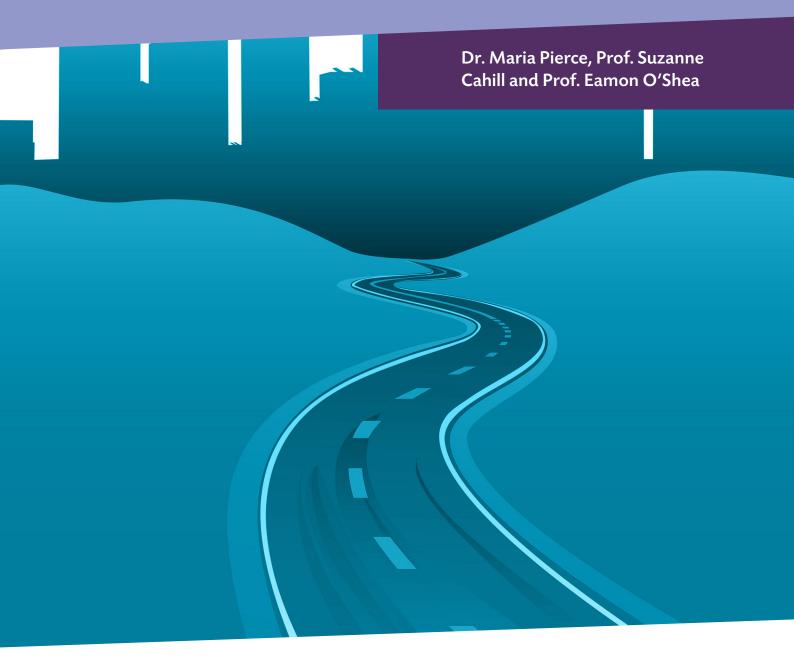
Prevalence and Projections of Dementia in Ireland, 2011 – 2046







A copy of this report can be downloaded free-of-charge from www.genio.ie.

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#### **Foreword**

This report provides detailed estimates of the likely growth in the number of people with dementia over the next 20 to 30 years in Ireland. Dementia is closely associated with age - the older people get, the more likely they are to develop dementia and increasing age remains the single strongest risk factor for dementia. We know that the population of Ireland is ageing and so we are likely to have more people with dementia who will need support and services in the future. How many people will have dementia? Where will they be living? This report provides estimates by county and by age group so that we can be ready as a country and as local communities and plan to have appropriate supports and services in place. The data in this report informed the development of the National Dementia Strategy which is due to be published shortly.

The increase in the number of people with dementia in the coming years will be significant and could be as high as 132,000 people by 2041, almost three times the current estimate of 47,000 in 2011. This increase undoubtedly presents a challenge to policy-makers and service planners but it also presents an opportunity to consider the services we currently provide for people with dementia and the adjustments that we will have to make to meet increased need in the future.

These estimates are based on Census data and population forecasts prepared by the Central Statistics Office. The population forecasts are used by all state agencies to plan services into the future. How many schools will we need? Where should we build our roads? It makes sense for the same numbers to be used in planning our health services into the future. The dementia prevalence rates applied to the Census data and population forecasts are based on combined data from several studies undertaken across Europe, given the fact that we do not have specific prevalence data for Ireland. Combining data from many countries allows the breakdown of prevalence by gender and age groups which is much more useful than one single prevalence figure.

Because they are estimates, we cannot know for sure how accurate these figures are, with some very recent studies suggesting that international dementia prevalence rates might be modestly lower now than previously thought. But even if existing prevalence rates are an overestimate, the number of people with dementia in Ireland is still likely to *at least double* over the next thirty years. As estimates, the numbers should be treated with caution as a planning tool and neither reported sensationally nor ignored. But, given demographic ageing in Ireland, all the evidence points to a significant increase in the number of people with

dementia in the coming decades. We must also remember that behind these figures exist the human faces of all those living with this illness, their family members and friends.

I would like to acknowledge the excellent work of the three authors; Dr. Maria Pierce, Prof. Suzanne Cahill and Prof. Eamon O'Shea and the support of the Atlantic Philanthropies in funding this work. I hope this work will be widely used in the coming years to plan early and wisely for the supports and services that will enable people with dementia to have full participative lives in our communities in the coming decades.

Dr. Fiona Keogh, Director of Research and Evidence, Genio

# **Table of Contents**

| 1. | Intr  | oduction  | . 5 |
|----|-------|---|-----|
| 2. | Met   | thodology   | . 6 |
|    | 2.1   | National level estimates and projections                                      | . 6 |
| :  | 2.2   | Local level estimates   | . 8 |
| 3. | Nat   | ional estimates of dementia for 2011  | . 9 |
| 4. | Pro   | jected population of people with dementia, 2011-2046                          | 11  |
| 5. | Nev   | w county estimates of dementia for 2011                                       | 15  |
| 6. | Der   | mentia Consortium project areas estimates and projections                     | 16  |
| Re | feren | ces   | 24  |
| Αp | pend  | ix 1. Prevalence of dementia in Kinsale - DEDs used in estimates              | 27  |
| Αn | pend  | ix 2. Prevalence of dementia in Stillorgan/Blackrock - DEDs used in estimates | 28  |

# **List of Tables**

| Table 1:  | EuroCoDe age and gender-specific prevalence rates of dementia   |
|-----------|---|
| Table 2:  | Estimates of number of people with dementia in Ireland, 2011  |
| Table 3:  | Estimate of the number of people with dementia aged 65 years and over living in the community, 2011                   |
| Table 4:  | Estimate of number of people with dementia (all ages) living in the community in Ireland, 2011                        |
| Table 5:  | Estimated number and projected growth in the number of people with dementia in Ireland by age group, 2011-2046 (M2F1) |
| Table 6:  | Estimated number and percentage of persons with dementia in Ireland by County and Province, 2011                      |
| Table 7:  | Estimated number of people with dementia in County Mayo, 2011   |
| Table 8:  | Estimated number of people with dementia in South Tipperary, 2011   |
| Table 9:  | Estimated number of people with dementia in Stillorgan/Blackrock, 2011  |
| Table 10: | Estimated number of people with dementia in Kinsale, 2011   |

# List of Figures

| Figure 1: | EuroCoDe dementia prevalence rates   |
|-----------|--|
| Figure 2: | Actual and projected population of older people by age group in Ireland, 2011-2046 (M2F1)                |
| Figure 3: | Estimated and projected number of people with dementia in Ireland and living in the community, 2011-2046 |

#### 1. Introduction

Worldwide, the number of people with dementia is currently estimated to be 44 million and expected to reach approximately 76 million by 2030 and 135 million by 2050 (Prince et al., 2013). Looking at the prevalence and projections of dementia in Ireland makes it possible to identify the size of the population that is currently affected by the condition, the proportion that might in the future be affected, and to ascertain what proportion of the population with respect to age and gender is and will be affected. Accurate up-to-date estimates are required for policymaking and planning for dementia services. Undertaking population-based epidemiological studies, whilst ideal for estimating the prevalence of dementia, is rarely an option because they are time-consuming, complex and costly (Gordon, Carter and Scott, 1997). Like several countries across Europe (Kiejna et al., Misiak et al., 2013), Ireland continues to lack reliable epidemiological data on dementia prevalence and in the absence of such data, the mapping of dementia prevalence rates onto known population data from the Census of Population in Ireland makes it possible to estimate numbers of people with dementia. Earlier estimates of dementia in Ireland based on EURODEM and EuroCoDe prevalence rates, linked to European population-based studies, are available for the years 2002 (O'Shea, 2007) and 2006 (Diaz-Ponce, 2008; Cahill, O'Shea and Pierce, 2012; Pierce, Cahill and O'Shea, 2013). These estimates now need to be updated, hence this report.

This report provides an update on current prevalence and future projections of dementia in Ireland for the year 2011 using the EuroCoDe dementia prevalence rates. The methodology used to prepare these estimates and projections is outlined in **Section 2**. **Section 3** provides an update of national estimates of the current number of Irish people with dementia (including those with early onset dementia) and for each of the 26 counties of Ireland. These estimates are based on the 2011 Census of Population. Estimates of where people with dementia are likely to be living are included, with information given on the prevalence of dementia in the community versus residential long stay care. **Section 4** provides estimates on the projected numbers of people with dementia in Ireland for the years 2011-2046. Such data is useful for informing the future planning of services. **Section 5** moves the focus of the report to a local level and presents estimates of the current and future numbers of people with dementia for the four areas where the Genio Dementia Project sites are located. These estimates will provide the relevant epidemiological context for the new Genio initiatives. It is hoped that the data can be used to help identify people with dementia at a primary and community care level and for future planning of services in these areas.

# 2. Methodology

## 2.1 National level estimates and projections

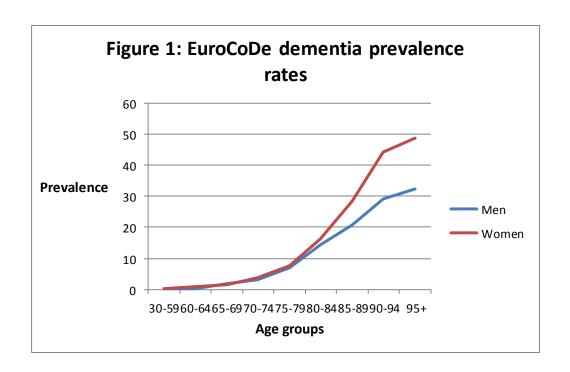
The revised numbers of people with dementia for Ireland were generated by applying EuroCoDe (Alzheimer Europe, 2009) dementia prevalence rates (as shown in Table 1 and Figure 1) to data from the Census of Population 2011. Data from the latter was first disaggregated by sex and age groups. As EuroCoDe does not specify prevalence rates for the age category 30-59, the relevant EURODEM gender-specific dementia prevalence rate for the 30-59 age group was instead applied.

Table 1: EuroCoDe age and gender-specific prevalence rates of dementia

| Age range | Men   | Women |
|-----------|-------|-------|
| 30-59†    | 0.2%  | 0.1%  |
| 60-64     | 0.2%  | 0.9%  |
| 65-69     | 1.8%  | 1.4%  |
| 70-74     | 3.2%  | 3.8%  |
| 75-79     | 7.0%  | 7.6%  |
| 80-84     | 14.5% | 16.4% |
| 85-89     | 20.9% | 28.5% |
| 90-94     | 29.2% | 44.4% |
| 95+       | 32.4% | 48.8% |

Source: EuroCoDe age/gender-specific prevalence rates of dementia. 10

Notes: † As EuroCoDe does not specify prevalence rates of dementia for 30-59 age group, EURODEM prevalence rates of dementia for this age group by gender as reported by Hofman *et al.*, Tables 4, 5 and 6, pp. 742-44, were used. <sup>16</sup>



Following the methodology used by Connolly et al. (2012), estimates of the number of people living in the community with dementia were derived by applying the AGECAT dementia prevalence rates for those aged 65 and over (Lawlor et al., 1994) to the population estimates based on the Census of Population 2011. To estimate those aged less than 65 with dementia living in the community we drew on the work of Haase (2005) who assumed that that approximately 85% of all younger people with dementia live in the community.

Estimates of future numbers of people with dementia in Ireland for the period 2016 to 2046 drew on the most recently available population projections from the CSO.<sup>4</sup> The latter provides population projections at five year intervals between 2016 and 2046 for six combinations of fertility and migration assumptions (M1F1, M1F2, M2F1, M2F2, M3F1, M2F3), disaggregated by gender and five yearly age groups. Careful consideration was given to which assumptions would be used for the purpose of generating these new estimates given that demographic trends have changed in recent years. One set of projections – that is the M2F1 - was selected on which to base the calculations. <sup>1</sup> These were chosen as they reflected best what we believe are the likely demographic trends. It must be remembered, however, that margins of error are likely to be significant, even with best estimates, given the experience of previous population projections.

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<sup>&</sup>lt;sup>1</sup> Future estimates of the number of people with dementia would have yielded the same if the M2F2 assumptions had been used.

The M2F1 projections are based on the assumption that net migration will return to positive by 2018 and will rise thereafter to +10,000 by 2021 (M2 assumption) and the highest fertility assumption (F1 assumption), that is, the assumption that the total fertility rate will remain at the level observed in 2010 of 2.1 for the lifetime of the projections up to 2046.

EuroCoDe prevalence rates of dementia were applied to this set of projections (M2F1) to estimate the number of people with dementia by age group at five yearly intervals from 2016 to 2046. The future estimates of people with dementia generated by the M2F1 assumptions are mid-range. In other words, the future estimates of people with dementia would have been lower if the M1F1 or M1F2 assumptions had been used and higher if the M3F1 or M3F2 assumptions had been used.

#### 2.2 Local level estimates

To generate estimates of people with dementia at a county level, the number of men and women in different age groups were calculated for each of the 26 counties. EuroCoDe age and gender-specific prevalence rates were then applied to this data. For sub-county level estimates, the number of men and women in these different age groups were calculated for each of the DEDs making up the Sillorgan/Blackrock and Kinsale areas, <sup>2</sup> using the Census Small Area Statistics and the Interactive Mapping Tool option. EuroCoDe age and gender-specific prevalence rates were then applied to this data.

New estimates of the future number of people with dementia were generated for each of the four Genio Dementia Project areas based on projected increases in the population of people with dementia for the country as a whole (Cahill, O'Shea and Pierce, 2012; Pierce, Cahill and O'Shea, 2013).

The new prevalence estimates for the respective areas can be compared against the common database (when they become available from four local Genio database on service users from all four sites), to ascertain what proportion of those people known to have dementia are actually availing of the new service initiatives.

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<sup>&</sup>lt;sup>2</sup> See Appendices 1 and 2 for DEDS used.

#### 3. National estimates of dementia for 2011

Table 2 shows that for 2011 the number of people with dementia in Ireland was estimated to be 47,849 a figure representing an increase of approximately 6,000 people from the 2006 estimate of 41,740. This increase is to be expected since age is a primary and immutable risk factor for dementia, and unless a cure is found, there will be a growth in the number of people with dementia as the population ages. This growth is in line with earlier forecasts, which had estimated that there would be 47,983 people with dementia in Ireland in 2011 (Cahill, O'Shea and Pierce, 2012: 41; Pierce, Cahill and O'Shea, 2013).

Table 2: Estimates of number of people with dementia in Ireland, 2011

| Age groups  | Total Po      | pulation  | Persons with d                     | ementia (estim  | ated using |  |
|-------------|---------------|-----------|------------------------------------|-----------------|------------|--|
|             | (Census 2011) |           | EuroCoDe (2009) age/gender-related |                 |            |  |
|             |               |           | dementi                            | a prevalence ra | ites)      |  |
|             | Men           | Women     | Men                                | Women           | Total      |  |
| 30-59 years | 953,715       | 959,396   | 1907¹                              | 959¹            | 2,866      |  |
| 60-64 years | 109,869       | 108,917   | 220                                | 980             | 1,200      |  |
| 65-69 years | 86,298        | 87,340    | 1,553                              | 1,223           | 2,776      |  |
| 70-74 years | 63,476        | 67,714    | 2,031                              | 2,573           | 4,604      |  |
| 75-79 years | 46,631        | 55,405    | 3,264                              | 4,211           | 7,475      |  |
| 80-84 years | 28,423        | 41,690    | 4,121                              | 6,837           | 10,958     |  |
| 85-89 years | 13,591        | 26,296    | 2,841                              | 7,494           | 10,335     |  |
| 90-94 years | 4,155         | 10,722    | 1,213                              | 4,761           | 5,974      |  |
| 95+         | 740           | 2,912     | 240                                | 1,421           | 1,661      |  |
| Total       | 1,306,898     | 1,360,392 | 17,390                             | 30,459          | 47,849     |  |

Source: CSO (2011) Census of Population – Profile 2: Older and Younger: An Age profile of Ireland Tables 7A-7C, pp. 47-49; Persons with dementia estimated by application of EuroCoDe gender/age-specific prevalence rates.

<sup>&</sup>lt;sup>1</sup> As EuroCoDe does not specify early onset prevalence rates, EURODEM early onset dementia prevalence rates were used instead.

Table 2 shows interesting gender differences in prevalence of dementia. Dementia affects more women than men, which is to be expected given that there is a higher age-specific prevalence rate for women than men. In Ireland, almost two-thirds of those affected by dementia are women.

Table 2 also shows the age distribution of dementia. Whilst the condition is often considered to be a condition of relevance only to older people, the table shows that for the year 2011, 4,066 younger people (that is, people under 65 years of age) are estimated to be affected by the condition.

Table 3 shows that there were an estimated 26,413 people with dementia aged 65 and over living in the community in 2011. Based on the assumption that 85% of younger people with dementia live in the community, an estimated 3,456 of the 4,066 people aged less than 65 with dementia were living in the community in 2011 (see Table 4). There are, therefore, almost 30,000 people with dementia estimated to be living in the community in 2011.

Table 3: Estimate of the number of people with dementia aged 65 years and over living in the community, 2011

| Age groups        | No. of people<br>living in the<br>community <sup>1</sup><br>(Census 2011) | Prevalence rates <sup>2</sup> (Lawlor et al., 1994) | Persons with dementia over<br>65 years living in the<br>community (estimated using<br>Lawlor et al.'s AGECAT<br>prevalence rates) |
|-------------------|---|---|---|
| 65-69 years       | 164,134   | 1.6   | 2,626   |
| 70-74 years       | 122,676   | 4.8   | 5,888   |
| 75-79 years       | 93,087  | 2.1   | 1,955   |
| 80-84 years       | 60,328  | 10.4  | 6,274   |
| 85 years and over | 42,229  | 22.9  | 9,670   |
| Total             | 482,454   |   | 26,413  |

#### Notes:

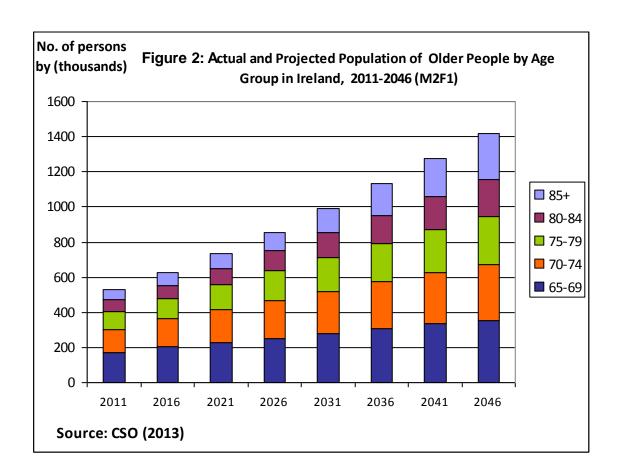
<sup>&</sup>lt;sup>1</sup> The number of people living in the community was based on those identified in the Census of as those living in a private household. In the census, a private household is defined as either one person living alone or a group of people (not necessarily related) living at the same address with common housekeeping arrangements. A household can contain one or more families.

Table 4: Estimate of number of people with dementia (all ages) living in the community in Ireland, 2011

| Persons   | Number | Proportion of total population with dementia |
|---|--------|--|
| People with dementia aged 65 and over living in the community   | 26,413 | 60%  |
| 85% of the 4,066 people with young onset dementia (i.e. aged 30-64) are estimated to be living in the community (Haase, 2005) | 3,456  | 15%  |
| Total number of people with dementia living in the community  | 29,869 | 63%  |

# 4. Projected population of people with dementia, 2011-2046

Figure 2 shows the population projections for older people (aged 65 years and over) for the years 2016 to 2046 drawing on those recently prepared by the CSO (2013) using the M2F1 assumptions. It shows that the number of people aged 65 and over is expected to increase significantly in the coming decades from 531,600 in 2011 to almost double (991,000) in 2031.



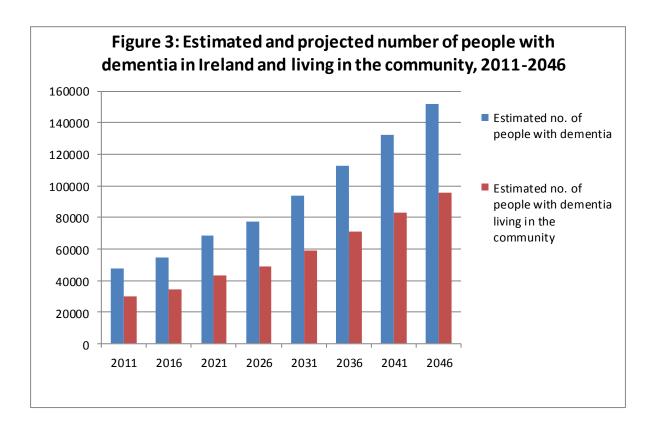
Commensurate with the ageing of the population, Table 5 shows estimates of the projected growth in the number of people with dementia by age group in Ireland at five yearly intervals from 2011 to 2046. These estimates were calculated by mapping the EuroCoDe prevalence rates onto the most recent CSO population projections (CSO, 2013). The projections show that the number of people with dementia in Ireland is expected to double over the next 20 years from the current estimate of around 47,000 people to an estimated 94,000 in 2031.

Table 5: Estimated number and projected growth in the number of people with dementia in Ireland by age group, 2011-2046 (M2F1)

| Age   | 2011   | 2016   | 2021   | 2026   | 2031   | 2036    | 2041    | 2046    |
|-------|--------|--------|--------|--------|--------|---------|---------|---------|
| group |        |        |        |        |        |         |         |         |
| 30-59 | 2,866  | 2,935  | 2,934  | 2,869  | 2,854  | 2,864   | 2,889   | 2,991   |
| 60-64 | 1,200  | 1,301  | 1,449  | 1,615  | 1,738  | 1,906   | 2,044   | 1,896   |
| 65-69 | 2,776  | 3,287  | 3,827  | 4,020  | 4,485  | 4,876   | 5,315   | 5,645   |
| 70-74 | 4,604  | 5,532  | 7,013  | 7,442  | 8,367  | 9,378   | 10,211  | 11,188  |
| 75-79 | 7,475  | 8,213  | 11,298 | 12,560 | 14,055 | 15,928  | 17,968  | 19,692  |
| 80-84 | 10,958 | 12,265 | 16,099 | 17,868 | 22,348 | 25,364  | 29,102  | 33,196  |
| 85+   | 17,970 | 21,260 | 25,595 | 31,085 | 40,195 | 52,512  | 64,654  | 77,549  |
| Total | 47,849 | 54,793 | 68,216 | 77,460 | 94,042 | 112,828 | 132,182 | 152,157 |

Note: Estimates for 2011 based on Census of Population 2011. Projections for 2016 to 2041 based on CSO (2013) Population and Labour Force Projections, 2016-2014, Stationary office, Dublin, Table 3, page 40 and EuroCoDe (2009) Age and gender specific dementia prevalence rates.

Figure 6 below shows that the number of people with dementia living in the community is likely to double in the next 20 years to approximately 60,000 in 2031.



# 5. New county estimates of dementia for 2011

Table 6 shows clear regional variation in estimated dementia prevalence rates across Ireland, with counties in the West of Ireland (Connaught) with the highest proportions of people with dementia (1.24%) and the counties in the Eastern part of the country (Leinster) conversely with the lowest proportion of people with dementia (0.95%).

Table 6: Estimated number and percentage of persons with dementia in Ireland by County and Province, 2011

| Province  | County                 | Population<br>(all ages) | Persons<br>with<br>dementia | % of total county/province population |
|-----------|------------------------|--------------------------|-----------------------------|---------------------------------------|
| Leinster  | Carlow                 | 54,612                   | 543                         | 0.99%                                 |
|           | Dublin                 | 1,273,069                | 12,498                      | 0.98%                                 |
|           | Kildare                | 210,312                  | 1,453                       | 0.69%                                 |
|           | Kilkenny               | 95,419                   | 1,057                       | 1.11%                                 |
|           | Laois                  | 80,559                   | 711                         | 0.88%                                 |
|           | Longford               | 39,000                   | 434                         | 1.11%                                 |
|           | Louth                  | 122,897                  | 1,198                       | 0.97%                                 |
|           | Meath                  | 184,135                  | 1,400                       | 0.76%                                 |
|           | Offaly                 | 76,687                   | 790                         | 1.03%                                 |
|           | Westmeath              | 86,164                   | 904                         | 1.05%                                 |
|           | Wexford                | 145,320                  | 1,524                       | 1.05%                                 |
|           | Wicklow                | 136,640                  | 1,274                       | 0.93%                                 |
|           | Total (Leinster)       | 2,504,814                | 23,786                      | 0.95%                                 |
| Munster   | Clare                  | 117,196                  | 1,282                       | 1.09%                                 |
|           | Cork                   | 519,032                  | 5,425                       | 1.05%                                 |
|           | Kerry                  | 145,502                  | 1,848                       | 1.27%                                 |
|           | Limerick               | 191,809                  | 2,013                       | 1.05%                                 |
|           | North Tipperary        | 70,322                   | 848                         | 1.21%                                 |
|           | South Tipperary        | 88,432                   | 1,054                       | 1.19%                                 |
|           | Waterford              | 113,795                  | 1,276                       | 1.12%                                 |
|           | Total (Munster)        | 1,246,088                | 13,746                      | 1.10%                                 |
| Connacht  | Galway                 | 250,653                  | 2,683                       | 1.07%                                 |
|           | Leitrim                | 31,798                   | 441                         | 1.39%                                 |
|           | Mayo                   | 130,638                  | 1,835                       | 1.40%                                 |
|           | Roscommon              | 64,065                   | 893                         | 1.39%                                 |
|           | Sligo                  | 65,393                   | 857                         | 1.31%                                 |
|           | Total (Connaught)      | 542,547                  | 6,709                       | 1.24%                                 |
| Ulster    | Cavan                  | 73,183                   | 851                         | 1.16%                                 |
| (part of) | Monaghan               | 60,483                   | 700                         | 1.16%                                 |
|           | Donegal                | 161,137                  | 1,929                       | 1.20%                                 |
|           | Total (Ulster part of) | 294,803                  | 3,480                       | 1.18%                                 |
| State     | Total                  | 4,588,252                | 47,849                      | 1.04%                                 |

Source: CSO (2012) Census of Population, 2011 SAPS Interactive Tables, CD204 and CD207 [Last accessed February 2014]; Persons with dementia as per EuroCoDe agerelated prevalence rates,

Note: <sup>1</sup> As EuroCoDe does not specify young onset prevalence rates, EURODEM young onset dementia prevalence rates were used instead.

## 6. Dementia Consortium project areas estimates and projections

New estimates of the current numbers of people living with dementia in community and residential long-stay care in each of the four Consortium Dementia Project areas are shown in Tables 6, 7, 8 and 9.

It is estimated that in 2011 there were 1,835 people with dementia living in County Mayo (see Table 6), 1156 of whom are estimated to be living in the community. Presuming that current trends persist, It is projected that there will be 3,633 people with dementia in County Mayo in 2031.

Table 7: Estimated number of people with dementia in County Mayo, 2011

| Age groups  | To       | tal Populati | on       | Person     | s with dementi  | a 2011    |
|-------------|----------|--------------|----------|------------|-----------------|-----------|
|             | (0 0044) |              |          | (estimated | using EuroCo    | De (2009) |
|             | ((       | Census 201   | 1)       | age/ger    | nder-related de | ementia   |
|             |          |              |          | pr         | evalence rates  | s)        |
|             |          | 10/          | <b>-</b> | N.4        | 10/             | <b>T</b>  |
|             | Men      | Women        | Total    | Men        | Women           | Total     |
| 30-59 years | 26,457   | 26,421       | 52,878   | 53         | 26              | 79        |
| 60-64 years | 4,096    | 4,096 3,644  |          | 8          | 33              | 41        |
| 65-69 years | 3,152    | 2,885        | 6,037    | 57         | 40              | 97        |
| 70-74 years | 2,311    | 2,313        | 4,624    | 74         | 88              | 162       |
| 75-79 years | 1,822    | 1,922        | 3,744    | 128        | 146             | 274       |
| 80-84 years | 1,123    | 1,527        | 2,650    | 163        | 250             | 413       |
| 85-89 years | 591      | 1084         | 1675     | 124        | 309             | 432       |
| 90-94 years | 166      | 453          | 619      | 48         | 201             | 250       |
| 95+         | 38       | 152          | 190      | 12         | 74              | 86        |
| Total       |          |              |          | 666        | 1,168           | 1,835     |

It is estimated that in 2011 there were 1,054 in South Tipperary, 664 of whom are estimated to be living in the community. It is projected that there will be 2087 people with dementia in County South Tipperary in 2031.

Table 8: Estimated number of people with dementia in County South Tipperary, 2011

| Age groups  | To     | tal Populati | on     | Persons with dementia (estimated |               |             |
|-------------|--------|--------------|--------|----------------------------------|---------------|-------------|
|             | (6     | Census 201   | 1)     | using EuroCoDe (2009) age/gend   |               | age/gender- |
|             | (0     | Densus 201   | ')     | related de                       | mentia preval | ence rates) |
|             | Men    | Women        | Total  | Men                              | Women         | Total       |
| 30-59 years | 18,419 | 18,015       | 36,434 | 37                               | 18            | 55          |
| 60-64 years | 2,381  | 2,347        | 4,728  | 5                                | 21            | 26          |
| 65-69 years | 1,867  | 1,809        | 3,676  | 34                               | 25            | 59          |
| 70-74 years | 1,438  | 1,468        | 2,906  | 46                               | 56            | 102         |
| 75-79 years | 1,054  | 1,189        | 2,243  | 74                               | 90            | 164         |
| 80-84 years | 707    | 914          | 1,621  | 103                              | 150           | 253         |
| 85-89 years | 316    | 616          | 932    | 66                               | 176           | 242         |
| 90-94 years | 108    | 223          | 331    | 32                               | 99            | 131         |
| 95+ years   | 9      | 39           | 48     | 3                                | 19            | 22          |
| Total       |        |              |        | 400                              | 654           | 1,054       |

It is estimated that in 2011 there were 725 people with dementia in Stillorgan/Blackrock, 557 of whom are estimated to be living in the community. It is projected that in 2031 there will be 1,436 people with dementia in the area.

Table 9: Estimated number of people with dementia in Sillorgan/Blackrock, 2011

| Age groups        | Total Population |        | Persons with dementia (estimated using |                                    |                 |             |
|-------------------|------------------|--------|--|------------------------------------|-----------------|-------------|
|                   |                  | (Con   | sus 2011)                              | EuroCoDe (2009) age/gender-related |                 |             |
|                   |                  | (Cen   | Sus 2011)                              | de                                 | ementia prevale | ence rates) |
|                   |                  |        |  |                                    |                 |             |
|                   | Men              | Women  | Total                                  | Men                                | Women           | Total       |
| 30-59 years       | 8220             | 9221   | 17441                                  | 17                                 | 10              | 27          |
| 60-64 years       | 906              | 1085   | 1991                                   | 2                                  | 11              | 13          |
| 65-69 years       | 751              | 1009   | 1760                                   | 16                                 | 15              | 31          |
| 70-74 years       | 706              | 976    | 1682                                   | 23                                 | 37              | 60          |
| 75-79 years       | 587              | 880    | 1467                                   | 46                                 | 66              | 112         |
| 80-84 years       | 355              | 630    | 985                                    | 63                                 | 119             | 182         |
| 85 years and over | 188              | 506    | 694                                    | 63                                 | 237             | 300         |
| Total (All ages)  | 26,633           | 23,455 | 50,088                                 | 230                                | 495             | 725         |

It is estimated that there were in 2011 approximately 239 people with dementia in the Kinsale area, 151 of whom are estimated to be living in the community. It is projected that in 2031 there will be about 473 people with dementia in the area.

Table 10: Estimated number of people with dementia in the Kinsale area, 2011

| Age groups        | Total Population |       | Persons with dementia (estimated using |                 |       |
|-------------------|------------------|-------|--|-----------------|-------|
|                   | (Census 2011)    |       | EuroCoDe (2009) age/gender-related     |                 |       |
|                   |                  |       | dement                                 | ia prevalence r | ates) |
|                   | Men              | Women | Men                                    | Women           | Total |
| 30-59 years       | 5,621            | 5,871 | 11                                     | 6               | 17    |
| 60-64 years       | 620              | 587   | 1                                      | 5               | 7     |
| 65-69 years       | 451              | 490   | 8                                      | 7               | 15    |
| 70-74 years       | 325              | 376   | 10                                     | 14              | 25    |
| 75-79 years       | 249              | 247   | 17                                     | 19              | 36    |
| 80-84 years       | 162              | 195   | 23                                     | 32              | 55    |
| 85 years and over | 81               | 192   | 19                                     | 65              | 84    |
| Total             | 7,509            | 7,958 | 91                                     | 148             | 239   |

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#### 7. Discussion and Conclusion

Our best estimate is that there are currently around 47,000 people with dementia living in Ireland and this figure is expected to rise to over 130,000 by 2041. This is consistent with the rising occurrence of dementia worldwide.

Estimates presented in this report show that, like in other countries, there is a strong gender gradient in dementia prevalence in Ireland, with dementia affecting many more women than men. This is especially the case in the older age cohorts. There are two possible reasons for this. First, women have a longer life expectancy than men and hence once diagnosed, the duration of dementia in women may be longer than in men. Second, there could be a higher frequency of risk factors for dementia in women, including hormonal and genetic factors, as well as socio-cultural factors such as low level of education (Coley, Berr and Andrieu, 2012). Whatever the reason, the disproportionate numbers of women who may in the future develop dementia highlights the importance of using a gendered analysis to look at dementia and to explore the impact of dementia on women and men, both from the point of view of their being care-recipients as well as caregivers. This is a topic which, according to some experts, remains largely under-researched (Bamford, 2011). It also points to the importance of including a gender dimension, when developing interventions for people with dementia and their family caregivers. Prevalence of dementia among older women will continue to rise due to the ageing of the population, and because higher proportions of older women will be in the oldest age groups where levels of dementia are highest (2009).

In this same context, it is worth noting that a special recent summit on dementia convened by G8 took place in London (December 2013) and during the summit a range of initiatives were announced aimed at tackling dementia.<sup>3</sup> The main outcome from the summit is that leading nations have committed to developing a cure or disease modifying treatment for dementia by 2025. Developing drugs that can reverse the damage caused by dementia once symptoms are severe enough to be able to make a diagnosis may be difficult, but if this does happen, these future projections will then obviously be rendered invalid.

The oldest old (i.e. those aged 80 years and older) make up a high proportion of the estimated population of people with dementia and expertise in caring for this group, many of whom will have coexisting illnesses and disabilities and most of whom are women, is needed. The inclusion of estimates of younger people with dementia in the prevalence

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<sup>&</sup>lt;sup>3</sup> G8 Dementia Summit Declaration, UK G8, London, 11 December 2013 [Available at: <a href="https://www.gov.uk/government/publications/g8-dementia-summit-agreements">https://www.gov.uk/government/publications/g8-dementia-summit-agreements</a>; Last accessed: 07.01.2014].

figures is important for three main reasons. First, these people are particularly disadvantaged in Ireland where there are little or no services specially designed for their age group. The inclusion of these figures reflects what advocacy organisations like the Alzheimer Society of Ireland and dementia experts are confronting on a day-to-day basis trying to meet the complex and unique needs of these younger people across the country. Those working with the Genio Dementia Projects are no exception to this and they likewise are attempting to support this group of people. Second, it can raise awareness that the condition affects younger people and is not confined to older people. This in turn may make it easier for these individuals to get a diagnosis, to confront those health professionals and members of the public who assume that dementia is only relevant to older people, and for advocating for better diagnostic and post-diagnostic supports appropriate to their age. Third, it can have a positive impact on those with young onset dementia who may feel validated and no longer invisible. When, for example, new prevalence data was released in Canada, which included for the first time estimates of people under 65 years with dementia (Dudgeon, 2012), this was considered by them as empowering.

Similarly to many other industrialised countries, we know that the majority of people with dementia in Ireland (circa 30,000) are living in the community. The likely doubling of the number of people with dementia to be living in the community in 20 years times is significant as it will result in a growing demand for community supports. It highlights the need for policy changes and for resources for dementia to be apportioned to community services and for health service professionals and the public at large to be better educated about dementia and more sensitive to these peoples' complex and unique needs and those of their families. Based on European research (Miranda-Castillo, Woods and Orrell, 2010; Schneider et al., 2003: 312), we suspect that between 6,000 and 10,000 of these people may be living alone in their own homes with family members living nearby, and these people and their families may have some distinctive needs.

It must be remembered that dementia prevalence estimates and projections are by their nature crude. An important benefit of having these figures available is that they can be used to distribute easily understandable information about the prevalence of dementia to the general public and to policy-makers. It was never our intention in generating these figures that they would be used pejoratively or to support an apocalyptic view of dementia. These estimates are an indicator of general trends and having them available will it is hoped help in planning the services needed to provide treatment, support and care to the affected population at both a national and a local level. These estimates can also be used to revise estimates of the social and economic costs of dementia in Ireland. Having prevalence figures

available means that they can be used in advocacy work and for making the case that dementia is an important public health issue that needs to be prioritised. We stress, however, that the estimated projections presented in this paper should be interpreted and treated with caution since making predictions about the future population of people with dementia is fraught with difficulty and involves uncertainty. The reasons for this have been previously outlined (Pierce et al., 2013). The human faces behind these figures must not be forgotten.

Finally, it needs to be acknowledged a recent study in Sweden and recent studies led by Carol Brayne in the UK have provided some preliminary evidence of a small reduction in dementia prevalence rates in the older population now compared with two decades ago (Matthews et al, 2013; Qiu et al., 2013). Based on a systematic review on prevalence rates, the ALCOVE project (<a href="www.alcove-project.eu/">www.alcove-project.eu/</a>) also reported a decrease in the total rate of dementia (Galeotti et al., 2013). Given that the findings from recent research suggest that dementia prevalence rates might be lower now than there were 20 years ago it is worth noting Brayne's comments:

"whether or not these gains for the current older population will be borne out in later generations would seem to depend on whether further improvements in primary prevention and effective health care for conditions which increase dementia risk can be achieved, including addressing inequalities."

Our estimates show clear regional differences in the prevalence of dementia across the 26 counties. Estimates of the number of people with dementia have been generated for each of the four areas in which the Genio dementia projects are currently operating. A next step will be to generate figures for 2013 showing the proportion of people with dementia in each of these areas known to Genio dementia services. The comparison between the local prevalence data and information from the Genio register/database, once provided, could be used to target those people who remain unknown to service providers involved in the Genio programme. Information from the database can also be used to identify the proportion of people with dementia on the register who remain living in the community over time. This will be subject to the availability of data from the projects. In addition, if GPs in primary care were to keep records (ideally a register) of all new cases of dementia diagnosed, it should also be possible to record and track the numbers of people diagnosed with dementia during the course of the Genio projects. Comparing these figures with prevalence estimates

generated by the researchers for the respective areas would provide for the first time data in Ireland on dementia diagnostic rates.

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Appendix 1. Prevalence of dementia in Kinsale - DEDs used in estimates

| List of DEDs  | Total population of DEDs |  |  |
|---------------|--------------------------|--|--|
| Ballinadee    | 486                      |  |  |
| Ballinspittle | 631                      |  |  |
| Ballyfeard    | 358                      |  |  |
| Ballyfoyle    | 355                      |  |  |
| Ballymackean  | 343                      |  |  |
| Ballymartle   | 1,185                    |  |  |
| Coolmaine     | 404                      |  |  |
| Cullen        | 492                      |  |  |
| Farranbrien   | 518                      |  |  |
| Kilbrittain   | 595                      |  |  |
| Kilpatrick    | 479                      |  |  |
| Kilmonogue    | 1,235                    |  |  |
| Kinsale Rural | 4,673                    |  |  |
| Kinsale Urban | 2,298                    |  |  |
| Kinure        | 306                      |  |  |
| Laherne       | 465                      |  |  |
| Leighmoney    | 743                      |  |  |
| Liscleary     | 4,385                    |  |  |
| Nohaval       | 281                      |  |  |
| Templebreedy  | 3,491                    |  |  |
| Templemichael | 695                      |  |  |
| Carrigaline   | 1,878                    |  |  |
| Total         | 26,296                   |  |  |

Appendix 2. Prevalence of dementia in Stillorgan/Blackrock - DEDs used in estimates

| List of DEDs             | Total population of DEDs |  |  |
|--------------------------|--------------------------|--|--|
| Blackrock-Booterstown    | 2,975                    |  |  |
| Blackrock-Carysfort      | 5,577                    |  |  |
| Blackrock-Central        | 3,637                    |  |  |
| Blackrock-Monkstown      | 3,062                    |  |  |
| Blackrock-Newpark        | 1,061                    |  |  |
| Blackrock-Seapoint       | 1,332                    |  |  |
| Blackrock-Stradbrook     | 1,180                    |  |  |
| Blackrock-Templehill     | 2,675                    |  |  |
| Blackrock-Williamstown   | 2,454                    |  |  |
| Blackrock-Glenomena      | 1,877                    |  |  |
| Stillorgan-Deerpark      | 2,828                    |  |  |
| Stillorgan-Kilmacud      | 3,842                    |  |  |
| Stillorgan-Leopardstown  | 2,067                    |  |  |
| Stillorgan-Merville      | 2,859                    |  |  |
| Stillorgan-Mount Merrion | 2,386                    |  |  |
| Stillorgan-Priory        | 2,036                    |  |  |
| Total                    | 41,848                   |  |  |

#### **About Genio**

Genio is an independent, non-profit organisation based in Ireland. We are driven by a vision of a society that benefits by valuing all of its citizens. Genio brings together Government and philanthropy to help develop and scale, cost-effective citizen-centred services so that everyone has the chance to live full lives in their communities.

Genio is supported by the Atlantic Philanthropies in collaboration with the Department of Health and the Health Service Executive. We work in partnership with all stakeholders to re-configure resources to reform services in order that they reflect national policy and international best practice.

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