

Planning dementia services: new estimates of current and future prevalence rates of dementia for Ireland

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Objectives. The paper provides new estimates of dementia prevalence at a national and local level in Ireland and new projections of future numbers of people with dementia.

Methods. The prevalence of dementia at a national and local level has been calculated by applying European Collaboration on Dementia (EuroCoDe) prevalence rates to data from the Census of Population 2006. The National Disability Survey has been used to estimate the number of people with Down syndrome and dementia. Projections of future numbers of people with dementia have been calculated by applying EuroCoDe prevalence rates to the most recently available population projections from the Central Statistics Office (CSO).

Results. It is estimated that there were 41 740 people with dementia in Ireland in 2006. Estimates show that there are clear regional differences in prevalence of dementia across Ireland, with the largest proportion of people with dementia in the West of Ireland, and the Dublin North Eastern region having the lowest share of dementia. Our best estimate is that there are 700 people with Down syndrome and dementia in Ireland. Applying EuroCoDe prevalence rates to the most recent CSO population projections shows that the prevalence of dementia in Ireland will increase to between 67 493 and 70 000 in 2021 and to between 140 580 and 147 000 in 2041.

Conclusions. Although there are several limitations to these estimates, the data provide timely and useful information for planning effective health and social care services, as well as raising public and professional awareness about dementia at a national level.

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Key words: Dementia, Ireland, policymaking, population projections, prevalence.

Introduction

The risk of developing dementia increases exponentially with age (Plassman *et al.* 2007), and population ageing means that, unless a cure is found in the foreseeable future, increasing numbers of people around the world will develop dementia. Accordingly, Alzheimer's disease and the related forms of dementia will take on increasing importance worldwide (Wimo *et al.* 2003). In 2010, there were an estimated 35.6 million people over 60 years of age with dementia worldwide, and estimates suggest that these figures will almost double every 20 years to 65.7 million by 2030 and 115.4 million by 2050 (Prince, 2009). Western Europe, with an estimated 7 million people with dementia in 2010, is the region with the highest prevalence of dementia, and this figure is forecast to increase to 10 million in 2030 and to 13.4 million in 2050

(Prince, 2009). In the United States it is estimated that there are 3.8 million people aged 71 years of age or over with dementia (Plassman *et al.* 2007).

Neurodegenerative diseases, particularly Alzheimer's disease, have been singled out as a domain of utmost importance at a European Union level, where joint action has been mobilised on dementia, including the development of a European Initiative on Dementia (European Commission, 2009), and member states have been urged to develop National Action Plans on dementia. Several countries in Europe and further afield, including England, Scotland, Wales, Northern Ireland, France, the Netherlands, Denmark, Norway, Sweden and Australia, have now developed strategies.

At just over 11%, the proportion of people aged 65 years or over in Ireland is low in comparison with most other countries in the European Union and the rest of the developed world. For example, in the European Union, where the average stands at 17%, the share of the total population aged 65 years or over is 16% in the United Kingdom and France, 18% in Sweden, and as high as 20% in Italy and Germany

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(Lanzieri, 2011). This compares with 13% in the United States and Australia and 22% in Japan (Australian Bureau of Statistics, 2011). In terms of future population ageing, however, Ireland will follow a similar pattern to that already experienced by most other high-income countries in that the number of older people is expected to grow substantially. The population of older people (aged 65 years and over) in Ireland is expected to double from ~0.5 million in 2006 to over 1 million by 2031 [Central Statistics Office (CSO), 2008a] and the population of the oldest-old (aged 85 years and over) is predicted to increase even more markedly. The expected growth in the numbers of older people in Ireland is noticeably higher than that of many other western countries, mainly because many of these countries have already experienced significant population ageing (Knapp *et al.* 2007).

In Ireland, dementia remains a hugely underfunded and underprioritised issue. However, against a backdrop of significant developments at a European level and following years of political advocacy to make dementia a national health priority, the Irish Government has in recent years promised to develop a National Dementia Strategy by 2013 and to implement this strategy over a 5-year period (Programme for Government, 2011). For this to happen, it is critical that up-to-date Irish estimates of the current and future prevalence rates for dementia become available to inform the direction of public policy on dementia, to influence the planning of health and social care services, and to generate awareness about this progressive complex illness.

Undertaking population-based epidemiological studies to estimate the prevalence of dementia is time-consuming, complex and costly. Similar to several other countries (Kiejna *et al.* 2010), Ireland lacks reliable epidemiological data on dementia prevalence rates, although earlier estimates based on standardised or EURODEM prevalence rates, linked to European population-based studies, are available (Government of Ireland, 2006; O'Shea, 2007; Diaz-Ponce, 2008). New dementia prevalence rates from the latest meta-analysis project in Europe are now available from the European Collaboration on Dementia (EuroCoDe) (Alzheimer Europe, 2009) (see Table 1) and have been used in this study to provide improved estimates of dementia prevalence for Ireland. As people with Down syndrome are at a heightened and earlier risk of developing dementia compared with the general population, this paper also expands our knowledge of dementia prevalence in this group by providing an estimate of the number of people with Down syndrome and dementia in Ireland.

Dementia prevalence estimates were calculated as part of a project aimed at creating an evidence-based research review on dementia required to inform the

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

Age range	Men (%)	Women (%)
30–59 ^a	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

EuroCoDe, European Collaboration on Dementia.

^a As EuroCoDe does not specify the prevalence rates of dementia for the 30–59 age group, EURODEM prevalence rates of dementia for this age group by gender as reported by Hofman *et al.* (1991), tables 4, 5 and 6, pp. 742–744, were used.

Source: EuroCoDe age/gender-specific prevalence rates of dementia (Alzheimer Europe, 2009).

development of Ireland's National Dementia Strategy (Cahill *et al.* 2012). In addition to estimating the current and future prevalence of dementia, the research review specified the main economic costs of dementia (Connolly *et al.* 2012), undertook a review of current service availability for people with dementia, and examined best practice in dementia care locally and internationally. This paper focuses solely on the current and future prevalence of dementia in Ireland.

Methods

Using data from the 2006 Census (CSO, 2007), estimates of the prevalence of dementia were generated. First, calculations were undertaken to estimate the number of men and women in each of nine age groups, namely, 30–59, 60–64, 65–69, 70–74, 75–79, 80–84, 85–89, 90–94 and 95+. Next, EuroCoDe age/gender-specific prevalence rates (Alzheimer Europe, 2009) were applied to each gender-disaggregated group, starting with the age group of 60–64 years. As EuroCoDe does not specify prevalence rates for the age category 30–59 years, the relevant EURODEM gender-specific dementia prevalence rates for the 30–59 age group (Hofman *et al.* 1991) were instead applied. Prevalence rates for early-onset dementia have been generated for Ireland on the basis of catchment area analysis, but these are available only for the age category of 45–64 years (Freyne *et al.* 1998).

To generate the estimates of dementia at a local level, the number of men and women in the same nine age groups was calculated for each of the Health

Service Executive's 32 Local Health Office (LHO) areas. EuroCoDe age and gender-specific prevalence rates were then applied to these data.

The Census of Population does not include information about people with Down syndrome and dementia. To address this deficiency, an estimate of the number of people with Down syndrome and dementia in Ireland was calculated by applying prevalence rates from an Irish study (Tyrell *et al.* 2001) to data from the National Disability Survey (CSO, 2008b).

Two sets of estimates of future numbers of people with dementia in Ireland for the period 2011–2041 were generated. These projections relied on the most recently available population projections from the CSO (2008a). The CSO population projections for the years 2011–2041 are based on assumptions relating to future trends in fertility, mortality and migration. The CSO opted for two sets of assumptions for fertility: one for mortality and three for migration trends up to the year 2041, which resulted in six sets of population projections for the period 2011–2041 (i.e. M1F1, M1F2, M2F1, M2F2, M0F1 and M0F2), disaggregated by gender and 5-yearly age groups. Two of these sets of projections – based on M0F2 and M2F1 assumptions – were selected. As CSO assumptions about mortality remained consistent across the six sets of population projections, the two particular sets of projections chosen reflect best what the researchers believed were the most likely and robust demographic (fertility and migration) trends.

The M0F2 projections, which forecast the lowest growth in the population (including of older people),

are based on the assumption that there will be zero net in-migration (M0 assumption) and low fertility (F2 assumption), that is, the assumption that the total fertility rate will decrease from the 2006 level until 2016 and then stabilise at this level until 2041. All of the other available projections (M1 and M2) are based on the assumption that net in-migration will continue into the future. 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 relating to the vagaries of the business cycle and consequent migration patterns.

The M2F1 projections are based on the assumption that immigration will continue at moderate levels (M2) and there is high fertility (F1 assumption), that is, that the total fertility rate will remain at 1.9, the level observed in 2006, for the lifetime of the projections (i.e. until 2041).

EuroCoDe prevalence rates of dementia were applied to the two sets of projections (M0F2 and M2F1) to estimate the number of people with dementia by gender and age group at 5-yearly intervals from 2006 to 2041.

Results

Prevalence of dementia

This study estimates that there were 41 740 people with dementia in Ireland in 2006 (Table 2) and indicates that 3583 (or ~ 8.6%) had early-onset dementia and were younger than 65 years.

Table 2. Estimated number of people with dementia by age group and gender in Ireland, 2006

Age range	Population			Estimated persons with dementia ^a		
	Men	Women	Total	Men	Women	Total
30–59 ^b	869 212	850 724	1 719 936	1738 ^b	851 ^b	2589
60–64	91 561	90 166	181 727	183	811	994
65–69	70 895	72 501	143 396	1276	1015	2291
70–74	56 540	62 612	119 152	1809	2379	4188
75–79	40 121	52 345	92 466	2808	3978	6786
80–84	24 694	40 190	64 884	3581	6591	10 172
85–89	11 021	22 281	33 302	2303	6350	8653
90–94	3231	8814	12 045	943	3913	4856
95+	593	2088	2681	192	1019	1211
Total	1 167 868	1 201 721	2 369 589	14 833	26 907	41 740

EuroCoDe, European Collaboration on Dementia.

^a New prevalence figures generated by applying EuroCoDe age-related prevalence rates (Alzheimer Europe, 2009) to Census 2006 data, CSO (2007, tables 2B and 2C, pp. 16–17 and table 5, p. 28).

^b As EuroCoDe does not specify prevalence rates for the 30–59 age group, EURODEM dementia prevalence rates for this age group by gender as reported by Hofman *et al.* (1991) were used instead.

Table 3. Estimated number and percentage of people with dementia in Ireland (2006) by local health administrative areas

HSE region	HSE LHO area	Population (all ages)	Persons with dementia	Total LHO population (%)
South	Carlow/Kilkenny	120 631	1196	0.99
	Cork-North Lee	167 701	1448	0.86
	Cork-South Lee	179 260	1681	0.94
	Kerry	139 835	1717	1.23
	North Cork	80 769	961	1.19
	South Tipperary	88 441	1010	1.14
	Waterford	120 017	1233	1.03
	West Cork	53 565	740	1.38
	Wexford	131 747	1287	0.98
	Total	1 081 968	11 273	1.04
Dublin North East	Cavan/Monaghan	120 000	1392	1.16
	Dublin North	222 049	1631	0.73
	Dublin North Central	126 572	1427	1.13
	Dublin North West	185 900	1406	0.76
	Louth	111 267	1048	0.94
	Meath	162 831	1190	0.73
	Total	928 619	8094	0.87
Dublin/Mid-Leinster	Dublin South City	134 344	1220	0.91
	Dublin South East	110 487	1297	1.17
	Dublin South West	148 362	1188	0.80
	Dublin West	133 080	841	0.63
	Kildare/West Wicklow	203 327	1313	0.65
	Laoighis/Offaly	137 927	1299	0.94
	Longford/Westmeath	113 737	1171	1.03
	South Dublin	136 382	1626	1.19
	Wicklow	109 202	969	0.89
	Total	1 216 848	10 924	0.90
West	Clare	110 950	1185	1.07
	Donegal	147 264	1694	1.15
	Galway	231 670	2364	1.02
	Limerick	151 290	1521	1.01
	Mayo	123 839	1692	1.36
	North Tipperary/East Limerick	98 788	996	1.01
	Roscommon	58 768	822	1.40
	Sligo-Leitrim/West Cavan	89 844	1155	1.29
	Total	1 012 413	11 429	1.13
	State	Total	4 239 848	41 720

HSE, Health Service Executive; LHO, Local Health Office.

Table 3 presents the estimated prevalence of dementia in each of the 32 LHO areas and shows that there are clear regional differences in estimated dementia prevalence rates across Ireland. The West region has the highest number of people with dementia (11 429) with each of the nine LHO areas estimated to have at least 1% of its population living with dementia. In contrast, the Dublin North Eastern Region has the smallest number of people with dementia at a little over 8000. Estimates for the South of Ireland Region and Dublin Mid-Leinster are 11 273 and 10 924, respectively.

On the basis of data obtained from the National Disability Survey (CSO, 2008b) showing that, in 2008, 5500 people in Ireland had Down syndrome, our best estimate is that there are ~700 people in Ireland with Down syndrome and dementia.

Projections of dementia

Table 4 shows estimates of the projected growth in the number of people with dementia by age group in Ireland at 5-yearly intervals from 2006 to 2041, using two different sets of assumptions.

Table 4. Actual number and projected growth in the number of people with dementia in Ireland by age group, 2006–2041 (M0F2) and (M2F1) (n)

Age groups	2006	2011	2016	2021	2026	2031	2036	2041
Projections based on M0F2 assumptions ^a								
30–59	2576	2803	2967	2982	2930	2869	2791	2686
60–64	983	1193	1303	1449	1592	1696	1853	2024
65–69	2258	2734	3334	3649	4069	4488	4842	5304
70–74	4130	4542	5575	6868	7576	8495	9397	10 141
75–79	6716	7378	8328	10 421	12 992	14 467	16 323	18 178
80–84	10 096	10 924	12 504	14 543	18 632	23 568	26 554	30 301
85+	14 688	18 319	22 392	27 581	34 131	44 464	58 441	71 946
Total	41 447	47 893	56 404	67 493	81 922	100 047	120 201	140 580
Projections based on M2F1 assumptions ^b								
30–59	2576	2954	3328	3532	3605	3608	3561	3473
60–64	983	1209	1331	1492	1658	1799	2030	2351
65–69	2258	2766	3401	3751	4219	4707	5191	5897
70–74	4130	4584	5670	7025	7792	8802	9850	10 851
75–79	6716	7436	8438	10 633	13 306	14 897	16 933	19 071
80–84	10 096	10 988	12 646	14 778	19 036	24 157	27 358	31 436
85+	14 688	18 376	22 518	27 854	34 634	45 310	59 812	73 936
Total	41 447	48 313	57 332	69 066	84 249	103 279	124 735	147 015

CSO, Central Statistics Office; EuroCoDe, European Collaboration on Dementia.

^a Calculations based on application of EuroCoDe age/gender-specific prevalence of dementia rates (Alzheimer Europe, 2009) to CSO population projections based on M0F2 assumptions (CSO, 2008, table 5, p. 42).

^b Calculations based on application of EuroCoDe age/gender-specific prevalence of dementia rates (Alzheimer Europe, 2009) to CSO population projections based on M2F1 assumptions (CSO, 2008, table 3, p. 40).

Under the M0F2 assumptions, the population of people with dementia is forecast to increase to an estimated 67 493 in 2021 and to 140 580 in 2041. Under the M2F1 assumptions, the population of people with dementia is predicted to increase more, to almost 70 000 in 2021 and to ~ 147 000 in 2041. In line with the projected growth in the number of the oldest-old, estimates show that the most marked increase will be among people aged 85 years and over and the largest increase will occur after 2021.

Discussion

The financing and provision of interventions to meet the ongoing care needs of people with dementia, including support for their family caregivers, is becoming an urgent political issue globally. It is also likely to become an important public policy issue in Ireland in the near future, particularly given the commitment by the government to produce a National Strategy for Dementia in 2013. Policymaking and planning for dementia services require accurate up-to-date estimates, and Ireland, like many countries around the world, continues to lack reliable epidemiological data on current and future dementia prevalence rates. Given that Ireland has a different population

structure from much of the rest of Europe, there is a clear need for a population-based epidemiological study in Ireland from which to derive population-based estimates of the prevalence of dementia. However, given the cost of generating these data, particularly in the current economic climate, it is unlikely that country-specific epidemiological data for Ireland will be generated in the short to medium term. Accordingly, we have applied the EuroCoDe dementia prevalence rates to 2006 Census data and used CSO population projections to generate current and future estimates of dementia in Ireland. We believe that this type of data is critical to enable formulation of appropriate, evidence-based policy on dementia in relation to service provision and resource allocation. The next step for policymakers is to align services to need – namely, in areas where population ageing is most evident and estimates of the numbers of people with dementia are highest.

The numbers of people living with dementia in Ireland have previously been estimated to be 21 500 (Government of Ireland, 2006), 34 286 (O’Shea, 2007) and 37 884 (Diaz-Ponce, 2008) in 2001, 2002 and 2006, respectively. Applying the new EuroCoDe prevalence rates, our estimate of the numbers of people living with dementia for 2006 has been revised upward to

41 740, thereby providing a reasonable baseline against which current and future services can be mapped. The small but not insignificant number of people who develop symptoms of dementia at a younger age raises awareness of the fact that dementia is not exclusively an age-related illness and that there is a need to plan age appropriate services for this group of people whose needs are complex and who do not fit easily into service systems and structures designed for older age cohorts.

Providing estimates of people with Down syndrome and dementia is more difficult given that neither the Census nor the National Intellectual Disability Database provides data on the numbers of people with Down syndrome in the country. However, the application of prevalence rates from an Irish study (Tyrell *et al.* 2001) to data on the number of people with Down syndrome from the National Disability Survey (CSO, 2008b) allows for the first time in Ireland an estimate of the numbers of people with Down syndrome and dementia to be generated. This new information, although less precise than the estimates relating to the rest of the population of people with dementia, is important for putting in place appropriate dementia services for this disadvantaged group.

Our estimates also show clear regional differences in the prevalence of dementia across LHO areas. This arises as a direct result of differences in the age structure across LHO areas. Having information on prevalence rates by LHO areas is particularly helpful for facilitating local service planning, and these data need to be carefully considered by service planners involved in making key resource allocation decisions in relation to primary care practices, mental health services, memory clinics, community care provision and residential care beds. For example, *A Vision for Change* recommended that mental health services for older adults should operate through specialised Community Mental Health Teams (CMHTs), with one team per 100 000 population (Government of Ireland, 2006). The geographical differences in prevalence rates of dementia highlight the importance of developing and expanding CMHTs in a way that takes account of local ageing patterns and the consequent need for a greater focus on dementia-specific skill sets within teams, which would reflect international best practice.

The estimates of the projected growth in the numbers of people with dementia provided in Table 4 are approximately double the estimates provided in *A Vision for Change* (Government of Ireland, 2006) and about 10% higher than the projections estimated by O'Shea (2007). The reasons for these differences are twofold. First, the calculations provided in *A Vision for Change* and by O'Shea used population projections produced by the CSO (2004) as baseline data (the most

up-to-date national demographic forecasts available at the time), whereas the estimates in Table 4 are based on more recent population projections produced by the CSO in 2008 as baseline data. Second, different dementia prevalence rates were used in the three studies. In *A Vision for Change* (Government of Ireland, 2006) the projected numbers of people with dementia were estimated using a standardised dementia prevalence rate of 5%, whereas O'Shea (2007) applied the EURODEM age- and gender-specific dementia prevalence rates, and the figures in Table 4 were estimated by applying EuroCoDe age- and gender-specific dementia prevalence rates (Alzheimer Europe, 2009).

The 2011 Census (CSO, 2012) recorded an increase of 14.4% in the population of people in the age group of 65 years or over [which is close to figures forecast in the most recent CSO population projections (CSO, 2008a)]. Using the 2011 Census as baseline data and drawing on new fertility, mortality and migration assumptions, the CSO will produce new population projections towards the end of 2012 (Personal Email Communication, 2012). These projections can then be used to provide improved estimates of future numbers of people with dementia in Ireland. The growth in the population of older people between 2006 and 2011 will clearly affect estimates of the future numbers of people with dementia.

Finally, the estimated projections presented in this paper should be interpreted and treated with caution, as making predictions about the future population of people with dementia is fraught with difficulty and involves uncertainty for two main reasons. First, predictions are based on the assumption that 'if certain trends continue, this is what will happen' (Fahey and Fitzgerald, 1997). Predictions cannot cover every eventuality, particularly unforeseen shifts in demographic trends that might occur in the future. Past experience in Ireland shows that even over short periods of time the assumptions underpinning population projections may prove to be incorrect (Dignan, 2009). Migration tends to be one of the most volatile components of population projections (Dignan, 2009). For example, the M0F2 projections used to calculate the estimates in Table 4 assume that Ireland will be characterised by zero net migration. However, during the intercensal period of 2006–2011, mainly arising from the economic downturn, Ireland changed from a country with net inward migration to one with net outward migration, thus illustrating the rapid change in migration patterns that has occurred since the last CSO population projections (CSO, 2011).

The second reason for treating the projections cautiously is that they rely on the assumption that dementia prevalence rates will not change over time (Comas-Herrera *et al.* 2011). This view is based on

long-term studies from Sweden and the United States, which suggest that the prevalence of dementia has changed little over the last 30–40 years in developed countries (Prince, 2009). However, these studies do not take account of the potential impact that preventative strategies or disease-slowing treatments may have on the future numbers of people with dementia (Brookmeyer *et al.* 1998; Sloane *et al.* 2002; Brodaty *et al.* 2005; Jorm *et al.* 2005; Jagger *et al.* 2009; Comas-Herrera *et al.* 2011). Expert opinion points to a small reduction in the prevalence of dementia over the next 50 years (Comas-Herrera *et al.* 2011). An Australian study estimates that, if future interventions succeed in delaying the onset of dementia by as little as 6 months or as much as 5 years, the prevalence of dementia would be reduced by 6% and 44%, respectively (Jorm *et al.* 2005). Conversely, improved medical and social care might reduce case mortality and thus increase the prevalence of dementia (Ferri *et al.* 2005). Of course, if a cure for dementia could be found in the foreseeable future then all current projections would be rendered meaningless.

In conclusion, estimating the numbers of people with dementia in any country is a difficult task that requires an understanding of the pitfalls involved in searching for too much precision given current knowledge and diagnosis patterns. Notwithstanding this, the estimates provided in this paper are important as an indicator of the general trends in dementia numbers in the Irish population. We believe that these estimates will assist in raising awareness about the magnitude of dementia in the country and the challenges the illness presents to present and future generations. In particular, the trend towards a significant growth in the numbers of people with dementia in the future highlights the need to develop more responsive services and interventions for this fast-growing and very vulnerable group of people.

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Conflict of interest

None.

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