

AN IRISH NATIONAL SURVEY OF

DEMENTIA

IN LONG-TERM RESIDENTIAL CARE

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REPORT AUTHORSHIP

This survey of nursing homes in Ireland was undertaken by the Dementia Services Information and Development Centre (DSIDC) and led by Associate Professor Suzanne Cahill.

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"Residential care does not reside in the building or its facilities but rather in the spirit of the people within" (Alan Gilsean, [The Irish Times, September 28th, 2010.](#))

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FOREWORD

Consistent with global demographic trends, Ireland's population is ageing at a rapid rate, this is particularly so for the older age groups. It is estimated that the proportion of people over 80 will increase by 60% over the next two decades.

The prevalence and incidence of dementia rises exponentially with age and dramatically so in those over 80 years. Dementia is one of the biggest challenges facing global health care and health economies. In middle and high-income countries it is estimated that over 60% of the residents living in long-term care (LTC) facilities, have a diagnosis of dementia. Dementia is characterised by multiple cognitive deficits that include memory impairment, impairment in orientation, expression, understanding, planning and execution of some or any activities of daily living.

It is generally agreed that the needs of people with dementia are unmet in LTC. In fact, in many studies, direct care workers feel incapable of meeting residents' social, psychological, and emotional needs, given that these vary considerably from people without dementia. Nonetheless, understanding and responding to the needs of people with dementia is of great importance, as unmet needs are both a source of reduced quality of life and increased disruptive behaviours. Some studies estimate that in these circumstances, as little as 10% of the residents' symptoms are caused by the dementia itself with the other 90% resulting from the quality of care people with dementia receive if in inappropriate settings.

Examples of the complex needs of residents with dementia in LTC are disruptive behaviors, inability to express pain and discomfort (a common cause of disruptive behaviours), need for stimulating daytime activities and social company, appropriate environment and dementia specific signage, psychological distress such as depression and anxiety and assistance with memory, eyesight, and hearing problems. All too often, at the end of life, care for physical symptoms and behavioral symptoms become the focus rather than other quality of life needs.

As a consequence, Specialist Care Units (SCUs) have evolved to address the needs of people with dementia and the needs of their families and health carers. Because Ireland has a mixed model of health care provision with private and publicly funded care the SCU is either funded by private operators or by the national health care provider - the Health Service Executive.

Remarkably, in Ireland, no systematic data set exists to capture the fundamental demographics and infrastructures of such units and their residents. Without this information, it is not possible to monitor quality of care; equity of care access or implementation of guidelines not to speak of the educational and training needs of staff and families.

This report is to be lauded as the first comprehensive survey to collate this important information. Of 602 Nursing Homes in the Republic of Ireland, 78% responded to the validated survey. Over two thirds of LTC facilities were privately operated and a further 13% categorised as not for profit. Overall 11% were SCUs and accommodated 7% of LTC residents.

The report highlights wide variation in location and availability, configurations inconsistent with national guidelines (i.e. excess numbers in individual housing units), variation in admission criteria, design, poor access to appropriate activities and leisure spaces, lack of objective details regarding quality of life and end of life quality.

The report is welcome as an initial approach to scope fundamental infrastructural elements of dementia specific to long-term care but raises many unanswered questions which will be necessary to address to ensure equity of access and implementation for the fundamental human rights of older people with dementia.



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FOREWORD

As seen in several other health care sectors (e.g. mental health and care for people with an intellectual disability), a change in care models has emerged in institutional care for people with dementia during the last decades. The medical model of care focusing on people's disabilities provides little guidance in care (e.g. Taft et al., 1997). Consequently, a paradigm shift has emerged towards psychosocial and person-centered models of care. These models emphasise individualised care, build on residents' personal strengths and support the overall wellbeing of residents. The most important element is providing a high quality of life. Values such as autonomy, individualisation, preservation of the individual's sense of identity and personhood are of vital importance to realise this goal (e.g. Eliopoulos, 2010). Alongside a change in care concept, there is a growing body of evidence that the environment influences residents' outcomes, such as physical and psychosocial functioning (e.g. Fleming et al., 2010). The environment should therefore be seen as an active component of care.

Both the change in care concept and increased recognition of the importance of environment in care has resulted in the development of new dementia care facilities, all aimed at proving care for residents in a small-scale and homelike environment. Current policies in many countries advocate this aim, such as the Netherlands. Despite this growth, the complexity of the concept of SCUs means that there still is a lack of understanding regarding active ingredients. As a result, many changes are implemented in daily practice, without knowledge and awareness of what, why and how these changes are most effective. Therefore, the current report on SCUs in Ireland is extremely important, as more knowledge on models of long-term care is highly warranted.



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EXECUTIVE SUMMARY

We identified 602 nursing homes across the Republic of Ireland (ROI), of which 469 responded to our survey questionnaire, yielding a response rate of (78%). Amongst these, two thirds (N=393) were privately operated, about one fifth were HSE operated and about 13% were voluntary and not for profit. Amongst the 469 nursing homes, a total of 54 (11%) claimed they currently operate SCUs for people with dementia (PwD) and another 14% stated they planned on establishing a Specialist Care Unit (SCU) in the foreseeable future. These 54 Units accommodated some 1034 PwD, a figure representing about 7% of all PwD living in long stay residential care. The same 54 SCUs had a total of 66 respite beds available to the 30,000 people in Ireland known to be living with dementia in the community. Our findings showed that the private sector provided the main bulk of specialist dementia residential care, (63%), followed by the HSE (30%) followed by the voluntary not-for-profit (7%). Whilst the private sector was the dominant provider of long-term residential care in SCUs, the public sector was the main provider of residential respite care.

The survey found significant inequities across the ROI regarding the location and numbers of SCUs available to older people with dementia. Over 50% of all SCUs were located in only four of the 26 counties. The counties of Sligo, Wicklow, Carlow, Kilkenny Westmeath, and Offaly appear to have no provision, whilst clusters of SCUs were evident in counties Cork, Dublin, Galway, Donegal, Cavan, Louth, Meath and Monaghan. Regarding Local Health Office (LHO) areas, and based on these results, no provision exists in six areas all of which are in Leinster and most of which are in Dublin. Inequities in distribution of SCUs were demonstrated in responses to questions asked about waiting lists. In areas with very low provision waiting lists tended to be very long, and as expected in areas where supply was good, waiting lists tended to be significantly shorter. Many providers failed to keep reliable records of waiting lists.

Whilst best practice in dementia care recommends that people with Alzheimer's disease or other dementias should ideally live in small domestic type dwellings and in configurations of no more than 10 people per unit (HIQA, 2009), our survey findings revealed considerable diversity across the SCUs surveyed, in relation to size and numbers of PwD resident within. In the voluntary sector, the average number of residents was 29, in the private sector it was 20 and in HSE operated SCU's it was 16. The overall average number of residents in each SCU was 19, a figure in accordance with that reported in recent reports (Cahill, O'Shea and Pierce, 2012a). The smallest variance was found in the public sector which catered for between nine and 25 residents. Four SCUs were configured around two or more houses to ensure that residents were cared for in smaller groups.

The survey showed that criteria most often used for new admissions to SCUs were pre-admission assessment (almost 90%), clinical diagnosis (66%), and behaviours that challenge (41%). Curiously, HSE operated facilities which receive the highest payments for care from the Nursing Home Support Scheme (Fair Deal) because they are said to accommodate those with highest dependency needs, were more restrictive than other providers in relation to admission criteria, and were more inclined to refuse admission to those not independently mobile. Our findings would suggest that the Health Information and Quality Authority (HIQA) requirement i.e. all new admissions to SCUs have a clinical diagnosis of dementia made by a suitably qualified medical practitioner is not being adhered to.

In general, findings showed that private SCUs, when compared with others, were more likely to be purpose-built and well designed. Private providers were more likely to offer residents individual bedrooms, often with en-suites. Indeed, a small minority of these private providers had double rooms available for married couples. Private providers were also more likely (when compared with public and voluntary) to have more of their nursing staff and health care assistants trained in dementia care. Private providers were also more likely to engage their residents in more innovative therapeutic activities. The HIQA supplementary criteria for dementia care stipulate that all new builds including those with more than one storey have a secure safe and multi-sensory garden available to PwD. In this survey, three SCUs had no therapeutic garden and 13 (25%) had no gardening activity available to residents.

Overall, responses to questions about end of life care provide positive affirmation of the person-centered philosophy underpinning the vast majority of the SCUs identified. Whilst by far the majority of these units had an “ageing in place” policy and offered residents who were dying with dementia, end of life care, a small minority (N=7) either sometimes or always transferred residents at end of life out of these SCUs. Transferring residents dying with dementia to other long stay facilities is not in compliance with best practice and is probably a further reflection of the high demand for long-term care beds in SCUs.

Finally a key finding from this survey is the fact that the private sector is the main provider of specialist long-term care to PwD, whilst the public sector is more likely to be the main provider of residential respite care. This finding is curious given the high dependency needs of PwD, and the comparatively smaller payments private providers receive from the National Treatment Purchase Fund (NTPF) for such residents. Our findings would lead us to conclude that the complex and high dependency needs of PwD in SCUs now need to be more realistically reflected in fairer resource allocation, in recognition of the skill mix of staff employed in SCUs, their training needs and the level of care expected to be delivered to residents with dementia. A new funding model is required if the private sector is to be further incentivised, with more funding allocated to private nursing homes in recognition of the specialist services needed to support PwD including those with behaviours that challenge.



BACKGROUND

Calls for the audit of nursing homes for (PwD) in the (ROI) have been made since 1999, when the Irish Action Plan on Dementia was first launched (O'Shea and O'Reilly, 1999). Like in other countries, in Ireland a significant proportion of people living in long-term residential care have a moderate to severe cognitive impairment, however many have never had a formal diagnosis of dementia. Prior research has shown how long-term residential care staff, often under-estimate, or conversely over-estimate, the level of cognitive impairment of residents in their care (Cahill, Diaz-Ponce, Coen & Walsh, 2010). Indeed up until recently, no policy was in place in long-term residential care to ensure that residents would undergo regular memory and cognitive assessment. This has changed since 2009, with the implementation of the national quality residential care standards in Ireland (HIQA). The latter require residential care staff to undertake regular comprehensive assessments of all residents.¹ A requirement also exists which stipulates that all new admissions to dementia-specific long-term residential care units will have a clinical diagnosis of dementia, made by an appropriately qualified medical practitioner (HIQA, 2009).

In the context of dementia-specific segregated long-term care, recent years have also seen a growth in the numbers of (SCUs) being established around the (ROI) catering for the complex and unique needs of PwD, a trend in line with other European and overseas countries. In the US for example, based on a national survey of long-term residential care in 2010, circa 17% of all residential care was found to be dementia-specific, (Harris-Kojetin, Sengupta, Park-Lee and Valverde, 2013). In Norway, about 33% of all service provision is dementia specific and in Sweden the figure is about 20% (Alzheimer Europe, 2013). In the Netherlands, whilst all long-term care for PwD is segregated, about 25% of it, is small scale and home like with a commitment on the part of the Dutch government to increase this figure to 33% by 2015 (De Lange, Willemse, Smit & Pot, 2011). Although across Europe, these small scale dementia specific units have different names, each shares a similar person-centred care philosophy; is committed to a household model of care, to staff training, to engaging residents in meaningful activities, to using other psycho-social approaches and to using architectural/interior design and multi-sensory gardens creatively, to help compensate for dementia-related cognitive deficits. In Ireland, no information is available on the location of these units and there is paucity of information available on who are the key providers of this form of specialist care.

¹ It needs to be remembered however that dementia is characterised by many different symptoms and behaviours apart from cognitive and memory deficits. All nursing home admissions of people with dementia should involve more extensive and comprehensive assessment over and beyond merely cognitive and memory testing.

As no information was available from HIQA, the Department of Health or the Health Service Executive (HSE) on the number and location of SCUs for PwD, a survey questionnaire was designed to capture data about dementia specific care in the ROI's long-term residential care sector. A deliberately broad working definition of a SCU was provided and based on this definition, all facilities were asked to identify if they had a SCU for PwD. To obtain a comprehensive overview of dementia care policies in SCUs, the survey instrument covered topics including:

- Numbers of residents with dementia living in the units
- Age profile (<65 or >65) of residents and their clinical diagnosis
- Admission and end of life (EOL) policies
- Waiting time for long stay residential care beds
- Number of respite beds
- Physical layout of the environment within these units
- Presence of therapeutic gardens
- Domestic /therapeutic activities for residents
- Visiting policy
- Training needs and training undertaken by staff

The questionnaire was piloted in four different nursing homes, two of which were SCUs. It was revised according to feedback.



INTRODUCTION

The Irish long-term care landscape has been transformed in recent years as a result of much needed health and social policy reform. One such transformation is reflected in the introduction of the Health Act (2007), which resulted in significant change to how residential care settings for older people in the ROI would in the future be inspected and registered. Prior to this, public nursing homes were not subjected to nursing home inspections and it could be argued that the inspection of private and voluntary nursing homes largely focused on health and safety issues (HIQA, 2009). The setting up of HIQA in May 2007 and the establishment of the national residential care standards for both public and private nursing homes has resulted in a much greater emphasis being placed on quality of care and quality of life. The aim of this policy reform was to ensure that every resident could expect to live as full and as independent a life as possible, and receive the highest quality of care.

The Fair Deal Scheme, now known as the Nursing Home Support Scheme (NHSS), administered through the HSE, has more recently ensured greater equity, both in terms of access to and payments for nursing home care. The NHSS is the mechanism through which the cost of long-term nursing home care for the majority of nursing home residents is funded. A gatekeeping system has been introduced whereby only older people assessed by health service professionals as in need of long-term care receive state funding. Whilst the HSE administers the NHSS and facilitates payments to individual nursing homes, the NTPF establishes the prices payable to approved private and voluntary nursing home providers. Currently the agreed average weekly price paid to private and voluntary operators is €888, whilst the agreed average weekly price paid to public (HSE nursing homes) under the NHSS is €1404. The NTPF has no role in establishing costs paid to the public sector and these costs are set down internally by the HSE.

This new system of access to and payments for long-term care has replaced what was considered to be a largely antediluvian and discriminatory aged care policy, since prior to the NHSS, gross inequities existed (BDO, 2014). Despite this recent reform in the area of aged care policy in general, to date, there remains in the ROI, an absence of public policy on dementia. There is also a paucity of information available on how and where people with Alzheimer's disease and the related dementias are supported. These are a very vulnerable group of people whose average length of stay in long-stay residential care far exceeds that of others (Cahill O'Shea and Pierce, 2012a).

Currently, all long-term care facilities must register with HIQA, although curiously no composite database is available on the number/type of registered facilities in existence. Indeed a recently commissioned report, has explicitly pointed to the 'multiple and conflicting sources of information available' regarding the number of nursing homes in the ROI (BDO, 2014, p.7). Nor is any accurate information available on dementia specific residential care units for older people.

Aims and Objectives

The main purpose of this survey was to collect information on the number and location of SCUs providing long-term residential care to PwD in the ROI. The national survey also sought to identify differences and similarities between the different provider types, the HSE or public providers, the voluntary (not-for-profit providers), and the private sector.

Literature Review

In the US, a national survey of long-term care providers, conducted in 2010, found that 17% of all residential care communities had dementia SCUs (Harris-Kojetin et al, 2013). The same study demonstrated that beds in dementia SCUs accounted for 13% of all residential care beds. Interestingly residential care communities with dementia SCUs were more likely than those without, to be located in the Northeast of the US and in metropolitan areas. These units were also more likely to have more beds, be chain-affiliated and less likely to be certified or registered to participate in Medicaid (Harris-Kojetin et al, 2013).

Alzheimer Europe has recently attempted to provide a cross-national European comparison of the provision of long-term care to PwD with specific reference to SCUs (Alzheimer Europe 2013). Whilst 18 out of the 33 countries surveyed had specialist nursing homes for people with dementia, most countries provided limited data on the extent of this provision. Luxembourg had the highest specialist provision at 40%, followed by Norway where approximately one in three nursing homes was dementia-specific, followed by the Netherlands where one in four was dementia specific (Alzheimer Europe, 2013).

A common difficulty in undertaking a cross-national comparison in this area is in ensuring that the concept of specialist care remains consistent across countries. Verbeek, in an excellent overview of the topic (Verbeek, 2011) identified 11 types of concepts describing such long-term care provision for PwD across the world. The countries referred to by her included Australia (CADE units), France (Cantau), Scotland (Care Housing), UK (Domuses), US (Green Houses) Japan (Group Homes), Sweden (Group Living), Germany (Residential Groups), Netherlands/Belgium (Small scale living), Canada (Special Care Facility), and United States/Canada (Woodside place). In this same overview, she shows how the numbers of PwD living in these respective units ranges between 6 to 15, however most (7 out of 11) have a maximum of 12 residents and almost half (5) have 10 or fewer residents (Verbeek, 2011).

In Ireland, we have limited information on the numbers of PwD resident in dementia-specific units (Cahill et al, 2012b). Since 2009, all registered nursing homes in Ireland must undergo regular inspections in accordance with a set of national residential care standards (HIQA, 2009). Supplementary criteria for use in dementia specific residential care units have also been developed for use during inspections. These criteria pay particular attention to the physical environment (including its design and architectural lay out), the recommended maximum number of PwD resident, the type of meaningful activities and psycho-social approaches which should be available, assessment procedures and staff training (HIQA, 2009). To date no information is available in Ireland on the extent to which these Supplementary criteria are implemented during inspections, or how compliance is monitored.

Methodology

To ensure the survey would be inclusive of all provider types, it was first necessary to compile an exhaustive list of all nursing homes providing long-term care to older people across the ROI. Therefore a number of different databases and websites were used to compile a list of all nursing homes. The sources used were Department of Health Long Stay Activities Statistics 2011; www.hiqa.ie <http://www.nhi.ie>; <http://www.nursinghomes.ie>; <http://www.irishnursinghomes.eu> and <http://www.myhomefromhome.ie>. Based on this approach, a listing of 603 nursing homes was compiled. Since one nursing home had already closed by the time the questionnaire was despatched, for data analysis purposes, our population of nursing homes surveyed in this study is 602.²

² HIQA figures list 566 nursing homes registered as designated centres on July 14th, 2014 <http://www.hiqa.ie/press-release/2014-07-30-have-your-say-new-nursing-home-standards-launched-nationwide-public-consultation>.

Questionnaire design and piloting: A brief self-administered questionnaire was designed for all nursing homes (including SCUs) and divided into two parts. The first asked questions about where the nursing home was located and whether, based on a given definition, it considered itself a SCU. The following broad definition of a SCU was provided.³

“A dedicated unit designed to cater exclusively for the complex needs of people with dementia; only residents with dementia live in these units which are generally small scale, domestic and safe. Within Europe the size of the SCUs differs according to how respective facilities have evolved”.

A question was also included in this part of the questionnaire about any plans the nursing home had for establishing a SCU in the foreseeable future.

The second part of the questionnaire was completed by those Directors of Nursing/Nurse Managers identified as working in SCUs. For coverage of topics covered in this questionnaire see page 4. The questionnaire was piloted in four different nursing homes (two of which were SCUs) and amended according to feedback.

Procedure: In late September/October 2013, a self-administered questionnaire was forwarded to the Directors of Nursing (DONs) in all 602 nursing homes identified. A cover letter was attached explaining the rationale behind the study and the fact that the DSIDC was commissioning the research. The letter encouraged participation by stating that information collected would be used to generate a database of SCUs to be posted on the DSIDC’s website (www.dementia.ie) and used to compile an information booklet for family caregivers and health service professionals.

It is likely that this approach may have incentivised some nursing homes to self-identify as SCUs even if strictly speaking they might not by any objective evaluator be considered “small scale”. This fact needs to be kept in mind when interpreting findings. On the other hand it is also likely that some nursing homes, which were SCUs, preferred not to be identified for a variety of reasons, including a fear/concern about being unable to comply with HIQA supplementary criteria for dementia specific residential care.

Response rate: During October 2013, a total of 302 (50.2%) postal questionnaires were returned. As respondents were required to give the name and location of the nursing home, non-respondents could easily be identified. Accordingly each non-respondent was later emailed (November 2013) and once again invited to participate. This initial follow up contact and reminder yielded a further 44 (7.3%) completed surveys.

During January 2014, all remaining non-respondents (N=256) were telephoned and a phone interview was conducted with the DON/Nurse Manager or with the Assistant Director of Nursing (ADON), or the Clinical Nurse Manager. This third phase of data collection (telephone interviews) yielded a further 121 (20.1%) completed survey forms. Two further surveys forms were received by post in January 2014.

In summary, the overall number of completed survey questionnaires is 469 yielding a response rate of 78%.⁴ For clarity of presentation, findings in this report will be presented in two parts. First the data on all nursing homes surveyed will be presented. This will be followed by findings relating only to the SCUs.

³ This definition was deliberately kept broad to capture all potential SCUs.

⁴ Non-respondents cited a number of reasons for opting not to participate; some indicated that they did not wish to participate, while others claimed pressure of work linked to HIQA inspections and re-registrations prevented them from participating.

FINDINGS FROM ALL NURSING HOMES

Nursing Home Categories and Response Rates

The 469 nursing homes were classified by provider type namely (i) public/Health Service Executive (HSE); (ii) private for-profit; and (iii) voluntary not-for-profit. Figure 1 highlights that 393 (65%) were privately operated whilst 133 (just over 22%) were HSE operated. Voluntary or not-for-profit providers constituted the smallest category, accounting for 76 Nursing Homes (13%).

Whilst the overall response rate was 78%, the response rate from the voluntary sector was lower than the HSE and private facilities (see Figure 2(a)). The figure illustrates that more than 80% of the HSE and privately operated nursing homes responded to the survey while only 60% of voluntary nursing homes responded.⁵

Figure 1: All Nursing Homes by Provider Type (N=602)

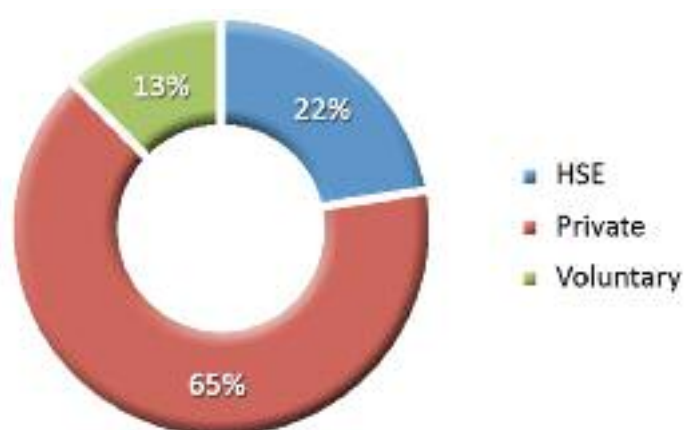
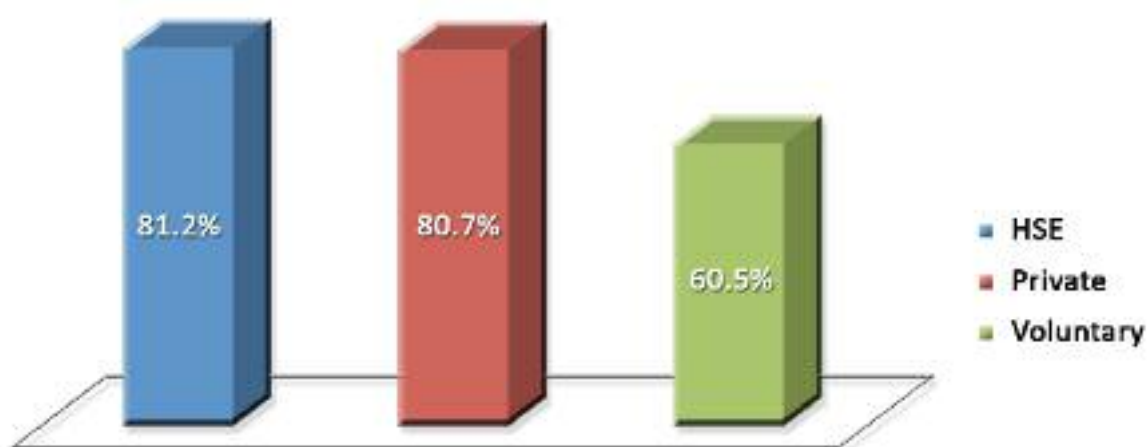


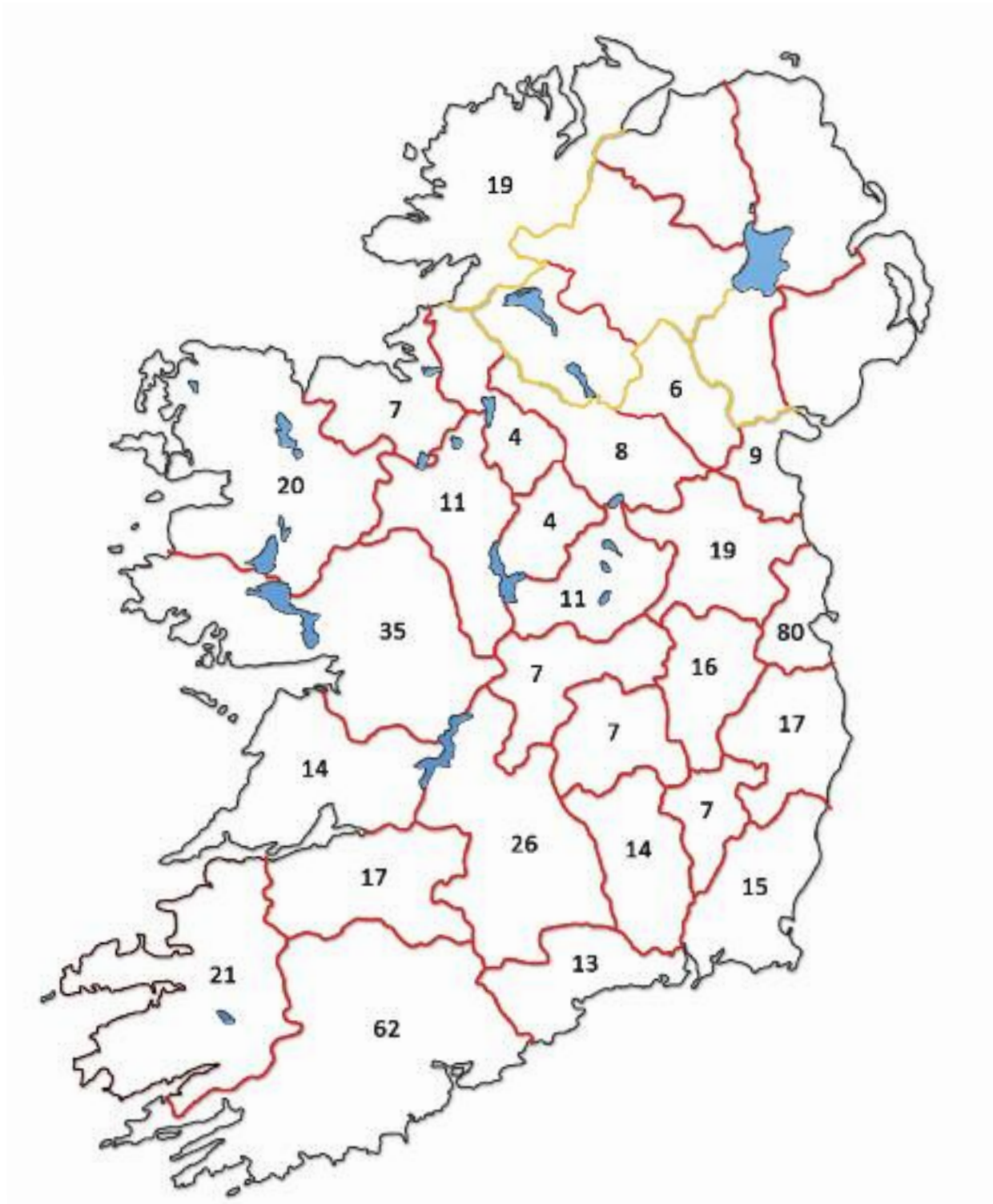
Figure 2(a): All Response Rates by Provider Type (N=469)



⁵ It remains unclear why a lower proportion of voluntary providers responded to the survey. Reasons might include the under-staffing of such units, greater concerns about research participation, and fear of future HIQA inspections against Supplementary criteria for SCUs.

Figure 2(b): Number of Nursing Home Respondents by County (N=469)

Figure 2(b) – map of Ireland, reports findings on the location of all long-term residential care units (including SCUs) for older people. The map shows that the Dublin Mid-Leinster area (east coast) and the West to South coast of Ireland tend to have the highest proportion of nursing homes. Caution needs to be exercised in interpreting these findings since the map reflects numbers of nursing homes but not numbers of beds. One must also keep in mind the fact that findings only reflect the 78% of nursing homes who participated in our survey.



Findings from Specialist Care Units

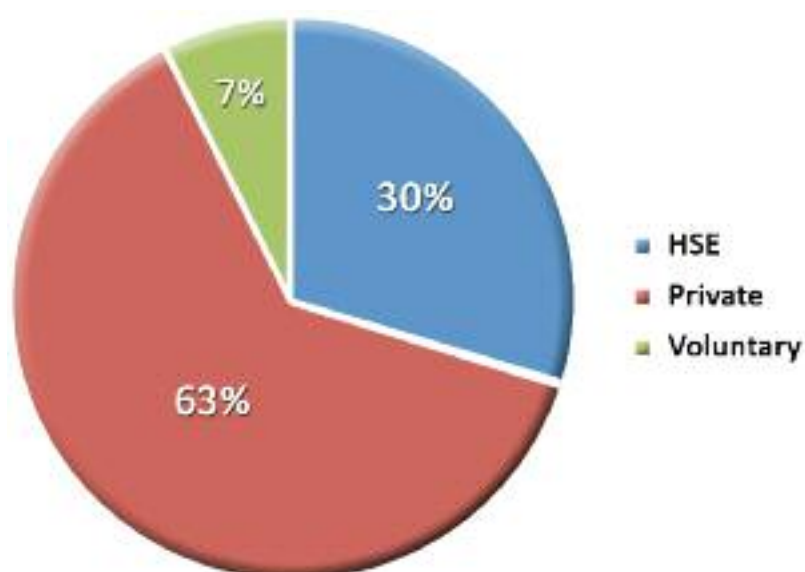
Number of SCUs

A total of 55 respondents (12%) claimed that in accordance with the definition provided, (see page 8), the long stay residential care unit where they worked was a SCU or had a SCU attached. However, one SCU was later excluded since it was considered to be inappropriately designated.⁶ For analysis purposes, a revised total of 54 SCUs was used.

Of these 54 units, 36 (63%) were privately operated, 14 (30%) were public units/HSE provided and only 4 (7%) were voluntary not for profit facilities. This extremely small representation of voluntary not for profit SCUs must be remembered when interpreting results.

The proportion of SCUs in the private sector (63%) was consistent with the overall proportion of private nursing homes in the population of nursing homes (65%) (Figure 3). However, there was a disproportionately low representation of SCUs in the voluntary sector (7% v 13%), whilst in contrast a higher proportion of SCUs were located in HSE long-stay residential units (30% v 22%).

Figure 3: SCUs by Type of Provider (N=54)



⁶ This nursing home although dementia specific catered for over 100 residents.

Location

Figure 4 (map of Ireland) shows the regional distribution across the ROI of the 54 SCUs who participated in the survey. Clusters of SCUs are in evidence in a small minority of counties. County Cork for example has by far the largest numbers of SCUs (N=13) followed by Dublin (N=6), Galway (N=5), Donegal (N=5), Cavan (N=3), Louth (N=3), Meath (N=3), and Monaghan (N=3).

Further analysis in relation to Local Health Offices (LHOs) shows no provision in six LHOs areas all of which are in Leinster and most of which (4 out of 6) are in Dublin. For example Wicklow, Carlow and parts of Dublin have no SCUs.

Even allowing for the known lower prevalence of dementia in the East, the number of SCUs in Leinster is disproportionately low.

Figure 4: Location of SCUs across the 26 Counties of Ireland

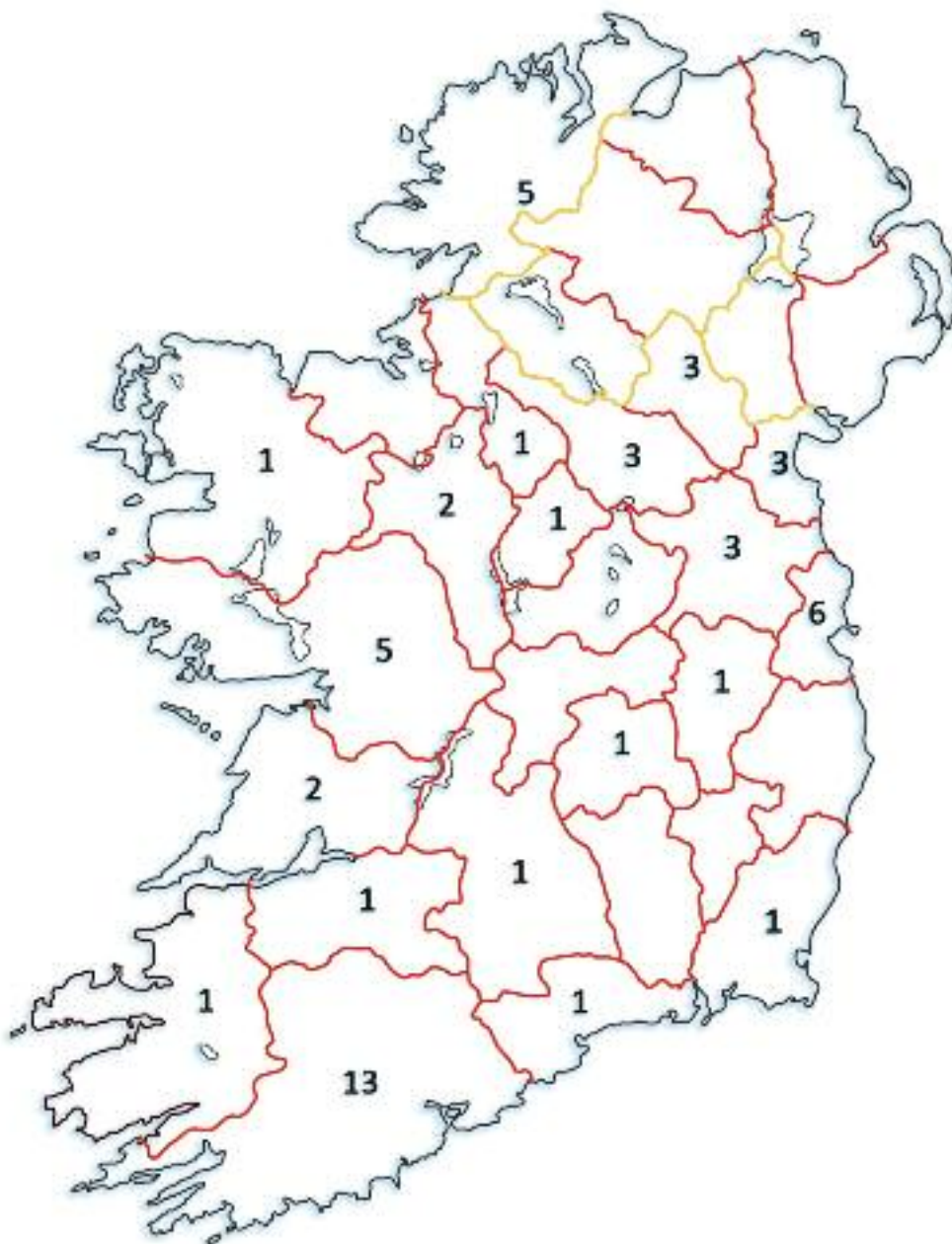


Figure 5 provides information on the location of the 54 SCUs that participated in the study. This information is also broken down by provider type. By far the majority (N=46) are located in either country towns (N=23) or rural hinterland areas (N=23) with only eight SCUs found in cities. The figure shows that in rural towns, the HSE and private providers tend to have similar numbers of SCUs, but in cities and in country towns, private providers far exceed the HSE in terms of service provision.

Figure 5: Location of SCUs by Provider Type (N=54)



Summary and Recommendations

1. Considerable inequities exist in the regional distribution of dementia specific residential care units (SCUs) across the ROI. Close to 54% of all SCUs involved in this survey are located in only four of the 26 counties. The counties of Sligo, Wicklow, Carlow, Kilkenny, Westmeath and Offaly appear to have no provision whatsoever. Other counties, especially Cork appears to have excellent provision. Regarding Local Health Office (LHO) areas and based on the results of this survey, no provision exists in six areas, all of which are in Leinster and most (four out of six) are found in Dublin.
2. Our findings raise interesting questions regarding the optimum time when a PwD should be admitted to a SCU. For example in geographical areas where provision is low, are PwD admitted at a later stage in the course of the illness, and does this inherently disadvantage them? Conversely in areas where provision is high, are they admitted earlier?
3. To plan future specialist long-term residential care for older PwD, there is an urgent need to review current and future dementia prevalence rates at a regional level. This will help to identify areas where greatest demand will arise.

Residents with Dementia

A total of 1034 residents, a figure representing about 2.2% of all people estimated to have dementia in Ireland and about 4.5% of the total number of people living in long-stay residential facilities⁷ were in residence in the 54 units surveyed. Further analysis revealed that circa two thirds (64%) were in private facilities; one in four (24%) were in HSE facilities and just over one in ten (11%) were in voluntary facilities. The average number of residents in all SCUs was estimated to be 19.

A significant variance was found in the size of SCUs across the three provider-types. In the voluntary sector, the average number of residents was 29; this compares to an average of 20 residents in private SCUs and an average of 16 residents in HSE operated SCUs.

Four privately operated nursing homes noted that residents with dementia were cared for in two or more separate houses or residences. If these “houses” are treated as separate operating units, the revised average number of residents in SCUs is 17.5.

Residents aged less than 65 and those with Down syndrome and Alzheimer’s disease

Based on survey findings, only 54 people (5.2% of all residents in SCUs) were under the age of 65 years and 78% of this age-cohort was cared for in the private sector. The survey only identified one resident with Alzheimer’s disease related to Down syndrome living in a SCU.

Respite Beds

A total of 66 respite beds were identified across the 54 SCUs surveyed.⁸ Interestingly despite the fact that the HSE account for only about one third of all SCU provision and the voluntary sector for an even smaller proportion, the HSE and the voluntary sectors were the principle providers of respite beds. All of the four voluntary SCUs provided respite beds and 15 of the 16 HSE facilities also provided this service. In contrast, only 8 out of the 34 (24%) private providers offered respite care.⁹

Figure 6: Number of Both long-term and Residential Respite Beds in SCUs



⁷ However based on the estimate that about two thirds of people living in long-stay facilities have dementia (Cahill, O’Shea and Pierce, 2012) this figure (1,034) suggests that less than 7% of all people with dementia living in long-stay residential facilities are being cared for in dementia specific SCUs.

⁸ In interpreting these results one must remember that organizations like the Alzheimer Society of Ireland provide residential respite care in Blackrock Dublin and in the Waterman’s Lodge, Co Mayo. The Western Alzheimer’s Foundation also provides residential respite in Ballindine, Co Mayo.

⁹ Three privately run SCUs failed to answer this questions about respite.

Summary and Recommendations

1. Family members caring for a relative with dementia need regular breaks from the all-intensive demands of dementia care (Twigg & Aitkin, 1994). Respite care has been shown to be instrumental in providing such breaks and is a service known to help sustain community care (Lee & Cameron, 2004; McNally, BenShlomo & Newman, 1999). The current provision of 66 residential respite beds in SCUs for PwD is inadequate, given there are 30,000 people estimated to have dementia and living in the community (Connolly et al, 2013). There is a need for a significantly larger proportion of respite beds to be made available in SCUs.
2. For the estimated circa 4000 people with young onset dementia in Ireland, there is a need for increased numbers of respite beds in SCUs.
3. Funding for residential respite in Ireland is limited and paid directly through the HSE with no NHSS or NTPF involvement. It is not surprising therefore that only a very small minority of private providers offered residential respite care. In the context of residential respite care, there is a need for an appropriate and transparent funding model to be developed and for a significant increase in resources to be allocated to private SCUs to enable them provide adequate residential respite.
4. There is a need to develop clear policies, procedures and protocols including well-designed assessment procedures and eligibility criteria for residential respite care.
5. In some LHO areas the HSE has adopted a policy of contracting out respite care. This is in recognition of the large cost differential between public and private facilities and to ensure 'that the most effective use is made of limited resources' (HSE, 2012, p.29). It may be that respite care for PwD is provided by the private sector outside SCUs. This policy needs to be reviewed.



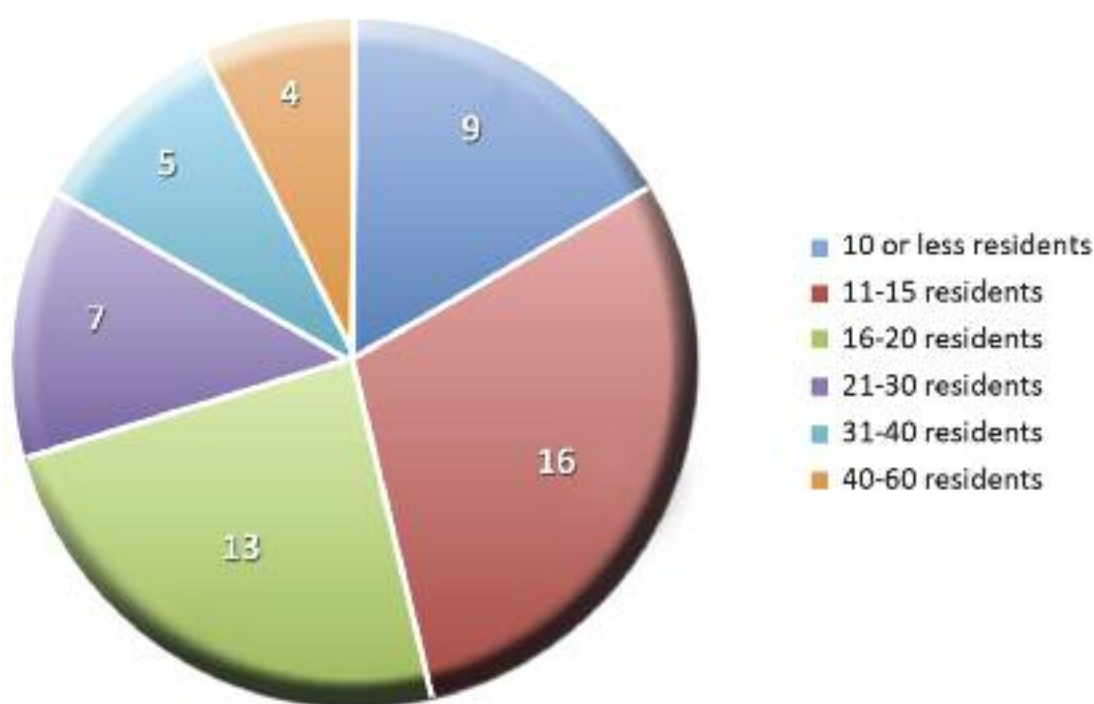
Number of People with Dementia in SCUs

In an earlier section of this report (see p. 14), it was shown how the 54 SCUs identified, were delivering long-term residential care to a total of 1034 PwD. A series of questions was also asked regarding the numbers of residents in each of the SCUs and analysis was undertaken by provider type.

Results revealed that the average number of residents in each SCU was 19 (range = 3 to 54). The smallest variance was found in the public sector (HSE Units), which catered for between nine to 25 residents, and the largest variance was found in the private sector where numbers ranged from three to 51 residents. None of the four voluntary not for profit SCUs had ten or fewer residents and like the private sector, these units varied considerably in size accommodating between 16 and 54 residents.¹⁰

Overall, only nine units (16.7%) had ten or fewer residents. Seven out of ten SCUs (70%) catered for 20 or fewer residents. Four SCUs were configured around two or more houses to ensure that residents are cared for in smaller groups and probably to comply with HIQA regulations/dementia specific supplementary criteria although the numbers living in such groups varied from ten to 22. If these individual 'houses' are taken as the effective unit size for operation purposes, the number of SCUs increases to 59 of which 11 units (19%) had ten or fewer residents and the proportion of units with 20 or fewer residents increases to 76%.

Figure 7: Numbers of Residents in each of the 54 SCUs



¹⁰ Strictly speaking and based on size, unless sub-divided into individual homes, a long stay care facility accommodating over 50 people cannot be classified as a SCU, however as the latter self-identified as such, we have included them in the survey results.

Summary and Recommendations

1. Consistent with findings reported by Nursing Homes Ireland (NHI, 2010) and other more recent research (Cahill, O' Shea & Pierce, 2012a), the average number of residents living in dementia specific residential care units for older people and identified in this survey was 19. In this survey, 70% of SCUs had 10 or more residents.
2. The purpose of small group living is to create an environment resembling a family unit with opportunities for family members; staff and residents to interact and develop close meaningful relationships (Verbeek, 2011). This is less likely to happen in units with more than eight residents living together. Four facilities identified in this survey that cater for large numbers of PwD, have re-configured their long-term care accommodation to enable smaller groups of residents to live together. This practice is recommended.
3. The cost of operating small-scale dementia specific units is a key consideration, particularly when the main bulk of specialist dementia care is provided by the private sector. The State is currently paying between 58% to 103% more per resident in a hospital or public nursing home than the comparable fee paid to private or voluntary providers (BDO, 2014).
4. For private providers, the current funding model (NHSS) acts as a disincentive to develop SCUs. A new funding model is required and the private sector needs to be incentivised if they are to continue to provide the main bulk of specialist dementia long-term care.
5. The direct and indirect costs of operating small-scale dementia specific units need to be documented and a cost-based and quality of care analysis needs to be undertaken.
6. There is a need to develop a standardised definition of what constitutes small-scale home like environments for PwD.

Waiting Times

The waiting time leading up to a person's admission into long stay care can be very stressful for both the individual and for family caregivers (Meiland et al, 2001). Recent policy changes now mean that assessment for financial approval under the NHSS takes up to 12 weeks, which has further extended waiting times. Findings from this survey reveal that many SCUs do not keep detailed records on wait-list experience and only about half of all respondents (N=28) could provide reliable information on their waiting lists.

Analysis of the available data showed that the mean waiting time was 22 weeks (range = 1 to 104 weeks). Six SCUs in areas with high provision had beds immediately on offer. One HSE unit claimed they were closed to permanent admissions¹¹ but continued to offer respite beds. In contrast in areas not well supplied, waiting periods of one to two years was not uncommon. Almost 40% of respondents who provided details of their wait lists indicated a waiting time of 26 weeks or more (see Table 1 below). The data show that most of the SCUs with waiting times of six months or more were located in the Leinster area. Given the comparatively small numbers of SCUs in this area this finding was not surprising.

Table 1: Waiting Time for Admission to SCUs (N=28)

	Leinster	Munster	Connacht	Ulster	Total
Number of SCUs	10	5	3	10	28
Waiting time of 6 months or more	6	1	2	2	11

Summary and Recommendations

1. Findings reflect significant inequities across the country regarding the length of time people were wait-listed for SCU admission. Some areas with good supply (high provision) had quick access but others such as Dublin/Mid Leinster had long waiting lists. There is a need for more equity across the country in relation to gaining admission to SCUs.
2. About one quarter (N=13) of all the facilities surveyed were unable to provide reliable information about wait-listing times. A typical response here was "waiting time varies" or "it depends on the Fair Deal". In order to assist family members plan and choose appropriate long stay residential care, there is a need for more accurate information to be made available to them about waiting lists for SCUs.
3. The limited information now collected on waiting lists for SCUs should be analysed in the context of current and future estimates of dementia prevalence rates and the current provision of dementia specific residential care. Such analysis will help estimate future demand for long-term care services and will facilitate planning for such increased demand.

¹¹ They provided no reason behind why they were closed for non-respite admissions.

Criteria for SCU Admission

Respondents were asked what criteria were used when admitting PwD into SCUs. Four criteria were outlined namely –(i) pre-admission assessment, (ii) a clinical diagnosis of dementia, (iii) challenging behaviours, and (iv) independence in mobility. A fifth criterion “other “ was an additional option. Criteria were not mutually exclusive.

Only five SCUs (three HSE and two private) reported that they used all of the four aforementioned admission criteria, while most (69%) claimed they used two or three. Curiously, one SCU used no criteria.

Pre-admission assessment

A total of 89% of all SCUs used a pre-admission assessment with all of the voluntary SCUs and almost all (94%) of the private SCUs using this as an admission criterion (see Figure 8). In contrast only about three quarters of the public (HSE) SCUs stated they used a pre-admission assessment.¹²

Clinical diagnosis

The HIQA supplementary standards specify that all new residents being admitted to SCUs must have a clinical diagnosis of dementia made by a suitably qualified medical practitioner. Findings showed how only two thirds of all SCUs used a clinical diagnosis of dementia as an admission criterion (see Figure 8). In the voluntary sector, the data show that clinical diagnosis was always used as a pre-admission criterion for admission but not as frequently in the public (81%) units or private sectors (56%).¹³

Challenging behaviours

Figure 8 shows that a total of 41% of all SCUs used challenging behaviours as an admission criterion, meaning that they would only take new admissions of people who had challenging behaviours. Data on this variable showed considerable variability by provider type. For example only 25% of voluntary SCUs cited challenging behaviours as an admission criterion; whilst 38% of private and 50% of all public (HSE) SCUs cited this as a criterion.

¹² One HSE unit indicated that pre-admission assessment may be completed by phone and noted that a Clinical Nurse Specialist always speaks to families before admission. Another HSE unit commented that assessment and referral could come from the Old Age Psychiatry team.

¹³ Curiously, one HSE operating SCU noted that while all residents are obliged to have a dementia diagnosis, this is often provided by a GP without full screening or without sub-typing by a specialist.

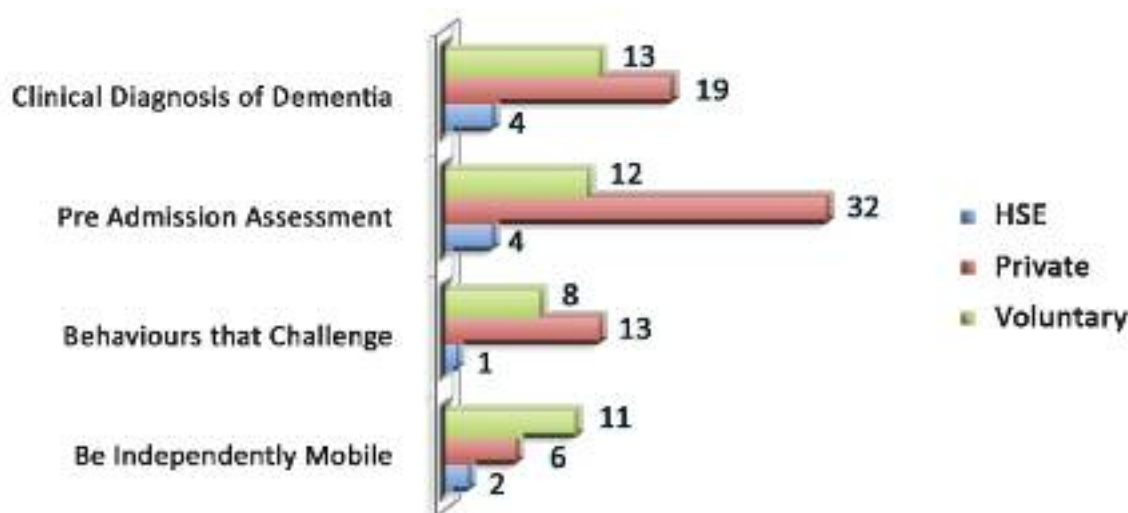
Be Independently Mobile

A total of 35% of all SCUs used “Be Independently Mobile” as an admission criterion. For HSE providers, who as shown earlier receive higher payments for care and where older people with high to maximum dependencies are cared for, as many as two thirds (11 out of 16) stated that being independently mobile was a requirement. This figure contrasts sharply with the private sector where only 18% required their in-coming residents to be independently mobile and with the voluntary sector where 50% used this criterion. These findings suggest that HSE operated SCUs are less likely than private and voluntary SCUs to admit a PwD if he/she is not independently mobile.

Other

A minority of SCUs identified ‘other’ criteria, which they used to admit residents with dementia. Two private SCUs stated they had consultant physicians conduct behavioural and functional assessments. Another respondent reported that social factors including caregiver burden was taken into consideration and one other respondent stipulated that a careful assessment of the degree of cognitive impairment was undertaken to ensure suitability.

Figure 8: Admission Criteria Used by SCUs (N=54)



Summary and Recommendations

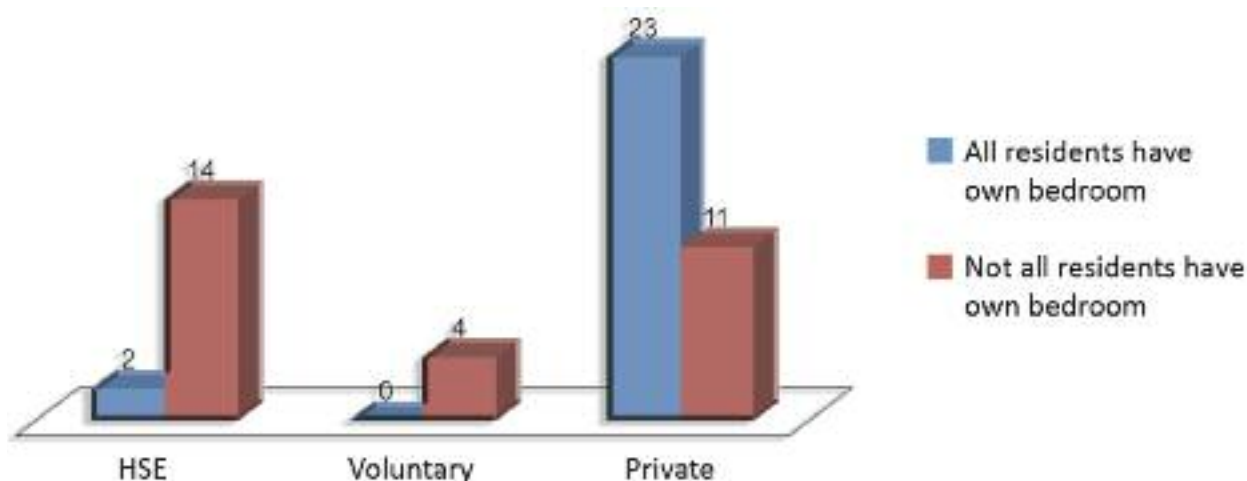
1. The survey showed that criteria most often used for new admissions to SCUs are pre-admission assessment (89%), clinical diagnosis (66%), behaviours that challenge (41%) and independence in mobility (33%). Based on these findings it is concluded that in almost all instances, residents are not admitted to dementia specific SCUs without some form of assessment.
2. The HIQA requirement that all new admissions to designated dementia specific residential care units have a clinical diagnosis of dementia is not being complied with. Our findings reveal that only two thirds of all the facilities surveyed applied this criterion.
3. The findings show that admission criteria used by HSE operated SCUs were in some instances more restrictive than those operated by the private sector. Of particular concern is the finding that over two thirds of HSE respondents (69%) stipulated an admission criterion of ‘being independently mobile’. This compares to 18% of privately operated SCUs. The application of this admission criterion is not consistent with the accepted orientation of public nursing homes and SCUs towards persons of high and maximum dependency.

The Physical Environment

Bedrooms

Findings show that less than half of the SCUs participating in the survey had private bedrooms available to PwD. None of the voluntary SCUs, and only two of the 16 HSE units provided private bedrooms. In contrast in the private sector, two thirds of residents had their own private bedrooms. Indeed a small minority of private providers also reported they had double rooms to accommodate couples or siblings.

Figure 9: Private Bedrooms by Provider Type (N=54)



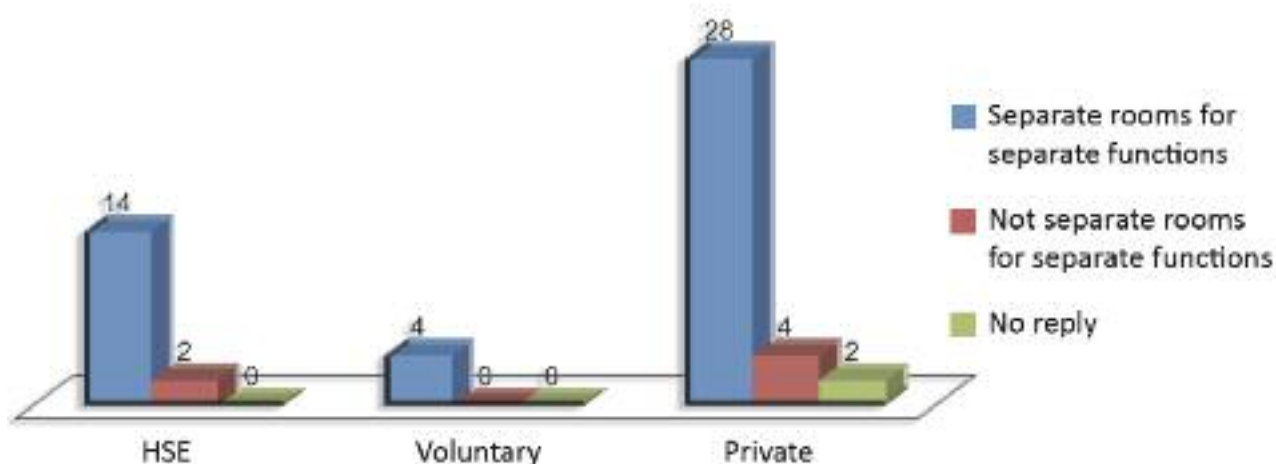
Bathrooms

Only about one third of these SCUs (N=20) provided private bathrooms/toilets to their residents. In almost all cases where private bathroom/toilets were available, the SCU was in the private sector.

Separate Rooms for Separate Functions

Figure 10 presents responses to the question asked about whether the SCU had separate rooms for separate functions. It shows that all but six units (four public and two private) adhered to this principle.

Figure 10: Separate Rooms for Separate Functions (N=54)



Summary and Recommendations

1. In general, our findings show that private SCUs are more ideally designed¹⁴ to cater for the complex and unique needs of PwD compared with HSE and voluntary SCUs.
2. The supplementary criteria (HIQA, 2009) for dementia specific residential care units require that all newly built units are divided into areas that resemble rooms found in a regular domestic dwelling with separate rooms for separate functions. A corollary of this is that separate bedroom accommodation should be available. Of some concern therefore in this survey is the finding that only 12% of the HSE units provided all residents with their own private bedroom, this compares with a 68% private bedroom provision in the private sector.¹⁵ Indeed as mentioned, some private facilities also offered double rooms to facilitate couples or siblings.
3. The use of the same room for multiple purposes, such as the dining room as an activity room or the day room for Mass may further confuse a resident with a moderate to severe dementia. Best practice in dementia care recommends that specific rooms should be designated for specific activities. It is of concern that six facilities (four private and two public) in this survey reported they that they failed to use separate rooms for separate functions.



¹⁴ Caution needs to be exercised here as good architectural design alone is not tantamount to “good quality care”. Whilst undoubtedly individual bedrooms are preferable to communal sleeping quarters, the former need to be personalised and domestic and not clinical or hotel-like.

¹⁵ The inability of HSE operated facilities to provide private bedrooms probably reflects the fact that a large proportion of HSE long stay residential care provision across the country takes place in older buildings.

Domestic Activities

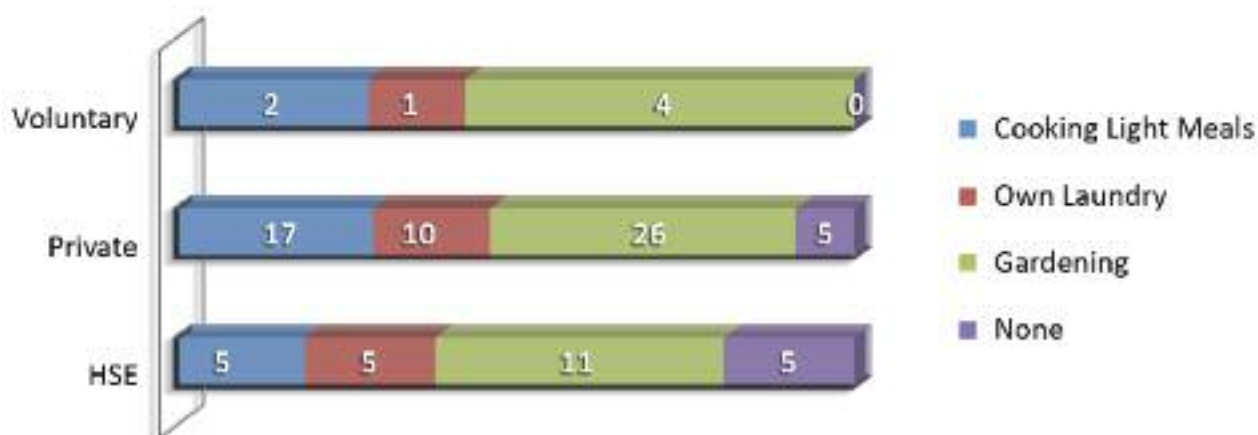
Three categories of domestic activities (i) cooking light meals; (ii) doing own laundry and (iii) gardening were listed and respondents were asked if residents were afforded opportunities to engage in these activities. A total of 44 SCUs (81%) stated residents regularly participated in at least one of these domestic activities. Responses were however at times qualified by comments such as 'depending on abilities', 'under supervision only' and 'limited'. Three respondents (two from the voluntary sector) claimed that the severity of their residents' dementia out-ruled them from engaging in these types of domestic activities.



Of the listed activities, gardening was most frequently available (76%), however, 13 SCUs (24%) had no gardening on offer and only three of these offered any other alternate domestic activities. Of the 13 facilities that offered no gardening, eight reported they had a therapeutic garden. One respondent said that their garden included wall murals and commented that a daily activity plan is prepared. Her comment suggests that the garden is very central to the activity focused care provided in this SCU.

A total of ten respondents (five public/HSE and five private), accounting for 19% of all units surveyed reported their residents did not participate in ordinary domestic activities.

Figure 11: Ordinary Domestic Activities by Provider Type



The average number of domestic activities available in SCUs was two and no significant difference was found by provider type. 'Other' domestic activities identified included dusting, sweeping the floor, washing up dishes and setting tables.

In a minority of cases, domestic activities reflected an innovative and creative approach to engaging PwD in meaningful recreational tasks appropriate to individual life stories and biographies. Examples include feeding chickens, watering plants, putting birdseed in containers, and painting fences. In one SCU where much effort was invested into developing life stories, the domestic activities selected for residents tended to match former occupational backgrounds. Examples included a teacher's corner complete with blackboard and an old immobile car for a former mechanic.

Therapeutic Activities

In response to another question asked about therapeutic activities, all but one of the SCUs surveyed, reported their facility had therapeutic activities available to residents. Specific activities mentioned in this context included (i) music, (ii) art, (iii) reminiscence, (iv) Snoezelen activities¹⁶, (v) beauty treatments, (vi) sensory rooms, (vii) Sonas¹⁷, (viii) aromatherapy and (ix) yoga.



Summary and Recommendations

1. Whilst the physical setting including the architectural design and layout of a SCU can facilitate a homelike environment, in itself it is insufficient, as social aspects including the philosophy of care and the attitudes and training of staff are equally important (Verbeek, 2011). As far as possible residents should be encouraged to exercise choice in their daily lives and participate in household activities. The principle of normalisation with care activities centering around everyday issues such as shopping, cleaning, cooking and other household chores should be encouraged in all SCUs. About one in five (19%) of these SCUs provided no opportunities to residents to enable them participate in household activities.
2. The HIQA supplementary criteria for dementia specific residential care stipulate that all new builds including those with more than one storey should have a secure garden available to PwD. The garden should be safe, accessible and should provide multi-sensory stimulation. In this survey three facilities (5%) reported they had no therapeutic garden and 13 (24%) had no gardening activity available for their residents.
3. SCUs should be rewarded for demonstrating creativity and innovation in relation to therapeutic activities. Currently funding is available to provide pharmacological interventions but no similar funding can be used to provide non-pharmacological such as reminiscence, Cognitive Stimulation Therapy, Snoezelen, life story work, aromatherapy and other such psychosocial approaches. More funding should be allocated to support staff to be trained appropriately to deliver these types of non-pharmacological interventions to PwD resident in SCUs.

¹⁶ Snoezelen therapy is an individual type of approach that uses multisensory stimulation, generally in an adapted environment: the 'Snoezelen room'. The 'Snoezelen' was introduced during the 70's by Hulsege and Verheul, who worked at the 'De Hartenberg' Institute, in northern Holland, for patients with learning disabilities. (Lopez et al, 2014).

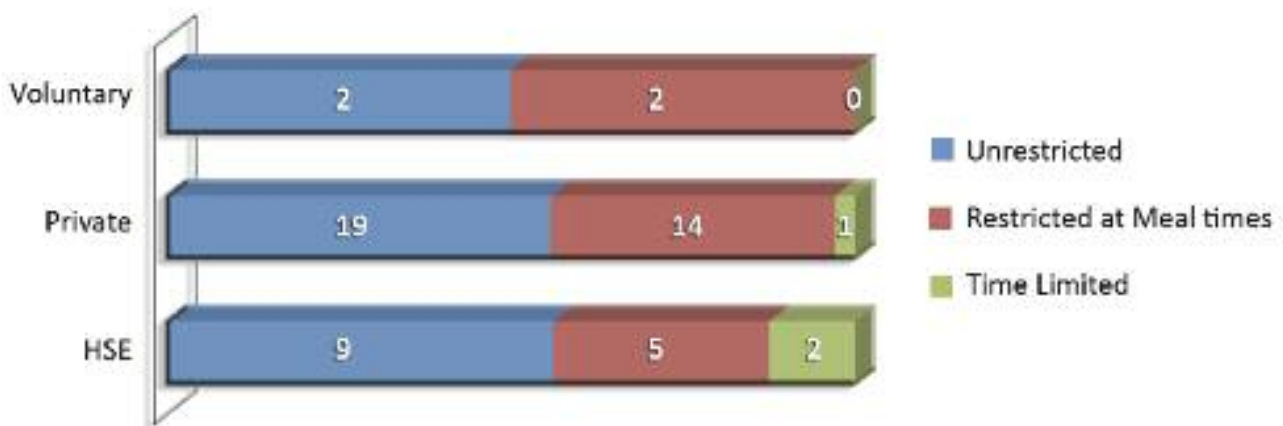
Snoezelen therapy works by stimulating the senses; it can help people with a dementia to connect to their environment, which due to their cognitive impairment they find hard to connect with. Snoezelen rooms contain many multi sensory devices such as glowing fibre optics lights, lava lamps, bubble tubes, music, and relaxing lights. Many of these are small and portable so they can be brought to the person's own bedroom if they are able to go to the Snoezelen room.

¹⁷ The Sonas programme is a therapeutic, communication activity for people with moderate to severe dementia. It incorporates multi-sensory stimulation, gentle exercises and a time for personal contributions, within structured group and individual sessions. The aim is to activate each participant's potential for communication, thereby enhancing wellbeing.

Visiting Policy

A total of 30 out of the 54 SCUs (55%) stated they had an open door visiting policy and 21 (39%) reported visitors were restricted during meal times (see Figure 12).

Figure 12: Visiting Policy by Provider Type (N=54)



Two public and one-private SCUs stated that their visiting policy was time limited. In one case, this was described as between '2-4pm and 6-8pm and other times as arranged with the unit manager'.¹⁸ In the other case, visiting was restricted to before 8.30pm for security and safety reasons.

Summary and Recommendations

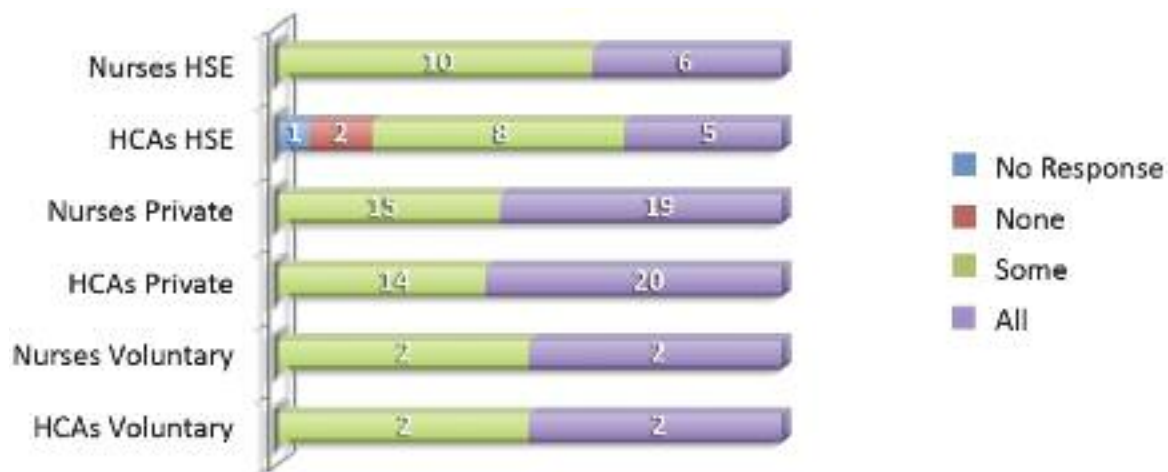
1. As life within a SCU should as far as possible resemble the resident's former life whilst living at home, an open-door policy should be supported and encouraged.

¹⁸ It was noted that this policy was in response to residents' and family members own requests for privacy and quiet times.

Staff Training

Given that all 54 units were providing specialist dementia care, one might assume that all staff employed had undergone dementia training. Results show that across all facilities surveyed, only about 50% of all nursing staff and 50% of all health care assistants (HCAs) had been trained in dementia care. A little over one third of all facilities indicated that all management staff had undergone training.

Figure 13: Training in Dementia Care of Nursing and Health Care Assistant Staff by provider type



Further analysis revealed that specialist dementia training varied according to provider type, with a significantly larger proportion of private SCUs reporting that all their nursing staff (56%) and all HCAs (59%) had received dementia specific training compared with HSE providers where only one third reported that all nursing staff (37%) and all HCAs (31%) had received specialist training. Only two of the four voluntary SCUs reported that all nursing and all HCA staff had been trained. Interestingly, two HSE operated SCUs reported that none of their HCAs had undergone dementia specific training.



Regarding the training of management staff, (see Figure 14) findings show that a slightly larger proportion of HSE and voluntary providers reported all management staff as opposed to nursing staff and HCAs had been trained. Findings show that management staff in private SCUs had similar levels of dementia specific training compared with nursing staff and HCAs, with the exception of one SCU, which reported that none of the management staff had undergone dementia specific training.

Overall, findings show that employees in SCUs least likely to have undergone dementia training were 'other staff' with only about a quarter of HSE and voluntary operated SCUs stating that all 'other staff' had dementia training compared with 50% of private SCUs. Indeed more than half (56%) of HSE operated facilities reported that none of their 'other staff' had received dementia specific training; this compares to 50% of voluntary SCUs and only 38% of private SCUs. (See Figure 15)

Figure 14: Dementia Specific Training-Management (N=54)

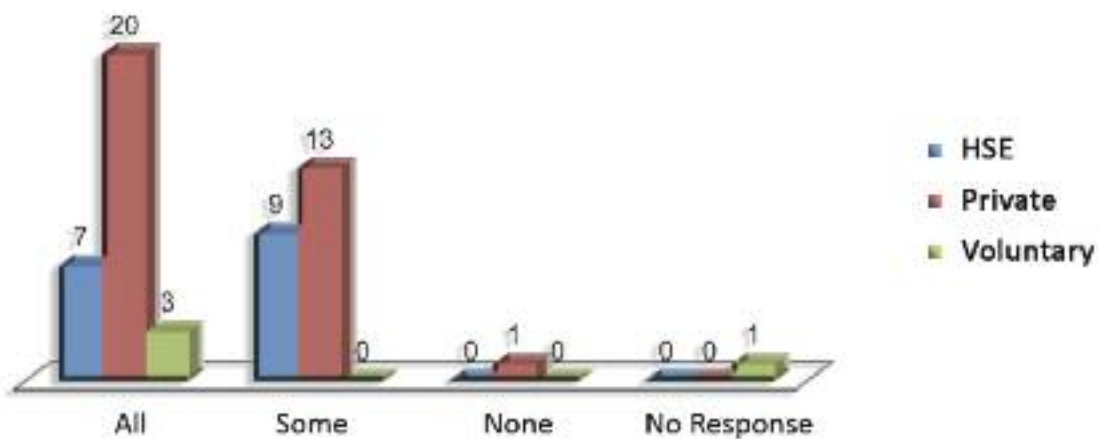
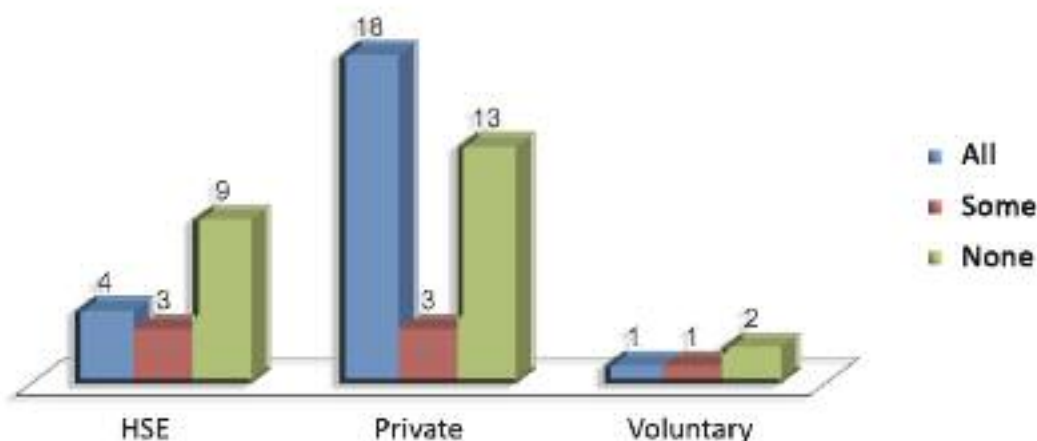


Figure 15: Dementia Specific Training-Other Staff (N=54)

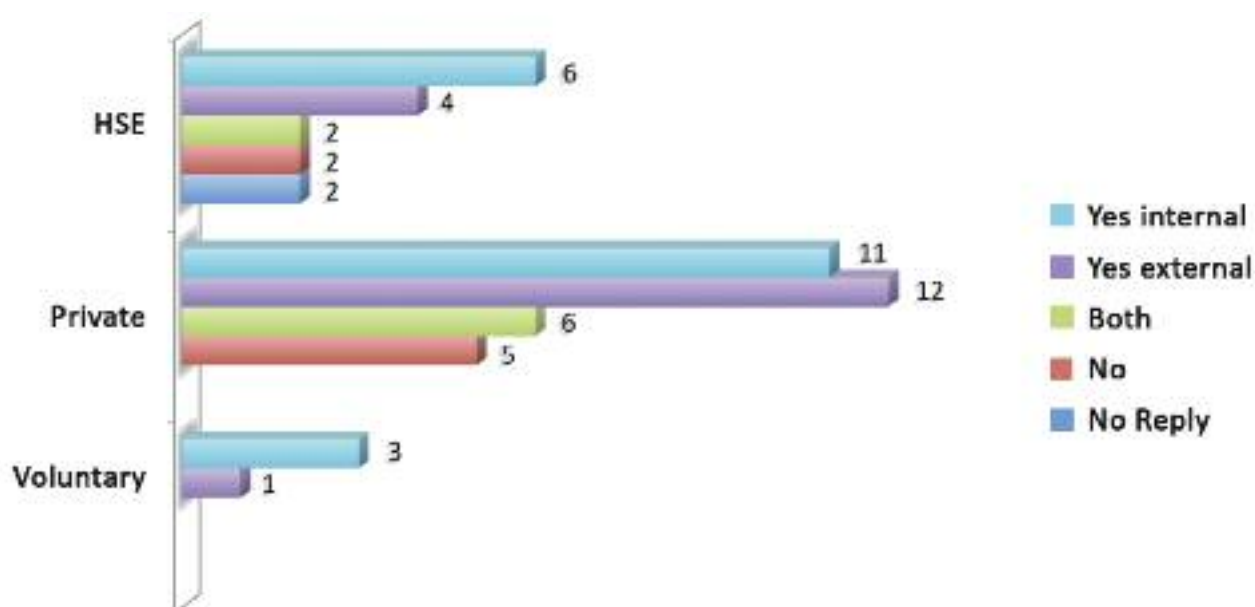


Future Training Needs

The survey also examined respondents' plans for the future training of staff across all SCUs surveyed (see Figure 16). A total of 75% of the facilities surveyed (40 out of the 54 units) expressed an interest in organising training over the next six months. Of these, one third (N=13) expressed an interest in external training, 45% (N=18) had an interest in internal training and nine (seven private and two HSE) planned on organising both internal and external training.

Analysis showed that six SCUs (five private) stated they were not interested in training their staff in the next six months. In these cases, the units may have had their staff recently undergo training. Responses may also reflect an erroneous view that training is a once off.¹⁹

Figure 16: Interest in Dementia Specific Training for Staff in the next Six Months. (N=54)



When asked which staff should receive further training, one third (N=18) said 'all staff'. Then following some probing questions, respondents mentioned in particular management, domestic and catering staff. Some of the answers provided included comments about- 'refresher training' and 'updating current staff. Eight others (14.5%) reported they were only interested in training their nurses and care staff.

¹⁹ Two HSE units did not reply to this question but one of these noted that at the time of completing the survey they were delivering 'the national dementia two day training to all staff'.

Summary and Recommendations

1. Findings showed that the training of SCU staff varied in relation to provider type. A significantly larger proportion of privately employed nursing care staff and HCAs had undergone specialist dementia training when compared with the same staff in the other two sectors.
2. Given that a HSE led National Dementia Training Programme is now well established, as is national dementia training available through the National Dementia Services Information and Development Centre, it is of some concern that only about one third of HSE providers reported that all their nursing staff and HCAs had undergone dementia training. A recommendation arising from this survey is that all staff working in SCUs should undertake regular training.
3. Training needs to be on going and appropriately funded thereby allowing dementia specific long-term care facilities back-fill positions when staff are off the premises.
4. In particular all providers need to ensure that all rather than some staff undertake dementia specific training.

Policy on End of Life Care

A total of 48 respondents (89%) gave detailed information about their end of life (EOL) policy. Four others said the SCU had some form of policy and two others failed to answer the question. The analysis of at times lengthy and rich narratives, revealed several common themes, which are described in the section below.

The involvement of family members at end of life

Twenty two respondents (40%) mentioned the importance of involving family members in the EOL care of their relatives:

“Within one month of admission, all residents and their families are engaged in end of life decisions using priorities for care.”

“Families are encouraged to stay overnight. Care is based on wishes and preferences of the individual if known and the family.”

“We provide end of life care for all residents according to their wishes and the family’s wishes.”

Nine of these same respondents referred to establishing and recording EOL care plans based on residents and family members’ wishes. One respondent very proud of the approach adopted commented:

“We have an identifiable form placed in residents’ case notes which visiting doctors see and become aware of. It is photocopied in the event of the resident having to transfer to hospital. Residents’ wishes or best interests are identified and signed off as having been discussed with family/residents/representative, by GP and DON. Works really well!”

Palliative care

A second key theme identified in the data on end of life care policy was palliative care. Thirteen respondents referred to this and nine said that the unit liaised with and had access to specialist palliative care services. Another respondent referred to using a ‘hospice philosophy’ in their approach to EOL care and two others referred to being ‘hospice friendly’ homes.

Accordingly while the provision of palliative care was an important element of EOL care in around 25%²⁰ of all SCUs, one respondent pointed out that SCUs could meet resistance if they seek to adopt a palliative approach:

“We are trying to promote palliative care sentiments but some relatives still expect full medical interventions.”



²⁰ This does not include the SCUs that reported they accessed specialist palliative care services.

Dignity Respect and Person-Centred Care

A third theme emerging in the rich narrative and cited by eight respondents was that of dignity and respect. Typical answers here included:

"All our residents are treated with dignity and respect according to their wishes..."

"All residents have the right to privacy and dignity at end of life."

Four respondents talked about providing holistic care that staff tailored to residents' individual needs, three others mentioned the importance of the autonomy of the dying resident and another three respondents referred to pain control.

Several others reported on the importance of residents being cared for at EOL by staff who know them and were familiar with their ways:

"The resident is cared for by staff who know them and their needs."

"We care for them in their own 'HOME' where EOL care is required using the same staff who cared for them all along".

Those few who did not specifically refer to EOL care plan referred to EOL care being individually tailored:

"Residents with dementia receive EOL care and support that is individualised to their needs, known wishes, preferences, values and beliefs."

Similarly, EOL care was described as:

"A continuation of our person centred ethos of care".

The Relocation of Residents with Dementia at End of Life

Three respondents (all HSE) said their normal practice was to transfer a resident dying with dementia to another facility. In these units it seems that the provision of EOL care was not routine.

"Following assessment and consultation with next of kin, transfer to a long stay unit where end of life care can be given, with access to the homecare team if required" (HSE).

"Although we have at times maintained the resident in the unit – the level of care and dependency can be difficult to balance" (HSE).

..."if a resident becomes unwell and we feel that end of life is within 2-4 weeks we will not transfer resident out." (otherwise at end of life the resident is relocated) (HSE).

Four others (two private, one public and one voluntary) reported that EOL care was only provided in certain circumstances:

“Residents requiring end of life care within the nursing home may be transferred to a general unit for privacy” (Private).

“If at all possible the clients remain in X” (HSE).

“Our residents die in place in so far as reasonably practicable” (Voluntary).

Overall the data suggest that SCUs that establish an EOL care plan view this as an integral part of person-centred care and a means to ensuring that residents’ and their families’ wishes are identified and respected as far as possible.

Summary and Recommendations

1. Most respondents saw EOL care as an extension of the person-centred philosophy underpinning all care practice within SCUs.
2. An unexpected finding is that as many as seven SCUs reported that they either sometimes or always transferred their residents with end stage dementia from the SCU to either an acute care setting or to a general nursing home. Whilst such a policy cannot be endorsed, it may well reflect demand for scarce SCU beds.
3. End of life care should as far as possible be provided in SCUs, and the latter should operate an ageing/dying in place, policy for PwD.

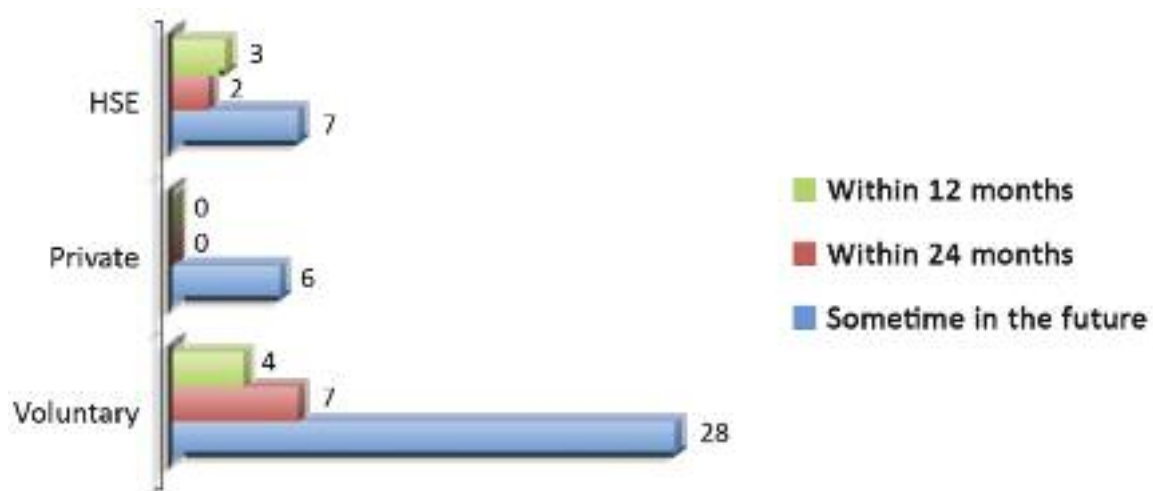


Plans to Develop a SCU in the Foreseeable Future

Finally, the 415 respondents who currently offered no dementia specific residential care were asked if it was their intention to open a SCU in the future. Figure 17(a) shows that only 57 (14%) stated they planned on establishing an SCU in the future. Analysis revealed that most of these were situated either in Leinster (N=26) or Munster (N=18).

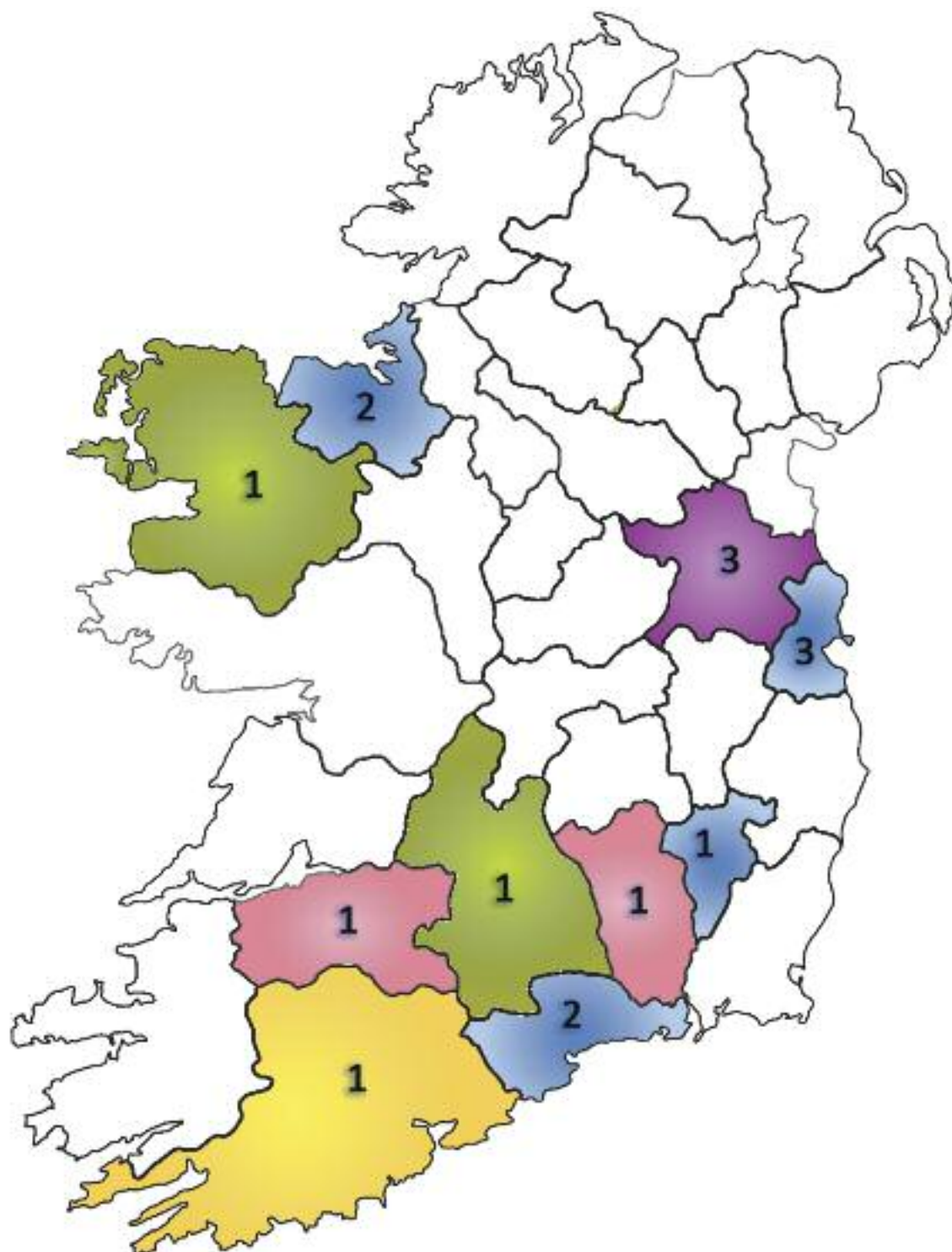
The majority of respondents were vague about when exactly these new SCUs might be developed and a total of 41 (28 private; seven HSE and six Voluntary) claimed it would be sometime in the future'. Nine others (seven private and two HSE) said they would open SCUs within two years and seven (four private and three HSE) reported that they would open SCUs within the next 12 months.

Figure 17(a): Intentions of Nursing Homes to open SCUs at a future date (N=57)



These results suggest that only a very small proportion of all nursing homes, plan on developing SCUs in the foreseeable future and most of these nursing homes are private.

Figure 17(b): Location of Nursing Homes planning to open SCUs in the next 12-24 months



Summary and Recommendations

1. In planning future specialist long-term care services for people with dementia in Ireland, data on future estimated prevalence rates of dementia need to be considered.

DISCUSSION

The survey has generated a wealth of valuable data on Irish nursing homes which provide long-term care to older people especially those with dementia. It has identified a total of 602 long-term residential care facilities across the ROI, of which 469 (78%) responded to the survey. Amongst these and based on a broad definition of a SCU, some 54 (11%) claim they have a SCU. Of those currently not offering SCU (N=415) results also show that only a small proportion (circa 14%) plan on developing SCUs in the foreseeable future.

The survey has revealed considerable inequities across the country regarding the location of SCUs, and much diversity regarding the number of PwD in residence therein. The majority are not found in cities but rather SCUs tend to be situated in rural areas and towns. The average number of PwD across all SCUs is estimated to be 19, a figure consistent with earlier Irish data but way in excess of that recommended by best practice guidelines.

Our analysis has distinguished between the different provider types-public (HSE), private and voluntary (not-for-profit) SCUs. It has identified that the private sector constitutes the dominant provider of both general and dementia specific long-stay residential care. However in drawing this distinction, it must be recognised that the vast majority of nursing home beds for all provider types are funded through the NHSS, administered by the HSE and require means tested payments from the individual based on income and assets.

Previous research has demonstrated the higher dependency needs of residents in public long-stay residential facilities which necessitates a more highly skilled staff mix and in particular a higher ratio of nursing staff (PA Consulting Group, 2009). It has been argued that the higher dependency needs of these residents accounts at least in part, for the significantly higher average weekly payment rates made to the public sector in respect of residents compared to payments made to support residents in private facilities (BDO, 2014). More recently it has been shown that the overall dependency level of residents in all long-stay facilities has increased (BDO, 2014). The Department of Health Long-Stay Activity Statistics for 2012 revealed that a significant proportion (63.7%) of those cared for in private facilities now also have high or maximum dependency levels (Department of Health, 2014, p.23). This may well be due to the fact that the private sector as confirmed by this survey's findings, appears to be the main provider of specialist dementia care and is delivering at times complex care to people with very high dependency needs.

Despite the fact that the private sector provides the main bulk of specialist dementia care, current weekly rates agreed with the NTPF are not differentiated on the basis of individual residents' dependency needs and private providers receive significantly lower average weekly rates per resident compared with public providers. This policy is inherently unfair and flawed and needs to be reformed. In this context and in future years, it is hoped that the Single Assessment Tool will help to facilitate a revised funding model for long stay residential care in the ROI.²¹

The inequities in the Irish system are further compounded by the fact that SCUs are expected to comply with a number of supplementary criteria²² likely to result in additional capital and revenue costs, yet no provision currently exists for higher weekly payments to be made from the NTPF for residents with dementia in SCUs. Accordingly, while more than six out of ten SCUs identified in this survey are privately operated, no financial incentive exists for them to provide this type of care. It would seem that some private operators have responded to a market demand despite the absence of any real financial incentive to deliver this form of complex care.

²¹ In Australia where most nursing homes are public, Commonwealth funding for long-term residential care is based on residents' dependency levels, irrespective of provider type. In the context of dementia, Australian Commonwealth funding has in the past been apportioned according to the type of challenging behaviours exhibited with additional funding set aside for residents who manifest behaviours considered to require more intensive care. (Australia Government, 2013). However this policy has more recently been terminated due to severe expenditure cuts (www.fightdementia.org.au/statement-cessatio-of-the-dementia-and-severe-behaviours-supplement.aspx).

²² This is in addition to the HIQA regulations which apply to all nursing homes (HIQA, 2009).

International best practice recommends that dementia specific SCUs should be domestic like and small scale, catering for no more than about 10 residents (Brawley, 2001; Habell, 2012; Verbeek, 2011). Based on this norm, our findings (70% of these SCUs accommodating 11 or more residents) demonstrate how the vast majority fail to comply with best practice design principles. The supplementary HIQA criteria for SCUs stipulate that newly built dementia-specific residential care units '*are configured in such a way*' that residents are cared for in groups of ten or less (HIQA, 2009, p.59). In the light of the additional costs involved in providing good dementia care, it is not surprising to note that the size of most of the SCUs identified in our survey, was considerably larger than that recommended by best practice. Only nine SCUs (17%) had ten or fewer residents. Findings also showed that a small minority of the SCUs (N=4) have adopted a configuration, which groups residents into a number of separate homes. The adoption of this approach might allow SCUs to care for residents in smaller groups in accordance with best practice.

Irish regulations which apply to all residential care settings for older people require that 80% of residents are accommodated in single bedrooms in newly built facilities, new extensions, and facilities registered for the first time (HIQA, 2009). These regulations also stipulate the minimum amount of usable floor space to be provided. As a design feature underpinning best practice in dementia care, (Judd et al. 1998) identify the provision of single rooms of adequate size to hold plenty of personal belongings and HIQA criteria for SCUs also stipulate that newly built units should display features, characteristic of a domestic setting with separate rooms for separate functions. All units are required to manage noise and visual stimuli, and to create an environment, which promotes orientation and independence. Our results show that while the design of private SCUs largely complied with accepted best practice, this was not the case for SCUs in the public and voluntary sector. This finding is not unexpected as the number of private nursing homes has expanded rapidly since the late 1990s, (McEnery, 2007) and consequently private nursing homes are more likely to be recently built and purpose-built. The deficits in the physical design of SCUs in the public and voluntary sector are of concern, as non-compliance with regulatory standards could result in the closure of SCUs and further reliance on the private sector.

The survey results regarding the admission policies of SCUs have raised unexpected findings. Most notable is the restrictive admission policies of publicly operated SCUs, given the latter receive high payments and are expected to be providing a maximum level of care. Of particular concern is the finding that over two thirds (69%) of HSE operated SCUs, compared with 18% of private facilities, require all new in-coming residents to '*be independently mobile*'. In our view, such an admission criterion is inconsistent with the alleged orientation of public nursing homes and SCUs towards persons of high and maximum dependency.

Overall, responses to the question on EOL care provide positive affirmation of the person centred philosophy underpinning the vast majority of the SCUs identified in this survey. Many respondents provided detailed answers to this question and the data clearly reflect the staff's desire to respect the wishes of residents and their families and to address the holistic needs of residents at EOL. Some respondents also recognised that EOL care was contingent on circumstances and could not always be provided. However it was disappointing to note that the standard practice in three public units was to transfer out residents in need of EOL care and in four other SCUs no policy was in place to ensure that end of life care occurred within the same unit. Transferring residents dying with dementia to other long stay care or acute facilities is not in compliance with best practice and is probably a further reflection of the excessive demand for SCU beds and staff efforts to free up beds for those most need.

CONCLUSION

The results from this national survey of nursing homes and SCUs support earlier findings (O'Shea & O' Reilly, 1999). They demonstrate that the private sector is the main provider of specialist long-term care to PwD in the ROI whilst the public sector is more likely to be the main provider of residential respite care in specialist facilities. This is despite the fact that private providers are expected to comply with specific dementia-related criteria without receiving any additional payments from the NTPF to help defray costs. In this context, additional costs including those of providing allied health services and other extra supports are likely to be borne by family members over and beyond the 80% income payment and 7% of assets required under the NHSS. Our findings would lead us to believe that the complex and high dependency needs of PwD in SCUs now need to be more realistically reflected in better resource allocation to such facilities. In particular, payments made through the NTPF need to be commensurate with level of care, staff training and skill mix and type of non-pharmacological interventions expected to be delivered. More funding needs to be allocated to private nursing homes in recognition of the specialist services needed to support PwD including those with behaviours that challenge.

The results of this survey show that across the ROI, SCUs have evolved in an arbitrary, fragmented and uncoordinated manner. Those privately operated seem to have been established based on the interests of individual providers rather than in response to rational planning based on need. While it might have been expected that public SCUs would be developed in a more structured fashion, the large gaps in service provision, especially in the Leinster area, suggest that this has not been the case. The high demand for such facilities particularly in Leinster reflects the current arbitrary dispersal pattern of SCUs. The age and condition of a large number of these public nursing homes and the lack of significant capital investment in same, raises critical questions about their suitability and sustainability for future dementia-specific care.

The location of nursing homes in rural areas has previously been the subject of inquiry and criticism. There have been calls for national design and location standards to regulate nursing home locations (An Taisce, 2011). Our findings suggest that there is still a preponderance of SCUs found in rural areas. Our data shows that there are as many SCUs located in the countryside (N=23) as in towns (N=23). Only eight are located in cities. The cost of development land has been linked to the shortage of nursing homes in Dublin and other major urban areas (Buckley, 2014) and this may also go some way towards explaining the location pattern of SCUs. The finding that the HSE is the principal provider of respite care within SCUs needs careful consideration, particularly given the HSE's mandate "*that the most effective use is made of limited resources*" (HSE, 2012, p.29). It may well mean that in the future respite care for PwD will be contracted out to private providers.

In conclusion, calls for a significant increase in the provision of long-term residential care for older people in Ireland have recently been made (BDO, 2014) and appeals made to ensure that the new government and philanthropic funding soon to be invested in home care and other services will not result in a further shortage of nursing home beds. Concerns have also been raised about the expected increase likely to be witnessed in the numbers of older people especially the old-old, those aged over 85. What has been omitted from this debate is the fact that many of these octogenarians/nonagenarians will have dementia and may ultimately need specialist long-term care. Useful age-gender dementia prevalence estimates have recently been generated for Ireland for the period leading up to 2041 (Pierce, Cahill & O' Shea, 2014). Linking these estimates with some of the key findings identified in this report would help policy makers and health service providers plan long-term residential care services including specialist dementia care services more rationally.

However, whilst the planning of such specialist long-term care services for PwD can be undertaken relatively easily, other more challenging philosophical, ideological, economic and socio-political questions need to be addressed. These include questions about the ideal size of SCUs, the need for a stronger evidence base about their effectiveness and how they can impact on quality of life; good cost benefit analysis and more transparent admission and discharge policies. There is also a need for a European consensus to be developed on what constitutes a SCU, since clearly and based on our studies' findings, much confusion exists even amongst service providers themselves about this concept, some interpreting any segregated dementia care environment (even nightingale wards) to mean specialist care and calling these units, SCUs.

In conclusion, a dementia movement is now in evidence across the ROI and Ireland's' first five-year National Strategy was launched in December 2014. We would argue that there is no better time than now to bring together a coalition of stakeholders in the dementia field to debate these important issues and to arrive at a true consensus about the fair allocation of public resources for the specialist long-term care of PwD. The time for action is now.





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