



National Educational Needs Analysis Report

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Foreward

At some point or other, dementia is something that will touch many of our lives, perhaps not directly, but indirectly, through a loved one or a friend. There is an undeniable upward trend in terms of the number of people, living in Ireland, being diagnosed with dementia. It is incumbent on us to increase our understanding of dementia, to reduce the stigma associated with it and to encourage and support people with dementia. As a society, we must seek to alleviate the fear and concerns that surround dementia by ensuring that the appropriate supports are in place to provide the best on-going assistance for anyone living with dementia - the person and the carer.

DCU is committed to the translation of knowledge into societal and economic benefit, to making a difference through addressing issues of national and international significance. One of the four pillars of our Research and Innovation Strategy is Health Technologies and Ageing. As educators, researchers and innovators, we recognise that we must step up to the challenges associated with dementia. For DCU this means a strong conviction that we have a key role to play in the many facets of dementia, from prevention to diagnosis and from diagnosis to care. DCU established the concept of the Age-Friendly University and through our AFU Initiative DCU is committed to showing leadership in preparing society for the multi-faceted opportunities and challenges of an ageing population.

The Elevator Programme, led by Dr. Kate Irving in DCU, is an excellent example of DCU's translation of research into societal benefit. Funded through the HSE and The Atlantic Philanthropies, Elevator represents an important partnership of key organisations working together to play our role in the kind of collective impact required to make meaningful improvements to the lives of people with dementia. Informed by best practice, the partnership will play an important role in supporting ageing in place for people living with dementia.

In highlighting the gaps that exist in dementia skills and knowledge, and in considering models of best practice in dementia training and education, the Educational Needs Analysis report will inform the development of appropriately tailored dementia-related training and education programmes in Ireland.

I very much welcome the report and its findings and I wish to extend my congratulations to the authors of the report –Dr. Kate Irving, Paulina Piasek, Sophia Kilcullen and Ann-Marie Coen from DCU and Mary Manning from the HSE.



Prof Brian MacCraith
President
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Table of Contents

1.	Executive Summary	6
2.	Introduction	9
3.	Methodology	10
3.1	Empirical Study Methodology	10
3.2	Scoping Study Methodology	15
3.3	Consensus Meeting Methodology	15
3.4	Summary	16
4.	Empirical Study	17
4.1	People with Dementia	17
4.2	Informal/Family Carers	18
4.3	Community Networks	19
4.4	General Practitioners (GPs)	21
4.5	Healthcare Professionals	22
4.6	Summary	27
5.	Scoping Study	29
5.1	Community (Awareness, Skills and Knowledge)	29
5.2	Health Care Settings (Training and Education Needs)	39
5.3	Primary Care	51
5.4	Summary of the Scoping Study	58
6.	Identifying the Priorities: synthesis of scoping and empirical findings.	60
7.	Consensus Report	62
7.1	Seven Priority Areas Generated via Nominal Group Technique for Dementia Education	62
7.2	Discussion and Prioritization	63
7.3	Eliminated Priority Areas	67
7.4	Summary	68
8.	Education Needs Analysis Matrix	69
9.	Conclusion	76
10.	References	78
11.	Appendices	88

11.1	Appendix A – Consensus Meeting Members	88
11.2	Appendix B – List of Abbreviations	89
11.3	Appendix C – People with Dementia Interview Schedule.	90
11.4	Appendix D – Informal/Family Carers Interview Schedule.	93
11.5	Appendix E – Community Members Interview Schedule.	96
11.6	Appendix F – General Practitioners Interview Schedule.	99
11.7	Appendix G – Health Care Professionals Interview Schedule.	101

1. Executive Summary

Background

The number of people with dementia in Ireland is predicted to rise in the coming years. To enable the widespread service reform required, offering improvements in quality and consistency of care, there will need to be extensive skills development in health and social care. Recent research has revealed the need to resolve educational gaps, which still persist in hospitals and long-term care. Awareness and knowledge of dementia in communities will also need to be further developed to promote social ownership of dementia and ensure that staying at home with dementia is a much more obvious alternative than is currently the case.

This report details the results of a Dementia Educational Needs Analysis (ENA) carried out in 2013/2014 regarding the educational and learning needs of a wide range of stakeholders with respect to life in Ireland for people with dementia. It attempts to build upon the previous HSE 2010 report, by providing a contemporaneous assessment of the information, education and training needs of the person with dementia, their care-giving network, healthcare system and the broader community in which they live. The ENA aims to determine the specific information needs of people with dementia, their carers and other stakeholders, how they would like to receive the information and their preferred timing for the delivery of this information. The report outlines the major gaps in education at present, as elucidated by the project, and provides recommendations for future educational and service reform, through the identification of seven priority areas for developing education and training programmes.

Methodology

The methodology guiding this ENA embodied three perspectives; an empirical study a scoping review, and an expert consensus meeting, resulting in a final triangulation and decision on seven priority areas for dementia education.

Congruent with the growing consensus about the value of qualitative studies to assess need in the area of dementia and the importance of hearing the voice of the person with dementia, the empirical study compliments the previous quantitatively-focused HSE ENA by adopting an in-depth qualitative approach to explore the information and educational needs of the person with dementia, their informal carers, healthcare staff and members of the community. A case study approach was used, placing the person with dementia at the centre of the research, while elucidating the perspectives of all relevant participants from the person's social network and detailing the interaction between participants. This enabled a deeper understanding of dementia education needs within the context of each participant and their particular social world. The selected case studies represented three different communities in Ireland, that of an urban, town-based and rural setting. Interviews were conducted with people living with dementia in each of these communities as well as their informal carers and a broad range of healthcare staff and other stakeholders in the community within a two-week period. Interview findings generated a list of dementia education needs, which were analysed for themes and combined with the findings of the scoping study.

The scoping study presents a picture of best-practice dementia education across the continuum of care in a range of settings. It involved a detailed search of the relevant literature, including electronic databases from the fields of nursing, psychology, education and science, containing articles on dementia and educational interventions. National Dementia Strategies from various countries and evidence-based practice guidelines for dementia care were also reviewed. The methods by which each government and independent training provider arrived at the decision to assess educational needs and/or address these needs through training were examined, alongside **timing, mode of delivery** and reported **outcomes** of such training, barriers encountered and solutions proposed.

Eleven key priorities areas were identified as areas that warranted further dementia education and training programmes, based on the synthesis of findings from the scoping and empirical studies. These eleven areas were then presented to a diverse group of dementia experts, involved in, or aware of, dementia planning at a national level. Through a process of Nominal Group Technique involving qualitative judgemental problem exploration, this panel of Dementia experts prioritised and reached consensus on seven national priority areas of dementia education needs. Additional levels were added to three areas to expand the reach of the training and education programmes to family carers and community members. The areas were then ranked in order of priority, taking into account the existing healthcare landscape. It was agreed that the themes of advocacy, human rights, environment and end of life will cut across all of the training and education programmes.

Findings

The seven priority areas identified for dementia education and training programmes were:

- I. **Awareness**, with the distinction made between general awareness and the need for awareness with some key skills. Specifically, this priority area is broken into 3 levels.
 - **Level 1** A brief community awareness programme for all public facing workers.
 - **Level 2** Short skills training for key public facing workers including financial services, solicitors, retail, police, travel, sport and recreational services (a pilot programme to be developed in one area as part of Elevator).
 - **Level 3** Further develop current two-day HSE National Dementia Awareness programme for anyone working in health or social care settings.
- II. Practice development/**dementia champions programme** for all nurses and Allied Health Professionals.
- III. **Therapeutic skills module** for any health care professional: psychosocial approaches to supporting cognition, validation and working with couples affected by dementia.
 - **Level 1** A practical online module (not accredited) targeted to informal carers but with open access addressing principals for validation, cognitive remediation and multi-sensory stimulation, with a toolkit for services who wish to deliver the initiative face to face.
 - **Level 2** Degree level module, which will develop a practitioner's skills in 3 therapeutic approaches – Validation, Cognitive Remediation and option of multisensory or dyadic support of couples with dementia.
- IV. A module specific on **clinical and ethical decision making** including nutrition, hydration and pain assessment.
 - **Level 1** The module above will be tailored to informal carers working with people with dementia in their own homes who face all of these ethical dilemmas. Health care assistants can also undertake this module.
 - **Level 2** Degree level blended learning module for health and social care professionals introducing them to ethical principles, theory of decision making (both applied to dementia) and focusing on 8 scenarios: hydration, nutrition, pain, mobility/restraint, sleep problems, responsive behaviours, sexuality and future care decisions.
- V. Training on **dementia awareness for managers and service leaders**.
- VI. **Skills in responding to memory complaints** - targeting health and social care practitioners (HSCPs).

- VII. Bespoke **GP training** including: diagnosis, disclosure, treatment (both social and medical), carer support, ethical and legal issues, therapeutic communication for dementia and formulation of person-centred care.

Conclusion

This report sheds light on the existing gaps in dementia skills and knowledge amongst a broad range of stakeholders in Ireland and internationally, but it also illustrates a number of high quality best-practice dementia training and education initiatives presently addressing these gaps. The Dementia Elevator project aims to build and expand upon the efforts of other education providers by addressing the current information and educational needs of the person with dementia and a very broad range of stakeholders, including community members. For the three people whose networks we studied for this report their daily lives were peppered with people with low awareness, misinformation and lack of skills. However, it was also true that our researches found individuals with more than adequate knowledge and skills. Importantly, we encountered people who expressed a wish to know more, to help out and to up-skill. The findings contained within this report will enable the development of training and education programmes that will be tailored in content and form of delivery to target the variety of stakeholders across the dementia pathway in Ireland.

2. Introduction

This report details the results of a Dementia Educational Needs Analysis (ENA) carried out in 2013/14 regarding the educational and learning needs of a wide range of stakeholders with respect to life in Ireland for people with dementia. The aim of the ENA was to decide several priority areas for developing education and training programmes. These priorities were chosen with knowledge of existing international best practice, a scoping review of current practice and educational opportunities and an empirical study of educational needs in three nominated areas in Ireland. The results of these studies were consolidated and reported to a consensus group of expert stakeholders in the field of dementia, who were invited to consider the options and recommend a number of priorities to best fill gaps and promote ageing in place for people with dementia.

The service reform required to respond to the rising numbers of people with dementia and the associated social and economic costs and to offer improvements in quality and consistency of care will necessitate extensive skills development in health and social care. Communities too will have to develop to ensure that staying at home with dementia is a much more obvious alternative than is currently the case. This has relevance for people with dementia, family carers, health and social care professionals and other public and private community service providers. It is increasingly recognised that built environment professionals such as architects and town planners also have an important role to play. Less obvious stakeholders in dementia care such as Gardaí, Post office workers, staff in leisure centres and other public spaces also need to be up skilled. Furthermore, in hospitals and long term care, notable gaps in educational need still persist. This educational needs analysis will build upon and update the Health Service Executive (HSE) report (de Siun and Manning 2010) by providing a contemporaneous assessment of the information, education and training needs of the person with dementia, their care-giving network, healthcare system and the broader community in which they live. The major gaps in education will be elucidated by this project and strong recommendations for future priorities will be made. The report is broken down into different sections - the methodology, the empirical study, the scoping study, the emerged priorities, and the finalised priority areas as outcomes of the consensus meeting.

3. Methodology

The methodology guided the processes of this ENA, which is built up from three elements: the **empirical** study, the **scoping** study, and an expert **consensus** meeting, resulting in a final triangulation and decision on seven priority areas for dementia education.

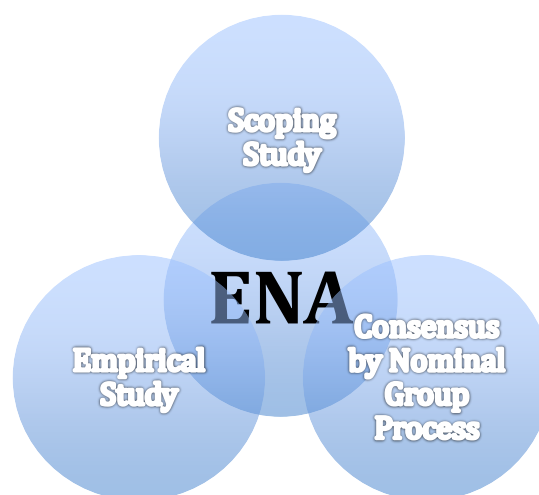


Figure 1 Dementia ENA perspectives

The overall aims of the ENA are:

- (1) To determine the specific information needs of **people with dementia and their carers**
 - a. To determine **how** people with dementia would prefer to receive this information (e.g. a combination of written and verbal communication, individual or group based, classroom-style or web-based format, delivered all in one sitting or spaced out to a period of time).
 - b. To determine the preferred **timing** for the delivery of this information.
- (2) To determine the specific dementia information needs of **other stakeholders** - formal care staff in acute, primary and community services and other members of the wider community with whom the person with dementia may interact.
 - a. To determine **how** these family members, informal carers, formal care staff and other members of the community would prefer to receive this information.
 - b. To determine the preferred **timing** for the delivery of this information

3.1 Empirical Study Methodology

The HSE 2010 Dementia ENA provides extensive information on the dementia education needs of **staff** in terms of knowledge, skills and attitudes to provision of person-centred care to people with dementia within Irish health services. The report focused on enhancing **professional capacity** to make a difference for the person with dementia. The HSE 2010 ENA used a **quantitative** survey-based approach with some qualitative interviews.

The Elevator empirical study complements the previous ENA by adapting an in-depth **qualitative** approach to explore the information and education needs not only of staff but also the person with dementia, their family and informal carers as well as members of the community. There is growing consensus about the value and importance of qualitative studies to assess needs in this area; particularly for people with dementia (Downs et al. 2000) . A qualitative approach aims to derive a **more in-depth understanding** of a phenomenon within its context.

3.1.1 Case Study

The context-bound nature of an education needs analysis led us to choose a **case study methodology** as the qualitative approach used in this ENA. Case studies enabled the identification of specific information and education needs of the person with dementia across a broad spectrum of the community in which they live, as well as the preferred mode of delivery of the information/education. Case study methodology uses any combination of methods and data sources enabling the exploration of dementia education needs through multiple lenses.

The case study approach placed the **person with dementia at the centre** of the research, giving voice to a person who has traditionally been marginalised in society by stigma and de-humanised by services underpinned by a medical model, which places an emphasis on disease and impairment. The need to include the voice of the person with dementia in research has been widely advocated in recent years, and has revealed significant findings (Downs et al. 2000) . To the best of our knowledge, there has been no previous ENA which places the person with dementia at the centre of the process of investigation and which is consistent with the person-centred ethos of dementia education. Our methodology represents an innovative approach to ENA, informed by the data, which emerges during these case studies. The study is designed to bring out details from the viewpoints of all relevant participants and the interaction between participants.

3.1.2 Study Design

The aim of this empirical study was to determine the **specific information needs** of people with early stage dementia and any member of the community they may interact with. Within this aim it was also intended to assess the preferred **method and timing** of delivery of this information. Our chosen approach to gaining such insight was by studying **particular cases of people with dementia within their communities in specific geographical locations** including that of a city, town and rural location.

Thus, we used individual case studies to gain deeper understanding of dementia education needs. Each case study was instrumental in identifying these information needs *within its specific context* – in other words, in the particular environment in which the person lives and interacts.

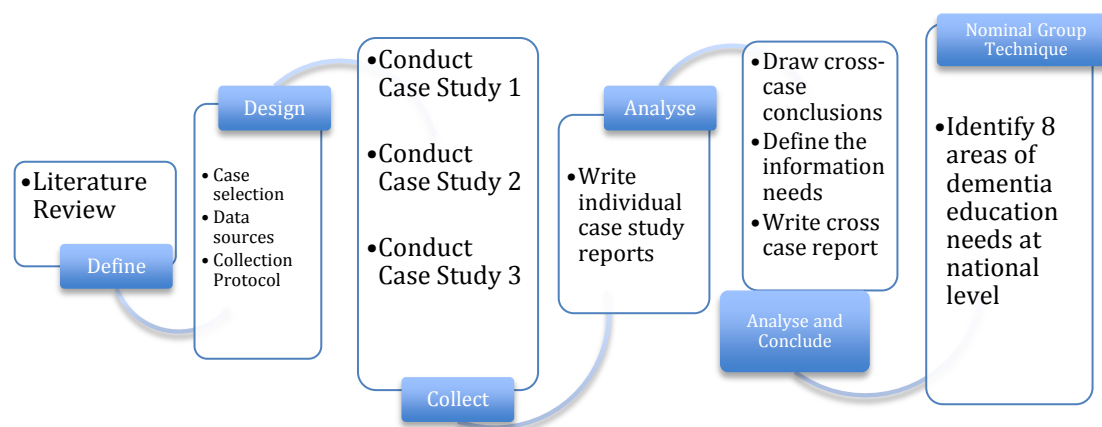


Figure 2 Case Study design plan (Based on Yin, 2003)

The **case study design plan** (Figure 2) was based on Yin's (2003) multiple-case study replication design. The initial step was to **review any literature** relevant to the dementia ENA. The case studies were then selected assuring representation of three different communities in different types of locations in Ireland, including that of a city, town and rural location.

Each **case study** was then conducted individually and during the same time period. After each case study, an individual case report was written up. These reports were then cross case analysed and findings and conclusions emerged from the cross case report. These findings generated a broad list of dementia education needs. This list was presented to a diverse group of dementia experts, who were tasked with prioritizing and reaching consensus on seven national priority areas of dementia education needs. The consensus was reached using the Nominal Group Technique (NGT), which is a method for prioritising information. The use of NGT composed of dementia experts enabled us to validate the findings further in a hierarchy of perceived importance at a national level. This method is discussed further under the "Nominal Group Technique".

3.1.3 Case Selection

Three GPs, one based in a town, one based in a city and one based in a rural area, who demonstrated an interest in the study and an awareness of educational need within their provision of care to people with dementia, were asked to participate in the study. Each GP took part in an interview and each nominated one person in their area who has been diagnosed with early- mid stage dementia.

Inclusion criteria for the person with dementia comprised of:

- (i) Diagnosis of early- mid stage Dementia (DSM-IV).
- (ii) Could hear well enough to participate.
- (iii) Could articulate their needs, wishes and preferences.
- (iv) Would be likely to be able to remain seated for the duration of interview (approx. 1 hour).
- (v) Wanted to participate.
- (vi) Had a relative or carer who was also happy to participate.

Each GP, or their nominated health care professional, approached these individuals and their carers with information about the study. Once they had agreed to participate in the study, the GPs, carers

and individuals with dementia took part in individual interviews to identify their dementia education needs and preferences. The interviews with individuals with dementia included a medical and social history. Individual interviews were of a questionnaire-based, semi-structured format and were audio-recorded. Following the interview with the person with dementia and their carer they were asked to nominate the people in the community with whom they interact, e.g. neighbours, shopkeepers, postman, Gardai (Figure 3).

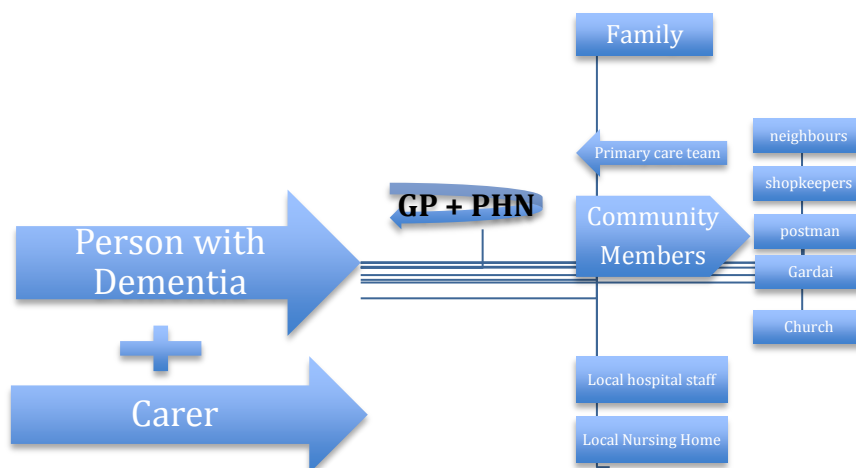


Figure 3 The nomination process for participants

The methodology protected the privacy of the person with dementia. If either the carer or person with dementia expressed any discomfort whatsoever about people knowing that this individual has dementia, we approached the nominated person on the premise that there are people in this community with dementia and we are doing a study *in this community* about dementia. Only in the case of close friends or neighbours who have full knowledge of a diagnosis, and with expressed consent from the person with dementia and the carer, did we mention by name the person with dementia in question. Anyone outside of the closest circle was informed only that the study is about people in this community – no individuals were named.

Once the list of people in the community was defined, as many people as possible were **interviewed** within the two-week local study period. Some community members were interviewed using **focus groups** to enable the collection of as many opinions as possible. Focus groups were audio-recorded for the purpose of thoroughness and precision in data collection. **Direct observation** was also used to characterise the domestic context of the person with dementia. The direct observations informed the study regarding any difficulties or obstacles in providing dementia education that may be present in that particular context.

3.1.4 Data Sources

In these case studies, data was collected from multiple sources including individual interviews, focus groups and observation field notes gathered from a spectrum of perspectives, including the individual with dementia, the closest carer, the extended family and the wider community. The various data sources were plaited together into a coherent description of the case. This technique is also called triangulation of data.

Multi-source data increases the validity and reliability of the data collected in a case study (Yin 2003).

- **Audio recorded individual interviews.** The main participants of this study were interviewed using this method. These included the person with dementia, their carer, their GP and PHN, and formal care staff. The audio-recorded interviews used in this study were semi-structured interviews, seeking to address a number of predetermined questions or topics relating to dementia information needs. Some questions arose during the interview based on participant's responses. The goal of using such interviews was to compare the responses of different participants while simultaneously seeking to fully understand their unique experiences.
- **Audio recorded Focus groups.** The focus groups were made up of several members with similar roles within the community (i.e. shopkeepers, formal care staff, and members of An Garda Síochána). In this study, the focus group interviews asked questions concerning the dementia information needs of focus group members. The interviewer acted as moderator, ensuring all questions were asked and all participants got a chance to express their opinion. A semi-structured approach allowed the moderator to structure the focus group around the core dementia-related themes whilst letting the group interaction flow as naturally as possible.
- **Observation field notes.** The observations carried out throughout the study were in the form of **direct observation** of the environment within each geographical location. They did not consist of direct human observation but included gathering information about the context in which services were provided like staff shortages in hospital settings. In community settings the observations focused on aspects like the presence of Internet access, a community hall, and transport links, which may all represent evidence of barriers or enablers to accessing dementia education. In a broader context, attention was paid to signs of stigma, such as general remarks from community service providers or health care staff.

3.1.5 Data Analysis

Data derived from the interviews, focus groups and direct observations were analysed for common themes by the research team. The themes identified in each case study (representing each geographical location) were placed in arrays across the three cases. Arrays are grouped by source, chronologically or thematically. Typically, the data is combined and recombined in several different ways in order to get a thorough understanding of the nuances and the different points of view in each case. As the dementia education needs are identified, information can be triangulated. The triangulation of data will allow the research team to derive categories of dementia education needs across the spectrum of participants. The advantage of using qualitative case study methodology is that the needs of participants may be identified in more detail than is possible with the standardised survey-type quantitative methods used in the previous ENA. However, based on the scoping review the themes included:

- dementia prevention,
- early intervention,
- diagnosis,
- treatment across the lifespan and
- education.

It was also predetermined that the data analysis identified the preferred modes of delivery for the different types of education needs, which were expressed (online, classroom, other) and the timing of delivery of this education (prior to dementia, after diagnosis, during the early stages dementia).

3.2 Scoping Study Methodology

In order to gain a comprehensive understanding of the state-of-the-art in dementia education, a detailed search of the relevant literature was carried out. Electronic **databases** from the fields of nursing, psychology, education and science, containing articles on dementia and educational interventions, as well as evidence-based practice guidelines for dementia care, were searched. In addition, the official **website** of Alzheimer Europe (www.alzheimereurope.eu) was referred to for a list of existing National Dementia Strategies in Europe and independent internet searches for other national strategies from the U.S.A, Canada, Australia and New Zealand were carried out.

All strategies were examined closely for information on **dementia education**. This data further informed the investigation about dementia education and current gaps in provision throughout the literature. The methods by which each government and independent training provider arrived at the decision to assess educational needs and/or address these needs through training were also examined. An analysis took place around the **timing, mode of delivery** and reported **outcomes** of such training. Where available, information about barriers encountered and proposed solutions, as well as the impact of culture, recipient's job and place of training on outcomes were reviewed. An extensive review of dementia related websites was carried out both in Ireland and internationally and personal contact was made with service providers in order to examine current practices. This presented a picture of **best-practice dementia education** in existence across the continuum of care (primary, general hospital, community and long-term care services), in diverse settings, and incorporating a broad spectrum of stakeholders in order to provide the **guiding framework** for the Elevator programme.

The information from the scoping study was triangulated with the findings of the empirical study and the outcomes of the consensus meeting with the intention of deriving **seven areas** of dementia education assigned as priority in the Elevator suite of training programmes.

3.3 Consensus Meeting Methodology

The priority areas for dementia education, which emerged from the analysis of the scoping review and empirical review were **discussed and prioritised** using Nominal Group Technique (NGT). The process of NGT has been described as qualitative judgmental problem exploration, which is particularly applicable to the subjective and judgmental character of many health and education planning efforts (Van de Ven and Delbecq 1972). NGT has been used previously in dementia educational intervention in primary care (Iliffe et al. 2002a) . NGT, along with the Delphi method, is one of the most commonly used methods of obtaining formal consensus from experts in the field. The distinct feature of NGT is the focus group setting, using face-to-face meetings. The group in this study was made up of **dementia experts** involved in, or aware of, dementia planning at a national level. They took part in a consensus meeting, which used NGT with the intention of **generating priority areas for dementia education**.

The broad list of priority areas presented to the group included the educational needs of people with dementia and the members of their communities, as derived by the scoping and empirical study. Using a combination of case study methodology and NGT ensured that the person with dementia remained at the centre of the research, but that the findings were also validated in a national context. This collaboration also encouraged the invited experts to take ownership of the prioritized issues, thus increasing the chances of changing clinical practice and policy within their area (Harvey and Holmes 2012).

NGT has the advantage of structured and clear processes involved in facilitating the meeting. The following format was followed during the two-day consensus meeting:

- **Introduction:** The meeting began with an introduction to the Elevator project, highlighting the importance of sharing perceptions, experiences and expertise of the invited members on the posed issues. The first priority area was then presented to the experts.
- **Generation of ideas:** the group generated ideas specific to the posed issues.
- **Round-Robin Listing of ideas:** the ideas were then shared one at a time round-robin style (Bartholomew et al. 2011). The participants were requested not to discuss the ideas until everyone has had a chance to make a statement.
- **Serial discussion of ideas:** The shared ideas were then discussed, resulting in clarification of some of the areas, addition of extra levels to others, and elimination of some areas.
- **Provisional consensus of ideas:** The participants expressed their level of interest in each idea in terms of practicality to changing dementia care.
- **Discussion of vote:** Spontaneous discussions took place during which participants re-clarified, defended and disputed the preliminary vote. Each area was voted in or out of the list of priorities. Furthermore the selected areas were discussed and prioritised under three relevant factors: timing of delivery, level of delivery, stakeholders.
- **Conclusion:** The facilitator briefly explained how the ideas obtained and consensus reached will be used to define the priority areas for each one of the posed issues. Members were thanked and the meeting concluded.

The use of NGT as a method for generating priority information in response to the issues offered a number of advantages. Firstly the two advantages of NGT included equal **representation** of a variety of dementia experts ensuring one education need did not overshadow the others. This creates an **environment** stimulating initiation of change in health practice and policymaking (Harvey and Holmes 2012). Secondly the use of NGT allowed for reaching of **consensus** during the session. Previous studies have reported that this creates a sense of achievement and effectiveness among the members (Harvey and Holmes 2012). Lastly, using NGT was **time-efficient** and offered financial advantages as the only expenditure was the refreshments provided during the meeting. Gathering a group of experts in a once-off meeting takes into account the limited availability of clinicians and other health practitioners, and also saved time for the project team. The invited experts were not required to do any preparation, which was an important consideration with regards to their busy schedules and encouraged their willingness to participate.

3.4 Summary

Findings from the analysis of the scoping study, the empirical study and the NGT were combined to identify the priority areas of dementia education that Elevator will address. Elevator's initiatives will maximise awareness and understanding of dementia across all sectors of society in Ireland. Our results will also be used to inform and develop other educational initiatives, now and in the future, which aim to improve the quality of life for people with dementia.

Longer term aims include empowering communities and professionals to better understand dementia, enabling caregivers to provide best-practice person-centred care and allowing people with dementia to live safely and autonomously in their own homes for as long as possible. Other positive side effects may include reduction of healthcare costs, improved distribution of resources to people with dementia and a reduced burden on caregivers.

4. Empirical Study

The empirical study was carried out by adopting a qualitative case study approach to explore in depth the dementia information and education needs not only of healthcare staff but also the person with dementia, their family and informal carers as well as members of the community.

Three specific geographical locations were chosen representing communities in Ireland, including that of a city, town and rural location. Within each location, together with the carer, the person with dementia nominated an exhaustive list of people in the community they interact with, including their GP and staff in hospitals. As many of the named people as possible were followed up and interviewed about their dementia awareness and education needs. This approach placed the people with dementia at the centre and unveiled the possible interactions facing them in their daily lives. Consequently, it led to the identification of the education needs of members of the nominated network.

All data was collected between December 2013 and February 2014. Data from all three sites were collated and cross case analysed. The findings are reported under the headings below: People with dementia, Informal family carers, Community networks, General Practitioners and Healthcare professionals (Community healthcare professionals, Hospital staff, and Nursing home staff).

Instances where there are variations in the reported educational needs of participants from the same background but different locations are highlighted throughout.

4.1 People with Dementia

The interviews with the three individuals with dementia were guided by a set of prepared questions, assessing their awareness and need for information on different aspects of dementia (Appendix C). The participants were recruited by liaising with local GPs in the specific geographical site. Whilst all three participants were identified as being in the early stages of dementia by their GPs, their awareness about their condition and ability to contribute to the discussion was limited. This illustrates the frequent late presentation of people with dementia in primary care. The three participants had similar level of awareness and education needs about their condition despite their varied geographical locations.

4.1.1 Existing Information

The participants had little awareness about the range of information currently available from varied sources, including the ASI. The need for information on **planning for the future** was largely dismissed by the participants either replying they *'have it all sorted'* (in response to a question regarding their Will) or that they are taking one day at a time. Similarly they did not see the need for information about driving regulations as they felt that they would know themselves when their driving may become a safety issue to other road users.

4.1.2 Current Information Needs

The people with dementia in this study had very poor awareness about the **progression of dementia**, with one participant believing the anti-dementia medication has stopped his deterioration indefinitely *"I'm on a tablet now this will stop it"*. All three expressed an interest in receiving more information about the progression of dementia. Furthermore, this also suggests that there may be a need for more information about dementia medication.

Similar to the lack of information about progression of dementia, their knowledge on **psychosocial treatment** was also minimal, apart from mentioning their usual hobbies and interests. These included walking, music and being members of clubs and societies. They all welcomed more

information on how to slow their dementia progression and maintain independence. They were all aware that they were on some form of medication for their memory problem. However, none were able to recall the name of the medication or had information about how to manage it.

All three people with dementia seemed to have awareness about maintaining **safety and independence in the community** but relied primarily on their families and neighbours for this. None of the individuals had received information on assistive technologies available to them, like personal alarms. Again, they welcomed more information on this area.

4.1.3 Mode of Delivery

All three participants would welcome information in a simple written format. Ideally, they would welcome a simple leaflet design with bullet points on tips or suggestions from which they could choose the options suitable to their personal lifestyle and stage of dementia.

4.2 Informal/Family Carers

The interviews with the informal family carers of people with dementia that participated in this study were guided by the prepared set of questions, assessing their need for information or education on different aspects of dementia (Appendix D). The informal carers shared the same understanding about dementia education, perceiving it as information on the disease progression, end stages and responsive behaviours. They were all reluctant to receive any of this information until the person with dementia in their care was at such stage or they had to deal with a form of responsive behaviour themselves. Thus, generally because of their perception of dementia education, initially they declined any need for information on dementia. However, when they were asked specifically about different aspects of dementia information like psychosocial support, assistive technologies they were interested in receiving such information.

4.2.1 Existing Information

None of the carers expressed an interest in **generalised information** about dementia as they felt that everything depends on the individual with the condition and their circumstances.

“I don’t think I’d like information on dementia because you see it’s so personal, like he’s doing fine as it is and a lot of the information wouldn’t apply to him. We just try to do our best” (carer, city).

There was also a very strong theme across the cases that carers didn’t welcome information about the **late stages of progression** of the disease. They expressed that this was due to the burden of current physical and emotional responsibilities of their recently acquired roles as carers. They felt it was impossible to process any information that does not apply to their current tasks. However, they did express a **need for an established point of contact** being a Public Health Nurse (PHN) or Occupational Therapist (OT) so that when a need arises they can get the necessary information, get help, or be pointed in the right direction. In one location the contact was provided by a charitable organisation, which offered a lot of reassurance for the carer – *“just to know it’s there when I need it”*. Similar to timing the information to their personal needs, the carers felt very strongly about welcoming information specific to their individual context – i.e. the specific symptoms of the individuals they care for as well as their needs and abilities to care.

“At the moment, he’s doing fine and we’re managing fine, and when the time comes that we need help it would be good to know someone who could give you the information” (carer, rural area).

4.2.2 Current Information Needs

The carers from the three locations expressed mutual disappointment in current availability of education immediately after diagnosis and identified this as the priority need for education.

“Everybody tells you about the end result but nobody tells you about this part, this part is very stressful. By the time we get to end stage the help is there, but there is no help for me in my day to day running of things...and it’s getting harder by the moment” (carer of person with early stage dementia, town).

“It was mostly I found that a lot of the information is about people in the late stages and how to look after them and that doesn’t apply to him yet... when they are diagnosed I think you need information, you’re in the dark, you need information on how to deal with it” (carer of person with early stage dementia, rural area).

They were also interested in brief education around the signs and **symptoms across different stages** of dementia. The need for information on how to **communicate with each other about dementia** was also recognised as an education need. The carers felt that because of this lack of information at the moment they completely avoid the discussion. They also identified a need for education (with support of a leaflet or online form) on how to **inform their extended family** (grandchildren, siblings, even children that live abroad) about someone having dementia. They felt that within existing courses there was not enough information addressing their own needs and how to care for themselves, in comparison to the amount of information provided to help them care for the person with dementia.

4.2.3 Mode of Delivery

The carer’s preferred mode of delivery was one on one, available to them as needed. This could be a nominated person like a healthcare worker, social worker, or other member of the primary or community care team. Ideally the carers would like to see the information being delivered by either another family carer or formal carer.

[This info could come from]...“Somebody who’s maybe looked after somebody or even somebody who works looking after people with dementia.... For somebody to explain it to you...you know rather than to get something and read it. I think it’s more relevant if somebody who has gone through it and knows people with dementia explains it to you” (carer, rural area).

4.3 Community Networks

The interviews with the community networks nominated by the people with dementia were guided by the prepared set of questions, assessing their awareness and need for information or education on different aspects of dementia (Appendix E). The people in the community networks interviewed included retail staff, post office workers, pharmacists, a priest, bank staff, real estate agent, taxi drivers, security officers and other people living and working in the community. Overall there were vast gaps in the information available to people in the community and a real hunger for knowledge on dementia. There were some divergent themes across the rural location when compared to the town and city locations. Evidence of stigma and ageism were also reported.

4.3.1 Existing Information

In most cases when the participants were asked about their understanding of dementia they assumed it was very poor. Despite that, once probed further they made very intelligent guesses and had some awareness about **dementia and its prevention**. Unfortunately there were also members of the community that showed high levels of ageism and stigma about dementia. A taxi driver referred to a nursing home as Alcatraz and expressed his apprehensions about providing his services to people with dementia.

“Well, here we are Alcatraz”

“I wouldn’t intentionally take someone with dementia...How could you leave them off on their own?”

(taxi driver – urban location).

4.3.2 Current Education Needs

All members of the community welcomed general information on **recognizing dementia** including the signs and symptoms. They also felt they should be educated on actions to take once they recognise an individual may have dementia, especially when they encounter a person with dementia on their own without a family member present. The main information that people felt they needed was who to contact next. There were differences in the attitudes of participants living in rural and city areas when asked about **maintaining the safety of people with dementia** in the community. In the city location the majority of people believed that this responsibility should be passed onto organisational security members (e.g. security officers).

“If I came across someone that’s lost and confused I would probably just call the security, they would know what to do” (retail staff, city location).

The security officers in turn believed that responsibility lay with members of An Garda Síochána. Despite community members passing the responsibility with best intentions, the attitudes of some members of the Gardaí towards maintaining the safety of people with dementia were alarming.

‘I’d treat them [people with dementia] the same as I would a drunk person, if they comply - great, if they don’t, I’d have to use force’ (member of the Gardaí).

In the rural location community members demonstrated a different attitude, which is likely due to a much smaller population size, with much fewer people living in the community, many of whom know each other. Most of the time, they responded stating that they would try and contact a family member.

The members of the community who interact with people with dementia on a regular basis (especially post office workers and pharmacists) identified a real need for increasing their **practical skills**. The main education need identified was how to **communicate** effectively with people with dementia (e.g. explain things like pension, or medication already collected). They also felt there is a need for practical information on how to deal with **responsive behaviours** to avoid relying on security or Gardaí members. Responsive behaviour reflects a reaction to something in the environment that is negative, frustrating or confusing to the person with dementia. Often referred to as challenging behaviour (responsive behaviours are discussed in detail on page 44).

‘That’s the real worrying part about it... people would come in to withdraw their pension on a Friday and then maybe on a Monday or Tuesday they would be looking to withdraw it again...This is very frustrating and where the issue of training, education and instruction would be of huge help’ (post office worker, town).

The pharmacists also welcomed information on where to signpost families for different services – leaflets for families (e.g. on psychosocial support or diagnosis).

“Families often come in here straight from the GPs and they would have a lot of questions that we wouldn’t be able to answer but having leaflets would definitely help to point them in the right direction” (pharmacist, city).

The need for education around the legal information was recognised by most businesses. They felt they had very little information in terms of their legal standpoint on people with dementia making transactions if they appear not to have the capacity to do so. Similarly the education need from the opposite path, meaning that if person with dementia does appear to have the capacity to understand, yet their carer or family members seem to take control and want to receive all the information on things like pension or medication.

4.3.3 Mode of Delivery

The preferred mode of delivery of dementia education or information was identified as provided by a reliable source specific to the organization. In addition, if the organization required staff to complete CPD courses, they suggested this was the ideal mode of delivery. It was recommended the practical skills on dementia education should be delivered in a case scenario format, followed by some literature.

“You have to do a set number of online CPD courses per year and there are very few available so if there was one on dementia more than likely it would reach all pharmacists” (pharmacist, city).

“If you were to get together with the Irish Pharmacy Union (re.). Giving a presentation to pharmacists that would be extremely beneficial and you’re going to go straight where it counts’ (pharmacist, town).

4.4 General Practitioners (GPs)

The interviews with the GPs were guided by the prepared set of questions (Appendix F), assessing their practice and education needs associated with delivering care for people with dementia and their families. These included diagnosis, disclosure, treatment (both social and medical), carer support, ethical and legal issues, therapeutic communication for dementia and formulation of person centred care.

4.4.1 Existing Information

All three GPs that participated in this study were very well informed about dementia with the majority having a specialist interest in medicine of the elderly or specifically in dementia. They reported that they themselves had few education needs and rated their current dementia care knowledge/practice as either good or satisfactory as compared to most GPs (Cahill, 2012). One of the GPs that did not take part gave the following explanation:

“We don’t generally tell our patients they have dementia because it’s such a devastating degenerative disease”.

4.4.2 Current Information Needs

Two out of the three GP’s had a good understanding about **dementia prevention**. However, they both acknowledged that they don’t explicitly mention risk of developing dementia to patients who present with modifiable risk factors for dementia, although they may talk about lifestyle behaviours in the context of heart or brain health.

“We would treat dementia as part of other cardiovascular diseases, we wouldn’t tell patients that if they continue to have a bad diet they are at risk of developing dementia” (GP, city).

“Concern would be that patients would have a good diet. If they are retired, which many of them are, other than the early-onset dementias, that they have enough stimulation in their lives to keep themselves active-cerebrally active” (GP, rural area).

All three GPs expressed uncertainty around the **dementia care pathway** – and pointed out that once they had referred their dementia patients to hospital there seems to be a lack of communication, which makes providing follow up care difficult. One GP also expressed concern about referral processes and gave the example of having to refer a person with dementia to a hospital in order for them to gain access to services such as respite. He felt strongly that GPs should have the authority to link people with dementia with these services, to avoid unnecessary hospital referrals.

“It’s a quagmire...What’s the likely outcome of referral? I don’t know” (GP, town).

The GPs felt they should be better informed about the **psychosocial services** available to people with dementia and their carers. They were aware of ASI, but not of more specific services like Alzheimer's cafés, or carer support groups. They expressed that due to the nature of their role, they wouldn't have the time capacity to inform people directly about all these services. However, they would welcome having sufficient up-to-date information so that they could pass on that information to people with dementia and their families.

The GP in the rural community said that he was fighting to get more psychosocial supports for people with dementia:

"That's why we're fighting so hard to get psychologists and other people to help the stimulation of persons with dementia".

This GP gave the impression that he was already devoting a lot of time and energy to improving services for people with dementia. He spoke mainly about his involvement in plans to build an Alzheimer specific care unit in the town.

All three GPs felt comfortable about prescribing dementia medication. Nevertheless, they all identified this as an information need. The GP in a rural area acknowledged the 'short shelf life' of dementia medication but didn't express any education needs in terms of prescribing. The GP in the town stated that GPs are reluctant to prescribe and that they wait for a definite diagnosis before they do so.

In terms of ethical decision making around end of life dementia care, one of the GPs expressed a need for information around how best to deal with ethical dilemmas, especially where family members are at odds with the decisions taken by their relative with dementia:

"What we need to know is, if a person with dementia gets pneumonia and recognises they are at the end of life and would like to die at home, but children or carers fail to recognise that and feel they should be treated medically".

4.4.3 Mode of Delivery

The GPs suggested that training needs to be flexible to take into account the GP's preferred method of education. This could be in the form of articles in medical journals, CPD or through GP meetings. They also felt that all education should be backed up by support.

"There is no point educating GPs about psychosocial treatment if this treatment is not available to them to direct their patients to" (GP, City).

"In terms of non-pharmacological alternatives, what's available? None. Nada. Nil. That's why we're working so hard to get psychologists and other people who will help the stimulation of people. There is nothing available" (GP, rural area).

The participating GPs also expressed a preference to be trained by GPs rather than any other healthcare staff. They also recognised that not all GPs see dementia education as necessary or required – if they are based in an area with a mainly young population they tend to have an interest in other areas like women's health or paediatrics.

"Education doesn't change behaviour. We need strategies to convert education to behavioural change" (GP, town).

4.5 Healthcare Professionals

The interviews with the healthcare professionals from all settings including: community, hospital and nursing homes, were guided by the prepared set of questions (Appendix G) assessing their practice and education needs associated with their role in caring for people with dementia and their families

within the community. These questions included, understanding dementia, signs and symptoms, improving quality of life, treatment, responsive behaviour, carer support, end of life, ethical and legal issues, communication for dementia and formulation of person centred care.

4.5.1 Community Healthcare Professionals (existing information, current information needs and mode of delivery)

The community healthcare professionals interviewed were mainly OTs and social care workers, as these were the health care professionals most often nominated by the people with dementia participating in the study.

4.5.1.1 Existing Information

The OTs felt they had good understanding about dementia and didn't have a need for general information about dementia. They expressed a real need for up-skilling in terms of the practical activities they may be carrying out with people with dementia.

4.5.1.2 Current Information Needs

The healthcare professionals identified the **practical up-skilling** that would enable them to better **communicate** with the person, help **stimulate the person cognitively**, or provide them with ways of encouraging the person to carry out **daily living tasks**, as their primary education need. They felt that by nature their work was very practical, but constrained because of time limits and caseload. They expressed practical skills are of main importance to the nature of their work.

"We would often be talking to people in their own home where they feel at ease and usually tell us more information about how it affects them as a couple and we don't always have the answers" (OT, city).

"We need to know how to get someone who is very physically able to get motivated mentally, to stimulate their cognition, which is something we are not used to and need more information and training on" (OT, city).

"Professionals working with people with dementia and their carers need to become better skilled at delivering effective group interventions for families and carers. Delivering information alone to families and carer groups is not enough because at the end of the group they go home and they are still left with the struggle" (community-based social worker, old age psychiatry team, rural area).

OTs identified the need for education on **assessing memory** complaints and would also welcome better liaison with GPs and other primary care team members about the person's diagnosis. They reported that they weren't always informed about whether the person had a diagnosis or not, or whether they had been assessed recently. Furthermore, they could recognise the memory complaints, but at times refrained from assessing the person as they were concerned that they may be repeating the GP's work.

"We are often referred the patient and only realise they have cognitive difficulties when we meet them, and even though we recognise their cognitive difficulties or memory complaints we don't assess them because that's not on their referral... it's pointless to keep assessing their cognition because we are not informed and the GP could have done it only the day before..." (OT, city).

They identified a need for information on development of a **clear pathway** that would enable the OTs and other health care staff (public health nurses (PHNs), physiotherapists) to communicate within the primary care teams about the assessment or other relevant information about the person with dementia's condition.

4.5.1.3 *Mode of Delivery*

The community healthcare staff felt they would like the education to be delivered as one or two full day workshops including examples of practical solutions and use of videos, case studies or narratives. It was important for them to have the education delivered by another practitioner or at least someone who has awareness about the nature of their work.

4.5.2 **Hospital Staff (existing information, current information needs and mode of delivery)**

The staff from three hospital sites adjacent to the geographical locations chosen as case studies for this ENA participated in the interviews. The hospital staff that participated in the interviews included geriatricians, nurses, health care assistants, occupational therapists, physiotherapists, a porter and social care workers. The participating staff came from various settings within the hospital including the A&E, acute and medical wards.

4.5.2.1 *Existing Information*

The majority of the hospital staff expressed their interest in dementia education. However, they also felt that due to their workload and staff shortages they might not get to firstly avail of dementia education on offer and secondly put what they had learned into practice. They felt that under the current time constraints within which they worked, they could barely manage to attend to patients' physical needs and anything extra is near impossible.

"This just simply isn't the setting" (A&E nurse, city).

4.5.2.2 *Current Education Needs*

Because of their focus on the acute medical needs of patients, it is not surprising that the majority of the hospital staff were mostly interested in **general dementia education** and didn't see the logic from a practical point of view in receiving information on **psychosocial treatments** or how to improve **quality of life** for people with dementia. They felt similarly about up-skilling their **communication skills**, and considered that responsibility for this lay with other staff members such as a social worker.

"We're very lucky we have a Social Worker here on the ward" (orthopaedic nurse, rural area).

The staff did recognise the need for more information on the **assessment of pain**. They were worried that in some cases people with dementia were under rating their pain due to communication difficulties resulting in lack of administration of pain relief and feeling of discomfort. Similar to healthcare staff in the nursing homes, the hospital staff also identified the management of **responsive behaviours** as the primary education need.

"Sometimes they might be in pain.... so they communicate that by shouting inappropriately" (A&E nurse, town).

"Its very hard if you're not trained, you don't know what's making them agitated" (hospital porter, town).

Furthermore, the staff felt that they had poor knowledge about **anti-dementia drugs** and their management, especially in terms of administering them with other medication. They were all interested in receiving education in this area. The use of **antipsychotic and sleeping medication** in conjunction with anti-dementia drugs was also recognised as a gap in nurses' knowledge.

Interviewer: *"In terms of dementia specific medication management is there good knowledge about it?"*

“No... definitely not... 100% not and especially regards to what medication and what times to avoid and how quickly may people be asking for a sedative or what things might set them off... No I definitely don't think we have enough” (assessment nurse, hospital, city).

4.5.2.3 Mode of Delivery

A predominant theme to emerge from interviews with staff in hospitals around the delivery of education was that it should be delivered on-site, with multiple opportunities to attend. Furthermore it was suggested that each session shouldn't be longer than half a day to a full day maximum. This was influenced by lack of time and difficulty in getting released.

“We have a teaching room. They have paediatric study days, so why not dementia? They could roll it out over a week” (A&E nurse, town).

Other suggestions included the use of flashcards for healthcare professionals in busy settings like paramedics and A&E, which are currently used for other conditions like hypothermia. Due to their familiarity with these, health care professionals would welcome the same method of delivery of information about dementia. The reliability of information received was also important, suggesting the education should be delivered by a qualified healthcare professional.

“You hear things and you never know if it's true or not...I don't know that as a fact. Even just one talk that covered everything would be fierce useful” (health care assistant, town).

4.5.3 Nursing Home Staff (existing information, current information needs and mode of delivery)

The staff from three nursing homes located within or close to the geographical locations chosen as case studies for this ENA, participated in the interviews. The nursing home staff that participated in the interviews included: nurses, day centre managers, activity coordinators, Healthcare Assistants (HCAs), social care workers, hairdressers and kitchen staff.

4.5.3.1 Current Education Needs

Communication skills weren't recognized as an education need by nurses from city and town based nursing homes. In comparison, in the rural based nursing home, staff felt it is an important factor and would welcome more information about it. However, in nursing homes across all three geographical locations, staff other than nurses (activity coordinators, day centre managers) who were aware of the effects of poor communication with people with dementia, were of the view that nurses' communication skills were often inadequate and identified this as a significant education gap for nurses.

“They really need the basic training at the very lowest level when it comes to understanding how the person with dementia feels and only then this should be followed by communication skills” (day centres manager – about nurses in the nursing home, city).

Similarly **Communication with families** wasn't considered to be an education need among nurses or other healthcare staff in the urban and city nursing homes. They didn't view talking to families as part of their role. Furthermore, they seemed to think families' informational and emotional needs are taken care of by other healthcare professionals, like GPs.

“We wouldn't talk to the families, they usually come in informed the GP's would do that” (nursing home nurse, city).

“I wouldn't have the right words to talk to the families, I do get emotional and they don't need that, they don't need to see me upset.. chaplain would know what to say they are much better at that” (activity coordinator, nursing home, city).

There were few nurses who saw working with families or couples as part of their role. The large majority did not express any interest in this area and considered that responsibility for this lay with other health care professionals.

“...Some guidelines on the pertinent questions to ask families” (day hospital nurse, rural area).

“Would be good to have help with the right words, the proper way of asking (re end of life)...need to be sensitive” (nursing home nurse, rural area).

In comparison the staff in the nursing home based in the rural location felt that communicating with families plays a vital role in the provision of good dementia care.

“We are lucky because most of us would know the families already; we would have a good relationship with them” (nursing home nurse, rural area).

The activity coordinators and day centre managers expressed a real education need to become skilled in psychosocial approaches to supporting cognition and emotional understanding of people with dementia in their care. Additionally, there were a small number of nurses who identified a need to become skilled in psychosocial approaches to supporting cognition and communicating with people with dementia.

Disturbingly, even though up skilling the communication skills was not recognised as an education need by majority of the nurses, dealing with **responsive behaviours** was identified as the primary education need by nurses. Similarly, the availability of emotional support to healthcare staff was not acknowledged as something beneficial to them. The majority nurses felt they didn't have or need to discuss any emotional burdens within a support network at work. When asked if they communicate **with other staff and healthcare providers** working with the person with dementia, a typical response was as follows:

“They have 10 people in there [residents' room] at a time and sometimes I have to go in and get them all out and start again... I try to explain to them to talk slow and keep eye contact but it's just like talking to a brick wall” (activity coordinator on communication and responsive behaviours, nursing home, city).

The majority of nurses also didn't see the need to be educated around the issues of **PEG feeding/NG feeding**. In most cases they considered this to be the responsibility of other healthcare staff, like palliative care teams. They seemed to be indifferent to receiving education in this area. Nevertheless, A&E staff were of the view that this was an important area of education for nursing home staff. Similarly, the use of **antipsychotic and sleeping medication** education was recognized as a gap in nurse training across all nursing homes by GPs, social workers and OTs, but not by nurses themselves.

“Nurses often put pressure on GP's to prescribe antipsychotic and sleep medication where there might be other solutions, or no real need for them” (GP, city location).

4.5.3.2 Mode of Delivery

Similar to the hospital staff, the nursing home staff suggested that the education should be delivered on-site, with multiple opportunities to attend. Again, it was suggested the session shouldn't be longer than half a day to a full day maximum, with lack of time and staff shortages as the main reasons offered for this. The staff also advised that the training should be flexible to the specific people receiving it and should include some practice elements to allow them to step into the person with dementia's position and ideally with a chance to be assessed through a shadow system. Moreover the staff desired use of videos, case studies, narratives and role-play.

“Not a lot of people like the books and not a lot of people like the slides and lectures all day, it has to suit the person but the role plays really make you see it how the person with dementia might be seeing it” (activity coordinator, city).

4.6 Summary

The findings from the empirical study presented above offer a synopsis of views on information, education and training from the perspective of the person with dementia and the network of individuals surrounding them in their everyday life. The themes that emerged from interviews with a range of individuals from three specific geographical locations were collated and give a depiction of the level of awareness and knowledge in the social and health care environments (community, primary and acute care, as well as long-term residential care settings) in which people with dementia live. While the level of dementia education currently received by many of those interviewed was limited and leaves room for improvement, this was matched in most settings by hunger for knowledge about dementia. Participants identified a number of challenges for dementia education provision in various settings with the predominant ones being staff shortages and limited time designated for education in healthcare settings.

The main themes about current education needs are briefly summarised for each of the participants' groupings in this study.

- **People with dementia:** felt they would like more information about progression of the disease, flexible choices of treatment available to them and maintaining independence in the community.
- **Informal/ Family carers:** felt they need more education on a day-to-day basis, flexible to their current needs and challenges. Ideally they expressed a need for one designated person they could contact as needs arise. Carers' needs included education and support immediately after diagnosis, means to communicate with each other about dementia and its impact on the relationship and education on informing extended family about the diagnosis and on living with dementia.
- **Community Networks:** felt they needed to be more aware about dementia as well as practical information about how to communicate, how to help maintain the safety of people with dementia within their community and how to deal with responsive behaviours.
- **General Practitioners:** felt they need more encouragement to inform patients about primary prevention of dementia specifically, rather than as part of other diseases. GPs expressed desire for a standardised dementia care pathway with clear and integrated follow up systems in place. They welcomed information on psychosocial interventions only if such are backed up with operative services within their jurisdiction.
- **Community Health Care Professionals:** expressed a need for practical up-skilling that would enable them to better communicate with and stimulate people with dementia cognitively. Similar to general practitioners, they expressed a need for a standardised pathway integrated with all healthcare settings, particularly with regard to assessing memory problems in a timely manner, and for the provision of post diagnostic supports.
- **Hospital Staff:** were interested in improving their general dementia education and despite their hunger for therapeutic up-skilling, deemed that due to the nature of their setting this would be impractical. They recognised assessment of pain, dealing with responsive behaviours and education on dementia specific drugs, as education needs most applicable to them.
- **Nursing Home Staff:** There was some inconsistency in the education needs identified by nurses and other healthcare staff in the nursing home setting. The main education need identified by nurses was dealing with responsive behaviours. They did not feel that there was a need for them to be educated on communication with people with dementia or their

families. They felt they had a satisfactory level of information about person centred care, improving quality of life and antipsychotic drugs. However, other members of the staff felt that the nurses need basic person centred care awareness or education. Similarly, the GPs felt that nurses in nursing homes need education around the use of antipsychotic medication. The above only arose with respect to the city and town locations. In the rural setting all staff had a hunger for knowledge on communication and improving quality of life and felt communicating with families was an important part of the care of a person with dementia.

5. Scoping Study

The scoping study presents the state-of-the-art in best practice in dementia care, existing services and educational opportunities, covering educational and training needs across the following areas:

- Community
- Primary Care settings
- Health Care settings

Within each setting the availability and accessibility of dementia education and training programmes were examined from a broad perspective, as well as specifically for targeted groups like informal carers in community settings or nurses in health care settings. The review covered both national and international standards and methods by which governments and independent parties assessed and provided education and training. Furthermore, the timing, mode of delivery and reported outcomes of such training were examined.

The findings do not provide a systematic review of education available in each individual area as such is beyond the scope of this study. The reported findings provide scoping examples of best practice in dementia education. Individual systematic reviews will be undertaken once the priority areas are identified at the end of this ENA study. The scoping study findings start with a discussion of educational and training needs in a community setting.

5.1 Community (Awareness, Skills and Knowledge)

An exploration took place of the published and grey literature, for examples of best practice in raising awareness, skills and knowledge on issues pertinent to dementia. What follows is a précis of best practice from the accumulated sources. We have divided this section into two areas:

- Dementia awareness among community members
- Information and Education for People with dementia and their family carers.

The outcomes discuss the best practice, existing practice and educational needs in these cases.

5.1.1 Awareness in Community Members – International State of the Art

Many people with dementia have described the ‘stuff of life’ as, being able to use buses, the local shops, banks, post office, pubs, libraries, leisure centres which “connected” them to their communities (Burton, Mitchell and Lynne Mitchell 2013). This leads to a broad target for awareness raising about dementia. Despite the growing impact globally, a lack of understanding of dementia contributes to fears and to stigmatization. For those who are living with dementia (both the person and their family), the stigma contributes to social isolation and to delays in seeking diagnosis and help (World Health Organization 2012). Miles (1981) defines stigma as “a societal reaction which singles out certain attributes, evaluates them as undesirable and devalues the persons who possess them”. Dementia awareness raising can help combat stigma by using interventions that are likely to involve a multifaceted approach that tackles public perceptions (Mukadam and Livingston 2012). The World Health Organisation, (2012) highlight the urgent need to improve the awareness and understanding of dementia across all levels of society.

Hallmarks of awareness campaigns appear to be cascaded approaches to training, delivered at a community level. The following are some examples of these types of initiatives.

The UK flagship awareness programme, Dementia Friends, is a government funded national initiative, run by Alzheimer’s Society UK, which was launched in February 2013. Trained Dementia Friends Champions complete a one-day training course. The course delivers information about

dementia, how it affects people, and the practical actions that a Dementia Friend can take that can help someone with dementia living in their community. The Dementia Friends Champion is then enabled to set up and run a 45 minute dementia information session in community settings such as, lunch clubs, knitting groups and book clubs, tenants' associations and residents' groups, social clubs, students unions, workplaces and at places of worship.

In a similar exercise in Japan, the 'Nationwide Caravan to Train One Million Dementia Supporters' programme established in 2005 aimed at training, in five years, one million 'dementia supporters' who understand the characteristics of the disability and provide support for people with dementia and their families. Through its training courses, 694,854 dementia supporters were trained nationwide as of 2008 (Yamamoto and Hoshi, Yamamoto and Hoshi 2011).

The Dementia Action Alliance (DAA) is comprised of 800 member organizations throughout the UK who have committed to supporting people with dementia and their families to live well in society. The organisations come from a wide range of sectors and have committed to deliver the National Dementia Declaration; a set of seven outcomes informed by people with dementia and their family carers. The Declaration provides a vision of how people with dementia and their families can be supported by society to live well. Alliance members work towards delivering this vision through committing to actions within their organisation and collaborating with other organisations. Through their website, the DAA calls on organisations to sign up and provides sector specific information in a dementia friendly toolkit, as well as telephone support.

Table 1 summarizes several examples of approaches to address community awareness, grouped according to the target of the approach, national remit, local businesses and community services, the arts, research, social media, minority groups and school pupils. This is not an exhaustive list of education and awareness initiatives - many other examples exist which could not be included in this report. It is also worth noting that a clear-cut distinction between educational and awareness initiatives cannot always be made and that the examples outlined in the table below may include elements of both.

Table 1 International Dementia Awareness and Educational Initiatives

Approach	Description	Examples project/s
National Organisation	<p>Draws on research and practice from across the world, to provide a comprehensive, up to date resource on all aspects of dementia. Stated aims are to improve the design of care environments, to make communities dementia friendly and to influence policy and improve services for people with dementia.</p> <p>Aims to improve the quality of dementia care in Australia by enabling people with dementia and their carers to get involved in dementia research activities, and through supporting projects that promote evidence-based best-practice in dementia care.</p>	<p>DSDC - Dementia Services Development Centre, Stirling University, Scotland.</p> <p>National Quality Dementia Care Initiative, Alzheimer's Australia (NQDCI)</p>
Targeting local business	<p>Provision of staff training on dementia to local businesses with the aim of becoming dementia friendly.</p> <p>Establishment of a collaborative with local businesses and key community service providers. Involves provision of dementia training for businesses and other community organisations.</p> <p>Provision of grants to local business who wish to become dementia friendly.</p> <p>Dementia awareness raising -staff, customers and wider community. Includes the use of the knotted handkerchief symbol in their shop</p>	<p>The Cooperative and Lloyds TSB, Bradford, UK.</p> <p>Western Isles Dementia friendly project, Scotland</p> <p>East Sutherland, Dementia Friendly Communities, Scotland.</p> <p>Dementia Without Walls project, York, UK.</p> <p><i>Together for a dementia friendly Bruges!</i> Bruges, Belgium.</p>

	fronts - a dementia friendly symbol to those in the earlier stages of the condition.	
Targeting public services	<p>Development of dementia awareness training package for local bus drivers, included in a certificate of professional competency. Collaboration between existing driver trainers and people with dementia and their families to inform about different needs and stages of dementia.</p> <p>Provision of dementia training to housing associations, including an introduction to life story work.</p> <p>Provision of dementia training sessions with local fire fighters and police officers</p>	<p>Ageing well programme, Northumberland, UK.</p> <p>Life Story Network, Merseyside, UK</p> <p>North Lankshire, Dementia Demonstrator Site, UK.</p>
Targeting the Arts	<p>Provision of practical and interactive dementia training in a museum setting using various objects, archives and stories.</p> <p>Provision of guided art gallery tours for people with dementia and their friends and family.</p>	<p>House of Memories, Liverpool, UK.</p> <p>Meet Me at MoMA project, Museum of Modern Art, New York, USA.</p>
Research approach	Aims to translate research into practice in the area of enabling environments for people with dementia. The project website provides information on best practice guidelines as well as providing audit tools for dementia design.	DEEP – Dementia Enabling Environments project, NQDCI, Alzheimer’s Australia.
Online approach	DASNI is an international group of people with dementia. Current activities include internet-based support to help ease the isolation of living with the disease and to educate people about living well	Dementia Advocacy Support and Network DASNI

	<p>with dementia.</p> <p>Provision of a resource to guide communities in becoming dementia capable, practice tools to assist professionals in identifying and managing dementia and new activities that can be shared.</p> <p>Provision of free online resources about vital aspects of psychosocial care for people with dementia.</p> <p>Educational online resource using dramatized scenarios involving a person with dementia in various community settings</p>	<p>Act on Alzheimer's Project, Minnesota, USA.</p> <p>The Caregiving and Dementia Wiki Project, Dementia Training Study Centre, NQDCI, Alzheimer's Australia</p> <p><i>Is it Dementia?</i> Alzheimer's Australia</p>
Targeting minority groups	A risk reduction project targeting Aboriginal people incorporating two sessions using a DVD followed by interactive discussion as well as Alzheimer's Australia <i>Mind your Mind</i> resource	Aboriginal and Torres Strait Islander Risk Reduction Project, Australia.
Targeting School goers	The dementia resource kit for schools presented a range of information on dementia that aimed to help school goers continue their relationship with a loved one who had received a diagnosis of dementia.	Ageing and Changing Project, Alzheimer's Australia
Media approach	TV campaign focusing on dementia awareness	<i>Leading the fight against dementia</i> campaign, Alzheimer's Association, UK.

Awareness raising is an integral part of several National dementia strategies, for example, within the French strategy where the provision of information to the public about dementia was one of the main objectives. Several different approaches in terms of the training medium (face to face, online and paper based) have been used. It would seem that one approach is not vastly superior to another. More importantly, the approach needs to be fit for purpose and flexibility in approach seems to be the predominant trend.

5.1.2 Awareness Among Community Members – State of the Art in Ireland

In Ireland work to support better awareness is evident. For example, the ASI have carried out two media campaigns to improve awareness and Genio dementia projects have made innovative attempts to highlight the issue of dementia. There are also on-line approaches to improving awareness on all aspects of dementia such as Freedemliving.ie – short online films about dementia targeting the general public. Little is known about the effectiveness of these awareness raising campaigns/initiatives and there is a need to evaluate these early attempts and instigate a well thought out plan to improve awareness skills and knowledge about dementia in community members, including front line public service staff and the general public.

Table 2 below outlines the aims of Irish community awareness schemes.

Table 2 Exemplar Irish dementia education projects

Approach	Description	Exemplary project
National Organisation	National Centre for excellence in dementia care. Engages in education and training, information and consultancy, research. Aimed at staff providing services to people with dementia.	DSIDC Dementia services and development centre.
Targeting local business	Provision of dementia awareness training to local shopping centre staff. Use of table tents containing key facts about dementia in local restaurants. Currently developing Universal Design Guidelines for Dementia Friendly Dwellings and provision of technical guidelines to various stakeholders including businesses	Genio Dementia Project – Dublin in collaboration with Dementia Services Information and Development Centre (DSIDC), Dublin Five steps to Living well with dementia – South Tipperary in collaboration with DSIDC, Dublin The Centre for Excellence in Universal Design, Dublin
Targeting local services	Provision of dementia awareness talks to local community services. Quarterly distribution of dementia education leaflets to GP clinics waiting rooms nationwide.	Community Action on Dementia, Mayo. KCord, Kinsale Community Response to Dementia, Cork. Alzheimer Society of Ireland
Targeting the	Based on the ‘Meet me at MoMA’ model the Azure project provided guided visits of art	Azure Project, Age and

Arts	works for people with dementia and their families and friends	Opportunity, Dublin.
Advocacy approach	<p>Advocacy and information project informed by people with dementia for people with dementia. Facilitates twice monthly information and support meetings for people with dementia.</p> <p>Awareness raising at national and international level, through national media and lobbying senior government. Representation of Irish people with dementia on the EU Working group of people with dementia.</p>	<p>Dementia Research Education Advocacy in Motion (DREAM), Galway</p> <p>Irish Working group of People with dementia, Alzheimer Society of Ireland</p>
Online Approach	Online resource through a series of short animated films. It addresses concerns around memory loss and dementia and provides practical advice about brain health.	Freedem Living project, Trinity College, Dublin
Media Approach	TV, Radio and billboard campaigns focusing on early diagnosis and living well with dementia.	Alzheimer Society of Ireland.
Targeting minority Groups	Delivery of awareness training to the Traveller community - included signs and symptoms of dementia and coping strategies for families of those that have been diagnosed.	Alzheimer Society of Ireland.
Targeting Schoolgoers	Raising public awareness and understanding of dementia of primary school children in Donegal. Involved a creative writing competition, called 'Dear Grandma'.	<i>Dear Grandma Project</i> , Dementia Aware Donegal.

5.1.3 Summary

Several high level attempts have been made to heighten awareness of dementia among community members. It is not clear to what extent such attempts address complex issues of ageism and stigma, which are part of the landscape to a person with dementia. Some of these issues require further evaluation. An evaluation of the House of Memories Dementia training project in the UK was carried out. The review found that participants reported overwhelmingly that the training increased their awareness and understanding of dementia and helped them to see those living with the condition differently. Participants also described feeling confident after the training to try new approaches with those they helped to care and also understood the importance of listening and communicating effectively (Hanna 2012) An evaluation of the ASI Traveller dementia awareness project highlighted that the training dispelled many of the myths and some of the stigma that surrounds dementia for the primary health care workers who work with the Traveller community. It reported that the primary health care workers felt more empowered and confident in their ability to educate older Travellers in the areas they work in about the signs and symptoms of dementia and also coping strategies for families of those that have been diagnosed. Additionally, it was highlighted that

resulting from the project, ASI staff understood more about the resources that are needed to improve awareness about dementia in the Traveller Community (The Alzheimer Society of Ireland 2012). Less obvious, is more specialized skills training for people in a range of different settings. There are international examples of such training but these would largely require localization to be appropriate to Irish audiences. Some resources exist which can be reused in a comprehensive package for up-skilling communities to respond to rising numbers of people with dementia. Training that is cascaded and locally delivered seems to be the favoured method of dissemination in addition to on-line approaches. A clear distinction needs to be made between awareness raising and skills development. Within any organization there is widespread need for awareness. Some people will require more communication skills and a more in depth appreciation of the needs of people with dementia.

5.1.4 Information and Education for People with Dementia and their Informal Carers.

People with dementia need to be equipped with information, self-advocacy skills and disease management education. Relatives of people with dementia will require timely and supportive education. Achieving a balance between support and education poses challenges and requires a high level of skill (Vernooij-Dassen and Dautzenberg 2003) and training and support for facilitators could help impart the messages much more effectively.

Psychoeducation approaches such as Alzheimer Cafes (which will be discussed later in the review) can target the person with dementia, the carer, or both together. Barriers exist to accessing social and psychoeducational support, such as limited time (as carers are often too busy with care activities), worries about costs involved and the stigma of dementia, particularly in older carers from rural areas (Winterton and Warburton 2011). These barriers should be borne in mind when designing education for people with dementia and their carers. It is likely that there would need to be a range of different support mechanisms in place in order to provide comprehensive access. According to the World Alzheimer Report (Prince, Bryce and Ferri 2011) early therapeutic interventions such as cognitive stimulation and reminiscence can be effective in improving cognitive function, treating depression, improving caregiver mood and delaying institutionalization.

Targeting people with dementia can address strengthening coping mechanisms or maintaining cognitive functions (the latter will be described later in the review). Most initiatives seem to target the time shortly after diagnosis, for psychoeducation to make best use of the individuals' capacity to engage, be involved in decisions and maximize skills. Successful programmes usually make a family member/friend/carer welcome to accompany the person with dementia. Participants have an opportunity to obtain information, talk confidentially with others in a similar situation, focus on maintaining and enhancing skills and abilities, and explore ways of managing now and in the future. In post-diagnostic support programmes, topics covered include: symptoms and diagnosis, adapting to change, practical strategies, looking after yourself and planning for the future. One such programme, which supports a dyadic/ couples based approach, is the ANSWERS (Acquiring New Skills While Enhancing Remaining Strengths) programme. ANSWERS combined educational skills, traditionally used with caregivers, and cognitive rehabilitation skills training traditionally used with people with dementia, into a single programme. Key areas addressed by the intervention included: education about dementia and memory loss; effective communication; managing memory; staying active and recognizing emotions and behaviors (Judge et al. 2013). Another form of post diagnosis support is the Meeting Centres Support Programme which integrates a range of support activities such as informative meetings, discussion groups and help with accessing respite care and practical help around the home for people with dementia and their carers (Dröes et al. 2006)

Working in partnership with families and carers involves health care staff's acknowledgement of the expertise of carers, helping carers and families to understand behaviours of the person with

dementia, showing sensitivity to carers' physical and emotional needs. It involves offering timely and personalised support, including discussion of meaningful activities, which can be shared. Staff should be able to empower carers to help inform the role and nature of care delivery by involving them in the education and training of care staff and professionals (Watkins et al. 2011) .

According to Stanbridge and colleagues (2013a) , working in partnership with families and carers is recommended in all national mental health policies for working age adults and older people in Ireland, together with guidelines on how services for carers should develop (Department of Health 2002) . Reports from carers' organisations (Morrissey 2006, Worthington and Rooney 2013) would suggest that implementation is patchy, with many families feeling excluded from their relative's care and without adequate information and support to look after their relative's or their own needs.

Families say that they would like to be listened to and acknowledged as partners in care in a respectful and culturally appropriate way. They require information on how services work, mental health issues (including diagnosis, treatment and medication), support services and who to contact in an emergency. They also want to know how to best respond to their relative and to develop additional coping strategies (Pinfold 2004, Kuipers, Onwumere and Bebbington 2010, Worthington and Rooney 2013) .

The prerequisite of carer support is that the practitioners must accept that it is also their task to support family carers (Moniz-Cook and Manthorpe 2009) . Coordinated care is not simply a reaction to a crisis but is focused on the duality of the personal consequences of the disease along-side the 'caregiving career' (Aneshensel et al. 1995) . Programmes aim to strengthen the primary carer's sense of competence by reducing the negative consequences of caring, to strengthen carers' satisfaction with his or her own performance as a carer and to strengthen carer satisfaction with the person receiving care. While the model was positively reviewed it was highlighted that a programme such as Support for Primary Carers with demonstrated effectiveness is not easy to manage in daily practice, as a range of efforts are required, such as support and supervision for the practitioner, routine systemic evaluation and finding appropriately motivated skilled practitioners (Vernooij-Dassen and Dautzenberg 2003) .

The STAR project and Caregiving and Dementia Wiki Project are examples of initiatives that create educational platforms with associated methodology and content for improving the skills of family members caring for people with dementia. The contents are based on leading dementia expertise and will be distributed in free and open resources about vital aspects of psychosocial care for people with dementia.

5.1.4.1 *Training to Support Informal Carers – International State of the Art*

There are few training programmes described in the literature focusing on family inclusive ways of working, designed specifically for staff working with people with dementia (Stanbridge et al. 2013a, Schweitzer et al. 2007a, Mottaghipour et al. 2006a) . However, some of the training programmes there are report obstacles in translating training in this area into routine clinical practice, related to staff shift patterns, pressures of competing workload demands, insufficient staffing levels and difficulty in releasing staff. Obstacles encountered in acute settings included: lack of experience, training, knowledge and confidence among staff; concerns about confidentiality and sharing of information; role boundaries; lack of time, resources and space; staff shift patterns and the pressures of the workload (Stanbridge et al. 2013b, Mottaghipour et al. 2006b) . Obstacles reported in a combined acute and long-term mental health setting were similar - confidentiality issues, limited resources and a lack of specific skills among professional staff (Schweitzer et al. 2007b) . Issues relating to the subtle boundaries of information sharing and confidentiality have been identified by professionals and families as needing attention (Pinfold et al. 2003) .

As part of the implementation of the Somerset Partnership NHS Foundation Trust's "Strategy to Enhance Working Partnerships with Carers and Families", a three-day knowledge and skills programme in family inclusive ways of working was developed (Stanbridge, Burbach and Leftwich 2009). This programme has a number of aims; to develop an increased awareness of family and carer's views (the stresses they experience and the benefits of family inclusive practice); consider strategies for overcoming obstacles to family inclusive ways of working; consider issues of information sharing and confidentiality; develop skills for holding meetings with families and carers as part of the assessment and admission process. Family members and carers are also involved in delivering the training (Stanbridge, Burbach and Leftwich 2009). The training specifically addressed staff attitudes, which has also been raised in other studies (Horvath et al. 2011). It has previously been shown that involving carers in the provision of training is an effective way of addressing the required shift in attitudes (Stanbridge, Burbach and Leftwich 2009).

5.1.4.2 Training to Support Informal Carers – State of the Art in Ireland

The Alzheimer Society of Ireland (ASI) operates a number of educational initiatives for family carers. These include printed materials such as leaflets, booklets and a carer information pack, a five week family carer training programme in different locations around Ireland, carer support groups and a 6 day a week information helpline which responded to over 4,000 calls in 2012 (The Alzheimer Society of Ireland 2012).

Memory remediation groups are currently in operation in Naas General Hospital, Loughlinstown Hospital and in a centre in Northern Ireland. Cognitive remediation is a behavioral treatment using practice and adaptive strategies to facilitate improvement in targeted cognitive areas like memory, attention and problem solving. These therapies are not well developed in Ireland and the skills are not taught in any detail in undergraduate health related disciplines. No discrete cognitive remediation course was found.

A number of different models of support are evident with unequal distribution nationally. The Alzheimer Café movement in Ireland started in 2011 in Dublin and there has since been a growth in the number of cafes nationwide, which currently stands at 14. According to Jones and Miesen (2004) the Alzheimer's cafe concept is about acknowledging the condition and providing a space to express emotions and discuss any practical difficulties involved in living with this chronic and long-term illness. Morrissey (2006) highlights its usefulness as a more easily accessible facility and maintains that the cafe plays a significant role in the provision of educational, mental health and emotional support for all those who are affected by dementia, without negating other approaches.

Recently a high quality programme has been commenced in DSIDC: *Understanding Dementia and Promoting Family Caregiver' Quality of Life* runs for 1.5 hours weekly for 6 weeks.

This review found that there are few examples of dyadic support in Ireland. Dyadic support offers interaction and communication to couples inclusive of both the person with dementia and their carer. Alzheimer Cafes offer this type of support in an informal setting. The ASI operates social clubs for the person with dementia and their loved ones promoting the concept of 'couplehood' (Hellström, Nolan and Lundh 2007) in dementia care, however the primary focus in the 'clubs' is recreation and mutual support rather than psychoeducation. In DCU a programme called *'With ourselves in mind'* is a 6 week dyadic support group for couples affected by dementia. It offers places to students who wish to become skilled in such strengths based support groups.

5.1.5 Summary

There is a dearth of advocacy training programmes for people with early stage dementia. Appropriate support is needed to enable the person with dementia to speak on behalf of themselves and of other people with dementia (Woods, Seddon and Keady 2007). One factor in successful attitude change would appear to be exposure. For family carers, many who have not received

training, who are dealing with problems we acknowledge as challenging to trained care staff, there is desperate need for supportive intervention. Involving carers in the provision of training has been found to be an effective way of addressing the attitude shift required. Significant resources need to be devoted to this group who will come under increasing pressure to provide adequate levels of care, due to the forecasted rise in dementia prevalence (Cahill, O'Shea and Pierce 2012) .

All people with dementia and their carers should be offered a structured programme post diagnosis, to help them adapt to the diagnosis as successfully as possible (Vernooij-Dassen et al. 2005) . However, if we are trying to make ageing in place a reality for people with dementia, some responsibility for helping people with dementia and their carers live well with dementia will need to be absorbed by communities. This does not mean communities taking on nursing care. It means ensuring that the person with dementia is free from the excess disability caused by stigma and poor levels of awareness and knowledge with regards to dementia.

5.2 Health Care Settings (Training and Education Needs)

Caring for people with dementia is highly skilled work that is emotionally and physically demanding and requires on-going specialist training (Brooker 2007) . The UK All Party Parliamentary Group on dementia (2009) stated that the acute care workforce must demonstrate effective knowledge and skills and concluded that dementia training can make a big difference to the quality of care received and the quality of life of people with dementia in hospital. Yet, available studies suggest that aged care workers, for example, generally have little formal training and minimal or no dementia specific education (Bowers, Downs and Bowers 2008 pg 419) .

It is estimated that about two-thirds of all people residing in long-term care have a form of dementia in Ireland (de Siun and Manning 2010) similar to many other industrialised countries. These people require adequate care and support both physically, emotionally and cognitively from staff. It is estimated that up to 25% of people in acute hospitals will have dementia. The Alzheimer Society 2009 report revealed worrying findings regarding the extended duration of stay, increased risk for moves to long-stay residential care facilities and increased mortality of people with dementia admitted to hospital. The recent HSE educational needs assessment suggested that many staff in both acute and residential settings had received no dementia specific training (de Siun and Manning 2010) . The HIQA standards on training cover Specialist Care Units for people with dementia. However, the majority of people in most nursing homes are not covered by this standard but have some form of dementia or cognitive impairment.

5.2.1 International State of the Art Practices

The dearth of dementia-specific knowledge and skills in acute and long-term care is a feature of many other countries, but several countries have made a commitment to address this through their national dementia strategies. The Scottish dementia Strategy is notable in this regard and its approach is described in more detail below. Despite a commitment to dementia awareness raising, education and training of staff in hospitals in the English and Welsh strategies, little change appears to be in evidence.

Findings from the National Audit on Dementia carried out in England and Wales (2011) revealed minimal evidence of person-centred approaches being used in hospital wards. Care was generally task-oriented and the hospital environments were deemed impersonal and non-dementia friendly. The audit showed that with regard to training by professions, doctors rated the sufficiency of their training 65% overall, as higher than nurses at 51%, and healthcare assistants at 46%. Nurses rated the frequency of their training as particularly weak in the area of mental health, for example dealing with responsive behaviours, knowledge of the Mental Capacity Act year and knowledge and use of restraints and sedation. Less than half of nurses and healthcare assistants reported that training

received in recognising pain in people with dementia was sufficient. Pain can be a trigger for responsive behaviours (Alzheimer Society 2009) , that if not investigated can lead to unnecessary prescription of antipsychotic medication (Banerjee 2009) .

A second National Dementia Audit carried out in England and Wales in 2013 reviewed progress on the recommendations of the first audit. There was a marked reduction in the use of antipsychotic medication on the wards. However, in terms of dementia awareness, 41% of hospitals are still not offering dementia awareness training to new staff. 41% have offered no awareness training to support staff, and 10% did not provide this training to nurses in the twelve months under review. Too few patients were being assessed for delirium risk and cognitive function.

The Scottish dementia strategy led to the development of the Scottish education programmes for acute care staff “Dementia Care in the Emergency Department” - a free resource for all staff in general hospitals and/or Emergency Departments. It includes “practice points” and links to helpful appendices related to dementia care. Content covers initial contact, assessment, intervention, and resolution. It also contains guidelines for the person with dementia who has to wait, covering such issues as helping the person with dementia find the toilet, remembering to ask about whether the person with dementia has had something to eat or drink, and importance of minimising noise in the Emergency Department. Furthermore, the Scottish strategy developed “Acute Care Dementia” is a free interactive DVD available to staff working in an acute ward environment. It includes practice points for staff and links to videos related to dementia care. It describes “coming into the ward”, “recognising and assessing care needs”, “The Care Experience”, “Meeting the Needs of the Person who is Distressed” and “Leaving the Ward/Transitions”.

The Scottish government has identified four levels of skill required to deliver excellence in dementia care:

1. **Informed Practice Level** provides the baseline knowledge and skills required by all staff working in health and social care settings including a person's own home.
2. **Dementia Skilled Practice Level** describes the knowledge and skills required by all staff that have direct and/or substantial contact with people with dementia and their families and carers.
3. **Enhanced Dementia Practice Level** outlines the knowledge and skills required by health and social services staff that have more regular and intense contact with people with dementia, provide specific interventions, and/or direct/manage care and services.
4. **Expertise in Dementia Practice Level** outlines the knowledge and skills required for health and social care staff that by virtue of their role and practice setting, play an expert specialist role in the care, treatment and support of people with dementia.

As education and skills development are a part of culture change, all staff in health care settings needs to step up one level in order to make a noteworthy change to the lives of people with dementia. For example, from poor awareness to good awareness and from good awareness to skilled practice level. Some forms of education are preferable for achieving culture changes in healthcare settings. Given the current difficulties in releasing staff for training there is a need to be creative in developing and delivering education and awareness programmes that put the person with dementia at the centre. A systematic approach towards education is required to enable the alignment of education efforts within and amongst the various organisations in the Irish healthcare landscape. Dementia education needs to be a standard component in all undergraduate and postgraduate courses in nursing and allied health disciplines as well as medicine. In order for the culture change to happen in terms of dementia education, healthcare staff at all levels, including senior and managerial levels, should avail of dementia education.

Chater and Hughes (2013) conducted a qualitative study with senior nurses and Health Care Assistants (HCAs) in a mixed gender acute elderly care unit in the North of England and showed that both senior nurses and healthcare staff reported comparable learning requirements. Barriers to the acquisition of knowledge expressed by both groups involved the pressures of the acute hospital environment, time constraints and challenges of nursing acute illness in people with dementia. Of note is that some strongly negative attitudes towards classroom learning were articulated in the focus groups, with some participants expressing a preference for experiential rather than didactic teaching style, and there was overall consensus on the value of learning from fellow staff. Both senior nurses and HCAs desired input from an external dementia expert on the ward to aid on-going learning and provide on-ward support. The authors recommended the appointment of a specialist dementia advisor to support ward staff. There are Dementia Champions in acute hospitals in Scotland, which may serve as a model for this.

They also expressed an interest in meeting with people who have dementia living well in the community in order to learn how to relate better to people with dementia in their care or on their ward. These findings were in line with existing recommendations to include people with dementia in service planning and education (Barnett 2000, Maslin-Prothero 2000). Integrating opportunities to reflect on practice in on-going workplace education is regarded as vital for learning and continuous skill improvement (Boud and Doherty 2006, Murphy and Timmins 2009). Corresponding to the UKCC (2000) recommendation for a peer support initiative for practitioners in clinical settings and the shift from individual to group-based models of reflective learning, Charter and Hughes suggested staff-facilitated teaching sessions, including staff-led ward-based reflection programmes, incorporating pastoral support and clinical supervision. Such an approach would enable shared learning and access to dementia resources leading to staff empowerment, which in turn enhances job performance (Clancy 2007, Ibrahim and Mahran 2010). Staff-facilitated teaching sessions may also result in greater saturation of learner involvement, as meetings may be timed and structured to suit most people at most times.

The literature reviewed highlighted two broad areas that should be focused upon in the planned and delivered training for health care professionals. The two areas are:

- Therapeutic skills education.
- Attending to physical health/acute medical needs of people with dementia.

5.2.1.1 *Attending to Psychosocial Needs of a Person with Dementia through Therapeutic Skills.*

Caring for people with dementia requires more than attending to their acute medical needs. Across several nations there is some consensus on health and social care professionals being up-skilled to adopt therapeutic approaches in their work with people with dementia (Bowers, Downs and Bowers 2008, de Siun and Manning 2010). These approaches enable staff to engage with the person with dementia as an individual and to understand their reality and context through meaningful verbal and/or non-verbal communication with people with dementia. Up-skilling healthcare professionals to adopt therapeutic approaches should also enable them to recognise the current level of cognitive impairment and remaining strength in people with dementia and equip them with the necessary skills to help maintain that level of ability and decrease excessive disability. These therapeutic approaches include:

1. Person-centred/relationship-centred care.
2. Communication and validation approaches.
3. Psychosocial approaches to supporting cognition.

Person-centred/Relationship-centred care

The underpinnings of person-centred care are the basic framework that all health care professionals should aim to follow in their practice as carers for people with dementia. The American psychologist Tom Kitwood was the first to highlight the value of relations to people with dementia in the theory of person-centred care (Kitwood 1997). The principles underpinning person-centred care include valuing the person and their family and treating people with dementia as individuals with perspectives and wishes that should be respected by those providing care. He placed major focus on the importance of continuity of positive relationships and social interactions throughout the dementia journey, inclusive of interactions with health care staff. He believed that these interactions, along with other psychosocial factors including personality, biography, and physical health, could help in the offset of the neurological decline (Kitwood 1997). Person-centred dementia care is a good starting point for high quality care, with principles highlighting that people with dementia continue to experience emotions, including pleasure and distress, in response to things they enjoy or dislike.

However, this focus on person-centeredness occasionally influences practice in the direction of promoting autonomy and an entirely individualistic view of a person with dementia. Thus, while it is important to adapt the underpinnings of person-centred care, more attention needs to be paid to the interrelationships that shape the lives of people with dementia (Davies and Nolan 2008). Given the centrality of relationships in the experience of people with dementia, it is argued that care for people with dementia cannot be person-centred unless it is also relationship-centred (Davies and Nolan 2008). Consequently, Woods et al. (2007) proposes "*The Dementia care triangle*" where the person with dementia is the key angle in the triangle, with the other two angles formed by their key relationships, the first being family members and friends (fulfilling the needs of the person's journey through life), the second being health care professionals (fulfilling the day-to-day comfort and needs). He argues the strengths or tensions between any parties can have an effect on the remaining relationships within the triangle. This is the base of relationship-centred care.

Keady and Jones (2010) showed how a person-centred approach can reveal the individual behind the behaviour and help tailor subsequent interventions. Using a composite case study of "Frank", a person with severe dementia who has been admitted to an NHS inpatient mental health assessment ward, the author explores ways of understanding responsive behaviours. They provide a 3-step approach to investigate, formulate and personalise a range of interventions (i cue-finding; ii motive identifying; and iii formulating, applying and evaluating interventions) together with ways of intervening in responsive behaviours using a needs-led approach, keeping the person with dementia at the centre of the assessment and intervention process.

The clear message is that the inter-relationships between people with dementia, family and healthcare staff are very significant to provision of skilled dementia care (Challis et al. 2010).

"Knowledge on how to empathically engage with people... sensitively engage in difficult conversations that may be upsetting to the person with dementia, their family and carers...actively support the person with dementia to maximise their ability to communicate their needs, wishes and desires" (The Scottish Government 2011).

Communication is fundamental to maintaining inter-relationships (Allan and Killick 2008). Communication also plays a major role in the person's well being and should continue to the end stages of dementia. However, the disease may impact ease and clarity of communication by people with dementia. This poses challenges for healthcare professionals working with people with dementia, as they require skills and knowledge to use effective and meaningful communication techniques (Allan and Killick 2008). Building relationships may require a great deal of attentiveness and skill in active listening and observation of non-verbal signs from people with dementia (Davies and Nolan 2008).

While the need for provision of training and education on forming and supporting meaningful relationships among the health care staff, people with dementia and their families has been recognised in dementia strategies, for example Scotland (through provision of a link worker) and England, (where a dementia advisor position has been created for this purpose), what appears less clear are the actions undertaken to equip these professionals with the essential knowledge and skills necessary to form and maintain such relationships.

Communication and validation approaches

There is a growing body of research evidence to illustrate that improving communication with people with dementia has a positive effect on their quality of life. Policy initiatives internationally highlight the need for improvement of communication practices in care environments in general and in medical contexts in particular as a priority (Young et al. 2011). A number of studies have demonstrated that communication training for staff in long-term care institutions has positive outcomes for people with dementia (Peterson et al. 2002, Savundranayagam et al. 2007). Effective communication with people with dementia also improves staff morale, increases job satisfaction and reduces staff turnover (Zimmerman et al. 2005). Young, Manthorpe, Howells and Tullo (2011) reported on the development of a communication tool that could be used in the care of people with dementia in a variety of care settings. The dementia toolkit for effective communication (DEMTEC) comprised three levels. The foundation level 1 details beliefs about the psychosocial effects of dementia on communication, the importance of communication with people with dementia and approaches which acknowledge the personhood and empower the person with dementia. Level 2 details practical considerations and advice in 8 key areas regarded as important for good communication. These eight components involve; conversation, nonverbal communication, environmental considerations, anxiety reduction, mindfulness and empathy, understanding behaviours, retaining a sense of self, checking and understanding. Each component deals with the “what”, “why” and “how” of that aspect of communication. Level 3 involves 5 case study scenarios to show how the principles in preceding levels are applicable to individuals and their families in different care contexts and at different stages of dementia. Killick (2004) claimed that if staff do not engage or connect with people with dementia, this could lead to the person with dementia withdrawing, becoming more passive, and relinquishing the desire to self-care and their efforts to interact.

Person-centred research stresses the inclusion of both verbal and non-verbal signs of communication, the skills of sensitive and empathetic engagement with people with dementia (Killick 2004, Killick and Allan 2001, Kitwood 1993). All of these principles, along with others, have been incorporated into a communication approach with people with dementia called validation therapy.

The validation therapy approach was developed in an attempt to provide practical solutions for difficulties experienced by health care professionals in communicating with people in the late stages of dementia (Feil 1993). Feil’s Validation Institute trains and accredits therapists wishing to practice validation therapy.

Validation, as a general term, can be defined as the acceptance of the reality and personal truth of another’s experience. This, in itself, is a key aspect of person-centred approaches to dementia care and a central element of all therapies originating from the humanistic perspective. The distinguishing characteristics of Validation therapy include the provision of a high degree of empathy and understanding of personal situation, however disturbed that might seem. Other important features of validation therapy include a means of classifying behaviours and provision of simple, practical techniques that help restore dignity and prevent deterioration (Feil 1993). These features are not, however, unique to validation. Feil (1993) identifies a number of beliefs and values that underlie the validation approach, (although again many of these are shared by other person-centred approaches), including that all people are unique and valuable, there is a reason for behaviours

displayed by people with dementia, the importance of empathy and that painful feelings, once validated, will diminish. The specific interventions and techniques used within the validation approach are based on a synthesis of behavioural and psychotherapeutic methods.

Various observational studies have indicated that there are positive effects in using validation therapy in terms of the amount and duration of interactions that participants are able to make during validation communication exchanges (Toseland et al. 1997). A systematic review found no significant effects of validation therapy (Neal and Briggs 2003) but noted that there might potentially be other, more indirect benefits from validation therapy for both patients and staff; for example, validation therapy might help to promote a person-centred approach, thereby improving patient care. However, Feil (1993) identifies the benefits of validation for people with dementia as including restoration of self-worth, promotion of communication and interaction with other people, reduction of stress and anxiety and stimulation of dormant potential.

Possible benefits for families may include reduced frustration with their relative, more effective communication, relief in terms of the improvement made by their relative in relation to speech and social functioning and increased visiting. Possible benefits for professional care-givers may include reduction in frustration, prevention of burn-out, promotion of joy in communicating and increased job satisfaction (Feil 1993).

Although the case for validation as a therapy requires further evidence, the case for validation as an approach to care and as it is embedded in person-centred approaches is undeniable. There is no way to communicate with people with dementia that is person-centred that does not validate their reality. However, these skills are not a part of undergraduate nurse training or health and social care programmes in Ireland. Post qualification training in validation skills is time intensive and expensive and there is no centre in Ireland currently to accredit people with validation approach training.

Psychosocial approaches to supporting cognition.

Two broad psychosocial approaches: cognitive rehabilitation and cognitive stimulation, show promising results based on findings from early studies (Spector, Orrell and Woods 2010).

Cognitive rehabilitation aims to enable people with cognitive impairments to achieve their optimum level of functioning and well-being through limiting their disabilities. Central to this process is the collaborative identification of personal outcomes and the development of interventions to address them (Clare 2005). Cognitive rehabilitation interventions draw upon a mixture of approaches aimed at restoration of function, implementation of compensatory strategies and environmental modification. While initially developed primarily for people with non-progressive brain injury, this approach is equally applicable to people with progressive conditions such as dementia (Clare 2008). The aim of cognitive rehabilitation for people with dementia is to deal with a variety of problems arising from cognitive impairment, rather than aiming to cure or reduce cognitive impairment at the neurological level. The goal of cognitive rehabilitation is to enable the person with dementia to participate to the optimum in their desired activities within their own social contexts (Clare 2005).

Rehabilitation works to identify specific strategies for dealing with difficulties resulting from changes in memory or other cognitive domains. According to Clare (2005) cognitive rehabilitation is also influenced by the psychosocial understanding of dementia. An important aim is to empower individuals by strengthening the sense of self and being in control. She further argues that in order to achieve this, it is important to take into consideration personal coping strategies. Thus, all cognitive rehabilitation interventions should be individually tailored and focus on real every-day situations and difficulties. Cognitive rehabilitation interventions draw on a range of principles and methodologies all with demonstrated usefulness for people with dementia. These can include cognitive training, spaced retrieval, cueing or prompting. As cognitive rehabilitation is a relatively new approach to improving wellbeing in dementia, there is only preliminary evidence suggesting

that cognitive rehabilitation interventions can produce significant improvement in targeted areas, at least for a proportion of participants (Clare 2008).

In Ireland, organisations such as Headway and the Peter Bradley Foundation conduct cognitive rehabilitation and cognitive training for people with a head injury which is not dissimilar to the interventions described by Clare and others in the UK. It would appear that these individuals providing the training completed a high level of education up to masters level abroad to practice these skills. There does not appear to be any Irish training for health and social care professionals in these skills outside of highly specialised clinical psychology education.

The second psychosocial approach to supporting cognition for people with dementia is **Cognitive Stimulation Therapy (CST)**. In comparison to the cognitive rehabilitation specific problem - strategy method, this approach aims to stimulate the person with dementia's cognition, through a more general, opinion-based discussion around reminiscence. Cognitive stimulation therapy evolved from Reality Orientation (RO). Its rationale is to try and re-provide information that people have lost through neurological impairment (Holden and Woods 1995). RO was usually conducted in residential or care settings and was one of the first structured psychosocial interventions for people with dementia (Clare 2008). However, the highly structured method was abused and in some cases became mechanistic and confrontational. Therefore, RO has become unpopular in recent years (Adams and Manthorpe 2003). The Cochrane review on RO also recognized the need for large and well-designed multi-centre trials on therapy for dementia.

Cognitive Stimulation Therapy (CST), aimed to improve and develop the RO programme to evidence-based therapy, focused on cognitive stimulation using a range of mental activities (Spector, et al. 2003). The development of the programme also involved a general review of psychosocial therapies, especially reminiscence therapy. CST was evaluated in a randomised controlled trial, which included 201 participants. The participants were randomised to treatment or activities as usual. The CST group improved on measures of cognition and quality of life (Spector et al. 2003) and communication (Spector, Orrell and Woods 2010). Providing cognitive stimulation therapy alongside usual care for people with mild to moderate dementia in both day-care centres and care homes is likely to be more cost effective than usual care alone (Knapp et al. 2006).

In Ireland CST training sites include Dublin City University and ASI where a group runs intermittently and offers the opportunity for interested people such as activity co-ordinators, nurses or occupational therapists to join these sessions to get the feel for the programme. The originator has online resources, which are very comprehensive and can be bought online: <http://www.cstdementia.com/page/the-manuals>.

Summary

The above described therapeutic approaches to person-centred/relationship centred care, communication and validation approaches, and psychosocial approaches to supporting cognition should enable the healthcare professionals to provide care to people with dementia. At the moment there is no module or course combining the training of all the therapeutic approaches, despite recognition of the value of these approaches in the national dementia strategies of, for example, England, Norway and Finland. In Finland's national strategy it is acknowledged that the range of rehabilitative options for restoring a person's ability to function while living with dementia had not, at the time of the plan's creation, been fully explored.

If the training specific to each intervention was combined into an accredited education module, equipping health care professionals working in dementia care with skills and knowledge of a variety of these approaches, it would help to increase the skill levels of staff and change the general perception of staff as being unskilled. Equipping staff with knowledge of these three areas would give them the skills to adapt these approaches/therapies to the specific needs of each person in their care.

5.2.1.2 *Attending Clinical Needs of People with Dementia in an Ethical Manner.*

While the therapeutic approaches should be central to providing every type of care to people with dementia, attending to the clinical needs in an ethical manner should also be a prerequisite among healthcare staff, especially in acute and residential care settings. The issues highlighted in the literature to target, over and above person-centred care, communication and validation and cognitive approaches, are: assessment of dementia and delirium, responsive behaviours (sometimes called behaviours that challenge), nutrition and hydration specific to dementia, End of Life, and Environment.

Assessment of dementia and delirium

Differentiating delirium and dementia is difficult because many of those who present with delirium also have a pre-existing dementia - about a quarter, according to Conn (1991) . When it comes to differential diagnosis, delirium, dementia and depression are frequently misdiagnosed, despite their prevalence in older people (Brock and Simpson 1990, Conn 1991, Cornelius et al. 1993) . Delirium increases morbidity, mortality and length of hospitalisation (Francis and Kapoor 1990, McCusker et al. 2001) .

While a diagnosis of dementia may come as a shock for family caregivers, the benefits of receiving a diagnosis for their loved one include a sense of relief from knowing what is wrong, ruling out of other reversible causes for memory or behaviour problems, facilitation of access to community-based information and support services, help with adapting, coping and impetus to plan for the future and enhanced communication during subsequent healthcare visits (Connell and Gallant 1996) .

For healthcare professionals, the picture is more complex. A specific diagnosis can increase uncertainty about treatment options and possible illness complications, as well as plans for future care based on the unknown clinical course of the illness (Foster 2001). Other authors including (Woods et al. 2003) echo this sentiment. They say that the process of diagnosis is not straightforward and the potential for the assessment process itself to become confrontational due to denial or other psychological defences on the part of the person with dementia and/or their carer. Because of these difficulties, planning for the future is also not a simple process, as it requires communication of a prognosis that is not predictable and is likely to be influenced by numerous other factors other than the progression of the brain disorder.

Responsive behaviours

Responsive behaviour reflects a response to something in the environment that is negative, frustrating or confusing to the person. It places the reasons or triggers for challenging behaviours outside rather than within the individual. It recognises that the problems in the physical and social environment can be changed (Alzheimer's Society of Ontario 2011)

Responsive behaviours including, repeated questioning, agitation, wandering, paranoia, hallucinations, delusions, sleep disturbance and resistance to care were highlighted in the literature as specific areas of need. Healthcare workers identified insufficient staff numbers and lack of dementia-specific skills in dealing with responsive behaviours as important issues hindering optimal care (McGlade et al. 2009) . Caring for those with these behaviours presented particular challenges for those working in an acute hospital environment (Nolan et al. 2004) .

Agitated, aggressive or responsive patient actions have been directly associated with increased nurse strain (Rodney 2000) . Some nurses who experience difficulty communicating with people with dementia had negative reactions which resulted in nurses spending less time with those with dementia on the ward than those without dementia (Ekman et al. 1991) . Given that improved communication is the very thing recommended to ease these problems this is potentially very serious. In an acute care setting in Australia, (Moyle et al. 2011) found that a risk management

approach by staff, directed at maintaining safety, included the use of physical and chemical restraints and was more common than care focused on individual patient needs and preserving patient dignity. By developing especially adapted services in small, safe areas, hospitals in Canada have shown their effectiveness in reducing responsive behaviours (Reimer et al. 2004, Morgan and Stewart 1999) .

Although the exact nature of the relationship between dementia and abuse is unclear, it appears that people with dementia who become aggressive or violent may be at increased risk of being abused, possibly within the context of an abusive relationship (Coyne, Reichman and Berbig 1993, Homer and Gilleard 1990) . Adams and Manthorpe (2003) report that education and training must be provided to health care professionals in all settings, in order to increase awareness and knowledge and support for the problem of abuse of this population.

How to deal effectively with responsive behaviours is a component included in all comprehensive dementia education and training programmes. A 10 week dementia education programme consisting of ten 1 hour sessions was developed for nurses on an aged care ward in acute setting and evaluated by McPhail, Traynor, Wikstrom, Brown and Quinn (2009) . The programme included a session on behavioural management using a behaviour log, and a separate session on restraint. On completion of the programme, staff recognition of pain as a contributory factor to behaviours increased from 25-44% and staff were able to recognise a range of physiological factors in general that influence behaviours. The number of environmental factors and carer attributes that staff recognised as contributing to responsive behaviours also increased. There was a decrease in incidences of “aggressive behaviour” recorded, reduced from 12 incidents in the three months pre-education period to 3 reported in the four-month post-education period. Behaviour management logs were also reported to be used more spontaneously by staff to identify incident triggers. The authors also reported less use of sedation. Sedation was also used as a last resort in general as staff were now more likely to follow a behaviour management flowchart. 64% of the programme attendees reported that the sessions were beneficial for enhancing dementia clinical skills in acute care.

McCabe, Davison and George (2007) reviewed studies on staff training programmes to address the behavioural problems associated with dementia among older people in residential care. They concluded that skills training for nurses appears to increase the knowledge and skills base of staff and reduce behaviours, although continuing refresher courses may be needed to sustain the impact of training. There is also an indication of greater staff satisfaction and reduced staff turnover.

Nutrition and hydration specific to dementia

Many people with dementia have eating difficulties and malnutrition and dehydration are two leading causes of death in dementia (Alzheimer Society 2009) . Healthcare assistants in the UK generally assist people with dementia to eat in hospitals and residential care settings, but research suggests they lack the knowledge and skills to assist patients safely and with dignity (Kayser-Jones and Schell 1997) .

The Cornwall Dementia Training and Communications Difficulties Scheme covers “7 steps to end hospital malnutrition”. There is growing evidence that the use of feeding tubes in patients with advanced dementia does not improve survival, prevent aspiration pneumonia, heal or prevent decubitus ulcers, or improve other clinical outcomes (Kuo et al. 2009, Sampson, Candy and Jones 2009) . Tube feeding may increase mortality and morbidity and reduce quality of life (Sampson, Candy and Jones 2009) . Nevertheless, research has shown that two-thirds of people with dementia in nursing homes had feeding tubes inserted during an acute care hospitalisation (Teno et al. 2010) . Decisions about tube-feeding were more likely to be based on particular hospital practices rather than on the wishes of patients and their families (Teno et al. 2010) .

There is a clear need for education among healthcare professionals and families with regards to tube-feeding of people with dementia. A report from the British Society of Gastroenterology stated that healthcare professionals are sometimes in disagreement over the merits and ethics of keeping people alive longer (British Society of Gastroenterology 2010) Staff in acute and residential care environments need to inform families of people with dementia that tube feeding does not extend life or improve quality of life and may even be harmful. Sorrell (2010) advises that staff explain to families that people in the advanced stages of dementia do not feel hungry or thirsty. Furthermore, staff can communicate that stopping tube feeding is a more difficult decision than deciding to have the tube inserted in the first place (Hanson et al. 2011)

End of life

End of life care is the term used to describe care provided in the period shortly before death. Ideally it is a continuation of skilled care provided over the long trajectory of the disease (Alzheimer Europe 2006) By contrast, palliative care is not bound to the closeness of death and can last up to several years depending on the illness.

A recent survey carried out by Alzheimer Europe revealed a lack of support for carers who care for people with dementia at home in the end stages of life. This finding indicates an important need for the continued support of the family of the person with dementia by the GP and other allied health professionals in the end stages of dementia.

Alzheimer Europe lists some special issues to be addressed by healthcare professionals in the end stages of the life of the person with dementia. It is important that these issues are addressed in dementia education and training programmes. Issues include: pain assessment, pain treatment, nutrition and hydration at end of life, breathing difficulties, process of dying and after, ethical issues (such as withholding and withdrawing treatment), advance directives or statements of values, capacity and other legal issues. Guidelines to assist nursing homes to develop end of life care policies have been developed for Ireland based on evidence from research and these highlight the need for training of staff around this issue. However, it is not clear if these guidelines are being followed or if they have been implemented anywhere.

Environment

The environment of a healthcare setting is an important part of quality of care for people with dementia. The environment should aim to be dementia friendly and healthcare staff should consider its impact on people living with dementia and their family members.

A study by a UK team of practitioners and academics highlighted a situation where nursing staff worked with their managers to create an area on the acute ward specifically for the care of patients with dementia. Staff created a more homely atmosphere (for example, armchairs, plants), more informal medical ward rounds and engaged more actively with people with dementia. Each member of the day staff chose to work with patients with dementia in this separate area in the hospital. Patients felt more relaxed, number of responsive behaviours reduced, and a higher tolerance and understanding of needs among staff was evident (Traynor, Brisco and Coventry 2005) .

Holden and Woods (1995) described a good communication environment as providing private and recognisable space in which people can talk at ease; active and interesting public spaces where there are things to see, touch and do; an encouragement to self-care and involvement in the activities of daily living; an involvement in making choices, for example in terms of meals and activities and things to do and information to update individuals, such as clocks and calendars.

5.2.2 State of the Art in Ireland

The Report of the Irish National Audit of Dementia Care in Acute Hospitals 2014 resulted in 47 detailed recommendations to ensure policies and practices in the acute care setting are appropriate for the care of the person with dementia. The first of 6 key recommendations is that

“Each acute hospital has responsibility for developing a training and knowledge strategy to ensure that all staff are provided with basic training in dementia awareness, and a locally agreed specified proportion of ward staff receive higher level training (including dementia champions).”

The report revealed that at present in Ireland only 6% of hospitals (2/33) include dementia awareness in their staff induction programmes and that no hospital has mandatory dementia awareness education for staff. Amongst the statistics reported, just over half of hospitals had provided dementia awareness training to doctors (54%, 18/33) and nurses (52%, 16/31) in the past 12 months. Fewer hospitals had provided training to healthcare assistants (29%, 9/31), allied healthcare professionals (16%, 5/31) or support staff (10%, 3/31). 6% of hospitals had provided training to doctors in communication skills specific to people with dementia, 26% had provided this training to nurses, while 13% had provided this training to healthcare assistants (HCAs). The report highlighted that even where training has been made available in the past 12 months, it is often delivered informally and is not accessible to all staff in the hospital. 41% of hospitals had provided training to doctors in assessment of capacity, 22% had provided this training to nurses and 3% had provided this to HCAs.

Like other health and social care staff in contact with people with dementia, nurses in Ireland need training in dementia care; 83% of nurses lacked specialist dementia knowledge and have not received specialist training, with no significant difference in training needs reported between nurse managers and clinical nursing staff. In particular practice nurses (and public health nurses) as opposed to community mental health nurses and nurses based in nursing homes (also assessed in the study) were less likely to have received specialist training (Farrell, Cahill and Burke 2007, de Siun and Manning 2010) .

DSIDC - the longest established dementia-specific training and education service in Ireland, delivers high quality training and education programmes nationwide. The education programmes place emphasis on the value of the person with dementia and promotes an awareness of dementia by providing education and training to health care practitioners. The programmes focus on increasing knowledge and skills and development of attitudes, which enhance ability to provide the best possible care. Scheduled and tailored courses include Dementia Care in an Acute Setting (1 day), a course for staff in residential settings, courses covering communication, responsive behaviours, Life Story activity and End of Life. Private consultant trainers advise on a broad range of issues including learning needs, assessment protocols, architectural design, assistive technologies, complementary therapies and quality of life.

Sonas aPc is a training and resource organization centred on non-pharmacological intervention in dementia care. This registered charity trains people to carry out therapeutic activities with older people who have dementia or any condition involving significant communication impairment. The Sonas programme is their evidence-based psychosocial therapeutic communications activity. Sonas also provide training in Green Candle Dance psychosocial approach, as well as, Ciunas and Serenity.

The National Dementia Education project (NDEP) is an education programme rolled out through HSE Centres for Nurse and Midwifery Education as well as non-HSE agencies in most parts of the country. This project is informed by an HSE education needs analysis (2010). The programme includes a two day education and awareness programme for all health care staff, a responsive behaviour one day programme, a staff E-Learning Programme on early identification of memory problems in the older person, Dementia Champions Programme, an information booklet for home care workers, a CD for community based workers and information posters on the differentiation between depression,

dementia and delirium for use in particular in a hospital setting. Related resources are also available to download.

Dementia Training Ireland, a dementia training consultancy established in 2007 deliver a number of standard training packages which can be adapted to suit the care setting. Among the one-day workshops offered is one designed to be directly applicable to the acute hospital setting. There is also a half day course available to help staff involved in emergency care to gain a better understanding of dementia and a half-day workshop aimed at those in Primary Healthcare to develop a better understanding of dementia from the perspective of the person living in a community or domestic setting. Dementia Ireland also provide practice development, coaching and managerial training services.

The Irish Hospice Foundation (IHF) delivers education and training programmes which cater for all levels of knowledge and experience among healthcare professionals. The IHF courses include dementia palliative care, end of life and bereavement care and a one-day workshop aimed at acute hospital staff designed to help bring hospice principles and practices to busy hospitals. The courses are offered through hospices, professional organisations and universities across the country. Additionally they provide online and printed resources prompting good practice.

5.2.3 Summary

While aging in place is the goal of emerging healthcare policy and service planning for people with dementia, due to particular circumstances, remaining in one's own home may not be an option for every person with dementia. Therefore, staff in acute, residential and community care need to have the necessary person-centered skills and dementia-specific knowledge to ensure the highest quality of life for people living with dementia in these settings.

While the current unsuitability of the acute care environment for people with dementia has been established, sizeable numbers of people with dementia will continue to avail of acute care for medical reasons because of, or separate to, their dementia. Acute care staff therefore also need to be equipped with person-centred and dementia-specific knowledge and skills to ensure the safe and dignified passage of people with dementia through the acute care system. This will involve education and up-skilling of all staff members in these settings, from doctors and nurses involved in direct care, to those peripherally involved in care, but who are in daily contact with people with dementia, such as porters, receptionists, kitchen and catering staff and paramedics and ambulance drivers.

In acute, residential and community care settings, there is a need for healthcare staff to address the therapeutic and person-centred needs of people with dementia as well as their acute and physical needs. The educational needs of healthcare staff in these settings are outlined in numerous reports and are targeted for improvement to varying degrees in many national dementia strategies. Outcomes of evaluated interventions to date show positive results in the main for educational programmes, but also highlight the present and urgent need to target healthcare staff with specifically tailored dementia education programmes, applicable to the particular setting and responsive to potentially nuanced staff needs. As well as tailored content therefore, an important component of this targeted approach to education should be flexibility in delivery of the programmes to accommodate particular staff needs and environmental contingencies.

The priority areas for education within acute, residential and community healthcare settings specifically identified by this scoping study are: person-centred communication; assessment of cognitive status; assessment of delirium and pain; promotion of a dementia-friendly environment; informed, inclusive discussion of end-of-life care and legal issues between staff, people with dementia and families and the appropriate use of psychosocial and therapeutic approaches. Risk management and an awareness of safety must be balanced with proper engagement in person-

centred care, entailing an in-depth knowledge of all of the above issues, underpinned by an understanding of the importance of ethics and communication with the person with dementia throughout the disease trajectory, including in the end stages of their condition.

Research suggests education alone is not sufficient, and there is a significant need for culture change across all the healthcare settings which needs to be supported at a managerial and organizational level. Educating healthcare staff will not always enable them to change their practice in dementia care. Healthcare staff face the burden of limited time availability, limited release time and overcrowding. Senior managers need to have increased dementia awareness in order to understand and implement the necessary change in dementia practice from a top down perspective. At the moment due to the constraints of healthcare settings dementia care is rather reactive. It is often the case that the person with dementia is only attended to once a physical or acute need arises. The goal is to create proactive dementia care, which is largely dependent on timely diagnosis and follow up systems in place, provided by integrated healthcare teams.

5.3 Primary Care

For all major chronic diseases the emphasis for future care provision will be redirected to primary care. Service reform cannot happen unless there is a culture change incorporating ownership of dementia in primary/community care, and acceptance of planned and positive risk taking as a part of quality care for people with dementia. There is evidence to suggest a large gap exists between desired proactive services and reportedly reactive, crisis-led services (Hinton et al. 2007) . This is, in part, due to a lack of infrastructure, but there are a range of factors including emphasis on/bias towards acute care (and residential care in respect of older people and people with dementia); lack of co-ordination and integration between service settings, primary care services being traditionally clinically led, with other allied health professional working separately rather than with the clinicians; patients not being involved in the development of primary care services; focus on diagnosis and treatment as opposed to prevention and long-term care (seen traditionally as the responsibility of families and in their absence nursing homes) and focus on acute illnesses as opposed to chronic health conditions (Hinton et al. 2007). In addition, there is a lack of education and skills and to some extent it is because the skills required to make alternative options realistic, or use resources creatively, are inconsistently present and the culture necessary to accept those changes is often absent.

There are strong ethical and logical reasons for a person with dementia to avoid acute care. Notwithstanding the need for admission when people with dementia are acutely unwell, acute care has repeatedly been found to be detrimental to people with dementia (MacNeill and Lichtenberg 1997) and undesirable for individuals and their carers (Ekman et al. 1991, McGillivray and Marland 1999, Tolson, Smith and Knight 1999) . The quality of primary care is an important factor determining admission to hospital for people with dementia. However, community care is a complex landscape with many stakeholders. An important part of this landscape is the GP. If GPs are to take on the extra redirected care from acute care and work towards prevention of admissions and promotion of independence, then they will need to feel confident to do so. They will also need to be supported by a wide range of other allied health and social care staff skilled in dementia care.

GPs will need to be at the highest level of the Scottish model of dementia training presented earlier, by virtue of their linchpin contact at all stages of dementia, particularly as a first point of contact. Survey data from the UK suggests GPs feel inadequately trained in the diagnosis and management of dementia, and in responding to the needs of people with dementia and their families (Downs et al. 2000, Iliffe, Manthorpe and Eden 2003) . This gap in knowledge and skills seems to be an international phenomenon (Rait, Walters and Iliffe 1999) . The literature recommends that values, attitudes, experiences and behaviours of those being trained need to be addressed (Vernooij-Dassen

et al. 2005) and training approaches need to be multi-faceted and varied (Illiffe et al. 2002b) . In terms of curriculum content, there is broad agreement that the areas of attention need to be:

- improved awareness of the benefits pro-active care can have on people with dementia and their carers;
- diagnosis and disclosure of dementia;
- dementia specific communication skills;
- ethical and legal knowledge and skills;
- treatment and ongoing care including pharmacological and non-pharmacological interventions and
- end of life care.

Illiffe, Manthorpe and Eden, (2003) have described the advantages and disadvantages of early diagnosis from a qualitative study of GP's; the difficulties in differentiating dementia from other changes, the lack of experience and skills of primary care practitioners and the limited resources available. However, participants had no difficulty in listing the investigative steps appropriate on suspicion of dementia (informant history taking, differential diagnosis, value of multidisciplinary input) and GPs could describe the ideal dementia care pathway. Following diagnosis of the person however, obstacles reported included uncertainty about referral criteria for accessing specialist services and a general lack of confidence in service provision. Rait *et al*, (2010) suggests that GPs are diagnosing at times of crisis or much later in the journey of dementia. The key point here is that it seems to be professional resistance rather than a lack of knowledge that is problematic, hence, traditional education would perhaps not be the most beneficial method to counter this.

Macro level barriers to diagnosis have been explored by Rait, Walters and Illiffe (1999) who found that the focus in the literature (particularly in systematic reviews) has been on prescribing and preventive medicine and on certain other chronic diseases rather than dementia. The psychological and biological complexity of dementia itself and the absence of a standardised diagnostic test, compound the difficulty. It has been suggested that an assessment specific to primary care is required (De Lepeleire, Heyman and Buntinx 1998)

The Norwegian strategy instigated a team approach to memory assessments and diagnosis of dementia. A dementia nurse and occupational therapist undertake the initial assessment and work up and report back to the GP who considers the information provided and undertakes further assessment, if needed, and either makes a diagnosis or refers the person to a memory clinic for diagnosis. Some cases are referred directly to memory clinic. The memory clinics also have a team of specialists, including specialists in geriatric medicine, geriatric psychiatry and neurology. In addition to the assessment and diagnostic carried out by healthcare teams, they also provide follow-up every six months, give support to family carers and guidance and education to other health personnel.

The Department of Veteran Affairs (VA) in Massachusetts (2007) identified the differential diagnosis of delirium, dementia and depression as one of the top priorities for learning activities. In 2008, a Dementia Education Workgroup (DEW) was established within the VA which developed primary care practice-based tools for the assessment of dementia, delirium and depression, consisting of a pocket card and accompanying assessment guide, and a supplementary distance-learning, didactic presentation targeted at primary care practitioners including family physicians and primary care nurses. In choosing the brief assessment tools the group considered a compendium of best practices in geriatric assessment and cue cards. For example, the card included recommendations for laboratory studies, common medical and medication causes of delirium, instrument scoring instructions and interpretation and documentation tips. The use of the pocket card and assessment guide in practice was evaluated positively in an online survey and the authors concluded that the tool was low-tech, easy to use and that the choice of educational content and format were well accepted (Kim and Salyers 2008) There are some mixed messages in these research findings

indicating that there would be a need for a multifaceted approach to changes in dementia care in the community and that education may need to be one part, alongside other approaches to service reform.

There is some evidence that GPs are open to making a diagnosis but resist doing so, based on concerns about the potential negative impact on the person with dementia and their family that disclosing a diagnosis would have, thereby adopting a protective approach (Iliffe, Manthorpe and Eden 2003) The authors concluded that while GPs seemed to adopt the principle of “doing no harm” the model of dementia care did not appear to inform their perspective on the rights of people with dementia to have a diagnosis. Since the early 1990s, attention has been drawn to the need for people with dementia to have their rights properly respected as autonomous individuals. The first item in an Alzheimer’s Disease Bill of Rights (1995) reads, “Every person diagnosed with Alzheimer’s Disease or a related disorder deserves to be informed of one’s diagnosis.” There is plentiful evidence for the benefits of an early diagnosis for a person with dementia (Prince, Bryce and Ferri 2011)

According to the World Alzheimer Report (2011), most people with early dementia would wish to be told their diagnosis. However, careful consideration must be given to the way in which the diagnosis is delivered. Information must be tailored to the individual, taking into account his or her perception of the difficulties (Woods et al. 2003) There is the potential for the assessment process itself to become confrontational due to denial or other psychological defences on the part of the person with dementia and/or their carer (Woods et al, 2003). In many cases, disclosure should be considered a process rather than an event (Moniz-Cook et al. 1998) allowing the person with dementia (and their carer or family) to absorb and assimilate the news. In a qualitative study exploring caregiver and physician perspectives on disclosure, caregivers recounted a wide range of experiences and reactions to what was said and how the news was delivered. A qualitative study by Connell et al (2004) reported that caregivers felt it important that the diagnosis is disclosed in such a way as to preserve a sense of dignity and hope for both the patient and family members. Many caregivers wanted physicians to ease them into the news, rather than use the words “Alzheimer’s Disease”. Some caregivers expressed frustration at what they perceived as resistance to diagnosing by physicians. In contrast, physicians sometimes felt pressured into making a diagnosis, in part because of the heightened awareness of dementia among the general public.

Both caregivers and physicians offered suggestions for improving the diagnostic and disclosure processes that could be incorporated into physician education such as, physicians taking more time to discuss the diagnosis and what it means and including the patient in the context of the office visit even if they do not fully understand the implications of their diagnosis. These factors are actually linked to caregiver satisfaction within the triadic relationship (patient-physician-caregiver) that is typical in cases of dementia (Beisecker, Chrisman and Wright 1997, Fortinsky 2001) Connell and colleagues (2004) recommend that diagnostic-disclosure techniques become a standard component of physician education programmes on dementia, adding that such techniques can help attune physicians to the emotional and psychological needs of those involved in the diagnostic process. One potentially relevant CPD offering, “Delivering Bad News” was a CPD accredited half-day workshop run by the Irish Hospice Foundation and provided to consultants by the Royal College of Physicians of Ireland (RCPI) in 2013. Content covered included the impact of communication, active listening, guidelines for breaking bad news and dealing with difficult questions.

Treatment/management

Treatment plans might consider the use of cholinesterase inhibitor therapy, the management of any comorbid conditions that the person with dementia may have, for example, depression or anxiety, the treatment of behavioural symptoms if they are present, provision and signposting of support and resources for the person with dementia and their caregiver and a discussion around fitness to drive and driving legislation, should the person with dementia currently drive. Driving retirement is an inevitable endpoint for which open, active communication and planning among patient, family

and health professionals are essential (Dobbs, Carr and Morris 2002) According to Wackerbarth and Johnson (1999) physicians who find themselves involved in decisions regarding driving and dementia frequently experience the process as challenging and somewhat confusing.

The continuous involvement of the GP is vital for guiding and helping the family throughout the disease process. In an approach of shared decision-making (Frosch and Kaplan 1999) the GP should encourage families to discuss difficult topics such as end-of-life. They should explain health care procedures and care options and help families to develop problem-solving strategies, and do all of this whilst respecting the wishes of all family members. Advance directives can include the execution of an Enduring Power of Attorney, estate management and advance directives pertaining to the management of the end-stage of the disease, including the use of antibiotics for infection and the initiation of tube-feeding. The GP is also responsible for determining the individual's competency for making significant personal and economic decisions.

Ethical issues

Following a 2 year inquiry, the National Council on Bioethics published a report in October 2009 on the ethical issues raised by dementia. This report sets out an ethical approach to care, alongside recommendations on specific ethical dilemmas which relate to balancing the needs of the person with dementia with those of loved ones, confidentiality, balancing freedom and risk, access to care, using assistive technologies and making decisions about the care of someone with dementia.

The report found that those involved in caring for people with dementia often felt unsupported when faced with ethical dilemmas and that while specific guidelines and laws can point the way towards resolving such dilemmas, they do not always provide definitive answers. A key conclusion of the report is that all professionals involved in the care of people with dementia should have access to ongoing education and support to equip them to respond appropriately to ethical questions that arise. Examples of best practice cited are the Bradford Dementia Group and the Stirling Dementia Services Development Centre which addresses ethical issues as part of their training and professional development for staff working directly with people with dementia.

Alzheimer Europe (2006) Working Party on End of Life Care in Dementia issued a paper, part of which addresses particular ethical dilemmas in dementia care in the advanced stages of the disease. Issues include: withholding and withdrawing treatment, advance directives, a statement of values, capacity, surrogate decision making and its standing and legal guardianship. It is important that health professionals display the necessary skills to handle these subjects sensitively and communicate effectively with all concerned.

An additional aspect of care with need for advanced ethical skills is abuse; physical, psychological, financial, sexual or by neglect. Behavioural symptoms are a predictor of elder abuse. In a review (Cooper, Selwood and Livingston 2008) the range in prevalence of abuse of older people reported in general population studies was wide-ranging (3.2 – 27.5%), possibly reflecting true variation in abuse rates across cultures as well as differences in defining and measuring abuse. In the general population, 6% of older people have experienced abuse in the last month, and this rises to approximately 25% in vulnerable populations such as dementia (Selwood and Cooper 2009) A cross sectional study of abuse experienced by people with dementia found that, notwithstanding the dedication most carers show, and the considerable strain they are under, a small minority (3 out of a sample of 220 caregivers in the study) engaged in physical abuse of people with dementia (Cooper et al. 2009) The authors point out that, carers might not view their actions as abusive, may be ill-equipped and may be responding to the difficult circumstances of caregiving in the only way they know how. This suggestion places even more onus on the GP and other primary care practitioners to continue to support carers throughout the caregiving journey. The authors suggest that future policy for safeguarding vulnerable adults must consider strategies directed towards families, who provided the majority of care, as well as formal carers.

5.3.1 International State of the Art

Beer et al (2009) examined the dementia knowledge of medical and primary care staff and worked with participants to help them identify their ideas for the content of an educational programme. Their findings supported the need for flexible, specially tailored, locally relevant educational sessions instead of a didactic format.

The Royal College of General Practitioners (RCGP) in the UK have launched dementia as one of the key clinical priorities for 2012-2015. It offers a number of modules about dementia (through e-GP) on Memory Problems in Older People, Care of People with Dementia, Assessing Mental Capacity, and Supporting Carers.

Dementia factsheets have been produced by Prof. Louise Robinson to assist GPs in the diagnosis and care of people with dementia. One of these titled *“Care of People with Dementia in Primary Care”* contains key learning points regarding psychological therapies, vascular risk management, advanced care planning discussions, cholinesterase inhibitors, clinical guidelines for responsive behaviours, early referral where possible to palliative care teams, assessment of mental capacity and the Mental Capacity Act 2005, end-of-life care and key elements of the UK national strategy on dementia. It also contains a reference guide to NICE guidelines, the Department of Health Mental Capacity Act 2005 and the UK national dementia strategy.

A separate factsheet titled *“Dementia: Diagnosis and Early Intervention in Primary Care”* covers key points within a broad range of areas, including epidemiology and aetiology, suspicious symptoms, history taking and cognitive assessment using brief tests (MMSE, GP-Cog, 6-item Cognitive Impairment Test (6CIT), Mini-Cog), NICE guidelines for tests prior to referral (including the advice that diagnosis may require detailed observation over time, MRI and CT scanning also help accurate sub-type diagnosis), early intervention and roles for primary care, driving and dementia, useful resources, and information on the UK National Strategy, *“Living Well with Dementia.”*

Much of the valuable and useful information available to GPs on the web about dementia contains a presentation format and style of information which makes it difficult to access in a timely fashion during appointments with patients (RCGP 2013). In response to this barrier, RCGP held a 6 hour, one day workshop in October 2013 to help design a more cohesive and coherent online guide on dementia diagnosis and management. The Dementia Roadmap is envisaged as ***“a navigational aid for what to do at different points during the course of a patient’s pathway through dementia, and to assist primary care with management of dementia for patients, families and carers”***.

Feedback from group discussion on questions regarding GP’s use of routine questions about memory functioning from those identified as at risk, routine reviews and case finding approaches, methods of evaluating cognitive impairment and managing diagnosed dementia cases are all being used to inform the development of the Dementia Roadmap. GPs participating in the workshop were also asked about available treatments for dementia and cognitive impairment; how they identify a carer’s and family’s needs; whether, after diagnosis, they signpost patients and their carers or families to local resources, information and support and how they go about doing this; how they code people with dementia on the register; whether they are aware of the advantages related to diagnosis of dementia and how they refresh their knowledge of dementia. Feedback is also guiding the presentation and style of the new website and how the Dementia Roadmap concepts and information will be organised.

Tullo and Allan (2011) carried out a review drawing together recommendations for UK undergraduate and postgraduate medical education on dementia. They concluded that a curriculum on dementia should be developed which involves the mapping of learning outcomes to ensure that practitioners working with people with dementia have the necessary skills at undergraduate level right up to postgraduate level.

Hasselbalch et al (2007) identified that whilst many countries in Europe have mandatory dementia teaching for medical students, the degree and level is not consistent across Europe. There was no formal dementia education at postgraduate level in many countries at the time the review was conducted.

Tsolaki et al (2010) did not find a comparable decrease in dementia education at medical postgraduate level, but did note a similar lack of consistency across the different countries in Europe. Their consensus statement states that education on dementia should occur at all stages (medical school, during specialty training as well as after specialty training). Emphasis should be given to early detection and diagnosis, pharmacological and non-pharmacological treatment and communication with people with dementia and their families.

A review of undergraduate and postgraduate dementia education was carried out by Innes et al (2012) to help inform a UK Dementia training curriculum based on best practice principles as agreed by Higher Education Dementia Network and Dementia UK. In terms of design, the post-registration/graduate education appeared to follow a more traditional route of educational input. However, in a description of one post-registration course reviewed by the authors, a more creative approach was used which blended traditional sessions with reflective, observational activities and practice-based projects in which the participants worked in groups of 4 to 5 to identify a project which could be implemented in a care home.

A difference in emphasis of teaching aims was noted between the 5 undergraduate/pre-registration courses reported and the 6 postgraduate/post-registration courses. In post-registration the focus appeared to be upon managing the dementia, using different teaching and learning strategies. In pre-registration courses, the focus was more on helping students to see beyond the diagnosis to the individual living with dementia. There was only one module within the papers reviewed by Innes and colleagues, which explored the personal perspective of students as part of postgraduate education (They point out that addressing unhelpful attitudes or ingrained biases of practitioners towards people with dementia is currently a central part of various policy initiatives, for example the UK Department of Health (2010) and that this should be taken into account when designing the mode of delivery of dementia education. None of the papers in the review were evaluated from the perspective of the person with dementia, which is considered an existing gap in the development of dementia education curricula.

5.3.2 State of the Art in Ireland

Cahill et al (2006) found that Irish GPs, like primary care doctors in other European countries, have difficulty diagnosing dementia and encounter structural and ideological barriers, including stigma when it comes to diagnosing. They expressed a particular need for medico-legal and pharmacological guidelines (not overly-prescriptive). When asked their views on who is responsible for the late presentation of dementia in primary care, the majority (35%) blamed themselves, citing (i) lack of confidence, (ii) lack of time, (iii) therapeutic nihilism, (iv) lack of GP education, (v) personal blame. A small minority (seven participants) saw no value in early diagnosis, providing rationales such as “no proven advantage to early diagnosis”. This compares somewhat favourably with a National Audit Office survey of GPs in the UK in 2006 which showed that while the majority of GPs surveyed agreed about the benefits of an early diagnosis and reported actively looking for signs, only half agreed that providing a diagnosis was more helpful than harmful or that much could be done to improve the quality of life for people with dementia (NAO, 2007). A very large proportion (83%) of the GPs surveyed by Cahill et al (2006) welcomed the prospect of dementia-specific training. The authors concluded on the basis of the survey and focus group findings in this study that education programmes for GPs need to contain special emphasis on supporting the transfer of dementia knowledge to change ideology and practice.

A focus group of rural GPs found undergraduate and post graduate medical curricula in Ireland insufficient in addressing dementia (Cahill et al 2006). However, the gap in dementia-specific knowledge and skills seems to be an international phenomenon (Rait, Walters and Iliffe, 1999).

5.3.2.1 Available Education in Ireland

Alzheimer Europe reports that currently GPs in Ireland receive one month's training in psychiatry and one month's training in neurology. Dementia is discussed in both areas but it is not treated as a separate issue. All GPs are obliged to partake in Continuous Professional Development (CPD) and must obtain a certain number of points (calculated in hours) per year in order to retain their registration. Dementia is not a mandatory element of CPD. There is no consensus about the best ways of assessing and diagnosing dementia in primary care in Ireland, or any other country, at present.

The main provider of training to GPs in Ireland is the Irish College of General Practitioners (ICGP). A search of the courses and e-learning pages of the ICGP website was carried out for the purpose of this literature review and showed that, at the present time, Dementia is addressed in two ICGP modules but both of these have had little take up from GPs and accordingly they were withdrawn. However, the ICGP developed a distance learning module on Alzheimer's Disease for GPs which appeared in April 2011 edition of Forum (Swanwick2011) ICGP Forum clinical meetings have focused on dementia related topics as part of continuous medical education. Two CPD courses not designed specifically for people with dementia, but relevant in any case, are the Certificate in Palliative Care and the Certificate in Gerontology Medicine. The Certificate in Palliative Care, due to begin in 2014, is a one year part-time course, covering topics such as management of pain, ethics and decision-making, bereavement, management of respiratory systems, palliative care in non-malignant conditions, the terminal phase, miscellaneous symptoms. As well as medical and technical topics, there is also coverage of psychosocial supports. The course is delivered in an e-learning environment through a combination of modules, interactive workshops and online discussion forums, reflecting all the major, current and debatable issues in Palliative Care.

5.3.3 Summary

A major focus on GPs has been taken in this scoping study owing to the vast amount of literature available and because they are so essential to effective dementia care. GPs have an important role as the first point of contact for people with dementia in the community, in keeping people with dementia living well in the community and delaying or preventing institutionalisation. A broad and in-depth medical and psychosocial knowledge and range of skills are required to cover the diverse role of GPs in dementia care. Targeted GP education programmes should address the key themes highlighted in this review, as well as the values, attitudes, experiences and behaviours of those being trained (Koch and Iliffe 2010) Such training approaches should be multi-faceted and varied (Iliffe et al., 2002), offering opportunities where possible for inter-professional learning. Education should be offered on an ongoing and flexible basis and take into account the existing barriers of time pressures, the current absence of a uniform dementia care pathway, the patchiness of available services and supports for people with dementia, not to mention the complexity of the illness itself and its uncertain trajectory. In terms of curriculum content, there is broad agreement that the areas of attention need to centre around:

- Improved awareness of the benefits pro-active care can have on people with dementia and their carer.
- Diagnosis and disclosure of dementia.
- Dementia specific communication skills.
- Ethical and legal knowledge and skills.

- Treatment and on-going care including pharmacological and non-pharmacological interventions.

Assessment and diagnosis of dementia within primary care is an area of growing importance, given the emerging paradigm shift in dementia care provision which calls for more timely diagnosis and provision of supports to people with dementia. However, the continued role of the GP in providing care to the person with dementia and their family throughout the course of the illness must be emphasised in all future educational supports, which concentrate on the areas outlined above. This necessitates the inclusion of person-centred, dementia-specific communication skills, particularly with regards to disclosure of diagnosis and end of life issues, as a core component of all education programmes in primary care.

5.4 Summary of the Scoping Study

This scoping study presented the state-of-the-art in best practice, existing services and educational opportunities, covering: educational and training needs across the community; healthcare settings (incorporating acute and residential care facilities) and primary care.

The review included both national and international standards and methods by which governments and independent parties assessed and provided education and training. The timing, mode of delivery and reported outcomes of such training were examined.

Regarding the information needs of people with dementia, the scoping study identified an absence of advocacy training programmes for people who are in the early stages of dementia. Education and support of the person with dementia will be required in order to enable the voice of people with dementia to be heard and for the needs of this group to be accurately represented and addressed by future policy. The scoping study also identified a need for more structured support in the immediate post-diagnostic period for both people with dementia and carers, particularly psychosocial support. Where indicated and appropriate, future caregiver interventions could include a dyadic element providing complementary emotional support to both the carer and the person with dementia.

In the primary care context, a large degree of attention was devoted to scoping the literature on available best-practice GP education and educational needs owing to the pivotal position which GPs occupy in primary care to help achieve the timely assessment, referral and diagnosis of people with dementia in the community. Numerous systemic obstacles over and above training for GPs which need to be addressed were revealed; nonetheless we identified through the literature that a simultaneously broad and in-depth range of skills and knowledge, inclusive of psychosocial approaches, need to be targeted in GP education programmes which are multi-faceted, focus on GP attitudes as well as knowledge and are offered on an on-going and flexible basis. Content covered should include diagnosis and person-centred disclosure processes, dementia-specific communication, ethical and legal issues, pharmacological and non-pharmacological interventions, with emphasis throughout on the importance of proactive and on-going care for the person with dementia and their family.

Notwithstanding the preference of many people with dementia to remain living in their own homes and in their own communities, this scoping study illustrates the need for targeted education for staff in acute care and residential care settings in which a large number of people with dementia currently reside or receive care. There is an urgent need to equip staff in these healthcare settings with the skills and knowledge to meet the psychosocial needs of people with dementia, as well as their physical care needs. This review did not find an education module combining psychosocial approaches that have been demonstrated to be effective in the care of people with dementia, namely validation, cognitive stimulation and cognitive rehabilitation. Training specific to each of these intervention approaches, possibly provided through a single accredited module on psychosocial approaches, would greatly enhance the ability of healthcare staff to improve the

quality of life of people with dementia. Similar to the primary care setting, attention to dementia-specific communication and awareness of dementia-specific ethical and legal issues, particularly in the end stages of the illness, should form a thread through future training programmes. Particular to the acute and residential care settings, a focus on assessment of cognitive status, delirium and pain, as well as an emphasis on the importance of a dementia-friendly environment is essential. Education needs to be delivered in a flexible manner tailored to the setting and staff needs and should be accommodating of resource shortages and time pressures in both acute and residential care environments.

The findings of this scoping study have been combined with the findings of the empirical study and consolidated and reported to a consensus group of expert stakeholders in the field of dementia who have recommended seven priority areas to be addressed by education.

6. Identifying the Priorities: synthesis of scoping and empirical findings.

Based on the findings of the empirical study and the scoping review, eleven key priorities areas were identified as areas that warrant further dementia education and training programmes, as outlined below. Despite the strong evidence from both empirical and scoping study a 12th area was eliminated: end of life care. This was following collaboration with the Irish Hospice Foundation (IHF), through which it was decided not to include a separate education module in this area.

The 11 priority areas identified (based on the scoping and empirical studies) for consideration by the Consensus Group were:

- Building on the current HSE National Dementia Education Programme, **expand the National Dementia awareness and communication skills training** –with a view to rolling out to public facing services.
- Continue to **upscale the dementia champions/practice development** programme for all Health and Social Care Professionals (HSCPs), taking into account the importance of achieving lasting care culture change.
- **Therapeutic skills training** for HSCPs: psychosocial approaches to supporting cognition, validation and working with couples affected by dementia.
- A **clinical module** specific for all HSCP’s on nutrition and hydration with ethical and clinical skills, responsive behaviours, assessment of pain in dementia and continence in dementia, sleep medication and antipsychotic medication, basic communication and carer support.
- **Leadership and dementia module** - training programmes for senior HSE, clinical and allied health professional management with a view to enhancing their understanding of dementia in order to secure their commitment to improving dementia care.
- Skills for HSCP’s in **responding to and assessing memory complaints** - in order to increase the number of HSCP’s who are able to engage people in a conversation about memory concerns and gather useful information towards making a diagnosis. This is not a module in diagnostics but will up skill the HSCP in the area of memory loss and memory assessment and support them to take the next steps towards helping the client receive a diagnosis.
- Bespoke **GP training** including diagnosis, disclosure, treatment (both social and medical), carer support, ethical and legal issues, therapeutic communication for dementia and formulation of person centred care.
- Best practice guide/online education in **carer support/psycho-education**. In light of recent proliferation of carer support groups nationally, a best practice guide could support people who wish to start a group and help to ensure quality standards in this area.
- **Advocacy training** for people with dementia - working with The Alzheimer Society of Ireland to develop self-advocacy for members of the National Working Group of People with Dementia with a view to hearing the voice of the person with dementia.
- A **module for qualified therapists** (such as psychotherapists, clinical psychologists) to specialise in dementia. Taking into consideration that a person with dementia may be experiencing a major life event as well as receiving a diagnosis of dementia, the scoping review found few talking therapists who are skilled in this area.
- **Best practice guide on the environment and dementia** – building on the work already underway in this area internationally and in Ireland by organisations such as the DSIDC and

more recently by the Centre for Excellence in Universal Design at the National Disability Authority.

The following section (section 7) sets out the process of the Consensus Group in evaluating the 11 areas identified.

7. Consensus Report

Based on the scoping review and ENA findings, a broad list of eleven key priority areas have been identified as being significant fields that merit further training and education programmes. These priority areas are outlined in section 6 above.

Fifteen key dementia experts (Appendix A) from a broad range of settings and organisations who are all involved in, or aware of, dementia planning at national level were invited to attend two consensus group meetings. These took place over two consecutive days with a view to reducing the number of priority areas from eleven areas to seven. The stakeholders came from the following settings and organisations:

- Hospital-based
- Nursing home-based
- University-based
- Palliative care setting
- Community based Genio projects
- Therapies
- HSE
- Alzheimer Society of Ireland.

The consensus group was presented with the eleven key priority areas identified.

A nominal group technique (NGT) was used with degree flexibility, in order to encourage a free flowing and informal contribution and sharing of ideas. Each member of the consensus group partook in the discussion on all priority areas, imparting their specific experience and expertise to the posed issues. As previously highlighted in the methodology section, the advantage of NGT is that it ensures the equal representation of a variety of experts, ensuring one education need will not overshadow the others, while also allowing for reaching of consensus by the end of the two sessions (Harvey and Holmes 2012) Through a process of discussion and prioritization the eleven selected areas were reduced to seven, with three areas having additional sub-levels added to expand the reach of the training and education programmes to family carers and community members.

The seven priorities areas identified for dementia education and training programmes are outlined below

7.1 Seven Priority Areas Generated via Nominal Group Technique for Dementia Education

1. **National Dementia awareness and communication skills training** – extend reach to a wide range of public facing services.
 - **Level 1** A brief community awareness programme to all public facing workers.
 - **Level 2** Short skills training for key public facing workers including financial services, solicitors, retail, police, travel, sport and recreational services.
 - **Level 3** Expand current two-day HSE National Dementia Awareness programme for anyone working in health or social care settings.
2. Expand practice development/**dementia champions programme** for all nurses and Allied Health Professionals.
3. **Therapeutic skills module** for any health care professional: psychosocial approaches to supporting cognition, validation and working with couples affected by dementia.

- **Level 1** A practical online module (not accredited) targeted to informal carers but with open access addressing principles for validation, cognitive remediation and multi-sensory stimulation, with a toolkit for services who wish to deliver the initiative face to face.
 - **Level 2** Degree level module which will develop a practitioner's skills in 3 therapeutic approaches – Validation, Cognitive Remediation and option of multisensory or dyadic support of couples with dementia.
4. A module specific on **clinical and ethical decision making** including nutrition, hydration and pain assessment.
 - **Level 1** a module tailored to informal carers working with people with dementia in their own homes who face numerous ethical dilemmas. This module can also be undertaken by health care assistants.
 - **Level 2** Degree level blended learning module for health and social care professionals introducing them to ethical principles, theory of decision making (both applied to dementia) and then addressing 8 scenarios, hydration, nutrition, pain, mobility/restraint, sleep problems, responsive behaviours, sexuality, future care decisions.
 5. Training on **dementia awareness for managers and service leaders**.
 6. Skills in responding to **memory complaints** - targeting HSCPs.
 7. Bespoke **GP training** including; diagnosis, disclosure, treatment (both social and medical) carer support, ethical and legal issues, therapeutic communication for dementia and formulation of person-centred care.

The discussion and prioritization of seven key areas will be outlined below in order of ranking. It was agreed that the themes of advocacy, human rights, environment and end of life will cut across all of the training and education programmes. The reasons for eliminating the remaining priority areas are also addressed.

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7.2 Discussion and Prioritization

7.2.1 Awareness

The importance of improved awareness among a very wide range of people was highlighted by all members of the consensus group. The point was made that exposure rather than education would be more effective in bringing about the type of culture change required. Several initiatives in the scoping study used exposure as a mechanism for changing stigma and attitudes. The distinction was made between general awareness and the need for awareness with some key skills. The need for flexibility in the resources so that they could be used as a face to face package or an on-line intervention was expressed to maximize uptake. It was expressed that random training of people in public services may absorb much time and if those trained do not use the skills soon after the training it would quickly become obsolete. The training may be more effective if it used an ecological approach using existing networks.

The current HSE National dementia awareness programme was discussed. It is intended to recruit additional facilitators to extend the programme to any healthcare provider or allied health professionals. It was expressed that the programmes should be extended to people in the community but that the 2-day programme was not suitable to meet the needs of certain groups in the community.

There is a strong need for certain community-based service providers/workers, for example, post office, retail and Gardaí to have more than just awareness, but rather to have communication skills and knowledge. A short dementia skills programme will be developed for customer facing service providers tailored to the profession.

It was agreed that an online or face-to-face short awareness session would be developed with a view to cascaded dissemination in the various organisations.

The challenge in promoting the training programmes was discussed and it was agreed that using existing networks such as ASI, The Carers Association and Age Friendly cities and counties would be effective.

Priority: High.

Timing: March-December 2014.

Stakeholders: ASI, HSE, Genio, Age friendly counties projects, key community service providers.

7.2.2 Practice Development/Dementia Champions Programme for all Health Social Care Professionals

The Dementia Champions course will continue in its current form providing person centred care and practice development skills for Health and Social Care Professionals. The aim is to strengthen the programme's reach by training facilitators in six locations around Ireland. It was discussed that the culture of each setting needs to be addressed (in other words, should the dementia champion leave other staff will be prepared), ensuring the value of the dementia training remains in the setting. It was suggested that dementia champions should have a network to discuss and share ideas, but some concern was expressed about confidentiality issues.

It was also agreed by the consensus group that management buy-in is of high importance and that the National Audit of Dementia Care in Acute Hospitals will provide a base line and motivation for clinical leaders. A follow up evaluation plan for the Dementia Champions module was discussed and how this could be effectively carried out.

Priority: High.

Timing: March-December 2014.

Stakeholders: Hospitals, HSE, ASI, residential care providers, existing dementia champions, all allied health professionals.

7.2.3 Therapeutic Skills Module for any Health Care Professional (psychosocial approaches to supporting cognition, validation and working with couples affected by dementia).

It was recommended that a module will be produced that will develop practitioners' skills in three therapeutic approaches – Validation, Cognitive Remediation and either multi-sensory or dyadic support. This will incorporate two levels - level 1 for family carers and level 2 for practitioners.

It was pointed out that there must be clarity around what the module is offering and that people will not be able to set themselves up as therapists at the end of the course. It was suggested that a basic

understanding of dementia is needed before undertaking the module, but concern was also expressed about too many pathways needed to do the training being a possible barrier.

The degree level module was considered a potential obstacle to members of community, therefore the development of a foundation course was proposed. The module aimed at practitioners would necessitate the provision of a clinical supervision and support aspect. It was also highlighted that there exists a cadre of experts within the area of intellectual disability with skills in nonverbal and responsive behaviours who may be willing to become involved with the training programmes.

The foundation module would provide the essential principles of validation, cognitive remediation and multisensory stimulation therapy. This would be aimed at family/informal carers, but access will be open.

Priority: High.

Timing: March- December 2014.

Stakeholders: Genio, ASI, HSE, Carers Association, home care providers, residential care providers, social care workers.

7.2.4 Clinical Skills Specific for Health and Social Care Professionals (on nutrition and hydration with ethical and clinical skills, responsive behaviours, assessment of pain in dementia and continence in dementia, sleep medication and antipsychotic medication, basic communication and carer support).

This will incorporate two levels - level 1 for family carers and level 2 for practitioners. The discussion on this area showed that this type of education must be multidisciplinary as the issues cross all professional boundaries. The group discussed how to approach such clinical skills training and it was felt that ethical/clinical decision making was a way to support HSCP's in these aspects of care. In addition carers also need the same skills as often they are encountering the same ethical dilemmas as professional carers. It was discussed that all the above mentioned aspects of care are linked e.g. the issue of medications was linked to many other areas such as nutrition, hydration, continence, sleep, pain and responsive behaviours.

The clinical skills module was also considered necessary for family carers in the community. It was pointed out that the prescribing of anti-psychotic medications in the community is often due to very stressed carers with little support. This module was considered beneficial in teaching a carer to see beyond the behaviour to the causes and it is intended to give the carer a framework with which to consider the problem they are facing and to support them in recognizing when a problem is an ethical one and give them options for enlisting help.

Priority: Medium.

Timing: January – September 2015.

Stakeholders: Hospitals, HSE, residential care providers, home care providers, Carers Association.

7.2.5 Leadership and Dementia Module.

The consensus group agreed that buy in and commitment from management is of critical importance to the roll out of training and education on dementia. It was acknowledged that it would be challenging to enlist this group. 'A day in the life' idea was proposed where managers could spend a day as a health care assistant to give them an opportunity to see how they could make a difference to the lives of people with dementia. It was agreed that making a business case and

arguing benefits to their service (e.g. quicker assessments) would be the best approach to secure commitment from this group.

The national audit on dementia care in acute hospitals was also considered a motivational tool which would encourage hospital managers to enlist in the training. It was suggested that this training course could be piloted with the Genio dementia projects and in connection with the Dementia Champions training to get critical mass in one area.

Priority: Medium.

Timing: January – September 2014.

Stakeholders: Senior HSE management, hospital managers, residential care management, home care management.

7.2.6 Skills in Responding to Memory Complaints, HSCP's

This priority area is intended to provide training for HSCP's on what to look out for regarding someone's memory. It was stressed to the consensus group that it is not intended as a module in diagnostics but it will enable health and social care professionals who work in community teams to play their part in skilled assessment of people who present with new memory concerns.

It was agreed that this may need to link with the forthcoming Single Assessment Tool (SAT). This priority will be similar to that used in the Norwegian strategy, as opposed to the UK approach where there is currently a high volume of memory clinics. It was highlighted that more skill in primary care is needed with a greater focus on a team approach. It was also acknowledged that it is crucial to get commitment from the GP who is central to this priority area. One participant raised concern around the importance of promoting a clear cognitive message of going to your GP with memory concerns, as opposed to a range of health care professionals a person could potentially approach. It was proposed that each primary care centre could nominate one person to take outcome of initial patient assessments back to the GP as per Norwegian model and that the new approach could be piloted first with interested primary care team in a selected geographical location.

Priority: Medium.

Timing: January- September 2014.

Stakeholders: Allied health professionals, primary care teams, ICGP.

7.2.7 Bespoke GP Training - including, diagnosis, disclosure, treatment (both social and medical), carer support, ethical and legal issues, therapeutic communication for dementia and formulation of person-centred care.

It was acknowledged that GP's are the cornerstone of the training and education programmes and that commitment from this cohort is essential. The ENA found that GPs feel that there is little advantage in dementia education unless a clear dementia care pathway and services are in place. It was emphasized that CPD training may not change GP's clinical practices nationally, but should be present and visible even for already knowledgeable GPs. The challenges in enlisting GP's into dementia training were discussed. It was deemed best to delay the start of this training so as the get the key partners in place.

Priority: Medium.

Timing: January – September 2014.

Stakeholders: ICGP, HSE, geriatricians, psychiatrists of old age.

7.3 Eliminated Priority Areas

7.3.1 Best Practice Guide/Online Education in Carer Support/Psycho-education

Support for carers supporting relatives in the early stages of dementia was identified as a significant need in the scoping study. There has been a recent proliferation of carer support groups nationally, and it was recognized that a best practice support guide could be valuable in ensuring quality standards. Different types of support groups were discussed such as men's groups, women's groups, dyadic support for couples and groups of couples, highlighting the range of needs individual groups may have.

Reason for elimination: This was described as a 'nebulous area'. One participant thought that promoting best practice would not be as simple as producing guidelines since, for example, the current guidelines for setting up Alzheimer cafés are often not being followed. It was also pointed out that with guidelines the outcome will not be guaranteed. While it was felt it would be a beneficial resource it would need to clarify that it is not training and education *per se*. It was proposed that this priority area could be addressed as part of level 1 therapeutic skills module, dyadic support option.

7.3.2 Advocacy Training for People with Dementia (working with ASI to develop self-advocacy in their dementia working group and to develop the voice of the person with dementia).

In contrast with the scoping study, the ENA found a striking lack of evidence on this topic. It was agreed among the consensus group that a paradigm shift is needed regarding how we perceive the person with dementia, in that they should be perceived as individuals who have something to contribute to society rather than focusing wholly on their needs.

Reason for elimination: Collaborating with the ASI with the Working Group for People with Dementia was considered initially. However, it was thought that more time is needed for ASI to build critical mass in this area as the working group is as yet in its infancy. Therefore the theme of self-advocacy will be included in the design in all of the other dementia training and education programmes.

7.3.3 A Module for Qualified Therapists (such as psychotherapists, clinical psychologists) to Specialise in Dementia

It was highlighted that a person with dementia often has a major lifestyle event and there are no qualified therapists who specialize with people with dementia and their carers. One participant spoke of a person with dementia that travelled over 200 miles for this therapy.

Reason for elimination: Other areas were viewed as being higher priorities. It was decided to actively encourage therapists to engage with the dementia champions' module and to establish a greater link with the therapists in training in DCU.

7.3.4 Best Practice Guide on the Environment and Dementia

The ENA found poor awareness of environmental issues relating to dementia. It was agreed that this area needs innovation and it was also pointed out that the person with dementia is rarely asked what they would like regarding design. It was acknowledged that small environmental changes can be a catalyst and that the participatory process is central to this area.

Reason for elimination: This priority area was perceived as fundamental to dementia care. The consensus group recognized that progress in this area is already underway, for example the

development of Universal Design Guidelines for Dementia Friendly Dwellings by the Centre for Excellence in Universal Design at the National Disability Authority and it was agreed that the environment will be a cross cutting theme within the other dementia training and education programmes.

7.4 Summary

Using a nominal group technique, seven key priorities areas on dementia were selected by 15 dementia experts, as topics to be addressed by training and education programmes. Through a process of discussion and prioritization each stakeholder contributed their unique experience and perspective on dementia towards the sharing and generation of ideas and eventually to the ranking of priority areas.

Subsequently, an action plan outlining the implementation of the training programmes throughout the course of the Elevator project was devised in accordance with their priority ranking. Furthermore, the nominal group technique encourages the nominated experts to take ownership of the prioritized areas and increases the likelihood of their on-going commitment throughout the course of the Elevator project.

The seven key priority areas have a number of cross cutting themes including the end of life (as per collaboration with the IHF), self-advocacy for people with dementia and dementia friendly environments. What follows is a matrix showing the educational needs, available training and gaps addressed by Dementia Elevator to provide education to people throughout the dementia trajectory.

8. Education Needs Analysis Matrix

The matrix below shows the educational needs of people throughout the dementia trajectory. Gaps in educational provision have been addressed by Elevator training to a large extent. Some gaps still exist in dementia education that are not currently being filled, however it is intended that they will be addressed in future projects arising from Elevator.

The general concept is that as the skill level increases from left to right the person builds on the skills at the previous levels. Where skills are particularly critical (such as person-centred care and empathy) they have been repeated, however the matrix represents a general building of skills from left to right.

There will be diversity in skills, for example, at 'expert level'. It is not necessary to be a diagnostician to become an expert and not every diagnostician needs to have all the skills of other experts. However, at 'enhanced' or 'expert level' there is an assumption that practitioners will have a broad range of skills, not being expert in just one. Indeed, we expect that some family carers are experts in the full sense of the word. We have not assumed professional groups fit into any of these categories. There is an assumption that there is a need for people with a range of skills in all professional groups and throughout the dementia trajectory.

We have mapped the major national educational opportunities into this matrix and added in blue, the gaps we intend to fill with the elevator education and training resources. This matrix will be available on the Dementia elevator website for the period of the project with a form that can be completed by course co-ordinators so that their training can be included in the matrix. Certain quality criteria will be checked before courses are placed in the matrix. The endeavour will be that the training matrix will be a live document, guiding potential students to training they wish to access.

Dementia Elevator Education Matrix - Prevention, Awareness and Assessment

Dementia trajectory	Person with Dementia Lay carer or Friend	Public facing services / Informed Practice Level	Dementia Skilled Practice Level	Enhanced Dementia Practice Level / Expertise in Dementia Practice Level
Prevention, Awareness and Assessment	<p>Awareness: Support available to reduce risk and where to go if there are concerns of early signs of dementia.</p> <p>Knowledge / skills: Risk factors for dementia. What is normal ageing versus early signs of dementia. How to open / respond to difficult conversations.</p> <p>Understanding: Pros and cons of early diagnosis and how these would impact on themselves and their loved ones / friends / neighbours</p>	<p>Awareness: What dementia is and where supports can be accessed.</p> <p>Knowledge/ skills: Early signs of dementia. What is normal ageing versus early signs of dementia. Immediate communication skills if they suspect dementia. Repertoire of responses appropriate to their setting. Empathy and compassion.</p> <p>Understanding: Risks or benefits to the person of any chosen action. What organisations can do to reduce stigma related to ageing and dementia.</p>	<p>Awareness: What dementia is and where supports can be accessed.</p> <p>Knowledge/ skills: Early signs of dementia. Repertoire of responses to suspected dementia. Empathy and compassion. Assessment of to what extent the problems are impacting on life for all concerned. Advocacy / promotion of self advocacy skills. Empathy and compassion. Change management / practice development.</p> <p>Understanding: Risks or benefits to the person of any action.</p>	<p><i>As for skilled Practice Level with the addition of:</i></p> <p>Awareness: Local referral processes if a dementia is suspected / diagnosed.</p> <p>Knowledge/ skills: Advanced communication, mediation and counselling skills. Dementia assessment/work up skills. Repertoire of responses to memory problems believed not to be dementia (memory supports, coping strategies, cognitive health promotion information). Leadership skills.</p> <p>Understanding: Ethical & moral issues & ability to relate these to the individual and their family circumstances.</p>
Available education	Elevator Level 1 Awareness training	Elevator Level 2 Awareness Skills Training for Public Facing Services	Elevator Level 3 Awareness Training, Elevator Dementia Champions	Elevator Memory Assessment Skills Training, Elevator Leadership Training, GP Training.

Dementia Elevator Education Matrix - Diagnosis and Post Diagnosis

	Person with Dementia, Lay carer or Friend	Public facing services	Informed Practice Level	Dementia Skilled Practice Level	Enhanced Dementia Practice Level	Expertise in Dementia Practice Level
Diagnosis and post diagnosis	<p>Awareness: Support available.</p> <p>Knowledge / skills: How to open / respond to difficult conversations. Advocacy / self advocacy in the consultation process. Emotional and cognitive coping strategies. Secondary prevention approaches.</p> <p>Understanding: Diagnostic process.</p>	<p>Awareness: support available.</p> <p>Knowledge / skills: A repertoire of supportive responses to difficult circumstances.</p> <p>Understanding: Impact of a diagnosis on a person and their family. Importance of maintaining activities and social connections.</p>	<p>Awareness: The challenges facing people with dementia and their carers in adapting to the diagnosis. Information sources and support available.</p> <p>Knowledge / skills: Communication, observation, detection, advocacy. Empathy and compassion. Basic coaching skills.</p> <p>Understanding: Impact of diagnosis. Person / relationship centred care.</p>	<p>Awareness: The challenges facing people with dementia and their carers in adapting to the diagnosis. Information sources and community supports available.</p> <p>Knowledge / skills: Strength based assessment. A range of therapeutic skills for the person with dementia and the carer. Empathy and compassion.</p> <p>Understanding: Impact of diagnosis. Person / relationship centred care.</p>	<p>Awareness: Emerging therapies and approaches. Ongoing research.</p> <p>Knowledge / skills: Ability to teach assessment and therapeutic skills. Empathy and compassion. Ability to support advanced care planning. Engaging hope and strengths. Service audit and change management skills.</p> <p>Understanding: Impact of diagnosis. Person / relationship centred care. Ethical moral and cultural issues.</p>	<p><i>As for enhanced Practice Level with the addition of:</i></p> <p>Awareness: Onward referral to services processes.</p> <p>Knowledge / skills: Differential diagnosis and sub-typing. Skills in disclosure. Advanced communication, mediation and counselling skills. Team Leadership and intra team communication skills. Teaching skills. Assessment and planning future support needs, such as advanced care directives and accessing driving assessments. Legal knowledge. Service audit and change management skills. Assessment of capacity processes. Supports available. How</p>

						<p>dementia can change over time. Psychosocial and pharmaceutical therapies.</p> <p>Understanding: Person centred / relationship centred care. Ethical and moral, cultural issues and ability to relate these to the individual and their family circumstances. Difficulties faced by people with dementia and their carers and services.</p>
Available education	Elevator Level 1 Awareness Training	Elevator Level 2 Awareness Skills Training for Public Facing Services	Elevator Level 3 Dementia Awareness Training (healthcare workers)	Elevator Dementia Champions	Elevator Level 2 Therapeutic Skills Module.	Elevator Leadership Skills Training, Elevator GP Training.

Dementia Elevator Education Matrix - On-Going Support, Care and Review

	PwD	Lay carer or Friend	Public facing services	Informed Practice Level	Dementia Skilled Practice Level	Enhanced Dementia Practice Level/Expertise in Dementia Practice Level
On-going Support, care and review	<p>Awareness: Need for adaptation as changes occur.</p> <p>Knowledge / skills: How dementia changes over time. Advocacy / self advocacy. Emotional and cognitive coping strategies. Anxiety management.</p> <p>Understanding: Importance of personhood and personal identity. Importance of the environment on the person with dementia.</p>	<p>Awareness: Need for adaptation as changes occur.</p> <p>Knowledge / skills: How dementia changes over time. Advocacy / Self advocacy. Emotional and cognitive coping strategies. Anxiety management.</p> <p>Understanding: Importance of personhood and personal identity. What everyday ethical situations can occur and how to get help with them. How to express a need for help. Importance of the environment on</p>	<p>Awareness: Support available. How dementia can change over time.</p> <p>Knowledge / skills: A repertoire of supportive responses to difficult circumstances in the particular service provided.</p> <p>Understanding: Importance of adaptation to activities and social connections so that personal identity can be maintained. Importance of the environment on the person with dementia.</p>	<p>Awareness: Ethical challenges in complex yet everyday care situations. Recognising and responding to stressed behaviours. Use of assistive technologies.</p> <p>Knowledge / skills: Support available. How dementia can change over time. Engagement in meaningful activity. Responsive behaviour, its causes and some helpful counter responses.</p> <p>Understanding: Person-centred care.</p>	<p>Awareness: Need for proactive responses to prevent carer burn out. Potential for / signs of abuse.</p> <p>Knowledge / skills: How to adapt a plan of care to individual and family changing needs. Psychosocial and pharmaceutical therapies. Pain assessment, nutrition, hydration, continence promotion prevention, detection and treatment of delirium. Assistive technologies. Responding to everyday ethical situations.</p> <p>Understanding: Person-centred care.</p>	<p><i>As with Skilled Practice Level plus:</i></p> <p>Awareness: Need for proactive responses to prevent carer burn out. Potential for / signs of abuse.</p> <p>Knowledge / skills: Leading clinical ethical decision making on areas such as nutrition, hydration, pain assessment, and delirium. Interactions with co-morbid illness. Teamwork, leadership and change management.</p> <p>Understanding: Person-centred care.</p>

		the person with dementia.		Importance of the environment on the person with dementia.	Importance of the environment on the person with dementia.	Need for creativity and innovation in care. Importance of the environment on the person with dementia.
Available education	Elevator Level 1 Awareness Training.	Elevator Level 1 Therapeutic Skills Training. Elevator Level 1 Clinical Decision Making.	Elevator level 3 Awareness and Skills Training for Public Facing Services	Elevator Level 2 Therapeutic Skills Training.	Elevator Level 2 Clinical Decision Making,	Elevator Level 2 Clinical Decision Making. Elevator Leadership Training.

Dementia Elevator Education Matrix – End of Life

	Person with dementia, Lay carer or Friend	Informed Practice Level	Dementia Skilled Practice Level	Enhanced Dementia Practice Level/Expertise in Dementia Practice Level (increasing complexity)
End of life	<p>Awareness: Advanced directive if one exists. Where to access emotional and practical support.</p> <p>Knowledge / skills: Human rights. Physical body care.</p> <p>Understanding: Person’s wishes. How to ask for support.</p>	<p>Awareness: Needs of carers and people with dementia at the end of life.</p> <p>Knowledge / skills: Empathy and compassion. Opening conversations. Assessment of physical and emotional needs.</p> <p>Understanding: Person-centred care. The importance of the environment at end of life in death and immediately after.</p>	<p>Awareness: Needs / wishes of carers and people with dementia at the end of life.</p> <p>Knowledge / skills: Empathy, compassion. Assessment of physical and emotional needs. Advocacy.</p> <p>Understanding: Person-centred care needs through dying, death and immediately after. Needs of carers through the dying process and after death.</p>	<p>Awareness: Personal wishes and advanced directives. Specialist service referral pathways. Spirituality.</p> <p>Knowledge / skills: Empathy and compassion. Advanced assessment, complementary therapies, pharmaceutical symptom management, grief and bereavement counseling. Clinical and ethical decision making in nutrition, hydration, active / palliative treatment etc. Critical reflection on practices. Self awareness. Advocacy.</p> <p>Understanding: Acceptance that good end of life care starts well before the end of life. Ethical decision making around treatment alternatives. Person-centred care. Importance of the environment on the person with dementia and their carer.</p>
Available education				Elevator Level 2 Clinical Decision Making

9. Conclusion

This educational needs analysis took a novel approach to studying educational need in a very wide section of the population from the perspective of the person with dementia. A scoping study of the literature was carried out. Three locations in Ireland were chosen, representing city, town and a rural area, and one person with dementia in each was selected. Subsequently educational needs in a broad range of contexts (the three individuals' social networks) were explored. As a result, the narrative is a bottom up analysis of education and training needs across a spectrum, not a comprehensive view of any one section of the dementia care trajectory or service that people with dementia experience (for example, the study interviewed just three general practitioners and three people with dementia, in order to study any one stakeholder in detail, a more in-depth investigation of more people in that sector would need to be carried out). In this study the general practitioners we spoke with had a good working knowledge of the dementia care pathway in principle, but very little confidence in its existence in their local area in most cases. The three GPs were selected for their special interest in dementia, so could not be thought of as representative.

It is important to note that while we did not get a quantitative, representative group of any one profession, we did get something close to a 360 degree evaluation of each group, as everyone we interviewed had stories to tell about encountering skills and knowledge dearth in other groups. These inductive findings could be put to use to inform educational needs analysis surveys in a specific group – such as general practitioners. Certainly, general practitioners have a lynchpin position in dementia care and a full ENA in general practice would be warranted. Similar arguments could be made for other health and social care groups and staff in nursing homes. Despite our small numbers in any specific grouping, our findings fit well into the continuum of previous ENAs in Ireland and internationally in many respects.

The inductive nature of this research and keeping the people with dementia at the heart of the process has been the guiding principle of the empirical work presented here. We have balanced this with the literature scoping study and the expert consensus group, which lend a top down element to the research. Overall we have presented the need for seven areas of education and training including:

- National dementia awareness and communication skills training (3 levels).
- Practice development/dementia champions programme for all nurses and allied health professionals.
- Therapeutic skills module for health care professionals and carers (2 levels).
- Clinical and ethical decision making module (2 levels).
- Dementia awareness for managers and service leaders.
- Skills in responding to memory complaints - targeting HSCPs.
- Bespoke GP training.

We have stayed close to our commitment to lifelong learning and inclusivity by offering foundation level training and many free resources in key areas where we believe that carers may benefit from the knowledge base. All education we offer will be cognisant of the need to address culture in care settings and that education alone may not achieve changes in practice. Wherever possible we will roll out education in local areas through existing networks such as age friendly organisations and ASI etc.

This study has not looked at educational need in dementia specialist centres such as memory clinics or dementia specific care centres. Indeed, these are pertinent areas but necessarily outside the scope of this study.

The future work of the Elevator will be to design the education described above over a 30-month period. Each priority area will detail an evaluation and dissemination plan and curriculum. Innovative modes of integrating education into workplaces and professional groups will be explored. We will continue our collaboration with key organisations such as ASI, IHF and DSIDC and continue to develop other collaborations in key areas.

Overall this report makes an addition to the knowledge base about life in Ireland with dementia. It reports a lack of skills throughout the care trajectory and at all levels of expertise. It also reports clear evidence of stigma and ageism in communities. We have found room for (and willingness in principle for) communities to take further responsibility in their dealings with people with dementia. In healthcare settings the need for ownership of the issue of dementia and of the risks associated with living well with dementia will be supported by the education planned here. However, it must be acknowledged that education on its own will not solve all the challenges we face. In addition to education, there is a need for changes in systems and services to support new ways of working, in order to make sustainable changes in the lives of people with dementia in Ireland.

10. References

Adams, T. and Manthorpe, J. 2003. *Dementia care*. London; New York: Arnold; Distributed in the USA by Oxford University Press.

Allan, K. and Killick, J. 2008. Communication and relationships: An inclusive social world. *Excellence in Dementia Care: Research into Practice*, pp.212-229.

Alzheimer Europe 2006. *Alzheimer Europe report: The use of advance directives by people with dementia*, Luxembourg : Alzheimer Europe.

Alzheimer Society 2009. *Counting the cost: Caring for people with demetia on hospital wards*. London: Alzheimer Society.

Alzheimer's Society of Ontario 2011. *Guidelines for care: Person-centred care of people with dementia living in care homes: Framework*. Ontario: Alzheimer's Society.

Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.H. and Whitlatch, C.J. 1995. *Profiles in caregiving: The unexpected career*. Academic Press.

Banerjee, S. 2009. The use of antipsychotic medication for people with dementia: Time for action. *London: Department of Health*,

Barnett, E. 2000. *Including the Person with Dementia in Designing and Delivering Care*. London: Jessica Kingsley Publishers.

Bartholomew, L.K., Parcel, G.S., Kok, G., Gottlieb, N.H. and Fernandez, M.E. 2011. *Planning health promotion programs: an intervention mapping approach*. Jossey-Bass.

Beer, C., Horner, B., Almeida, O.P., Scherer, S., Lautenschlager, N.T., Bretland, N., Flett, P., Schaper, F. and Flicker, L. 2009. Current experiences and educational preferences of general practitioners and staff caring for people with dementia living in residential facilities. *BMC Geriatrics*, 9(1), pp.36.

Beisecker, A.E., Chrisman, S.K. and Wright, L.J. 1997. Perceptions of family caregivers of persons with alzheimer's disease: Communication with physicians. *American Journal of Alzheimer's Disease and Other Dementias*, 12(2), pp.73-83.

Boud, D. and Doherty, P. 2006. *Productive reflection at work*. Oxon: Routledge.

Bowers, B., Downs, M. and Bowers, B. 2008. A trained and supported workforce. *Excellence in Dementia Care: Research into Practice*, pp.414-437.

British Society of Gastroenterology 2010. *Difficulties, oral feeding; dilemmas. A guide to practical care, particularly towards the end of life*.

Brock, C.D. and Simpson, W.M. 1990. Dementia, depression, or grief? the differential diagnosis. *Geriatrics*, 45(10),

- Brooker, D. 2007. *Person-centred dementia care: making services better*. London: Jessica Kingsley Publishers.
- Burton, E., Mitchell, L. and Lynne Mitchell, M. 2013. *Inclusive urban design: Streets for life*. Routledge.
- Cahill, S., Clark, M., Walsh, C., O'Connell, H. and Lawlor, B. 2006. Dementia in primary care: The first survey of Irish general practitioners. *International Journal of Geriatric Psychiatry*, 21(4), pp.319-324.
- Cahill, S., O'Shea, E. and Pierce, M. 2012. *Creating excellence in dementia care: A research review for Ireland's national dementia strategy*. Ireland: Department of Health (DoH).
- Challis, D., Clarkson, P., Hughes, J., Chester, H., Davies, S., Sutcliffe, C., Xie, C., Abendstern, M., Jasper, R. and Jolley, D. 2010. Community support services for people with dementia: The relative costs and benefits of specialist and generic domiciliary care services. *Manchester: Personal Social Services Research Unit at the University of Manchester*,
- Chater, K. and Hughes, N. 2013. Strategies to deliver dementia training and education in the acute hospital setting. *Journal of Research in Nursing*, 18(6), pp.578-593.
- Clancy, T.R. 2007. Organizing: New ways to harness complexity. *Journal of Nursing Administration*, 37(12), pp.534-536.
- Clare, L. 2005. Cognitive Rehabilitation for People with Dementia *IN: Marshall, M. (ed.) Perspectives on Rehabilitation and Dementia*. London: UK: Jessica Kingsley Publishers, pp.180.
- Clare, L. 2008. *Neuropsychological rehabilitation and people with dementia*. Hove, East Sussex ; New York, NY: Psychology Press.
- Conn, D.K. 1991. Delirium and other organic mental disorders. *IN: Sadavoy, J., Lazarus, L.W. and Jarvik, L.F. (eds.) Comprehensive Review of Geriatric Psychiatry*. Washington: American Psychiatric Press, pp.312-321.
- Connell, C.M. and Gallant, M.P. 1996. Spouse caregivers' attitudes toward obtaining a diagnosis of a dementing illness. *Journal of the American Geriatrics Society*, 44(8), pp.1003-1009.
- Connell, C.M., Boise, L., Stuckey, J.C., Holmes, S.B. and Hudson, M.L. 2004. Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *The Gerontologist*, 44(4), pp.500-507.
- Cooper, C., Selwood, A. and Livingston, G. 2008. The prevalence of elder abuse and neglect: A systematic review. *Age and Ageing*, 37(2), pp.151-160.
- Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, R. and Livingston, G. 2009. Abuse of people with dementia by family carers: Representative cross sectional survey. *BMJ: British Medical Journal*, pp.583-586.

- Cornelius, J.R., Fabrega Jr, H., Mezzich, J., Cornelius, M.D. and Ulrich, R.F. 1993. Characterizing organic mood syndrome, depressed type. *Comprehensive Psychiatry*, 34(6), pp.432-440.
- Coyne, A.C., Reichman, W.E. and Berbig, L.J. 1993. The relationship between dementia and elder abuse. *American Journal of Psychiatry*, 150pp.643-646.
- Davies, S. and Nolan, M. 2008. Attending to relationships in dementia care. *Excellence in Dementia Care: Research into Practice*, pp.438-454.
- De Lepeleire, J., Heyman, J. and Buntinx, F. 1998. The early diagnosis of dementia: Triggers, early signs and luxating events. *Family Practice*, 15(5), pp.431-436.
- De Siun, A. and Manning, M. 2010. *National dementia project: Dementia education needs analysis report*. Ireland: Health Service Executive.
- Department of Health 2010. *Improving care for people with dementia*. London: Department of Health.
- Department of Health 2002. *Developing services for carers and families of people with mental illness*. London: Department of Health.
- Dobbs, B.M., Carr, D.B. and Morris, J.C. 2002. Evaluation and management of the driver with dementia. *The Neurologist*, 8(2), pp.61-70.
- Downs, M., Cook, A., Rae, C. and Collins, K.E. 2000. Caring for patients with dementia: The GP perspective. *Aging & Mental Health*, 4(4), pp.301-304.
- Dröes, R., Meiland, F., Schmitz, M. and Van Tilburg, W. 2006. Effect of the meeting centres support program on informal carers of people with dementia: Results from a multi-centre study. *Aging and Mental Health*, 10(2), pp.112-124.
- Ekman, S., Norberg, A., Viitanen, M. and Winblad, B. 1991. Care of demented patients with severe communication problems. *Scandinavian Journal of Caring Sciences*, 5(3), pp.163-170.
- Farrell, A., Cahill, S. and Burke, S. 2007. Rural practice, dementia and CMHN activity. *Partnerships in Community Mental Health Nursing and Dementia Care: Practice Perspectives*, pp.142.
- Feil, N. 1993. *The validation breakthrough: Simple techniques for communicating with people with "Alzheimer's-type dementia."*. Health Professions Press.
- Fortinsky, R.H. 2001. Health care triads and dementia care: Integrative framework and future directions. *Aging & Mental Health*, 5pp.35-48.
- Foster, N.L. 2001. Barriers to treatment: The unique challenges for physicians providing dementia care. *Journal of Geriatric Psychiatry and Neurology*, 14(4), pp.188-198.
- Francis, J. and Kapoor, W.N. 1990. Delirium in hospitalized elderly. *Journal of General Internal Medicine*, 5(1), pp.65-79.

Frosch, D.L. and Kaplan, R.M. 1999. Shared decision making in clinical medicine: Past research and future directions. *American Journal of Preventive Medicine*, 17(4), pp.285-294.

Hanna, J.R.,C. 2012. *An evaluation of national museums liverpool: Dementia training programme*. Liverpool: Museum of Liverpool.

Hanson, L.C., Ersek, M., Gilliam, R. and Carey, T.S. 2011. Oral feeding options for people with dementia: A systematic review. *Journal of the American Geriatrics Society*, 59(3), pp.463-472.

Harvey, N. and Holmes, C.A. 2012. Nominal group technique: An effective method for obtaining group consensus. *International Journal of Nursing Practice*, 18(2), pp.188-194.

Hasselbalch, S., Baloyannis, S., Denislic, M., Dubois, B., Oertel, W., Rossor, M., Tsiskaridze, A. and Waldemar, G. 2007. Education and training of european neurologists in dementia. *European Journal of Neurology*, 14(5), pp.505-509.

Hellström, I., Nolan, M. and Lundh, U. 2007. Sustaining 'couplehood': Spouses' strategies for living positively with dementia. *Dementia*, 6(3), pp.383-409.

Hinton, L., Franz, C.E., Reddy, G., Flores, Y., Kravitz, R.L. and Barker, J.C. 2007. Practice constraints, behavioral problems, and dementia care: Primary care physicians' perspectives. *Journal of General Internal Medicine*, 22(11), pp.1487-1492.

Holden, U.P. and Woods, R.T. 1995. *Positive Approaches to Dementia Care*. 3rd ed. Edinburgh, UK.: Churchill Livingstone.

Homer, A.C. and Gilleard, C. 1990. Abuse of elderly people by their carers. *BMJ (Clinical Research Ed.)*, 301(6765), pp.1359-1362.

Horvath, K.J., Tumosa, N., Thielke, S., Moorer, J., Huh, T., Cooley, S., Craft, S. and Burns, T. 2011. Dissemination strategies: The evolution of learning resources on the evaluation of delirium, dementia, and depression. *Gerontology & Geriatrics Education*, 32(1), pp.80-92.

Ibrahim, S.A. and Mahran, S.M. 2010. Attributes of nursing staff development in port said hospitals. *Journal for Nurses in Staff Development : JNSD : Official Journal of the National Nursing Staff Development Organization*, 26(1), pp.E6-E13.

Iliffe, S., Wilcock, J., Austin, T., Walters, K., Rait, G., Turner, S., Bryans, M. and Downs, M. 2002a. Dementia diagnosis and management in primary care developing and testing educational models. *Dementia*, 1(1), pp.11-23.

Iliffe, S., Wallace, P., Drennan, P., Blanchard, M. and Harris, A. 2002b. Applying community-oriented primary care methods in british general practice: A case study. *British Journal of General Practice*, 52(481), pp.646-651.

Iliffe, S., Manthorpe, J. and Eden, A. 2003. Sooner or later? issues in the early diagnosis of dementia in general practice: A qualitative study. *Family Practice*, 20(4), pp.376-381.

Innes, A., Barker, S., Board, M., Ferge, L. and Heaslip, V. 2012. *Review of HEDN curriculum for dementia education*. Bournemouth: Bournemouth University Dementia Institute.

Judge, K.S., Yarry, S.J., Looman, W.J. and Bass, D.M. 2013. Improved strain and psychosocial outcomes for caregivers of individuals with dementia: Findings from project ANSWERS. *The Gerontologist*, 53(2), pp.280-292.

Kayser-Jones, J. and Schell, E. 1997. The effect of staffing on the quality of care at mealtime. *Nursing Outlook*, 45(2), pp.64-72.

Keady, J. and Jones, L. 2010. Investigating the causes of behaviours that challenge in people with dementia. *Nursing Older People*, 22(9), pp.25-29.

Killick, J. 2004. Dementia, identity and spirituality. *Journal of Religious Gerontology*, 16(3-4), pp.59-74.

Killick, J. and Allan, K. 2001. *Communication and the care of people with dementia*. Buckingham ; Philadelphia, Pa: Open University Press.

Kim, H. and Salyers, M.P. 2008. Attitudes and perceived barriers to working with families of persons with severe mental illness: Mental health professionals' perspectives. *Community Mental Health Journal*, 44(5), pp.337-345.

Kitwood, T. 1997. *Dementia reconsidered : the person comes first*. Buckingham ; Philadelphia, PA: Open University Press.

Kitwood, T. 1993. Person and process in dementia. *International Journal of Geriatric Psychiatry*, 8(7), pp.541-545.

Knapp, M., Thorgrimsen, L., Patel, A., Spector, A., Hallam, A., Woods, B. and Orrell, M. 2006. Cognitive stimulation therapy for people with dementia: Cost-effectiveness analysis. *British Journal of Psychiatry*, 188(6), pp.574-580.

Koch, T. and Iliffe, S. 2010. Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: A systematic review. *BMC Family Practice*, 11(1), pp.52.

Kuipers, E., Onwumere, J. and Bebbington, P. 2010. Cognitive model of caregiving in psychosis. *The British Journal of Psychiatry*, 196(4), pp.259-265.

Kuo, S., Rhodes, R.L., Mitchell, S.L., Mor, V. and Teno, J.M. 2009. Natural history of feeding-tube use in nursing home residents with advanced dementia. *Journal of the American Medical Directors Association*, 10(4), pp.264-270.

MacNeill, S.E. and Lichtenberg, P.A. 1997. Home alone: The role of cognition in return to independent living. *Archives of Physical Medicine and Rehabilitation*, 78(7), pp.755-758.

Maslin-Prothero, S. 2000. The rhetoric of user participation in health care. *Nurse Education Today*, 20(8), pp.597-599.

McCabe, M.P., Davison, T.E. and George, K. 2007. Effectiveness of staff training programs for behavioral problems among older people with dementia. *Aging & Mental Health*, 11(5), pp.505-519.

McCusker, J., Cole, M., Dendukuri, N., Belzile, E. and Primeau, F. 2001. Delirium in older medical inpatients and subsequent cognitive and functional status: A prospective study. *CMAJ : Canadian Medical Association Journal = Journal De L'Association Medicale Canadienne*, 165(5), pp.575-583.

McGillivray, T. and Marland, G.R. 1999. Assisting demented patients with feeding: Problems in a ward environment. A review of the literature. *Journal of Advanced Nursing*, 29(3), pp.608-614.

McGlade, C., O'Connell, S., Linehan, J. and Timmons, S. 2009. Challenging behaviour in an acute hospital: incidence, implications, staff perceptions and patient experience. *Irish Journal of Medical Science*, 178(S8), pp.S335.

Mcphail, C., Traynor, V., Wikström, D., Brown, M. and Quinn, C. 2009. Improving outcomes for dementia care in acute aged care: Impact of an education programme. *Dementia*, 8(1), pp.142-147.

Miesen, B. and Jones, G.M. 2004. The Alzheimer Cafe concept. *Care-Giving in Dementia V3: Research and Applications*, 3pp.301.

Miles, A. 1981. *The mentally ill in contemporary society*. St. Martin's Press New York.

Moniz-Cook, E., Agar, S., Gibson, G., Win, T. and Wang, M. 1998. A preliminary study of the effects of early intervention with people with dementia and their families in a memory clinic. *Aging & Mental Health*, 2(3), pp.199-211.

Moniz-Cook, E. and Manthorpe, J. 2009. *Early Psychosocial Interventions in Dementia: Evidence-Based Practice*. London: Jessica Kingsley Publishers.

Morgan, D.G. and Stewart, N.J. 1999. The physical environment of special care units: Needs of residents with dementia from the perspective of staff and family caregivers. *Qualitative Health Research*, 9(1), pp.105-118.

Morrissey, M.V. 2006. Rethinking the benefits of an adapted version of 'alzheimer cafe' for individuals with alzheimer's and their partners. *The International Journal of Psychiatric Nursing Research*, 12(1), pp.1393-1401.

Mottaghypour, Y., Woodland, L., Bickerton, A. and Sara, G. 2006a. Working with families of patients within an adult mental health service: Development of a programme model. *Australasian Psychiatry*, 14(3), pp.267-271.

Mottaghypour, Y., Woodland, L., Bickerton, A. and Sara, G. 2006b. Working with families of patients within an adult mental health service: Development of a programme model. *Australasian Psychiatry*, 14(3), pp.267-271.

- Moyle, W., Borbasi, S., Wallis, M., Olorenshaw, R. and Gracia, N. 2011. Acute care management of older people with dementia: A qualitative perspective. *Journal of Clinical Nursing*, 20(3-4), pp.420-428.
- Mukadam, N. and Livingston, G. 2012. Reducing the stigma associated with dementia: Approaches and goals. *Aging Health*, 8(4), pp.377-386.
- Murphy, F. and Timmins, F. 2009. Experience based learning (EBL): Exploring professional teaching through critical reflection and reflexivity. *Nurse Education in Practice*, 9(1), pp.72-80.
- Neal, M. and Briggs, M. 2003. Validation therapy for dementia. *Cochrane Database Syst Rev*, 3
- Nolan, M.R., Davies, S., Brown, J., Keady, J. and Nolan, J. 2004. Beyond 'person-centred' care: A new vision for gerontological nursing. *Journal of Clinical Nursing*, 13(s1), pp.45-53.
- Peterson, D., Berg-Weger, M., McGillick, J. and Schwartz, L. 2002. Basic care I: The effect of dementia-specific training on certified nursing assistants and other staff. *American Journal of Alzheimer's Disease and Other Dementias*, 17(3), pp.154-164.
- Pinfold, V. 2004. Guest editorial. *Journal of Psychiatric and Mental Health Nursing*, 11(3), pp.250-252.
- Pinfold, V., Toulmin, H., Thornicroft, G., Huxley, P., Farmer, P. and Graham, T. 2003. Reducing psychiatric stigma and discrimination: Evaluation of educational interventions in UK secondary schools. *The British Journal of Psychiatry*, 182(4), pp.342-346.
- Prince, M., Bryce, R. and Ferri, C. 2011. *The World Alzheimer's Report 2011, The benefits of early diagnosis and intervention*. Alzheimer's Disease International (ADI).
- Rait, G., Walters, K., Bottomley, C., Petersen, I., Iliffe, S. and Irwin, N. 2010. Survival of people with clinical diagnosis of dementia in primary care: Cohort study. *British Medical Journal*, 34pp.c.3584.
- Rait, G., Walters, K. and Iliffe, S. 1999. The diagnosis and management of dementia in primary care: Issues in education, service, development and research. *Generations*, 23(3), pp.17-23.
- Reimer, M.A., Slaughter, S., Donaldson, C., Currie, G. and Eliasziw, M. 2004. Special care facility compared with traditional environments for dementia care: A longitudinal study of quality of life. *Journal of the American Geriatrics Society*, 52(7), pp.1085-1092.
- Rodney, V. 2000. Nurse stress associated with aggression in people with dementia: Its relationship to hardiness, cognitive appraisal and coping. *Journal of Advanced Nursing*, 31(1), pp.172-180.
- Sampson, E.L., Candy, B. and Jones, L. 2009. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev*, 2(2),

Savundranayagam, M.Y., Ryan, E.B., Anas, A.P. and Orange, J. 2007. Communication and dementia: Staff perceptions of conversational strategies. *Clinical Gerontologist*, 31(2), pp.47-63.

Schweitzer, J., Ginap, C., Von Twardowski, J., Zwack, J., Borst, U. and Nicolai, E. 2007a. Training psychiatric teams to do family systems acute psychiatry. *Journal of Family Therapy*, 29(1), pp.3-20.

Schweitzer, J., Ginap, C., Von Twardowski, J., Zwack, J., Borst, U. and Nicolai, E. 2007b. Training psychiatric teams to do family systems acute psychiatry. *Journal of Family Therapy*, 29(1), pp.3-20.

Selwood, A. and Cooper, C. 2009. Abuse of people with dementia. *Reviews in Clinical Gerontology*, 19(1), pp.35.

Sorrell, J.M. 2010. Use of feeding tubes in patients with advanced dementia: Are we doing harm? *Journal of Psychosocial Nursing and Mental Health Services*, 48(5), pp.15-18.

Spector, A., Orrell, M. and Woods, B. 2010. Cognitive stimulation therapy (CST): Effects on different areas of cognitive function for people with dementia. *International Journal of Geriatric Psychiatry*, 25(12), pp.1253-1258.

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M. and Orrell, M. 2003. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia. *British Journal of Psychiatry*, 183(3), pp.248-254.

Stanbridge, R.I., Burbach, F.R. and Leftwich, S.H. 2009. Establishing family inclusive acute inpatient mental health services: A staff training programme in somerset. *Journal of Family Therapy*, 31(3), pp.233-249.

Stanbridge, R.I., Burbach, F.R., Rapsey, E.H.S., Leftwich, S.H. and Mclver, C.C. 2013a. Improving partnerships with families and carers in in-patient mental health services for older people: A staff training programme and family liaison service. *Journal of Family Therapy*, 35(2), pp.176-197.

Stanbridge, R.I., Burbach, F.R., Rapsey, E.H.S., Leftwich, S.H. and Mclver, C.C. 2013b. Improving partnerships with families and carers in in-patient mental health services for older people: A staff training programme and family liaison service. *Journal of Family Therapy*, 35(2), pp.176-197.

Swanwick, G. 2011. Dementia: Alzheimer's disease', module 164 of the forum distance learning programme in association with the ICGP, forum, April, 2011.

Teno, J.M., Mitchell, S.L., Gozalo, P.L., Dosa, D., Hsu, A., Intrator, O. and Mor, V. 2010. Hospital characteristics associated with feeding tube placement in nursing home residents with advanced cognitive impairment. *JAMA*, 303(6), pp.544-550.

The Alzheimer Society of Ireland 2012. *The Alzheimer Society of Ireland: Annual report*. Ireland: The Alzheimer Society of Ireland.

The Scottish Government 2011. *Promoting excellence: A framework for all health and social services staff working with people with demetnia, their families adn carers*. Edinburgh: The Scottish Government.

Tolson, D., Smith, M. and Knight, P. 1999. An investigation of the components of best nursing practice in the care of acutely ill hospitalized older patients with coincidental dementia: A multi-method design. *Journal of Advanced Nursing*, 30(5), pp.1127-1136.

Toseland, R.W., Diehl, M., Freeman, K., Manzanares, T., Naleppa, M. and McCallion, P. 1997. The impact of validation group therapy on nursing home residents with dementia. *Journal of Applied Gerontology*, 16(1), pp.31-50.

Traynor, V., Brisco, S. and Coventry, T. 2005. Developing person-centred dementia care in acute settings: Findings from a study tour in australia. *Nursing Older People*, 17(8), pp.20-23.

Tsolaki, M., Papaliagkas, V., Kounti, F., Messini, C., Boziki, M., Anogianakis, G. and Vlaikidis, N. 2010. Severely stressful events and dementia: A study of an elderly greek demented population. *Psychiatry Research*, 176(1), pp.51-54.

Tullo, E. and Allan, L. 2011. What should we be teaching medical students about dementia? *International Psychogeriatrics*, 23(07), pp.1044-1050.

Van de Ven, A.H. and Delbecq, A.L. 1972. The nominal group as a research instrument for exploratory health studies. *American Journal of Public Health*, 62(3), pp.337-342.

Vernooij-Dassen, M. and Dautzenberg, M. 2003. Collaboration between lay and professional care. *Jones R, Britten N*, 5

Vernooij-Dassen, M.J.F.J., Moniz-Cook, E.D., Woods, R.T., Lepeleire, J.D., Leuschner, A., Zanetti, O., Rotrou, J.d., Kenny, G., Franco, M., Peters, V. and Iliffe, S. 2005. Factors affecting timely recognition and diagnosis of dementia across europe: From awareness to stigma. *International Journal of Geriatric Psychiatry*, 20(4), pp.377-386.

Wackerbarth, S. and Johnson, M.M. 1999. Predictors of driving cessation, independent living, and power of attorney decisions by dementia patients and caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 14(5), pp.283-288.

Watkins, J., Stanton, L., Saunders, B., Lasocki, G., Chung, P. and Hibberd, P. 2011. Working in partnership with family carers: The importance of learning from carers' experiences. *Quality in Ageing and Older Adults*, 12(2), pp.103-108.

Winterton, R. and Warburton, J. 2011. Models of care for socially isolated older rural carers: Barriers and implications. *Rural & Remote Health*, 11(3),

Woods, B., Seddon, D. and Keady, J. 2007. *Involving families in care homes: a relationship-centred approach to dementia care*. Jessica Kingsley Publishers.

Woods, R., Moniz-Cook, E., Iliffe, S., Campion, P., Vernooij-Dassen, M. and Zanetti, O. 2003. A dementia: Issues in early recognition and intervention in primary care. *Journal of the Royal Society of Medicine*, 96pp.320-324.

World Health Organization. 2012. Alzheimer's disease international (2012) Dementia: A Public Health Priority. *World Health Organization*,

Worthington, A. and Rooney, P. 2013. *The triangle of care carers included: A guide to best practice in mental health care*. London: Carers Trust.

Yamamoto, C. and Hoshi, T. 2011. Steadily decreasing prevalence of dementia in community-dwelling Japanese elderly during six-year follow-up.

Yin, R.K. 2003. *Case study Research: Design and methods*. Ed. Sage.

Young, T.J., Manthorp, C., Howells, D. and Tullo, E. 2011. Developing a carer communication intervention to support personhood and quality of life in dementia. *Ageing and Society*, 31(6), pp.1003.

Zimmerman, S., Williams, C.S., Reed, P.S., Boustani, M., Preisser, J.S., Heck, E. and Sloane, P.D. 2005. Attitudes, stress, and satisfaction of staff who care for residents with dementia. *The Gerontologist*, 45(suppl 1), pp.96-105.

11. Appendices

11.1 Appendix A – Consensus Meeting Members

- Anna Ayton: Lecturer/Practitioner, Course Co-ordinator, Gerontological Nursing, St James's Hospital/Trinity College, Dublin.
- Emma Benton: Therapy Professions Advisor & Portfolio Manager (Diagnostic/Support Services), HSE.
- Rodd Bond: Director of Netwell Centre, Dundalk Institute of Technology.
- Tadgh Daly: CEO, Nursing Homes Ireland.
- Elizabeth Fahey-McCarthy: Assistant Professor, Course Co-ordinator MSc, Dementia, School of Nursing & Midwifery, Trinity College, Dublin.
- Grainne Flanagan: Dietetic Manager, Peamount Hospital, Dublin.
- Cecilia Hayden: Clinical Nurse Specialist in Dementia, Le Cheile, St Vincent's Hospital, Athy.
- Eilis Hession: Project Manager, Living well with Dementia, Genio, Stillorgan/Blackrock, Dublin.
- Elaine Howard: Genio Dementia Programme Manager with responsibility for developing Learning Network.
- Catherine Keogh: Occupational Therapy Manager, Bloomfield Care Centre, Dublin.
- Fiona Keogh: Director of Research and Evidence, Genio.
- Doreen Lynch: Director of the Centre of Nurse Education (CNE) Mercy University Hospital, Cork.
- Grainne McGettrick: Research and Policy Manager, Alzheimer Society of Ireland.
- Lorna Peelo Kilroe: Nurse Lead with the Palliative Care Clinical Programme, HSE.

11.2 Appendix B – List of Abbreviations

A&E	Accident and Emergency
AHP	Allied Health professional
ASI	Alzheimer Society of Ireland
CDP	Continuous Professional Development
CST	Cognitive Stimulation Therapy
DoH	Department of Health
DSDC	Dementia Services and Development Centre
DSIDC	Dementia Services Information and Development Centre
ENA	Educational Needs Analysis
GP	General Practitioner
HCA	Health Care Assistant
HIQA	Health Information and Quality Authority
HSCP	Health and Social Care Professional
HSE	Health Service Executive
ICGP	Irish College of General Practitioners
IHF	Irish Hospice Foundation
MMSE	Mini Mental State Exam
MRI	Magnetic Resonance Imaging
NAO	National Audit Office
NDEP	National Dementia Education Programme
NGT	Nominal Group Technique
NICE	National Institute for Health and Care Excellence
OT	Occupational Therapist
PEG	Percutaneous endoscopic gastrostomy
PHN	Public Health Nurse
RCGP	Royal College of General Practitioners
UK	United Kingdom
USA	United States of America

11.3 Appendix C – People with Dementia Interview Schedule.

1. How did you know you had dementia, where did you get that information how easy was it to get diagnosis?
2. Do you have any information about how your symptoms may change over time?
 - a. Where did you receive this information?
 - b. Would you like to know any more about that?
 - c. If mention mood / communication – *tell me more* – how would you like to receive this information - *only if they state they have a need* (would you like information to help you understand the way in which dementia will affect your mood, memory and your communication with others?).
3. What Treatment are you having?
 - a. Drugs / tablets (prompt if not mentioned), then ask have you received information to help you manage any medications? What do you know about them – side effects etc.?
 - b. Have you heard of any therapies (explain therapies – e.g. “are you taking part in any activities that support you, help with your symptoms?” (e.g. CST)? Are you doing any, would you like any information on them?
4. Living well in your community
 - a. What do you do to stay well in the community (explain living well – “do you do anything to keep on the ball/ keep ticking?” – reading, television, walking)?
 - b. Who told you about these – would you like to know more?
 - c. Do you do anything to maintain a regular routine?
 - d. Would you like anything to help you with this, how would you like to receive this help?

Prompts:

Maintaining independence: Have you received information on how you can maintain your independence and retain your skills?

Managing physical health problems: Have you received information on how to manage any co-existing physical health problems [arthritis, hypertension, limited mobility, diabetes, etc.] which you are currently experiencing or may experience in the future?

Taking care of your mental health: Have you received information on how to i) best manage any psychological difficulties or mental health conditions [e.g. Depression, anxiety] which you may have at present or in the future? ii) maintain your confidence in yourself? iii) manage your worry about your condition?

Keeping safe in your home: Have you received information on how to keep yourself safe while you are in your home?

Keeping safe in your community: Have you received information about how to manage a situation arising where you feel you are lost after you have left your house?

Managing confusion and other emotions: Have you received information to help you self-manage feelings like confusion, feeling frightened, agitated or sadness as a result of your condition?

Staying socially active/participating or contributing to the community: Have you received information on ways you can participate in, and contribute to your community [offering company and socialising with others, volunteering, sharing your skills, being involved with groups]?

Staying physically active: Have you received information on i) the importance and benefits of staying physically active for your health while you have dementia? ii) opportunities for becoming and remaining physically active in your local community (gym, pool, walking group, etc.)?

Keeping a healthy diet: Have you received information about the importance and benefits of a healthy diet while you have dementia?

Dietary supplements: Have you received information on possible dietary supplements you can take to enhance your wellbeing?

Dementia-friendly adaptations to your home: Have you received information about changes or adaptations that may need to be made to your current residence [mobility aids, safety handrails, etc.] to enhance your independence and safety?

Assistive technology: Have you received information about types of assistive technology available to you and how they may help you in your daily life?

Managing self-care: Have you received information to help you prepare for, and manage, changes you are currently experiencing or expect to experience to your self-care abilities [eg. feeding, bathing, toileting]?

Communication: Have you received information on how to manage difficulties you may experience when you are trying to communicate with others?

5. How do you feel about planning for the future?
 - a. Do you drive, have you thought about time you may not be able to drive?
 - b. Have you received information on driving guidelines and regulations affecting you as an individual with dementia?

“These can be particularly difficult questions to answer - you don’t have to answer them if you don’t want to;”

- c. Have you thought about making a Will?
 - i. Have you received information to help you understand the following legal issues which may affect you and your family in the future?
 - i) *Property inheritance*
 - ii) *Your personal competency and ability to consent*
 - iii) *Ward of court and power of attorney*
 - iv) *Legalities involved in making your Will*
 - v) *Enduring Power of Attorney (EPA)*
 - ii. Have you received information on how to best manage your financial affairs?
 - d. These questions might be difficult to discuss with people in your family or friends: Have you received any help on how to discuss them? Would you like any tips on how to discuss ?
6. Have you been told where to go to get access and support?
Prompts:

Supports for you and your dementia in your community: Have you received information about support services for you as a person with dementia in your local community:

- i) *day-care centres*
- ii) *Alzheimer's cafe*
- iii) *respite care services*
- iv) *nursing homes*
- v) *other long-term care and residential facilities*

For each of the above information needs: What information would you like to receive? How would you like to receive this information? When would you like to receive it? How would you rate your need for information about support services in your community?

Supports for your family and friends: Have you received information about additional emotional supports available to your family and friends? What information would you like to receive? How would you like to receive this information? When would you like to receive it? How would you rate your need for information about support services for your family and friends in your community?

Concluding question

What do you think the people in your community should know about you to make this and surrounding areas a more friendly and helpful place for you to live in?

11.4 Appendix D – Informal/Family Carers Interview Schedule.

1. How did you know your relative had dementia, where did you get that information how easy it was it to get diagnosis?
2. Do you have any information about how your relative’s symptoms may change over time?
 - a. Where did you receive this information?
 - b. Would you like to know any more about that?
 - c. If mention mood / communication – *tell me more* – how would you like to receive this information - *only if they state they have a need* (would you like information to help you understand the way in which dementia will affect your mood, memory and your communication with others?)
3. What treatment is your relative having?
 - a. Drugs / tablets (prompt if not mentioned), then ask have you received information to help you manage any medications? What do you know about them – side effects etc.?
 - b. Have you heard of any therapies (explain therapies – e.g. “are you taking part in any activities that support your relative, help with their symptoms?” e.g. CST?) Is your relative doing any? Would you like any information on them?
4. Living well in your community
 - a. What is your relative doing to stay well in the community (explain living well – “do they do anything to keep on the ball/ keep ticking?” – reading, television, walking?)
 - b. Who told your relative (and you) about these – would you like to know more?
 - c. Do you do anything to help maintain a regular routine for your relative?
 - d. Would you like anything to help you with this, how would you like to receive this?

Prompts:

Maintaining independence: Have you received information on how your relative can maintain their independence and retain their skills?

Managing physical health problems: Have you received information on how to manage any co-existing physical health problems [arthritis, hypertension, limited mobility, diabetes, etc.] which your relative is currently experiencing or may experience in the future?

Taking care of your mental health: Have you received information on how to i) best manage any psychological difficulties or mental health conditions [eg. Depression, anxiety] which your relative may have at present or in the future? ii) help your relative maintain their confidence in themselves? ii) manage their worry about their condition?

Keeping safe at home and in the community: Have you received information on how to help keep your relative safe while they are at home or outside in the community?

Staying socially active/participating or contributing to the community: Have you received information on ways your relative can participate in, and contribute to your

community [offering company and socialising with others, volunteering, sharing your skills, being involved with groups]?

Staying physically active : Have you received information on i) the importance and benefits of your relative staying physically active for your health while you have dementia? ii) opportunities for your relative to get physically active in your local community (gym, pool, walking group, etc.)?

Keeping a healthy diet: Have you received information about the importance and benefits of a healthy diet for your relative?

Dementia-friendly adaptations to your home: Have you received information about changes or adaptations that may need to be made to your current residence [mobility aids, safety handrails, etc.] to enhance the independence and safety of your relative?

Assistive technology: Have you received information about types of assistive technology available to your relative and how they may help them in their daily life?

Activities of daily living: Have you received information to help you prepare for, and manage, changes in your relative's activities of daily living [eg. feeding, bathing, toileting]?

Communication: Have you received information on how to manage difficulties you may experience when you are trying to communicate with your relative?

5. How do you feel about planning for the future?
 - a. Does your relative drive, have you thought about time he/she may not be able to drive
 - b. Have you received information on driving guidelines and regulations affecting your relative as a person with dementia?

“These can be particularly difficult questions to answer - you don't have to answer them if you don't want to;”

- c. Have you thought about making a Will?
 - i. Have you received information to help you understand the following legal issues which may affect your relative, you and your family in the future?
 - vi) *Property inheritance*
 - vii) *Personal competency and ability to consent*
 - viii) *Ward of court and power of attorney*
 - ix) *Legalities involved in making a Will*
 - x) *Enduring Power of Attorney (EPA)*
 - ii. Have you received information on how to best manage their financial affairs?
- d. These questions might be difficult to discuss with people in your family or friends: Have you received any help on how to discuss them? Would you like any tips on how to discuss?

6. Have you been told where to go to get access and support?

Prompts:

Supports for you and your dementia in your community: Have you received information about support services for you as a person with dementia in your local community:

- i) *day-care centres*

- ii) *Alzheimer's cafe*
- iii) *respite care services*
- iv) *nursing homes*
- v) *other long-term care and residential facilities*

For each of the above information needs: What information would you like to receive? How would you like to receive this information? When would you like to receive it? How would you rate your need for information about support services in your community?

Supports for your family and friends: Have you received information about additional emotional supports available to your family and friends? What information would you like to receive? How would you like to receive this information? When would you like to receive it? How would you rate your need for information about support services for your family and friends in your community?

11.5 Appendix E – Community Members Interview Schedule.

1. Understanding Dementia

Do you know, or are you aware of person(s) with dementia in your community?

What is your understanding of dementia and how it affects a person?

Prompt: Have you received information to help you understand the way in which dementia affects the person's mood, memory and their communication with others?

Do you know anything about dementia prevention?

Does Dementia affect people in the same way?

Prompt: Have you received information about the stages of dementia and associated symptoms and behaviours?

What is your greatest information need about dementia?

I am going to ask you a number of questions on the information needs related to specific areas of dementia. When answering please consider aspects like:

- What information would help you with this?
- How would you like to receive this information?
- When would you like to receive this information? (leaflet, course, app).
- How would you rate your current understanding?

2. Treatment and intervention in dementia - Knowledge of treatment options including psychosocial interventions for dementia

What do you know about the treatment of dementia?

What do you know about medications for dementia?

What do you know about psychosocial therapies in the treatment of dementia?

What is your understanding of "Person-Centred" treatment?

For each of these information needs:

- What information would better help you to understand each of the treatment approaches above?
- How would you prefer to receive this information?
- When would you prefer to receive this information?

How would you rate your need for information on treatments and interventions for dementia?

Dementia-friendly community:

Have you heard about Dementia Friendly Communities? (Give definition if necessary: "An integrated society where people with dementia live in "normal" home like situations throughout their lives with support to continue to engage in everyday community activities")

What do you think about that?

3. Maintaining independence

What do you know about how you can help individuals with dementia maintain their independence and retain their skills? (If not already addressed)

4. **Promoting inclusion**

Have you received information or do you know of ways in which you can encourage the inclusion and involvement of individuals with dementia in the community?

Have you received information or do you know of specific ways in which individuals with dementia can contribute to their community?

Prompt: Assistive technology (give definition) - Have you received information about types of assistive technology available to persons with dementia and how they may help the person with dementia in their daily life?

5. **Meaningful communication**

Have you received information, or do you know of ways to communicate appropriately with an individual with dementia) *in general day-to-day interaction ii) when the individual with dementia is confused, fearful or agitated iii) when the individual is not able to speak?*

Prompt: - Have you received information or are you aware of i) your own body language and posture when you meet someone with dementia and the possible effect on them? ii) How to tell if a person with dementia is happy? iii) How to use respectful language which the person with dementia will understand?

What information would you like about this?

How would you like to receive this information?

When would you like to receive this information?

How would you rate your need for information on communicating with persons with dementia?

Have you received information on the types of needs and wants which the person with dementia may be trying to communicate through their behaviour?

Have you received information on, or do you know how, to respond to agitated behaviours a person with dementia may show?

6. **Keeping people with dementia safe in the community**

Have you received information or do you know of ways you can help ensure the safety of individuals with dementia in your community?

Have you received information or do you know what steps to take if you come across someone in your community who has (or is suspected of having) dementia and who appears to be lost or in a confused or frightened state?

Have you received information or are you aware of what types of medications a person with dementia may be required to take on a daily basis?

Have you received information, or do you know about types of personal safety alarms and safety aids which a person with dementia may carry?

Have you received information about, or do you know what elder abuse is?

How would you recognise the signs of elder abuse in a person with dementia living in your community?

Prompt: Have you received information or do you know what steps to take if you suspect a person with dementia living in your community is being subjected to elder abuse?

Do you know what steps to take if it comes to your attention that the ability of a person with dementia living alone (without a carer) in your community to take adequate care of themselves is declining (e.g., they appear underweight or malnourished, have an unkempt appearance, have episodes of wandering or have suffered a fall or accident)?

7. **Business as usual**

If you are a business-owner, have you received information, or do you know of ways in which you can make your business dementia-friendly?

8. **Enhancing navigation**

What do you know about the types of difficulties a person with dementia may experience in finding their way?

9. **Legal and ethical information around dementia**

Have you received information about the new Capacity Bill affecting the individual with dementia and their family?

10. **Care and Support**

Do you know about the specific types of support services that are available to the families, friends and carers of individuals with dementia in the community?

Have you received information about, or do you know of ways, in which you can provide emotional and practical support to a person you know living in your community with dementia?

Have you received information about, or do you know of ways, in which you can give practical or emotional support to a carer or loved one of someone with dementia who is living in your community?

11.6 Appendix F – General Practitioners Interview Schedule.

1. As a GP, what are your thoughts/feelings about dementia prevention? (There is a growing evidence of associated risk factors with dementia similar to chronic disease risk factors – obesity, smoking, high cholesterol low physical exercise) Do you feel as a GP and maybe in general GP's are aware of that or
 - Would you like to see more information / education on this available for GP's?
 - Would it be through CPD, CME?
 - What would encourage GPs to not only receive but use this information (basic medical training or post grad training) – specific / general?
2. What are your thoughts on delaying dementia?
3. How many people with dementia do you have in your clinic?
 - a. Does the number of people in your practice diagnosed with dementia correlate with the local prevalence figures?
 - b. Would you consider setting up a dementia register?
 - c. Do you think there should be more information available to GP's on the benefits of dementia registers in terms of improved care plans and follow up?
4. How do you arrive at your decision of diagnosing dementia?
 - a. Do you feel diagnosis of dementia could be better supported for GPs in terms of the cognitive or memory, communication assessments available? More information about the importance of early diagnosis?
5. How many older people with suspected dementia did you refer last year?
 - a. How do you find out about what services there are in your area (clear pathway, where to refer the person)?
6. As a GP you must disclose many diagnoses all the time, what people have told us is that dementia diagnosis disclosure is particularly difficult – how do you feel about that? If they agree – *"tell us more"*
 - What's difficult about it, how do you negotiate the process, what supports would help?
 - Would you like more info about it?
 - Do you think disclosure could be made easier for GP's by up-skilling?
 - What are the ethical issues?
7. After diagnosis, what follow-up do you provide to people with dementia and their carers? Dementia register?
8. I'm sure you have heard about person-centred dementia care? What is your understanding of it in the context of primary care?
9. How effective do you think cholinesterase inhibitors are and how effective have you found them in your practice?

10. What non-pharmacological alternatives do you have available to help your patients (and their carers)? Alzheimer Cafés, ASI, Genio?
11. Another area of intense activity is the end of life in dementia – what do you perceive your role to be in the end of life in people with dementia (liaising with nursing home, home, hospice)? Would you like more information? How would you like to receive this information?
12. Based on your experience, what do you think are the important quality markers in caring for people with dementia? (What would you want for yourself?).
13. How would you rate your current care for people with dementia and their carers (using a simple scale of good enough/satisfactory/needs substantial improvement)?
14. What grounds or criteria is your rating based on?
15. In your community where do you see the major educational gaps – (for instance with the dementia strategy we are trying to move away from long term care to independent home care with increased primary care support – where is there an educational gap; is it with carers or a professional grouping or community at large – (if answer is everywhere – ask “where would you prioritise?”).
16. Is there anything else that you would like to see improving in dementia care? If yes, what is it and why would you like it to change it?
17. Are you using a shared care protocol for cholinesterase inhibitors? If ‘yes’, then: (i) who was involved in producing the protocol; (ii) who is involved in its implementation (for example, hospital consultants, community psychiatric nurses, care of older people team)?
18. In terms of the education models – can you tell me more insight of what you think would really make them effective – in terms of mode of delivery:
 - Once off, annually, continuous?
 - CPD, CME, credits?
 - Online? Wokshop? Conference?
 - Build in system? (for example GPs suggested build into chronic disease management)?
 - Paper guidelines?
 - GP delivering it to GPs (it was suggested that if a GP is interested enough they create dementia friendly excellence in terms of primary care for people in dementia and then invite other GPs in the locality to learn from that?)

11.7 Appendix G – Health Care Professionals Interview Schedule.

1. Understanding Dementia

To what extent do you work with people with dementia in your working day?

Have you received information on person-centred care for people with dementia?

What are your thoughts/feelings about dementia prevention?

Do you think you will need to receive more information?

Would it be through (CPD, CME)

What would encourage staff to receive this info (basic training or post grad training) – specific / general?

Recognising the signs and symptoms of dementia: Have you received education about how to recognise signs and symptoms of dementia versus normal aging?

Recognising conditions that may mimic dementia: Have you received education on how to recognise conditions that may mimic dementia (such as delirium)?

Recognising each stage's symptoms: Have you received education about how dementia progresses?

Understanding the impact of dementia on mood, memory and communication: Have you received education to help you understand the impact dementia has on the individual's memory, mood and communication?

2. Improving Quality of Life

Have you received education on ways of improving quality of life for people with dementia?

Following questions as potential prompts:

Working with the family and relatives of the person with dementia: Have you received education that has helped you work effectively with the families of persons with dementia in planning and delivering care?

Promoting social activity and skill maintenance: Have you received education to help you design person-centred day programmes (for example, activation programmes) to enable persons with dementia retain the skills they have and enhance their independence and quality of life?

Dementia-friendly environment: Have you received education to enable you to make environmental changes to maintain the independence of a person with dementia?

Keeping the person with dementia safe: Have you received education to help you address wandering and other safety issues affecting the person with dementia?

Assistive technology: Have you received education about types of assistive technology available to you and how they may help the person with dementia in their daily life?

3. Understanding and dealing with responsive behaviours

Can you tell me about responsive behaviours you may have encountered in people with dementia?

Prompt: Have you received education on the types of needs and wants which the person with dementia may be trying to communicate through their behaviour?)

4. Treatment and Intervention for Dementia

What information have you received about treatments and interventions for people with dementia?

Prompt – Medication; Therapies such as Cognitive Stimulation Therapy and Counselling.

Have you received education about medication treatment for dementia?

What information would you like to receive about medication treatment for dementia?

5. End of Life information

Practical care information in late stage dementia: Have you received education to help you understand the special palliative care or end-of-life needs of individuals with dementia, such as:

- *peg-feeding;*
- *naso-gastric feeding;*
- *deterioration of the individuals self-care;*
- *deterioration of mobility and any associated safety concerns;*
- *transitioning to long-term care or palliative care [how to liaise effectively with the other care organisation if applicable, how to ensure transition is comfortable, smooth, stress on the individual with dementia and their family is minimised];*
- *advanced care planning [how to include wishes and needs of the person with dementia, how to keep family fully informed and involved in decision-making];*
- *emotional support services available to the family and you as a carer and*
- *how to access support services available?*

For each of the above information needs: How would you like to receive this information? When would you like to receive this information? How would you rate your need for information about end-of-life or palliative care needs of persons with dementia?

Legal information regarding end-of-life: Have you received education about end-of-life legal issues affecting the individual with dementia in your care and their family? (Prompts to follow):

- *the new capacity legislation;*
- *ward of court and power of attorney;*
- *legalities involved in making a Will and*
- *do-not resuscitate orders?*

[The following section on medication and pain management refers to you if you are employed in the care of persons with dementia as a NURSE]

6. Medication management

Have you received education on how to administer Dementia-related assessments?

Have you received education on medication management specific to dementia care?

Have you received education on how to manage co-morbid health concerns such as delirium?

Have you received education about pain assessment and management of pain in persons with dementia?

7. Communication

Communicating with the family of the person with dementia: What education have you received regarding how to communicate with the **family/relatives** of the person with dementia [i) after diagnosis ii) when person with dementia is transitioning to another care setting, for example long-term residential care]?

How would you like to receive this information?

When would you like to receive this information?

How would you rate your need for information on how to communicate with the families of individuals with dementia?

Communicating with the person with dementia: Have you education about how to communicate with the **individual with dementia** i) when trying to carry out self-care and other tasks with the individual with dementia ii) when the individual with dementia is agitated, confused or upset?

How would you like to receive this information?

When would you like to receive it?

How would you rate your need for information on how to communicate with individuals with dementia?

Prompts: Have you received education on

- i. *How to understand the person with dementia's facial cues and body language?*
- ii. *How to be aware of your own body language and how to adopt appropriate body language towards the individual with dementia?*
- iii. *How to tell if the individual with dementia is content or enjoying an activity or experience?*
- iv. *How to use appropriate language when interacting with the individual with dementia?*
- v. *How to become more familiar with the unique history, personality, likes and dislikes of the individual with dementia (e.g., use of a Life Story book)?*

How would you like to receive this information?

When would you like to receive it?

How would you rate your need for information on how to communicate with persons with dementia?

Communicating with staff on your team and other healthcare providers: Have you received education about i) how to communicate **with other staff and healthcare providers** working with the person with dementia ii) what type of information is appropriate to share iii) the

history, medication details and family background of the person with dementia, as well as their current condition and needs?

How would you like to receive this information?

When would you like to receive this information?

How would you rate your need for information on how to communicate with other staff and healthcare providers working with the individual with dementia?

Communicating with managers of your service or organisation: Have you received information to facilitate the confidential sharing with management of any concerns you may have relating to your job or to an individual with dementia?

How would you like to receive this information?

When would you like to receive this information?

How would you rate your need for information on how to communicate with other staff and healthcare providers working with the individual with dementia?

8. Supports for carer of person with dementia

Have you received information about additional emotional supports available to you as a carer for persons with dementia?

Prompt/Tool-box: may be answered under previous sections.

9. Cultural sensitivity and managing cultural challenges

In your experience how often do you care for people with dementia from another background? (Adapt according to participant).

If your country of origin is different to Ireland: Have you received information on Irish culture that would help you build relationships and enhance quality of life of the person with dementia?

10. Consistency and recognition of dementia training received

Have you received information on Dementia Education Programmes available to you?

Prompt: Do these programmes give you a qualification/certificate?

11. Other information needs

What information have you received about recognising elder abuse?

Prompt: What steps would you take if you are aware of, or suspect that, the person with dementia in your care setting is being subjected to elder abuse?