



THE ALZHEIMER
SOCIETY *of* IRELAND

Clinicians Roundtable on the National Dementia Strategy Report



25th January 2013

Newman House, Dublin

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Introduction and Background

The Alzheimer Society of Ireland's Advocacy Work on the National Dementia Strategy

The Alzheimer Society of Ireland (ASI), as the leading advocacy organisation for people with dementia, believes that engaging with all the stakeholder groups is an essential element in our advocacy work to promote the delivery of a transformative National Dementia Strategy. As an organisation, ASI has already engaged with people with dementia, families, our staff and volunteers, other NGOs, allied patient organisations and politicians as part of its advocacy work in relation to the development of the NDS. We were aware that we had not engaged directly with clinicians in any dialogue around the dementia strategy. Therefore, we invited psychiatrists of later life, geriatricians, neurologists and psychologists to come together to share their expertise and discuss the core clinical elements of the National Dementia Strategy. The Dementia Services Information and Development Centre (DSIDC) actively supported the recruitment of the participants.

The primary aim of the Clinicians Roundtable was to engage clinicians in an open discussion around the forthcoming National Dementia Strategy. It was also envisaged that the Roundtable would highlight the ways in which the ASI could support clinicians, as a major stakeholder group, to be actively involved in the development of the strategy. By engaging in this process with the ASI, clinicians will have initiated a dialogue that will lead to a consistent and clear message in relation to the core clinical aspects of a National Dementia Strategy. Moreover, by adding the clinical voice, ASI is enhancing its own advocacy capacity on behalf of people with dementia, carers and their families.

Background to the National Dementia Strategy

There is commitment in the Programme for Government that the Irish Government will develop a Dementia Strategy in 2013. The Department of Health has undertaken a number of initiatives to progress the development of a Strategy. In July 2012, the Department of Health initiated a consultation process and invited interested parties to make submissions on their views of what should be contained in the forthcoming National Dementia Strategy. As part of this process, ASI made a comprehensive submission entitled "Reclaiming dementia; transforming the lives of people with dementia"¹. A brief analysis of the submissions made by the clinicians groups (Faculty of Old Age Psychiatry and the Irish Society of Physicians in Geriatric Medicine) reveals how consistent the messages are between the patient organisation and the clinicians. These include a call for supporting early diagnosis, the need for clinical leadership within the HSE, investment in dementia research, the need for baseline data and the development of a dementia register.

The next stage of the planning process as outlined by the Department of Health is to develop a terms of reference and appoint members to a working group. The terms of reference and the working Group will play a central role in the development of a progressive and successful Dementia Strategy. It will be critical that members of the working group have a consistent and clear message and one

¹ A copy of the ASI Dementia Strategy Submission can be accessed here <http://www.alzheimer.ie/Alzheimer/media/SiteMedia/The-Alzheimer-Society-of-Ireland-Submission-on-the-NDS-Aug-12.pdf>

way of facilitating this is to provide space for dialogue, discussion and an exchange of expertise between the key stakeholders within the dementia field.

Roundtable Structure

Participants at the Roundtable included healthcare professionals from four of the core clinical areas involved in the diagnosis and treatment of dementia, which included Old Age Psychiatry, Geriatric Medicine, Neurology and Psychology. Participants were invited to the Roundtable discussion to share expertise and discuss the core clinical elements of the National Dementia Strategy. Twenty seven clinicians participated in the Roundtable².

The Roundtable Discussion was structured around three thematic areas as follows³:

1. Clinical Leadership and Developing a Dementia Register
2. People with Younger Onset Dementia
3. Early Diagnosis and Memory Clinics/Services

Each thematic area formed the basis of a keynote presentation delivered by an invited clinician from three of the clinical areas represented. The presentation was followed by a fifteen minute group discussion. This allowed each participant an opportunity to input on the three different thematic areas during the course of the Roundtable.

Participants were then provided with the opportunity to choose from one of the three thematic areas to engage in a more lengthy and focused discussion on that particular theme. This allowed for more resolute and robust discussion guided by a number of core questions for consideration⁴.

The Roundtable concluded with a more general open group discussion among all participants of how clinicians can be facilitated to impact on the core clinical aspects of a National Dementia Strategy.

Notes were taken at each discussion group by ASI staff present on the day. The notes captured responses to the presentations as well as the lengthy and focused themed discussion. Feedback was also noted as well as general comments and suggestions at the open group discussion, which concluded the Roundtable. It was agreed that the notes would be collated into a report to document the format and content of discussion on the day.

² See Appendix 2 for an overview of participants.

³ See Appendix 1 for a more detailed overview of the agenda.

⁴ See Appendices 3,4,5 for an overview of questions.

Core clinical elements of the National Dementia Strategy

Theme 1: Clinical Leadership and Developing a Dementia Register

1.1 Presentation

Dr. David Robinson, Geriatrician, St. James's Hospital, gave an overview of the role of clinical leadership and the need for data collection as part of the development of the forthcoming National Dementia Strategy.

Dr. Robinson spoke about the need to mobilise existing resources rather than a need for more resources. He also noted that the access to primary care was good in Ireland but raised the question as to whether the expertise exists at this level for diagnosis given that people with dementia are dependent on GPs to diagnose.

Looking at clinical leadership, he noted the large number of HSE Clinical Care Programmes (CCP) already in existence and posed the question as to whether dementia needed to be a stand-alone CCP or embedded in another core programme. He touched briefly on the success of the Stroke Programme pointing to the dual role of leadership and accurate data collection as key elements. Dr. Robinson highlighted the lack of data and the role that a dementia register could play in this regard. He cited registers in other countries such as America, France, and the UK, whilst referring to the different ways in which the registers were developed.

1.2 Response to presentation

Following the presentation, a number of issues were discussed as follows:

- The need for a CCP for dementia patients with further discussion as to whether dementia merits a specific CCP or becomes embedded in another programme such as Older People or Primary Care.
- A CCP for dementia would need to have clear and achievable goals. Scotland was cited as an example of a region that was proactive on diagnostic rates.
- The challenge was identified of developing a CCP involving a range of diverse disciplines.
- The idea of a single phone number that all people diagnosed with dementia can call when they get a diagnosis that can gain them access to all required services.
- The success of the Stroke Programme was noted as a good sample to learn from. Key aspects of the success of this programme included strong clinical leadership and knowledgeable specialist clinical nurses. It was pointed out that the Stroke Programme is embedded in the Chronic Illness Programme.
- The need for a register and further discussion around the logistics of collating data and other logistical considerations such as staff and technology.
- The register would provide information on numbers and geographic locations of people with dementia and would allow for a more proactive capturing of data rather than a reliance on international comparisons. From a patient point of view it may quantify care needs, prevalence and incidence.
- A general discussion took place about the HSE Single Assessment Tool (SAT) and the role it could play in providing a common language between clinicians for the care of older people whilst supporting a database of dementia (SAT currently being trialled in Blanchardstown and South Tipperary).

1.3 Themed Group Discussion on Clinical Leadership and Dementia Register

The advantages and disadvantages of an embedded CCP or an individual CCP were discussed at length. Embedding a dementia CCP within an existing CCP may have its benefits. The difficulty with single CCP's is that there may be gaps in expertise and services due to lack of additional funds. If you work with an existing one, you can draw on their existing resources – and elect a chair from other unrepresented groups. Also if it was a standalone – it would require the crossover of so many multiple care pathways.

However, a stronger argument was made for the dementia CCP being an individual CCP due to the need for so many different disciplines. Dementia is so complex in its diagnosis and manifestations it could not fit appropriately in with another CCP. It needs to be cross speciality driven, not an age disease, and not embedded. It was suggested that a small group of clinicians need to collaborate and formulate a good business plan and take it to the National Director for Clinical Strategy and Programmes (Dr. Aine Carroll) for consideration. It was suggested that champions from the clinical professions involved need to come centre-stage to make this happen and to drive it.

A more general discussion ensued regarding the resources required for a dementia CCP, which included the need for two clinical leads. It was agreed that four areas of expertise were needed: Old Age Psychiatrists, Neurologists, Geriatricians, and Primary Care (GPs). An effective CCP would also need an integrated IT system that spans community services and feeds into memory clinics. Linking in with the Single Assessment Tool would be critical as is the role of administration support and community nurses. Key performance indicators need to be clear as was the case with the success of the Scottish model.

A dementia register is necessary to discover needs (equivalent of a national audit) related to medical care post diagnosis. It was acknowledged that diagnosis of dementia is made in so many different places that it would be a challenge to have everyone working together to ensure that there would be a fully operational and successful dementia register. However it was suggested that use be made of existing resources such as the Single Assessment Tool and to follow the examples set by prior successful CCPs such as the Stroke CCP. Also beginning is a national audit that may be useful to lay the foundations for a dementia register.

Further discussion took place with respect to the audit on dementia Care⁵. Within the ISPGM's⁶ submission for the National Dementia Strategy, they recommend early implementation of a National Audit on Dementia Care, similar to that undertaken in the UK, and mirroring the broad scope of the Irish National Audit of Stroke Care (hospitals use their own staff to collect data– and hired (Stroke) Nurse Specialists input the data).

⁵The Irish National Audit of Dementia (INAD) will be performed in all acute and orthopedic hospitals in the Republic of Ireland. This audit will be comprised of four parts: Hospital organisation; hospital chart review; ward organisation and ward environment. Further details available from the Centre for Gerontology and Rehabilitation in UCC at <http://www.ucc.ie/en/cgr/>

⁶ The Irish Society of Physicians in Geriatric Medicine

Theme 2: People with Younger Onset Dementia

2.1 Presentation

Dr. Siobhan Hutchinson, Neurologist, St. James's Hospital, gave an overview of the clinical issues for younger people presenting to health services with dementia. Dr. Hutchinson highlighted the complications with diagnosis but stressed that management of cases is more difficult than diagnosis. Once diagnosed with younger onset dementia (YOD), a person faces services and supports tailored for older people. Dr. Hutchinson posed the question as to whether 65 is an accurate marker as it is not a biological marker.

Dr. Hutchinson gave an overview of the numbers and demographics related to people presenting with younger onset dementia. She noted how patients are more likely to have multiple referrals to various clinicians before getting a diagnosis when compared to older counterparts. Dr. Hutchinson also highlighted how behavioural issues for early onset patients raised complex issues for support services. She suggested that case management was a clear area for development as was patient advocacy. Dr. Hutchinson also identified the care gap that presents for patients with dementia at a younger age as well as outlining other aspects characteristic of this group such as a reliance on community services as other clinical-based services are age dependent; employment and income issues; carers being more isolated and relationship breakdown.

2.2 Response to presentation

The presentation gave rise to a number of discussion points as follows:

- The inappropriateness of an age barrier for dementia services was discussed. Age barriers are based on practice and not the needs of people.
- The complex/multiple paths to getting a diagnosis for younger people, was highlighted.
- Geriatricians and old age psychiatrists would be good to manage multidisciplinary teams on dementia but an expertise gap arises with younger onset dementia and the need, in that regard, to engage neurologists.
- It was argued that there needs to be nationwide access to memory clinics for people with younger onset dementia (for example the MIRA clinic in James's does not have an age limit with regard to the people they see). However, it is important that there is specialist knowledge available for the more complex cases.
- A real shortage of specialist neuro-psychologists available to diagnose the more complex cases. There are very few available and they are only located in certain regions. Use of video technology for assessments was discussed.
- General discussion took place on care gaps for younger people with dementia and associated behavioural issues.
- There needs to be dedicated regional case management/nurse led services for people under the age of 65. However, this was questioned in a wider discussion of quality of services and stigma for older person services. It was suggested that rather than have ageist service division that services are revamped to be universally accessible.
- The need for joined up thinking across different clinical areas is essential in cases of YOD.
- It was noted that the number of people with younger onset dementia here is small (circa 8-10% of total dementia population) but that the needs were significant, usually complex and almost entirely unmet.
- The idea of "less tests, more care" was offered as a guiding value for developing services for this group of people with younger onset dementia.
- There is a real need for evidence-based psycho-social interventions to be developed.
- Must avoid inappropriate placement of people with YOD in long term care.

2.3 Themed Group Discussion on Younger Onset Dementia

A general discussion took place about the journey from diagnosis to end of life care and the need for co-ordination across various clinical areas. The debate between specialist services and embedding dementia services within primary care was a core aspect of the discussion with a focus on regional memory clinics feeding out to more generic services in the community. Diagnosis for younger onset dementia can be time-consuming and there cannot be specialist clinics everywhere. Clinics could have specialist nurses who link the regional clinic to patients in the community setting. The number of people with younger onset dementia is small per region so this could be feasible. Having a one-stop-shop for diagnosis and care would give GPs a contact point that saves multiple referrals.

The Brain Bank in Beaumont⁷ was also mentioned and it was agreed that people and families should be given information and made aware of the brain bank and what it offers in terms of a possible diagnosis after death and further benefit to other people when brains are then used for research purposes.

Other diseases have a direct link between diagnosis and care teams so that a person diagnosed with cancer will be introduced to other care professionals like social workers etc. However, younger people with dementia are diagnosed and there is no case management in place to ensure other care professionals are engaged. Early diagnosis is the key. A model was suggested of case management, operated regionally, with an outreach aspect central to continued care.

If there are a small number of regional specialist diagnostic clinics then waiting lists for neurologists is not as much an issue. Cross referral system between clinicians is critical to working well informally. This could be formalised with a multi-disciplinary team who could in turn address the major issue as to who takes case management responsibility once a person is diagnosed. A resource manager could act as a link between different services and a case manager. GP education was also discussed with respect to diagnosis.

People with dementia and their families need to know who is who in the care team and care plan. A number of specific cases were discussed, which highlighted the difficult issues that present with younger people with dementia.

A brief discussion took place regarding the CCP and the impact on younger people with dementia with the point being made that embedding dementia within the Older Persons CCP could have a negative impact on care developments for younger people with dementia.

Good examples of services being tailored to age include UK services where day centres are younger person orientated with a greater focus on activity.

It was agreed that although existing services could be better utilised and/or adapted to address needs of younger onset dementia patients, additional resources would be needed for respite or day facilitates that are tailored for a younger age group.

⁷ Further information available on the Brain Bank at <http://www.beaumont.ie/index.jsp?p=103&n=142&a=190>

3.1 Presentation

Dr. Henry O'Connell, Psychiatrist of Later Life, Laois-Offaly Mental Health Services, gave an overview of the submission to the National Dementia Strategy by the Faculty of Old Age Psychiatry. Dr. O'Connell also included references to an expert policy paper⁸ that wrote for ASI on the National Dementia Strategy

Dr O'Connell stressed that the National Dementia Strategy ideally should address dementia at all stages, from prevention and early detection right through to treatment and support for diagnosed dementia, research into future treatments and palliative care. He maintained that the key principles to underpin a National Dementia Strategy should include increased emphasis on prevention, early diagnosis and access to the best available treatments and social supports.

Dr. O'Connell highlighted the need to include the voice of the person with dementia noting how they may be less interested in the clinical elements of the strategy and more interested in developing everyday supports for themselves and their families, such as adequate home-care, respite care and access to long-term care.

Dr. O'Connell also highlighted core clinical aspects underpinning successful dementia strategies in other countries before concluding with a list of what should be in a National Dementia Strategy for Ireland.

3.2 Response to presentation

- The Assisted Decision Making Bill that is due to be published early this year was noted as being significant. It is unacceptable that in this day and age people with dementia are still legislated for as a Ward of Court under the Lunacy Act which is over 140 years old.
- GP training and support was highlighted with participants articulating the need to engage primary care whilst being aware of the increasing pressures on GPs.
- There needs to be further education on encephalopathy (disease of the brain) for correct diagnosis. Diagnosis is often so difficult; memory clinics need full teams to decipher all symptoms and clues.
- Hospital experiences for people with dementia was discussed and the need for training for hospital staff.
- The role of memory clinics was debated with some arguing for a more central role for memory clinics and other participants making an argument for a more phased role for memory clinics embedded in other service developments. A general discussion developed as to specialist services versus general services and the need to embed specialist services like memory clinics within primary care services and a care pathway more generally.
- The environment/place where people are assessed is an important factor in diagnosis hence the need for discussion around services that can respond to the development of the disease rather than specialising in assessment.
- A note was made that service development should be bottom up and not top down so that way dementia becomes like any other disease and is not seen as a specialist area.
- Greater awareness and education around polypharmacy is needed.

⁸ Policy paper available from the ASI website

<http://www.alzheimer.ie/Alzheimer/media/SiteMedia/ImageSlider/Fixed/National-Dementia-Strategy-for-Ireland.pdf>

3.2 Themed Group Discussion on Early Diagnosis and Memory Clinic/Services

The discussion highlighted that it is not necessary to refer all patients with suspected dementia to memory clinics; local services should be able to meet that need. However, there is a role for them to diagnose the more complex and atypical cases and there should be regional access to this type of specialised service where they can be offered the more intensive time and expertise than a de facto intermediate service.

People spoke about the diverging roles of memory clinics and what should a memory clinic or service do. People said memory clinics should be a place where people can:

- Receive a diagnosis
- Access the appropriate treatment (medication)
- Possibly identify the cause of their symptoms
- Engage in care planning for the future
- Receive recommendations to access other appropriate services
- Gain access to information
- Get clarification of another diagnosis

There is a role for a clinical nurse specialist in Memory Clinics that would manage more of the post diagnostic care by linking people up to services e.g. counselling, ASI services etc. People do not need an extensive amount of clinical input post diagnosis but they do need support to access the appropriate services for them and their family in the community.

There was a long discussion about the need to extend and improve primary health care services. The Community Mental Health Nurse model needs to be extended and incorporate more people with dementia. Often people are living with dementia in the community and they and their families are in complete isolation until a crisis arises where they need extra support. One of the participants remarked that “the carers who care are abandoned”.

It was suggested that in many cases the clinical service provided is crisis driven and as a result it is very reactive. Families are given very little understanding about the journey of dementia so if a person has an episode of delirium they do not know what to do or they may be unprepared. It was agreed that GPs and families both need more training in dementia care. The routine visits from the Public Health Nurse in the community can be useful but they too need to have the dementia specific knowledge.

A number of people referred to their outpatient service and how valuable people find this. It provides people diagnosed with dementia with a sense of reassurance as they may hear that they are doing well. Therefore, it is very useful to keep in touch with people following diagnosis.

Overall, it was felt that there needs to be a single point of entry to services so that people are not diverted all over the place before they get the help and support they need. The primary care pathway needs to be clearer in general as even consultants working in the system find it difficult to navigate.

GPs need more information and communication about dementia services; they often do not know who to refer people to or where to go. However, it was agreed that there is often a sense of apathy and nihilism when it comes to GPs treating their patients with dementia. Someone mentioned the system that they have in Scotland where there is a payment linked to diagnosis with the GPs. There has been strong emphasis on the diagnosis of diabetes as people have been incentivised to diagnose.

Although there is a need for a proactive approach from GPs around referring people to memory clinics, there is also a need to manage people's expectations when they come into a service. Often people do not want to be there because of what they may be told or alternatively they may have very high expectations about the service the memory clinics can deliver. Memory Clinics need to give a clearer message through their information (websites, leaflets etc) about what they do and do not do.

In many cases it is very difficult for the health care professionals to identify regional memory clinics as there is no standardised way of identifying and promoting themselves. Consultants need to raise more awareness about their roles in dementia care. There were a couple of outlets for this mentioned including GP Buddy; Healthlink; Health Matters HSE Magazine, the Royal College of Surgeons and the Irish College of General Practitioners.

The question was asked as to whether there is a network of memory clinics and if there is not there should be one that drives their standards and quality. They could each learn from each other about the work they are undertaking.

Summary of key points

The following table summarises the key issues raised by participants in response to the three thematic areas presented at the Roundtable discussion.

Table 1: Key points discussed by Roundtable Participants

Topic	Summary
Clinical Leadership	<ul style="list-style-type: none"> • A Clinical Care Programme (CCP) for dementia needs to be agreed and a business plan developed, with dual clinical leads appointed • Approach the National Clinical Lead for CCPs with a business plan • Analyse other successful CCPs to identify a model of best practice • Performance indicators need to be developed in tandem with CCP
Dementia Register	<ul style="list-style-type: none"> • Dementia register is essential for collation of core data for future service and care planning; understanding of demographics of dementia population • Development of a dementia register could draw on existing / forthcoming resources: National Audit on Dementia and the HSE Single Assessment Tool
Younger Onset Dementia	<ul style="list-style-type: none"> • The establishment of multidisciplinary teams involving geriatricians, old age psychiatrists and neurologists to respond to YOD cases and accept under 65 referrals, with links to memory clinics where necessary • Greater focus needed on early diagnosis and clear care pathways • Additional resources needed to develop age appropriate services • Regional nurse-led case managers are needed to support the person to navigate the system in terms of diagnosis and care supports
Early Diagnosis	<ul style="list-style-type: none"> • Focus should be on early diagnosis, with post-diagnostic and early intervention supports made available • Role of research and Brain Bank critical here • GPs need to be resourced to diagnose and treat people with dementia at the primary care level and to refer to specialists if necessary • Red flag system is needed for unusual diagnosis • Community/social model of care needed in addition to clinical care
Memory Clinics/ Services	<ul style="list-style-type: none"> • Care pathway needs to be clearly defined and resourced using a case management approach • GPs need training in the diagnosis and management of the person with dementia to include information and communication about dementia services including the specialists • Develop capacity at primary care level to address dementia in a community setting • Outpatient clinic plays an important role for continued contact with people after diagnosis • Dementia care does not need to be confined to specialised centres such as memory clinics • A network of memory clinics is needed and a standardised model of practice is needed across all clinics

Clinicians influencing the development of the National Dementia Strategy

The following suggestions were made regarding moving forward on the issues discussed at the Roundtable. In addition, participants also discussed ways in which ASI could facilitate clinicians to play an active role in developing the forthcoming National Dementia Strategy.

Table 2: Summary of further actions

Suggestions
<ul style="list-style-type: none"> • Explore how to utilise the planned National Audit on Dementia and the Single Assessment Tool to develop a Dementia Register.
<ul style="list-style-type: none"> • A small clinicians group to be facilitated by ASI to come together to examine the various aspects of a CCP for dementia, develop a business plan and make proposal to the CCP.
<ul style="list-style-type: none"> • Some research around other successful CCP such as the stroke programme should be undertaken.
<ul style="list-style-type: none"> • Roundtable discussion to be held for other key clinicians involved in the care of people with dementia.
<ul style="list-style-type: none"> • Engage GPs in dialogue, training and ongoing education in relation to diagnosing and managing the person with dementia in the community.
<ul style="list-style-type: none"> • The need to balance specialist and general support services so that a community approach to dementia care is included in further dialogue and discussions.
<ul style="list-style-type: none"> • There is a need to influence the political agenda in relation to the upcoming National Dementia Strategy. In particular, there is a need for ASI to have very strong, bold messages and branding in relation to the dementia agenda. The Alzheimer Australia example was cited. This discussion included reference to how we need to engage with the wider ageing sector and make it a wider civil society issue.
<ul style="list-style-type: none"> • Key clinical and other leaders (champions) need to “champion” the dementia agenda in the public and political arenas. The example of the English government’s dementia champions programme was cited.
<ul style="list-style-type: none"> • Opportunities for influencing the research agenda must be taken advantage of such as the Horizon 2020 Programme, which is EU funding for science research. There is a need to influence the MEPs in relation to the spending on research in order to prioritise investment in dementia research on a pan European basis.
<ul style="list-style-type: none"> • There needs to be a strong push for an Ombudsman for vulnerable adults. This is significant with the decision making bill due to be published.
<ul style="list-style-type: none"> • The Roundtable could be a useful tool for building the capacity of clinicians to be key influencers and advocates for dementia care. The roundtable is also a place where clinicians could feed into the emerging National Dementia Strategy. Engaging with Professor Alistair Burns, the Clinical Director for Dementia in England to learn from their experience and build collaboration to in turn enable a coherent and unified clinical input to the Irish Dementia Strategy.
<ul style="list-style-type: none"> • The report generated by the Roundtable will be a critical political advocacy tool for ASI. It will be circulated to politicians and other stakeholders with a view to influencing the terms of reference for the forthcoming Dementia Strategy.
<ul style="list-style-type: none"> • ASI to consider the development of a Medical Advisory Committee as part of the structure of the organisation.

Appendix 1

Agenda

Clinicians Roundtable on the National Dementia Strategy

25th January 2013

Agenda

09:30 - 10.00	<i>Arrival and refreshments</i>
10:00-10:10	Welcome and overview, Maurice O'Connell, CEO The Alzheimer Society
10:10 – 10:20	<u>Theme 1: Clinical Leadership and Developing a Dementia Register</u> Dr. David Robinson , Geriatrician, St. James's Hospital
10:20- 10:35	Group response and feedback
10:35 – 10:45	<u>Theme 2: People with Younger Onset Dementia</u> Dr. Siobhan Hutchinson , Neurologist, St. James's Hospital
10:45-11:00	Group response and feedback
11:00-11:10	<u>Theme 3: Early Diagnosis and Memory Clinics/Services</u> Dr. Henry O'Connell , Psychiatrist of Later Life Laois-Offaly Mental Health Services
11:10 – 11:25	Group response and feedback
11.25-11.35	<i>Break for refreshments</i>
11:35 – 12:30	Core clinical elements of the National Dementia Strategy Further discussion and reflection on the thematic areas feedback
12:30 – 12:50	How clinicians can influence the development of the National Dementia Strategy Next steps Role of The Alzheimer Society of Ireland?
12:50- 13.00	Final remarks, Maurice O'Connell, CEO The Alzheimer Society of Ireland
13.00	<i>LUNCH</i>

Appendix 2

List of Participants

Title	Name	Surname	Role	Location
Dr	Avril	Beirne	Geriatrician	St James's Hospital
Dr	Kate	Bielinski	Old Age Psychiatrist	Locum
Dr	Alberto	Blanco	Neuropsychologist	HSE North Eastern Area - Meath
Dr	Robert	Coen	Neuropsychologist	St James's Hospital
Dr	Catriona	Crowe	Old Age Psychiatrist	South Tipperary
Dr	Conal	Cunningham	Geriatrician	St James's Hospital
Dr	Aishling	Denihan	Old Age Psychiatrist	HSE North Eastern Area - Meath
Dr	Colin	Gallagher	Senior Clinical Psychologist	St. John of God Hospital
Mr	Matthew	Gibb	Acting Director	DSIDC
Dr	Jeanette	Golden	Old Age Psychiatrist	St James's Hospital
Dr	Elaine	Greene	Old Age Psychiatrist	St James's Hospital
Dr	Nola	Greene	Old Age Psychiatrist	Locum - Tallaght Hospital
Dr	Odile	Hally	Old Age Psychiatrist	North Dublin Mental Health Service
Dr	Siobhan	Hutchinson	Neurologist	St James's Hospital
Dr	Sean	Kennelly	Physician in Geriatric and General Medicine	Tallaght Hospital
Prof	Brian	Lawlor	Old Age Psychiatrist	St James's Hospital
Prof	Tim	Lynch	Neurologist	Mater Hospital
Dr	Geraldine	McCarthy	Old Age Psychiatrist	Sligo/Leitrim Mental Health Service
Dr	Mia	McLaughlin	Old Age Psychiatrist	St Luke's Hospital, Kilkenny
Prof	Declan	McLoughlin	Old Age Psychiatrist	St Patrick's University Hospital
Dr	Anne Marie	McMahon	Psychologist	St John of God Hospital
Dr	Siobhan	Ni Bhrian	Old Age Psychiatrist	Tallaght Hospital
Dr	Henry	O'Connell	Old Age Psychiatrist	Laois/Offaly
Prof	Des	O'Neill	Geriatrician	Tallaght Hospital
Dr	David	Robinson	Geriatrician	St James's Hospital
Dr	Eileen	Sweeney	Old Age Psychiatrist (Registrar)	St James's Hospital
Dr	Siobhan	Kennelly	Geriatrician	Connolly Hospital

Appendix 3

Theme 1 Group Discussion Questions

Theme 1: Clinical Leadership and Developing a Dementia Register

Clinical Leadership

What do you see as the advantages and the disadvantages in terms of developing a clinical care programme/clinical directorate for dementia?

What type of resources would be needed to make the clinical care programme/directorate effective?

Dementia Register

What are the opportunities and challenges to developing a national dementia register? (Any good practice examples from other disease areas in Ireland or elsewhere)

What are the first steps to getting a dementia register in place and who are the stakeholders that need to be involved?

Appendix 4

Theme 2 Group Discussion Questions

Theme 2: People with Younger Onset Dementia

Within which clinical area should people with younger onset dementia be located?

What needs to happen to improve the patient journey from assessment, diagnosis, treatment and social supports for people impacted by younger onset dementia?

What are the resource and capacity issues within the health care system (primary care, community services, acute hospitals, specialists) that need to be addressed in order to deliver a service to people with younger onset dementia?

Appendix 5

Theme 3 Group Discussion Questions

Theme 3: Early Diagnosis and Memory Services/Clinics

What is needed within the GP and specialists clinical settings to promote early diagnosis?

What do you see as the “core” and “potential” functions of a memory clinic/service? (Identifying good practice models operating in practice)

Should there be tertiary level, regional memory clinics for the more complex cases, similar to the cancer care model in Ireland?