar	Westmeath	1 day a week	6	ASI
Mullingar	Westmeath	5 days a week	175	HSE

In this region there were ten day centres identified. Three in Louth; two in Meath and Westmeath and Longford had one. Total capacity (where information was provided) was 464 places.

Laois was the only county in this region with no reported dementia-specific day centre.

Table 24: Dementia day care location and availability in CHO9 (Dublin North, Dublin North Central, Dublin North West)

Town	County	Availability	Capacity	Provider
Raheny	Dublin	5 days a week	100	ASI
Raheny	Dublin	Twice a month	10	ASI
Clonsilla	Dublin	5 days a week	80	ASI
Balbriggan	Dublin	4 days a week	80	ASI
Glasnevin	Dublin	5 days a week	80	ASI

In total there were five day centres identified in CHO9. Total capacity for this region was 350 places.

Dementia day care summary:

- A total of 63 dementia-specific day centres were reported.
- There were three counties which did not have a dementia specific day centre – Wexford, Laois and Leitrim.
- Capacity varied between centres and across CHO area ranging from 106 to 350 places, where information had been provided.
- Availability ranged from one day once a month to a six day service, with most offering a five day service.
- The main provider of dementia-specific dementia day care was the ASI, providing 82% of the services.

2.4.2 Dementia Carer Support Groups

Described as: These support groups are for carers of people with dementia. They provide an opportunity to meet others in a similar situation, to share stories and experiences, and access information and practical advice in a supportive environment.

A total of 45 dementia carer support groups were reported through the mapping project, as outlined in Table 25 below.

Table 25: Location, number, provider, capacity and availability of carer support groups

Location	No.	Providers	Capacity	Availability
Carlow	1	ASI	15	Once a month
Cavan	2	ASI	8	Once a month
		ASI	3	Once a month
Clare	2	ASI	20	Once every two months
		ASI	10	Once a month
Cork	4	ASI	15	Once a month
		HSE (Crystal Project)	15	Twice a week
		HSE	20	Once a week
		ASI	Unlimited	Once a month
Dublin	7	HSE	20	Once a month
		ASI	20	Once a month

		ASI	15	Once a month
		ASI	10	Once a month
		ASI	10	Once a month
		ASI	4	Once a month
		ASI	4	Once a month
Galway	1	ASI	15	Once a month
Kildare	4	ASI	20	Once a month
		ASI	15	Once a month
		ASI	15	Once a month
		ASI	15	Once a month
Kilkenny	1	ASI	15	Once a month
Laois	1	ASI	15	Once a month
Limerick	1	ASI	5	Once a month
Longford	1	ASI	10	Once a month
Louth	2	ASI	20	Once a month
		ASI	15	Once a month
Mayo	2	Community Action on Dementia Mayo	35	Once a month
		Western Alzheimers	Unlimited	Once every two months
Meath	2	ASI	15	Once a week
		ASI	8	Once a month
Monaghan	1	ASI	10	Once a month
Offaly	1	ASI	8	Once a month
Roscommon	2	Western Alzheimers	Unlimited	Once every two months
		Family Carers Ireland	Unlimited	Once a month
Tipperary	2	ASI	15	Once a month
		ASI	10	Once a month
Waterford	1	ASI	20	Once a month
Wexford	3	Family Carers Ireland	14	Once a month
		ASI	Unlimited	Once a month
		ASI	Unlimited	Once a month
Wicklow	4	Wicklow Dementia Support	20	Once a week
		Wicklow Dementia Support	10	Once a week
		ASI	12	Once a month
		ASI	12	Once a month

A number of services (N=6) were reported as having unlimited capacity. Outside of these six groups, the number of places available ranged from 3 – 35 places. The average number of places for dementia carer support groups was 14. The most common occurring number of places was 15. The sum of places (where data was provided) was 538 places.

The majority of groups met once a month (N=37). A number met once a week (N=5), one twice a week and three met once every two month.

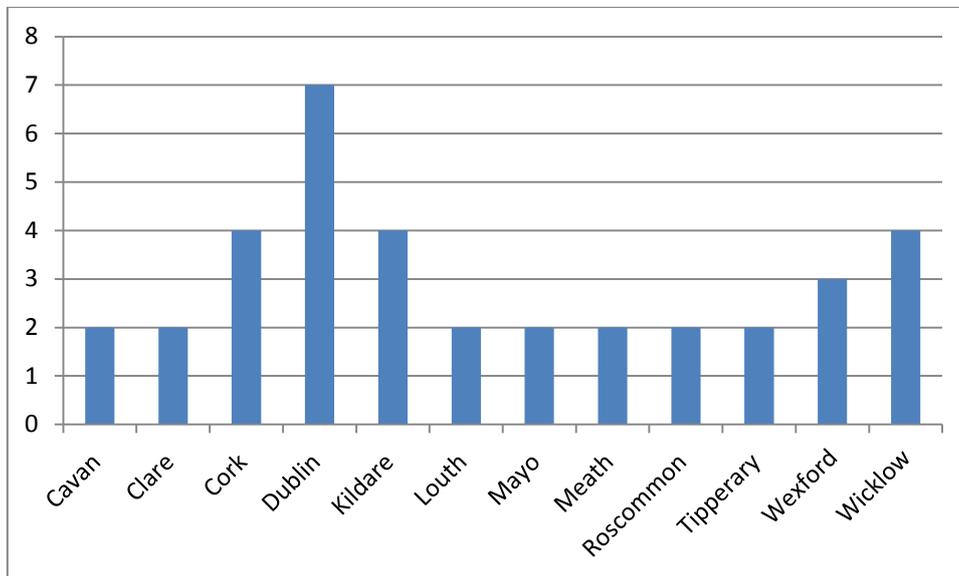
In terms of location the data shows that not all counties had a support group, for example the following counties did not, the majority located in the West of the country:

- Westmeath

- Sligo
- Leitrim
- Donegal
- Kerry

A number of counties had multiple dementia carer support groups, as shown in the chart below.

Chart 4: Counties with multiple carer support groups



The majority of groups were located in Dublin (15.5%); 9% in Cork, Kildare and Wicklow and 7% in Wexford.

Chart 5: Service providers, carer support groups

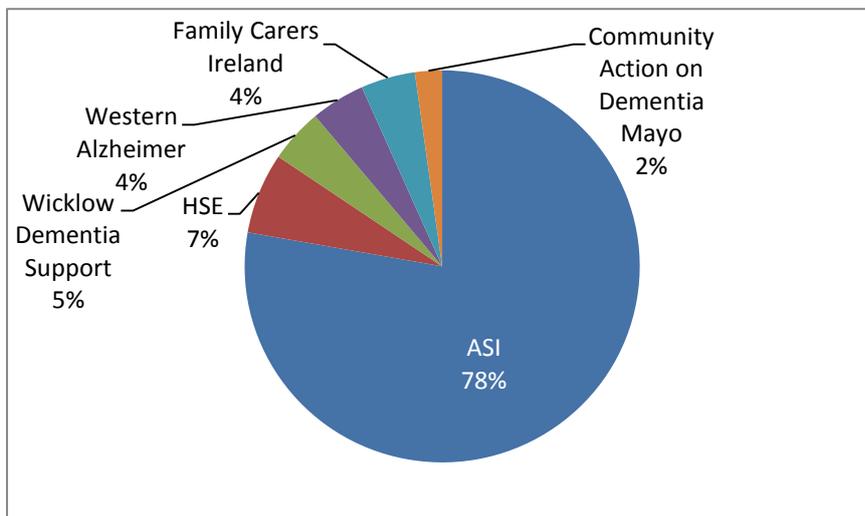
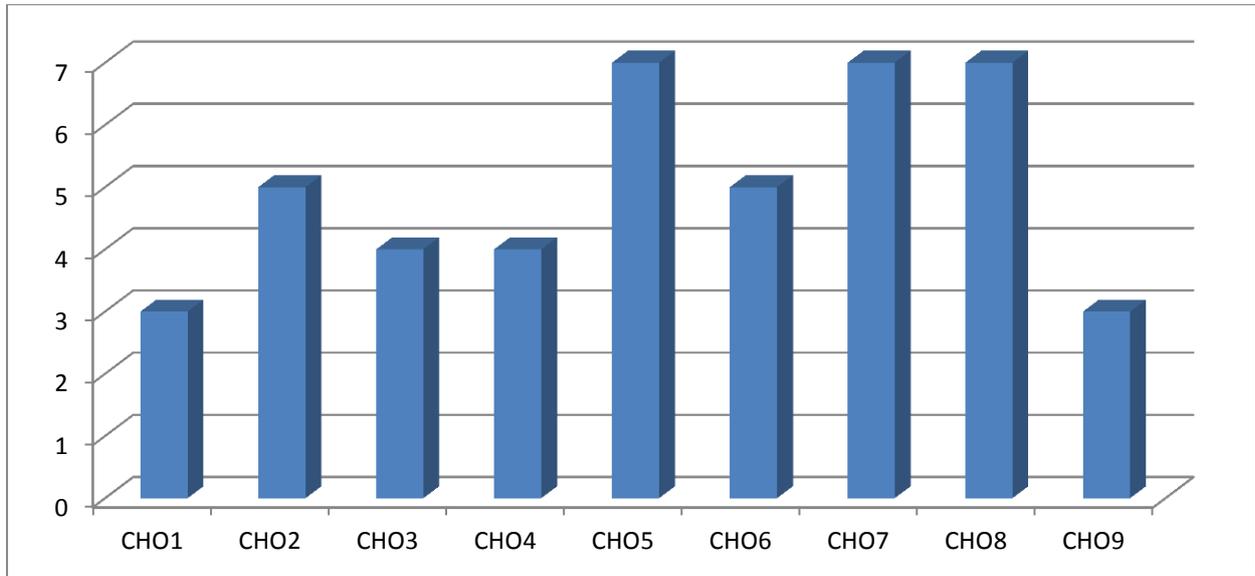


Chart 5 to the left shows who provided or facilitated this service. In the main these were ASI services, followed by the HSE and local groups.

In terms of CHO distribution the following chart shows the spread of carer support groups across the country:

Chart 6: CHO distribution of carer support groups



CHO’s 5, 7 and 8 have the most carer support groups with seven each. CHOs 1 and 9 have the least with three identified groups in each area.

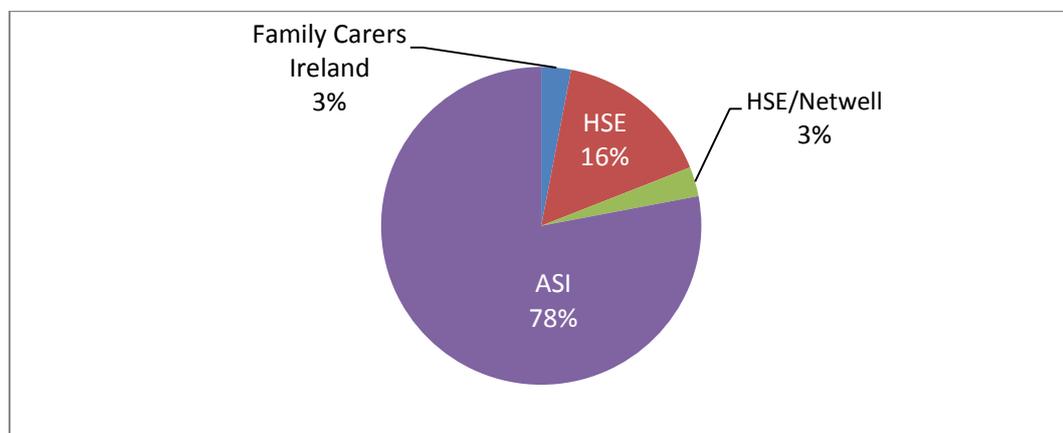
2.4.3 Dementia family carer programmes

Described as: Programmes developed to support and educate families and carers who care for a person with dementia. They aim to enable families and carers to recognise the emotions, goals and coping strategies of the person with dementia. They follow a set programme and run for a number of weeks.

In total, 36 dementia family carer programmes were identified. One of these services operated as a national service out of a Dublin-base; the others were based in specific locations across the country. We know that there are other family carer training programmes run by DCU/HSE Elevator programme and Dementia Service Information Development Centre (DSIDC) for example, these were not captured in the mapping project.

The following chart outlines who provides these programmes across the country.

Chart 7: Providers of dementia family carer programmes



In terms of the location of the programmes, they were largely provided on a county-basis. The following table provides more detail.

Table 26: Location and number of dementia family carer programmes

Location	No. of Groups	Location	No. of Groups						
Carlow	1	Cavan	1	Clare	1	Cork	3	Donegal	3
Dublin	3	Galway	1	Kerry	1	Kildare	1	Kilkenny	1
Laois	1	Leitrim	1	Limerick	1	Longford	1	Louth	2
Mayo	1	Meath	1	Monaghan	1	Offaly	1		
Roscommon	1	Sligo	1	Tipperary	3	Waterford	1		
Westmeath	1	Westmeath	1	Wicklow	1	National	1		

There were multiple programmes running in Cork, Donegal, Dublin and Tipperary with three each. Only one county, Wexford, did not have this service.

In terms of CHO distribution, the table to the right outlines where the programmes were concentrated.

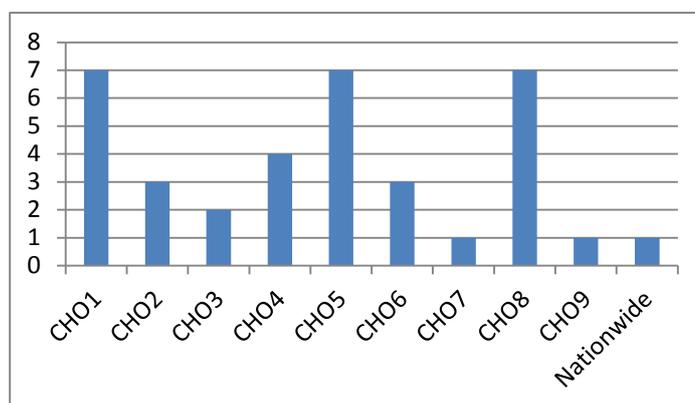


Chart 8: Distribution of dementia family carer programmes by CHO area.

There was wide distribution with the programme running in each CHO area. It spanned from 7 programmes in CHO areas 1, 5 and 8 to one programme in CHO areas 7 and 9.

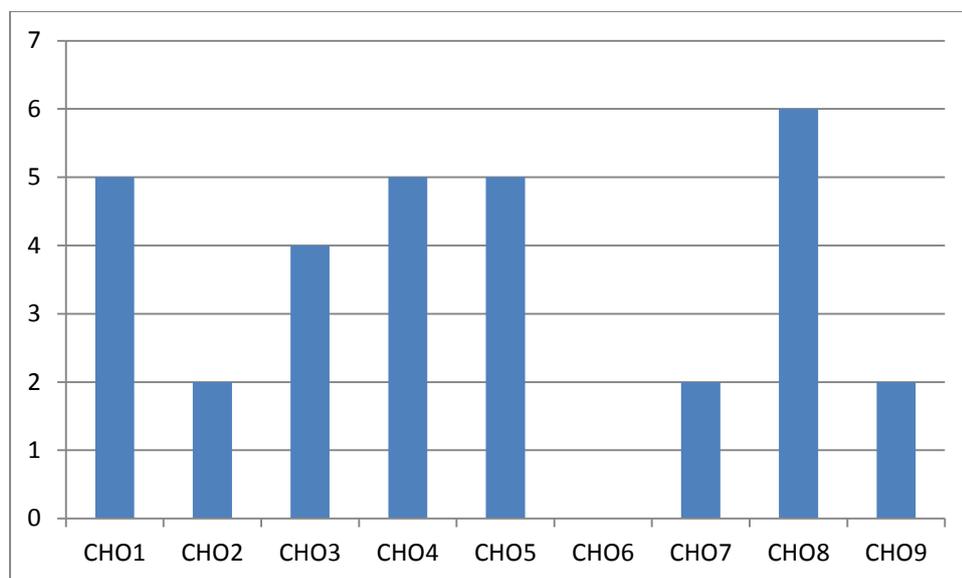
2.4.4 Dementia Specific Home Care

Described as: Dementia-specific home care is delivered by fully trained staff who are familiar and understand the different symptoms and stages of dementia. There is also a focus on consistency and continuity of care, where the same carer will deliver care to the individual.

For the purposes of the mapping project centres which coordinate this type of care were captured rather than the number of specific home care workers. The project also did not examine how many people received this type of home care. It's equally important to mention again that many people with dementia/family carers access generic home help and home care packages through the HSE and other providers. Its estimated for example that 37% of all users of Home Care Packages are people living with a dementia. Generic home care was not captured in the mapping project.

In terms of provision across CHO area, the following tables shows that all CHO's except CHO 6 had a centre which organized and coordinated dementia-specific home care.

Chart 9: CHO distribution of dementia-specific home care



The ASI was the main providers of this service, operating 29 of the 37 services identified. A more detailed look at location shows the following distribution across counties.

Table 27: Location of dementia-specific home care

Carlow	1	Donegal	2
Clare	1	Dublin	2
Galway	1	Kerry	2
Kilkenny	1	Longford	2
Wexford	1	Limerick	2
Meath	1	Kildare	2
Offaly	1	Tipperary	3
Roscommon	1	Sligo	3
Westmeath	2	Cork	3

A number of counties did not have this service, including:

- Louth, Wicklow, Laois, Waterford, Mayo, Leitrim, Monaghan, Cavan

Other counties had more than one reported dementia-specific home care service, including Tipperary (N=3), Dublin (N=2), Sligo (N=3), Donegal (N=2), Longford (N=2), Cork (N=3), Kildare (N=2), Kerry (N=2) and Limerick (N=2).

2.4.5 Dementia Friendly Activities

Described as: These are activities that are designed or adapted to support the involvement of people with dementia in their local communities. They can include clubs, events or other initiatives tailored to enable people living with dementia to retain their traditional networks.

A total of 29 dementia friendly activities (DFAs) were captured in the mapping project, as shown in Table 28 below.

Table 28: DFA activity by organization, location and capacity

Type of activity	No. of services	No. of places	Availability	Provider	Location
Choirs	10	See table 29	See table 29	See table 29	See table 29
Azure projects	7	See table 30	See table 30	See table 30	See table 30
Dance	2	75 16	Twice a week	HSE	Dublin
Dementia working groups	2	50 Unlimited	Every two months Once a month	ASI	National Cork
Physical activity groups	2	Unknown 40	Twice a week	HSE	Dublin
Bridge	1	75	Once a week	HSE	Dublin
Dementia friendly town	1	12	Unknown	Kilkenny Age Friendly County Programme	Callan
Dementia carers campaign group	1	60	Every two months	ASI	National
Befriending	1	Varies	Varies	Wicklow Dementia Support	Wicklow
Art	1	14	Twice a week	HSE	Dublin
Memory resource room	1	Unknown	Twice a week	HSE	Mallow

Dementia choirs (N=10) were the most common dementia friendly activity captured. Table 29 below provides more information on their location and composition.

The Azure programme also ran DFAs across the country in seven locations. Table 30 below provides more information on these. Other DFA activities captured included Dance, Art and Physical Activity groups. In addition bridge and a befriending service were reported. Captured also under DFA were

the memory resource room in Mallow and the Dementia Friendly Town initiative in Callan, Co Kilkenny.

In relation to the Choirs, they were spread across the East of the country as follows:

Table 29: DFA Choirs – location, availability, capacity and provider

County	Town	CHO	Capacity	Availability	Organisation
Carlow	Carlow	5	12	1 day a week	HSE
Dublin	Baldoyle	9	52	1 day a week	Forget-me-nots Choir
Dublin	Cabinteely	6	10	1 day a week	ASI
Dublin	Crumlin	7	Unknown	1 day a week	Dublin City Council & St Agnes' Community Centre
Dublin	Deansgrave	6	Unknown	1 day a week	ASI
Dublin	Shankill	6	Unlimited	1 day a week	HSE
Dublin	Stillorgan	6	Unknown	1 day a week	HSE
Kildare	Celbridge	7	16	1 day a week	Cellbridge Community Choir
Kildare	Naas	7	120	1 day a week	Past-times Community Choir
Kilkenny	Thomastown	5	Unlimited	7 days a week	HSE

Dublin had the majority of Choirs with six out of the ten. The West and South of the country had no reported Choirs. The majority of Choirs ran one day a week, except for the Thomastown Choir which was reported as meeting every day. The size of Choirs varied considerably; where data was provided it ranged from 10 to 120 people. The HSE was taking the lead on running most of the Choirs (N=4) but other providers were involved in providing the service including the ASI, local community groups and a local council.

In relation to the Azure projects, the following table outlines their location. The majority were organised through existing art galleries.

Table 30: Azure programmes by location availability and capacity

Location	Town	County	CHO area	Number of places
Crawford Art Gallery	Cork	Cork	4	30
Irish Museum of Modern Art	Kilmainham	Dublin	7	14
Municipal Gallery, DLR, Lexicon	DunLaoghaire	Dublin	6	Unknown
Marino Institute of Education	Marino	Dublin	9	Unknown
Butler Gallery	Kilkenny	Kilkenny	5	30
Hunt Gallery	Limerick	Limerick	3	Unknown
Highlane Gallery	Drogheda	Louth	8	25

In the main the Azure projects were not held on any specific day but ran 'as required', except for the Crawford Art Gallery in Cork which ran the project one day a week. Where information was provided the number of people the projects accommodated ranged from 14 to 30.

Many of the dementia friendly activities were supported by a consortia of organisations and individuals. However, only the lead organisations were identified for the purposes of the mapping project:

Table 31: Organisations leading Dementia Friendly Activities

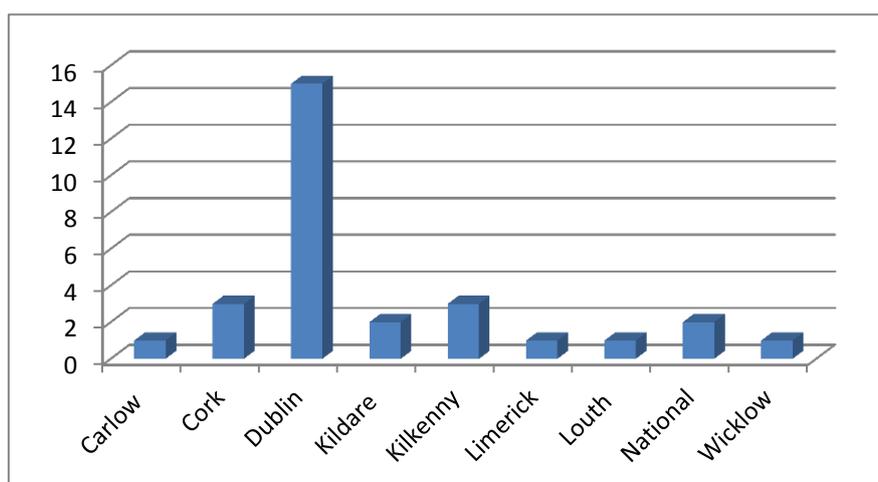
Age and Opportunity Butler Gallery	Kilkenny Age Friendly County Programme Dublin City Council and St Agnes's Community Centre
Community response* Crawford Art Gallery	Forget-me-nots The Hunt Museum
ASI Dun Laoghaire/Rathdown County Council	Wicklow Dementia Support HSE
Highlanes Gallery	Irish Museum of Modern Art

*This was identified in three cases for the Celbridge, Past-times and Forget-me-nots Community Choirs.

Summary of Dementia Friendly Activities

- The majority of dementia friendly activities were located in Dublin (N=15), as shown in the bar-chart below.

Chart 10: Location of DFAs by county



- There were parts of the country with no DFA, most notably the midlands and west of the country. These included Meath, Wexford, Laois, Offaly, Westmeath, Longford, Waterford, Kerry, Clare, Tipperary, Galway, Mayo, Sligo, Leitrim, Roscommon, Donegal, Monaghan and Cavan.
- Choirs were the main DFAs reported.
- The majority of DFAs were provided by the HSE (N=11).
- The ASI provided four DFAs.
- A number of community organisations and art galleries were also instrumental in running Choirs and Azure art programmes.

2.4.6 Dementia Social Clubs

Described as: Dementia social clubs centre around social gathering where people can drop-in to chat, access information and support, and meet other people as well as to exchange ideas and experiences. They are provided as a resource for both people with dementia and their carers or family members.

Findings from the mapping project show that there were 28 social clubs operating across the country.

Table 32: Number of social clubs, location, provider, capacity and availability

Location	No. of groups	Organisation	Capacity	Availability
Cork	2	ASI	25	Once a month
		Youghal Community Group	20	Once a month
Donegal	4	ASI	16	Once a week
		ASI	12	Once a week
		ASI	16	Once a week
		ASI	12	Once a week
Dublin	12	ASI	25	Once a week
		ASI	20	Once a week
		ASI	18	Once a week
		ASI	6	Once a week
		ASI	20	Once a week
		ASI	8	Once a week
		ASI	8	Once a week
		ASI	20	Once a week
		HSE	30	Once a week
		ASI	6	Once a week
		ASI	12	Once a week
		ASI	12	Once a week
Kerry	1	North Kerry Alzheimer's Association	6	Once a week
Kildare	2	ASI	20	Once a week
		ASI	20	Once a week
Laois	1	ASI	20	Once a week
Limerick	1	ASI	20	Once a week
Monaghan	1	St Vincent de Paul	10	Once a week
Waterford	1	ASI	30	Once a month
Wexford	1	ASI	20	Once a week
Wicklow	2	Wicklow Dementia Support	12	Once a week
		Wicklow Dementia Support	12	Once a week

The majority of social clubs ran once a week (N=25) while the remainder operated once a month (N=3). The total capacity of the groups (based on the information that was provided) across the country was 456 people; ranging in number from six to 30 places. The average number of places was 16 while the most common number of places was 20.

The vast majority were provided by the ASI (77%). Other providers included Wicklow Dementia Support; Youghal Community Group, North Kerry Alzheimer Association, St Vincent de Paul and the HSE; as shown in the pie chart.

In terms of distribution across CHO area, you will see that CHO2 had no social clubs while CHO 9 had seven and CHO areas 5 and 6 have five.

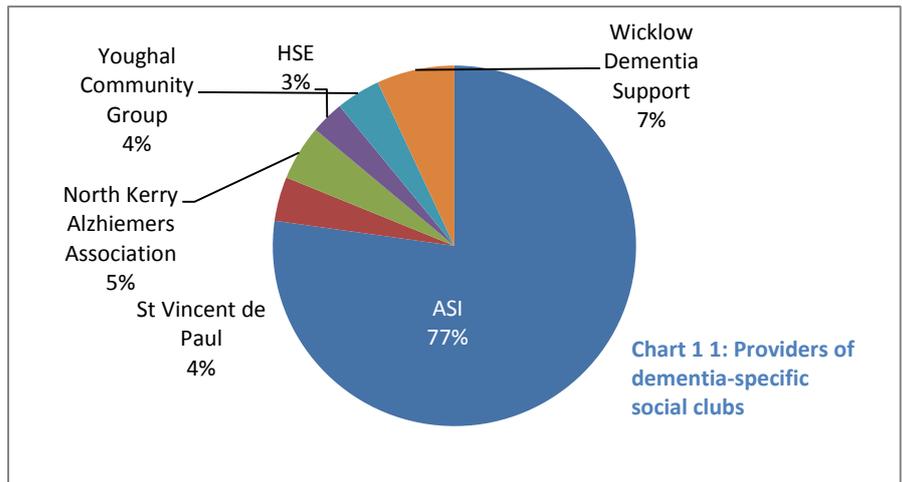
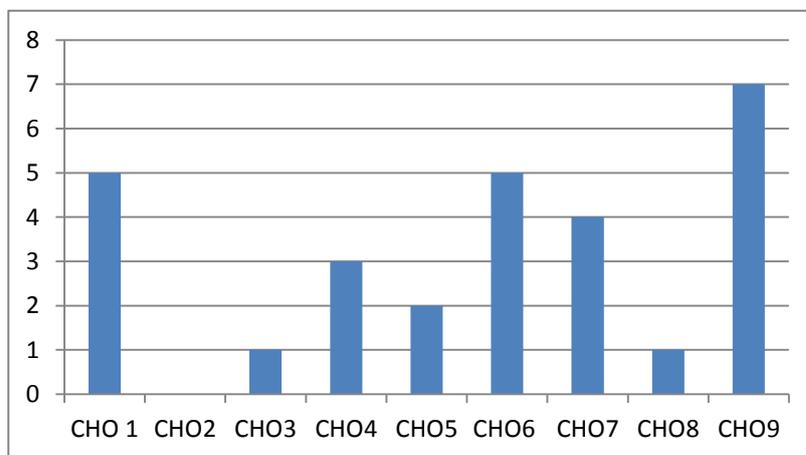


Chart 12: Distribution of social clubs across CHO area.



2.4.7 Alzheimer Society of Ireland Branches

Described as: Alzheimer Society of Ireland branches provide information and support at a local level to people living with dementia and to family carers. They also engage in fundraising activities locally to support Alzheimer Society of Ireland services locally.

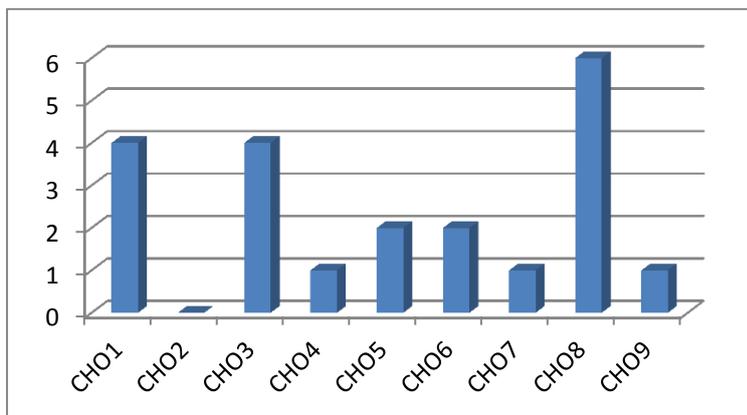
Table 33: Number of branches by location

County	Number of branches	County	Number of branches
Carlow	1	Limerick	2
Cavan	1	Longford	1
Clare	1	Louth	2
Cork	1	Meath	2
Donegal	1	Monaghan	1
Dublin	2	Sligo	1
Kildare	1	Tipperary	1
Kilkenny	1	Wicklow	1
Laois	1	Total	21

In total 21 ASI branches were identified through the mapping project. They were run by volunteers and met once a month. Table 33 outlines their spread across the country. The majority of counties had one branch other than Louth (Dundalk and Drogheda), Meath (Meath and Old Castle), Limerick (Limerick City and Adare) and Dublin (Dublin North and Dublin South branches) where there were two branches each. A number of counties had no branches, including Wexford, Offaly, Westmeath, Waterford, Kerry, Galway, Mayo, Leitrim, Roscommon.

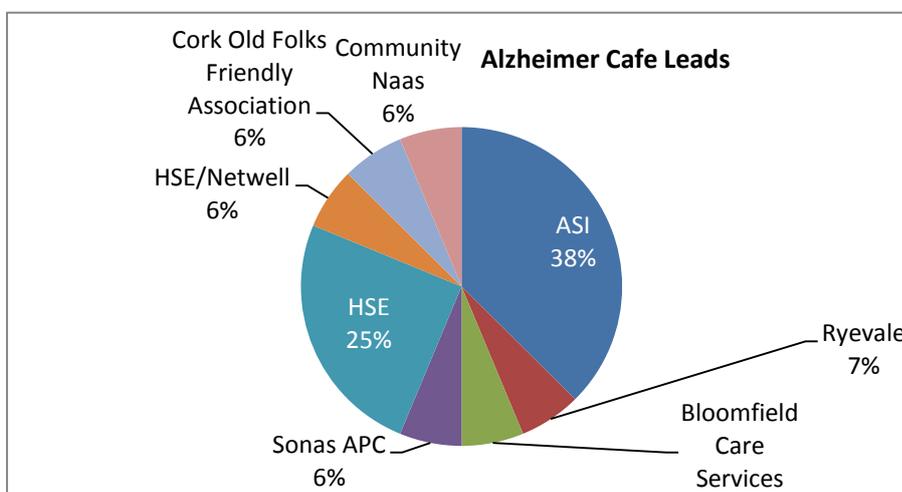
The chart below shows the distribution of branches across each CHO area. CHO area 8 had the majority, with six branches, followed by CHO areas 3 and 4 which had four branches each. CHO2 was the only area to have no reported branches.

Chart 13: Distribution of ASI branches across CHO area



2.4.7 Alzheimer Cafes

Described as: Alzheimer Cafes provide a welcoming space for a couple of hours for people with dementia, their family and friends and social and health care professionals to meet and exchange ideas. The cafes provide an informal way to meet others living with dementia and to meet health and social care professionals. Usually an expert speaker is invited each month to talk at the Cafe about a topic of interest, however the cafe is also a space to chat and enjoy a social occasion in a supportive environment.



The mapping project and verification process identified 16 Alzheimer Cafes. They were run across the country by a number of leads as shown in the pie chart below.

Chart 14: Providers of Alz Cafes

Alzheimer Café's are led by consortia of different professionals, organisations and volunteers. Generally one organisation will take the lead to run the café; the providers presented here are not representative of the full schema of organisations involved in operationalizing the cafes. The ASI were the main reported provider (38%), followed by the HSE (25%).

In terms of their location, the 16 Cafes identified were in the following locations.

Table 34: Location of Alzheimer Cafes.

Town	County	CHO
Carrick	Donegal	1
Letterkenny	Donegal	1
Carrick-on-Shannon	Leitrim	1
Monaghan	Monaghan	1
Sligo	Sligo	1
Galway City	Galway	2
Cork	Cork	4
Douglas Road	Cork	4
Youghal	Cork	4
Bray	Wicklow	6
Donnybrook	Dublin	6
Rathfarnham	Dublin	7
Naas	Kildare	7
Leixlip	Kildare	7
Dundalk	Louth	8
Dunshaughlin	Meath	8

CHO area 9 had no café, while CHO 1 had five, CHO 4 and CHO 7 had three each. All café's met once a month for two hours. Some were in the evenings while others met during the day. In terms of availability, it's difficult to judge as they operate as a walk-in service/support and numbers will not be consistent from month to month. However, respondents did give some indications around the number of available places, as shown in table 35.

Table 35: Capacity and location of Alzheimer Cafes

Location	Capacity	Location	Capacity	Location	Capacity
Monaghan	18 places	Leixlip	30 places	Sligo	30 places
Naas	50 places	Dundalk	50 places	Galway	50 places
Cork	Unknown	Douglas Road	Unknown	Letterkenny	Unknown
Carrick	Unknown	Bray	Unlimited	Donnybrook	Unlimited
Rathfarnham	Unlimited	Carrick on Shannon	Unlimited	Dunshaughlin	Unlimited
Youghal	Varies				

In some cases no answer was given for their capacity and this is included in the table above as an unknown (N=4). While others indicated that there was no limit to the number of people who could attend (N=5). For the others they ranged from 18 – 50 places.

2.4.8 Dementia Advisers (DA)

Described as: Local Dementia Adviser work with individuals to provide information and advice throughout their journey with dementia. Helping the person connect with local dementia supports and services. They also work to help communities be more dementia friendly.

A total of nine dementia adviser services were identified in the mapping project. Eight of the nine dementia adviser services were run by the ASI. The ninth was run by Community Action on Dementia in Mayo. One service could span a number of counties as shown in the table below. In some cases the service operated in only one section of a county, also outlined in the table below.

Table 36: Location and availability of dementia adviser service

	County	CHO	Availability
1.	Cavan, Monaghan, Louth	1 & 8	5 days a week
2.	Sligo, Leitrim, South Donegal	1	5 days a week
3.	Galway	2	5 days a week
4.	Limerick, Tipperary, South Clare, North Cork, East Kerry	3	5 days a week
5.	Cork City, South and West Cork, South Kerry	4	4 days a week
6.	Dublin South	6	5 days a week
7 & 8.	Dublin North (2 advisers)	9	5 days a week
9.	Mayo	2	4 days a week

There were a number of counties (N=12), and parts of counties, which did not have a DA service. They were largely centred around the Midlands and South East of the country and included:

- Waterford
- Offaly
- Roscommon
- North Donegal
- Carlow
- Westmeath
- Kildare
- South Clare
- Laois
- Longford
- Meath
- North & East Kerry

You can see from the chart below that CHO areas 5 and 7 had no DA service. While CHO areas 1, 2 and 9 were covered by three. This is likely to be as DA's covered different counties in these CHO regions.

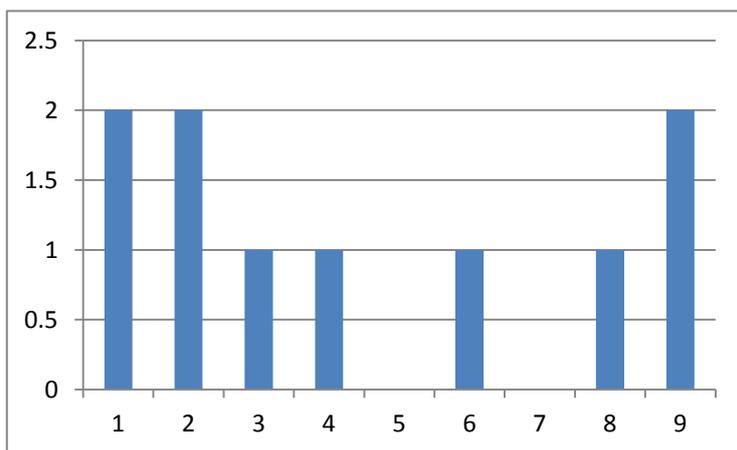


Chart 15: Number of days of DA service by CHO area.

Note: Information was not provided on how many people receive the service as the mapping project did not go directly to service provider but dependent on key knowledge holders to provide the information.

2.4.10 Dementia Clinical Specialist

Described as: Various health and social care professionals who are specialized in dementia and provide services and supports to those living with the condition.

In total seven dementia clinical specialists were captured in the mapping project. They included:

- Sligo Social Work Health Psychiatry for Older People identified by a respondent as a dementia-specific service. It operated five days a week, as required and was located in Sligo Town (CHO1).
- Sligo/Leitrim Occupational Therapy were identified as having a dementia-specific service which runs as required five days a week from Liscarney House in Sligo town (CHO1).
- HSE Dementia Community Support Nurse who operated in Roscommon (CHO2), working three days a week.
- HSE Occupational Therapist who operated from primary care in Mallow, Co Cork (CHO 4).
- A Dementia Nurse Specialist working in Kinsale, Co Cork (CHO 4).
- A Dementia Nurse Specialist, Clonmel Co Tipperary, who works five days a week (CHO 5).
- The HSE CHO 6 Living Well with Dementia located in DunLaoghaire, Co Dublin also had an Occupational Therapist.

Three of these roles were occupational therapists, three were nurse specialist roles and one was a social work role. Similarly to the DFA data the role of the Genio/HSE community programmes has left a legacy in relation to the health and social care professionals now specialising in dementia, with four of the seven specialist roles a result of the investment into the Genio/HSE community and acute dementia projects.

In terms of their location, two were in CHO1, two in CHO4 and one each in CHO areas 2, 5 and 6. Therefore CHO3, CHO7, CHO8 and CHO9 had no reported dementia specialist clinical service.

*Where information was provided on frequency of service it is shown above.

2.4.11 Dementia Cognitive Therapies

Described as: Dementia cognitive therapies, such as cognitive stimulation (CST) and cognitive rehabilitation therapies for people with dementia focus on cognitive function, quality of life, well-

being, communication and social interaction for people in the early to mid-stages of dementia. Depending on the type of therapy and the approach taken, they can be provided either one-to-one or in a group setting.

Seven cognitive therapy programmes were identified through the mapping project.

Table 37: Location, provider and availability of dementia cognitive therapies

Location	Provider	Name	Availability	CHO
Dublin	HSE	Dementia cognitive therapies	5 days a week	6
Cork	HSE	Le Cheile	Unknown	4
Cork city	HSE	Memory Gym	2 days a week	4
Meath	HSE	Memory Clinic	5 days a week	8
Sligo	ASI	CST group	2 days a week	1
Galway	ASI	CST group	1 day a week	2
Tipperary	ASI	CST group	As required	2

In the case of the three CST groups run by the ASI they had capacity for eight people in two groups and nine people in the other. Access to HSE dementia cognitive therapies were by appointment/referral. Two of the programmes operated from St Finbar’s Hospital in Cork and were run through the Memory Assessment and Treatment Centre and old Age Psychiatry services. There was also variance in the frequency of the service with some operating five days a week (N=2) and others as required.

With the small number of cognitive therapy programmes identified there were large parts of the country with no service, including CHO areas 3, 5, 7 and 9.

2.4.12 Dementia In-home Respite

Described as: Dementia in-home respite care is short-term care that provides a planned programme of care visits, from a few hours in the day to a few weeks. The care programmes are designed to provide unpaid carers with a valuable, time-limited break while minimising any upheaval and stress to the client.

Six dementia in-home respite services were identified including:

- Western Alzheimer, Roscommon town (CHO2); operating five days a week.
- Western Alzheimer, Claremorris, Mayo (CHO2); operating five days a week.
- Western Alzheimer, Galway City (CHO2); operating five days a week.
- Family Carers Ireland, Roscommon town (CHO2); operating seven days a week.
- HSE, Meath Community Services, Dublin 8 (CHO 7); operating seven days a week.
- HSE CHO 6 Living Well with Dementia, DunLaoghaire (CHO6); operating as required.

Note: Information was not provided on how many people receive this service.

The majority of these services were offered in CHO2 by Western Alzheimer’s. Their service operated five days a week. Family Carers Ireland’s service, also in CHO2, ran a seven day a week service. It’s unclear from the data how dementia in-home respite differs from dementia-specific home care. It

could relate to the flexibility within the service and the longer periods of time offered to the carer/person with dementia. This will be followed up when the NDO meets with CHO personnel over the coming months.

2.4.13 Assistive Technology (AT) Libraries

Described as: The AT library is for people with memory difficulties and dementia, and their family and friends. There are a large range of Assistive Technology (AT) products that are useful for people with memory difficulties. The library offers a space where these products can be seen and tried out with a member of staff on an individual basis.

At the time the information was collected for the mapping project four AT libraries were identified. We know however that there are plans to have an AT library (now called a Memory Technology Resource Room) operational in each CHO area and a number of these have since been established.

Information on the AT libraries identified for the mapping project include:

- Memory Resource Room, Memory Matters, HSE Carlow (CHO5). The service was available twice a month.
- Memory Technology Library, in Clonmel, Co Tipperary (CHO5). The service was run by appointment only.
- The Memory Harbour in Clonskeagh, Dublin (CHO6). It operated five days a week by referral.
- Assistive Technology Library in Mallow Primary Care Centre (CHO4).

All AT libraries were run by the HSE.

2.4.14 Dementia Case Management

Described as: Dementia case managers work with the person and their family carers to coordinate care. This includes the assessment, planning, implementation and monitoring of care to the individual.

Four dementia case managers were identified through the mapping project. Where roles had similar characteristics they were collapsed into the category of case management.

They included:

- Dementia Case Manager, Memory Intervention and Support Service, St Finbarr's Assessment and Treatment Centre in Cork (CHO 4). This was an integrated care role where the case manager engages with both MDT within the hospital and works with colleagues in the Community. The service was reported as running five days week.
- Dementia Case Manager, HSE CHO 6 Living Well with Dementia based in Dun Laoghaire, Co Dublin (CHO 6). The service was run one day a week.
- Dementia Case Manager, the Alzheimer Society of Ireland, Rose Cottage, Dublin (CHO 7). The service was offered two days a week and was incorporated as part of a broader role within a local service.
- Dementia Case Manager, HSE/Netwell Centre, Dundalk, Co Louth (CHO 8). This service was offered on an 'as required' basis.

Note: Information was not provided on extent of caseload.

2.4.15 Dementia Support Worker Programmes

Described as: Dementia Support Workers provide one-to-one individualized support; aiming to prolong independence and improve self-esteem for the person with dementia. Their interventions are primarily activity based.

Three dementia support worker programmes were identified through the mapping exercise. These included:

- Community Action on Dementia in Mayo (CHO2). Operating out of Castlebar in Co. Mayo. The service offered clients from 2 hours per week to up to ten hours per week depending on need. They operated seven days a week.
- Ideas Project, HSE/Genio (CHO4), Cork city. This service included two carers operating five days a week.
- Living Well with Dementia South Tipperary (CHO5), located in Clonmel. The respondent stated that the service was unlimited and operated five days a week.

Interestingly, all three programmes presented here were originally developed through Genio/HSE projects.

Note: (i) Information was not gathered on how many people use the service. (ii) The DFA befriending service operating in Co Wicklow could also fall into this category.

2.4.16 National Information Service

Two national information services identified in the mapping were the ASI national helpline which operated a 6 days a week service and their mobile information bus which was available 7 days a week and operates as required. The ASI national helpline was based in their national office in Dublin. These were the only national information services captured in the mapping project.

2.4.17 Support Groups for People with Dementia

Described as: Support groups provide an opportunity to meet others in a similar situation, to share stories and experiences, and access information and practical advice in a relaxed, understanding and supportive environment.

The number of people with dementia support groups identified through the mapping project was very small (N=2). They included:

- The DREAM Kilkenny group (CHO 5) which meets twice a month and had 14 places available for people with dementia.
- The Alzheimer Society of Ireland Person with Dementia Support Group which was Dublin-based (CHO 7) and meets once a month, had four places available.

*Note: waiting to hear back from DREAM group in Galway.

2.4.18 Dementia Counseling Services

Described as: Dementia counseling addresses the emotional and psychological impact of living with dementia. Counseling provides an opportunity for the person with dementia and/or family carer to speak in confidence about issues that are affecting them.

Only one dementia specific counselling services was identified in the mapping project. This related to the HSE CHO 6 Living Well with Dementia which operated the service one day a week from their base in DunLaoghaire Co. Dublin (CHO 6).

4. CONCLUSIONS AND RECOMMENDATIONS

The findings show that there were significant gaps in service provision and inconsistency of availability of types of services by both county and CHO area. The mapping exercise and this report offers the NDO, HSE and other providers including the ASI a greater opportunity for the systematic development of new services in-line with identified local need. The findings will also assist Government in determining the locations which are most in need of developing dementia specific services. A number of recommendations arise from the report and these are listed below.

Recommendations:

1. Both the NDO and ASI to hold meetings with senior personnel in each CHO area to outline the findings of the report and support local service development consistent with the needs of the region and county.
2. The generation of CHO estimates on the prevalence of dementia in each area will identify potential demand for services. This should be linked to the 2016 Census data.

Findings highlight the lack of supports and interventions targeted specifically towards people with dementia and those earlier in the dementia journey, particularly in relation to post-diagnostic supports such as dementia counselling, dementia cognitive therapies, dementia information and signposting services/resources.

Recommendations:

3. The HSE, working with partners, to roll-out the NDO post-diagnostic support pathway project.
4. The development of the post-diagnostic support pathway should be used to inform CHO/HSE operational plans in relation to dementia specific services from 2019 onwards.

The low number of dementia friendly activities identified in the mapping project highlights the need for a greater community response to dementia.

Recommendation:

5. The HSE Understand Together Campaign with partners including the ASI and Genio, to use findings from the mapping project to target areas and mobilise local support where there has been little or no investment in dementia friendly activities or other services/supports within the community.

The mapping exercise shows the low number of dementia-specific clinical and case management roles in the community. Evidence of the effectiveness of these roles is available through evaluations of the Genio/HSE projects.

Recommendations:

6. The HSE to use evidence on the effectiveness of case management/coordination and specialist dementia clinical roles to inform the roll-out of these nationally.
7. The NDO to further develop clinical dementia specialist role job descriptions and support their implementation in geographical areas where there is an identified gap.
8. The NDO to progress the 'key worker' priority action as outlined in the National Dementia Strategy.
9. The NDO, in the development of such roles, will take account of the implementation of the Community Healthcare Network governance and management requirements as outlined in the Healy Report.

In order to develop and deliver a broad range of dementia services and supports, the HSE will need to work with a variety of providers, including those from the community and voluntary sector. These providers will need to be supported to evaluate and further develop their services, basing development on identified good and best practice to ensure value for money and quality of care for people with dementia and their families.

Recommendation:

10. The ASI and other community providers to work with the NDO and HSE local services, taking a cohesive and collaborative approach to identify local service need and ensure greater utilization and integration of current resources.

This mapping project has provided baseline data only. There is a requirement now to look more closely at service quality and to also scope-out the potential for other community services not readily available. Deeper analysis is required for all services which have not undergone or are not undergoing evaluation or systematic review⁷ building and identifying best social care practice.

Recommendations:

11. NDO and ASI to identify the models and approaches being used in dementia-specific day-care; examining international best practice.
12. The NDO and ASI to explore the occupancy and attendance of day services, the quality of service as well as exploring and piloting alternative day models reflecting the changing regulatory environment.
13. Through the NDO's Post-diagnostic Support Pathway project, explore the potential to examine the existing Alzheimer Café model and delivery. Identifying where providers need additional support to successfully establish or run this service/support.
14. ASI to undertake a review and examine available evidence on the effectiveness of dementia social clubs and various support groups.

⁷ The ASI Dementia Adviser service is currently undergoing an independent evaluation. The ASI Cognitive Stimulation Therapy Programme underwent an evaluation in 2015. See <https://alzheimer.ie/About-Us/Research/Cognitive-Stimulation-Therapy-Evaluation.aspx>. Intensive Home Care Packages for People with Dementia are undergoing an extensive evaluation by Genio.

15. The NDO to support the development of a national network around the Assistive Technology libraries (now called Memory Technology Resource Rooms) which will support information and knowledge sharing/transfer and quality control.
16. The NDO, ASI and other key stakeholders to work to identify and deliver appropriate home care for people with dementia – one aspect of this is the two organisations’ involvement in the Centre for Economic and Social Supports in Dementia (NUI Galway) on the Applied Partnership Award titled ‘Resource Allocation, Priority Setting and Consensus in Dementia Care in Ireland’.
17. Both organisations, the HSE and the ASI, to examine the appropriateness of the current dementia-specific service response by undertaking a needs-analysis to identify the preferences of people with dementia and family carers.
18. Adequate resources to undertake evaluation of services needs to be budgeted for in future NDO and HSE annual budgets.
19. NDO and ASI to examine the challenges of the geographical spread of the services, particularly the unique challenges of accessing and providing services within rural communities.

Findings from the mapping project also shed light on the current pathway of care for people with dementia and family carers in the community.

Recommendation:

20. Findings from the mapping project to inform the development of a dementia care pathway as prioritized in the National Dementia Strategy and to influence future operational budgets of HSE CHO areas.

It was evident from the data that people aged under 65 living with dementia have little or no specialist services. Also not evident in the data were community-based dementia-specific services for people with intellectual disabilities. This also warrants further investigation as respondents identified for this study may not have had this expert knowledge. They also fell mainly within social care and a further exploration of primary care responses to dementia is needed.

Recommendations:

21. Undertake a mapping exercise to identify dementia-specific services for people with intellectual disabilities.
22. A strategic approach to the needs of people aged under 65 with dementia is required – a review of their service needs to be undertaken as a first step.

As stated above, the results of this mapping project were dependent on the quality of the data provided by identified stakeholders and there may be some gaps in the data where services were not reported.

Recommendations:

23. The NDO and ASI to meet with key personnel in each CHO area to update them on the findings and to further identify services which were not captured in the mapping project.
24. The NDO to verify all services three times a year to ensure information provided in the on-line service finder remains up-to-date.
25. A mechanism for people to send amended or updated information to the NDO on dementia-specific services to be developed through www.understandtogether.ie and through the NDO newsletter.

Not everyone requires a dementia-specific service and generic services maybe a more appropriate response for many. A phase two review of services and supports for people with dementia and dementia family carers is required to identify dementia-appropriate supports/services.

Recommendations:

26. The NDO to liaise with HSE personnel on the review of generic day care and respite services.
27. The NDO to take the lead on gathering information on dementia services provided in acute and residential settings, across primary care services, Intellectual disability services and by private providers.

Appendix 1: Survey Guidance Document

Can you offer any tips for completing the survey?

Based on feedback from the survey pilot, here are some tips that may help you complete the survey:

1. Prepare some information in advance:

The survey lists 20 **dementia specific** service categories. You will be asked to select the range of services available in your catchment area. For each service, you will be asked to enter how many of that specific service are available. The survey will then show you the exact number of contact information pages. So if you click two memory clinics, the contact page will show two times and request information for each of these two clinics.

2. Consider the information that will be required:

Keep in mind the service has to be **dementia specific**. The information required for each service includes a contact address, telephone number and other basic contact information. It also asks how many places (if applicable) are available for people with dementia and how many days per week or month the service is available.

3. Remember what is excluded:

The survey does not include:

- Nursing homes and / or Dementia specific units within residential care;
- Any non-dementia specific service that people with dementia use;
- Acute, regional or community hospital services;
- Private organisations that provide dementia specific services not funded by the HSE;
- Dementia-specific home care packages.

4. Staff from the Alzheimer Society of Ireland will provide all information on ASI services:

To avoid duplication, it has been agreed that staff from the Alzheimer Society of Ireland (ASI) will enter all information for services provided by the ASI.

5. Nominate a colleague(s) or staff member(s) who may be able to complete the survey in addition to you:

You will receive the survey via email. You cannot forward the survey as it is connected to your email address. However, you may wish to nominate a colleague(s) or staff person(s) to complete the survey in addition to you, or on your behalf. To do so, please send his/ her email address to mapping.project@alzheimer.ie and we can send the survey to them for completion.

6. Start and stop entering data as you please:

You can start the survey, leave the survey and return to it at any time. To do so, you must press NEXT at the end of the page you are stopping on in order to save that information. **National Dementia Specific Mapping Of Services Within The Nine HSE CHO Community Settings In Ireland: 2016** Survey guidance document. Simply close the tab in the usual way you close an internet page and the information is still saved once you had clicked NEXT. To return to the survey at any time press the Begin Survey tab at the bottom of the original email you received.

7. Remember to press NEXT each time you want to save information to the survey:

You must click NEXT at the end of each page to save data entered on that page. You can return to any page and edit data by clicking PREV. Remember; you must first always click NEXT to ensure that you save the data on any given page in the first place. Once you click DONE at the end of the survey, you can still return to the survey and check that you are satisfied with the information entered.

8. When you click DONE, we will receive the survey automatically:

Once you click DONE, we will automatically have the completed survey. However, as stated above, you can still edit it after you have clicked DONE until the deadline of the 9th of December. Please note that a message may show stating that 'you have already taken this survey'. This is a standard message and you are still able to edit what you have entered even when you have completed the survey.

9. You don't need to save the survey onto your computer:

The survey is connected to your email address so you do not need to save it to your own computer. You can always enter the survey through the original email and every time you click NEXT at the end of the page, the information is saved. You can still always edit information at any stage even after you have clicked NEXT.

10. The survey allows you to enter up to 10 services in each service category:

As stated above, on page 4 of the survey, you will see a list of dementia specific service categories. You will be asked which services exist in your catchment area. The survey is designed to allow you to enter up to 10 services in any of these categories. If you have more than ten services in a specific category, please contact mapping.project@alzheimer.ie and we will provide you with an additional survey link.

11. Start the survey as soon as possible:

You have two weeks to complete the survey. We advise that you open the survey as soon as possible. This will allow you to gauge the information you need to provide and allow you time to contact us and to nominate any other staff person(s) to help complete the survey.

Please return the completed survey by Friday 9th December 2016.

Frequently Asked Questions

What is this survey about?

This survey supports the implementation of the National Dementia Strategy. It is collecting baseline information on all community based **dementia specific** services in Ireland. The data collected will not only support people with dementia and their families in finding and availing of all relevant Dementia Specific Services within their area, but will also help the HSE to critically review health and social services, identifying gaps in existing provisions and to prioritize action areas.

Who is conducting this survey?

This survey is being conducted jointly by the Health Service Executive (HSE) and the Alzheimer Society of Ireland (ASI). In the correspondence you received from Michael Fitzgerald and Pat

McLoughlin on 25th November 2016, they outlined the importance of this survey for service planning.

Why am I being asked to complete this survey?

You have been identified as a key stakeholder with information on dementia specific services operating in your area. You can also nominate a colleague(s) to complete this survey, too. To do so, you can send their email address to mapping.project@alzheimer.ie

Why is it important to take part in this survey?

This survey will inform a directory of dementia specific services and allow a geographic mapping of services. It will also be used for service planning and identify gaps in the existing provisions and prioritise action areas. For this reason, it is imperative that we collect information for every county.

Is this survey easy to use?

Yes. We have piloted this survey with a selected number of HSE and ASI staff. The survey was revised based on feedback from this pilot in order to enhance accessibility and ease of use. It was also tested by researchers and other members of the Project Advisory Group.

How long will this take to complete?

This will depend on how many **dementia specific** services you need to enter and how much information you have to hand or have to source for each service. The survey requires contact addresses for each service so if you have 2 memory clinic services in your catchment area, the survey will request 2 addresses and other contact information for each of these 2 services.

Do I have to enter all the information requested?

The contact information is vital so that geographic maps can be generated for each county. For some services, the survey asks how many places are available for people with dementia and when is the service available. Please give an approximate answer but if you do not have the information then type NA.

Can I include other services utilised by people living with dementia?

No. The service must be **dementia specific**. A follow-on piece of research will capture the availability of wider services and integrated services.

What else is excluded?

The survey does not include:

- (i) Nursing homes and / or Dementia specific units within residential care;
- (ii) Any non-dementia specific service that people with dementia use;
- (iii) Acute, regional or community hospital services;
- (iv) Private organisations who provide dementia specific services not funded by the HSE; and
- (v) Dementia specific home care packages.

Is there support to complete this survey?

A member of the project team will make contact with you via telephone. However, you can contact the project team at any stage with questions. For technical queries contact mapping.project@alzheimer.ie and for all other queries contact 086 8091778.

Appendix 2: Members of the Advisory Group

- Ms. Mary Manning (HSE)
- Dr. John Linehan (HSE)
- Ms. Eilis Hession (HSE)
- Dr. Patricia Carney (NUIG)
- Prof. Eamon O'Shea (NUIG)
- Dr. Fiona Keogh (Genio)
- Mr. Pat McLoughlin (ASI)
- Ms. Anne Flynn (Family Carers Ireland)
- Dr. Emer Begley (HSE)

Appendix 3: Survey Letter of Invitation



RE: National Dementia Specific Mapping Of Services Within The Nine HSE CHO Community Settings In Ireland

Dear (Head of Social Care in CHO Area X),

I am writing to request your assistance in an important project currently being jointly undertaken by the HSE and The Alzheimer Society of Ireland. This project is a key follow-on from Ireland's first National Dementia Strategy (NDS), published in 2014. The successful implementation of one of the NDS's key priority areas, namely *Integrated Services, Supports and Care for People with Dementia and their Carers*, is dependent on the acquisition and collation of full information about the provision of dementia-specific services across the country. This information is currently largely unknown.

The *National Dementia Specific Mapping Of Services Within The Nine HSE CHO Community Settings In Ireland* Project aims to fill this information gap by establishing the current service mix of dementia specific services on offer at a particular point in time within the nine CHO areas. This will be achieved through the use of a national online questionnaire which will be used to gather information from key stakeholders who have knowledge of, or are delivering dementia specific services in their region.

The online questionnaire will be circulated by The Alzheimer Society of Ireland to the Heads of Social Care in each CHO area in November/December 2016 for completion and internal distribution within the HSE in each area to the relevant stakeholders.

The outcome of this project will be a beneficial overview of dementia specific services in Ireland, containing a complete service directory, local and regional service maps and service schedules and calendars. This will support the implementation of the NDS's key priority area *Integrated Services, Supports and Care for People with Dementia and their Carers* by ensuring accurate and complete information on how to access dementia specific resources is given to people with dementia and their families, and will allow the HSE to critically review health and social services for people with dementia to identify gaps in existing provision, and prioritize areas for action in accordance with resource availability.

As I'm sure you appreciate, this is a highly valuable endeavour, and your support in its successful delivery is greatly appreciated.

Yours Sincerely,

Michael Fitzgerald