

NATIONAL STRATEGY ON DEMENTIA

SUMMARY OF CONSULTATION PROCESS

Please Note –

The Views & Comments contained in this summary report are derived from written submissions received following a call for submissions to inform the development of a National Strategy on Dementia. They do not necessarily concur with those of the Minister for Health, the Minister of State for Disability, Equality, Mental Health and Older People, nor officials of the Office for Older People at the Department of Health.

INDEX

	Page(s)
Introduction	3-5
Executive Summary	5-7
Analysis	8-28
Index of submissions	29
Appendix (Questionnaire)	30-31

NATIONAL STRATEGY ON DEMENTIA

INTRODUCTION

The Programme for Government gives a commitment to develop a *National Strategy on Dementia* by 2013 which will increase awareness, ensure early diagnosis and intervention, and enhance community based services for people living with this condition.

The first stage of the process was to assemble the research and evidence upon which the strategy will be developed. This was completed in 2012 and the report of the findings *Creating Excellence in Dementia Care: a Research Review for Ireland's National Dementia Strategy* (Research Review) was published. A guide for the general public, *Future Dementia Care in Ireland: Sharing the Evidence to Mobilise Action* was compiled to disseminate the report's findings and to give a better understanding of dementia. Both the report and the guide are available at www.doh.ie.

Among the key elements arising from the research which need to be considered in light of the strategy are:

- Enhancing public awareness about dementia
- Increasing the numbers of early diagnoses
- Measures to improve quality of life and quality of care for those with dementia

This was followed by a public consultation process which commenced on 4 July and concluding on 31 August 2012.

Methodology

A notice was placed in the national media and on the Department's website inviting submissions from interested parties, whether individuals or organisations, to help inform the development of the strategy. People were also invited to participate in the process by completing a questionnaire. The questionnaire was developed on the basis of the Research Review findings (see appendix).

Submissions were received either by post or via a dedicated e-mail address as set up by the by the Department.

A total of 73 responses were submitted to the Department. 36 of these responded by completing the questionnaire, 1 response highlighted an article published in *The Irish Journal of Psychology* and the remaining 36 provided written submissions. These submissions ranged in length from very short e-mails to one submission that was almost 80 pages long (including appendices).

This summary document captures the core messages conveyed from both the completed questionnaires and the submissions.

Following on from this process a working group will be established to develop the strategy in 2013.

Acknowledgement

The Department of Health would like to thank all of the respondents to the consultation process, whose valuable contribution made this report possible.

While no individual identified themselves as suffering with dementia, the range of responses from carers & family members, to health care professionals, representative bodies and advocacy agencies is welcome. In particular the Department would like to acknowledge the contributions from family members and carers who discussed their personal experiences of caring for people living with dementia.

EXECUTIVE SUMMARY

Summary of Main Findings

The majority of respondents broadly welcomed the research report, *Creating Excellence in Dementia Care: A Research Review for Ireland's National Strategy* (Cahill et al, 2012). In fact it is worth noting that 25% of responses reflected that it was difficult to prioritise any one of the core elements identified in the report.

One respondent welcomed the “*opportunity that the National Dementia Strategy presents to provide evidence based guidance and strategic direction to enhance dementia services that are fit for such purposes and promote quality of life and quality of care*”.

Key themes from the responses emphasise the need for a Government commitment to provide sufficient funding & resources. One respondent said “*the beginning and end of this Strategy is, and always will be predicated on funding*”. Indeed adequate resources and funding featured in several responses under the various headings with recommendations for dementia to be acknowledged as a national priority.

Having regard to the guidance put forward in the research review the questionnaire identified 7 key headings as follows;

Awareness

Both primary prevention and addressing public awareness featured significantly in submissions. Respondents felt that the issue of stigmatisation should be challenged and highlighted the need for more information about dementia itself and what services are available. A number of respondents also pointed to the need to highlight that many of the risk factors for dementia are the same as those which increase the risk of cardiovascular disease, such as poor diet, smoking, excess alcohol consumption and physical inactivity.

Early Diagnosis and Intervention

There was a general consensus that early diagnosis is essential in ensuring timely interventions. Respondents highlighted the need for developing a structured and standardised education programme for health professionals. A number of respondents stressed the need for systems, structures and age appropriate services to ensure early diagnosis among people experiencing early onset dementia, including people with Down syndrome.

Community Based Services

A number of respondents identified dedicated and flexible community-based services (supported by local multidisciplinary dementia care teams) as a priority to enable individuals to remain in their own home for as long as possible. Respondents highlighted the need for more information on what services were available and how people could access them. In addition a number of respondents felt strongly about pressures families and carers face on a daily basis and stressed the need for supports to avoid “burn out”.

Long Stay-Residential Care

It was generally recognised in the submissions that on-going development, education and training (in particular with regards to effective psychosocial supports) for all staff caring for residents with dementia was vital in the delivery of quality person-centred care.

Acute Care

Respondents highlighted the challenges and difficulties experienced by people with dementia in hospitals. The core message coming through a number of the submissions was that people want a service similar to the “Hospice Friendly Hospitals”. Respondents recommended the introduction of a dementia champion initiative and identified a need for increased staff awareness.

Community/Long-Stay Residential Care/Acute

In general respondents felt that *“quality case management and integrated care is and should be at the core of all dementia care regardless of setting.”* Respondents felt that an integrated care approach between all services is vital to deliver effective, efficient and person centred care pathways and that, in particular, a case worker should coordinate all services.

Research

Respondents identified research and evidence as a priority for service planning, provision and future costings.

Conclusion

Finally, and most importantly, it must be acknowledged that the key message emerging from this consultation was the need to place the person with dementia, irrespective of settings, at the centre of service planning and in particular decision making processes about all aspects of their lives. In this regard a recurring theme throughout the submissions highlighted the need for increased awareness and enhanced training for health professionals in all settings.

The following summary table was prepared following a review of the responses to both the questionnaire and submissions.

	HEADINGS	SUB-HEADINGS	% WHO IDENTIFIED AS A PRIORITY
1	Awareness	Primary Prevention and ways of avoiding or delaying the illness	38%
		Public Awareness about dementia	38%
2	Early diagnosis and intervention	Early diagnosis	51%
		Specific training in dementia for health care professionals	33%
		Appropriate services for people with early-onset dementia, including people with Down syndrome	12%
3	Community-based services	Dedicated and flexible community based services	51%
4	Long-stay residential care	Psychosocial approaches to complement existing medical and neurological models of service delivery	18%
		Dementia-specific residential care units	18%
5	Acute Care	Awareness, ownership and leadership of dementia in acute hospitals	23%
6	Community/Acute/Long Stay residential care	Case management models of integrated care	16%
		End of life care services for people with dementia	18%
7	Research	Information systems on the number of people with dementia, severity of disease, placement patterns and quality of life	36%
	All of the above	All of the above	25%

Question A

What is your particular interest in/experience of dementia, e.g. health-care professional/ diagnosed with dementia/ caring for someone with dementia?

Submissions

Respondents ranged from carers, health professionals, academics, researchers, service providers, regulator, professional and representative bodies. Some respondents covered more than one category – ie. health care professional & family carer. No individual identified themselves as having dementia.

Question B

The Research Review, *Creating Excellence in Dementia Care: A Research Review for Ireland's National Strategy* provided the following guidelines as to the future direction of public policy for dementia in Ireland covering:

- greater emphasis on prevention, particularly in relation to heart disease and stroke
- increased public awareness about dementia
- increase in early diagnosis through improving access to memory clinics and enhanced training and education for primary care workers, especially for general practitioners and nurses development of a case management model of integrated care
- expansion of dedicated community-based services, for example, day care services, for people with dementia and their carers
- development of new and expanded psychosocial approaches to complement existing
- medical and neurological models of service delivery in the community and in residential care units
- development of small-scale, appropriately designed, residential care units
- development of appropriate services for people with early-onset dementia, including people
- enhanced information systems on the number of people with dementia, severity of the disease, placement patterns and quality of life.

Of the areas outlined, what should the main priorities for the Strategy be?

Responses

At the outset it must be acknowledged that some 25% of respondents did not wish to place significance on any one of the areas identified above the others, rather a comprehensive strategy should include all the elements outlined in the review without exclusion.

1. Awareness

The Research Review concluded that there was a general lack of awareness in the minds of the public and policymakers when it comes to priority-setting and the allocation of scarce public resources in relation to dementia. The review highlighted that other countries had developed action plans that addressed what needs to be done in relation to primary prevention, changing private and public attitudes to the disease and training and education.

Responses

- **38% of responses identified that primary prevention and ways of avoiding or delaying the illness as a priority.**

A number of submissions highlighted that many of the risk factors for dementia are the same as those which increase the risk of cardiovascular disease - poor diet, smoking, excess alcohol consumption and physical activity. One submission noted *“the importance of **primary prevention** of dementia must be stressed. For example, management of established risk factors for dementia, such as vascular risk factors, depression and social isolation are likely to help prevent the development or worsening of cognitive impairment and dementia.”* It was also asserted that physical activity has been shown to have the potential to reduce the risk of or delay the onset of dementia.

- **38% of responses also identified public awareness about dementia as a priority.**

Submissions highlighted that research has shown that components of stigma - discrimination, devaluation and stereotyping are clearly apparent in the daily lives of persons with dementia - *“de-stigmatising dementia is essential to ensure those living with dementia in the community are diagnosed but this must be accompanied by clear referral pathways to timely and appropriate diagnostic services.”*

In particular respondents suggested that greater public awareness about the disease would address the stigmatisation associated with the illness, identifying a need for *“greater public awareness to reduce stigma, isolation and anxiety felt by family members and people with dementia.”*

Some submissions highlighted that greater public awareness would normalise the illness, encourage people to seek a diagnosis and enable people to remain more involved in the community for longer.

One respondent noted that the prioritisation of areas for the strategy should be balanced and reflect where the greatest outcomes could be achieved, given the current fiscal and economic climate. In this regard greater public and professional awareness of: the onset and condition, the health and social needs of people with dementia and the interventions available to this population is paramount for a future strategy.

Finally, there was a recommendation that there is a need for more information to be disseminated regarding “living wills, power of attorney and end-of life decisions.”

Some examples of what you said;

“Family members can be slow to seek help because symptoms may be ignored, brushed aside, misunderstood, even ridiculed. Hence valuable time may be lost both for the sufferer and for family carers.”

“Communication should challenge the misconception that dementia is a normal part of the ageing process”

“Health promotion initiatives aimed at increasing awareness & developing models for primary prevention /delayed onset is central to overall strategy.

“Public awareness of the importance of lifestyle modification in relation to prevention of cardiovascular disease and cancer is high. However the important role that modifiable cardiovascular risk factors play in the prevention of dementia has not entered the public consciousness and needs to be highlighted.”

“Health promotion aims to build public policies that sustain health, create supportive environments, strengthen community action, develop personal skills and reorient health services, especially toward partnerships with the community.”

“Physiotherapy is an integral part of the management of dementia both for people with dementia and for their carers and should be recognised as such in the forthcoming strategy.”

2. Early diagnosis and intervention

The Research review concluded that there is convincing evidence that early and accurate diagnosis through improving access to memory clinics and enhanced multidisciplinary training and education in dementia is critical to best practice in dementia care. The review also identified a need for appropriate services for people with early onset dementia, including people with Down syndrome.

Responses

- **51% of responses identified early diagnosis as a priority issue.**

There was a general consensus that early diagnosis is essential for ensuring timely interventions. It was proposed that early diagnosis is something that the majority of people with dementia would want and that it gives individuals the time needed to come to terms with the diagnosis, to plan for the future and begin to access appropriate and available services. One respondent described how the experience of people with dementia and their families “is echoed” by people with other neurological conditions in terms of lengthy periods to obtain a diagnosis and lack of expertise and incentives at primary care level.

Respondents identified the important role served by memory clinics in diagnosing and supporting those with dementia. One submission suggested that an early diagnosis of dementia followed by relevant information and support may reduce outpatient costs by almost 30%.

While strongly endorsing the research review one respondent was more cautious on this issue. Unlike a number of respondents who championed the advantages of early diagnosis in contrast this submission aired some reservations by noting that “*early diagnosis is not always an uncomplicated good thing. Like almost every other intervention in healthcare it will depend on the individual’s preference and will involve benefits and potential hazards.*” In this context it was considered important that the Strategy approached the issue of early diagnosis “*in a balanced and nuanced manner.*”

- **33% of responses identified specific training in dementia for health care professionals as a priority issue.**

It should be noted that enhanced training/professional development was a cross-cutting issue featuring across all the headings.

A number of respondents felt that a dementia strategy should provide for the development of a structured and standardised education programme for all professionals- “*nationally co-ordinated, accessible and frequently occurring training programmes should be available for all health professionals to improve understanding of the needs of people with dementia as well as promoting early recognition of symptoms.*”

- **12% of responses identified the need for appropriate services for people with early - onset dementia, including people with Down syndrome as a priority.**

Respondents felt that the provision of services should be equitable across the country, based on need and not contingent on which client group people belong to. One respondent stated that *“the dilemma of who cares for people under 65 years of age with a diagnosis of dementia needs to be urgently addressed – age should not be a barrier – a person centred approach to care is essential.”*

For example it was noted that people with Down syndrome who go on to develop dementia have unique needs which are best catered for by collaboration between intellectual disability services and older people services.

Finally the establishment of at least one dedicated respite facility for younger people with dementia was recommended.

Some examples of what you said;

“...a multi-pronged approach to the detection of dementia is preferable with diagnosis occurring in primary and secondary care services and memory clinics. A specialist memory clinic should be available in every HSE area and each clinic should have the services of a full multidisciplinary team.”

“Early detection requires a high index of suspicion, use of screening tools and enhancement of current training for GPs at specialist and continuing professional development level.”

“This is in fact rare as the disease process is well established usually prior to diagnosis.”

“Screening at the primary care level should use a validated protocol. Further screening at the secondary level would be more sophisticated, including interpretation by a professionally recognized Psychologist with specialist competency in the Neuropsychological assessment of dementia”

“...health and social care programmes, at all levels, incorporate knowledge and skills training about dementia paying particular attention to diagnosis, prognosis and application of the palliative care approach when caring for people with dementia and their families.”

“it is pivotal that knowledge and understanding of dementia and approaches to person centred should be a component of all undergraduate health and social care programmes.”

“ People with early onset dementia are currently not eligible to be seen by the specialist Old Age Psychiatry team due to the fact that they are under 65”

3. Community-based services

The Research Review concluded that community support services for people with dementia and their carers are under-developed and fragmented in this country. It further suggested that the baseline profile of community services is low and only a small proportion of people with dementia are known to service providers.

Responses

- 51% of respondents identified community based services as a priority issue.

People want to remain in their own community for as long as possible and the respondents identified dedicated and flexible community services as pivotal in achieving this. It was suggested that services should be age appropriate.

Respondents felt that it was important to receive information on what services are available and a number of respondents proposed that a “key worker/champion/team” would be a vital resource for both the community, residential and acute settings- *“knowing what and who is available to help... thus helping to avoid delays in necessary interventions.”*

It was also proposed that that services, in particular, respite in the home, need to be available on 24 hour basis.

A number of submissions called for better recognition of carers given the financial, physical, emotional and mental challenges they faced on a daily basis.

One submission noted that initiatives such as the Alzheimer’s Café and the Genio Dementia projects should be embraced and expanded to provide crucial supports to those living with dementia.

It was also proposed that the overall framework for access and delivery of health care services should be Dementia Friendly and there was a recommendation to support the development of Dementia Friendly Communities to adapt our neighbourhoods and mainstream services to ensure they provide supportive living spaces for people with dementia to remain engaged and included.

The need for legislation to underpin access to community services was highlighted on a number of occasions.

However, it was also cautioned that while *“reconfiguring services with increased emphasis on community care will in some way alleviate the pressure for increased resources in the economic climate, however the demographic projections are such that a more radical restructuring may be required with less emphasis on medical models of care (which are resource heavy) and more on psychosocial models which*

utilise dementia trained staff (non-professionals) which will be more cost effective and still meet the needs of people with dementia and family carers.”

Some examples of what you said;

“We found it most beneficial to keep our relatives at home for as long as possible, where familiarity and comfort was at its greatest, which kept distress and disorientation at a minimum.”

“...care should be taken to avoid unnecessary and inappropriate hospital admissions. A range of community support services are needed which are available day and night. The identification of a ‘key worker’ who would be responsible for the management of care through the disease from diagnosis would alleviate a considerable amount of concern for the person with dementia and their family. The key worker would ensure both continuity of care and access to services”.

“primary health care teams should play a major role in assessment and screening for mental illness (including dementia) in older people and should work in a coordinated and integrated manner with the specialist team to provide high quality care, particularly care that is provided at home”

“we see the task of the strategy as being more than just services but also about harnessing community goodwill and resources.... .in other words normalise the involvement of people with dementia in the everyday life of communities so they become dementia friendly...”.

4. Long-stay residential care

The Research Review estimated that there are currently 14,000 people with dementia living in residential long-stay settings. It concluded that most residents with dementia are living in generic settings, living with other residents who do not have dementia. The research made a number of recommendations including the need for a new dementia skills and knowledge programme to guide staff and to consider whole range of psychosocial approaches that can be used by trained staff to promote well-being and improve quality of life.

Responses

- **18% identified the benefits of psychosocial approaches to complement existing medical and neurological models of service delivery as a priority.**

While respondents stressed the importance of supporting people to live in dignity in the community, they also recognised the need for quality long-term residential care when that was no longer possible.

It was proposed that specific education and training should be provided to residential and nursing home staff to enable them deliver person-centered support to the individual with dementia. The British Psychological Society was referenced in this regard

“training in dementia care in residential care settings should include basic training from occupational therapists, psychologists, speech and language therapists and physiotherapists as to the neurological difficulties that people have. This training should also address how these difficulties relate to emotional, relationship, memory, communication, and personality changes as well as to movement disorders and to environmental issues.”

It was highlighted that *“further research is required to identify the most effective psychosocial approaches for use in long-stay residential care which deliver real outcomes for residents and staff.”* It was suggested that regardless of the setting, people with dementia must have equitable access, to all proven approaches and it was recommended that education and training in the selected methods should be provided for all registered designated centres to maximise implementation.

It was also noted that deficiencies in the environment can further disable a person with cognitive and other impairment and that *“many existing Irish residential care settings fall far very short of the ideal in terms of adequately providing psychosocial fit for elderly people in general, not to mention PWD.”*

- **18% identified the need for dementia - specific residential care units.**

It was proposed that “generic care settings” do not have the space or facilities to provide evidence based care. Similarly it was noted that, in common with other

neurological conditions, people with dementia are often accommodated in settings that are inappropriate to their individual needs.

One submission, however, while recognising the benefit of specific residential care units in providing a centre of excellence type service questioned, whether there was actual evidence that showed better outcomes for people with dementia in such settings.

It was suggested that provision of the Nursing Homes Support Scheme on a statutory basis, as opposed to the “discretionary” basis of home care supports had inadvertently prioritised nursing home care over home and community care.

It was noted that there will be an increased demand for residential care for older people in the coming years and concerns were expressed regarding the reduction of public capacity and the reliance on the private sector to adequately cater for patients with dementia.

Some examples of what you said;

“Psychologists are skilled in working with staff teams to support increased psychological practice in everyday care. In addition, Clinical psychologists based in community teams with a specific remit to meet the needs of older adults could offer liaison service to nursing/care homes and wards to give advice and support on behavioural, cognitive and personality matters and working with systems, helping preserve personhood and optimize the quality of care people in long term care receive.

Art Therapy as well as being beneficial in residential care has proven to be of benefit across a wider spectrum of care settings in Dementia, home care, including family work, work with carer groups and community care.”

“At no case was a psychologist (clinical, health or neuro) involved in my grandmother’s house-the only model of care offered was the medical model and medication to manage any disruptive or challenging behaviour...she never received a formal diagnosis.”

“such units should have the highest levels of environmental design, staff training and programming so that they are important supported of person-centred care addressing pressing health and care needs particularly as dementia advances and not isolating and warehousing.”

“These centres should comprise small units where care can be patient orientated rather than driven by schedules.”

5. Acute Care

The Research Review found that up to 25% of all hospital patients may have dementia and it highlighted the fact that the hospital experience can be hugely frightening and disturbing to a person with dementia. It also found that the evidence suggests that people with dementia usually stay longer, at greater expense and are more likely to be discharged to a nursing home. The research recommended that a dementia champion's programme in general hospitals would facilitate a more patient - centred approach to care. It further suggested a greater need for staff awareness and a need for up-skilling in recognising symptoms and in communication with a view to providing dementia - friendly care.

Responses

- **23% identified awareness, ownership, and leadership of dementia in acute hospitals as a priority issue.**

It was felt that people with dementia experience difficulty in having their needs understood and met in hospitals. One explanation offered in this regard was that hospital staff are naturally focused on the acute medical and surgical condition that led to hospitalisation, and that the further or on-going care of the person with dementia is often overlooked.

The general consensus arising from the submissions was that a key worker (with responsibility for facilitating communication and coordinating care) would be beneficial for individuals with dementia and their families. Such a service would ensure appropriate referrals and assist in education provision for general hospital staff. This echoes submissions recommending the need for a key worker operating across both community and long stay settings.

While the time a person with dementia spends in acute care is short relative to their overall disease duration, however it was felt that “ *it is a crucial time as it is often the time of first diagnosis or at least an opportunity for diagnosis - in reality the opportunity is often missed*”.

Another submission identified a clear need for new intake procedures that ‘stream’ people with dementia towards specialist staff and ‘dementia-friendly’ areas of the hospital. This would not only improve the patient experience but may result in economic savings by reducing the time spent in hospital. It was suggested that a project similar to the “Hospice Friendly Hospitals” could be developed for people with dementia in hospitals.

The following suggestions were also offered: that acute hospitals need to introduce dementia champions to promote awareness of the difficulties that hospital setting poses for people with dementia; that A&E staff are specifically trained in the area of dementia awareness; that dementia specific units are developed in hospitals; that the hospital setting may not be the appropriate place

to make a diagnosis of dementia as patients with acute illness causing confusion do not perform well on cognitive testing; the need for the development of the psychiatric consultation liaison (service) nurse; and that acute general hospitals develop their own strategies on how they can minimise the negative effect to patients with dementia.

Some examples of what you said;

“The appointment of case managers as proposed by Cahill et al 2012 would go along away to improving services for people with dementia admitted to acute care as they would be the patients advocate and link person between services and the facilitator of effective discharge planning.”

“People with dementia requiring acute admission should, where possible, be admitted to designated “dementia friendly” wards with staff trained in understanding and responding to the particular needs of clients with dementia.”

“A new model is needed that reflects partnerships in care provision between hospitals and dementia/ID provision in which acute care is not an isolated event but part of the overall plan of care.”

“there is a need for proper discharge planning and effective care plans from acute care.”

6. Community/Acute/Long-stay residential care

The Research Review considered that the best way to ensure that people get the services they need is to develop a system of case management for people with dementia and have available 'dementia champions' to assist and support people in their journey through the disease trajectory.

The review asserted that there has been little research undertaken internationally focusing on the obstacles and facilitators to home based end-of-life care for people with dementia. It further asserted that the palliative care services within its current service system are underdeveloped and that many people with dementia will die in hospital.

Responses

- **16% of responses identified case models of integrated care as a priority issue.**

In general, respondents felt that an integrated care approach between all services is vital to deliver effective, efficient and person centred care pathways. It was noted that case management models of integrated care are highly commendable and should be routinely developed, in view of the complex nature of dementia that affects all aspects of physical, psychological and social health and well-being.

One submission identified the lack of a co-ordinated approach to dementia diagnosis and dementia care in Ireland. It was proposed that a single point of access for healthcare and social support would be advisable and also that Psychiatry of Later Life, Geriatrics, Neurology, Psychology and other disciplines need to be integrated into an organised care pathway that is clearly marked out for the user. This is particularly necessary in relation to young people with early onset dementia.

It was also proposed that a whole system approach to the delivery of dementia care that recognizes the contribution that all sections make to the delivery of patient centred quality care should be adopted. It was also proposed that an audit of services be completed in order to map out the services available, identify deficits and plan effectively for future services.

- **18% of responses identified end of life services for people with dementia as a priority issue.**

There was a general consensus that palliative care should not only be considered as having a role at end of life, but that it extends from point of diagnosis through the trajectory of the illness, to end of life and bereavement support for family members.

It was considered that this approach would provide people with dementia opportunities to plan their future care needs and address any fears and apprehensions they may have. Furthermore, the introduction of a palliative approach in dementia care would also support family members as advocates for the person with dementia.

It was noted that while old age psychiatry services frequently interact with palliative care services there is a need for a more coherent and adequately funded system in this regard.

Some examples of what you said;

“Patient journeys through the healthcare system cannot be considered in the silos of acute, intermediate or community care, but rather as an integrated, interdependent system. In this way, parochialism and the myopia of focusing on individual budgets will be removed, and replaced with a more holistic view of the patients care.”

“We think that the recommendations made in the strategy may be well issues related to dementia in tiered and staged approach, so that needs at different levels are met, i.e., individual, family, carer, services, society needs at early, middle, late stages of the disease”.

“The wide range of health needs of people with dementia often requires joint working between many sectors, such as specialists in care for older people and palliative, primary and mental healthcare services”.

“The concept of palliative care as an intervention that can be offered alongside potentially curative treatment must be developed and used to meet the needs of ageing populations, as well as those of younger people who develop dementia. Indeed, we would like to emphasise that the provision of palliative care is the responsibility of the whole healthcare system and not just specialist palliative care services.

“Inevitably, as dementia progresses, there is a move from rehabilitative and health promoting care to a more palliative care approach. All health and social care workers need to be able to deliver the palliative care approach.”

7. Research

The Research Review identified a need for further research on all aspects of the disease. Accurate national estimates of current and future prevalence of dementia will be essential for effective planning of health and social care services and for generating awareness.

Responses

- 25% identified case models of integrated care as a priority issue.

In general, those who identified research as a priority acknowledged this was vital for service planning provision and future costings of services. In this regard it was felt there was a need to establish what range of services need to be provided to support people to live in the community, to investigate the outcome of service provision, and to investigate what models of care support best practice.

According to one submission research provides the basis for the development of treatments, services etc., to ensure their validity, reliability, effectiveness and appropriateness. In this regard it was recommended that a “*dementia strategy should outline how a coordinated and focused national research programme that takes cognisance of international research can be established...*”

Finally, it was recommended that a substantive focus on Alzheimer’s disease and related dementias should be formally included in the research strategies of all research councils in Ireland, consistent with, and supportive of, the pioneering initiative on Alzheimer’s disease in the Joint Programme for Neurodegenerative Disease of the European Union.

Some examples of what you said;

“Research and prevention must form a substantial part of any strategy to do otherwise would be to fail future generations”.

“The involvement of General Practice in community based research programmes is desirable to inform service delivery models and improve quality of care for patients”.

“There is a wide acceptance of the lack of empirical research in the field of end-of-life care for people with dementia”

“Psychologists are instrumental in undertaking vital research on mental health issues. A highly visible research focus on dementia and related issues would help raise awareness.”

“Primary focus should be on delay the onset of dementia and on prevention, to be achieved through research, the development of interventions and awareness campaigns aimed at prevention with a key focus on translating

empirical knowledge into useable, practical information aimed at the general public.”

“Research is essential in addressing prevention and treatment of dementia generally and particularly in nonpharmacological treatments like physiotherapy as some aspects of physiotherapy intervention, apart from physical activity which is irrefutable, look promising.”

“The purpose of research is to create an evidence base on which to develop interventions and appropriate supports. There are huge gaps in what we know about dementia, despite increases in knowledge in recent years. More research is needed to generate pharmacological evidence as well as psychosocial evidence on quality of life and quality of care information, social connectedness of people with dementia.”

Question C

What specific issues would you like addressed in any or all of the priorities that you have selected?

Responses

A recurring theme in the responses identified adequate resources, both financial and staffing, as key to the delivery of future services.

The vast majority of submissions identified the need to increase supports in the community, recommending a variety of measures, in particular flexibility of services (respite & home respite provision), provision of Home Care Packages and also recommending community based teams/ identification of a key worker to support individuals and coordinate services. A number of submissions promoted the development of dementia friendly communities.

Early diagnosis and intervention featured prominently in the submissions. The general consensus is that there is a pressing need to develop early intervention supports as currently there are almost none for people post diagnosis.

A significant number of submissions identified priority actions that would span a number of the headings (ie person centred philosophy, equity of access to services, increased awareness about dementia, training and education, dementia champions, advocacy etc.). A number of submissions also highlighted the benefits of applying palliative care principles to dementia care.

The following are recurring priorities identified in the submissions:

Awareness

- **Recognition of the person with dementia as a unique individual**
- **Identifying ways to challenge stigmatisation**
- **Emphasis on education and continuing professional development to assist GP and Primary Care Teams in providing timely diagnosis**
- **Raising awareness and promoting intervention in primary care**
- **Promotion of healthy lifestyles and in turn highlighting modifiable risk factors (vascular health, smoking alcohol consumption & diet etc.)**
- **Guidelines for health professionals**
- **Promotion & development of dementia friendly communities**
- **Identification and provision of a suite of information about dementia and services available that people with dementia & carers need**
- **Education and training for family & carers**
- **Recognition of the not for profit sector**

Early diagnosis and Intervention

- Greater emphasis on primary prevention and ways of avoiding or delaying the illness
- Introduce a National Screening Programme
- Memory Clinics developed in each Local Health Office and extending their role
- Enhanced training for health care professionals
- A national referral protocol on diagnosis and investigation of patients with dementia
- Appropriate services for people with early-onset dementia, including people with Down syndrome.
- Assessments on every adult with Down syndrome at age of 30 to establish baseline and regular screening for over 40's
- Develop core information packages for people & carers to be provided on diagnosis
- Improve information for people aged less than 66 who experience dementia needs to be a priority
- A more integrated approach to disability and older person policies and information collection

Community-based services

- Equity of access - tackle barriers created by administrative boundaries based on age or geographic categories that impede diagnosis or appropriate care
- Appropriate and realistic allocation of resources
- Legislation to underpin home care supports
- Develop standards for community based care
- Patient centred services - one that respects and listens to patients and takes heed of what families and carers are saying
- Focal point for dissemination of information.
- Multidisciplinary dementia care team promoting highest possible level of independence and quality of life
- High quality physiotherapy services as part of the dedicated and flexible community services
- Acknowledgement of family carers
- Increased use of technology to support people at home

Long-stay residential care

- Develop specialist care units
- Introduction of a national policy on the size, design, layout, location and resourcing of dementia-specific units
- Dementia education, training and on-going support for staff.
- Continued roll out of National Dementia Education Programme
- Database of dementia specific units
- Enhanced rate of financial support (under Nursing Homes Support Scheme)
- Specialist residential care options for people with dementia who are under 65
- Develop social models (sheltered housing)
- Stronger emphasis on psychosocial approaches

Acute care

- Develop Dementia Friendly Hospitals
- Improve dementia awareness and training of staff
- Develop step-down services
- Focus on discharge planning
- Examine ways of avoiding unplanned or unnecessary admissions and reducing the length of stay in hospitals
- Introduce a dementia champion

Community/ Acute/ Long-stay residential care

- Multiagency person - centred planning and communication
- Individualised budget for person with dementia - “*funding to follow person with dementia*”
- Quality case management and integrated care & partnership in care provision between service providers
- Develop the role of the Dementia Clinical Nurse Specialist
- Advocacy programmes to support the person with dementia
- Designated clinical placements for students in care of the elderly settings, and an educational focus for age related health care
- Develop alternatives to residential care for people with dementia (ie. supported housing)
- Adopt the recommendations from the Irish Hospice Foundation (2008) report in relation to service model, research, education and policy
- More considered role for palliative care as part of interdisciplinary care provided

Research

- Information systems on the number of people with dementia, severity of disease, placement patterns and quality of life
- Analysis of what is provided - what works, what doesn't and why
- Audit of Specialist Staffing resources for Dementia Care
- Research needed on delaying the onset of dementia and on prevention, the development of interventions and awareness campaigns
- Develop formal arrangements for networking/pooling research

Question D

Is there anything else that should be considered for inclusion in the Strategy?

The general consensus from the submissions is that people want a person centred quality service, regardless of settings. They want a commitment that dementia is a national priority; they want systems, structures and resources in place to achieve this.

The following is a compilation of key themes which emerged from the responses to the consultation process. While efforts were made to group these in an ordered manner no weight is provided to any one suggestion

High Level

- Whole of Government approach
- Public Health Priority
- Clinical and Policy Leadership
- Establishment of a National Dementia Care Programme / National Clinical Directorate
- Dedicated budget lines
- Develop structures, policies and resources to enable joint planning of dementia care between primary care, voluntary sector geriatric medicine and old age psychiatry services
- Structures should support effective governance, implementation, monitoring & review
- People with dementia and their carers should be included as key stakeholders to give their unique perspectives on their experiences
- Strategy should be integrated across other health strategies, ie. *Vision for Change, Carer's Strategy, Positive Ageing Strategy, National Disability Strategy, National Cardiovascular Strategy* etc.
- Strategy should also be cogniscent of other relevant legislation (ie. Mental Capacity etc.)
- Rights, Dignity and Personalisation - *“recognition of the person as a unique individual who belongs in a social world of roles and relationships and who has a biography is required.”*
- The Strategy should be *“flipped to a strengths based approach where assessment is about maximizing abilities not assuming liability.”*

Implementation

- High level implementation Group
- Identify the main priorities over specific time periods.
- Clear set timelines, responsibilities and review dates to ensure progress in implementation of strategy
- Establish a solid basis for successful implementation that includes continued stakeholder engagement and monitoring.
- Reporting Mechanism (including annual report)

Operational

- Communication Strategy
- Equity of Access to services regardless of age
- National Audit of Dementia Care
- Establish clear pathways of care following diagnosis
- Register of Persons with Dementia
- Develop responses to dementia in different settings
- Strengthen formal links between all stakeholders

**Education/
Training/
Information**

- Formal guidelines for the training and accreditation of staff in dementia care as a core component of their gerontological training and continuing education
- Dementia care training for all providers of health and social care working with adults
- Guidelines for diagnosis & disclosure
- Provision of information regarding living wills, power of attorney and end of life decisions
- Improving information about people aged less than 66 who experience dementia needs to be a priority
- Develop practice guidelines for the prescription of medications at end-life.

INDEX OF SUBMISSIONS

Oonagh B McPhillips	Disability Federation of Ireland	The Irish Hospice Foundation
Carole King	Elizabeth Mansfield	Mercer's Memory Clinic
Niall McLoughlin	Dr. Shaun O' Keeffe	The Carers Association
Ursula Collins	Dr. Elizabeth Flether Glenn	Irish Heart Foundation
Tony O' Mahony	Age & Opportunity	The College of Psychiatry of Ireland
Anne C Grace	Mary Cahillane	Irish Psychiatry of Old Age Nurse Education & Development Group
Noelle O' Hanlon	Mary F McCahill	Cathy Dalton
Edel Mc Glanaghy	Emily Mc Carthy	Age Action
Jonathan Egan	Nursing Homes Ireland	Carol Smith
Teresa O' Mahony	CARDI	Irish Association for Palliative Care
Aisling Mc Mahon	Joan Brangan	Irish Medical Organisation
Carol McCann	Fiona Timlin	Dementia Services Information & Development Centre
Ann Quinn	Jackie O'Toole	Dental Health Foundation
Agnes Higgins	National Disability Authority	Genio (Fiona Keogh)
Malachy Nugent	Ageing Well Network	Irish Society of Chartered Physiotherapists
Brothers of Charity Services, Roscommon	Dr. Robert Coen	Beaumont Hospital & St Francis Hospice Medicine Teams (Joint Submission)
Clare Devaney	The Alzheimer Society of Ireland	DeafHear.ie
Kathleen Farrell	Deirdre McGrane	Aine O' Riordan
Irish College Of General Practitioners	Irish Society of Physicians in Geriatric Medicine	Neuro-Enhancement for Independent Lives – Trinity College Dublin
Dr.Suzanne Timmons	Care Alliance Ireland	Jimmy & Mae Murphy
Neurological Alliance of Ireland	Dr Aideen Lewis	An Bord Altranais
All Ireland Institute of Hospice and Palliative Care	Daughters of Charity Service, Dublin	Later Life Mediation
Wicklow Dementia Support	Mary Flannagan	Dr. Karen Ryan
Kathleen Griffin	Older & Bolder	
Christine Broe	The Institute of Public Health in Ireland	

National Strategy on Dementia Consultation Questions

Throughout our community we are caring for an older population with varying needs and conditions including Alzheimer's disease and other dementias. These are progressive conditions that not only have a huge impact on the physical, psychological and emotional state of the person with dementia but also on their families and carers.

Question A

What is your particular interest in/experience of dementia, e.g. health-care professional/ diagnosed with dementia/ caring for someone with dementia?

Question B

The report, *Creating Excellence in Dementia Care: A Research Review for Ireland's National Strategy* (Cahill et al, 2012) has outlined the following elements for inclusion in the Strategy, which have been grouped below under 6 broad headings.

Of the areas outlined, what should the main priorities for the Strategy be?

Awareness

- Primary prevention and ways of avoiding or delaying the illness
- Public awareness about dementia

Early diagnosis and Intervention

- Early diagnosis
- Specific training in dementia for health care professionals
- Appropriate services for people with early-onset dementia, including people with Down Syndrome

Community-based services

- Dedicated and flexible community-based services

Long-stay residential care

- Psychosocial approaches to complement existing medical and neurological models of service delivery
- Dementia-specific residential care units

Acute care

- Awareness, ownership and leadership of dementia in acute hospitals

Community/Acute/Long-stay residential care

- Case management models of integrated care
- End of life care services for people with a dementia

Research

- Information systems on the number of people with dementia, severity of disease, placement patterns and quality of life

Question C

What specific issues would you like addressed in any or all of the priorities that you have selected?

Question D

Is there anything else that should be considered for inclusion in the Strategy?