Supporting Older People with Complex Needs at Home:

Report 2: What Works for People with Dementia?

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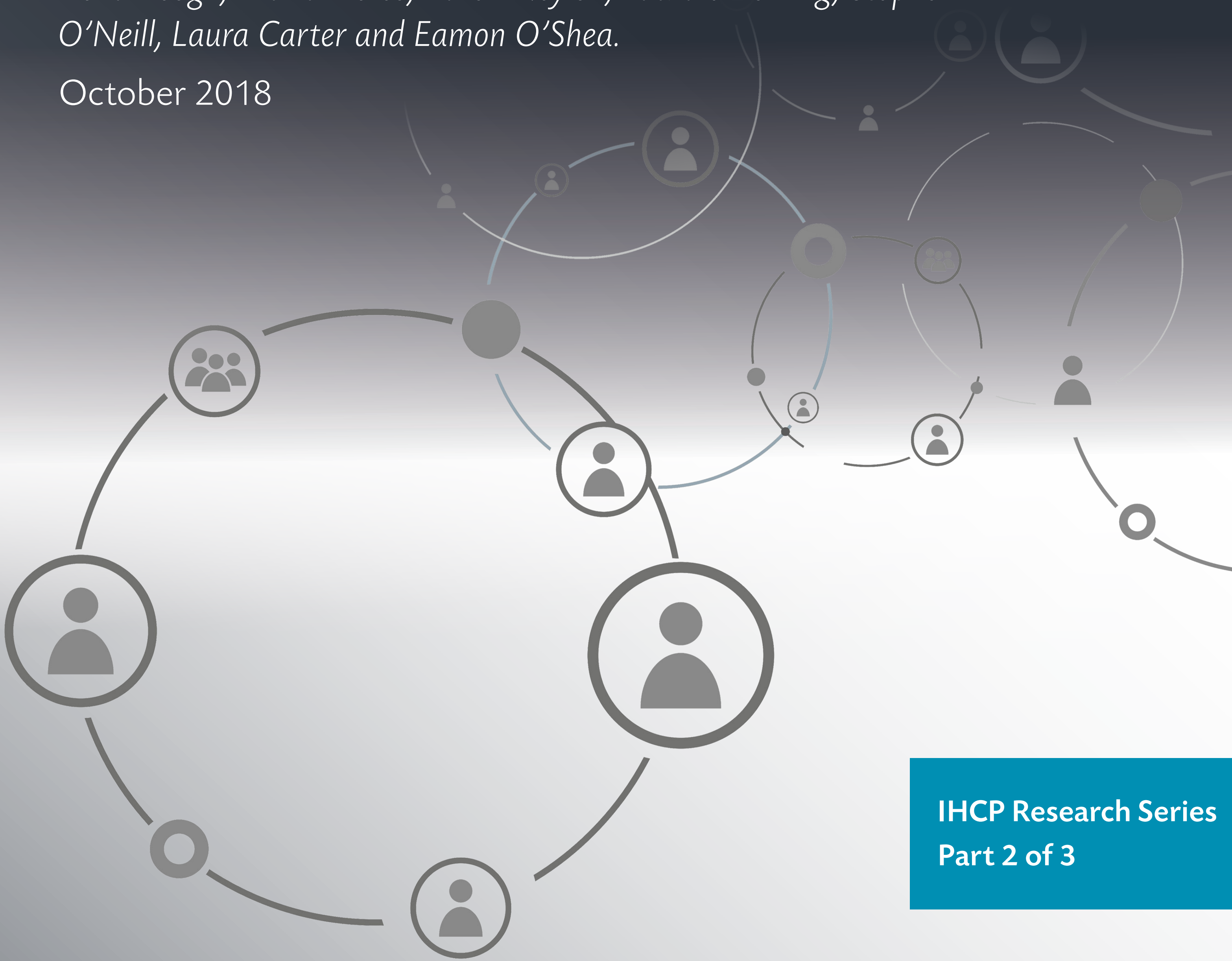

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Executive Summary

1. People with dementia are high users of home care but little is known about the profile of people who use home care, what is provided in home care, or how effective it is, in Ireland or internationally. This is particularly the case when considering the feasibility and effectiveness of home care for older people with complex needs, including those with dementia.
2. A substantial increase in the provision of home care is a key recommendation of both the Sláintecare report and the Health Service Capacity Review.
3. A sample of 42 people with dementia and family carers were identified from the group of 297 people with dementia who had a received an Intensive Home Care Package (IHCP) over the first three-year period of the IHCP initiative. The average age of the sample was 80 years, 24% lived alone, 74% were referred from the community 52% had severe dementia, 48% had at least one fall in the past year and 83% had high or maximum dependency as measured by the Barthel Index. This sample was largely representative of the whole group of people with dementia who had received an IHCP.
4. The initiative demonstrated that it is feasible in an Irish context to support people with a high level of complex needs at home, including people with dementia. The evaluation found that the delivery of intensive home care was effective at maintaining people with dementia at home for an average of 42 weeks in this sample, which is longer than anticipated. The range was from 1 week to 159 weeks.
5. IHCP recipients with dementia were less likely to be admitted to LTC and less likely to have died than similar recipients without dementia. These results may be attributable to unobserved differences in health status between the groups that were not captured by the Barthel Index. However, further research is necessary to examine how and whether disease classification matters for the effectiveness of IHCPs.
6. The quality of life of the person with dementia did not deteriorate significantly for the majority of the sample which is important considering the progressive nature of dementia. The carers' rating of the person's quality of life improved slightly but not significantly after the commencement of the package.
7. The majority of carers and people with dementia were satisfied or very satisfied with their package. The quality of life of carers was also maintained with the package for the majority.
8. Family burden decreased slightly but not significantly as measured by average scores before and after the commencement of the package. However, burden is a complex construct and is also affected by other demands and stresses in the carer's life.

9. At the outset, there was no way of knowing if the IHCP Initiative would result in changes to the way in which home care was organised for people with dementia. To examine what, if any, changes occurred, a typology of dementia-IHCPs was derived from a systematic examination of data relating to 42 IHCPs. The typology comprises three distinct types of packages, demonstrating the main ways in which services went about organising dementia-IHCPs in response to the IHCP Initiative. These are summarised in the table below. It is important to emphasise that these types were not in place at the beginning of the initiative as options to choose for different individuals. This range of different responses that were implemented in the production of home care and the differing content of the package types, is new to the Irish system. It indicates that a major shift in home support services is occurring through the IHCP Initiative, with a move away from a 'one size fits all' approach to one where different formulations of care are being used to address different needs of the person with dementia and family caregivers. This new understanding could very usefully influence how home care is delivered in the future, with the possibility of matching care more closely to the needs of the person and family.

Typology of dementia IHCPs formulated from study data		
Classic	**Block**	**Combination**
Shorts visits Focus on personal care	Blocks of hours Support person; Support carer to work/with respite	Short visit + Block Personal care + carer respite + meaningful occupation for person
94% 75+ years Chair/Bedbound High/Max dep: 95% 56% Severe dementia	54% 75+ years Mobile, but difficulties High/Max dep: 77% 54% Severe dementia	66% 75+ years ¼ Chair/Bedbound High/Max dep: 75% 50% Severe dementia
Average hours per week (range)		
36 (28-56)	35 (14-48)	29 (13-42)
Average cost per week (range)		
€826 (€634-€1,268)	€819 (€317-€1,176)	€652 (€294-€951)

10. The packages worked well for families when: home care workers were well trained, particularly in relation to dementia care and person-centred care; when there was certainty in terms of scheduling; when there was consistency in terms of carers and continuity of care; when hours were organised so that there was time for a break for the carer; and when there was good communication between the provider and the family.

11. The main elements of 'care' available to the person were; IHCP hours (average 34 per week), informal care hours (average 80 hours per week) and private care hours purchased by the person/family (average 19 per week). People with dementia in this sample were relatively low users of community care services. The most frequently used community service was public health nurses (PHNs) with 61% of the sample seeing a PHN in the month prior to interview. Use of outpatient and inpatient services was very low at around 10%.

12. The average cost of an IHCP for this sample was €774 per week, with lower and upper limits of €294 and €1,268 respectively. Private care cost €391 on average per week. Informal care cost €593 on average per week using an opportunity cost method and €1,811 on average per week using a replacement cost method.

13. The estimated weekly average cost of home care per person with dementia in this sample was €1,124 per week (this includes IHCP hours, primary and community care, consumption and housing). The average weekly cost of long-stay care in residential settings ranges from €1,526 in public facilities to €909 in a private nursing home outside Dublin and €1,149 in private nursing homes in Dublin.

14. Adding family care inputs to care, valued using an opportunity cost methodology, raises the average cost of home care to €1,717 per week. Adding private out-of-pocket expenditure for care increases home care costs further to €2,108 per week.

15. Informal care and private care combined account for 47% of overall costs for people with dementia living in a community setting.

16. A striking finding from the study was the strong family commitment to caring. This was evidenced by the quantitative data showing a high level of family care hours provided and also the funding of private care by families. The qualitative data gave an insight into why carers are so committed, with the main reasons being to honour the wishes and preferences of the person, a strong belief that home was the right place for the person, a distrust of care in nursing homes or poor experience of care in nursing homes.

17. The overall picture of care from this study is that home care in Ireland is a family care system which, even at this high level of formal care from the IHCP, is only being supplemented by the state. The input from families is substantial and is

not replaced by the IHCP. If we want to support older people to remain at home as their needs increase, significant hours of care, as provided by the IHCP are required, but they are effective in keeping the person at home.

18. Privately-funded home care is an evolving part of the home care landscape in Ireland. This presents the possibility of inequities in the future if there is an over-reliance on privately funded care which may not be within the reach of all families.

19. There were some very good examples of IHCPs that had the hallmarks of personalisation. With training for key personnel and attention to issues such as communication and continuity of care, there is significant potential to make this a reality for all home care. Personalisation did not rely on the number of hours of care but was a function of the skill level of providers and home care workers and the attention paid to understanding the person, joint decision making and good interpersonal relationships.

20. Our results indicate that investment in IHCPs can keep people living at home for longer, including people with significant levels of disability and cognitive impairment. However, even with significant additional spending on intensive home care packages, informal care and, increasingly, private care are still needed to keep people with dementia living at home for longer. Home care in Ireland is essentially a family care system, which is being supplemented by the state. Without families, it is difficult to see the community care system as being a viable alternative to residential care. This makes the provision of responsive, personalised support to older people, people with dementia and their families all the more important to ensure the home care into the future.

1. Introduction

In 2014 the Health Service Executive (HSE) Older Persons' Services began a process of strategic realignment of the existing model of care towards home care and community support services. A key driver of this strategy was the provision of €10m funding to address pressures on acute hospitals through the allocation of individualised Intensive Home Care Packages (IHCPs), providing a greater range and level of services to the older person and their families (HSE 2014). This IHCP initiative also aligned with the *Irish National Dementia Strategy* (NDS) (Department of Health 2014).

Following the publication of the NDS at the end of 2014, the HSE and The Atlantic Philanthropies jointly developed and invested in a programme aimed at supporting the implementation of the strategy. *The National Dementia Strategy Implementation Programme* (NDSIP) has three priority action areas, one of which is the further development of integrated services for people with dementia – particularly home support. Under this action, the HSE, as part of its IHCP initiative, prioritised the roll-out of IHCPs for people with dementia in nine sites across Ireland over three years (2015-2017). A fund of €20.5m from Atlantic Philanthropies, the HSE and the Department of Health was made available to deliver dementia-IHCPs over three years. A key feature of the dementia-IHCPs was that they were to be flexible and tailored to the assessed needs and preferences of the person with dementia and their family members, with the aim of personalising service delivery.

An evaluation and support arrangement was built into the NDSIP. Under a Service agreement with the HSE, Genio's role was to:

1. Support the HSE in the development of a suite of indicators for IHCPs and related data collection tool and provide on-going data analysis and reporting of IHCPs, with a particular focus on dementia-IHCPs. The data from this part of the work is the subject of **Report 1**, titled *Supporting Older People with Complex Needs at Home: Evaluation of the HSE Intensive Home Care Package Initiative - Context, Recipients and Costs* (Keogh, Pierce, Neylon, Fleming, et al. 2018) which can be found here www.genio.ie/dementia-report1-ihcp
2. Design, manage and undertake an in-depth study of a sample of dementia-IHCPs to evaluate their effectiveness and how well they are working. The conduct and findings of this in-depth study are the subject of this **Report 2**, titled *Supporting Older People with Complex Needs at Home: What Works for People with Dementia?* www.genio.ie/dementia-report2-ihcp
3. Support the HSE in the implementation of personalised dementia-IHCPs. Genio Programme Managers have been working collaboratively with multidisciplinary groups in eight sites (Cork, South Dublin, Galway, Dublin North City, Waterford, Limerick, Dublin South West and Dublin North), to promote a personalised response to home care, by creating and testing enhanced pathways for delivery. This work is still underway and will be reported in **Report 3,** *Recommendations: Developing Personalised Supports that are Integrated for People with Dementia* www.genio.ie/dementia-report3-personalised

1.1 Evaluation objectives

Strands 1 and 2 are primarily concerned with evaluating IHCPs and providing hitherto unavailable detail on *who uses home care* and on *what type of care is provided.* The evaluation is designed to address key objectives to inform the future development of home care.

The first report in this series described in detail the IHCP initiative, the policy background and the complex service context within which the initiative is delivered. A unique Irish dataset was collected for the evaluation of this initiative, providing a prospective longitudinal cohort of all recipients of IHCPs over a three-year period 2015-2017 inclusive. In the first report, the 505 recipients of IHCPs were described in detail, including the 297 people with dementia who received an IHCP over the three-year period of the initiative. The outcomes and costs of all IHCPs were also described. The following objectives have been addressed in **Report 1**:

- Examine the existing arrangements that have been developed nationally for the delivery of IHCPs;
- Identify the key components of IHCPs and characteristics of recipients;
- Investigate differences between the three groups of people in receipt of IHCPs (i.e. people with dementia, older people without dementia and younger people with disabilities);
- Establish the costs of IHCPs for these three groups of recipients from a funders (HSE) perspective;
- Investigate the factors driving variations in costs;
- Compare the costs of IHCPs vis-à-vis acute hospital care and long-stay residential care.

This report describes the findings from an in-depth study of a sample of people with dementia who received an IHCP, which is the second strand of work described above. The aim of this part of the evaluation is to obtain a greater insight into individual outcomes and to carry out a more detailed examination of how IHCPs worked in practice for people with dementia.

The following objectives are addressed in **this report**:

- Identify the key components and characteristics of IHCPs for people with dementia, and their association with specific outcomes for people with dementia and their family carers;
- Contribute to an understanding of 'what works, for whom, under what circumstances' with respect to IHCPs for people with dementia, with a focus on user satisfaction and quality of life;
- Identify the outcomes for people with dementia and their family caregivers in receipt of IHCPs;
- Determine the costs of IHCPs for people with dementia from a societal perspective and compare the costs of IHCPs vis-à-vis acute hospital care and long-stay residential care;
- Establish the costs of both informal care-giving and financial contribution of families to care for people with dementia with complex needs in receipt of IHCPs.

Work in Strand 3 is still underway and will be reported in **Report 3,** *Recommendations: Developing Personalised Supports that are Integrated for People with Dementia*

2. Background

Dementia is an age-related condition. The challenge posed by dementia, which is the confluence of increasing life expectancy, population growth and the lack of curative treatments, has been well documented (WHO 2012, Prince et al. 2015) . The overall societal cost of dementia is high, estimated at US$818 billion globally (Prince et al. 2015) and at €1.69 billion in Ireland (Connolly et al. 2014). Although the personal impact of dementia has been documented for both the individual and the carer (Livingston et al. 2017), less attention has been placed on the combination of services and supports needed by the person and family throughout the dementia journey (Dawson et al. 2015).

In Ireland, it is estimated that there are approximately 55,000 people with dementia, the majority of whom are women. While it is not known for certain how many are living at home in the community, the best estimate is 34,818, but many of these people will not have received a diagnosis of dementia (Pierce and Pierse 2017). There is uncertainty with regard to the levels of severity of the condition among those people with dementia. However, it has been suggested that just under 8,000 people with dementia living at home have severe to advanced dementia that requires significant support from the health and social care system. It has also been estimated that between 7,000 and 11,500 community-dwelling people with dementia are living alone, who could potentially be more vulnerable and have more unmet needs than those living with others (Pierce and Pierse 2017).

It is the preferred wish of most people with dementia to continue living in their own homes for as long as possible. In December 2014, the Irish government published its first National Dementia Strategy (NDS), which supports this preference (Department of Health 2014). It stated that: *"People with dementia should be facilitated to remain living in their own homes and to maintain existing roles and relationships for as long as possible ..."* (p. 24). The provision of integrated home care services is a priority action of the Strategy, which is underpinned by the dual principles of personhood and citizenship.

2.1 Home care services for people with dementia

The main formal services underpinning the policy aim of supporting people with dementia to remain at home, are home help services and the Home Care Package (HCP) scheme. Since the beginning of 2018 these have been combined into *Home Support Services*[1]. Since family carers provide the bulk of care, formal home care comprises a small component of overall home care (Murphy et al., 2015) and only a small proportion of older people in Ireland use state-funded formal home care services. This is evidenced by the TILDA study, which estimated that 8% of older adults In Ireland use home help services, with utilisation increasing gradually with age (Murphy et al., 2015). Almost half (45%) of those using formal home care had no self-reported difficulties with activities of daily living such as washing dressing etc. (ADLs), highlighting an 'apparent

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[1] Home support services have been described in detail in Report 1. The change from home care to home support services has only happened since January 2018. As the study is on intensive home care, and this new term still has limited awareness, we use the term home care throughout this report.

mis-targeting' of home care services to this group of older people (Murphy et al., 2015). This is consistent with findings from another Irish study showing that 37% of older adults in receipt of home help services were assessed by community nurses as being independent (Kelly et al. 2017). However, relying solely on ability in ADLs as a measure of need for home care is problematic as needs in other areas, such as supervision with medication or help with cooking a meal, can be missed, especially for people with dementia. Increasing age, living alone, greater difficulties with activities of daily living (ADLs), and receipt of informal help were the most significant predictors of home care use in this study (Murphy et al. 2015). It is clear that a range of factors other than need come into play in the decision to allocate formal home care services to an individual. Little is known about the type of care that is provided, although due to the scarcity of home care hours, there is an emphasis on task-oriented care (Dempsey, Normand, and Timonen 2016), illustrated by the half-hour or hourly slots typically allocated for home care workers' time with clients.

While only a small proportion of older adults in Ireland use formal home care services, an audit of older people receiving state-funded HCPs in one local area of Dublin found that people with dementia make up a sizeable proportion of this group. O'Brien et al. (2017) found that 37% of those receiving HCPs were recorded as having dementia and received on average 13 hours of home care per week (O'Brien et al. 2017). When older adults with and without dementia were compared, significantly fewer people with dementia were found to be self-caring and had significantly higher weekly home care hours, by an average of an additional two hours per week. While dependency levels, as measured by the Barthel Index, did not differ significantly between the two groups, people with dementia were more likely to have communication difficulties (O'Brien et al., 2017). Reliable data on the use of home care by people with dementia are not available nationally (Cahill, O'Shea, and Pierce 2012).

The concept of a continuum of care in the community involves an array of services that are coordinated and responsive to need. Simply put, those with lower need get a lower level of service and those with higher needs get a wider array and a greater quantity of services. This ideal relationship between need and level of service does not always exist in relation to community care services for a variety of reasons. There may be geographical gaps in the type and amount of service available in different areas; people who need services may not be in contact with services; and people may not want to use the services on offer. A lack of standardised assessments for services also means there may not be a consistent relationship between a person's needs and the amount of service they receive. The introduction of the single assessment tool (SAT) should help address this gap. In the context of home care, IHCPs are at the highest end of provision in the continuum. This study gives us a unique insight into the range and type of care provided to older people and people with dementia at the high needs end of the continuum of care.

2.2 Hospital admission and dementia

Dementia is common among older people admitted to acute hospitals; about 29% of older people admitted to public hospitals in Ireland have dementia (Timmons et al. 2015). People with dementia typically have longer length of stays in acute hospitals (Connolly and O'Shea 2015, Timmons et al. 2015) and their outcomes are generally poorer than people without dementia (Sampson et al. 2009). Frail older people, and particularly people with dementia, can acquire a range of 'geriatric syndromes' in the course of a hospital admission, namely, delirium, falls, incontinence, poor nutrition, immobility, functional decline and pressure sores (Long et al. 2013). The sometimes-devastating impact of a hospital admission for a person with dementia is described very well in the case of Dr John Gerrard, whose hospital experience inspired the establishment of John's Campaign in England (John's Campaign, 2014):

> *Dr John Gerrard was diagnosed with Alzheimer's in his mid-seventies. He went into hospital at age 86 because he had infected leg ulcers which weren't responding to antibiotics. He was there for five weeks. John Gerrard went into hospital strong, mobile, smiling, able to tell stories about his past, to work in his garden and help with things round the house. He was able to feed himself, to go the lavatory, to keep clean, to have a good kind of daily life. He came out skeletal, incontinent, immobile, incoherent. He required 24-hour care and barely knew those around him. He wore a nappy, could not stand up or walk, could not lift a mug to his mouth or put words into a sentence.*

A comprehensive, integrated, well-resourced system of community care services, including home care, is required to support people with dementia to remain living at home for as long as possible, to facilitate timely discharge home after an acute hospital admission and to support the avoidance of unnecessary admission (WHO 2012).

2.3 Carer burden in dementia

The bulk of care to people with dementia living at home is provided by family members. The largest proportion of cost falls on family or informal carers (48%), with 43% attributed to residential care costs (Connolly et al. 2014). This caring can come at considerable emotional and financial cost (Joling et al. 2015, Wimo et al. 2011). In the Irish De-Stress study (Brennan et al. 2017) 36% of spousal carers of people with dementia reported moderate to severe levels of burden while 9% had severe burden. Most spousal carers (79%) reported that they themselves provided 81% – 100% of the care for their spouse and 15% said they had given up their jobs in order to care for their spouse.

In a seminal paper on caregiver stress in dementia, (Pearlin et al. 1990) described caregiver stress as a process with a number of interrelated components; primary stressors (objective demands of care-giving); secondary stressors (for example effects on relationships and the carer's emotional response to care-giving) and the family context and background (such as the support network, income, employment etc.). Using this model, we see carer burden as a multi-dimensional construct with at least two elements; care demands (objective burden) and the carer response (subjective burden), occurring within a specific context. Care demands include basic activities of daily living (ADLs) such as washing, dressing, toileting and eating; and instrumental activities of daily living (IADLs) such as cooking, cleaning and shopping. The person may just require support or may be completely dependent on the carer for these activities. Another care demand is coping with the behavioural and psychological symptoms of dementia (BPSD). These can include agitation, aggression, disinhibition, repetitive motor behaviours, wandering, anxiety, depression and hallucinations. The emotional and psychological response of the carer to these care demands is related to the level of objective burden (ADLs + BPSD), but also depends on intrapersonal characteristics of the carer, such as their coping skills and resilience, and the other demands and stressors in the carers life. Both the objective care demands, and subjective response of the carer constitute what is typically measured as 'carer burden'.

In several studies, BPSD have been found to be the strongest predictor of carer burden, followed by physical/functional dependency and lastly cognitive impairment (Bass et al. 2012). The timing of the occurrence of care demands in dementia is important in considering supports for family carers. The decline in functioning, such that the person is dependent on others for all activities of daily living, tends to be a feature of the later stage of dementia or severe dementia. There is a particularly physical aspect to caring at this stage which can be exhausting. BPSD are usually most predominant in the moderate stage of dementia about 3-4 years following diagnosis (and at early stages depending on the dementia sub-type). BPSD are more distressing because they are unpredictable, disruptive, potentially embarrassing or abusive, sleep depriving and difficult to manage (Cheng 2017). The person is usually still mobile which means constant supervision may be required. The relationship between BPSD and greater carer stress is supported by recent evidence from an Irish study (Pertl et al. 2017).

The particular demands associated with BPSD, which are not typically present in a consideration of a general older population, and the timing of different needs in the course of dementia, set people with dementia apart in important ways from the general older population. Thus, measures which are focused predominantly on physical dependence, may not fully capture the high level of care demand on a carer of someone with BPSD. Similarly, an assumption by virtue of the terms, that someone with *severe* dementia will have more care needs than someone with *moderate* dementia, may also underestimate the different care demands at these stages.

We need to better understand the nature and timing of care demands, the wider context of the carers' life and their emotional response, in order to target supports such as home care more effectively. The limited evidence on home care from Ireland, although there is significant qualitative evidence from this study in support, is that most of the focus on home care in Ireland is on providing supporting with personal care or ADLs, which is just one of the several demands on carers. Our understanding of how best to support carers of people with dementia can be based on somewhat simplistic assumptions, for example, that there is a linear relationship between formal care and burden such that more formal care means less burden for the carer, or that once the person is in residential care, burden and negative impacts cease. However, the literature suggests that these relationships are more complex (Gaugler et al. 2009). We also know little about what type of formal care might be most effective at addressing carer stress. This study uses both quantitative and qualitative methods to gain a better understanding of how the content and amount of formal care may affect carer burden.

2.4 Realist evaluation

Evidence on the effectiveness of community based services supporting people with dementia living at home is limited and systematic reviews point to many gaps in the evidence base (Dawson et al. 2015). The best outcomes for people with dementia are associated with services that are timely, responsive, flexible and tailored to individual need (Dawson et al. 2015). Systematic reviews have noted the heterogeneous nature of social care interventions, populations and methodologies and the challenging nature of conducting effectiveness research in this area (Boland et al. 2017).

This evaluation of the IHCP initiative was tasked with addressing the question of effectiveness – does this initiative work? This question is usually addressed through studies which compare two groups – one of the groups gets the intervention and the other does not. It has been argued that such designs are excellent to assess the effectiveness of highly structured interventions in controlled situations but they do not necessarily provide sufficient or valid information when applied to complex and dynamic systems such as healthcare organisations (Sturmberg and Martin 2009, Fiss 2007).

The complexity of the IHCP initiative and the system within which it operates have been described in detail in Report 1 (Keogh, Pierce, Neylon, Fleming, et al. 2018). This complexity presented a challenge to conducting a highly controlled evaluation and was further compounded by (i) the lack of accessible comparison groups to conduct a controlled trial; (ii) the need for evidence that addresses the variability in the population of interest (people with dementia and family carers); (iii) the variability in the delivery of IHCPs; and (iv) changes to the initiative in response to the initial roll out (Keogh, Pierce, Neylon, and Fleming 2018). Realist evaluation (Pawson 2013, Pawson and Tilley 1997, Pawson 2006) addresses some of these concerns about the limitations of effectiveness research designs and specifically addresses questions that are of key concern to decision makers; what works, how, in which conditions and for whom, rather than simply – does it work?

Realist evaluation is increasingly used in the assessment of complex interventions (Wong et al. 2012). It operates at the 'middle range' *"using concepts that describe interventions at a level between big policy ideas and the day-to-day realities of implementation"* (Pawson and Tilley, 2004, p.18), hence it is particularly useful for the evaluation of IHCPs. A realist approach to the evaluation was deemed the most likely to yield relevant outputs to inform decision-making by policymakers regarding the future development of IHCPs and implementation of personalised home care more generally.

2.5 Informing service development – formulation of an IHCP typology

Optimum dementia care is complex, necessitating a multitude of services and supports from a range of providers, in a variety of settings, to meet the medical, personal care, social and psychological needs of people with dementia, in addition to providing responsive support to family carers. The services that address these needs are located within different divisions of the health service such as primary care and social care and integration can therefore be a challenge. Faced with this complexity, the challenge for a system that seeks to provide person-centred care is how to manage this complexity within a 'one size fits all' delivery system.

Home care is highly individualistic and dynamic, responding to a specific set of needs for a specific individual within a family context, all of which change over time. In unit terms, what is delivered is easy to measure – hours or parts of hours provided by a home care worker. However, for an individual, the number of hours, how they are apportioned over the day and week and the content of *what* is delivered in those hours may be different from one person to the next and is much harder to measure.

It was intended that under the IHCP initiative that home care would not be provided on a 'one size fits all' approach but would be individualised to each person. This begs the question 'were the IHCPs that were delivered organised in the same way for everyone or were there important differences introduced into the ways in which home care was organised under the IHCP initiative?' One way of addressing this is to systematically examine the typical ways in which services organised home care hours in response to the IHCP Initiative and formulating a typology of these responses (Mandara 2003). In this study, an inductive approach was used to formulate a typology. This involved sorting the IHCPs into different groups according to commonalities, which were identified from an analysis of data in this study. This approach is helpful for addressing complexity and creating manageable 'types' while maintaining a focus on the unique features of different types of home care for different types of individuals. In this study, the classification that arranges IHCPs into groups is based on data relating to the characteristics of the IHCP that was provided and not the people receiving them. A typology is essentially a 'middle ground' between a highly quantitative approach (e.g. just considering hours of care) and a highly qualitative approach (e.g. just looking at detailed individual case studies).

In the quantitative approach, measures such as the average hours of care can conceal significant differences in the allocation and content of packages. In contrast, a case study approach is usually too unwieldy to usefully inform questions around the 'how' of service delivery. Both types of information are very useful in themselves but are limited in terms of gaining a deep understanding of a complex system.

In this evaluation, the typology created describes the typical ways in which services were found to respond to the IHCP Initiative with regard to the organisation of home care. It is derived from an integrated analysis of both quantitative and qualitative data. The method for deriving the typology and the types formulated are described in section 3.6 in this report.

2.6 Balance of Care

How are decisions made about the amount of service to provide or the best setting in which to provide care for an individual? The 'Balance of Care' (BoC) approach can be used to identify the types of dependent older people who could equally be cared for at home or in a nursing home (O'Shea and Monaghan 2017, Tucker, Sutcliffe, et al. 2016, Challis et al. 2014). A large UK BoC study found that up to half of new nursing home entrants could be cared for in alternative settings (Challis et al. 2014). For each of these case-types, nursing home care could be delayed by 3-12 months with sufficient community supports. Similarly, (O'Shea and Monaghan 2016) highlighted the economic potential of enhanced individualised supports for keeping people with dementia living in their own homes for longer. Their estimates suggest that the weekly average cost of community care for those on the boundary between community and residential care, including formal care provision, new personalised supports, consumption and housing, was €418 per week, less than half the cost of potential residential care. However, monetising informal care provision nearly trebles the cost of community-based care. The resource constraint is crucial in relation to the potential of community-based care to delay or reduce admission into long-stay care. Additional resources are required for community-based care to make a difference to placement decision-making. Keeping people at home in the absence of sufficient community-based scale is not an easy task (Spijker et al. 2008, Toot et al. 2017, Rothera et al. 2008).

The types of cases that have been identified that could be cared for in the community rather than a nursing home tend, not surprisingly, to be those that are less complex (Challis et al. 2014, Tucker, Brand, et al. 2016). Case types that are more likely to be viable for home care are those *without* a combination of high levels of physical dependency, cognitive impairment or challenging behaviours (Challis et al. 2014). All of the case types identified as being suitable for home care by Tucker, Brand, et al. (2016) had low levels of challenging behaviour. Women and younger people are also more likely to be viewed as suitable for home care (Challis et al. 2014). In practice, however, it may be difficult to target community supports at people who will be most affected by them, very often because of poor communication, particularly with people with dementia (Dooley, Bailey, and McCabe 2015), and a failure to understand the importance of joint production with family carers in community-based care. Complexity of delivery, particularly when it involves multiple providers of care in the home can be difficult for families to co-ordinate and manage. Even for people with a dedicated family carer, there may come a point where a long-term care facility is the most appropriate place (Tucker, Sutcliffe, et al. 2016).

2.7 Unique opportunity to transform home care

Although people with dementia are high users of home care/home support services, little is known, nationally or internationally, about who uses home care, what is actually delivered and how effective it is. Yet two crucial reports mapping the future of the Irish health services; the *Health Service Capacity Review 2018* (PA Consulting 2018) and *Sláintecare Report* (Committee on the Future of Healthcare 2017), both place a huge emphasis on primary and community care, and home care in particular, as a central plank of health services into the future and both recommend a large increase in the provision of home care. The key question is do we simply provide more of the same? Or do we take this opportunity to seriously implement what has been government policy for the last four decades and support older people to remain living in the community by not just providing *more* homecare but changing *how* we provide care and support in the community so that it is personalised and responsive support, valuing the expertise of the older person and their family and working with them to design services that meet their needs in the most cost-effective way.

We are at a critical juncture and, auspiciously, one that is full of potential. There is political consensus and cross-party political support on the need for community care and home care (*Sláintecare Report*). There are well worked funding estimates and plans for how this might be achieved (*Health Service Capacity Review*). There is a demographic imperative that cannot be ignored, with the population over 85 years set to almost double by 2031 (CSO 2013). The Department of Health is currently engaged in a review of home care in preparation for a statutory home care scheme.

This study provides data which is the first of its kind in Ireland on older people with complex needs in a prospective cohort of over 500 people, 59% of whom have dementia. A detailed picture is provided on the type and range of services used by this cohort, the impact of these services in terms of their life and their families' life, the amount of time that can be spent at home given the right support and the costs of these services. It does not provide all the answers, but it does provide an insight into the huge potential of home care and how it can be provided in a different way. The challenge to us all is to seize this opportunity to bring about a sea change in how we support older people and people with dementia in the coming decades.

3. Methods

3.1 Description of the sample

A total of 505 IHCPs were active at some time between December 2014 and December 2017 and 297 (59%) of these were for people with dementia. An administrative dataset was collected from multiple sites around Ireland to gather information on both the characteristics of persons receiving IHCPs (such as age, living arrangements etc.) and the content of the IHCPs. This dataset and the characteristics of all 505 IHCP recipients are described in detail in Report 1 (Keogh, Pierce, Neylon, Fleming, et al. 2018). This data set was not focused on outcomes. In order to determine the outcomes and practical implementation of IHCPs, a sample of 42 dyads, i.e. people with dementia supported by an IHCP and their family carer, was recruited from this larger group of 297 people with dementia, to the in-depth study.

3.2 Recruitment of the sample

An important focus of this evaluation was to include the voice of the person with dementia as far as was practicable and for them to be full participants in the study alongside family carers, HSE staff and service providers. The value of including people with dementia has been well described (Sabat 2003). Ethical approval for the evaluation of IHCPs was granted by the Royal College of Physicians of Ireland Research Ethics Committee in September 2016. This included approval for the interviews with people with dementia and family carers.

People with dementia who were approved for an IHCP and/or their family carer were invited to participate in the in-depth study between October 2016 and January 2018. The dyads (person with dementia and their family member) were selected from all of those people who had been approved for an IHCP and for whom there was evidence of a diagnosis of dementia (or, in the absence of a recorded dementia diagnosis, evidence of moderate to severe cognitive impairment). The dyads invited to participate in the study included those where the person with dementia was being discharged from hospital and dyads where the person with dementia was living at home and needing more support to remain there. Because it was not possible to randomly select a sample, those who responded and were interviewed are not necessarily representative of the overall group. However, analysis was carried out to determine their representativeness on key variables (section 4.1).

There was a two-step recruitment process:

Step 1: Upon receiving an application for an IHCP from a person with dementia, the HSE sent out a letter to each new applicant informing them about the study and seeking an expression of interest to participate in the study. Four HSE offices were involved in sending out the letters of invitation. A participant information sheet was included, which emphasised that their application or access to services would not be affected if they decided not to participate. Those who were interested in participating were asked to contact a nominated person on the research team by telephone or email to indicate an expression of interest.

Step 2: Once an expression of interest was received from potential participants, the person with dementia and/or family carer was contacted directly by telephone or email, according to their preference. The purpose of this contact was to confirm that they had received, read and understood the information sheet and to answer any questions they had. Time was taken to explain what participation would involve and ensure that the person understood that participation was voluntary, that there was no obligation to participate, that their application or access to services would not be affected if they decided not to participate, and to assure confidentiality.

An inclusionary consent process was used (Dewing 2008), whereby this conversation included an initial discussion about the person with dementia's level of decision-making capacity for research participation and on enabling the person with dementia to participate in the study if that was their wish. A date was set for the person and/or their family carer to meet with one of the researchers at a time and place convenient to the participants. Most of the interviews took place in the person's home.

Participation in the study involved taking part in one or two meetings with the researchers, the first meeting was scheduled to take place before the IHCP commenced or shortly after it had commenced. A second meeting was scheduled to take place at least two months after the IHCP had been in place.

3.2 Interview process

Concerns are often expressed regarding the ability of people with dementia to provide informed consent to participate in research (Sherratt, Soteriou, and Evans 2007), thus the ethical issues and the process for approaching and obtaining consent from people with dementia were carefully considered. The approach adopted in the study for obtaining consent from people with dementia for this study was 'process consent' (Dewing, 2008). Consent is obtained at a face-to-face meeting (most likely at the person's home) and is sought separately from persons with dementia and family carers. Given that people with dementia have different levels of capacity and that this might vary for individuals depending on the day or time of day, the issue of consent and capacity to consent is considered in each instance. The process consent approach comprises five parts:

- Background and preparation – clarification of permissions, establishing basic biographical knowledge e.g. good days or times of day, building rapport and trust;
- Establishing a basis for capacity - researchers adapt or sensitise their approach to seeking consent to the level of the person's ability. Where the person with dementia had capacity to give informed consent, a formal consent process was followed, whereby the person with dementia was asked to sign the consent form. Where it is judged that a person with dementia was unable

to consent on the grounds of incapacity, the researcher sought the assent of the person with dementia and validation from the person's nearest relative. The relative was consulted about the wishes of the person with dementia and advised on whether or not they should take part in the study. This is consistent with guidelines issued by the Royal College of Psychiatrists in the UK (Sherratt, Soteriou, and Evans 2007).

- Initial consent - obtaining initial consent. This involved providing information, adapted to the individual needs and preferences of the person with dementia. Plenty of time was given to explain and discuss this and to answer any questions. Consent was then judged on how the person with dementia responded and what feelings they expressed. Decisions taken by researchers were standardised as far as possible.
- Ongoing consent and monitoring - Consent with the person with dementia was an ongoing process. Initial consent was revisited and re-established on each occasion. A family member or other person who knows the person with dementia was asked to validate the process, depending on the context and circumstances. The right to withdraw from the study was also revisited on each occasion.
- Support - At the end of each meeting, the researcher took time to support the person to reflect on what has been discussed and give feedback on their overall experience of participating in the study. Time was taken to ensure that the meeting was brought to a successful conclusion.

Records were kept of all consent and assent processes and forms.

3.3 Quantitative data collection

The in-depth study is a mixed-methods study and both quantitative and qualitative data were collected at interviews with people with dementia and/or their family carers. Socio-demographic information was collected at the baseline meeting via a structured questionnaire. The instruments/questions administered at the baseline and follow-up meetings are shown in table 1. Permission was received from the authors for the use of the Resource Utilisation for Dementia (RUD) and the Zarit Burden Interview, through the MAPI Research Trust for QOLAD (Logsdon et al. 1999, 2002) and from EuroQol for the EQ5D3L. People were defined as having responsive behaviours based on reports by family carers in qualitative interviews. Only where it was very clear from interviews that there were responsive behaviours present was a person recorded as having responsive behaviours.

Data on resource utilisation was collected through the Resource Utilisation in Dementia (RUD) questionnaire. The RUD collected data on the full range of services provided to people with dementia including the number of home help/HCP hours/week that the person was in receipt of before the IHCPs commenced, the number of home care hours/week provided as part of the IHCP, medication usage and the amount of time the caregiver spends caring for the person with dementia (i.e. informal hours of care). However, there is no scope within the RUD to record the detail we required on home care hours and arrangements. A schedule of care form was specially developed to record this information during interviews. Family carers did not always know exactly how many hours of home care they were getting a week but could readily report the time of day of each visit and how long the visits lasted and how many carers attended and who was providing the care. The IHCP schedule was also used to record any home care that was being privately funded, hours of in-home respite provided by organisations such as the Alzheimer Society of Ireland or other voluntary organisations and use of day care. This schedule was also helpful for arriving at an estimate of the amount of time that family carers contribute to care-giving on a typical day.

Table 1: Variables on persons with dementia and family members in the in-depth study

Variables and measures	Person with dementia	Family caregiver
Socio-demographic information		
Age	✓	✓
Sex	✓	✓
Marital status	✓	✓
Living accommodation and arrangements	✓	✓
Education level	✓	✓
Health		
Dementia sub-diagnosis	✓	
Year of diagnosis	✓	
Dementia severity - Dementia Severity Rating Scale (DSRS)	✓	
(Clark and Ewbank 1996)	✓	
Health conditions	✓	
Falls	✓	
Medications	✓	
Ability with activities of daily living - Bristol Activities of Daily Living		
Scale (BADLS) (Bucks et al. 1996)		✓
EQ-5D-3L (standardised measure of health status)		✓
Overall health – question from TILDA survey (Kenny et al. 2014)	✓	
Responsive behaviours		
Quality of life (QOL-AD) (Logsdon et al. 1999)	✓	
Caregiver burden (ZBI) (Zarit, Bach-Peterson, and Reever 1980)		✓
Resource Utilisation (RUD) (Wimo, Jonsson, and Zbrozek 2010)	✓	✓
Schedule of home care supports	✓	
Satisfaction with IHCP	✓	✓
Preference for care setting	✓	✓

3.4 Qualitative data collection

Interviews with people with dementia (if feasible) and their family members were conducted at baseline and follow-up. Participants were asked about their experiences and views on the IHCP scheme, including the process of applying for an IHCP, their involvement in care planning, the actual delivery of the IHCP and its key features, the consistency and quality of care, the impact of the IHCPs on factors such as their ability to stay at home, quality of life, the carer's well-being.

Table 2 gives details of the interviews with the sample. Where possible, the participants took part in both a baseline and a follow-up interview. In 29 cases, participants took part in a baseline interview, the majority of whom (n=26) were followed up and interviewed a second time. However, in three cases a follow up-interview was not undertaken as the person with dementia had either been admitted to long-term residential care, had died or for some other unforeseen reason.

In one of these three cases, a qualitative interview was conducted at follow-up with the family carer. An additional 13 interviews took place after packages had been in place for some time and therefore only one interview was conducted. We called these retrospective interviews. One qualitative interview was also conducted with a family carer whose relative with dementia had been approved for discharge home with an IHCP but had died before the package commenced.

As described above, a central aim of the evaluation was to include the voice of the person with dementia and their experience of IHCPs as much as possible. However, the majority of participants were at an advanced stage of dementia and had no verbal communication. While the interviewers met with and interacted with almost all participants with dementia, there was only one person with whom an interview could be conducted alone and a further nine people with dementia were interviewed with the assistance of the family carer.

Table 2: Participants and interviews

Quantitative data	**Participants**			
	Person with dementia and family carer	**Person with dementia only**	**Family carer only**	**Total**
Baseline (T1) and follow-up (T2)	5	1	20	26
Baseline only (T1)	1	--	2	3
Retrospective only (T2)	2	--	11	13
Total	**8**	**1**	**33**	**42**

Qualitative interview only	--	--	1	1

3.5 Methods for data analysis

Qualitative data was transcribed verbatim and analysed with the aid of NVivo. Data from interviews with service providers was first analysed to develop realist programme theory and analysed thematically to identify facilitators and challenges for the implementation of the IHCP initiative. This process is explained in more detail in the protocol paper for the study (Keogh, Pierce, Neylon, and Fleming 2018).

The quantitative data was analysed using SPSS. Descriptive statistical analysis was undertaken to provide a profile of the characteristics of the sample of people with dementia in receipt of the IHCP and their family carers. The representativeness of the sample to the wider cohort of people with dementia in the larger dataset was examined.

A typology was derived from a systematic analysis of data relating to 42 dementia-IHCPs. This was undertaken to identify the typical ways in which home care was organised by services in response to the IHCP initiative and to categorise the different responses into types. An inductive approach was used and involved a combined and iterative analysis of quantitative and qualitative data. Once the typology was created, nodes were created for each IHCP type. The interviews with people with dementia and their family carers were then coded to the relevant type and analysed. Constant comparisons were made between and within interviews in each type and the related quantitative data. Service provider interviewers were also coded to IHCP type for analysis. Interviews from service providers and people with dementia and their family carers were also analysed to test realist programme theories. This part of the analysis is ongoing.

The qualitative and quantitative data from the study is jointly presented according to this typology in section 4 of this report. The methods for developing services costs are described in detail below and the results of this analysis are reported in section 5.

More advanced statistical analysis was carried out in order to explore key relationships between the costs associated with IHCPs and the characteristics of the recipients and of the packages using a statistical method called generalized linear models (GLMs). In a separate analysis to explore the impact that having dementia has on the probability that IHCP recipients are admitted to long-term care or die, we estimate bivariate probit models for these outcomes. This analysis was carried out using the larger data set of all IHCPs (which includes dementia and non-dementia IHCPs, see Keogh et al, 2018) and this in-depth data set. In order to account for differences in characteristics between recipients with and without dementia in the dataset, we reweigh the data for the IHCP recipients without dementia such that, after weighting, their characteristics (age, gender, Barthel index score etc.) and the length of time they are in receipt of the IHCP, are similar to those IHCP recipients with dementia. The results of both these analyses are reported in section 5.7 and 5.8.

The full quantitative data set and qualitative data from interviews with staff (from Report 1, (Keogh, Pierce, Neylon, Fleming, et al. 2018) was used in interpreting and synthesising the data from the in-depth study.

3.5.1 Cost analysis

The cost of service provision was calculated by attaching the appropriate unit cost to the relevant averaged resource use across all elements of provision. There is no common, uniform database that covers unit costs in health care in Ireland. Consequently, information on unit costs comes from a variety of Irish data sources. Thus, where necessary, unit cost data obtained prior to 2017 were adjusted using an appropriate inflation index (Central Statistics Office 2018b). Labour costs were calculated using consolidated salary scales available from the Health Service Executive for public-sector employees, with associated non-pay costs estimated according to the methods outlined by the Health Information and Quality Authority (HIQA, 2018). Duration of visit was calculated according to the methods outlined in the Regulatory Impact Analysis guidelines issued by the Department of the Taoiseach (HIQA, 2018). Table 3 provides details of the source and amount of unit costs.

IHCP costs: These were calculated by multiplying the number of support hours provided to each individual by the unit cost of a support hour. For those individuals who received all home support hours from approved private providers, a unit cost of €22.64 per hour was applied; this was the average cost of a home care hour based on four approved private care providers in Ireland. For those individuals who received home support hours from both an approved private care provider and the HSE, a unit cost of €23.71 was applied; this was the average cost of a home care hour based on private care providers in Ireland and the HSE salary scale of a home help, including associated non-pay costs.
Private Care hours: A unit cost of €22.64 was applied, based on the average cost of a private care hour across various HSE approved private providers in Ireland. An average nightly rate of €160 was applied to instances where individuals were receiving care from approved private providers at night.

Informal Care costs: Informal care inputs were estimated from data provided by family carers on the total hours of informal support provided to the person with dementia in an average day in respect of each type of support: basic activities of daily living (ADLs); instrumental activities of daily living (IADLS); and supervision. The labour force participation status is available for the carers of individuals with dementia; information is available on whether people gave up paid work entirely or reduced their hours of paid working in order to care. An opportunity cost methodology was used to measure the cost of informal care (Gillespie et al. 2016). The opportunity cost of time for caregivers categorised as having given up paid work time to care is valued at €22.34, which is the average hourly wage for all industrial sectors in Ireland in 2017 (Central Statistics Office 2018a). For those categorized as retired or not available for work, the opportunity cost of time was valued at leisure time; a percentage (25%) of the average hourly wage equating to €5.58 per hour was used as a proxy for leisure time (CSO, 2018). An alternative replacement cost method was also used to value informal care provision where each hour was again valued at €22.34.

Acute hospital costs: A unit cost of €856, which is the average cost across all nights in all hospitals and in all types of in-patient cases, was applied to acute hospital admission and emergency hospital admission (Health Care Pricing Office 2017).

Nursing home costs: The cost of care for every private and voluntary home in the country and for all public long-stay care facilities is available from the HSE (Health Service Executive 2018). Given the variation in nursing home costs across the country and in public or private settings, we show the average cost of public long-stay care, private nursing home care in the Dublin area and private nursing home care in the rest of the country.

Standard economic methods were used to calculate the cost of medication, personal consumption and capital costs.

Table 3: Source of Unit Cost Estimates

Resource Activity	Activity	Unit Cost	Source of Estimates
General Practice	Per visit	€54	Connolly et al., 2014
Public health nurse	Per visit	€24	PHN salary, HSE consolidated salary scales, 2018
Community mental health nurse	Per visit - 30 mins	€25	CMHN salary, HSE consolidated salary scales, 2018
Allied Health Therapies	Per visit - 30 mins	€21	HSE consolidated salary scales, 2018
Day Care	Per visit	€112	O'Shea & Monaghan, 2016
Meals on Wheels	Per meal	€8	O'Shea & Monaghan, 2016
Geriatrician (out-patient visit)	Per visit - 30 mins	€167	Connolly et al., 2014
Psychiatrist (out-patient visit)	Per visit - 30 mins	€167	Connolly et al., 2014
Neurologist (out-patient visit)	Per visit - 30 mins	€167	Connolly et al., 2014
Psychologies (out-patient visit)	Per visit - one hour	€62	Psychologist salary, HSE consolidated salary scales, 2018
A&E attendance	Per visit	€278	Brick et. al, 2015
Anti-dementia medication	Per week	€14	HSE PCRS, 2018 & NCPE, 2011
Anti-psychotic medication	Per week	€28	HSE PCRS, 2018 & NCPE, 2011
Anti-depressant medication	Per week	€7	HSE PCRS, 2018 & NCPE, 2011
Acute hospital admission	Per night	€859	HIPE, 2018
Emergency Acute Hospital admission	Per night	€859	HIPE, 2018
Psychiatric admission	Per night	€859	HIPE, 2018
Day Hospital	Per visit	€171	HSE, 2018
Home Help: non-market value	Per visit - one hour	€28	Home help salary, HSE consolidated salary scales, 2018
Health care assistant: market value	Per visit - one hour	€22.64	HSE approved private acre providers
Night duty (non-live)	Per night - 9 hours	€160	HSE approved private acre providers
Opportunity cost method: caregivers in employment	Per hour	€22.34	Average Hourly Earnings, Q2 2017, CSO
Opportunity cost method: caregivers not in employment	Per hour	€5.58	Leisure time: (25% of Average Hourly Earnings)
Public nursing home	Per week	€1,526	HSE, 2018
Private nursing home - Dublin area	Per week	€1,149	HSE, 2018
Private nursing Home rest of country	Per week	€909	HSE, 2018

3.6 Development of IHCP typology

The IHCP schedules of care completed at the interviews were used as a starting point for formulating a typology of the ways in which IHCPs were designed by services in response to IHCP initiative. A set of criteria was developed with respect to the design of the IHCP (i.e. length of home care visits, number of visits per day, numbers of days per week, whether one or two home care workers attended), and the main purpose behind the IHCP (e.g. personal care, practical assistance, psychosocial support, or support for family carers). The IHCP schedules were examined against the criteria developed and using an iterative process; beginning with the quantitative data, verifying with the qualitative data and checking back to the quantitative data. Through this iterative process, the IHCP types were initially identified and then further refined along with the criteria until clear types with strong internal validity and a close fit to the criteria emerged. The three IHCP types which were identified fit 41 of the 42 cases in the data set. Statistical analysis was carried out using these types on the cost and outcome data to explore relationships between the IHCP typology and outcomes.

4. Findings

4.1 Characteristics of in-depth study sample

The characteristics of people with dementia receiving an IHCP in the in-depth study sample are presented in Table 4 and compared with the characteristics the larger group (n=297) of people with dementia who had received an IHCP. Analysis was carried out to determine how representative the smaller sample was of the larger group. The only significant difference between the two groups was the higher proportion of referrals from community in the in-depth sample which can be explained by the timing of recruitment. This means we can be confident about generalising from this in-depth sample to the wider group with dementia in this IHCP cohort.

The sample comprised more women than men (57.1% females compared to 42.9% males), with a mean age of 80 years. The proportion of this sample who had a third level education is comparatively high for this age group at 29.3% and is higher than the general population where 18.9% of people aged 65 years and over have a third level education (Central Statistics Office 2017). Data on education level was not available for the larger group.

Almost a quarter of the in-depth sample (10 people) lived alone. However, most could not be left alone and so families had arrangements in place, such as rotas for family members to stay over or live-in carers or combination of both in order to provide care. Some of those living with a spouse/partner also shared accommodation with others, e.g. son/daughter who may or may not be involved in caring. Not all family members interviewed were principal carers, six were secondary informal carers.

Table 4: Characteristics of people with dementia in in-depth study, compared with all dementia-IHCP recipients

	Dementia-IHCPs (n=297)	In-depth study sample (n=42)
Sex, n (%)		
Male	117 (39.5)	18 (42.9)
Female	179 (60.5)	24 (57.1)
Age, mean (SD), range	80.6 (8.9) 51-101	80.1 (9.9) 56-99
Age groups, n (%)		
<65 years	15 (5.1)	4 (9.5)
65-74 years	53 (17.8)	7 (16.7)
75-84 years	120 (40.4)	13 (31.0)
85-94 years	102 (34.3)	17 (40.5)
95+ years	7 (2.4)	1 (2.4)
Level of education, n (%)		
Primary or less	N/A	19 (46.3)
Secondary level	N/A	10 (24.4)
Third level	N/A	12 (29.3)
Marital Status, n (%)		
Married/Remarried	158 (54.5)	26 (61.9)
Widowed	105 (36.2)	15 (37.5)
Single	25 (8.6)	1 (2.4)
Separated/Divorced	2 (0.7)	0 (0.0)
Other	0 (0.0)	0 (0.0)
Principal Carer, n (%)		
Spouse/Partner	123 (41.7)	22 (52.4)
Adult child	126 (42.8)	17 (40.5)
Sibling	11 (3.7)	1 (2.4)
Other family member	20 (6.8)	2 (4.7)
Other	8 (2.8)	0 (0.0)
None	7 (2.4)	0 (0.0)
Living Accommodation, n (%)		
Owner occupied	N/A	37 (88.1)
Rented	N/A	2 (4.8)
With family/friend	N/A	3 (7.1)
Living arrangements, n (%)		
With Spouse/partner	155 (52.7)	24 (57.2)
Alone	84 (28.5)	10 (23.8)
With son/daughter	43 (14.6)	7 (16.7)
With other family	7 (2.3)	1 (2.4)
With other	5 (1.7)	0 (0.0)
Referral Source, n (%)		
Acute hospital	145 (49.3)	9 (21.4)
Community hospital	21 (7.1)	0 (0.0)
National Rehabilitation Hospital	0 (0.0)	0 (0.0)
Nursing home	3 (1.0)	1 (2.4)
Psychiatric hospital	2 (0.7)	1 (2.4)
Community	123 (41.8)	31 (73.8)

4.2 Diagnostic and health data

The dementia sub-type, where known or specified, of people with dementia participating in the in-depth study is presented in Table 5. Among the people with dementia in the sample, the most common forms, as reported by family members, were Alzheimer's disease and Vascular Dementia. Mixed dementia was reported in two cases. Other types of dementia among the sample included Fronto-temporal Dementia, Lewy Bodies Dementia and Pick's Disease. The number of years since dementia diagnosis varied widely from less than one year to 7 or more years. Over half of the sample had dementia that was at a severe stage (using the Dementia Severity Rating Score, DSRS).

Table 5: Dementia type, years diagnosed and dementia severity

	In-depth study sample (n=42)
Dementia sub-type n	n (%)
Alzheimer's disease	8 (19.0)
Vascular dementia	8 (19.0)
Fronto-temporal dementia	3 (7.1)
Lewy Bodies Dementia	2 (4.8)
Pick's Disease	1 (2.4)
Parkinson's Disease Dementia	2 (4.8)
Stroke-related dementia	1 (2.4)
Post-operative dementia	1 (2.4)
Mixed dementia	2 (4.8)
Sub-type not specified/known	9 (21.4)
Years diagnosed, n	
Less than 1 year	6 (16.7)
1-2 years	10 (27.8)
3-4 years	8 (22.3)
5-6 years	7 (19.4)
7+ years	5 (13.9)
DSRS score, mean (SD) range	36 (10.9), 12-52
Dementia severity (DSRS), n (%)	
Mild	4 (9.5)
Moderate	16 (38.1)
Severe	22 (52.4)

The health status of people with dementia in the in-depth study sample and their dependency score as measured by the Bristol Activities of Daily Living Scale are presented in Table 6. There was a high level of co-morbidity in the sample, with only two people having no other health conditions and 16 having three or more health conditions. There are strong indications of polypharmacy in this group. The number of medications that people with dementia were taking ranged from 6 to 16. The average number of medications was 3.7. Over half of the sample (57%) were taking anti-dementia medication, 27% were taking an antipsychotic medication and 31% were on anti-depressants. Dependency was high, with 16 people (38%) confined to a bed or chair, and 81% of the in-depth sample had maximum to high dependency on the Barthel Index, compared to 78% in the larger group. Close to half the group had at least one fall in the past year.

Table 6: Health status and dependency levels

	Dementia-IHCPs (n=297)	In-depth study (n=42)
No. of health conditions, n (%)		
0	N/A	2 (4.8)
1	N/A	12 (28.6)
2	N/A	12 (28.6)
3	N/A	10 (23.8)
4+	N/A	6 (14.2)
No. of falls in last year, n (%)		
0	N/A	22 (52.4)
1	N/A	5 (11.9)
2	N/A	8 (19.0)
3	N/A	3 (7.1)
10+	N/A	4 (9.6)
Barthel score, mean (SD), range	6.6 (4.7)	5.4 (4.8), 0-19
Dependency level (BI), n (%)		
Maximum dependency	137 (46.9)	27 (65.9)
High dependency	94 (32.2)	7 (17.1)
Medium dependency	51 (17.5)	5 (12.2)
Low dependency	8 (2.7)	2 (4.9)
Independent	2 (0.7)	0 (0.0)
BADLS score, mean (SD), range	N/A	42.0 (11.8), 16-60
Confined to bed/chair, n (%)	N/A	16 (38.1)
No. of Medications, mean (SD), range	N/A	6 (3.7), 0-16
Anti-dementia medication, n (%)	N/A	24 (57.1)
Anti-psychotic medication, n (%)	N/A	11 (27.5)
Anti-depressants medication, n (%)	N/A	13 (31.0)

4.3 Family carers

The majority of carers were female (66.7%) and this is a typical finding in studies of family carers (Table 7). The mean age of carers was 63 years, reflecting the fact that half are the person's spouse or partner. While 13 carers are categorised as not residing with the person with dementia, many stay overnight with the person. The level of education among this sample is high, with over half having received a third level education, although this is similar to the general population where the rate of attainment of third level education is 42% (CSO, 2017).

Self-rated health of family carers participating in the study was measured using a question from the TILDA study (Kenny et al. 2014), whereby participants were asked to rate their health using one of five categories ranging from excellent to poor. On this scale over half of carers (56%) rated their health as excellent or very good.

Table 7: Characteristics of family carers sample

	In-depth study sample (n=42)
Sex, n (%)	
Male	14 (33.3)
Female	28 (66.7)
Age, mean (SD), range	63.3 (12.0) 42-84
Age groups, n (%)	
35-44 years	3 (7.5)
45-54 years	7 (17.5)
55-64 years	11 (27.5.0)
65-74 years	11 (27.5.5)
75+ years	8 (20.0)
Level of education, n (%)	
Primary or less	5 (12.2)
Secondary level	14 (34.1)
Third level	22 (53.7)
Marital Status, n (%)	
Married/Remarried	31 (75.6)
Widowed	0 (0.0)
Single	9 (22.0)
Separated/Divorced	1 (2.4)
Other	0 (0.0)
Relationship to the Person with Dementia, n (%)	
Spouse/partner	21 (51.2)
Son/daughter	18 (43.8)
Other related person	1 (2.4)
Other unrelated person	1 (2.4)
Main/secondary informal carer, n (%)	
Main informal carer	35 (85.4)
Secondary informal carer	6 (14.6)
No. of children living with informal carer, n (%)	
0	24 (58.5)
1	8 (19.5)
2	4 (9.5)
3	2 (4.8)
4+	3 (7.1)
Resides with person with dementia, n (%)	
Yes	28 (68.3)
No	13
General health, n (%)	
Excellent	11 (26.8)
Very good	12 (29.3)
Good	15 (36.6)
Fair	3 (7.3)
Poor	0 (0.0)

4.4 Outcome scores

A total of 25 carers completed the standardised outcome questionnaires at time 1 (T1) before or shortly after the commencement of the IHCP, and at time 2 (T2) about eight weeks after the package had been in place. The carers rated the quality of life of the person with dementia. This showed a slight improvement in quality of life (25.7 to 27.7) but this difference was not statistically significant. The ZBI score showed a slight decrease from 30.8 to 28 but this was also not a statistically significant difference. This lack of statistical significance is not surprising given the small number of cases.

Table 8: Outcome measures – QoL AD as rated by relative and Zarit Burden score, means and ranges

Outcome measure	**Time 1** **n=25** **Mean (range)**	**Time 2** **n=25** **Mean (range)**
QoL AD (Carer's rating of person's QoL)	25.7 (15-42)	27.7 (19-43)
Zarit Burden Interview (ZBI) Score	30.8 (11-57)	28.0 (6-56)

4.5 Preference for home care

Interviews revealed that caring for their relative at home was very important to family carers, irrespective of how they rated the person's quality of life. Many wanted their relative to remain at home and avoid hospital admission or placement in a nursing home. When asked what their preference would be if the person's care needs were to increase further than they were at that time, 95% (37/39) of those who responded expressed a preference for home care. More than half (60%) of these family carers expected their relative to continue to be cared for at home, even if their needs increased further, with the remainder expecting that the person would most likely be transferred to a nursing home (35%) or admitted to an acute hospital (5%). Some family carers, however, spoke about being put under pressure by health professionals to place their relatives in nursing home care. However, keeping their relative at home could be much more than a preference:

> *"[Keeping husband at home] is without a shadow of a doubt our aim, and it is not a preference, it is a very sincere commitment, it is much more than a preference" (FC, 06).*

Several of the family carers (both spousal and adult children) were resolute about caring for and keeping their relative at home and did not want their relatives to be admitted to a nursing home under any circumstances. Even when dementia had reached a very advanced stage of dementia, some would not enter into discussion with health care professionals about transfer of their relative to nursing home care. The following comment from one daughter sums up how resolute some family carers were with regard to caring for their relative at home:

> *"I would fight it [Mum going into a nursing home] with every last breath that I had" (Family carer, 17)*

Others were less resolute and wanted their relative to be in the place where they would receive the best care. Family carers gave a range of reasons for their preference for home care. Some wanted to honour the wishes and preferences of their relative who did not want to 'end up in a nursing home' and to keep promises they had made. Some family carers spoke of witnessing their relative's distress in the past during a hospital admission or stay in a nursing home for respite and vowed never to subject them to this again. Others reported bad experiences of nursing home care.

The family carers felt that home was the best place to care, as the person was secure and content in their own home surrounded by people who know and love them. An important benefit of the IHCPs was that it enabled people with dementia to remain at home in a familiar environment.

> *"… even though we don't get any verbal response or even a facial response, he is in his own environment, at least he can see the hill he walked on all his life, he can see the cattle out there. We assume at least that he has some awareness that he is in his own place" (Family carer, 6)*

Other reasons given for care at home being better included: home care was provided on a one-to-one basis; it had the added benefit that family members could 'see what is going on' and could keep a watchful eye over how, for example, personal care was being done and that it was being done correctly and appropriately. Family carers felt that at home they had more control over the care and did not have to leave their relative 'at the mercy of the nursing home'. Some added that they did not want to be separated from their relative and if the person was transferred to a nursing home or admitted to hospital, they, the family carer, would have to spend a lot of time there to make sure that they were being well cared for. Some believed that their relative would decline rapidly and would not survive for long if they were admitted to a nursing home.

> *"Homecare is definitely better [than nursing home care] because you have a family member that loves them, is watching out for them, that is putting them first whereas a nursing home that is not necessarily the case and people decline much more when they are not around people they know" (Family carer, 24).*

In only one case was the person's contribution towards the costs of nursing home care put forward as an argument against nursing home care. While some family carers were resolute about keeping their relative at home, others said that without the IHCP the person with dementia would definitely or most likely be in a nursing home and welcomed the IHCP as an alternative to nursing home care:

> *"We couldn't [manage]. I think if we weren't able to get this service [IHCP] it might have come to the crux that she would have had to go into a nursing home" (Family carer, 37).*

> *"Will it be possible to provide 24-hour care at home? I don't think so. Will she probably need 24-hour care at home at some stage? Perhaps, I don't know. I would have said would she ever have needed this level of care at home? I didn't see that on the horizon and, in some ways, I didn't think maybe it was possible, but it is possible. And I think for families it is a nice alternative …" (Family carer, 39)*

An application for the Nursing Home Support Scheme (NHSS) had been made for almost 20% of persons with dementia in this cohort of 42 people. Interestingly, family carers expressed a clear preference for home care in all but one of these eight cases. In two cases, nursing home care had been considered, but the costs deemed prohibitive as the person was ineligible for the HSE co-payment following financial assessment. In another two cases the NHSS application had been made at the request of hospital staff.

Being at home was also important to people with dementia who participated in an interview. One person reflected on time spent in a nursing home after a hospital admission which led to the application for the IHCP:

> *"I thought I wanted to stay there [nursing home] sometimes but I don't think I would like it at all now, I think it would be a big mistake to just go ahead with things … because I would end up with no house or no nothing, just my few bits in a bag" (Person with dementia, 07).*

4.6 Dementia-IHCPs: An emergent typology

Report 1 highlighted that the major component of all IHCPs, including those for people with dementia, was hours of home care, provided by home helps and home care workers. However, the total number of home care hours per week tells us little else about the nature of home care as provided under IHCPs. It tells us nothing about the main purpose of these home care hours, how these hours are allocated during a day or week, or what type of care or supports are provided during these hours.

We know that home support allocation in Ireland 'is heavily weighted on level of dependency and need for assistance with day-to-day personal care' (O'Brien et al., 2017: 3), and this was strongly borne out by interviews with health service professionals undertaken for this study:

> *"You see a lot of the time it is very difficult to articulate it to the people in offices that it is not so much the tasks that are the problem, it is to have someone there with them and … it is not always about the basics, personal care and hygiene, there are other issues …" (PHN)*

People with dementia often require support with mobility and personal care, although support needs can extend well beyond these domains to include support with thinking and memory, where the person may need prompting or support with decision-making such as when to eat or drink. Support with instrumental activities like housework and managing the home is also important. Another domain is social interaction which can involve taking part in meaningful activities both inside and outside the home, staying connected to other people. People with dementia and their family carers may need support with behavioural and psychological symptoms of dementia such as anxiety, agitation, aggressive behaviour, sleep disturbances and mood swings. Family carers are doing their best to meet most of the support needs of people with dementia, supplemented by home support services. However, there is a high level of unmet need among people with dementia in relation to many of these domains, and particularly high in relation to behavioural and psychological symptoms of dementia BSPD (Meaney, Croke, and Kirby 2005).

While the IHCP Initiative was aimed at providing a higher level of hours, it also provided an opportunity for orientating home supports away from a focus on personal care and tailoring the supports to meet a whole range of needs of people with dementia and their family carers, from personal and practical needs to social, psychological and emotional needs.

The in-depth study provided an opportunity to gather more detail about IHCPs at the individual level and how each one was delivered. An analysis of data relating to the 42 cases in the in-depth sample has led to the formulation of an IHCP typology. The method for generating this typology has been described above (Section 3.5).

Three distinct types of dementia-IHCPs were formulated. These are referred to as; 'Classic' IHCPs; 'Block hours' IHCPs; and 'Combination' IHCPs. The three types of dementia-IHCPs are summarised in Table 9. They can be distinguished from each other by both the main purpose and the typical characteristics of each type of package. Each is described in greater detail below and comparisons and contrasts are made between the different types. Findings in relation to outcomes are then presented.

It is important to emphasise that these dementia-IHCP types were *not prescribed types* and the forms that they took developed freely as the initiative was rolled out. In other words, since the types did not exist, the health professionals organising and delivering the IHCP were not deciding to select and provide one of these types. Rather, the types represent different responses by the service system to the availability of IHCP hours, i.e. the IHCP hours were used for different things and put together in different ways depending on different factors. One explanation is that dementia-IHCP types resulted from an interplay between the resource (IHCP hours), an understanding of personalisation and willingness to use the hours differently by those designing the IHCPs (an underlying mechanism), operating within a supportive context.

The individualisation of home supports through IHCPs generally, and the extent which different IHCP types are personalised, is addressed in Section 6.

Table 9: Description of IHCP types formulated from the study data (i.e. not in place as part of the IHCP rollout)

Characteristics	Type 1 'Classic' IHCP n=16	Type 2 'Block' IHCP n=13	Type 3 'Combination' IHCP n=12
Main purpose	Focus on personal care – providing support with basic activities of daily living (ADLS) such as washing, dressing and toileting. Support with instrumental activities of daily living (IADLS) for some – cooking, cleaning etc. for two cases with additional needs.	Main focus on supporting family carers to work; to combine caring with family duties; to provide respite; to deal with responsive behaviours. Provide support with personal care to the person with dementia. Some therapeutic/activity engagement for some persons with dementia	Equal attention to: Provide support with personal care to person with dementia. Provide meaningful activities for the person with dementia. Provide respite for main informal carer.
Typical characteristics			
Number of care workers	Two home care workers (for hoisting)	One home care worker	Usually one home care worker – two for shorts visits where hoisting was required
Characteristics of visits	Short visits of 1 hour or less, 3 or more visits per day, 5 to 7 days per week	One visit per day of between 2 and 10 hours, 4 or more days per week	Short visits 1 hour or less for personal care; blocks of hours ranging between 2 and 7½ hours. Typically, one short visit and one block hour visit per day.
Average hours per week (range)	36 hrs/week (range 28-56)	35 hrs per week (14 to 48)	29 hrs per week (13* to 42)
Average cost per week (range)	€826 per week (€634 - €1,268)	€819 (€317 - €1,176)	€652 (€294 - €951)
Characteristics of IHCP recipients			
Age 75+years	15 (94%)	7 (54%)	8 (67%)
Living with family member	11 (69%)	9 (69%)	11 (92%)
High or max dependency	15 (94%)	10 (77%)	9 (75%)
Bed/chair bound	14 (88%)	0 (0%)	3 (25%)
Severe dementia	9 (56%)	7 (54%)	6 (50%)
Responsive behaviours	1 (6%)	8 (62%)	6 (50%)
Referral source			
Discharge from acute hospital	5 (31%)	2 (15%)	4 (33%)
Living in the community	11 (69%)	11 (85%)	8 (67%)
Outcomes			
Average length of time at home (range)	57 weeks (7 to 159 weeks)	36 weeks (range 8 to 64 weeks)	29 weeks (range 1 to 58 weeks)
Quite Satisfied/Very satisfied with IHCP	81%	90%	100%
Other points of note	Most people in this group had home help/HCP in place before the IHCP, often for several years. Some were at end stage dementia. All had family carers. There was a strong commitment to caring at home evident among carers in this group. Only one NHSS application had been made in these 16 cases, despite the high levels of dependency.	There were lower levels of physical dependency in this group and none were bed or chair bound. Almost half were aged under 75, several had early onset dementia or frontotemporal dementia. The majority of this group had responsive behaviours.	Combination IHCPs represented a flexible way to meet the needs of the person and the carer combining personal care visits with longer visits for breaks for the carer. These longer visits were used to provide meaningful activities for the person as well.

4.7 Description and comparison of dementia-IHCP-types

4.7.1 'Classic' IHCP

The type of IHCP most frequently provided to people with dementia is the **'Classic' IHCP** (n=16 or 39% of the sample). An overview is provided in Table 9. Almost all of these IHCPs focused exclusively on providing assistance with personal care (88% of this group), although unusually in a few cases, home care workers also undertook some light household tasks, e.g. washing up or ironing, once personal care tasks were complete. In 14 of the 16 cases, the person was confined to a bed or chair and all, but one had high or maximum dependency. With hoisting required, family carers were not able to manage personal care on their own or were finding it extremely difficult. Case 1 below provides a picture of a typical 'Classic' IHCP.

In these 'Classic' IHCPs, all care is carried out within the home and home care workers made short visits a number of times a day, generally for five or seven days a week. The visits are short, lasting either 30 minutes, 45 minutes, or one hour and there are usually three visits per day. If there are no visits at the weekend, family members, often adult children, undertake the personal care tasks.

While the average hours for 'Classic' IHCPs was 37 per week, in all but two cases, two home care workers attended at each visit because of the need for hoisting, which in effect meant the person and their family experienced half the allocated hours, i.e. an average of 18.5 hours of care per week. In two cases, the family member provided the second 'pair of hands'; which meant that these two cases had lower than average weekly hours. In other cases, family carers spoke about willingly 'standing in' as the second person including when one of the home care workers was unavailable due to unforeseen circumstances.

We have referred to this type of IHCP as a 'Classic' IHCP, because it holds very closely to the conventional approach to the provision of home support in Ireland, i.e., providing assistance with day-to-day personal care for people who are highly dependent, and providing this according to a set pattern of short visits of 30 minutes or one hour. This is the task-oriented approach that was repeatedly referred to in interviews with staff. For example:

> *"The main issue that I have with home help, and I do understand to a degree where they are coming from, is that they are aimed at practical tasks. This is task-oriented. With the person with dementia, you shouldn't focus that much on task but go at the pace of the person. So instead of rehabilitating them or enabling them we are almost disabling them because we are doing things for them because we don't have time. I arrive here at 9.00 and I need to be in the next house in three-quarters of an hour … Families are saying to me 'you are giving me five hours; can I have two days of two and a half hours each' … 'No', that goes against the … it is depending at the minute on personal views of the home help organisers" (Hospital based medical social worker).*

'Classic' IHCPs are a necessary and valuable type of IHCP, particularly for older people with varying types of dementia at an advanced stage, who have high or maximum levels of dependency and are confined to a chair or bed, and where responsive behaviours are not an issue. These were common characteristics of the people with dementia receiving this type of package (see Table 9).

Case study 1: Mr. C's 'Classic' IHCP

Mr. C. is in his 90s and has a diagnosis of Lewy Body Dementia. He is widowed and his daughter who is his main carer lives with him and works full time. He was admitted to hospital after a fall at home and while in hospital his mobility deteriorated substantially. He was discharged home with an IHCP of 25 hours. Mr. C. has severe dementia, maximum dependency, needs full-time care and two persons for hoisting. Four shorts visits of either 30 minutes or one hour are provided each weekday under the IHCP. Two care workers attend at three of the visits. The first visit in the morning is to get the man out of bed, empty overnight catheter bag, wash, dress and transfer, midday and afternoon visits are for transfers from chair to bed or bed to chair. One care worker attends in the evening to assist daughter getting Mr. C to bed. Each weekday, an extra four hours of care is purchased privately for other personal care tasks such as shaving and cleaning teeth, and for preparing meals, feeding at breakfast and lunch time, and for transfers. Daughters and other family members provide care in the evenings and over the weekends. The family also avail of overnight respite care occasionally. Mr. C's daughter is very satisfied with the IHCP, and having carers come in during the day to undertake care while she is at work has been instrumental in enabling the family to keep Mr. C at home. She rated his QOL as 'fair to good'. Without the IHCP, Mr. C's daughter believes that he would definitely be in a nursing home.

The hours provided by this package cost €488 per week, and the package has been in place for three years.

4.7.2 'Block hours' IHCP

Mobility and personal care were the primary support needs of most of the people in receipt of a 'Classic' IHCPs. However, this is not the case for all people with dementia, many of whom will not have such an advanced stage of dementia and will not be confined to a bed or chair. They may be of a younger age and some will have responsive behaviours. Regular short visits of 30 minutes or 1 hour throughout the day and week will not usually be appropriate for these people and shortcomings of the task-oriented approach for this group have been documented (Ducharme et al. 2013).

A very different type of package that emerged through the IHCP Initiative is one that we have referred to as a '**Block hours' IHCP**, received by 31% of the sample (see Table 9 for summary overview). In stark contrast to regular short visits characteristic of the 'Classic' IHCPs, in 'Block hours' packages, care hours were organised into longer blocks of time usually one 'visit' per day, although both had a similar average number of hours per week (36 and 35 hours respectively). Although all of this group had either moderate or severe dementia and 70% had high or maximum levels of dependency, in contrast to the Classic IHCP group, they tended to be younger in age (less than half were aged 75 years or older) and all were mobile. Responsive behaviours were common (54%) among this group. Again, in contrast to Classic IHCPs, family carers in this group frequently referred to risks (poor balance, risk of falling or frequent falls, wandering, accidents) and reported not being able to leave the person alone.

The blocks of time varied in length and could last from two hours up to seven hours during the day, or up to 10 hours if the block hours were used for overnight stays. Typically, one home care worker attended at each visit, but in a small number of cases a second home care worker also attended to assist with personal care tasks. In all but two cases, instead of the same home care worker attending for the full block of time, up to three workers could cover the block. Case study 2 below provides a brief picture of the Block hours IHCP.

The nature of the care provided in the 'block hours IHCPs was qualitatively very different to that provided in 'Classic' IHCPs. Important benefits of Block hour IHCPs to the person with dementia were that personal care tasks could be completed without rushing and care could extend beyond these tasks to meaningful activity or occupation. Examples included, getting outside to walk and maintain mobility, playing games or cards and making jigsaws, reading newspapers, accompanying the person to a choir, bringing them out to lunch, engagement in activities that the person enjoyed, that enhanced personal identity and that stimulated the person as well as providing opportunities for social interaction:

> *"... there's one guy [home care worker] ... he brings Daddy outside, Daddy's a farmer so he straight away twigged 'farm', 'outside' and you know he's a big tall man, he was always the boss and he sets him up outside and he says to him 'now [John], what would you like me to do?' ... So, he puts himself in the position to allow Daddy to sort of 'boss him'. And Daddy is raving about this guy, he's like 'is [care worker] coming back?' ... so engages him with stuff outside, even if it's just tidying the garage or fixing a plug or something ... it's just ... he has a better sense of worth and I can see Daddy being a little bit more engaged because it's very easy for him to just sit back and have his naps during the day, wake up, he doesn't read paper he looks at it and then the T.V. ..." (FC, 22)*

A common use of 'Block hours', which was not evident in the 'Classic' IHCPs, was to explicitly enable family carers (spouses or an adult child) return to or continue to work, either full-time or part-time, whilst at the same time care was being provided to the person with dementia. This was particularly important for carers of people with fronto-temporal dementia and younger onset dementia. In several cases, family carers had given up work when the person was first diagnosed, but wanted to return to work or wanted to continue to work, often for financial reasons:

> *"The package as a whole has been a very good thing to our life in the sense that I am able to go to work and get some income and I am able to be there without worry so I know there is somebody at home, I know she is safe and I know she is looked after, she will be fed, everything. And I am in work with peace of mind. So that on its own is quite a good relief on my part. And also knowing that she has got somebody also that is caring for her is a good thing. The package itself, like I said before, I am very grateful because it is quite a good thing for me, and mostly for her." (Family carer, 19).*

The block hours were designed to fit in with the working hours of the family carer and day care or to supplement or replace home care hours that had been privately arranged by families if these were in place. A portion of the block hours was also used to provide respite at the weekend for the family carer, all of whom were spousal carers. Packages that included respite had a higher number of care hours, between 40 and 47 hours per week.

In the remaining cases in this category, 'Block hours' packages were used to provide respite for carers who were finding caring challenging because of responsive behaviours or where there was a difficult caring relationship, as well as addressing the care needs of the person with dementia:

> *"So, I sat down and worked out what basically worked best. How I could make sure, based on my schedule and Dad's schedule and Dad's life in terms of giving him enough space during the day as well so he wasn't [spending too much time with his wife]. So, what I didn't want was him ... just going completely spare and having to be with her all the time. So, based on that I did the sums of 'if I have 31½, how do I divvy it out?'" (FC14).*

The provision of home care hours in blocks of time might not seem all that significant. However, it is an indicator that a major shift in home support services is occurring through the IHCP Initiative. These 'Block hours' packages are not solely focused on personal care but are meeting the needs of people across a range of domains. In striking contrast to the 'Classic' IHCPs, 'Block hours' were useful for providing respite for spousal carers; support with responsive behaviours; to replace day care which had broken down or for several of these reasons, while at the same time addressing the personal care needs of the person and engaging them in meaningful activities. These cases are good examples of one element of personalisation – tailoring each package based on the needs of the person and family with three different packages as a result in terms of hours and what is done in those hours.

Case study 2: Ms. P's 'Block hours' IHCP

Ms P is a woman in her late 60s with frontotemporal dementia (FTD), who prior to her diagnosis had experienced depression for about 10 years. She lives alone. All of her children are involved in caring for her to varying degrees, with one daughter acting as her main carer. After spending four weeks in an acute hospital for a hip operation, she was transferred to another hospital for recuperation and remained there for 20 weeks. She was then admitted to a nursing home where she stayed for 16 weeks. However, the woman was unhappy in the nursing home and her family felt that she would be better cared for at home. The family was worried about leaving the woman at home alone, and to enable her to return home, one of her daughters took leave from work for a year to take care of her. During this time, the family also began paying out of pocket for care and privately arranged for a carer to cover 15 hours a week (three hours, five days a week). With the end of the daughter's leave period approaching, the family contacted the HSE asking for assistance with home care. Up to this, the woman had not received any home care support from the HSE. The family wanted to use the home care hours to supplement the private care already in place, and when combined the publicly and privately funded hours to be enough to allow the daughter to return to work. A package of 16 hours, made up of two blocks of two hours per day for four days a week was approved by the HSE and put in place. One carer attends at each visit. The package has supported the daughter to return to work and the family are appreciative of the financial contribution that it makes. The 16 IHCP hours are used to provide supervision, falls prevention, and for engagement with the woman. Personal care tasks are also part of the package, which mainly involve prompting and encouraging the women to shower and take care of her personal hygiene. Outside of the 31 hours of HSE and privately funded care, the family provides the remainder of the care.

Included in these 13 cases are two exceptional cases, in which the person with dementia was living alone and home care workers were present in the person's home 24 hours a day, on either seven days a week or five days with informal carers covering the weekends. The IHCP hours amounted to 30 hours in one case and 48 hours in the other. The person and/or their family financed the remaining hours of formal home care. Essentially, in these two cases the IHCP funding from the HSE was perceived by carers to be a contribution towards the full costs of formal home care.

4.7.3 'Combination' IHCP

A third type of dementia-IHCP to emerge is referred to as a '**Combination' IHCP**, provided to 29% of this sample. Typically, these packages comprised a mixture of short visits (i.e. 30 mins or 1 hour) plus block hours, which could vary from two hours to seven and a half hours. These packages averaged at 29 hours per week but were wide-ranging from 13 hours to 42 hours per week. A summary overview of this type of package in provided in Table 9.

There were some similarities between the people with dementia receiving 'Combination' IHCP and 'Block hours' IHCPs. Roughly three-quarters of both groups had high or maximum dependency, and most were mobile. They were younger on average than those in receipt of 'Classic' IHCPs. Reports of responsive behaviours were relatively common among this group. The 'Combination' IHCP was different to the two other groups in that all but one were living with family members. Several people in this group were also attending day care and/or availing of in-home respite provided by the ASI or availing of overnight respite.

The short visits in the 'Combined' IHCPs were typically used to provide assistance with ADLS. These short visits usually took place in the morning and/or evening, or in some cases in the afternoon. Two carers were required for hoisting or to assist with care when responsive behaviours were present. As with the 'Classic' IHCPs, the family carer provided the 'second pair of hands' in some cases.

> *"Because of [name of person with dementia]'s needs around changing and toileting and all of that, I physically can't do that anymore by myself and that really is the bottom line. If I didn't have the intensive care package [name of person with dementia] wouldn't get changed in the middle of the day ... that would be it. And if I didn't have the two people in the morning I would be doing it with another carer, the way I am at night, and it is very, very difficult because he fights it all the way. So, it is full on. So, it just eases the burden, it really does ease the burden, I don't think I could cope without it. And we are hoping to keep him here as long as possible and it means I can." (Family Carer, 36)*

Block hours, the second element of the 'Combined' IHCP, could last between two hours and seven and a half hours. During these hours, the home care workers usually spent time with the person. How the time was spent varied. For someone with advanced or end stage dementia, this could involve body care such as care for the person's hands and feet, providing drinks, feeding with snacks, toileting. Where a person was mobile, home care workers might bring the person for a walk to ensure that they got outdoors for fresh air and exercise, do physical exercises with them, involve them in practical activities such as preparation of meals to help maintain abilities or spend time interacting with them such as by holding conversations, looking through photograph albums, knitting or playing games. There may also be an element of supervision where the person has responsive behaviours.

For the family carer, the block hours mostly 'freed up time' which was used by the family carer in varying ways including for work, catching up on chores such as housework or shopping, attending doctor and dental appointments, and attending church or a funeral.

> *"It [block of three hours] gives me time to do something, to free up my time a bit because I have a farm here, so I have to do a bit of that … or like today, I went to a funeral this morning and done a bit of shopping. I wouldn't be able to do that if I hadn't someone here" (FC, 02).*

The 'Combination' IHCP is another indication of a shift away from the conventional approach to home care. They are similar to the 'Classic' IHCPs in that one of the elements of the 'Combination' IHCP is short visits, generally for personal care tasks. However, unlike the 'Classic' IHCPs, 'Combined' packages had some time built in for a break for family carers, who highlighted that having a break from caring was particularly important for sustaining them to continue to provide care:

> *"I was getting an hour in the morning and an hour in the evening and an hour in the afternoon … seven days but it was very short … effectively I was a prisoner here and there was no respite from it. What was happening was my battery was running down and down and down and I didn't know how long, and I was thinking all the time about institutional care. I was wondering just how long, what day would that be, so it went from me doing practically everything with a visit … so when we moved to the Intensive Home Care Package things changed drastically. It meant I could go if I wanted to and I am a lot fresher than I was …" (FC, 20).*

The case study below gives an indication of how the 'Combined' IHCP can work to provide reassurance for a person with dementia living alone.

Case study 3: Ms. M's 'Combination' IHCP

Ms M. is a woman in her 70s recently diagnosed with Alzheimer's disease, which is at a mild stage. The woman lives alone in her home. Her daughter is her primary support but lives abroad as do all her other adult children. Following her diagnosis, the woman was assessed by the PHN and a HCP of 11 hours put in place, made up of 45 minutes in the morning and the same in the evening. However, the woman was becoming increasingly anxious, had several urinary tract infections, and was not sleeping well at night. Following a fall one night she was admitted to hospital. The hospital staff were recommending that the woman would be best placed in a nursing home, but the family didn't feel that this was the most appropriate place for her. The woman was then put forward for an IHCP and a family meeting was arranged. An IHCP of 33.5 hours was put in place, with family input on how the hours would be arranged. The morning visit each day was maintained and the remainder of the time was used to provide four hours of additional home care support in the evenings. These additional hours have made 'such a huge difference' to the woman who feels reassured knowing that there is someone coming in to help her with any chores, manage her medication and help with preparing a meal. In the evenings the home care workers also spend time with her doing things she likes such as listening to music, chatting, baking, watching TV, walking the dog, pottering around the garden, painting her nails, and running the bath for her. The woman's daughter remains highly involved in her care, albeit from a distance, and maintains close contact with the approved private provider and the IHCP provided reassurance that the woman was safe. The GP is acting as the first port of call. The PHN is much less involved now but is available when needed.

4.7.4 Summary comparison of IHCP types

In summary, 'Classic' IHCPs are instrumental in supporting people with dementia with high levels of dependency to continue to live in their own homes. They do this by providing personal care and thus support families with the hard, physical labour of caring and relieve them of some or all of the responsibility for personal care tasks. By comparison, block IHCPs provide a different type of support. Blocks of hours presented a way of providing support for the person with dementia whilst responding to a range of different needs for family carers; to remain in or return to work; to provide support for responsive behaviours; to provide time for other caring duties (e.g. for young children); or to address some combination of these needs. While the personal care needs of the person with dementia were addressed, the blocks of hours meant that personal care tasks could be completed without rushing. Care could extend beyond personal care tasks to include support with instrumental activities of daily living such as cooking and washing and spend time engaging the person in meaningful activity or occupation, thus helping to provide stimulation, enhancement of personal identity, and an opportunity for social interaction. 'Combination' IHCPs were so called because they had elements of both 'Classic' and 'Block hours' IHCPs. In this type of package, shorts visits made an important contribution to supporting people with dementia with personal care and where a person was living alone, support with other tasks. One or more block of hours was also built into all of these packages, and family carers were able to use all or some of these block hours to get a break from caring and were reassured knowing that their relative was being well cared for. There was little evidence of change in the type of package that was provided over time or as needs changed. Once an arrangement was in place it tended to stay the same in form, although hours might be increased.

4.8 Dementia-IHCPs types and outcomes

The outcomes of the three types of IHCPs were positive in many cases. All IHCP types were instrumental in supporting people with dementia with high levels of dependency to continue to live in their own homes. In the case of Classic IHCPs, 75% were enabled to remain at home for six months or more; 62% for Block hours IHCPs and 67% for Combination IHCPs.

An important outcome in terms of QoL and satisfaction for the person and family, was the added value of being at home that was enabled by all IHCPs. Being at home was important for both persons with dementia and family carers. This strong preference for home care was described in detail in section 4.5.

4.8.1 Outcomes - Satisfaction

In examining outcomes across the different package types, we need to keep in mind that these are not different interventions for similar people – the circumstances of the person/family had some influence in shaping the type of package that was provided.

Satisfaction with all three types of dementia-IHCPs was generally high. The majority of family carers (13/15) in receipt of '**Classic' IHCPs** were either 'very satisfied' or 'quite satisfied' with this type of IHCP, as were the four people with dementia in receipt of this type of IHCP who participated in an interview. Of those in receipt of '**Block hours IHCPs**, 11 of the 12 family carers who responded were 'Quite satisfied' or 'Very satisfied'. This type of package worked well for people with early onset dementia and fronto-temporal dementia. There was a high level of satisfaction with this type of IHCP, particularly in its capacity to enable the person to remain in or return to work. With respect to **Combination IHCPs**, all of the family carers who responded stated that they were either 'Quite satisfied or 'Very satisfied', as did the four persons with dementia who participated in an interview. Often family carers stressed that they wouldn't manage to keep the person with dementia at home without the IHCP:

> *"I think really again just to emphasise the fact that he wouldn't be at home only we have this." (Family Carer, 36).*

For the small number of carers who were not satisfied, the reasons were specific to each case. For example, a breakdown in relationships and the escalation of conflict between the family carer, the approved private provider and the HSE, due to constant changeover of home care workers and unhappiness with the approved private provider and home care workers that had been allocated; and the stopping of a second visit per day for a person who had pressure sores and end-stage dementia due to a shortage of home care workers. In this instance the family carer felt very let down, and very upset at the way in which the news had been communicated. In on Block hours IHCP the blocks were split between different carers resulting in rushed personal care causing upset for the person and further upset due to the multiple care workers involved.

4.8.2 Outcomes – QOL person with dementia

For the whole sample, there was a slight improvement in average quality of life (QoL) scores for the person with dementia as rated by the family carer (from 25.7 to 27.7) before and after the IHCP, but this difference was not statistically significant (see section 4.4). Generally, we see a similar pattern across the three different types of dementia IHCPs. A small number of people with dementia rated their own QoL; five in receipt of a '**Classic' IHCP** rated their QoL as 'fair to good' or 'good to very good'; and four in receipt of **'Block hours' IHCP** rated their QoL as 'Fair to good' or 'good to very good' and this was maintained with the IHCP in place. No people with dementia receiving a **Combination IHCPs** rated their QoL.

4.8.3 Outcomes – family carers

For the 25 family carers with interviews before and after the IHCP commenced, the average burden score showed a slight decrease. The qualitative interviews provide as greater insight into the nature of care demands and how the IHCP did or did not make a difference. Most people with dementia in receipt of '**Classic' IHCPs** were confined to bed or a chair and physically, family carers were not able, or finding it extremely difficult to manage the personal care on their own. The main effects on carers in this group were physical strain; psychological strain of the full responsibility for personal care; being uncomfortable with carrying out personal care; and the stress of combining personal care with work and other family responsibilities:

> *"We couldn't manage it because I am working but any time I wasn't working I was down there and we were having to put her to bed and get her up. And it became exhausting. And turning her then in the bed, we couldn't do it on our own anymore. I just couldn't manage my mother. Her needs were getting too great ...I was getting burnt out ... her care was becoming almost like near nursing care, that I couldn't do, that I wasn't trained to do" (Family carer, 13)*

Classic IHCPs worked by relieving family carers of the responsibility for personal care, or at least carrying it out on their own, and of the strains associated with it. In some cases, it meant a welcome change in the caring role:

> *"Well it means when the family are calling now that there isn't a strain on actual physical care duties ... that we are here visiting Mum from more a family point of view rather than coming as homecare assistants. So, there is a different slant on your visit."*

Even with about 18 hours of care per week, families continued to provide the bulk of care or arrange care privately for their relative with dementia and co-ordinate and manage care provision. Providing such a high level of care did not affect some family carers, who were assessed as experiencing 'little or no burden', both before and after the IHCP was put in place. Two family carers who had moderate to severe burden before the 'Classic' IHCP was put in place, experienced a reduction in burden with the IHCP in place. One of these carers, who had been feeling physically and emotionally exhausted and burnt out before the commencement of the IHCP, made the following comment with regard to the impact that the IHCP was having:

> *"The stress has gone out of the caring. There is a reliability in that these people are coming every day at regular times. ...I always had the responsibility of all the things that had to be followed through. So that is gone. I don't think I could do it again ... you have still some of it, but there is no comparison. What I have now is normal responsibility for some things that are fine, that are reasonable ... It is an okay level of stress" (Family care, 13).*

For those who still experienced burden even with the IHCP in place, carers who lived with the person had little or no other day-to-day support with caring and because of the way in which these IHCPs are structured, they had little or no opportunity for a break. Where the person with dementia lived alone, they felt that the person was completely dependent on them, and found the responsibility for caring, along with working and other family responsibilities, was very stressful. It left them with little time for themselves and made it hard for them to plan ahead.

Of the 13 '**Block hours' IHCPs**, eight reported 'little or no' or 'mild to moderate' burden with the IHCP in place. Acceptance seems to at least partly explain this:

> *"I don't find any particular pressure on me, I am not worn out from caring for [name of wife], I am here in the evening and I am happy to do it. I am happy to do it. That is it. Maybe over time that might change, I don't know but I don't think so. We are fairly intensive now for more than four years and of course I have been doing it myself apart from four hours a week until two or three months ago. So that is it, the way I look at it is it is something that has to be done and we will do it and that is it. That applies to most people ... when it comes to it, you either do it or you don't. If you are going to do it you do it and that is it, you don't think about it, you get on with it." (Family Carer, 33).*

In contrast, the remaining family carers on 'Block hours' IHCPs had 'moderate to severe' burden with the IHCP in place and this had either remained the same or had increased from the level observed before the IHCP had been put in place. All four family carers experiencing moderate to severe caregiver stress at follow-up were adult children:

> *"I'm constantly on call and I fix my work around what I need to do here ... when the carers aren't here I am on duty" (Family carer)*

> *"I think the dementia is getting worse and the hours have been just an absolute godsend and really have changed everything, but we are now mentally getting ready for the next phase which is evening. And then after that I think it is a two-person type job, but we don't know what that entails, we really don't know. Evenings and weekends. But if I had a normal regular job you could schedule it, but I can't schedule from week to week. We are just working through the dilemma of that at the moment, but we are in a much, much better place than we were." (Family carer)*

For the '**Combination' IHCP** group, half of carers had 'little or no' burden and five 'mild to moderate' burden and half were rated as having 'moderate to severe' caregiver burden with the IHCP in place. There was little change in burden for this group before and after the IHCP commenced.

Quite a lot of variation existed between the 'Combined' packages, including the amount of IHCP and other formal supports received as well as variations with regard to the dependency levels of the person, whether or not there were responsive behaviours, living arrangements and family circumstances. This makes it difficult to explain differences observed in family carer burden. However, some tentative suggestions can be made. For family carers with 'little or no burden', it seems they were getting good support with personal care tasks, and the time allocated for carer respite was sufficient to give the family carer a complete break. One of these family carers described the extra hours of care received as 'more than hoped for'.

These carers had a good supportive network of family members and friends who were available to them and called in regularly and were also availing of additional in-home supports from the ASI or out-of-home day care.

Those carers with 'moderate to severe' burden emphasised that the IHCP hours were making a difference, but they continued to find caring demanding and 'full-on'. It was more common for these family carers to talk about being constantly on call and refer to the number of hours of caring that were still left in the day outside of the IHCP hours:

> *"Yes, we still have our problems because there are still a lot of hours left in a week. I am not complaining mind you but there is still a lot more hours left in the day. So, we still have our problems but when you have an afternoon, like this afternoon, to look forward to it makes a difference" (FC, 16).*
>
> *"... it is very tying, that is the biggest problem of it, very tying. You are on call more or less all the time" (FC, 20).*

In addition to the IHCP hours, there was a relatively high use of overnight respite among this group. However, some family carers felt that it was too limited, and that greater availability of overnight respite care was needed. Overnight respite care had to be planned well into the future and some reported that it had being cancelled at very short notice, which sent family carers 'into a spin'. More frequent overnight respite was suggested by some as the single thing that would make the most difference to them.

Like the two other types of dementia-IHCPs, adult children in this group who had responsibility for managing and co-ordinating care as well as providing care and combining this with work and family responsibilities found this stressful.

4.8.4 Summary – Outcomes

All IHCP types were instrumental in supporting people with dementia with high levels of dependency to continue to live in their own homes. In the case of Classic IHCPs, 75% were enabled to remain at home for six months or more; 62% for Block hours IHCPs and 67% for Combination IHCPs. There was a significant added value for both persons with dementia and carers and the quality of life of people with dementia stayed largely the same after the IHCP commenced (about eight weeks after commencement) which is important given the deteriorating nature of dementia. 'Classic' IHCPs help to relieve family carers of the stresses and strains associated with personal care work. However, family carers are still making a large contribution to the care of people with dementia in receipt of 'Classic' IHCPs and it does not seem possible for this type of home care package to work without a high level of family carer involvement. However, they may not relieve all of the stresses associated with other aspects of care-giving, especially for family carers residing with the person and who have little opportunity for respite, or for family members who are caring for people with dementia living alone and combining this with working and other responsibilities. Block IHCPs provided a different type of support to family carers than Classic IHCPs, responding to a range of different needs for carers; to remain in or return to work; to provide support for responsive behaviours; to provide time for other caring duties (e.g. for young children); to provide periods of respite; or to address some combination of these needs. While this package relived burden for several carers in this group, a number who were working and/or had young children still experienced moderate to severe burden with the package in place. All were adult children. One or more block of hours was built into all of 'Combination IHCPs, and family carers were able to use all or some of these block hours to get a break from caring and were reassured knowing that their relative was being well cared for. Family carers were satisfied with 'Combined' IHCPs, and many stressed that they would not be possible for their relative to remain at home without it, which was the preferred option of both people with dementia and their family carers. Both having support with the practical aspects of care and time for a break from caring were highlighted as important aspects of these packages by many family carers. However, this did not always translate into reduced caregiver stress.

4.9 What works well...or not?

Interviews with family carers identified several indicators of what worked well in IHCPs generally and for specific package types. Generally, packages were described as not working well when these factors were absent or lacking.

4.9.1 Skilled care workers

In general, the family carers and people with dementia in receipt of IHCPs spoke very highly of the home care workers, describing them as '*great*' or '*super*' or '*brilliant, every single last one of them is brilliant*' and as being '*professional*':

> *"I have to say all of the carers, I really couldn't find fault with the people who come in, they are great, they are committed, and they are lovely, and I couldn't say a word about them." (FC, 36)*

For Classic IHCPs family carers particularly appreciated when home care workers were well trained in undertaking personal care tasks with a person with dementia such as dressing, toileting, manual handling and hoisting. Although a few questioned the level of personal care training or dementia care training of some home care workers, for the most part, families felt that home care workers were well trained to do this type of care work.

Family carers in receipt of Block hours noticed differences between care workers, with some more attentive to the person's needs than others and some better skilled than others at communicating with people with dementia. A challenge for some care workers in moving from shorts visits for personal care to block hours was not knowing how the time could be most appropriately used. Another challenge was that more than half of persons with dementia receiving 'Block hours' IHCPs were reported to have responsive behaviours and some care workers did not appear to be equipped for this.

> *"She [person with dementia] says 'no' to everything so the girl [care worker] then just goes and watches the telly or reads a book or something. It is great peace of mind though to have somebody there in case anything happened" (Family carer, 15).*

This variability in skills for interaction during the blocks of hours was also noticed by family carers in the Combination IHCP group. A few family carers in this group reported some home care workers to be better than others when it came to interacting with the person during block hours. Most seemed to be proactive in engaging the person in meaningful occupation during the block hours but there were some who would not interact much with the person during this time.

> *"I mean there is good and bad with everything. Some of them are quite content to just leave her sitting there in the chair and then go off and do their own thing ... So, you get some of them they would be there, and they would be very involved, we came in there once and ... they had the colours out there for her" (FC, 21).*

4.9.2 Certainty

A very important aspect of the Classic IHCPs was that it provided assistance to family carers with hoisting for personal care and transfers and these family carers found having home care workers come at definite times during the day and week to be a real benefit. They greatly appreciated when home care workers arrived punctually and at the allocated time. They were very understanding of the fact that home care workers could sometimes be delayed, for example, with a previous client, or stuck in traffic, but liked to be kept informed by the home care worker or their employer, i.e. the HSE or an approved private provider, when there was a delay.

4.9.3 Consistency and continuity of carers

Having the same home care workers consistently was very important to family carers, and across the three types of dementia-IHCPs they highlighted the importance of familiarity for their relatives. Most reported that the same home care workers attended consistently. Family carers were accepting of the fact that different home care workers sometimes needed to be scheduled to cover for such events as holiday or sick leave. They greatly appreciated it when new home care workers were introduced in advance and welcomed shadowing, a practice whereby one of the regular home care workers introduced the new carer and showed them the house and demonstrated the care work. One person with dementia spoke about how confusing it was to have so many different home care workers coming into the house but added that she understood that it was inevitable for this to happen with all the hours that were being covered. In a small number of cases, there was a high turnover of home care workers, and this together with poor communication from the approved private provider, caused great upset for family carers and dissatisfaction with the IHCP.

4.9.4 Communication

Across the three types of dementia-IHCPs, Family carers placed a huge emphasis on good communication from the HSE and approved private providers about issues such as turnover of staff, or changes in staff rotas and being kept informed about cover for bank holidays or holiday and sick leave. While some family carers found communication with the home care providers to be excellent, others reported having to constantly chase them for such information, which they found aggravating and stressful, and felt that communication could be greatly improved. We can sometimes underestimate the difference that can be made with simple, timely communication, especially in maintaining good relationships.

4.9.5 Support to continue working

Because of the way in which the care hours were configured to provide care to persons with dementia, Block hours IHCP were particularly good at facilitating working spousal carers and adult children to continue in employment. One spousal carer had been bringing the person with dementia to work every day when day care broke down but with the IHCP the person with dementia could be cared for at home while the spouse went to work. Work provided an income, much needed in many cases, but was also important for the social and psychological wellbeing of family carers who worked. Having a care worker present in the home over a block of hours gave family carers a little bit of leeway timewise and relieved then of the pressure of constantly trying to 'beat the clock'.

> *"It is great, great to get out, have a focus, there is a social entity to it ... and I work with great people ... It means that my head is free. I finish work at 1:00 and the [care worker] finishes at 1:30. Now sometimes I would have a bit of paperwork and I wouldn't finish until 1:10, today it was 1:12 but one of the boys ... would come in and have his lunch at that time and then I would cook dinner in the evening" (Family carer, 06).*

4.9.6 Reassurance

Before the IHCP, some family carers had been relying on the goodwill of neighbours to alert them if something happened while away from their relative, but with the Block hours IHCP, they could get on with their work without continuously worrying and they no longer felt like they were on constant alert waiting for the next call:

> *"I know she is perfectly well cared for, so we are not on alert, we are not, ding, ding, ding in the back of the mind, what the hell is happening?" (Family care, 04).*

4.9.7 Maintaining mobility and ability

A recurring theme in interviews with family carers in receipt of 'Block hours' IHCPs was deteriorating health and mobility of the person and the progression of their dementia. For example, none of the 13 people with dementia in this group were confined to a bed/chair, but approximately two-thirds still had mobility difficulties. Family carers were keen to maintain the person's level of mobility for as long as possible. However, there was concern about the person's mobility and its deterioration, which contributed to uncertainty about what the future holds for the person and what would happen if more care was needed and if more care hours would be available.

In some areas, however, family carers reported that home care workers (both those from HSE and approved private providers) were not allowed to bring the person out of the house during the block hours, which they found hard to understand, especially when they believed it would improve the person's quality of life and enhance their wellbeing. A consistent policy would be helpful in this regard.

In summary, the packages worked well for families when: home care workers were well trained, particularly in relation to dementia care and person-centred care; when there was certainty in terms of scheduling; when there was consistency in terms of carers and continuity of care; when hours were organised so that there was time for a break for the carer; and when there was good communication between the provider and the family. The IHCPs didn't work well when one or more of these elements was absent, for example, multiple different carers on different visits, a lack of communication and so on.

4.10 IHCPs supporting discharge from hospital

Of the 42 cases included in the in-depth study, 12 were people with dementia who were approved for an IHCP whilst an in-patient in an acute hospital. The following is a summary profile of these 12 cases:

- 9 female, 3 male, aged between 70 and 99 years of age
- Range of dementia sub-types including Alzheimer's disease, Vascular Dementia, Lewy Body Dementia, Mixed dementia, Post-operative and Stroke-related dementia
- Varying stages of dementia: Mild (2), Moderate (3) and Severe (7)
- Living arrangements: spouse/partner only (5); their spouse and an adult child (1), adult child only (3), alone (3)
- Falls were most common reason for admission (7)
- Length of stay was from 7 days to 5½ months
- 9 people had some home care prior to admission, which ranged from 2-5 hours (2 cases) and 7-14 hours (6 cases). 3 had none.

Four people were discharged home from hospital on 'Classic' IHCPs, two on 'Block hours' IHCPs and four on 'Combination' IHCPs.

5. Costs evaluation

The service utilisation data from the RUD was analysed and costed according to the methods described in section 3.4.1. The RUD collects data on resource use in the last 30 days.

5.1 Primary and Community Care

Primary and community care resource utilisation among people with dementia is presented in Table 10. The most commonly used services include public health nurse visits (61%), GP visits (51%), day care (28%) and occupational therapy (21%), with relatively little use of community mental health nurse visits (8%) and social workers (5%). In general, despite a relatively high risk of residential care, a large number of participants in the study were not in receipt of community-based formal provision. For example, despite public health nurses being the highest level of service provision in the community care setting, 39% of respondents had not received a visit over the last month. Furthermore, less than one fifth of participants received a physiotherapy visit, speech and language therapy visit or chiropodist visit. The overall picture is one of scarcity in regard to public community-based care provision for people with dementia living at home in Ireland. The total average cost per week was €98, almost 77% of which was accounted for by day care. This was followed by public health nurse visits which accounted for approximately 8% of the total average cost. Allied health therapies (i.e. physiotherapist, occupational therapist etc.) contributed less than 5% of the overall average cost.

Table 10: Resource utilisation of primary and community-based care and average cost per week

Service	Yes, %	No, %	Average cost per week, €
GP	51%	49%	€7.07
Nursing			
Public Health Nurse	61%	39%	€7.63
Community Mental Health Nurse	8%	92%	€0.63
Allied Health Therapies			
Physiotherapist	10%	90%	€0.88
Occupational Therapy	21%	79%	€1.25
Speech and Language Therapy visit	13%	87%	€0.63
Chirpodist	15%	85%	€0.75
Social Worker	5%	95%	€0.38
Other Health Professional	21%	79%	€1.13
Services			
Day Care	28%	72%	€75.04
Meals on Wheels	5%	95%	€2.33
All			€97.72

5.2 Out-patient and In-patient visits

Resource utilisation for out-patient and in-patient visits among people with dementia is presented in Table 11. Psychiatric (13%) and geriatrician (10%) visits were the most commonly used out-patient service for people with dementia living in the community. Only, 8% of participants experienced an in-patient acute hospital admission in the last month, while only 3% had an emergency admission to an acute hospital. Average costs of out-patient visits were €12.69 per week for this sample. Table 11 also includes the cost of in-patient care. Only two people incurred in-patient costs, but one of them spent the previous 30 days in hospital, accounting for 71% of entire acute hospital admission costs. Information was provided on the other person admitted to hospital, but no data was available on length of stay. We assumed a length of stay of 12 days for this person, based on previous findings from a generic study on hospital admissions and discharges for people with dementia by (Connolly and O'Shea 2015).

Table 11: Resource utilisation of out-patient and in-patient care and average costs per week

Use of service in last 30 days	Yes %	No %	Average cost per week €
Out-patient visits			
Geriatrician	10%	90%	€4.00
Psychiatrist	13%	87%	€5.00
Neurologist	0%	100%	€0
Psychologist	3%	97%	€0.37
A & E attendance	5%	95%	€3.32
In-patient visits			
Acute hospital admission	5%	95%	€215
Emergency admission to acute hospital	3%	97%	€5.12
Psychiatric hospital	0%	100%	€0
Day hospital	5%	95%	€2.00
All			**€234.81**

5.3 Medications

Just over half (56%) of people with dementia living in the community were prescribed an anti-dementia drug in the last 30 days (Table 12). A smaller proportion of individuals were prescribed anti-depressant medication (33%) and anti-psychotic medication (27%). The total average cost of medications over a one-week period was €17.47, of which 45% is accounted for anti-dementia drugs.

Table 12: Medication usage in the community care setting and average cost per week

Prescribed medication in last 30 days	Yes, %	No, %	Average cost per week, €
Anti-dementia medication	56%	44%	€7.90
Anti-psychotic medication	27%	73%	€7.57
Anti-depressant medication	33%	67%	€2.00
All			**€17.47**

5.4 Care hours in the community

IHCP hours: The average number of IHCP hours is presented in Table 13. The mean number of hours provided per week was 34 hours (ranging from 13 hours to 56 hours per week). The mean number of hours is also categorised by three distinct types of IHCPs. The Classic IHCP receives the most home support hours. Typical characteristics of this type of package include two persons to assist with hoisting, a focus on personal care, three or more short visits per day, up to five to seven days per week. The average cost of an IHCP per week was €774. The variation in provision is evident with weekly costs ranging between €294 to €1,268. Individuals receiving a Classic IHCP have the highest Intensive Home Care Package cost at €826 (range €634 - €1,268) per week.

Private Care: In 35% of cases, private out-of-pocket care hours were purchased in order to supplement public care for individuals with dementia living in the community setting. An average of 19 hours of private care was bought per week (Table 13). Not everyone purchased private care as is clear from the range data. Block IHCP recipients purchased the most private home care hours, averaging 29 hours per week. Typical characteristics of this type of package include one home care worker, visits lasting between 2-10 hours, four or more days per week. Combination type IHCPs only purchased an average of two private home care hours per week.

Informal Care: On average, carers of people with dementia reported providing 80 hours of informal care week, or just over 11 hours per day (Table 13). It cannot be underestimated the role that families play in providing care and support for people with dementia. Even with IHCP provision, there is a considerable reliance on families to support people with dementia in Ireland. Carers of people with dementia receiving a Combination type IHCP provide an average of 90 hours of informal care per week. Typical characteristics of this type of package includes a combination of short visits for personal care and short blocks of intensive support hours.

Table 13: Average weekly hours of care in the community setting

Hours of Care	Classic IHCP mean hours (range)	Block IHCP mean hours (range)	Combination IHCP mean hours (range)	All mean hours (range)
IHCP hours	36 (28-56)	35 (14-48)	29 (13-42)	34 (13-56)
Private care hours	23 (0-168)	29 (0-138)	2 (0-15)	19 (0-168)
Informal care hours	78 (3-126)	73 (2-133)	90 (28-122.5)	80 (2-133)

Table 14: Average cost of different types of care hours in the community setting

Hours of Care	Classic IHCP mean cost (range)	Block IHCP mean cost (range)	Combination IHCP mean cost (range)	All mean cost (range)
IHCP hours	€826 (€634 - 1,268)	€819 (€317 - 1,176)	€652 (€294 - €951)	€774 (€294 - €1,268)
Private care hours	€461 (€0 - €3,497)	€621 (€0 - €2,818)	€53 (€0 - €340)	€391 (€0 - €3,497)
Informal care hours (opportunity cost method)	€599 (€33 - €1,295)	€451 (€45 - €826)	€754 (€156 - €1,354)	€593 (€33 - €1,354)
Informal care hours (replacement cost method)	€1766 (€68 - €2,853)	€1,653 (€45 - €3,011)	€2,038 (€634 - €2,785)	€1,811 (€68 - €3,011)

5.5 Capital and personal consumption costs

Table 15 shows capital and personal consumption costs for people with dementia living at home in a community setting. The average cost of capital per week is €115. This estimate includes people who were living in their own property and those living in rented accommodation or living with a family member/friend. The average estimated cost of personal consumption was €137 over a one-week period.

Table 15: Capital and personal consumption costs in the community setting

Cost item	**Average cost per week €**
Capital	€115
Personal consumption	€137

5.6 Overall Cost of Care

Table 16 shows the total average care costs for people with dementia living in the community setting. The overall average cost per week for care is €2,108. We exclude out-patient, impatient and medication costs in our comparative calculations, based on the assumption that they are similar whether a person is resident at home or in a long-stay care facility, although they are shown in Table 16 for completeness. The estimated weekly average public expenditure cost of home care per person with dementia, which includes IHCP hours, primary care and community care, is €872. When consumption and housing are added costs rise to €1,124 per week. Costs increase further to €1,730 per week when informal costs are estimated, using an opportunity cost methodology. Adding out-of-pocket payments to private providers brings the cost of care to €2,108 per week. On average, informal care and private care account for 47% of the overall cost of care for people with dementia living in a community setting.

Table 16: Overall care costs for people with dementia

Activity	Average costs, per week €	% of overall care
Intensive Home Care Package	€774	37%
Primary and Community Care	€98	5%
Private care	€391	19%
Informal care (opportunity cost method)	€593	28%
Capital	€115	5%
Personal consumption	€137	6%
All	**€2,108**	**100%**
In-patient visits	€222	
Out-patient visits	€13	
Medications	€17	
All	**€2,360**	

We also examined the potential cost of care for people with dementia if they had been placed in residential care rather than cared for in the community (Table 17). If the comparison is only with IHCP support hours, primary and community care, consumption and housing, the average home care cost of €1,124 per week is almost comparable to the average cost of a private nursing home per week in the Dublin area. When compared to the average cost of a public nursing home, there is a cost saving of €402. However, when informal care costs are included, community care is more expensive than residential care for people with dementia in Ireland, although still considerable below acute care costs.

Table 17: Nursing home costs

Type	Average weekly cost €
Public nursing home	€1,526
Private nursing home - Dublin	€1,149
Private nursing home - rest of country	€909

5.7 Exploratory relationships between costs and other characteristics

In order to explore key relationships between the costs associated with IHCPs and the characteristics of the recipients and of the packages, a statistical method called generalized linear models (GLMs) was used. The outcome we focus on is the weekly cost associated with the IHCP. Given the limitations of the data, most estimates did not reach conventional levels of statistical significance and hence the relationships should be viewed tentatively as representing possible associations, warranting further exploration rather than as definitive statements of causality.

Costs tended to be higher for individuals aged less than 65, perhaps reflecting differences associated with early onset dementia. From the age of 65 years, costs then increased with age as one might anticipate. Individuals living alone or requiring greater assistance with daily activities (higher ADLS scores) received more costly packages, again as one might expect.

Greater overall family care contribution and engagement after the IHCP commenced is also associated with lower cost IHCPs, suggesting the potential existence of substitution. Recipients whose carers report greater burden (Zarit Burden Index) receive less costly packages (significant at the 10% level), suggesting a possible relationship between reduced formal support and burden. Recipients who were in receipt of more hours of informal caring tended to receive more costly packages (significant at the 5% level), presumably reflecting higher levels of need overall. Recipients with greater baseline quality of life, who may have less need, received lower cost packages.

5.8 Dementia, admission to long-stay care and mortality

In order to explore the impact that having dementia has on the probability that IHCP recipients are admitted to long term care or die, we estimated bivariate probit models for these outcomes using reweighted data (see section 3.4).

IHCP recipients with dementia were 17 percentage points less likely to be admitted to LTC, and 22 percentage points less likely to have died, than similar recipients without dementia. While this difference may be attributable to unobserved differences between the groups, such as their underlying health status, which may not be fully reflected in measures such as the Barthel Index, it is striking nonetheless, and suggests IHCPs may be more effective at keeping recipients with dementia alive and out of LTC than they are for other types of individuals. However, further research is necessary to examine how and whether disease classification matters for the effectiveness of IHCPs.

Age, gender and marital status do not appear to statistically significantly influence the probability of admission to LTC or mortality in this cohort. Individuals living alone have a lower probability of death, although this most likely reflects omitted variables such as health status which may influence whether an individual is considered to be suitable to live alone, thereby influencing the probability of death.

Individuals without a main carer are at significantly higher risk of death but are also less likely to be admitted to LTC. This may reflect failures to identify individuals at immediate risk of negative outcomes in a timely fashion where carers are not present. But it may also reflect higher levels of risk and need in this group of people in the first place. More information is needed before anything more definitive can be said about this finding.

Individuals that receive more care were less likely to be admitted to LTC, and more likely to die, than those receiving 0-8 or 8-12 hours of informal care daily. The increased mortality may be a confounder for the reduced likelihood of LTC admission. Individuals with high dependency, reflected in a Barthel Index of 10 or below, were more likely to die, although dependency did not significantly impact on the probability of being admitted to LTC.

6. Personalisation of Dementia-IHCPs

One aim of IHCP initiative was to develop a personalised approach to care, which is an approach that elicits the needs, preferences and priorities of the person and/or their carer and develops an appropriate response. It applies at any stage of dementia and any level of dependency (described in Report 1, (Keogh, Pierce, Neylon, Fleming, et al. 2018). The in-depth study provided an opportunity to examine the extent to which the different types of packages were personalised.

Genio has been supporting the HSE in the implementation of personalised dementia-IHCPs. Its Programme Managers have been working collaboratively with multi-disciplinary groups in eight sites (Cork, South Dublin, Galway, Dublin North City, Waterford, Limerick, Dublin South West and Dublin North), to promote a personalised response to home care for people with a diagnosis of dementia, by creating and testing enhanced pathways for delivery. As this work only commenced in December 2016, well after the IHCP Initiative had commenced and follows a staged process of engagement, the testing of a small number of personalised dementia-IHCP only began towards the end 2017, and only one of these test cases was captured in the in-depth study. The impact of this implementation support work will be reported in a separate report titled (title to follow). Nevertheless, it still worth examining personalisation of home care within the IHCPs provided over the period December 2014 to December 2017, the subject of this section.

Based on a concept synthesis of the literature, Wilberforce et al. (2017) have generated a framework for person-centredness in the community care of older people. The framework is organised according to three headings: understanding the person, engaging the person with dementia in decision-making around their care, and promoting the care relationship. This framework is used here for examining the extent to which the different types of IHCPs are personalised. With regard to decision-making, two levels at which people with dementia and their family carers can be involved in decision-making (that is, at a meso level and micro level), are of relevance in our analysis. At the meso level, personalised care 'reflects the degree to which services users/carers are involved in the processes of care planning through which support needs, care goals, preferences and available services are assessed and organised' (p. 91), in other words, the extent to which the person's wishes shape decisions and care plans (Wilberforce et al. 2017). At the micro level, personalised care is evidenced in the direct care delivery and interpersonal exchanges between the home care workers and the person with dementia in completing tasks.

This framework is used here for examining the extent to which the different types of IHCPs identified and described in this report are personalised.

6.1 Understanding the person

Understanding the person is a core element of personalised care. When people with dementia in receipt of 'Classic' IHCPs were assessed for home care supports, basic personal care needs were the main priority and, with respect to delivery, the focus was on short visits by home care workers to undertake care tasks aimed at meeting the person's personal care needs. Given that most were confined to a chair or bed and had high or maximum levels of dementia, the personal care needs of these people were manifestly high. A person-centred approach, however, highlights the inter-relationship between physical, psychological, social and emotional needs. Using a person-centred approach, personal care can be understood not only as meeting a person's physical care needs but also as an opportunity for enriching the lives of people with dementia. Transfers can serve as an example. Transferring a person with advanced dementia from a bed to a chair and back to bed is physically hard work, often requiring two persons, and because of the effort involved, it may be easier and more convenient to leave the person in bed. However, when the focus is on the person as a sentient human being rather than simply on the task at hand, the significance of getting the person up sitting in a chair becomes evident:

> *"There was times when people or one of the nurses said, 'maybe we should leave him in the bed', but we didn't push for that either. We pushed for the opposite because he is part of the family and we don't want him lying down on his own in the bedroom when we are all up in the kitchen or the sitting room. So, he is very happy with that, he is up there sitting, looking at us, smiling, watching everything going on, even though he doesn't really partake too much or communicate too much" (Family Carer, 24).*

In reporting on their experiences of 'Classic' IHCPs, family carers of person in receipt of 'Classic' IHCPs generally spoke about how understanding of the person home care workers were and this was very important for family carers:

> *"… the two … ladies had experience of working with older people and they just seemed to have just a natural ability to understand, to get how to manage her, to get how to care for her and to get how to relate to her" (Family carer, 13).*

Some family carers explained that their relative with very advanced dementia sometimes got distressed when being hoisted, or washed or changed, highlighting the importance of home care workers getting to know and understand each individual and how they react in such circumstances, and what is the most appropriate way to respond. There were examples of how the home care workers approached this, and good communication and interaction directly with the person with dementia was always central to this. The following offers an example of how the service provider and its home care staff work to provide personalised care in such a situation:

> *"… they [approved private provider] did spend a long time on the phone with me going through how she was likely to react to this personal care. So, I suppose they were under no illusions … she wasn't going to be happy with it … they handled it very well…*
>
> *They [home care workers] are very sympathetic and they are very professional, and they tell her 'now we are going to lift you' and 'now we are going to do this' and 'now we are going to do that'. And they have learned she likes to laugh and I can hear the carer going … so they have tuned into her" (Family carer, 30).*

Family carers quite often stressed that they were the ones who knew and understood the person the best, what they want, what they need and what they like. They often highlighted, especially when the person with dementia was at an advanced stage and had difficulty communicating, the role that family carers played in facilitating home care workers to get to know and understand the person. They stressed that this took time and there were examples of family carers modelling person-centred care for home care workers.

However, focusing only on meeting personal care needs means that other care needs were treated as completely separate. This is not in keeping with a person-centred approach, which highlights the inter-relationship between different care needs. A difficulty with short visits was that home care workers were tied to specific times, which meant that they could only focus on and complete essential personal care tasks, leaving little or no time to assist with other essential activities of daily living such as drinking and feeding. Meeting other care needs was typically seen as the responsibility of family members. It was quite striking how much family carers, especially those caring full-time, spoke at length about the preparation of a varied range of nutritious and appetising meals and about what feeding involved, and the amount of time it took. Making sure that the person was eating well and drinking enough to prevent dehydration were also top priorities for family carers of people living alone, and although they were willing to do this - "we were always prepared to put our tuppence ha'penny in" - it took a lot of planning, organisation on the part of family members and depended on good communication between family members and home care workers:

> *"So, the morning, they [approved private provider] said it is tight … but they will do their best [to feed person]. So, I tried then buying a flask and leaving it ready for them but … if they can get the Weetabix into her she had got a breakfast and some roughage and all the rest of it … Between us [family members] we get food ready, we might even leave it in the freezer and it only has to be defrosted. And the lady who comes in on Tuesday then will mark a box for the Wednesday … so it is getting a communication system going" (Family carer, 30).*

For people with dementia who were mobile and at a milder or more moderate stage of dementia, the emphasis was on support with activities of daily living and supervision, rather than solely on direct personal care. This was more evident in Block and Combination IHCPs. Care plans were tailored to these persons, health professionals and approved private providers engaged with the person and/or their family carers, and home care workers were highly responsive to the needs of the person with dementia. The packages were vital for keeping the person with dementia at home. However, the extent to which care was explicitly aimed at maintaining ability was limited and support for meaningful occupation or therapeutic engagement was seen as the responsibility of day care centres or left to family members. Neither were there any examples of people with mild or moderate dementia being provided with cognitive therapies such as cognitive stimulation therapy or cognitive rehabilitation to help preserve cognitive and social functioning.

In Block hours IHCPs, the packages were used in varying ways, either to support a family carer to continue or return to work, to combine caring for the person with dementia with working and other family responsibilities, or support family carers in coping with responsive behaviours.

There were many positive reports of how home care workers engaged the person with dementia in meaningful activities during the block hours and the positive impact that this was having for the person with dementia, as previously reported (see page 41). Therefore, the 'block hours; and 'combination' IHCP demonstrate a movement towards a perception that assessing and caring for psychosocial needs, as well as physical care needs, is important. In some cases, however, the use of block hours for psychosocial supports and engaging the person in meaningful activities seemed to be left to individual home care workers rather than it being routine practice for all home care workers.

> *"What has been brilliant with [Mum] is the carers have come in and done stuff, like one of them brings in Connect 4 and that Pirate Pop-up game and did it off her own bat. And as a result, we ended up implementing it into her care plan because the reaction was incredible, so it is kind of working that we get people [home care workers] like that in there. Still a few like one or two aren't doing it and I need to get across the care plan a little bit more and that is not something that is going to naturally happen" (Family carer, 14).*

Family carers were very good at discriminating between those home care workers who were most skilled at providing care that was personalised to the person with dementia and those who were less skilled at and perhaps less concerned about doing so. Family carers welcomed opportunities to communicate with, provide feedback to and work with approved private providers and HSE community care staff to ensure that their relative was receiving the best possible care, but experiences and responsiveness of approved private provider in this regard were mixed.

Several family members reported difficulties with responsive behaviours and block hours were used to support family carers struggling to cope with challenging behaviours and give them a break, as well as providing care and support to people with dementia. Family carers were highly appreciative of the home care workers who could cope with responsive behaviours and spoke highly about how they interacted with the person. However, there were examples of where home care workers themselves appeared to lack knowledge or experience of responsive behaviours among people with dementia, which impacted on the quality of care and support provided to the person with dementia:

> *"... and [home care workers] probably tries her best and she [person with dementia] says no to everything so the carer then just goes and watches the telly or reads a book or something (Family carer, 15).*

In some cases, 'block hours' IHCPs were used to provide care and supports to an older person with dementia and respite for an older spousal carer who was finding caring challenging because of responsive behaviours or a difficult caring relationship. While these were good examples of packages tailored to the needs of person with dementia and their family carer, there was little evidence of the use of any other type of support for family carers such as counselling, psycho-educational supports or short-lived intensive one-to-one support for family carers to help them better understand and respond to challenging behaviours.

6.2 Engagement in decision-making

People with dementia do not usually make autonomous decisions when it comes to care planning decisions relating to, for example, returning home or remaining at home or moving into nursing home care (Smebye, Kirkevold, and Engedal 2012) and this was the case for people with dementia in receipt of IHCPs. The vast majority of these people had severe dementia, some at an end-stage, and often were unable to respond to or communicate with others. It is clear though, that many family carers were making decisions about care with the person's wishes and preferences to return to or remain at home in mind. A clear pattern evident from the qualitative interviews was that the process worked best when health care professionals worked in partnership with family carers to try and make this become a reality.

Family carers and the person with dementia did not always have a say in the IHCP type that they received. Nor did they always have a say in the timing of visits, and although some would have preferred a different time, they accepted without complaint the time that had been allocated. Some family carers were reluctant to request a change in the timing of a visit, as they did not want to appear demanding or feared they would 'lose' a highly valued home care worker who might not be available at a different time.

The extent to which persons with dementia and/or their family carers were engaged in the processes of care planning of 'Classic' IHCPs was limited. The hours of care were mainly organised around the person's needs for personal care, with decisions made for the most part by health professionals with little input from families:

> *"The girls [home care workers] talk and the [public] health nurse sees. I can't say there was no assessment; people see what they see when they come in. The public health nurse came in and she said, 'we want to just do a quick interview with your Mum, there is a chance that you will get more hours.' It was actually the public health nurse who came in and asked Mum a few questions about memory tests and things like that and then we heard fairly quickly [about approval for IHCP]" (Family carer, 17).*

Other family carers pointed out that their opinions and views were sought but there were not always taken on board:

> *"So, we were asked for our opinions and we were consulted but I felt as a family member I had to push from our side to get what we felt my Dad [needed], to get our point across" Family carer 24).*

Family were generally satisfied with the extra hours. However, when decisions were made primarily by health professionals, the way in which the hours were used was pre-determined by them instead of being co-produced by service providers and the person with dementia and their family carer. The result was that traditional types of packages tended to be put in place with short visits focusing solely on personal care tasks. This is illustrated by the response of an older spousal carer when asked about involvement in the design of the IHCP:

> *"The [public health] nurse came up with her theory on it [IHCP], [she said] 'what you really need is someone in the morning and maybe someone in the middle of the day and then maybe someone to put her to bed at whatever time at night'" (Family carer, 27).*

Family carers expressed satisfaction with this type of care package. However, on further exploration with interviewees, it became clear that with their involvement, the package could have been designed differently to better meet their needs. This could include, for example, giving consideration in the design of 'Classic' IHCPs to providing a short break for the family carer, or moving beyond a sole focus on personal care supports for the person with dementia. Often, this would require only slight tweaks to the home care hours or minor modification to the package design. The 'Combination' IHCPs are useful for illustrating an alternative approach where, in contrast to 'Classic' IHCPs, time was built in for a break for family carers, the importance of which was highlighted by family carers for sustaining them to continue to in this caring role.

One example of involving people with dementia in decision-making comes from an observation of a social worker's engagement with a person in receipt of a 'Classic' IHCP. Day care provided the only opportunity for this person to get out of the house and a place had become available for the person to attend a day care centre on a second day. The social worker spent time telling the person about the day care centre, what it was like, the activities there and suggested that it would be beneficial as it would allow the person to get out of the house and interact with people for two days a week instead of one. The person was reassured that a decision didn't need to be made straight away, but the social worker left the person to think about it, promising that they could discuss it again the next time he visited. This exchange of information and the awareness on the part of the social worker to ensure that the person was consulted about their views and preferences, that information provided was understood and time was given for the care option to be considered is illustrative of a shared approach to decision-making, and in keeping with a person-centred approach. With regard to the allocation of hours, the general practice across the country was that a number of hours were allocated and then family were involved to varying degrees in decisions about how these hours would be organised. The 'Classic' IHCPs in particular were a largely pre-determined form of care focusing primarily on physical or personal care needs. Family carers in receipt of 'Block hours' and 'Combined' IHCPs tended to have a greater level of input into how the home care hours would be allocated:

> *"I was saying to myself, 'What do I prioritise?' Getting her up, that was the main thing and, as much as I love my Mam and everything, I would rather somebody else washing her. So, from that end, that was my priority. And she [the PHN] said: "Ah no, you have to get time off, you need to have time". So, she wrote down an example timetable and asked me to have a look and said if you agree with that then that's what we will go with, so that's where that came from" (Family carer, 21)*

The 'Block hours' and 'Combined' IHCPs provided more scope for home care hours to be used to extend the focus beyond personal care and support the family carer at the same time as providing meaningful occupation for the person with dementia and enhancing their personhood and a sense of self. However, there was little evidence of persons with dementia or their family carers being offered any other form of support or care other than home care hours.

6.3 Promotion of caring relationships

Another important element of person-centred care is interpersonal relationships. This includes interpersonal relationships between the home care workers, the family carer and the person with dementia.

One view held by family members was that 'no matter who the agency is, it's the person who comes out that really matters'. In most cases, relationships between the home care workers, family carers and the person were good and there were plenty of examples of successful care relationships. People with dementia who participated said about the home care workers: 'they are all very nice ... and they are good fun' or 'they are so kind. They couldn't be nicer'. Family carers highlighted the importance of the relationship and the positive impact that it had:

> *"What is working really well now is the relationship that they [home care workers] have all built up with my mother and my father. And I suppose in a way the ease that it has brought to my parents' home" (Family carer).*

Important relationships that family carers highlighted were relationships of home care workers with each other, relationships between home care workers and person being cared for, and relationship of home care workers and family carers. However, when staff did not turn up, or where there was regular turnover of staff, as experienced by some recipients, there was a disruption to care relationships, thus undermining person-centredness.

Respectful interactions between service providers and family carers are also a hallmark of person-centred care, and while many described these relationships positively not all family carers felt respected by HSE staff or approved private providers.

6.4 Summary

In summary, for a home care package to be personalised, physical and personal care should not be seen, assessed or addressed separately to other care needs, irrespective of the type of IHCPs or severity of dementia. A person's psychosocial needs are as important as their basic or personal care needs and these can be addressed simultaneously. Where home care workers are assisting with personal care or domestic tasks, the way in which they converse, communicate and interact with the person is important for meeting the person's need for social contact and engagement. This needs to become a deliberate and integral part of the assessment process and of care practice, irrespective of IHCP type or severity of the person's dementia.

Greater involvement in decision-making around care is pivotal to personalised care. There was some evidence of family carers being involved in decision making about the package of care. However, the number of hours allocated was largely pre-determined and family carers were more likely to be involved in decisions about how the allocated hours would be distributed during the week. The block hours and combination IHCPs demonstrate that where service providers have discretion and family carers have a say in the distribution of hours, care packages that are more tailored to the needs of the person with dementia and their family carers tend to emerge.

The interviews with people with dementia and their family carers highlighted the importance of interpersonal relationships for providing IHCPs that promote personalised care for people with dementia. It is quite telling that packages where care relationships had broken down were those where family carers were least satisfied with the IHCPs. Key relations include those between the triadic relationship of the person with dementia, family carer and home care workers. However, good interpersonal relationships between key staff in the HSE, particularly PHNs but also social workers, occupational therapists and physiotherapists, and staff coordinating and managing IHCPs, are also important, as are the relationships between family carers and approved private providers. There were some very good examples of IHCPs that had the hallmarks of personalisation which can be built upon to make this practice more widespread.

7. Understanding how dementia IHCP-types may address caregiver burden

To evaluate the IHCPs within a realist framework, an initial or formal programme theory was developed based on a review of relevant documents and interviews with HSE staff, and further developed to incorporate changes to the Initiative. The programme theory includes the desired outcomes of the IHCP Initiative at the outset (see Figure 1).

Figure 1: Formal programme theory for IHCP initiative

CONTEXT	INPUTS	OUTPUTS	OUTCOMES
» Policy & preferences » Limited home supports » ED crisis » NDS » Funding opportunity » HSE & Genio demonstration sites	» Funding » Existing HSE personnel » SOP » Specified number of personalised IHCPs to be delivered.	» Personalised IHCPs delivered	» People with dementia discharged from acute care/ diverted from LTC » People with dementia remain at home for longer » Good QOL person & carer » Reduced caregiver burden

A desired outcome of the IHCP Initiative was to enable older people with complex needs, including people with dementia, to remain living at home for longer. The study has shown that providing a higher level of home care supports makes it feasible to care for older people with complex needs at home, including people with dementia, and that it is possible to do so for significant periods of time (Report 1, Keogh, Pierce, Neylon, Fleming, et al. 2018). The in-depth exploration of a group of people with dementia in receipt of IHCPs has reconfirmed this finding. It has also shown that in addition to enabling a person with dementia to remain at home, the person's quality of life can be maintained, another desired out of the IHCP Initiative. This is an important finding given the progressive nature of dementia.

While in quantifiable terms, the IHCP Initiative was designed to provide a higher level of home care, it was also the intention that IHCPs would herald a qualitative change in the content and delivery of home care supports. The evidence from this study is that this occurred to quite a substantial extent. In response to the IHCP initiative, the various actors in the system responded in three main ways and the typology that was derived from the data has described the three typical ways in which home care was organised. While Classic dementia-IHCPs typify the conventional way in which home care is usually organised, the emergence of Block hours and Combination dementia-IHCPs is an indication that some remodelling of home care services has taken place (see Table 9). The IHCP initiative presented an opportunity to develop a personalised approach to care, and through the in-depth study, it was possible to examine the extent of personalisation, and how this varied across IHCP types.

One of the most striking findings from the in-depth study is the extent to which home care in Ireland is a family care system. The IHCP Initiative was targeted at supporting both the person with dementia and their family carer. Reducing caregiver burden was another laudable intended outcome of the IHCP Initiative. The in-depth study provided an opportunity to examine in more detail, caregiver burden as an outcome of the IHCP initiative. The findings however were enigmatic, and because of this, we have decided to take a closer look at the different IHCP types and explore them through a realist lens. The purpose of this was to elucidate the theoretical assumptions underpinning the different dementia-IHCPs types and identify the mechanisms through which they could be modifying caregiver stress. Realist evaluation is a theory driven approach and we have chosen the caregiver stress process framework to help us make sense of our findings in relation to caregiver burden and the different types of IHCPs. The caregiver stress process framework, outlined briefly in section 2.3 of the Background to this report, is a widely used framework for the development of interventions to support family carers and alleviate caregiver stress. We are theorising that different elements of caregiver burden act as underlying mechanisms through which the IHCP hours produce an effect on the overall experience of burden. This effect differs depending on which type of IHCP was in place and family context.

The main assumption underpinning **Classic IHCPs** is that caregiver stress strongly relates to the burden of providing physical care to the person with dementia, and that providing a greater level of home care through frequent, daily, short visits by home care workers to assist with personal care will relieve family carers of the physical demands of caring and thereby reduce caregiver stress. This study found that the majority of people with dementia in receipt of Classic IHCPs were highly dependent and confined to a bed or chair, and at an advanced stage of dementia, and these people had very high levels of need with regard to personal care. These IHCPs were clearly supporting family carers with the hard, physical labour involved in assisting with personal care. As such, the additional home care hours provided in this type of IHCP acted as 'mediators of stress', helping to sustain the caregiver and lessen the effects of one primary stressor – help with ADLs and IADLs (see Section 2.3). However, we know that care-giving involves far more than the burden of providing physical care, and that care-giving stressors are multiple and complex (Cheng 2017). It was clear from the qualitative interviews that some family carers of people in receipt of a Classic IHCP were also experiencing subjective burden, that is, they perceived the demands of caring to be stressful and they were experiencing high psychological stress. In addition, other demands or roles outside the care-giving arena, such as employment or family responsibilities, were placing a strain on some family carers in this group, in spite of the additional home care hours.

A feature of the Classic IHCPs was that the same pattern of home care hours was provided to each person, irrespective of the care-giving context. While almost all family carers in the Classic IHCP group were women, other characteristics differed with respect to age, level of education, caregiver relationship, level of social support and employment. Yet, each of these can have significant implications for the type of stressors a family carer faces, the way in which a family carer assesses and copes with those stressors, and the outcomes of care-giving. A discernible difference in the pattern of home care hours in this group of Classic IHCPs relating to care-giving context was with packages where home care hours were not provided over the weekend when adult children were available to undertake the care. There were also differences in the number of visits per day and length of time of visits, which varied quite a lot, but it was not clear how these decisions around the timing and allocation of hours was made.

The key characteristics of the family carers and of the context in which they care are different from one family carer to another and these, interacting with the range of primary and secondary stressors, no doubt impact family carers differently. This would explain differences in levels of caregiver burden before the commencement of the IHCP. It would also suggest that Classic IHCP could act as a mediator in lessening the effect of primary objective stressors when these are linked to high dependency and advanced levels of dementia. They could also act as a mediator in lessening but not eliminating role strains for some family carers. Yet, these are only some of the factors that influence the caregiver experience. By using one pattern of home care hours, Classic IHCPs are essentially a one size fits all approach to care provision. This type of home care is not tailored to the individual family carer context or the care environment, nor does it take account of, or try to address, the carer's psychological and emotional response to caring. The supports provided by a Classic IHCP are therefore unlikely to alleviate caregiver burden for all family carers. Some remodelling of Classic IHCPs is needed to make them more effective in reducing caregiver burden, which could include for example offering home care hours in conjunction with some form of psychoeducational training or support for family carers who are experiencing caring as stressful and continue to do so even after additional home care hours have been put in place. The care-giving stress process framework has been used extensively to guide the development of interventions to support family carers and would be a useful reference framework in the future development of home care services.

Dissatisfaction with the Classic IHCP arose when there was a breakdown in relationships and the escalation of conflict between the family carer, the approved private provider and the HSE. This was attributed by the family carer to constant changeover of home care workers and unhappiness with the approved private provider and home care workers that had been allocated. The context in which families provide care is shaped by both amicable and problematic relationships, including those between family carers and service providers. Where these are problematic they can have a significant impact on the family carer, the stresses they experience and how they cope. As well as the other domains of stress, the care-giving stress process framework emphasises the importance of attending to the nature of relationships. The promotion of good and healthy relationships, as we have seen (Section 6.3), is also central to the framework for person-centred care. Thus, assessment processes, care design and care delivery should explicitly attend to and understand the relationships that are important, such as that between the caregiver and the person with dementia and relationships between the care providers and the person and family carer.

The **Block hours IHCP** are distinctly different to the Classic IHCPs in two important ways. Firstly, home care hours are allocated in a block of time to the person with dementia and their family carer; secondly, the focus is no longer solely on assisting the person with personal care. By responding to a range of care needs as well as to the person's physical care needs, the assumption underlying this type of IHCP is that supporting family carers involves more than merely supporting them with the burden of providing physical care. In contrast to the Classic IHCPs, there were people with dementia in receipt of Block hours IHCPs with responsive behaviours. Configuring IHCPs into blocks of time suggests that it is recognised that family carers need support with primary objective stressors such as responsive behaviours and BPSD. This is also an indication that providing regular, short hours of home care would not be the most appropriate way of supporting family carers in coping with responsive behaviours. However, there was little evidence of the use of other interventions or supports that may have targeted these needs more effectively, such as a carer educational intervention or other support for responsive behaviour for example.

Unlike the Classic IHCPs, an intentional aim of some Block hours IHCPs was to support family carers with role strains, particularly around employment, and this was greatly welcomed by family carers. The configuration of care hours into blocks of time thus demonstrates an effort on the part of health professionals to configure home care hours in such a way that it takes some account of the caregiver context rather than simply providing home care hours according to a pre-determined conventional pattern.

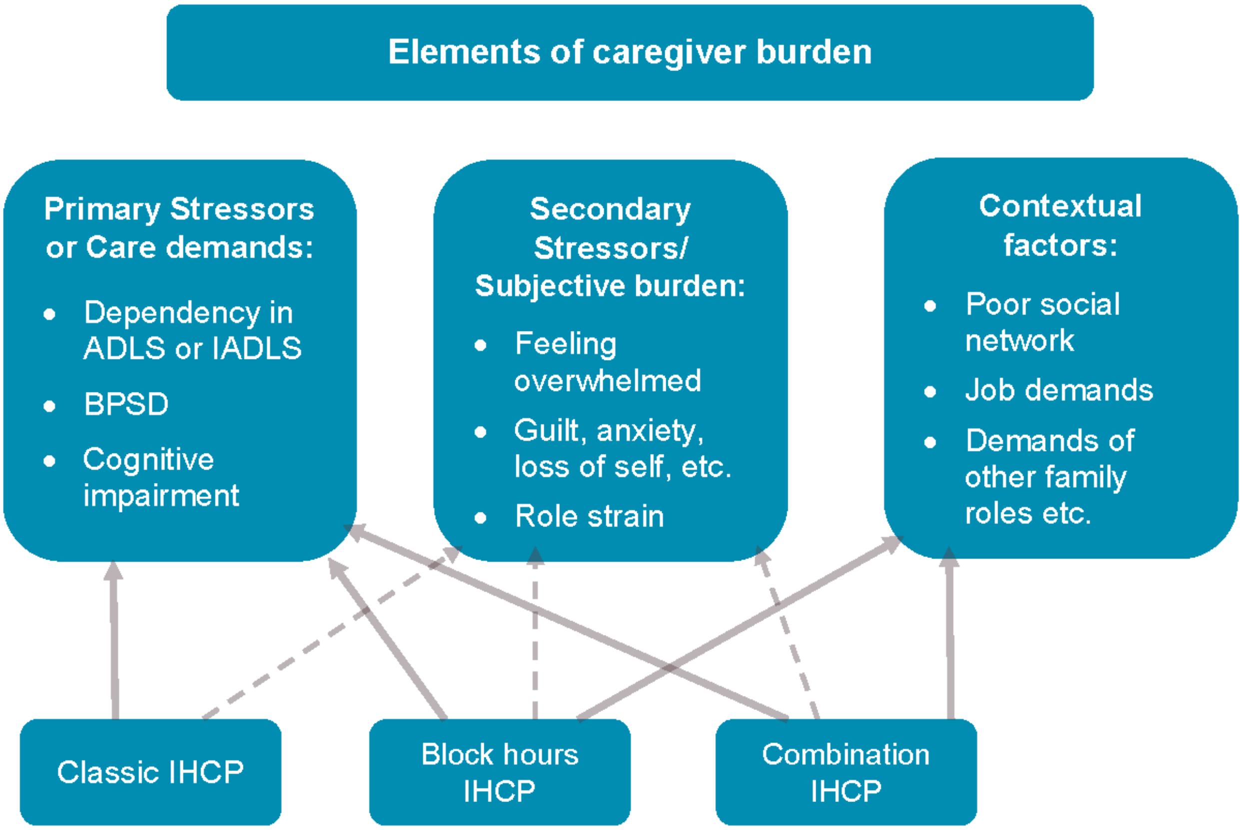
In several of the Block hour packages a number of home care hours had been purposely built into them to give family carers a break from caring, which again was a major difference between this type of IHCP and the Classic IHCPs. It seemed to be more usual for this to happen when the primary carer was a spousal carer than when the primary carer was an adult child. In some cases, this did not seem to be tailored to caregiver burden. For example, regular blocks of hours were provided in some cases when only an occasional break was required. This practice could lead to the granting of IHCPs with a higher number of hours than is actually needed for the purposes of reducing caregiver burden and seemed to come about due to the inflexible processes for allocating hours i.e. the same amount every week. It highlights the importance of understanding the different types of stressors, which of these stressors family carers are experiencing and then using this information to tailor home care services with the aim of lessening the effects of the actual stressors identified.

The number of family caregivers assessed as having moderate to severe caregiver burden even with the Block hours IHCP in place suggests that there are stressors experienced by family carers that are not being alleviated by IHCPs. A high number of hours of home care may be useful in relieving the workload of care and providing carers with a break, but a different response is needed when, for example, the family carer is feeling isolated or emotionally distressed or finding it difficult to accept the situation.

Finally, **Combination IHCPs** are so called because the IHCP provides a mixture of short visits focusing on personal care and a longer block of time, which was used to provide care to the person with dementia whilst at the same time freeing up time for family carers. There are two main assumptions underpinning Combination IHCPs. Firstly, that caregiver stress strongly relates to the burden of providing physical care to the person with dementia, and the provision hours to assist with personal care will support family carers with the physical demands of caring and by doing so will reduce caregiver stress. Secondly, that supporting family carers involves more than merely supporting them with the burden of providing physical care and blocks of hours are required to provide support with other identified stressors such as responsive behaviours and employment demands. Another assumption underpinning the Combination IHCP is that providing a break from caring will reduce caregiver burden. It could be argued that Combination IHCPs are the most well-developed response to supporting family carers, as the different configuration of hours (short + block) as well as the different content of the hours (personal care + meaningful activities + break) addresses more of the different components that may be involved in caregiver burden. However, the qualitative interviews reveal that some of the stress experienced by family carers of people with dementia is subjective stress that was not addressed by the Combination IHCP, even though it seems to be a more well-developed response to carer burden. To reduce subjective stress, the IHCP Initiative could be developed to incorporate psychosocial supports targeted at improving family carer coping strategies.

Figure 2 attempts to graphically illustrate the main elements of caregiver burden and the ways in which the different packages may support the caregiver through the targeting of different elements. This is a simplistic representation and should not be interpreted as meaning any of these elements are fully addressed. The dotted lines indicate how all three dementia-IHCP types did not fully address subjective or secondary stressors for the carer. Many carers described some relief, but this was an indirect result of the home care hours. Specific interventions may be needed in addition to home care hours to effectively alleviate this component of burden in particular.

Figure 2: Representation of caregiver burden and the possible differential effects of three different dementia-IHCP types



The different types of dementia-IHCP that have been identified in the IHCP initiative by this study are a welcome and major shift in the way in which home care is delivered, with different formulations of care being used to address different needs of the person with dementia and family caregivers. However, if we are to effectively address caregiver burden, a wider response is needed to home support than simply home care hours. The assessment of caregivers' needs will need to be more nuanced to capture the dimensions described in Figure 2 so that tailored responses can be developed that may include carer education, psychoeducation, brief counselling interventions, family mediation, as well as home care hours which are tailored to different needs.

8. Discussion

This study has provided further confirmation of the key finding of the overall study; that given a high level of support, it is feasible to care for people with dementia with complex needs at home and for significant periods of time (Report 1, Keogh, Pierce, Neylon, Fleming, et al. 2018). This in-depth look at a group of people with dementia has further revealed the effectiveness of IHCPs in maintaining the person's quality of life which is an important finding given the progressive nature of dementia. It has also shown that family burden can be relieved for some carers and has given us a better understanding of the many other demands on carers, apart from caring for the person, which can contribute to feelings of stress and burden. This in-depth sample has also shed light on the production of home care, that is, different ways home care can be provided in terms of the distribution of hours and what is done in those hours, which can inform how home care might develop in the future.

8.1 Dementia IHCP typology

Although the label 'people with dementia' can convey an impression that individuals with dementia are a largely similar or homogeneous group of people, we know from research evidence and accounts of personal experience that people with dementia are a diverse, heterogeneous group with as many unique experiences as there are individuals. Statistics such as average hours of care or average cost of care, can conceal important differences within this group. An important finding from this study is that at least three different ways of organising home care for people with dementia emerged in response to the extra home care hours available through the IHCP initiative. There are important differences between these, both in terms of what is delivered and in terms of the recipients. For example, in the 'Classic' IHCP almost all recipients were bed or chair bound and the care provided consisted of short frequent visits focused on personal care. In contrast, all recipients of a 'Block' IHCP were mobile, younger on average than those receiving a 'Classic' IHCP, had a high level of responsive behaviours and received long blocks of hours to provide an opportunity for carers to work and/or to provide respite for carers, as well as providing usual personal care.

Although HSE and DoH plans and policy promote the delivery of home care that is tailored and responsive, delivering home care in this way has been stymied by the continual constraint in resources for home care. This constraint has meant that particular needs have been prioritised even though there is a strong desire within the HSE to meet the wider range of needs of home care recipients. In effect, task-oriented care became the norm, with regular short visits to meet personal care needs being the pre-dominant form of home care. This is not unique to Ireland and the shortcomings of a task-oriented approach to home care has been documented in the UK (Equality and Human Rights Commission 2011) and in France (Daniol-Shaw and Lada 2011). The different types of dementia-IHCP that have been identified by this study are a welcome and major shift in the way in which home care is delivered, with different formulations of care being used to address different needs of the person with dementia and family caregivers.

This dementia-IHCP typology that emerged from an analysis of actual packages that were delivered, offers a new way of understanding, in a more person-centred way, what configuration of care might be more appropriate for different individuals and how best it might be provided. It demonstrates in an Irish context a different production model, that is, different ways of providing essentially the same service (home care hours) to address the different needs of people with dementia and family caregivers. It also demonstrates how the needs of a group that are typically not well served in home care (i.e. those whose needs are not solely for personal care as demonstrated by recipients of Block and Combination IHCPs) can be met in the same way and with roughly the same costs as 'typical home care' i.e. Classic IHCPs.

8.2 Delaying admission to residential care

Another important finding is the effectiveness of dementia IHCPs in delaying admission to long-term residential care. As was demonstrated in the analysis of the 505 IHCPs in Report 1, the packages have significant potential for maintaining older people at home for longer, both those with and without dementia, with about 50% of recipients supported at home for at least one year. However, further analysis using data from the in-depth sample, has revealed that IHCP recipients with dementia were 17 percentage points less likely to be admitted to residential care, and 22 percentage points less likely to have died, than similar recipients without dementia. While this latter difference may be attributable to unobserved differences between the groups, such as their underlying health status, which may not be fully reflected in measures such as the Barthel Index, it suggests that IHCPs may be more effective at keeping recipients with dementia alive and out of LTC than they are for other types of individuals. However, further research is necessary to examine how and whether disease classification matters for the effectiveness of IHCPs.

8.3 Supporting family carers

One of the most striking findings from the quantitative data on hours of informal care and the funding of private care by families, is the extent to which home care in Ireland is a family care system, which is being supplemented by the state. Without families, it is difficult to see the community care system as being a viable alternative to residential care. A deeper understanding of this family care system is revealed through the qualitative interviews which richly described the very strong family commitment to caring for their loved one at home. This was motivated by a variety of reasons including honouring the person's wishes and also a belief that home care was intrinsically better that nursing home care due to the high level of one-to-one attention that could be provided.

The narrative around nursing homes from some carers was very negative, with some family carers saying they would "fight it with every last breath I had" or that keeping the person at home is "a very sincere commitment, it is much more than a preference". However, there is a cohort of people for whom the level of their medical or care needs eventually necessitates nursing home care. This can present a very real dilemma when home may not be the best place for the person's needs, and the family may need help in negotiating and coming to terms with this necessity. It is often assumed that entry into residential care results in a reduction in stress for the family carer, but the evidence does not support this binary understanding of carer stress. There is evidence that placement in nursing home is associated with guilt, anger, despair, resentment and general psychological distress (Ryan 2002, Ryan and Scullion 2000).

It may be that this is a self-selected group in some regards, as part of the assessment process for the IHCP (whether the person was in hospital or at home) included the extent to which the family are willing and able, to at least some degree, to care for their family member at home. In fact, many families actively advocated for home care for their relative. Whether or not this is the case, this study demonstrates that there is a substantial cohort of family carers who are willing to provide very significant hours of care to their loved ones and also, in many cases, to pay for care to supplement what they can do and what the state can provide. There is little public discourse on where responsibility for care-giving lies. One of the recommendations of the Citizen's Assembly, with 60% in agreement, was that the family/older person should be principally responsible for providing required care for older people but that the State should have at least some responsibility. However, the mix of care in Ireland is already subtly shifting, with those who can afford to, using their resources to buy private care, usually to supplement what they can do themselves and what the state care system is providing. An average of €391 per week was being spent on private care in this sample. The variation was wide, from those buying no private care to a small number using the resources of the person and the wider family to spend over €2,000 per week for almost full-time private care. The emergence of a private market for care is a significant feature of the social care system in Ireland. If this trend continues it opens up the possibility of exit from the public system for many people, leading to less voice for those left behind and raises equity concerns given that not everyone can afford to buy private care.

As with persons with dementia, carers are not a homogeneous group, ranging from older spousal carers with multiple medical needs themselves, to sons and daughters with jobs and young children to care for. The formal care system needs to recognise this diversity in carers, with more input from carers as to what they need and greater flexibility in terms of how and when hours of care are provided. The overall average family burden score for those interviewed before and after the package commenced, showed a slight decrease in burden which was not statistically significant. Average scores conceal lots of variation however. Some carers, in the face of significant demands have consistently low levels of burden. In contrast, other carers have consistently high levels of burden in spite of the provision of significant hours of care. We need to understand more about resilience among carers, but we also need to recognise that more home care hours are not the answer for everything. Other responses, such as a brief counselling intervention for carers, or an intervention for responsive behaviours may have greater effect and be more cost effective than more home care hours in the long run.

8.4 Personalisation

This diversity of needs among carers and among the individuals they support, points to the need for greater personalisation in how services are provided. There were some very good examples of IHCPs that had the hallmarks of personalisation; understanding the person; engagement in decision-making and promoting a good care relationship. The way in which hours were allocated in two of the dementia-IHCP types – the Block hours and Combination IHCPs, evidenced family input into the allocation of hours and a greater variety of activities and engagement with the person with dementia. However, even when personal care is the predominant form of care provided, this can be highly personalised, particularly when attention is paid to understanding the person, and good examples of this were evident in the Classic IHCP also. With training for key personnel and attention to issues such as communication and continuity of care, there is significant potential to make personalised care a reality for all home care. It is important to note that personalisation did not rely on the number of hours of care but was a function of the skill level of providers and home care workers and the attention paid to understanding the person, joint decision making and good interpersonal relationships.

8.5 Resource allocation decision making

Our results indicate that investment in IHCPs can keep people living at home for longer. They are effective in keeping people with dementia living at home even when significant levels of disability and cognitive impairment are present. In terms of the economics of care, the average weekly cost of home care funded through public expenditure on standard community-based provision and IHCPs was €872 per week; adding private consumption and housing raises home care costs to €1,124 per week. The latter figure is equivalent to average Dublin private nursing home costs and well below public long-stay care costs of €1,526 per week.

If traditional 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, as well as a major contributor to costs. Informal care comprises 28% of the total cost of care. Adding family care inputs to care, valued using an opportunity cost methodology, raises the average cost of home care by €593 per week. Therefore, when measured in social terms, home care is more expensive than residential care, even public long-stay care. But then it is possible to see this differential as the price people are willing to pay to support home care over residential care. Adding private care costs further inflates the cost of home care. But even with all costs accounted for, keeping people with dementia living in their own homes is less than half the weekly cost of a bed in an acute hospital.

Our results are consistent with previous studies which have identified higher costs in institutional long-term care settings compared to formal, exchequer–funded community care provision. Data from a study involving eight European countries found that residential costs were higher than basic home care costs (Wübker et al. 2015). The same study also found that home care costs are sensitive to the valuation of informal care. Similarly, (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. The research also reflects findings for people with dementia on the boundary between community and residential care in Ireland (O'Shea and Monaghan, 2016), albeit that the latter population were not receiving IHCPs.

8.6 The continuum of care and potential for prevention

IHCPs represent the highest level of home support currently available in the Irish home care system. While they were effective in supporting many people with dementia to be discharged home from acute care (49% in the whole dementia-IHCP cohort and 29% in this dementia sample), the potential of IHCPs to support people in the community to remain at home was also significant. This is important, not just from the point of view of residential care cost avoidance, but equally importantly for quality of life. However, there is another benefit to supporting people to remain well at home, which is in the potential to prevent premature decline in ability. Many of the staff and carers interviewed for the study noted how helpful it would have been to have a lower level of support earlier in the course of the person's dementia. It may be that intervening earlier in the continuum of care and providing a low level of hours which gradually increase in response to increasing needs, may achieve even better results than those achieved through IHCPs and may be a more effective use of resources. We know little about the 'tipping point' of hours required to prevent entry to residential care or an unnecessary hospital admission but this is an important area for further exploration if we are to increase investment in home care as recommended in the Sláinte Care report. The argument becomes even more pressing if the possibility of avoiding inappropriate hospital admissions is considered, or the possibility of shortening hospital admissions, given the potential for deleterious effects for people with dementia of an inpatient admission (Sampson et al. 2013, Long et al. 2013). Considering the benefits demonstrated in this study, as well as the potential benefits in prevention, the case for a highly personalised, enabling approach to home care, to prevent premature disability becomes more compelling. In this study the need for two carers per visit (e.g. for hoisting) was a significant cost driver. Thus, measures which maintain ability and mobility for as long as possible are not just good for the person, but they have significant cost saving potential.

8.7 Policy questions and implications

A number of policy implications arise from the findings of this study. The emergence of three IHCP types, which seem to represent a care system response to different needs of people with dementia and their carers, along with the personalisation of care that was evident in some IHCPs is a very welcome development. This approach has implications for how care is managed, what it is people do, how assessments are done and how we work with families. For example, assessments for both the person and family carer need to focus on understanding both, and their particular needs for care and support. Training is also required for home care workers so that all aspects of the care they provide are personalised. Support is needed for the wider system to effectively implement this approach to care.

The procurement processes for home care providers can now incorporate the findings in relation to personalisation and other hallmarks of what worked well for families. The things that made a big difference to family carers and the person with dementia were simple and, on the surface, seem mundane – so much so that they can be easily ignored in favour of more technical or complicated solutions to dissatisfaction with care. However, communication with care providers, continuity of carers, the availability of skilled carers who related well to the person, were very highly valued by carers. Families are not unrealistic. They understand that home care workers take holidays, may be out sick or may be delayed for a visit, but they need to know this and appreciate a simple text to communicate. They welcome the chance to discuss the best way to cover holidays or sick leave to ensure the least disruption to the person.

The feasibility of caring for people with complex needs at home has been demonstrated and the outcomes that can be expected given this relatively high level of home care hours have been described in this study. The study has also provided good data on the length of time people can be supported at home. IHCPs provide an important option for people at one end of the continuum of care and a less costly alternative to acute care and, in many cases to residential care. While it is acknowledged that some people need a dramatic increase in home care hours (following a stroke for example), it may that IHCPs could be more cost effective if hours increase at a more gradual pace from a lower base, ‘smoothing out’ the provision of support hours to care needs.

The continuation and expansion of IHCPs has implications for resource allocation and potential eligibility and charging regimes for home care. There is no currently no charging or co-payment required for state provided home care. This is in stark contrast to the Nursing Home Support Scheme which has detailed eligibility and co-funding criteria in place for nursing home care. The financing of care did not seem to be a factor in the majority of cases in this sample in terms of the commitment to keep people at home. Potential changes to the financing of home care will need to take careful account of the significant commitment already made by the vast majority of family carers in terms of the hours of care and supervision they provide. Even where families may not provide direct hours themselves, they are often supplementing informal care through the purchase of private care hours.

The data from this study tells us that increasingly people are using their own time and spending their own money to get what they feel is not being currently provided by the state. The equity issue posed by greater reliance on the private sector is that not everyone can afford to buy care. The increasing participation of women in the workforce, emigration of young people, smaller family sizes and changing attitudes to family responsibility mean that family care may not be available to the extent that it has been heretofore. This presents a stronger imperative for the formal care system to work in partnership with families to ensure the continuation of family care into the future. This will require a genuine and open engagement between families and care providers, working out the best solutions for all, while working within resource constraints.

One of the issues that emerged in the course of this study was the increasing difficulty for providers in sourcing home care workers. This grew as the overall economy improved following the recession. Home care workers are expected to be highly skilled and experienced in caring for the personal, practical, social, emotional and psychological needs of people and skilled in communication with the families and the person and in developing strong interpersonal relationships. However, home care workers are not very well valued in terms of pay or working conditions and need not just to be trained, but to have ongoing support and mentored/ supervision to do this work. This is not easy work although it is described by workers as very rewarding (Dempsey, Normand, and Timonen 2016). Workforce issues for this sector will need to be addressed if a reliable supply of well-trained workers is to be maintained.

8.8 Conclusion

Our results indicate that investment in IHCPs can keep people living at home for longer, even people with significant levels of disability and cognitive impairment. The research shows it is possible to increase the availability of intensive home supports to augment existing formal provision in the community and still cost the exchequer less than 60% of weekly public residential care costs. People with dementia receiving IHCPs also appear less likely to be admitted to residential care than similar dependent older people, although further research is needed to confirm this finding. Investment in intensive supports for people with dementia is good value for money for the public sector, especially for people on the boundary between community and residential care. Although the implementation of the National Dementia Strategy is ongoing, and significant progress has been made in meeting targets, even the Department of Health acknowledges that full implementation of the Strategy will require further investment in the health and social care system (Department of Health 2018). New investment in community-based care may take some of the burden of care off family carers, who continue to do so much for people with dementia in the absence of formal supports, allowing them to care for longer. The growing importance of private care for some people should also be noted, particularly the potential for inequities to develop as that market evolves. Finally, the study highlights the importance of providing a richer and more varied set of personalised responses for older people and people with dementia so that they can remain living well at home for as long as possible.

9. Recommendations

Based on the findings of this study the following observations and recommendations are made:

1. IHCPs should be part of the complete continuum of care, with home support provision being planned jointly with the person and family in response to needs that have been assessed jointly. There should be a transparent relationship between need and support provision while allowing for flexibility to take account of the differing personal and social circumstances within which care is delivered. IHCPs should continue to be funded to support people with complex needs to remain at home with funding expanded to meet ongoing need. If IHCP funding and provision is incorporated into the home support service, care needs to be taken to ensure that home support can be effectively targeted where it is needed most.
2. The content of IHCPs should consist of a package of responses to best meet the needs of the person and family carer and should not be limited to home care hours. A much closer relationship is required between the hours that are provided and the specific needs being addressed. Thus, as well as home care hours, evidence informed interventions such as physiotherapy and rehabilitation to maintain mobility and ability; brief counselling interventions; support with responsive behaviours; and others, should be included as targeted short-term interventions to address specific needs rather than providing generic home care hours to address all needs.
3. Families should be treated as key care partners and included and involved in the assessment, design and reviewing of care packages though shared-decision making processes. The roll-out of carers needs assessment as part of the SAT will help address this but training will be needed to support shared decision-making and identification of priority needs and goals for the person and carer.
4. The commitment of family carers in this study to caring was powerfully evident, not just in terms of the hours they provided and the funding of private care by many, but in the strong sense of duty and loving care that was observed. However, many carers were constrained in their ability to provide care through family and work commitments and the challenge of caring ‘from a distance’. This study found that providing support that is attuned to these differing circumstances can be very effective. Other measures, such as flexible working arrangements and carer leave schemes should be considered to provide practical support to family carers.
5. While the evidence from this study shows that family commitment is strong, there is no certainty that this family commitment will remain unchanged into the future. Wider societal changes (for example in relation to gender roles and attitudes to intergenerational responsibilities) and demographic changes (such as migration and smaller families) are happening and will continue. These changes mean that the availability of family carers, their perception of their role and responsibilities, their expectations and willingness to care, are likely to change substantially and perhaps more rapidly

than we expect. Policy makers need to anticipate and plan accordingly for this changing caring landscape.

6. The value of home care as an 'early intervention' mechanism to prevent premature loss of abilities and mobility should be recognised. Reablement approaches to home care and appropriate physiotherapy interventions should be supported in this regard. Such approaches are also pertinent for preventing premature loss of abilities and mobility during an acute hospital stay of a person with dementia and could help to minimise the need for home care, or at least its intensity, following discharge home.
7. While this study considered people with dementia and their families, a personalised approach to the delivery of care is relevant for all recipients of home care services. The re-orientation of the current system towards one that is providing personalised and integrated care requires a programme of investment into training, assessment and coordination of care.
8. Education and training on the personalised care approach is required for all home care workers and Health and Social Care Professionals, in particular PHNs who often take the lead regarding care needs assessment.
9. A workforce plan which addresses the training needs, pay and working conditions of home care workers is required to ensure an adequate supply of these workers into the future.
10. The learning from this evaluation such as continuity of care and ongoing communication with the person and carer should be incorporated into procurement processes to improve the experience of care for older people, people with dementia and their families.
11. The use of technology such as scheduling apps and other software to share real time data, could be considered to improve communication for the person and family carer and to streamline the provision and scheduling of care.
12. If home support services are to act as a realistic alternative to long term care for older people (including people with dementia), or as a support to acute care to facilitate timely discharge and the avoidance of inappropriate admissions, increased funding for Home Support Services will be required as recommended by the *Health Service Capacity Review* and *Sláintecare Report*.
13. The mix of care is changing with privately funded care hours increasingly evident as a new element in what was heretofore a 'binary' care landscape of family care supplemented by state-funded care. The equity implications of this need to be recognised and acknowledged by the care system and policy makers, particularly in the framing of a new home care scheme. It is not clear how private care will be integrated into the overall mix of public and family care or to what extent private care will supplant or supplement other elements, but it will need to be considered in how care is provided and regulated in the near future.
14. Routine data gathering and the collection of meaningful indicators on home care relating to people with dementia and all older people is essential to monitor the quality of home care and to provide evidence on the type of services received and outcomes for individuals.

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