An Economic Analysis of a Community-Based Model for Dementia Care in Ireland: A Balance of Care Approach

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1 Introduction

Dementia is a neurodegenerative disease characterised by a progressive loss of cognitive and functional abilities and social skills, often impinging on quality of life and the individual's capacity for independent living. Dementia poses a significant burden to health and social care systems throughout the world; an estimated 35 million people currently live with dementia, and this number is expected to increase significantly in coming years (Prince et al., 2013a). Dementia is a major contributor to the global burden of disease and is the second largest cause of disability for people over 70 (OECD, 2015). The growing numbers of people with dementia (PWD) who will require health or social care supports present a substantial caring and financial challenge to governments to plan accordingly (WHO, 2012). The recent World Alzheimer Report estimated the current worldwide cost of dementia at $818 billion (Prince, 2015); 40% of these costs are attributable to informal care provided by family and friends in the community. Assuming the age-specific prevalence of dementia, patterns of service use and unit costs remain the same, it is predicted the worldwide societal costs of dementia will increase to $1,117 billion by 2030 (Prince et al., 2013b).

The Irish National Dementia Strategy (NDS) commits to caring for people with dementia in their own homes for as long as possible, rather than in residential care. However, as dementia is a degenerative disease, the changing needs of the individual will eventually mean that, for some people, the home is no longer the most appropriate setting for care. At any given time, therefore, there are significant numbers of people with dementia on the borderline between community and residential care. There is much uncertainty surrounding the timing of this transition, as the decision to institutionalise a person with dementia is based on multiple factors, including: the preferences of the person with dementia; family preferences and expectations; level of dependency; multimorbidity; formal care provision; location; family care networks; social connectivity; and the vagaries of local and national financing arrangements (Afram et al., 2014). Furthermore, decisions on resource allocation are also likely to be influenced by the costs of care for people with dementia on the boundary between community and residential care and information on the cost-effectiveness of interventions aimed at preventing long-term care placement (Wübker et al., 2014).

Within Ireland, dementia has long been rooted in a medical model of care which focuses on the pathology of the disease and interprets behaviour according to disease stage progression. This conceptualisation of dementia is increasingly being recognised as too narrow, carrying the additional risk of diminishing the personhood of the individual with dementia. While the Irish National Dementia Strategy represents a shift toward a more holistic, psychosocial model of dementia care, it will take some time for this philosophy to become embedded within the health and social care system. The HSE & Genio Dementia Programme is an attempt to accelerate the development of a new social model of care by supporting an individualised, person-centred community-based approach, to caring for people with dementia (O'Shea and Murphy, 2014). Keeping people with dementia living at home for longer by postponing or preventing admission into residential care through adherence to a more socially oriented system of care is a secondary objective of the HSE & Genio Programme. This programme is described further in Section 5 and in a programme description document (Genio, 2015).

The objective of the current study is to provide an economic analysis of the cost of care for people with dementia on the boundary between home care and residential care within the innovative HSE & Genio Dementia Programme. We identify people with dementia living at home who are at significant risk of admission to residential care in the medium term. This is our reference group for the study on the basis that it is people within this cohort who may be kept at home for longer as a direct result of the investment. By concentrating on the margin between community and residential care, we may be able to provide some insight into the benefits of investing in personalised community-based supports for this group rather than having them face the alternative of admission into long-stay care. We estimate the various formal and informal supports and interventions that people with dementia are currently receiving from the state, the additional supports arising from the HSE & Genio Dementia Programme and informal care provided from their own families. While the analysis is focused on actual provision rather than optimal provision, the study provides valuable insight into resource use and costs of community-based care at the boundary between community and residential care.

2 Dementia spending in Ireland

In Ireland, an estimated 55,000 people currently have dementia, with projections suggesting the number could rise to 94,000 by 2031 and 152,000 by 2046 (Pierce et al., 2014). The total burden of dementia in Ireland is an estimated €1.9 billion, incorporating both formal and informal care costs (Connolly et al., 2014). The average cost per person with dementia in Ireland is approximately €40,500 (Cahill et al., 2012). There is no data on how much the government actually spends on dementia. However, the estimated non-capital expenditure on services for all older people in 2013 was €1.36 billion. Of this amount, €0.97 billion or 71 per cent was spent on Long Term Residential Care (Central Statistics Office, 2013b), wherein up to two thirds of residents are likely to have dementia (Cahill et al., 2012). Total spending on older people in Ireland amounts to approximately 0.8% GDP which is just under half of the average of what other OECD countries spend on this group (Central Statistics Office, 2013b). Public long-term care (LTC) expenditure, both residential and community-based, accounted for 1.5% of GDP in OECD countries in 2008, while private LTC expenditure accounted for an additional 0.3% of GDP (Colombo et al., 2011). Differences across countries occur for many reasons but largely depend on population age structure, care needs, universality and family caring cultures. Demand for better quality and more responsive, person-centred social-care systems will lead to an increase in LTC costs in the future, with the OECD predicting public LTC expenditure to double and potentially triple by 2050 (Prince et al., 2013b). An OECD study on LTC found that while formal LTC is typically provided in home-care settings, accounting for 67 per cent of all LTC users, two thirds of all LTC expenditure occurs in institutional settings (Colombo et al., 2011).

Keeping people with dementia living at home and out of nursing home beds which cost around €1,000 per week is an important goal of government policy. So too is ensuring that older people currently in acute care beds can be appropriately discharged to their own homes when treatment is complete, thereby freeing up expensive acute care beds for other uses. Appropriate placement is, therefore, a key goal of public policy and has tended to dominate public discourse in recent years, driven largely by increasingly tight cost constraints associated with financial austerity. However, even if more resources were to be directed to community care, high quality nursing home care will still be needed for some people with dementia. According to a recent review of the Nursing Home Support Scheme in Ireland, at current utilisation rates there will need to be over 36,000 long-stay beds in the system by 2024, an almost 25 per cent increase from 2014 (Department of Health, 2015). These projections make it all the more important that only those people who need to be admitted to a long-stay care bed actually end up there, given the pressures likely to be placed on the overall funding system from the ageing of the Irish population.

A major driver of long-term care expenditure for people with dementia is the relative share of informal and formal care in the community-based care system. Over 30,000 PWD are currently living in the community in Ireland, and this number is likely to double in the next 20 years to approximately 60,000 in 2031 (Pierce et al., 2014). The vast majority of these people are cared for by family and friends and informal care accounts for just under 50 per cent of the total cost of care in Ireland (Connolly et al., 2014). Informal caregiving is typically unpaid, and is defined as providing help with personal care or basic activities of daily living (ADLs) to people with functional limitations, as well as providing support with instrumental activities of daily living (IADLs) and supervision. Family carers are the first line of care for people with dementia in Ireland, although their contribution to care is often not taken into account by the formal health system when the cost of care is being considered. Any potential decline in the availability of informal carers in the future due to decreasing family size and increasing female workforce participation will have an impact on the demand for, and future cost of, formal services leading to higher levels of exchequer burden (de la Maisonneuve and Martins, 2015). The relative cost-effectiveness of community-based interventions and models of care which delay the transition to institutional care is also impacted by the inclusion of informal care costs in the accounting framework. Once you place a monetary valuation on informal care costs, community care may no longer be cheaper than residential care alternatives.

3 Boundary of care issues

Figuring out where people with dementia should be cared for and by whom is a major issue now for governments across the world. Government measures to increase efficiencies within LTC schemes have often focused on the choice of setting for the delivery of dementia care (Colombo et al., 2011). People with dementia have a strong preference for remaining at home in their communities and this has been reflected in numerous consultations with older people in Ireland. This is also true of other European countries and is reflected in the trend in recent decades of governments producing policies which encourage ageing in place and care at home (Colombo et al., 2011, OECD, 2015). Many European countries have already published dementia strategies which have the primary aim of supporting people with dementia to live in the community for as long as possible (OECD, 2015). The direct expansion of home care supply, through the development of community-based services, enables people with dementia to continue living in their own homes.

Since the publication of The Years Ahead policy document in 1988 (Department of Health, 1988), there has been an emphasis on community-based care for dependent older people in Ireland. Current health and social policy in Ireland is focused on caring for people with dementia in their own homes for as long as possible, rather than in residential care (Department of Health, 2012). The Irish National Dementia Strategy (Department of Health, 2014) aims to transform the current service delivery through: timely diagnosis and intervention; integrated services, supports and care for PWD and their carers; training and education; and leadership. The strategy also concentrates on increasing awareness and understanding of dementia within local communities, as well as on improving the collection of data and evidence to inform government responses to the needs of PWD and their carers. The biopsychosocial model is central to the current approach in Ireland, as is a determination to support people to live well at home for as long as possible.

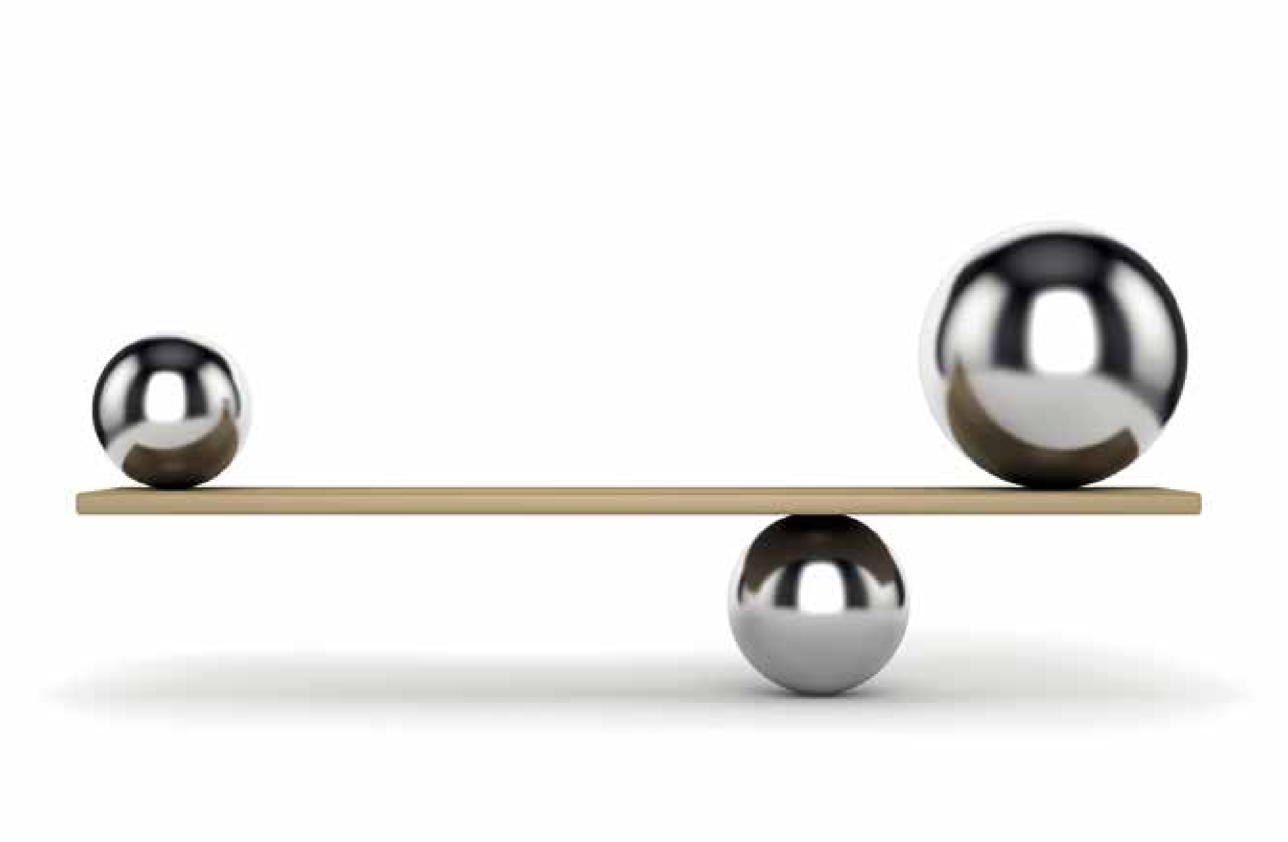
Unfortunately, the de facto allocation of resources in Ireland for people with dementia has not always matched the rhetoric of care that can be found in various policy documents, including the most recent National Dementia Strategy. Prior to the financial crisis in 2008, the Irish health care system was already reflecting a number of key policy disjunctures, including an underdeveloped primary and community care sector. Since then, Ireland has seen substantial cuts in public expenditure in health and social care, with savings achieved through reductions to staff numbers and staff pay, as well as increased efficiencies across the public health system (Nolan et al., 2014). When savings are required, cuts are often directed at an already fragmented community care services for older people rather than areas where costs are largely fixed and difficult to reduce, such as spending on acute care services or residential care services.

In this environment, statutory services, such as the Nursing Home Support Scheme for residential care, are often prioritised, leaving home care services, which do not have a statutory basis, more vulnerable to cuts. Community care is less visible and does not always get the same public and media attention that bed closures in acute care hospitals or in public long-stay facilities receive. The paradox is that cutbacks in primary and community care services make it more likely that people with dementia are admitted to expensive acute care or long-stay care facilities, as family carers find it difficult to cope without adequate home-based supports. Preventing costly in-patient admissions requires investment in community care, not cutbacks to the very services that enable people to live longer in their own homes. While the health system recognises this paradox, the challenge of reconfiguring spending is difficult to address in the face of on-going ‘crisis’ management.

The optimal mix of services and supports for people with dementia on the boundary between community-based care and residential care has become an important issue for governments seeking to prevent and postpone unnecessary admissions into long-stay care and responding to the stated desire of older people to remain living well at home. Providing the most cost-effective mix of health and social services is becoming a priority for policy-makers in all countries, giving rise to a convergence of policies aimed at reducing the growth of institutional care, while further developing community care (Tucker et al., 2013, Prince et al., 2013b). As budgetary constraints limit opportunities for major investment in long-stay care, making the best use of existing resources for people with dementia is a compelling priority (Tucker et al., 2015). Not surprisingly, variations in the balance of resources invested in nursing home care and community based care governs the locus of care of frail older people (Challis and Hughes, 2003). Resource allocation depends on funding models, which in

Ireland tend to favour residential care over community-based care. Finding optimal levels of community and institutional care is further impacted by a lack of robust evidence on the relative cost-effectiveness of community and institutional provision. Information on what people get, where and when, is sparse and unit cost data is uniformly absent, especially in respect of community-based supports. This is particularly so for people with dementia where little is known about costs or outcomes in either community-based care or residential care facilities (Cahill et al., 2012).

Generating data on costs and outcomes for people with dementia is not an easy task in the absence of formal data collection procedures and systems. A number of cost-of-illness (COI) studies of dementia have been conducted worldwide, including Ireland (Connolly et al., 2014), and while these studies have provided decision makers with valuable information regarding the economic impact and broad cost components of dementia, less is known about the comparative costs of community and institutional care (Wimo, 2010, Schaller et al., 2015). Balance of care (BoC) studies offer a more nuanced and systematic approach to determining the optimal mix of services by focusing on the identification of groups of people whose dependency characteristics are such that they are at the margins of care between community and institution (Tucker et al., 2008). For these people, their care needs can potentially be met through providing enhanced community-based supports rather than by admission to long-stay care facilities (Challis and Hughes, 2002, 2003). One of the key aspects of the BoC approach, therefore, is to help identify how investment in community care, such as the HSE & Genio Dementia Programme, can impact on the "tipping point" for admission to long-stay care facilities. This approach provides decision makers with a strategic framework for exploring the potential costs and outcomes associated with changes in the overall allocation of resources to people with dementia on the margins of care. BoC research suggests that, all other things being equal, shifting the balance of resource allocation towards more community supports at the local level can reduce the risk of institutionalisation for some older people (Tucker et al., 2015).



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Current patterns of care for people with dementia in Ireland

It is difficult to get a precise measure of current patterns of care for people with dementia in this country. Services for people with dementia are not routinely disaggregated in the official statistics covering community care provision for older people in Ireland. In Ireland, community-based formal care for dependent older people is mainly funded by the state and is usually provided through direct HSE service provision and by private or voluntary agencies in receipt of state funding. An increasing, but so far undocumented, trend is for people to purchase home care directly from private care agencies, sometimes in response to the cutbacks in public community-based care that have occurred in recent years.

Similar to other categories of dependent older people, the HSE provides a small number of supports for people with dementia focused mainly on public health nurse visits, home help services and, in more recent years, home care packages to support people living at home. While public health nurses are the cornerstone of community care provision for older people, the reality is that only a tiny proportion of people with dementia living at home actually receive any services from this source. The vast majority of people with dementia living at home in the community have not even been diagnosed with the disease and those that have a diagnosis must compete with many other categories of need emanating from a variety of patient groups, young and old, for the time and attention of the public health nurse. Home helps provide assistance with day to day tasks such as cleaning, cooking, personal hygiene, housework, and increasingly with personal care tasks such as dressing and bathing. Home helps do not usually provide dementia specific services given the task-oriented nature of the support that they provide within the home. Overall, approximately 8 per cent of the population over 65 years received home help services with an average of 5 hours per week provided to recipients (Department of Health, 2015). So, even when people with dementia are in receipt of home help support, the amount of care provided is likely to be low.

Home care packages are now available in the community to support older people with medium to high dependency requirements, including people with dementia, through personalised care services such as nursing, physiotherapy and occupational therapy. As part of a recent review of the Nursing Home Support Scheme (NHSS), the HSE undertook an analysis of home care packages in four of the seventeen HSE Integrated Service Areas (ISAs) in Ireland (Department of Health, 2015). The analysis found that home care packages are currently being allocated and delivered in different quantities across the country; the number of home care packages ranged from 1,182 in Dublin North to 153 in Donegal. Some variation across counties is not surprising given population differences, but waiting times for these packages did vary by location and the level of service, measured in hours, often fell short of optimal provision (Department of Health, 2015). A further challenge to the delivery of a demand-led system of home care is the absence of a resource allocation system to calibrate demand against a finite budget over the course of a year.

In a new HSE initiative in 2015, linked to the National Dementia Strategy, approximately €10 million was made available for the provision of Intensive Home Care Packages, of which €3 million was allocated to dementia-specific supports, covering approximately 70 people with dementia by the end of that year. The packages were worth between €800 and €1200 per week and were focused on people with dementia in eight acute hospitals to facilitate their return to their own homes following treatment. However, that initial focus is about to change, as the HSE has concluded that once a person is discharged from hospital, carers are often too fatigued to resume caring for them at home, irrespective of the availability of a home care package. Consequently, for 2016, the HSE will prioritise people in the community at risk of admission to the eight acute hospitals, with a view to putting in place supports earlier in the care continuum, before people are admitted to acute care facilities.

Other generic community-based services are also available to people with dementia, but an even smaller number of people with dementia are likely to be in a position to avail of these services such is the general paucity of provision. For example, day care services and residential respite care are available in some areas, but dementia specific day care and respite care provision is very rare. Respite services, which are often affiliated with community hospitals, include short-stay beds for the purpose of respite, rehabilitation and transitional care. Day care centres provide a range of social activities and some medical services, while offering support and respite to carers. Voluntary groups and other community organisations play a significant role in addressing other issues for people with dementia, such as poor nutrition and social isolation, through services such as Meals-on-Wheels and Friends Groups. But provision is, once again, idiosyncratic and depends on local circumstances and organisation.

Although the number of people with dementia is expected to treble over the next 30 years as the population continues to age, dementia does not figure prominently in public health and social care budgets. There is no budget line for dementia, nor any measurement or accountability in respect of spending trajectories, targets or outcomes. The resulting funding weakness has led to a system of dementia care in Ireland that is characterised by an absence of dementia specific services and an over reliance on family carers who carry a disproportionate burden of responsibility in the absence of a comprehensive and integrated public response. The voice of PWD is also largely absent from the policy process, leading to a disconnect between policies and practices and the individual's experience of dementia and preferences for care. The social care system is inadequate, with critical links often missing in the chain of optimal support services available to meet the complex individual needs of these vulnerable people.

People with dementia often experience considerable difficulty accessing appropriate community care services (Cahill et al., 2012). In Ireland, early diagnosis and sometimes any diagnosis is the exception rather than the rule; the first point of contact with formal health and social services for people with dementia is often during an acute care crisis. Making good placement decisions during a crisis is more difficult than developing optimal care pathways in an orderly manner following a timely diagnosis. Even with the advent of the National Dementia Strategy, the majority of people with dementia receive very few in-home dementia-specific support services, and it remains to be seen whether the new dementia home care packages are comprehensive enough to address the vast amount of unmet need. Unlike home care services available in other countries (such as the UK, Norway, France and Australia), community-based services in Ireland, with the sole exception of the public health nurse, are not provided on a statutory basis. Knowledge about dementia in Irish society and, more worryingly, amongst health and social care professionals is also lacking (Cahill et al., 2012). The result is that services for PWD lack specificity, flexibility and depth. Personalised, comprehensive and accessible community-based services delivered by competent, well trained, staff are urgently needed. The reality is that progress has been painstakingly slow in recalibrating the social care system in Ireland towards a personalised, needs-led, person-centred model of care for PWD.

5 HSE & Genio Dementia Programme

The HSE & Genio Dementia Programme is designed to provide an innovative personalised response to the care of people with dementia in Ireland. Genio is a non-profit organisation which works to bring government and philanthropic funders together to support social innovation with a view to facilitating those who are socially excluded to live full and active lives in their own communities. So far, Genio has supported over 220 projects and has provided personalised supports to more than 5,500 people with disabilities, mental health difficulties and dementia living in communities across the country.

In 2011, Genio received a grant of €2 million from The Atlantic Philanthropies (AP) which, along with a matching contribution from the HSE, was used to support innovative, community-based, personalised care for people with dementia in Ireland. A major element of this grant was the development of dementia consortia in four local demonstration sites, the purpose of which was to build community-based, person-centred supports and resources for PWD and their families/carers. An expected outcome of the grant was that, through the delivery of personalised supports, PWD would be more engaged and enabled, resulting in them living well for longer in their own homes and communities, thereby diverting them from institutional care. After an in-depth and competitive screening and evaluation process the funding was used to support four innovative dementia projects. The selected projects were located in four distinct geographical areas (Mayo, South Tipperary, Stillorgan/Blackrock in Dublin and Kinsale in County Cork) and were hosted by different organisations across the care spectrum (Table 1).

Table 1: HSE & Genio Dementia Programme Sites

Project	Host Organisation
Living Well with Dementia (LWwD) in Stillorgan-Blackrock	HSE Dublin Mid-Leinster
Community Action on Dementia in Mayo (CADM)	Alzheimer Society of Ireland
The 5 Steps to Living Well with Dementia in South Tipperary	South Tipperary Mental Health Service
Kinsale Community Response to Dementia (K-CoRD)	Primary Care, Kinsale

This Dementia Programme is based on a "whole community" holistic approach to dementia incorporating a combination of formal and informal supports that offer the best opportunity for achieving an optimal outcome for the person with dementia and their carer. The four demonstration sites have implemented an integrated programme of individualized supports designed to enhance community-based living, thereby enabling PWD to live longer in their own homes and local communities.

As the dementia care journey can sometimes be complex and difficult to negotiate, the projects have focused on the co-ordination and integration of services across the care continuum. Facilitating integrated care provision in each of the four sites is a single point of contact or connection that allows for the matching of resources to need, care coordination, the identification of gaps in coverage and the linking of mainstream services with dedicated personalised supports from the projects. Individual supports have varied across the four sites but have always included the provision of information about dementia, the creation of care pathways and personalised respite care. The HSE & Genio Dementia Programme has succeeded in developing and delivering a range of holistic person-centred, flexible and responsive personalised supports and services that are largely determined by the PWD's needs and preferences (O'Shea and Murphy, 2014, O'Shea and Monaghan, 2015). These supports have enabled the individual to fully participate in his or her community and to continue enjoying activities of interest, while providing valuable support and respite to the carers (Table 2).

Social connection has been a major part of the programme, facilitating self-expression for people with dementia through their involvement and participation in a number of social activities based on their own preferences. A major focus in this regard has been on creating links in the community to the dementia population through working with local organisations and businesses to develop, maintain and sustain these connections (Table 3).

Table 2: Personalised Supports for people with dementia

Personalised Support for the Person with Dementia	
Description	In keeping with the innovative, person-centred nature of the projects, a mix of personalised supports was offered to PWD. These supports were normally delivered in the individual's own home, thereby giving some relief to family carers. Some of the supports were activity based in the sense that they facilitated the person with dementia leaving their home and engaging in personal and social activities in the community. Almost all of these supports were provided following an assessment process.
Delivery of Supports	Personalised supports were provided by support workers who were generally sourced through outside organisations such as ASI and Carers' Association and paid for by the innovative funding. In some places, funding was made available to partner with organisations to provide these supports. Support workers were matched to people with dementia based on common interests.
Training	Training was provided to support workers in the form of: Fetac Level 5 training; bespoke dementia training; and City & Guilds Dementia Awareness Award.

The HSE & Genio Dementia Programme has also recognised the need for appropriate, dementia-specific information and training to ensure that individuals caring for, or interacting with, PWD have the necessary skills to provide high-quality and effective care to the individual. The four sites have provided information events, training for volunteers and support workers, as well as developing dementia-specific reference material and guidelines.

Table 3: Social Supports for People with Dementia

Individual Support	Description
Befriending	Social befriending is provided by volunteers who are matched with PWD based on individual needs, preferences and common interests. Volunteers visit the person with dementia in their home and/or can provide transportation, enabling PWD to participate in various activities within the community. Volunteers are given dementia training, supervision and support.
Community Connecting	Community connecting is facilitated by project personnel in the form of community connectors and activity co-ordinators, support workers and volunteers. The projects have engaged with community organisations to promote community participation through supports and events, and support workers are available to provide transportation. PWD are enabled to re-engage with previous past times such as golf, and participate in community-based projects including music, dancing and art.
Connecting with others who have dementia	Space was provided by the sites for people with dementia to engage socially with their peers. PWD are able to participate in activities, and support workers are available to facilitate.
Activities	Choirs, Exercise Groups, Bridge Group, Arts and Crafts, Creative Writing, Memory Group

Assistive technology, which has the potential to reduce caregiver burden and increase independence for PWD, has also been used to augment person-centred care for people with dementia in the sites (Table 4).

Table 4: Technology for People with Dementia

Site	Advancing Technology	Type of Technology Provided
Stillorgan-Blackrock	Assistive Technology Expo Information Stands	Intruder Alarm Fall Sensors Safety Package GPS
Mayo	Generally supplied as requested as part of one to one support	Monitoring (Wander Reminder, door and bed exit sensors)
South Tipperary	Memory Technology Library	Fall Sensors Monitoring Memory Aid (e.g. specialist clock)
Kinsale	Demonstration Home Initial installation trial period	Ambient Assisted Living

6 Methodology

The purpose of the study was to calculate the cost of care for people living at home in the community with a view to shedding some light on how innovation on the supply side (the mix of services available within local contexts) can help shape care pathways for people with broadly similar levels of need. The HSE & Genio Dementia Programme allows us to take advantage of a comprehensive data set on current resource allocation for PWD living at home across four sites in Ireland to investigate boundary of care issues between community and residential care.

Our key baseline assumption is that without the Programme, there is a 50 per cent chance that all of the people who are currently on the margin between community-based care and residential care would be admitted to the latter in the medium-term. While this premise may be considered too strong by some people, it is based on the subjective probability risk rating of respondents and on individualised data using the Institutional Risk Trigger scale. Using this approach allows for an exploration of the potential economic gains associated with the Programme through its potential in postponing or preventing the admission of PWD into long-stay care facilities.

The HSE & Genio Dementia Programme developed incrementally, with the four projects working over a 3-year period to develop a more integrated provision of community-based supports for PWD within distinct geographical areas. Data was collected on PWD from the time they entered the project to the date of their discharge or final completion of the project. The study examines the costs and potential benefits of investment in community-based care, including the financial implications of placement decision-making, taking account of both formal and informal provision, as well as probability-based residential care alternatives. Knowing the cost of care for PWD on the boundary between community care and residential care will also facilitate better decision-making in regard to the optimal allocation of public resources necessary to support people to live well with dementia in their own homes.

6.1 Identification of PWD on the Margins of Residential Care

Two criteria were used to estimate the number of people who might be considered to be on the boundary between community care and residential care. First, the Institutional Risk Trigger (IRT) identified people within the HSE & Genio Dementia Programme who had impaired physical and cognitive functioning and therefore were at high risk of admission to residential care in the next six months. The IRT is part of the InterRAI suite of tools that Ireland is currently adopting for use as a Single Assessment Tool (SAT) for assessing the care needs of all older people in need of health and social care supports in the country. Any person with dementia who had at least four of the specified conditions on the IRT was considered to be on the margins of nursing home placement and therefore eligible for inclusion in the study. The second criteria used was a subjective Institutional Probability Scale, which asked care respondents their views on the likelihood of the person with dementia entering residential care in the next six months. This measure is aligned with the work of Wübker et al. (2014), where formal caregivers in that study made judgements on whether institutionalisation for people with dementia was likely, and to what extent, over the following six months. For our study, any person with dementia who scored 50 per cent or higher probability of admission to long-stay care within the next six months was included as part of our marginal boundary of care group. Any person who did not have either the Institutional Risk Trigger or the subjective Institutional Probability Scale completed was excluded from the analysis.

6.2 Cost Analysis

The cost of community care for people with dementia identified as being at high risk of institutionalisation includes the following costs: formal HSE services; personalised project supports; informal care provided by the families; personal consumption; and housing costs. Data on resource utilisation was collected in each of the four sites. Information on unit costs comes from a variety of Irish data sources; where necessary costs have been adjusted to 2013 prices (Table 5). Labour costs were calculated using consolidated salary scales available from the Department of Health for public-sector employees, with associated non-pay costs estimated according to the methods outlined in the Regulatory Impact Analysis guidelines issued by the Department of the Taoiseach (HIQA, 2015).

Table 5: Source of Unit Cost Estimates

Resource Activity	Activity	Unit Cost	Source of Estimates
Formal Health and Social Care			
Home Help (Not part of HSE Health Care Package)	Per visit	€19	Home help salary, Department of Health
PHN Visits	Per visit	€34	PHN salary, Department of Health
HSE approved Home Care Package	Per week	€274	Department of Health, Evaluation of HCP (2009)
Community Mental Health Nurse	Per visit	€35	CMHN salary, Department of Health
Meals on Wheels	Per meal	€8	Gillespie et al. (2014)
Other Community Organisations (ASI)	Per visit	€19	Home help salary, Department of Health
OT	Per visit	€29	OT salary, Department of Health
Respite	Per Week	€1139	Nursing Home Support Scheme
HSE & Genio Programme Supports			
Information Provision	Per hour	€45	PHN salary, Department of Health
Develop Support Plan	Per hour	€45	PHN salary, Department of Health
Befriending	Per hour	€16	Opportunity cost of time
Community Connecting	Per hour	€29	Project funding
Connecting with other PWD by choice	Per hour	€16	Opportunity cost of time
Paid Personalised Supports	Per hour	€33	Healthcare assistant salary Department of Health
Memory Assessment	Per hour	€186	Gillespie et al. (2014)
Dementia Advisor	Per hour	€29	Dementia Advisor, from project grant funding
Exercise/Physical Activity	Per hour	€12	Physiotherapist salary, Department of Health
Case Meeting/Case Conference	Per hour	€45	PHN salary Department of Health
Respite	Per hour	€33	Healthcare assistant salary, Department of Health
Day Care	Per visit	€109	Gillespie et al (2014)
Carer Group/Training	Per hour	€19	from project grant funding
Choir (Stillorgan-Blackrock)	Per hour	€13	Artistic Director, Choir, IUA Salary Scales
Creative Arts Support (Stillorgan-Blackrock)	Per hour	€14	OT salary, Department of Health; facilitator, Genio
Activities (K-CoRD)	Per hour	€16	Activities Co-Ordinator, K-CoRD
Informal Care			
Opportunity cost: caregivers in employment	Per hour	€21.73	Average Hourly Earnings Q4 2013, CSO
Opportunity cost: caregivers not in employment	Per hour	€5.43	Leisure Time (25% of Average Hourly Earnings)
Replacement cost: healthcare assistant	Per hour	€22	Healthcare assistant salary, Department of Health

6.2.1 Formal Care

Data on resource utilisation was collected on the following formal services and supports provided to people with dementia: home help visits; public health nurse (PHN) visits; home care packages (HCP); community mental health nurse visits; meals on wheels; other community organisations (e.g. ASI); day care and respite care. Data on the utilisation of formal supports from within the health and social care system was collected at intervals throughout the duration of the HSE & Genio Dementia Programme. The total cost of formal service provision is calculated by attaching the appropriate unit cost to the relevant resource activity and aggregating across all elements of provision.

6.2.2 Personalised Project Supports

The costs attributable to the HSE & Genio Dementia Programme include: personalised supports, social supports, respite and technology. Information was extracted from the clients' records on the following activities: the type and duration of personalised and social supports; the type and cost of technology items; and the type and hours of respite care. Where available, the market price for the resource items is used to cost the relevant resource. The costs for services such as befriending, which rely heavily on volunteer time, are based on the value of leisure time foregone (Drummond et al., 2005). For this analysis, 25 per cent of the average hourly wage is used as a proxy for leisure time to value the opportunity cost of volunteer time.

Drummond et al. (2005) noted that there is no unambiguously right way to apportion costs for shared resources. Indirect project costs such as programme management, administration, utilities, rental space, office equipment, etc. which are shared by multiple activity areas are allocated to the various resource items proportionate to the amount of time the project spent on each service. In allocating programme and administrative costs, it is assumed that project managers spent 50 per cent of their time on administrative duties and 50 per cent of their time providing individual supports. These overhead costs are reflected in the unit cost for each resource activity.

6.2.3 Informal Care

Informal care inputs were estimated from data provided by family carers on the total hours of informal support received by the person with dementia in an average day in respect of each type of support: activities of daily living (ADLs); instrumental activities of daily living (IADLS); and supervision. Gillespie et al. (2015) valued informal care using the opportunity cost method, as data was available on the labour force participation status for each caregiver. While in this analysis, the labour force participation status was not available for every carer, it was available for a sample of carers in each of the demonstration sites, thereby allowing us to extrapolate the results to the whole population of carers. The opportunity cost of time for caregivers categorized as employed is valued at €21.73, which was the average hourly wage for all industrial sectors in Ireland in 2013 (Central Statistics Office, 2013a). This valuation was used for the first 8 hours of caring if the carer was in full-time employment and the first four hours of caring if the carer was in part-time employment. Additional caring hours are costed the same as caring hours for informal caregivers not in employment. For those categorized as unemployed, the opportunity cost of time was valued at leisure time; a percentage (25%) of the average hourly wage equating to €5.43 per hour was used as a proxy for leisure time (Gillespie et al., 2015). Utilising the replacement cost method, each hour of informal care was valued using the equivalent market price of a close substitute. For this study, the market wage for a healthcare assistant (€22 per hour) was used to value replacement informal care.

6.2.4 Institutional Care

People with dementia in the HSE & Genio Dementia Programme were considered to be on the boundary of institutional and community care based on their IRT score and/or if their carers reported a greater than 50 per cent probability of them entering institutional care within the next six months. Therefore, when estimating the potential cost of institutional care as the alternative to community-based care, the potential time saved in LTC was calculated as the number of weeks the individual might have spent in residential care if the HSE & Genio Dementia Programme did not exist (time in the project by weekly cost of residential care by 0.5). The weekly cost of residential care is based on the average cost of public and private long-stay care in each of the four Genio sites. Private care estimates are based on the maximum weekly agreed prices for private and voluntary nursing homes available from the HSE under the Nursing Home Support Scheme.

6.2.5 Personal Consumption

People living in their own homes in the community expend resources in the personal consumption of items such as food, fuel, light and household maintenance. If those identified as being on the margins of residential care had in fact been institutionalised, these costs would be included as part of the direct costs of care by the institution. Recent studies (Tucker et al., 2015, Wübker et al., 2014) which were part of the RightTimePlaceCare project involving eight European countries included hotel costs in the costs of institutional care, but similar estimates were not available for the community care part of their work on a transnational basis. Wübker et al. (2014) suggest that the exclusion of personal consumption for people living in their own homes would diminish some of the differences between community care and institutional care costs, as this consumption could amount to 15 per cent or more of nursing home outlays. Personal consumption costs must, therefore, be included to make the costs of institutional and community care comparable. The costs of personal expenditures for people living in the community in this study are based on the Household Budget Survey 2010 estimates of household expenditures of a retired household inflated to 2013 prices using the CPI.

6.2.6 Capital Costs

Capital costs are normally included in the pricing structure of private nursing homes. For this reason, the cost of housing for people with dementia living in the community must also be calculated if valid comparisons are to be made between the cost of community-based care and residential care. The two components of capital cost are the opportunity cost of keeping the capital item another year, in this case the house, and the depreciation over time of the asset itself. One method of valuing major capital costs such as the cost of housing for those in the community is to calculate the equivalent annual cost by annuitizing the initial capital outlay over the useful life of the asset itself. In calculating the opportunity cost of housing in this study, the average price of housing in each of the four localities is used to determine the replacement value of the house. The analysis assumes a zero per cent interest rate, implying the increasing value of the house cancelled out any depreciation, over 50 years to calculate the equivalent annual cost.

7 Results

There were a total of 568 people with dementia who were assessed and available for inclusion in this study. Based on the boundary of care risk analysis, it was estimated that there were 181 people with dementia (32%) on the boundary of care between community and residential care (Table 6): 36 in Stillorgan-Blackrock, 38 in Mayo, 59 in South Tipperary and 48 in Kinsale. The mean age of the people with dementia on the boundary of care was 81 years. The average duration of time spent in the project for these people was 63.53 weeks or approximately 15 months. Their mean score on the Dependence Scale (DS) was 9.65 with a standard deviation of 2.85. The DS score ranges from zero, meaning not dependent at all, to 15, which would indicate a patient is fully dependent, so average dependence was relatively high overall.

Table 6: Descriptive Analysis: Sample Characteristics

Variable	Measure
N	181
Age in Years: mean (SD)	81.33 (8.01)
Male Female	39% 61%
Dependence Scale (0 min –15 max): mean (SD)	9.65 (2.85)
Living Alone	29%
Number of caregivers: mean (SD)	0.96 (0.18)
Caregivers in full time employment	20%
Weeks in the project: mean (SD)	63.53 (35.5)

7.1 Resource Allocation

Formal health and social care resource use among those with dementia on the boundary of community and residential care is shown in Table 7. Based on the data collected, there were approximately 13,000 support visits made by home help providers during the course of the HSE & Genio Dementia Programme. Just under 9,500 visits were recorded for public health nurses in the same timeframe. Less than half of people with dementia (47%) on the boundary of care between community and residential care received any visit from the home help services, while only 50% received a visit from the public health nurse. Only 12% of respondents received a home care package. Less than one fifth (18%) of people with dementia on the margin of care were attending day care. The picture is one of scarcity in regard to formal community-based provision, with many people not in receipt of basic nursing and home help coverage, even though their risk of institutionalisation was relatively high. This confirms our earlier description of community-based care in Ireland as being one of scarcity and fragmentation where there are likely to be large tranches of unmet need among people with dementia living at home.

Table 7: Formal Health and Social Care Provision During the Project

Formal Support	Number of Visits	Number of Clients Receiving the Service
Home Help	12,884	85
PHN Visit	9,483	91
Home Care Package (HSE approved)	1,043 (Weeks)	22
Community Mental Health Nurse	2,402	24
Meals on Wheels	2,539 (Meals)	9
Other Community Organisations (ASI)	3,293	18
Other (Day Care)	939 (Days)	26
Other (Respite)	7.71 (Weeks)	4
Other (OT)	418	22
Other (Nurse)	709	8

Table 8 shows the number of hours of individual and collective support provided through the HSE & Genio Dementia Programme to PWD on the boundary between community care and long-stay care. Personalised hours of support was a defining feature of the Dementia Programme and is different to existing formal provision, given the emphasis on the uniqueness of each person receiving the care and the social orientation of the services

Table 8: Personalised Project Supports (individual and collective) over the Duration of the Project (n=181)

Project Support	Total Hours
Information about Services for PWD	57
Information about Dementia for PWD	53
Develop support/care plan	150
Befriending	841
Community Connecting/Peer Support	1,515
Connecting with others who have dementia	5,076
Direct care hours	18,876
Memory Assessment	9
Support from dementia advisor	515
Exercise/physical activity support	1,351
Other	812
Case Meeting/case conference	30
Information about dementia	216
Information about services for MIC	260
Support from Dementia Advisor for MIC	241
Exercise/Physical activity for MIC	512
Other support for MIC	370
Choir (Dublin)	671
Activities (K-CoRD Only)	1,910
Creative Arts (Dublin)	71
Respite for the Carer	1,102
Total	**34,635**

that are provided. Personalised support which was flexible and responsive to the needs of the individual proved to be essential to enabling people with dementia to continue living at home, while promoting social inclusion and active engagement in their communities (O'Shea and Monaghan, 2015). Community connecting, befriending, social supports and communal activities (e.g. exercise, choirs and art workshops) were used to connect people with dementia with their communities and former past-times, while also helping the person to maintain and improve their physical and mental wellbeing communities (O'Shea and Murphy, 2014). A total of 34,635 support hours were provided over the duration of the Dementia Programme for this subgroup of 181 people. Over half of these hours (18,876) were delivered directly and uniquely to individuals, while one third was provided collectively to groups of people with dementia in different areas such as choirs, exercise classes and information evenings. Approximately 15% of the total provided hours were used to connect people with dementia to others with the disease.

Only a small number of people with dementia utilised assistive technology supports; 23 clients, or 8 per cent of people on the margin of care, accessed 31 assistive support items. The type of technology accessed is shown in Table 9.

Table 9: Technology Resource Use (n=181)

Type of Technology	Number of Items
Intruder Alarm	2
Fall Sensors	3
Safety Package	2
GPS	2
Monitoring (Wander Reminder, door and bed exit sensors)	13
Memory Aid	4
Ambient Assisted Living	4
Other (Supply and installation monitoring system)	1
Total	**31**

A total of 1,179,875 hours of informal care were provided by family and friends to people with dementia on the boundary between community care and residential care. On average, carers of people with dementia reported spending 15 hours per day providing informal care. If formal community-based care is characterised by its absence in this study, family care is the opposite and is the main bulwark of care for people with dementia.

7.2 Cost of Care

The total cost of on-going formal HSE supports was €1,429,171 (Table 10). Home help visits are the largest driver of costs for formal supports provided by the HSE, followed by public health nurse visits. The costs of day care visits and home care packages (HSE approved) are also substantial. The cost of respite care provided in community hospitals is small reflecting the fact that this support was only provided to a minority of people.

The total cost of the provision from the grant funding was €953,533 (Table 11). Paid Personalised supports are the largest driver of costs overall, approximately 3.6 times higher than collective supports. Technology was not a large contributor to costs, adding only €13,980 to total costs, due to the small number of clients utilising this support.

The total cost of housing for people with dementia on the margin of residential care for the time spent in the project was €780,221. The total cost of personal consumption over the duration of the project was €1,641,638. Including both consumption costs and housing costs raised the overall cost of care to €4,804,563 (Table 12).

Informal care was a major contributor to the cost of community care. Utilising the opportunity cost method, the total cost of informal care over the duration of the project for people with dementia identified as being on the boundary of care was €8,586,096. Alternatively, the total cost of informal care was €25,957,254 when the replacement cost method was used to value the care input. The total cost of community care when informal care is included is shown in Table 13.

The estimated weekly average cost of community care per person with dementia on the boundary of care between community and residential care, which includes HSE provision and the project supports, was €207 per week. When the costs of housing and personal consumption for

Table 10: Cost of Formal Provision

Formal Support	Total Cost[1]
Home Help	€734,401
PHN Visit	€322, 432
Home Care Package (HSE approved)	€285,673
Community Mental Health Nurse	€84,055
Meals on Wheels	€20,313
Other Community Organisations (ASI)	€62,559
Other (Day Care)	€102,355
Other (Respite)	€8,782
Other (OT)	€12,323
Other (Nurse)	€36,323
Total	**€1,429,171**

Table 11: Cost of Provision Funded by Grant

Support Type	Cost
Individual	€716,650
Collective	€198,659
Respite for the main informal carer	€24,244
Technology	€13,980
Total Grant-funded	**€953,533**

Table 12: Total Cost of Community Care

Cost	Total
Project Supports	€953,533
Formal HSE Services	€1,429,171
Personal Consumption	€1,641,638
Housing	€780,221
Total Cost	**€4,804,563**

[1] Home Help visits are assumed to have three hour duration; all other costs are calculated assuming a one hour visit to include travel and other associated costs.

people with dementia remaining in the community are included, the estimated average cost of formal community care per person with dementia increases to €418 per week (Table 14). Including the costs of informal care increases the average cost of care to €1,164 per week under the opportunity cost method and to €2,675 per week under the replacement cost method.

Table 13: Total Cost of Community Care (HSE, Project supports, Consumption, Housing and Informal Care)

Cost	Total
HSE + Dementia Programme + Consumption + Housing	€4,804,563
Informal Care: Opportunity Cost	€8,586,096
Informal Care: Replacement Cost	€25,957,254
Total Cost: Community Care (OC Method)	€13,390,659
Total Cost: Community Care (Replacement Method)	€30,761,817

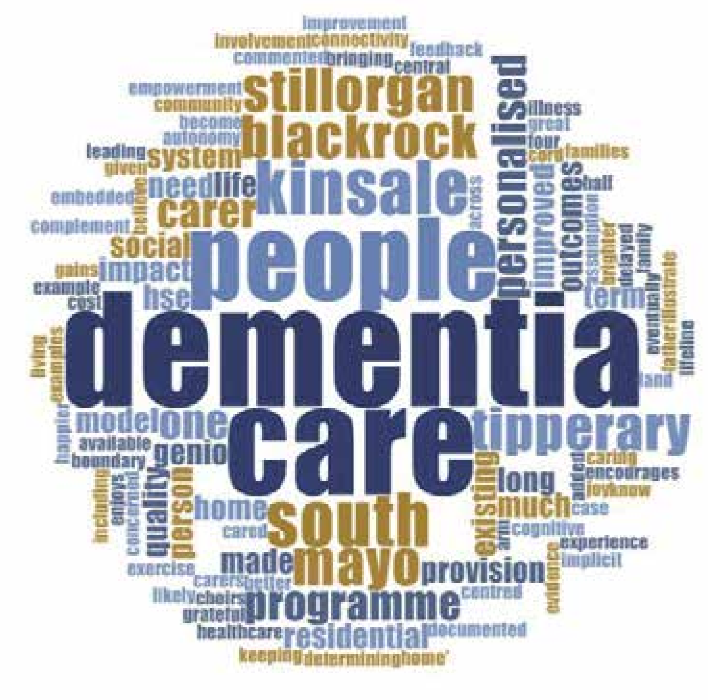
This paper also examined the potential cost of care if these clients had been institutionalised rather than cared for in the community. Our estimates suggest a potential total cost of €5,552,265 for institutionalised care, based on a 50 per cent chance of people ending up in long-stay care for the average length of time spent in the project (63.53 weeks). In contributing to potentially keeping people living at home for longer, the overall estimated potential savings associated with the programme was €3,169,561, if the comparison is only with HSE and project support services. The inclusion of personal consumption and housing costs reduces the cost-savings associated with keeping people living at home rather than in long-stay care to €747,702 over the duration of the project. The inclusion of informal care costs makes community care more expensive than residential care, marginally so when informal care is valued on an opportunity cost basis and significantly so when informal care is valued at replacement cost. Sensitivity analysis was also performed on a number of key variables without changing the overall trends in the results.

Table 14: Average Cost of Community Care for People with Dementia on the Boundary of Care

Average Costs	Without Informal Care	Opportunity Cost Method	Replacement Cost Method
Average cost per person per year	€21,726	€60,553	€139,106
Average cost per person per week	€418	€1,164	€2,675

8 Outcomes

This paper is only concerned with the cost of care for people with dementia on the boundary between community and residential care. The implicit assumption is that outcomes for people with dementia are similar, whether they are cared for at home or in residential care. But that may not be the case. Given what we know about the impact of the HSE & Genio Dementia Programme on dementia care across the four sites it is likely that outcomes have been improved for people living at home (O'Shea and Murphy, 2014, O'Shea and Monaghan, 2015). This is not surprising, since there has been significant recalibration of the existing care system towards a personalised model that respects and encourages personhood, autonomy, empowerment and social connectivity for people with dementia. Person-centred care has become embedded within the social care system, resulting in people with dementia and their families playing a much more central role in determining both need and provision.



The added value of the HSE & Genio Dementia Programme has been well documented (O'Shea and Murphy, 2014, O'Shea and Monaghan, 2015). A few examples will suffice to illustrate the origin and impact of the gains that have been made. In Stillorgan-Blackrock, a variety of personalised supports have been made available to complement existing healthcare services, including Cognitive Stimulation Therapy, physical exercise, and Musical Memories choirs, leading to an improvement in quality of life for those people in the project. In South Tipperary, there is qualitative evidence that their tailored 5-arm support model has delayed the need for long-term care for recipients and improved their overall quality of life. For example, one carer commented that, 'I believe the person I was caring for would have been in long-term care one and a half years before she eventually went in without the Dementia Programme'. In Kinsale, the feedback from people with dementia and their carers is that they see themselves in a better place now than before their involvement with the K-CoRD Dementia Programme. One carer in Kinsale spoke of his wife being 'much happier and brighter' as a result of personalised care provision. Similarly, in Mayo people with dementia are reconnecting with things that they used to do before the illness, bringing great joy, as referenced by a family carer talking about her father's experience 'grateful… enjoys walking the land, trips… lifeline that is keeping him at home'.

9 Discussion

This analysis explored data from the HSE & Genio Dementia Programme on the risk of institutionalisation, resource utilisation and costs for people with dementia who were on the boundary between community and residential care. The results suggest that increased investment in community care services, particularly in the form of personalised supports, can potentially impact on the balance of care for people with dementia. The average weekly cost of formal HSE services and the Dementia Programme supports combined was significantly less than the potential cost of institutionalisation for high risk people on the boundary of care between community and residential care. Including housing and personal consumption costs raised the cost of community-based care, but costs were still well below residential care alternatives. Not surprisingly, placing a monetary valuation on family care based on an opportunity cost methodology raised community care costs significantly; and to even higher levels when replacement costs were used to value the family care input.

The HSE & Genio Dementia Programme supported the development and testing of an integrated range of community-based services and supports that were largely determined by the needs and preferences of people with dementia. The Programme is unlike other interventions in that the supports offered are responsive to individual needs. A key feature of the investment has been the demonstration areas' ability to modify the supports throughout the life of the project and to adapt them to better meet the evolving needs of people with dementia based on learning from the programme and feedback from people with dementia and their carers. Moreover, over time, engagement with the HSE and other stakeholders has led to better integration of services and improved provision of formal services, such as home help services, in some places.

The cost of community care received by people with dementia on the margin of care between community and residential care is based on actual resource allocation rather than optimal allocation. Resource utilisation, particularly of formal HSE supports provided outside of the Genio Programme was subject to the availability of the resources in each of the sites and the vagaries of the allocation process therein. Hence, these formal supports may not always be meeting the needs and preferences of the individual in an optimal manner. There is evidence of fragmentation and curtailment in relation to community care services for people with dementia. Even when services are provided, it is not always clear that people are getting what they really need. There is a better chance that the HSE & Genio Dementia Programme supports were directly responding to the expressed needs of people with dementia and their family carers, given that the objective of the programme was to do just that, by providing more personalised supports to clients.

More generally, when estimating the cost of care in the community it is important to acknowledge that resource use in this area has typically been determined by the supply-side rather than by people with dementia themselves. Historically, home support from social care, through the HSE and local authorities in Ireland, has been provided largely in a 'generic' manner, rather than being tailored specifically to the needs of people with dementia. Changing to a demand- led model of care would require significant changes in supply-side structures and behaviours, including changes to information systems and work practices within the formal care sector. Flexibility in provision is a key ingredient in supporting people with dementia, including evening and night-time support. It would also leave open the possibility of developing a rich tapestry of tailored psychosocial supports in response to the expressed needs of people with dementia and their family carers. Finding out what people actually want and value is the first step in the development of this new model of care. That means asking people with dementia about their needs and preferences and then finding innovative ways to meet them once expressed. Ultimately, it is about professionals within the care system embracing the biopsychosocial model, which seeks to promote personhood through the integration of the biological and social approaches to caring for people with dementia (Clarkson et al., 2015). Mainstreaming the HSE & Genio Dementia Programme is the next step in the development of person-centred care for people with dementia in Ireland.

While this paper has focused on people with dementia on the boundary of care, it is often too late to change the trajectory of care when intervening at a point close to institutionalisation. In general, the impact of supply-side factors on the risk of long-term care placement over the course of a disease like dementia has not been given enough attention in the literature (Miller and Weissert, 2000). Local context plays a key role in shaping opportunities to age at home, particularly the willingness and ability of local government to reconfigure resources towards community-based care at earlier stages of the care continuum (Kuluski et al., 2012). Priority-setting really does matter and setting up viable, resource-intensive pathways to care for people at the earliest possible time in the trajectory of the disease can have far-reaching and positive consequences. Anecdotal evidence from the HSE & Genio Dementia Programme suggests that building confidence at an early stage of the illness that a person can continue to be supported at home in the longer-term, is likely to increase the probability that the person actually remains at home for longer. While this is an area that warrants further research, it is related to the concept of option demand (Weisbrod, 1964). This recognises the satisfaction and, therefore, the premium people might be prepared to pay for the option of consuming a particular commodity, in this case community-based care, in the future. If people know that services and supports are available should they need them in the future, it may be easier to contemplate living with dementia in their own homes for much longer.

Our results are consistent with previous studies which have identified higher costs in institutional long-term care settings compared to formal community care provision. Data from the RightTimePlaceCare project found that residential costs were higher than basic home care costs for eight European countries (Wübker et al., 2014). The study also found that home care costs are sensitive to the valuation of informal care. Leicht et al. (2013) suggest that the societal cost of caring for people in the community can be considerably higher than nursing home costs if informal care is taken into account. This is similar to our findings for people with dementia on the boundary between community and residential care.

There are some limitations with the present analysis. Data collection was collected locally, leading to variation in how some personalised supports were recorded and reported across the four sites. While data collection templates were provided for both formal and informal resource use, the fragmented and irregular nature of existing provision meant that it was not always possible to record retrospective activity with any great precision. For example, the data for public health nurses and home helps were only available in categorical visiting ranges, which were subsequently transformed into median estimates. Unit cost data was not available for some services and estimates were drawn from a variety of sources, which undoubtedly led to further imprecision. However, while the data underpinning the cost analysis is far from perfect, it is more comprehensive than what is currently available elsewhere in relation to community care services in Ireland.

Another potential limitation of the analysis relates to the valuation applied to informal care provided by family and friends. This study employed an opportunity cost approach which assigned a higher rate per hour to carers in employment than those not currently in employment. There is still some disagreement around the use of the opportunity cost approach for the valuation of caregiver time. Moreover, we did not differentiate between types of informal support; therefore, all tasks were valued at the same rate, irrespective of the level or complexity of the task. Supervision time was also valued and it was possible, therefore, to have carers reporting 24 hours of care per day (Van den Berg et al., 2004). In contrast to this approach, Wübker et al. (2014) placed a limit on the time informal carers could spend caring – up to a maximum of 16 hours per day assisting with ADLs and IADLs -and valued supervision time at zero cost. Finally, we did not address the benefits associated with caring, which may carry significant utility for some family carers. Consequently, our estimates of informal care costs may be further exaggerated as a result of not providing a monetary valuation of these benefits.

10 Conclusion

Personalised supports are likely to support family carers to continue caring for longer, through providing the person-centred care that is so necessary for optimal community-based provision. The results of this economic evaluation suggest that significant numbers of people with dementia could potentially be supported to live at home for longer as a result of the HSE & Genio Dementia Programme, thus resulting in savings to the exchequer when comparisons are made between public expenditure in the community and in residential care. Adding personal consumption and housing costs decreases the overall cost advantage associated with community-based personalised care. Placing a monetary valuation on informal care further increases the cost of community care, moving it slightly above the cost of residential care, based on an opportunity cost methodology.

Our conclusion is that any future investment in community-based care should learn from the success of the HSE & Genio Dementia Programme in responding to individual needs. The lives of people with dementia and their family carers have been enhanced and enriched by a more responsive and socially-oriented community care system. But community care is not cheap and it has depended for too long on the goodwill of family carers. Community care has a social cost for family carers. If we want to keep people with dementia living well at home then we need to provide family carers with greater supports than they currently receive.

The study has shown that it is possible to increase the availability of personalised supports to augment existing HSE provision and still not exceed residential care costs, even when personal consumption and housing costs are included in the analysis. Investment in personalised supports for PWD is good value for money for the HSE, especially for people on the boundary between community and residential care. The time is right to radically change the resource allocation system for community care in Ireland to reflect the social model of care. For a relatively small investment in innovative, personalised supports lives can be transformed and residential care costs postponed.

11 References

AFRAM, B., STEPHAN, A., VERBEEK, H., BLEIJLEVENS, M. H., SUHONEN, R., SUTCLIFFE, C., RAAMAT, K., CABRERA, E., SOTO, M. E. & HALLBERG, I. R. 2014. Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. Journal of the American Medical Directors Association, 15, 108-116.

CAHILL, S., O'SHEA, E. & PIERCE, P. 2012. Creating excellence in dementia care. A research review for Ireland's National Dementia Strategy. Dublin and Galway: Trinity College School of Social Work and Policy and National University of Ireland.

CENTRAL STATISTICS OFFICE 2013a. Earnings and Labour Costs. Dublin, Ireland: CSO.

CENTRAL STATISTICS OFFICE 2013b. Statistical Yearbook of Ireland. Dublin, Ireland: CSO.

CHALLIS, D. & HUGHES, J. 2002. Frail old people at the margins of care: some recent research findings. The British Journal of Psychiatry, 180, 126-130.

CHALLIS, D. & HUGHES, J. 2003. Residential and nursing home care—issues of balance and quality of care. International journal of geriatric psychiatry, 18, 201-204.

CLARKSON, P., GIEBEL, C. M., LARBEY, M., ROE, B., CHALLIS, D., HUGHES, J., JOLLEY, D., POLAND, F. & RUSSELL, I. 2015. A protocol for a systematic review of effective home support to people with dementia and their carers: components and impacts. Journal of advanced nursing, 72, 186-196.

COLOMBO, F., ANA, L.-N., JÉRÔME, M. & FRITS, T. 2011. Help Wanted? Providing and Paying for Long-Term Care: Providing and Paying for Long-Term Care, Paris, OECD Publishing.

CONNOLLY, S., GILLESPIE, P., O'SHEA, E., CAHILL, S. & PIERCE, M. 2014. Estimating the economic and social costs of dementia in Ireland. Dementia, 13, 5-22.

DE LA MAISONNEUVE, C. & MARTINS, J. O. 2015. The future of health and long-term care spending. OECD Journal: Economic Studies, 2014, 61-96.

DEPARTMENT OF HEALTH 1988. The Years Ahead: A policy for the Elderly. Report of the Working Party on Services for the Elderly. Dublin: Stationary Office: Department of Health.

DEPARTMENT OF HEALTH 2012. Future Health: A Strategic Framework for Reform of the Health Service 2012-2015. DOHC Dublin.

DEPARTMENT OF HEALTH 2014. The Irish National Dementia Strategy. DOH Dublin

DEPARTMENT OF HEALTH 2015. Review of the Nursing Homes Support Scheme, A Fair Deal. Department of Health, Dublin.

DRUMMOND, M., O'BRIEN, B., STODDART, G., TORRANCE, G. & SCULPHER, M. 2005. Methods for the economic evaluation of health care programmes: Oxford University Press. New York.

GENIO 2015. HSE & Genio Dementia Programme 2012-2018. Mullingar, Co. Westmeath, Ireland: Genio.

GILLESPIE, P., O'SHEA, E., CULLINAN, J., BUCHANAN, J., BOBULA, J., LACEY, L., GALLAGHER, D., MHAOLAIN, A. N. & LAWLOR, B. 2015. Longitudinal costs of caring for people with Alzheimer's disease. International Psychogeriatrics, 27, 847-856.

HIQA 2015. Guidance on Budget Impact Analysis of Health Technologies in Ireland. In: HEALTH INFORMATION AND QUALITY AUTHORITY (ed.). Dublin.

KULUSKI, K., WILLIAMS, A. P., BERTA, W. & LAPORTE, A. 2012. Home care or long-term care? Setting the balance of care in urban and rural Northwestern Ontario, Canada. Health & social care in the community, 20, 438-448.

LEICHT, H., KÖNIG, H.-H., STUHLDREHER, N., BACHMANN, C., BICKEL, H., FUCHS, A., HESER, K., JESSEN, F., KÖHLER, M. & LUPPA, M. 2013. Predictors of costs in dementia in a longitudinal perspective. PLoS ONE, 8(7): e70018.

MILLER, E. A. & WEISSERT, W. G. 2000. Predicting elderly people's risk for nursing home placement, hospitalization, functional impairment, and mortality: a synthesis. Medical care research and review, 57, 259-297.

NOLAN, A., BARRY, S., BURKE, S. & THOMAS, S. 2014. The impact of the financial crisis on the health system and health in Ireland. WHO/European Observatory on Health Systems and Policies Case Study.

O'SHEA, E. & MONAGHAN, C. 2015. Genio Dementia Programme Evaluation of Year 2. Galway: Irish Centre for Social Gerontology, NUI Galway.

O'SHEA, E. & MURPHY, E. 2014. Genio Dementia Programme Evaluation of Year 1. Galway: Irish Centre for Social Gerontology, NUI Galway.

OECD 2015. Addressing Dementia: the OECD Response. OECD Health Policy Studies. OECD Publishing, Paris.

PIERCE, M., CAHILL, S. & O'SHEA, E. 2014. Prevalence and Projections of Dementia in Ireland 2011. Mullingar: Genio Ltd.

PRINCE, M., BRYCE, R., ALBANESE, E., WIMO, A., RIBEIRO, W. & FERRI, C. P. 2013a. The global prevalence of dementia: a systematic review and metaanalysis. Alzheimer's & Dementia, 9, 63-75. e2.

PRINCE, M., PRINA, M. & GUERCHET, M. 2013b. World Alzheimer Report 2013. Journey of Caring: An analysis of Long-Term Care for Dementia.

PRINCE, M., WIMO, A. GUERCHET, M., ALI, G.C., WU, Y., PRINA, M. 2015. World Alzheimer Report 2015: The Global Impact of Dementia. London: Alzheimer's Disease International.

SCHALLER, S., MAUSKOPF, J., KRIZA, C., WAHLSTER, P. & KOLOMINSKY- RABAS, P. L. 2015. The main cost drivers in dementia: a systematic review. International journal of geriatric psychiatry, 30, 111-129.

TUCKER, S., BRAND, C., WILBERFORCE, M. & CHALLIS, D. 2013. The balance of care approach to health and social care planning: Lessons from a systematic literature review. Health Services Management Research, 26, 18-28.

TUCKER, S., HUGHES, J., BURNS, A. & CHALLIS, D. 2008. The balance of care: reconfiguring services for older people with mental health problems. Aging and Mental Health, 12, 81-91.

TUCKER, S., SUTCLIFFE, C., BOWNS, I., CHALLIS, D., SAKS, K., VERBEEK, H., CABRERA, E., KARLSSON, S., LEINO-KILPI, H. & MEYER, G. 2015. Improving the mix of institutional and community care for older people with dementia: an application of the balance of care approach in eight European countries. Aging & mental health, 1-12.

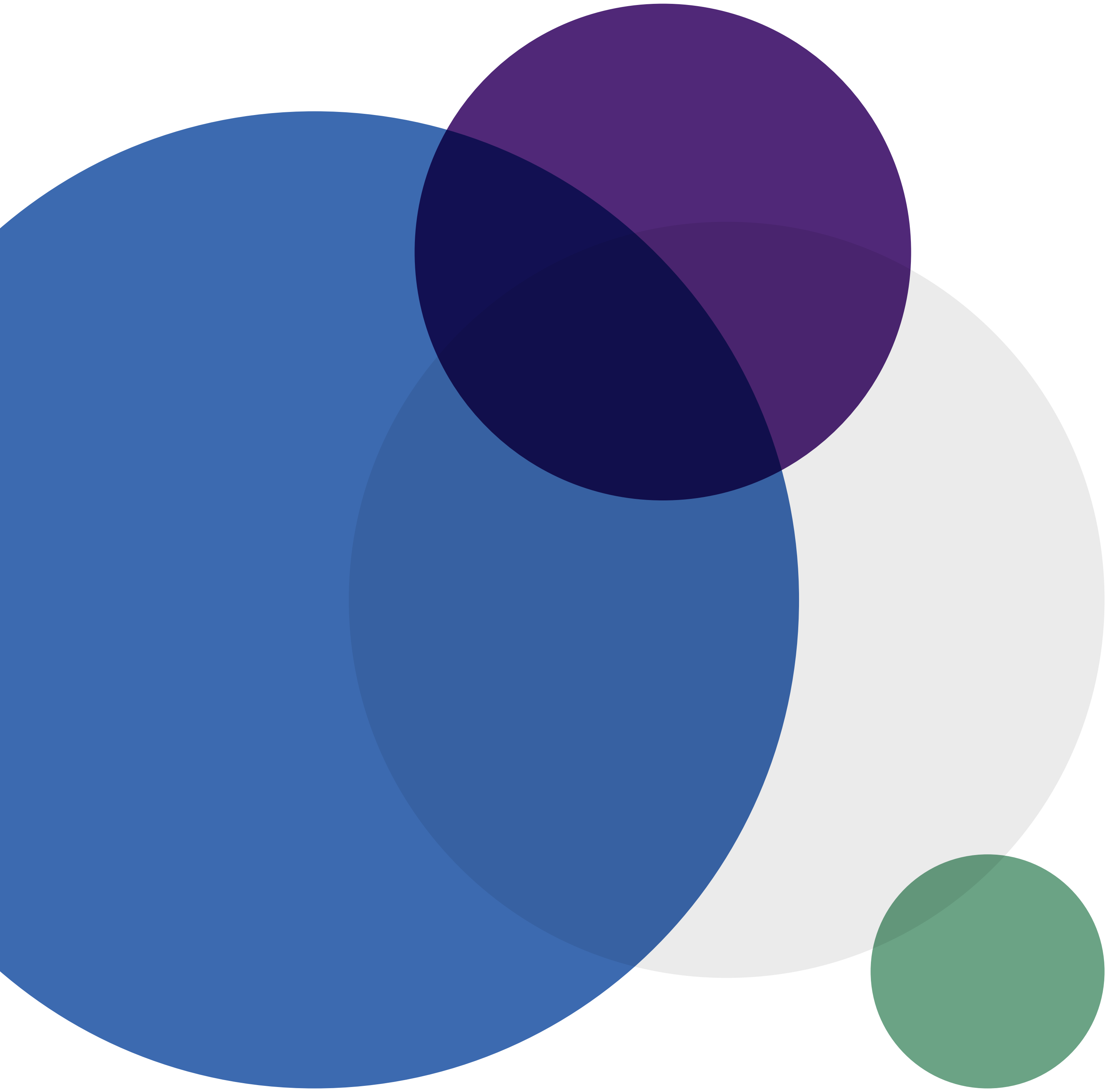
VAN DEN BERG, B., BROUWER, W. B. & KOOPMANSCHAP, M. A. 2004. Economic valuation of informal care. The European Journal of Health Economics, formerly: HEPAC, 5, 36-45.

WEISBROD, B. A. 1964. Collective-consumption services of individual-consumption goods. The Quarterly Journal of Economics, 78, 471-477.

WHO, A. 2012. Dementia: A Public Health Priority. Geneva: World Health Organization and Alzheimer's Disease International.

WIMO, A. 2010. The art of cost of illness. Journal of Alzheimer's disease: JAD, 19, 617.

WÜBKER, A., ZWAKHALEN, S. M., CHALLIS, D., SUHONEN, R., KARLSSON, S., ZABALEGUI, A., SOTO, M., SAKS, K. & SAUERLAND, D. 2014. Costs of care for people with dementia just before and after nursing home placement: primary data from eight European countries. The European Journal of Health Economics, 1-19.



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