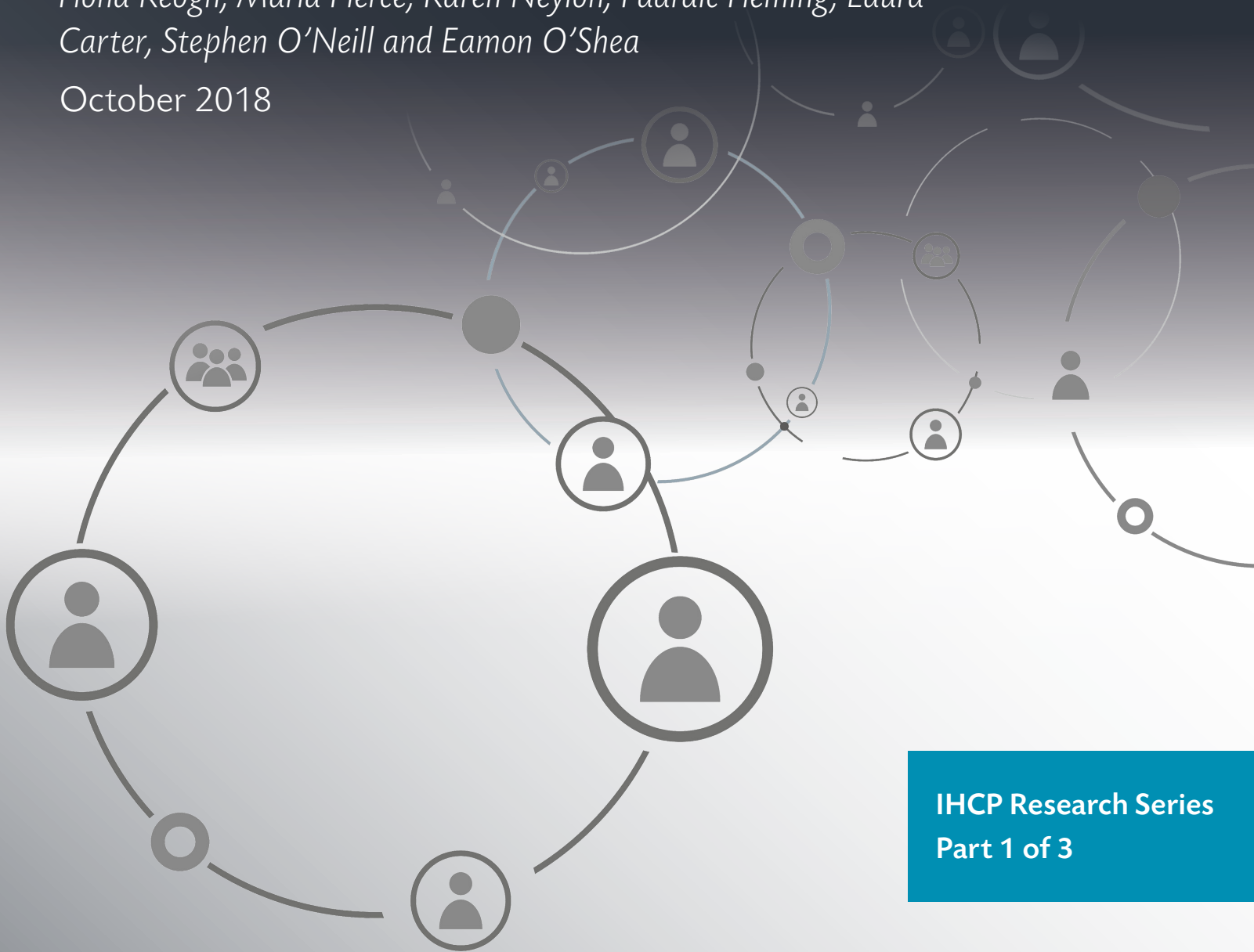


Supporting Older People with Complex Needs at Home:

Report 1: Evaluation of the HSE Intensive Home Care Package Initiative

Fiona Keogh, Maria Pierce, Karen Neylon, Padraic Fleming, Laura Carter, Stephen O'Neill and Eamon O'Shea

October 2018



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Executive summary

1. As part of a process of further development of home care, the HSE funded an Intensive Home Care Package (IHCP) initiative in 2014. The aim of this initiative was to provide a greater range and level of services to older people and their families, to tailor and individualise home care delivery and to help address the pressures on acute hospitals. The initiative was aligned with the actions of the National Dementia Strategy (NDS) and part of the investment to support the implementation of the NDS was directed towards the provision of IHCPs for people with dementia from 2015 to 2017.
2. An evaluation of the IHCP initiative was commissioned as part of the NDS implementation programme. The aims of the evaluation were to examine the feasibility and effectiveness of IHCPs in providing care for older people with complex needs at home. Objectives of the evaluation included; identifying the key components of IHCPs and the characteristics of the recipients; determine the costs and compare costs to acute care and nursing home care and to examine outcomes through an in-depth study of a sample of IHCP recipients with dementia.
3. This prospective three year evaluation has found that it is possible to support older people with complex needs at home in Ireland given sufficient provision of home care and other services. Over the first three years of the IHCP initiative, 505 people, 83% of whom had maximum or high dependency (Barthel Index) were supported to remain at home, often for significant periods of time.
4. It was not known at the commencement of the initiative, how long these high support packages might last. Based on the data from this large sample, we can now provide estimates as to the likely duration of such packages. After 12 months it can be expected that about half of all packages (52%) will be active. The proportion of IHCP packages likely to be active after 24 months falls to almost a quarter (28%) and continues to fall to close to zero after 36 months. This demonstrates that IHCPs can keep people at home for significant periods of time. For recipients whose package ceased in the course of the three years, the IHCP gave people at least an additional 9 months at home on average, before death or entry to long-term care.
5. The provision of IHCPs for older people with complex needs has been effective in a variety of circumstances; in urban and rural settings; for people with maximum and high dependency levels; for people with little or no family or informal care (30% living alone); and for people who were at the end of life. Almost two thirds (65%) of IHCP recipients were discharged from an acute hospital; 27% were living at home but were at risk of entering long term care.
6. The major component of all of the IHCPs was hours of care provided by home helps and home care workers and there is robust data on the number of hours supplied. The number of hours provided by a standard IHCP ranged from 14 to 168 hours with a mean of 45 hours per week provided. For disability packages, the number of hours provided per week ranged from 28 to 168 hours with an average of 47.4 hours per week. The

number of hours provided by dementia-IHCPs ranged from 6 to 168 hours per week with a mean of 39 hours per week provided. IHCP recipients with dementia received significantly fewer hours per week than non-dementia recipients (6.4 hours fewer on average).

7. The average weekly cost of the IHCPs was €925 for dementia-IHCPs, €1,024 for standard-IHCPs and €1,137 for disability IHCPs. Excluding outliers (i.e. the small number with very high and very low costs) did not substantially change the average weekly costs.
8. The average weekly cost of residential care ranges from €1,526 in public long stay settings, to €1,149 in nursing homes in Dublin to €909 in the rest of the country. At this rate, most, but not all IHCPs cost about the same as residential care. The average weekly cost of acute care was calculated as €5,992. At this rate, all IHCPs, even the most expensive, were more cost effective than acute care.
9. Intensive home care has been demonstrated to be feasible for supporting older people with complex needs, including dementia, at home for significant periods of time, at least 6 months for half this cohort. IHCPs represent a valuable addition to home care as part of a continuum of care based on need, ranging from low levels of support to the relatively high levels seen in the IHCPs.
10. There are indications that home care may have an untapped preventive role. Providing home care earlier, i.e. for people who are at risk but with lower levels of need, and focusing on reablement and maintaining mobility, may prevent premature entry to residential care and may reduce home care costs in the long term through maintaining ability for longer. This would require further research.
11. A lack of home care workers was a barrier to the timely implementation of IHCPs in several cases. Workforce planning which addresses the training and working conditions of home care workers will be essential to ensure the availability of such workers into the future.
12. 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.
13. 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. 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).

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. A detailed description of the IHCP Initiative, changes made to it over time and the wider administrative and clinical context within which it operates, are presented later in this report.

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. This included a particular focus on dementia-IHCPs. The data from this part of the work is the subject of this report (**Report 1**). 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. This work will be reported in **Report 2: Supporting older people with complex needs at home: What works for people with dementia?** (Keogh et al. 2018) 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 for people with dementia, by creating and testing enhanced pathways for delivery. This work is still underway but a report based on the work of four of these sites has been published to accompany this series (**Report 3**). 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 and analysis 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 data from Strand 1 is the subject of **Report 1**. It covers all recipients of IHCPs, i.e. older people without dementia, people with dementia (including early onset dementia); and a small cohort of people with disabilities under 65 years.

The following objectives are 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.

The focus of the second strand is on the in-depth study of people with dementia in receipt of IHCPs.

The following objectives are addressed in Report 2:

- ➔ 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 perspective¹ and compare the costs of IHCPs vis-à-vis acute hospital care and long-stay residential care;
- ➔ Establish the costs of both informal caregiving and financial contribution of families to care of people with dementia with complex needs in receipt of IHCPs;
- ➔ Analyse the costs data to contribute to a better understanding of findings from the process and outcomes evaluations that are being undertaken as part of the overall evaluation.

Work in Strand 3 is still underway and will be reported in **Report 3** of this series.

¹ Full costs of IHCPs including formal care costs, housing and personal consumption costs and the value of informal carer input.

2. Background

In order to consider the context within which the IHCP initiative took place, this section provides an overview of the relevant policies and of home care services for older people generally.

While the majority of people over 65 years of age in Ireland report that they are in good health (Finucane et al. 2014, CSO 2017), those who do have health and care needs, in general, prefer to stay in their own homes (Garavan, Winder, and McGee 2001, O’Hanlon et al. 2005, McGee et al. 2005). It is not just older people who express a preference for home care. A survey of 1,000 people in the general population (Browne 2016) found that, if they needed it in the future, people would most prefer to receive long term care in their own home (81%). Care in a nursing home (29%) was one of the least preferred options among people responding to the survey (Browne 2016).

Home care has strong long-standing support across Irish health and ageing policies, dating back as far as the 1960s and described clearly in *The Years Ahead Report* (Working Party on Services for the Elderly 1988), which spoke of core principles such as *maintaining older people in dignity and independence at home in accordance with the wishes of older people and restoring to independence at home older people who become ill or dependent*.

A preference for home care over residential care continues to be embedded in many health and related policies, such as the Sláintecare Report (Committee on the Future of Healthcare 2017), the National Carers’ Strategy (Department of Health 2012) and the National Positive Ageing Strategy (Department of Health 2013). However, this public preference and policy

commitment to home care has not been followed through with the required resources for the development of community care services. The current community care system in Ireland, which includes home care services, is underdeveloped and fragmented, with a small range of services and inconsistent availability (Cahill, O’Shea, and Pierce 2012, O’Shea, Cahill, and Pierce 2017). In terms of resource allocation and prioritisation, there is a longstanding imbalance in favour of residential care over home care (Cahill, O’Shea, and Pierce 2012, O’Shea, Cahill, and Pierce 2017). For 2018, €962m was allocated for the Nursing Home Support Scheme (NHSS) to provide residential care for approximately 23,334 older people, while €408m was allocated to provide 17m home support hours to approximately 50,000 older people (HSE 2017). This pattern of resource allocation has been in evidence for many years.

The share of the overall health budget for older person’s services has increased by small increments in recent years. Notwithstanding this, the HSE acknowledges in its Operational Plan for 2018 that demand for older person’s services exceeds funded levels and that:

“In cases where total demand for services exceeds what can be supplied ... the HSE is required to manage within available resources while seeking to prioritise services to those in greatest need. Within older persons’ services, this primarily applies to the provision of home support” (HSE 2017).

Further demands will be placed on these resources as the proportion of older people in the total population is increasing (from 11% in 2011 to 13% in 2016), with the proportion of people over 85 years increasing

to an even greater extent, and the demand for home care is projected to increase substantially by 2030 (Wren et al. 2017).

Publicly-funded home care is an important element of home care provision. Home care for older people cannot, however, happen without informal or family carers. There are over 195,000 carers (people providing regular unpaid help for a friend / family member) providing at least 6.6 million hours of care per week (CSO 2017). Almost 1,800 carers are aged over 85 years. Many family members are committed to providing this care but the need for more support for family carers has been strongly articulated (Family Carers Ireland 2017, Ireland 2013). The care provided also has an economic value, estimated at €807m per annum for informal carers of people with dementia alone, accounting for 48% of the total annual cost (€1.69bn) of caring for people with dementia (Connolly et al. 2014). There is also evidence that privately-purchased home care is increasing in Ireland, with estimates that private home help provides approximately one-quarter of all home help hours (Wren et al. 2017).

Shortcomings in the current system of home care have been recognised by Government and the Department of Health (DoH) is in the midst of a process to review home care and develop:

“a new scheme that will improve access to the home care services that people need, in an affordable and sustainable way. The Department will also introduce a system of regulation for home care so that the public can be confident that the services provided are of a high standard” (p.4) (Department of Health 2017).

Home support is recognised as an essential service at the individual level. However, it is also a core element of the interdependent array of services within the wider health system. This is acknowledged in the recent significant *Health Service Capacity Review 2018*, which undertook a detailed analysis of health demand and capacity requirements in Ireland to 2031 (PA Consulting 2018). This capacity review broadened its original scope beyond hospital beds to take account of primary care and services for older persons, thereby taking a whole system view of capacity. The review examined two scenarios; a baseline status quo scenario and a reform scenario. It demonstrated the potential impact on capacity across the health service of three inter-linked reforms, one of which is ‘an improved model of care that repositions the health service towards a community-based care model with a specific focus on older persons’ (p4) (PA Consulting 2018).

Some of the key findings of the capacity review are:

- The demand for healthcare is expected to grow significantly across the primary, acute and social care settings in the next 15 years as a result of demographic and non-demographic change
- There is broad consensus that it is neither feasible nor appropriate to plan investments around the current pattern of service delivery
- The full implementation of the three reforms specified would alter the capacity needed across all sectors by 2031 to:
 - » 13,000 residential care beds
 - » 120% increase in homecare (home help hours and homecare packages)

The *Capacity Review* will shape the development of health services, including home care, in the coming decade. The findings of the evaluation of IHCPs reported here, provides a unique insight into a new form of home support for people with complex needs, those who are older and younger, with and without dementia. It will inform both the Department of Health's development of a new scheme for home care and the wider reform of home care as an essential part of overall health service capacity.

2.1 Overview of home care services

The main services and supports provided with state funding to enable older people to remain living at home generally consist of home care, respite care, day care, housing adaptation and mobility grants, supports provided by voluntary groups (such as meals on wheels) and social welfare supports in the form of Carer's Allowance, Carer's Benefit and the Carer's Support Grant. Home care, which is the key focus of this report, is described in more detail here.

In the 2017 consultation on home care, the Department of Health used a definition of home care from the Health Research Board evidence review:

"Home care in Ireland is typically understood as home help services, which include cleaning, cooking and other light household tasks that a person is unable to do themselves due to old age or disability. The scope of home help has subsequently developed to include more personal care assistance such as support with personal hygiene, washing, and dressing also" (Kiersey and Coleman 2017).

While the home care service in Ireland is mainly used by older people, it is also provided, in a limited way, to some people with disabilities and others with identified care needs, including, for example, people leaving hospitals who need support. People with disabilities can also avail of the personal assistant service, which is funded by the HSE under a separate funding stream to home care.

With regard to home care provision, a distinction is usually made between informal and formal (professional) home care. The former refers to care provided by family members, friends, neighbours and other individuals who provide regular unpaid care. Formal home care involves a mix of funders and providers, with the largest funder in Ireland being the HSE. These categories are described further in Table 1.

Table 1: Structure and description of home care provision

adapted from Timoney (2018) and Mazars (2016)

Provider	Description
<i>Informal</i>	
Family / friend caregiver - Unpaid	The bulk of home care is provided by family members / friends mostly in an unpaid capacity. Informal care includes both hands-on care, monitoring and supervision and taking a role in managing / co-ordinating with formal care providers.
<i>Formal (Professional) home care</i>	
<p>Health Service Executive (HSE)</p> <p>Includes home care provided under three arrangements:</p> <p>(i) Arranged by the HSE and provided by HSE staff</p> <p>(ii) Arranged by the HSE and provided under contract by approved voluntary service providers</p> <p>(iii) Arranged by the HSE and provided under contract by approved for-profit private providers</p>	<p>Home help service – introduced in 1970 for providing help with personal care such as dressing, bathing etc. as well as help with essential domestic duties related only to the individual client. Typically, up to 5 hours per week of care can be provided under this service during the hours of 8am to 8pm, Monday to Friday. This is generally referred to as task-oriented care.</p> <p>Home Care Packages (HCPs) – introduced in 2006 to help people with medium-to-high support needs to continue to live at home independently. Packages include more home help hours, over and above the average level available locally. The content of the ‘package’ of care is intended to be flexible and based on assessed need and may include nursing, physiotherapy, occupational therapy, speech & language therapy, day care services, respite care, etc. Typical hours per week range from 6 to 21 hours. Approximately 20,000 HCPs are approved each year.*</p> <p>Intensive Home Care Packages (IHCPs) – prioritises delayed discharges and acute hospital pressures and provides a more intense range of the same services as under HCP. IHCPs also cover people living at home who are significant risk of admission to long-stay residential care. Approximately 200 IHCPs are allocated each year. The hours and content of IHCPs will be described in detail in this report.</p>
<p>Private</p> <p>Arranged by the individual/family and funded by them</p>	<p>Fee-per-service care provided by voluntary or private providers or other agencies. Care can also be provided through a private arrangement between an individual carer and the family. Approximately one in five carers providing this type of care is not attached to an agency.</p>

* While the home help service and Home Care Packages were combined in January 2018 and are now officially known as Home Support Services, in this report we have chose to adhere to the terms home help and HCPs that were formally and conventionally used during the course of this study.

Table 1 shows a complex mix of public, informal and private provision of home care, with different providers and different contractual arrangements across these sectors and funders. Within this complex context there has been a welcome development from January 2018, when the HSE set about streamlining home help services and HCPs by moving towards a single funded model referred to as *Home Support Services*, thereby combining the resources for home help and HCPs. Until this development, HSE spending on these two forms of home care occurred under different budget headings, which led to discontinuities in the provision of home care. It is anticipated that the single funded model will simplify the process of application for and allocation of these home support services (HSE 2017). However, IHCPs continue to be provided under a separate funding stream, which means that discontinuities will continue between IHCPs and Home Support Services.

Currently, home care services are not means tested or 'limited' in any other way, e.g. services are not restricted to medical card holders and there are no charges for these services. This is in contrast to the Nursing Home Support Scheme (NHSS, also known as Fair Deal), where people availing of this scheme undergo a financial assessment of their income and assets and, based on this, make a contribution towards their nursing home care, with the HSE making a co-payment when the person's contribution is less than the amount of the nursing home fees. The provision of home care services has a basis in law but there is no statutory entitlement to these services. The absence of a statutory underpinning for home care provision has led to inconsistencies in how

State-funded home care is delivered across the country. These issues of eligibility and entitlement are under consideration in the DoH's review of home care services, following which it is intended to develop plans for a new statutory scheme and system of regulation for home support services (Kiersey and Coleman 2017, Department of Health 2017).

We know very little about the people using home help services and HCPs in Ireland or what is delivered in terms of home care. Kelly et al (2017) undertook a study of 1,312 older adults in North Dublin who were receiving low level home help (less than five hours per week) and found that frailty in this population was associated with higher home help utilisation; 41.5% of this population were classified as mildly to severely frail, while 69% of participants lived alone (Kelly et al. (2017)). In a related study in North Dublin, O'Brien et al. (2017) carried out an audit of all clients aged 65 years and over receiving HCPs. In this sample of 935 community-dwelling older people, a documented diagnosis of dementia was recorded for 347 people (37.1%) and a further 81 (8.7%) were categorised as suspected cognitive impairment (CI) using a validated cognitive screening tool. Over half of this sample lived alone (55.1%) and 40% were self-caring. An examination of the implementation of HCPs (NESF 2009) found that the majority of those who were consulted, including individuals receiving HCPs and their carers, organisations involved in home and community-based care provision and HSE staff, were positive about the introduction of HCPs and their potential to improve the lives of older people.

Dempsey, Normand, and Timonen (2016) studied the preferences of older adults receiving home care services and of home care workers in Ireland. They found that both the care recipients and those providing home care felt the model of home care placed too much time pressure on home care workers, resulting in the recipients feeling rushed and the workers being dissatisfied with the amount and quality of the time they spent with clients. While many of the home help recipients in the study were generally satisfied with the service, they wanted more communication with the managers of the service and expressed a desire to become more involved in the planning of their own care. Companionship was a key concern for these individuals and the carer played a vital role in fulfilling this need. Dempsey, Normand, and Timonen (2016) concluded that the home help model was *“task-based and does not facilitate the carer working with the older person to promote independence in the home”*.

2.2 Towards personalised home care

A task-based model of home care with an emphasis on meeting personal care needs is recognised as far from ideal for users of home care services as well as for home care workers (Doniol-Shaw and Lada, 2011; Dempsey, Normand and Timonen, 2016). The shortcomings of such an approach to home care were highlighted in interviews by all concerned for the study reported here; recipients and their family members, providers and the HSE. The requirement for personalised services has long been acknowledged (NESF, 2005) and the IHCP

Initiative, as well as offering a higher level of hours, provided an opportunity to re-orientate the model of home care away from one focused on tasks and personal care towards a personalised model of home care. A personalised approach to care is one which elicits the needs, preferences and priorities of the person and/or their carer and develops appropriate responses based on the person’s interests and focused on maintaining their abilities. The supports are tailored to meet a whole range of needs of the recipients and their family carers. While personal and practical care needs continue to be a focus, social, psychological and emotional needs are also addressed in a personalised approach. Because it is tailored to the person at a particular point in time, a personalised approach applies at any level of dependency, and any stage of a person’s condition, e.g. dementia, stroke, or Parkinson’s disease.

However, given the constraints on the home care resource and in an attempt to meet increasing demands from population ageing, the focus of home care has largely been on the provision of essential personal care assistance and visit times allocated are often the ‘bare minimum’ to get the task done. Other countries in Europe (e.g. Denmark and the UK) have been faced with similar issues (EHRC, 2011; Rostgaard, 2012; UNISON, 2013). A task-oriented approach presents two dilemmas which impact on recipients of home care generally, and have specific and significant repercussions for people with dementia.

Firstly, task-oriented care may not be the most appropriate care for a person. An IHCP may be provided to help an older people to get out of bed, or with a shower, dressing, or toileting, but the short duration of visits

can leave little or no time for companionship, which has been identified as a key need in the life of an older person (Dempsey, Normand and Timonen, 2016). Where task-oriented care is provided at low levels, it can result in home care workers carrying out the specific tasks for, rather than working with or 'doing with', the person (Dempsey, Normand, and Timonen 2016). This can be disabling rather than enabling for the person, and may lead to a need for an even greater level of home care sooner than would otherwise be the case. For people with dementia, it is particularly important that home care supports, rather than simply addressing specific care tasks, enable the person to continue to use their own skills and maintain independence for as long as possible. For a person with dementia who is still physically able to do such tasks (maybe with prompting) it may be more appropriate to offer supervision, or support with social participation or with activities such as shopping. As non-task-oriented care is not typically available due to constraints, people with dementia can, as a result, receive no home care hours, leaving carers with little formal support and leaving people with dementia can be particularly vulnerable to exclusion and isolation.

The second dilemma is the portrayal of task-oriented care and personalised care as opposites. Like task-oriented care, personal care can be an essential part of an overall personalised care package for an older person. However, in a personalised approach, the quality of the care relationship, the interaction with the person and responsiveness to their wishes in terms of what is done, is central. For example, people can have different preferences for how their hair is washed and dried and a personalised

approach would respect these and build them into the personal care for that individual.

Personalised care is relevant to all people in receipt of home care. However, through the funding that has been made available to support the implementation of the NDS, the personalisation of home care supports has largely concentrated initially on people with dementia to test feasibility, evaluate and learn. Arguably, programmes that are effective with people with dementia are highly likely to be effective with people without dementia, thus the findings and learnings from work on personalising services for people dementia will have application to those without dementia.

Since 2012, personalised care has been implemented and tested in a number of sites in Ireland through the HSE & Genio Dementia Programme (Genio 2016b). In nine community sites, a range of personalised supports was developed with the person with dementia and family carers, by eliciting their needs, preferences and priorities and developing appropriate responses based on the person's interests and which focused on enhancing their abilities. These supports avoided an exclusive focus on deficits, decline and risk and instead provided responsive, flexible supports that could, for example, support a person with dementia to come to terms with a diagnosis; help maintain a social life and relationships after diagnosis; and help with maintaining ability – all with a view to retaining quality of life and supporting personhood (Genio, 2016a). Personalised supports do not discount the range of clinical and medical services the person may need, but give equal weight to the range of supports and services required

by the person in order to maintain abilities and skills thereby allowing the person to remain living well at home, connected to their families and communities (Keogh and Pierce, 2017). Personalised community-based supports have been found to be beneficial to people across the spectrum of need (Cahill, Pierce, and Bobersky 2014a, b) and cost effective (O’Shea and Monaghan, 2016). They have also been found to be effective in enabling people with advanced dementia and/or complex needs to remain living at home (Genio 2016a, Brady, Ciblis, et al. 2017, Brady, Bracken-Scally, et al. 2017). International evidence has also shown that 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).

The focus of the HSE & Genio Dementia Programme was not just on increasing the range of services and supports, but on bringing about a deeper transformation in the service landscape for people with dementia. Arguably, the current system is resourced and constructed to provide pre-determined forms of care primarily for physical care needs, through rigidly structured processes and settings that are determined by the funders, regulators and providers of care, resulting in a system that cannot easily take account of, or provide for, individual preferences and wishes. In a personalised approach, the preferences of recipients and carers inform not only a wider service choice-set, but more importantly the way services and supports are conceptualised, constructed, delivered and communicated. The testing of a consumer directed care model CHO 3 is a welcome development in this regard (Phelan et al. 2018).

In summary, while there is a strong commitment in Ireland to supporting older people at home, there are long-recognised shortcomings in the home care service, including variability in both the quantity and quality of provision across the country and across different groups who need home support, coupled with a lack of resources in absolute terms to meet the current and growing demand. The current system is characterised by a complex array of providers and funding arrangements, underpinned by millions of hours of care provided by families and informal carers each year. Developments such as the streamlining of funding by the HSE and the DoH review of home care, point to the desired future for home support services – seamless, high quality, integrated care, responsive to need, that is flexible and personalised. This evaluation marks an important and timely contribution to this reimagining of home care, providing hitherto unavailable detail on who uses home care and on what type of care is provided – a picture of the intensive home support delivered to older people without dementia, older and younger people with dementia, and younger people with disabilities.

3. Methods and findings

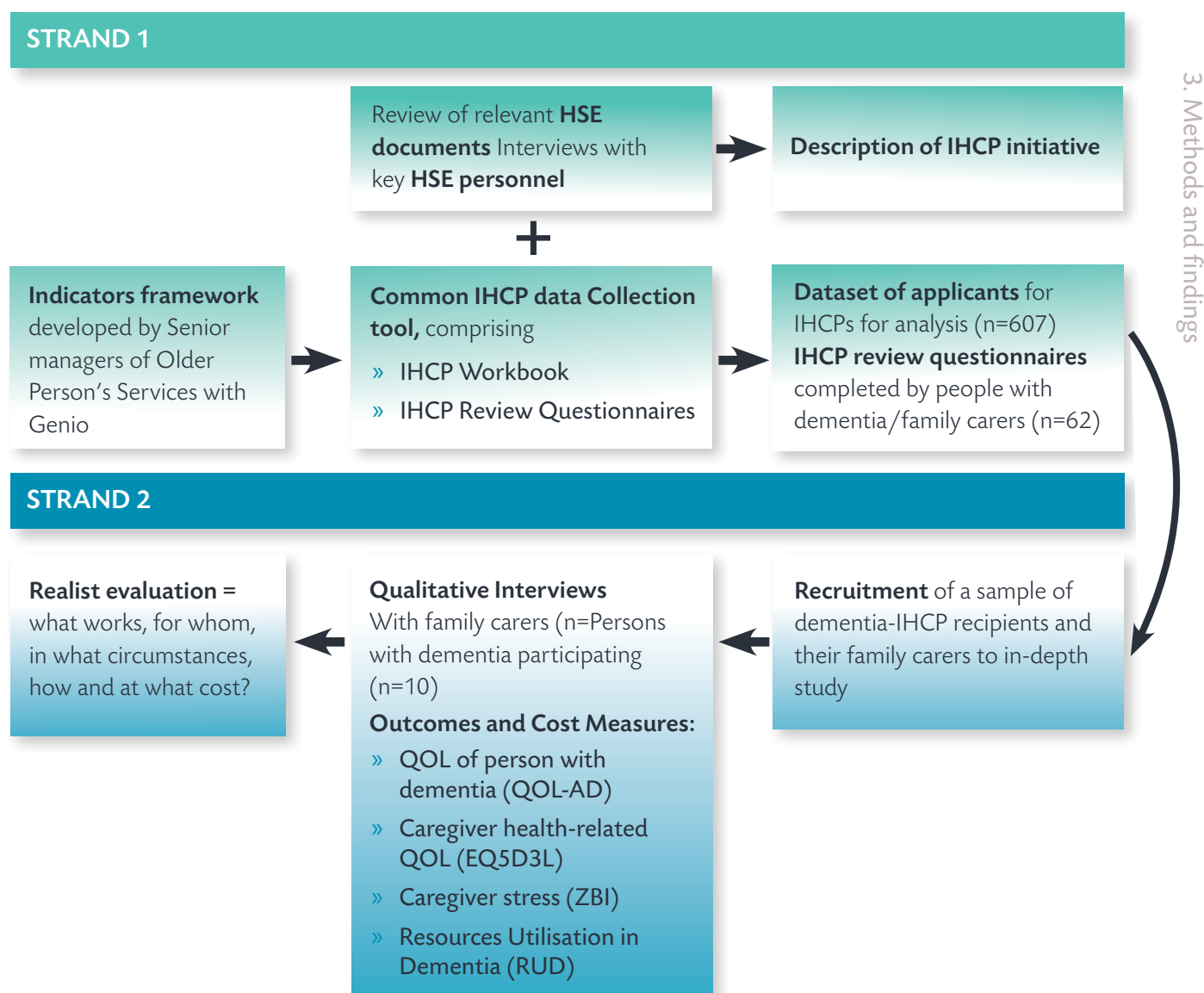
The evaluation was designed as a mixed-methods, multi-participant study within a realist evaluation framework. Figure 1 gives an overview of the methodology for the overall evaluation. A brief description of the methods used for data gathering is interwoven with the findings under the following headings:

- Description of the Intensive Home Care Package (IHCP) Initiative.
- Description of indicators to monitor IHCPs, and;

- Detailed description of the IHCP initiative outputs and outcomes (for all IHCPs, and broken down by dementia-IHCPs and non-dementia IHCPs, the latter are referred to as standard-IHCPs).

A more detailed description of the methodology is available in Keogh et al (2018) and the realist evaluation approach is more fully described in Report 2 (Keogh et al. 2018) www.genio.ie/dementia-report2-ihcp

Figure 1: Methodology for evaluation of IHCP initiative



3.1 The Intensive Home Care Package (IHCP) Initiative

A detailed description for the IHCP Initiative, including a timeline and programme theory, was developed as part of the study. This is based on a documentary review of relevant HSE documents such as Standard Operating Procedures (SOPs) for the initiative and operational plans; semi-structured interviews with key personnel involved in implementation including Older people service Specialists, Managers of Services for Older People, Home Care Managers, Home Help/HCP Coordinators, CMHNs, Directors of Public Health Nursing, hospital based Medical Social Workers/Discharge Coordinators; and observations over the implementation period 2015 to 2018.

Having commenced planning in mid-2014, the HSE introduced IHCPs for older people at the end of 2014 as one element of a range of initiatives to address pressure on acute hospital beds. Initially, the primary aim was to facilitate timely discharge home from acute hospitals, for people who require *“very significant interventions to an extent not previously provided as part of the HCP Scheme or current community services”* (HSE January 2015) The IHCP initiative was primarily aimed at older people, which included people with dementia, both over and under 65 years. It was additionally used for some people with disabilities under 65 years of age, e.g. those with other neuro-degenerative disorders or traumatic brain injuries. It was also intended that the scheme would be available to people living in the community at risk of hospital admission. As with other home care, eligibility for the scheme was based on an assessment of care needs. In line with other home care services funded by the HSE, there was no means test for IHCPs.

In addition to facilitating timely discharge home from hospital, a broader intention of the IHCP initiative was to test the feasibility of providing this level of support and to evaluate its effectiveness in supporting older people and people with dementia, who had a high level of need, to remain at home. The monitoring and evaluation of IHCPs was important in this context.

At the individual level, the intention was that the content and delivery of IHCPs would not just provide more support, but would provide a wider range of supports and would be qualitatively different from usual home supports, building on the work of the Genio & HSE Dementia Programme already described in Section 2.2 (Genio 2016c) (Genio 2016c). The IHCPs aimed to be flexible in their design and delivery, and tailored to the individual person’s assessed physical, psychological and social needs. The range of supports and services to be provided could include, for example; home care hours to provide personal care, supervision and maintenance of personhood and life roles; nursing and/or allied therapy interventions; aids and appliances; respite care including in-home respite; and overnight care. There was also a strong emphasis on supporting family carers. The IHCPs could be provided on a short, medium or long-term basis, depending on assessed need and regular review. The different elements of the package were delivered either by trained health and social care professionals or by home care workers, the latter employed either directly by the HSE or by an approved private home care provider, who have basic, generic training and may (or may not) have training in dementia care.

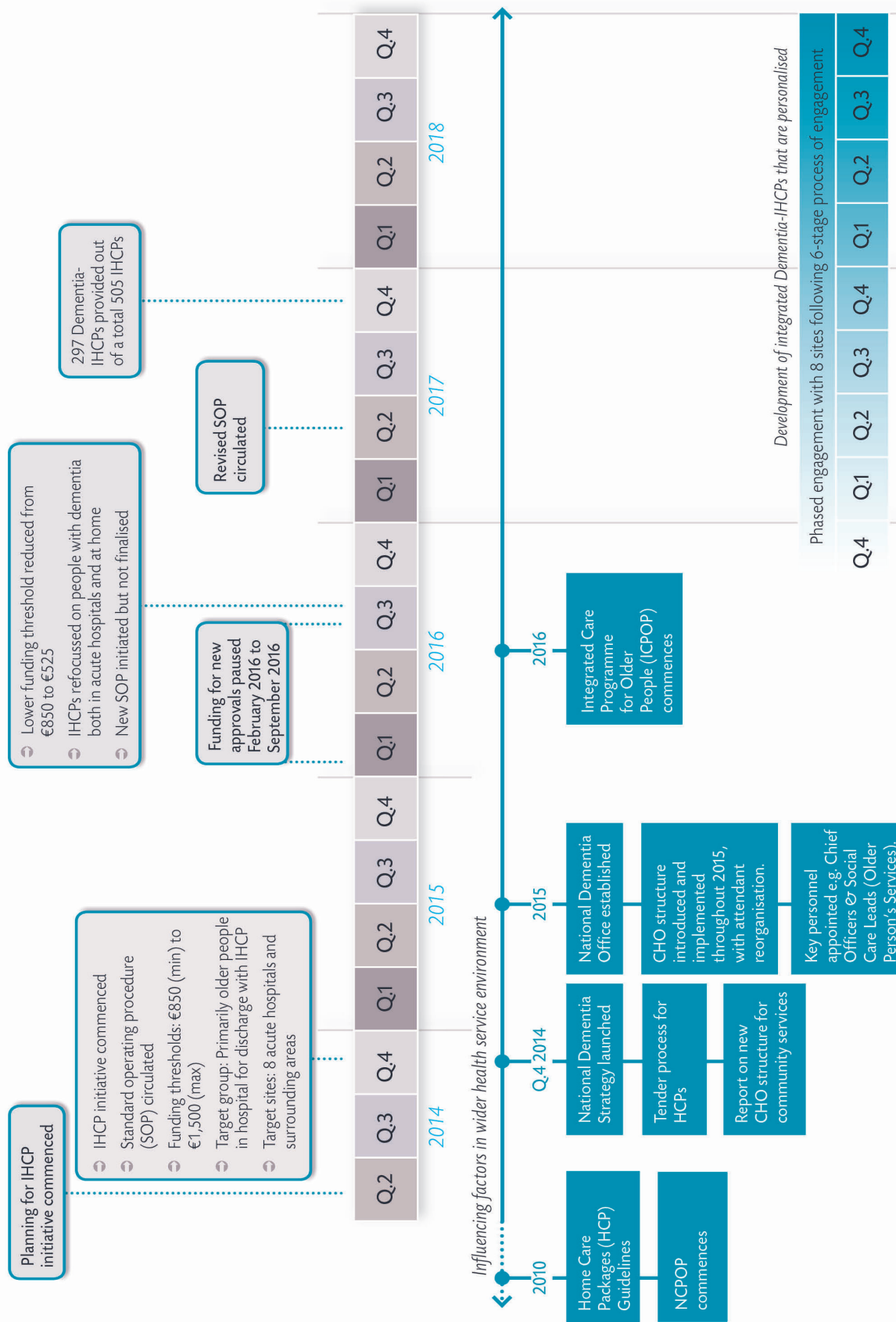
The amount of hours available and the funding thresholds were substantial compared to what was typically available at that time under the home help services and HCP scheme; between €850 and €1,500 per week. The lower funding threshold was provided to distinguish these packages from existing HCPs, which had a maximum limit of €525 per week, highlighting the difference in quantum and content from existing provision. At the outset, IHCPs were made available to people in nine identified acute hospitals and their associated care pathways.

A Standard Operating Procedure (SOP) was developed and circulated in the HSE and relevant acute hospitals to inform managers and staff about the initiative, its eligibility criteria, application process, funding approval, review and evaluation. Roles of various staff and the tasks to be carried out, specifically in relation to key worker, clinical lead and General Manager roles, were outlined. In addition to the SOP, meetings aimed at explaining the IHCP initiative were held in some areas with some of the staff in relevant hospital and community services involved in implementing the scheme.

The initiative was dynamic, responding to events in the wider health service environment and to feedback and learning from staff involved in the implementation. Figure 2 provides a timeline of the initiative, highlighting changes that were made and events in the wider health service environment. For example, with respect to eligibility criteria, HSE staff interviewed for this study expressed concern about the prioritisation of people in acute hospitals for IHCPs. There was a consensus among staff that if good quality and better integrated primary and community care services were

in place (including making IHCPs available to people living in the community, rather than prioritising hospital in-patients), demand on acute hospitals would almost certainly be reduced as unnecessary admissions to hospital could be avoided. They believed that waiting for a hospital admission before an application for an IHCP could be made was ill-considered. Some HSE staff also highlighted the gap between the upper threshold for funding for a HCP and the lower threshold of funding for an IHCP. They reported that, on the one hand, a HCP is not enough to meet the needs of some people, while, on the other hand, they did not need the amount of funding required to be eligible for an IHCP. But, because of the gap between what can be provided with a HCP and an IHCP, some people have ended up 'getting hours' earlier than actually needed, which staff justified to some extent by the knowledge that these people will eventually need a greater number of hours as the condition progresses.

IHCP initiative timeline



After the first year of operation several changes took place, some of which were in response to this feedback from staff, specifically in relation to eligibility criteria, geographical areas targeted and funding thresholds. The eligibility criteria were clarified and from September 2016, as well as facilitating timely discharge from acute in-patient care, more IHCPs were allocated to support older people and people with dementia to remain in the community and prevent frequent acute hospital attendances/admission to residential care. Changes were made to the IHCP funding thresholds, specifically the lower limit of the IHCP was revised down in September 2016 to a level of €525 per week, bridging the gap to the HCP maximum level. These changes were welcomed by HSE staff.

In addition, the IHCP Initiative gave priority at different times to particular cohorts, to address specific needs, for example, people with disabilities. The experience with this particular group highlighted the importance integrated pathways so that hospital and community services could work together for the best outcome for the person. In this case, the initial admitting hospital, the National Rehabilitation Hospital (NRH) and community services needed to work together to successfully discharge the person from the acute hospital, to ensure rehabilitation was provided, where relevant, and crucially to ensure the last piece of the pathway was in place – supports to return home.

3.1.2 Networks, Structures and Organisational Reform Processes

Figure 3 shows the different steps involved in the process developed for allocating an IHCP, from identification of persons who need/

could benefit from the package, through assessment, care planning, application and approval process, to delivery and review. Implementing the IHCP process required the involvement of a wide range of health and social care professionals across hospital and community settings and across public and private sectors. It could involve hospital-based personnel such as geriatricians, discharge coordinators, medical social workers and others, working closely with personnel across two or sometimes three divisions in community services to implement the process outlined in Figure 3. Personnel in these divisions included PHNs, GPs, OTs and others in primary care; old age psychiatrists and community mental health nurses in mental health; and managers of older person's services or home care managers, home care package coordinators and, HSE home helps in the social care division. Depending on local arrangements, structures such as Local Placement Forums could be involved. These personnel and others all had essential roles in this process and when key personnel were missing, not well informed or not engaged in the process, the implementation of IHCPs was not as effective. In practically all cases, it also required the involvement of approved private providers and home care workers and other staff engaged by them.

Figure 3: IHCPs Process - Flow Diagram

Report 1: Context, Recipients and Costs

STAGES

Stage 1:
Identification process

Stage 2:
Assessment process

Stage 3:
Local level application/
approval process

Stage 4:
Regional level application
/approval process

Stage 5:
Implementation process

Stage 6:
Review process

PROCESS

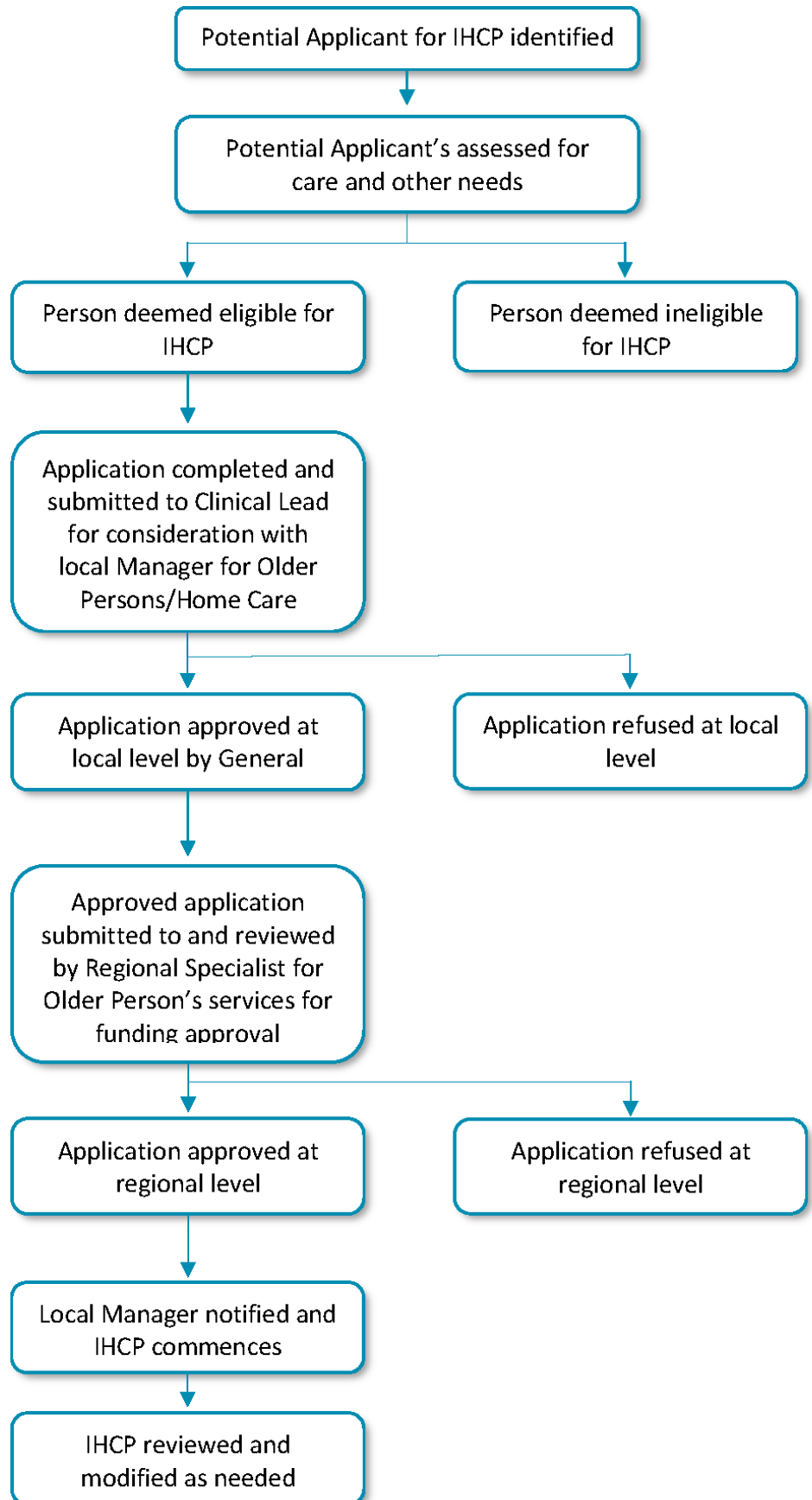
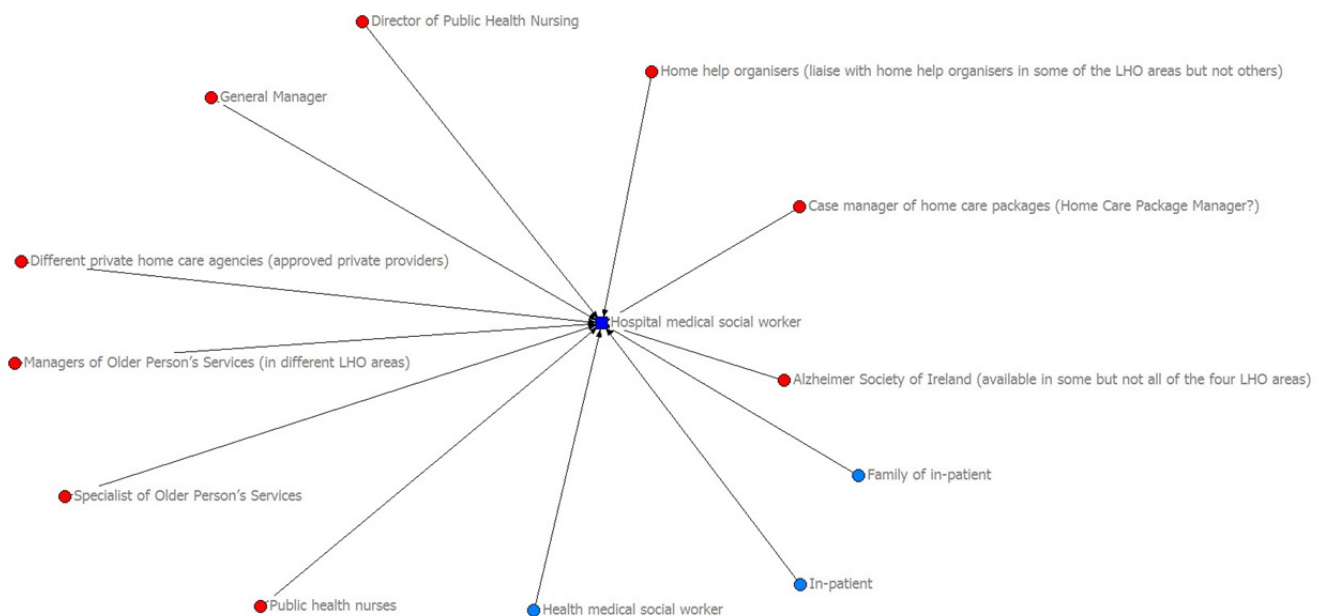


Figure 4 provides a social network analysis of one member in this process to illustrate the breadth of relationships required to facilitate the operation of IHCPs. This data was collected from an individual interview with a hospital social worker and mapped using special software. As we can see from Figure 4, the medical social worker within the hospital (at the centre of the network) has a diverse and wide set of contacts when asked to consider the organisation of an IHCP. The social worker supports the

person and family in this process and liaises with the various contacts. The majority of the contacts are community based including health professionals such as public health nurses. In addition to these, various managerial positions were also integral to the organisation of IHCPs including: managers of home care packages, home help organisers and managers of older person's services. Finally, organisations such as the Alzheimer Society of Ireland (ASI) and private home care agencies were key.

Figure 4: Social network analysis of hospital-based medical social worker (example)



While playing a role in implementing IHCPs, each of the individual health professionals, administrators and managers are working in an everyday context with multiple demands, including ongoing structural and organisational reform processes. Figure 2 captures some of the strategic and organisational changes and developments which were happening at the time the IHCP

initiative was implemented, or were running in the background having started before the initiative. For example, all community-based services underwent a significant restructuring in 2015 with the roll out of CHO structures; initiatives running under the National Clinical Programme for Older People (such as the National Frailty Education Programme) were underway before the IHCP

commenced; other programmes, such as the Integrated Care Programme for Older People commenced in the middle of the IHCP initiative.

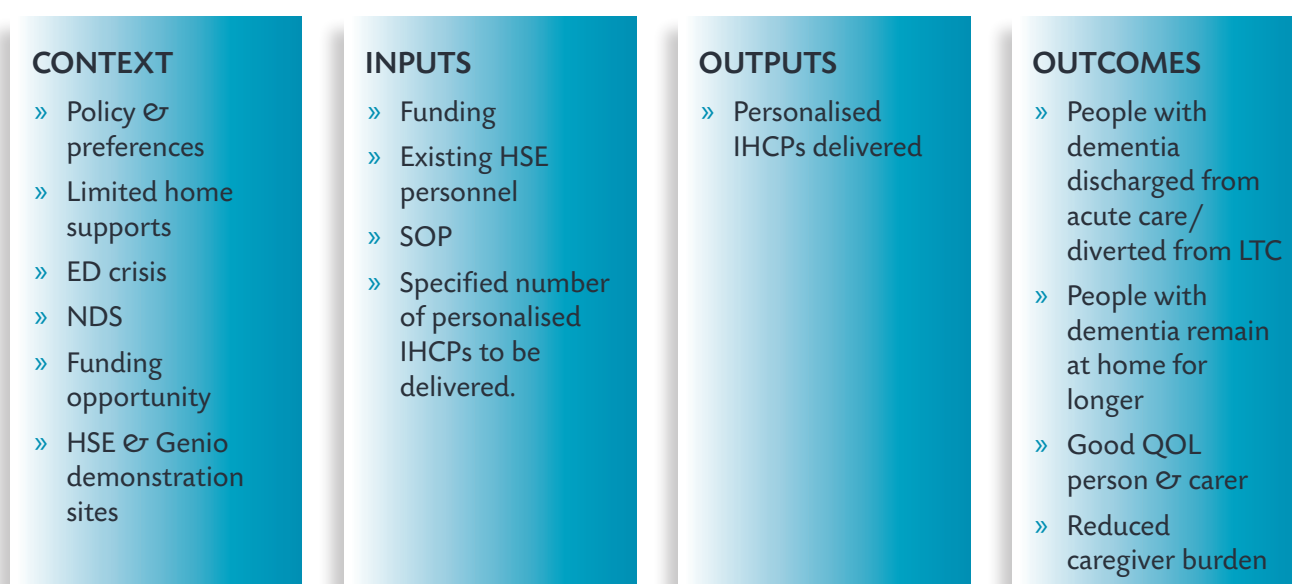
This context illustrates the complexity of the health and social care system within which the IHCP initiative was implemented and was required to operate. The system fits the definition, as proposed by Plsek and Greenhalgh (2001), of a complex adaptive system: “...a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent’s actions changes the context for other agents” (p.625). This multi-layered, complex context has important implications in considering implementation effectiveness and competing demands for time and human resource.

3.1.3 IHCP Formal Programme theory

Based on document review and interviews with key personnel involved in designing and delivering the initiative, an initial or

formal programme theory was developed. A programme theory explains how an intervention (such as the IHCP initiative) is understood to contribute to intended outcomes or impacts. This initial programme theory is displayed in Figure 5 and includes key elements in the context, inputs, outputs and intended outcomes. The context includes that which has been described thus far in this report. The programme inputs include the funding for the IHCPs, the existing personnel to implement the initiative and to provide the care and the Standard Operating Procedure to guide the process nationally. The desired outcomes included the delivery of personalised IHCPs, the discharge of older people with complex needs from acute care or their diversion from long term care (LTC), people remaining at home for longer and individual outcomes relating to the quality of life of the person and carer. As part of the overall evaluation, a realist programme theory was developed and will be presented, along with the process evaluation, in Report 2 from this series.

Figure 5: Formal programme theory for IHCP initiative



3.1.4 Implementing the IHCP Initiative: Examples of facilitators and challenges

Semi-structured interviews were carried out with key HSE staff involved in managing and delivering IHCPs. Those interviewed included Managers of Services for Older People, Home Care Managers, Home Help/HCP Coordinators, CMHNs, Directors of Public Health Nursing, community based social workers, and hospital based Medical Social Workers/Discharge Coordinators. Some facilitators and challenges for the implementation of the IHCP initiative are described and illustrated with quotes from staff interviews.

HSE staff perceptions and readiness to adopt IHCP Initiative

As the Programme Theory shows, one of the inputs into the IHCP Initiative, and a huge resource available to it, was a wide range of existing HSE staff. Health and social care professionals, however, are not passive recipients of any new initiative, and the way they act and react is highly complex and potentially an important influence on its adoption. Many interviewees welcomed the introduction of IHCPs. For example, the emphasis on putting the person at the centre made the IHCP Initiative very attractive to many staff. They spoke about how personal care needs have traditionally been prioritised over social care needs, with the latter largely ignored. One of the biggest benefits of the IHCP scheme they believed, was that it allowed them to put supports in place that were not solely focused on personal care needs and could go ‘beyond practical care’ to include social care and social aspects of a person’s needs. As one interviewee put it:

“The big change was because typically, before the IHCPs came along, those people with dementia, ‘wandering’ people, who were physically very well, but just very demanding and I suppose needing all that supervision essentially, that was a new phenomenon in terms of being allowed to be funded.”

A challenge these staff faced was working alongside other staff working within a task-oriented model of home care. There were staff with a poor understanding of the support needs of people with dementia and who have difficulty seeing the value of personalised support that was not solely task oriented, which they equated to a ‘sitting service’.

“You see a lot of the time it is very difficult to articulate it to 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 just about the basics, personal care and hygiene, there are other issues.”
(PHN)

Staff implementing IHCPs believed that there is a great need to change mind-sets and perceptions of staff within the HSE about the needs of older people and people with dementia and how these might be best supported. Planning and designing a personalised care package is however, just a first step, and the challenges encountered by those tasked with delivering personalised packages of care highlights the needs for training of staff in this approach:

“So initially it [IHCP] was a challenge for the [HSE home care staff] at the start because they would be so used to it being a task service and suddenly they had this block of hours and it was like ‘what do we do in that time?’” (PHN)

Communicating with HSE staff

Communication is an important factor for the effective implementation of any new initiative and there is evidence that effective communication within an organisation enhances the success of implementation (Greenhalgh et al. 2004). As described above, the circulation of a Standard Operating Procedure (SOP) and convening meetings with staff involved in implementing the IHCP scheme were the main modes of communication used to inform staff nationally about the initiative.

A recurring issue raised in interviewees was that awareness and understanding about the scheme was generally low. From some interviews it appeared that relevant staff were not well informed about the IHCP scheme and misunderstood important aspects, such as for example, reporting that people with dementia were not eligible for an IHCP. In another example, a hospital based social worker reported that some local managers had never heard about the scheme. This meant that the social workers had to spend a lot of time explaining the initiative whenever an IHCP was put in place for the first time in a local area. A PHN described how she heard about the scheme from an Alzheimer Society employee;

"...the [ASI staff member] informed me of these intensive homecare packages that were coming on stream." (PHN)

The challenge of communicating across different areas from a hospital base is illustrated in this quote:

"We need to know where they are and how to access them properly... my clients can come

from anywhere but I have no knowledge of where [IHCPs] are and I know you can get them in [name of county] and I know they are available in [name of area] and I have heard anecdotally that you can get them in [name of area] but I am not so sure who is accessing and where in the country. And that would be really valuable to know" (Hospital-based social worker).

Interviewees were particularly critical of the lack of information about changes to the IHCP scheme and how these were communicated. Most criticism was around the lack of communication regarding the suspension of funding for IHCPs in February/ March 2016, which staff found particularly difficult as it was not clear if or when funding for IHCPs would become available again. Some managers spoke about a waitlist of people for IHCPs and having to constantly field phone calls from PHNs looking for decisions about HCPs and IHCPs.

Communication about the IHCP scheme was largely top down from senior managers to HSE staff implementing the scheme, but staff preference would be to have a two-way or 'double-loop' process of communication with an opportunity for feedback to be given.

Private home care providers – capacity and staff training needs

The major component of IHCPs was hours of care provided by home care workers and most home care workers are supplied by approved private providers. Since around 2016 private providers have been struggling with capacity arising from difficulties in recruiting and retaining home care workers. This lack of capacity of private providers to

meet the increasing demands of IHCPs in particular, was raised in many interviews by HSE staff who saw this as a major challenge to IHCP implementation. This challenge was particularly prominent in some areas such as CHO 4 and CHO 6. This problem is not unique to Ireland and studies have shown that the turnover of staff in the private care sector is common due to insufficient rates of pay and low status and valuation of staff (Prince, Prina, and Guerchet 2013), and this was commonly acknowledged by staff interviewed. Interviewees reported one consequence of these capacity issues was potential delays in the commencement of IHCPs. For example, for a person ready to leave hospital, difficulties in securing an approved private provider could mean a delay in being discharged home or moving the person instead to a community hospital or transition care bed while waiting for home care to be put in place. These capacity issues appeared to be further exacerbated by the Tendering Process for approved private providers, as it limited the number of providers available.

There is a requirement in the home care tender for home care workers to have attained training on home care to FETAC Level 5. HSE staff putting in place IHCPs understandably had little knowledge any other training (e.g. training on dementia care) home care workers employed by approved private providers may have had. In several areas, concern was expressed that home care workers may not have received an adequate level of training and may be lacking skills crucial to providing optimum levels of care, particularly to persons with dementia and with regard to personalised care. There was no requirement in the 2016 tender that staff

required specific training on dementia care. Separately from the IHCP Initiative, the HSE has been developing and delivering training courses for home care workers. Training on personalised home care for home care workers was not incorporated as an integral part of the IHCP initiative at the outset, which was potentially a shortcoming. Our understanding is that this gap is now being addressed through the development and implementation of a dementia education programme for home care workers as part of the NDSIP (Department of Health 2018).

3.2 Development of indicators for IHCPs

In order to effectively monitor and evaluate the IHCPs, Genio worked with a group of Senior Managers of Older Persons' Services in the HSE to develop a framework and suite of indicators (performance indicators or PIs). The framework has seven outcome domains:

1. Individualised
2. Effective
3. Efficient
4. Equitable/Accessible
5. Safe
6. Fit for purpose
7. Sustainable

The indicators under these domains were developed to reflect three perspectives; (i) the perspective of the person supported by the IHCPs, (ii) the carer/family and (iii) the wider service provision system (i.e. HSE), as relevant. Under each domain and for each stakeholder, several outcomes were agreed. These outcomes were then used to develop

a set of indicators to measure the extent to which these outcomes are achieved. Detailed information on the KPI framework and indicators can be found in Appendix 1.

Once the indicators for monitoring IHCPs were developed and agreed, an IHCP data collection tool was developed to collect data for each indicator. The data collection tool comprises (a) a shared IHCP workbook and (b) a set of questions, referred to as review questionnaires, both of which are briefly described:

3.2.1 Shared IHCP workbook

The shared IHCP workbook developed by the HSE with the support of Genio was extensively tested and refined and used by HSE staff in Dublin North East (DNE), Dublin Mid Leinster (DML), the South and the West to record data on all persons who applied for an IHCP across all nine CHO areas. As well as indicator data, the IHCP workbook was designed to facilitate the collection of data needed by the National Office and the Finance Office in the HSE. Since January 2017, data on clinical reviews for IHCPs was recorded in the workbook.

Information on both the characteristics of persons receiving IHCPs (such as age, living arrangements etc.) and characteristics of the IHCPs is available from this dataset (See Appendix 2 for full list of variables in the IHCP dataset). The anonymised IHCP excel workbook was submitted to Genio on a monthly basis for review, analysis and reporting up to January 2018. Data on IHCPs were imported into IBM SPSS Statistics Version 24 for statistical analysis. 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 approvals for the secondary analysis by the research team of the anonymised IHCP workbook data.

3.2.2 Review questionnaire to collect outcomes data

The KPI framework has a strong focus on outcomes, which is in keeping with an outcomes-oriented approach that is recommended for policy implementation (NESF 2009). A review questionnaire was developed to capture key outcomes for people and their family carers receiving IHCPs, outcomes which were based on the aims of the overall initiative. The questionnaire comprises a set of 12 questions for the person and 13 questions for the family carer and was designed for measuring progress with outcomes for both and to be administered as part of the reviews that are conducted by key workers assigned to people receiving IHCPs.

The development of the indicator framework, its implementation through the IHCP workbook and review questionnaires and the significant data collection process came about through close collaborative working with HSE staff. The generosity of data collectors, senior managers and specialists of older people's services in the HSE with their time greatly facilitated this process. However, because of constraints within the HSE, the collection of data by way of the review questionnaires was limited to people with dementia and their family caregivers.

3.3 IHCP outputs and outcomes

The IHCP Initiative commenced in December 2014 and while the initiative is still ongoing, this report covers the period between December 2014 and December 2017. Over that time period, a total of 607 applications were made for an IHCP. This total includes applications for an IHCP from people both with and without a diagnosis of dementia as well as younger people with disabilities. For the purposes of this report, the former are referred to as dementia-IHCPs and the latter as standard-IHCPs (this term includes the small number of IHCPs for younger people with disabilities). More detailed information on each of these three groups is presented in the sections to follow.

3.3.1 Breakdown of IHCPs and status at December 2017

Of the 607 applications for IHCPs between December 2014 and December 2017; 355 (58%) were for a dementia-IHCP and 252 for a standard IHCP. Figure 6a gives a breakdown of the IHCPs by both groups and shows the status of these packages at the end of December 2017.

Of the 252 applications for a **Standard-IHCP**, 208 commenced and were active at some point between December 2014 and December 2017, with 80 still active at the end of December 2017. The remaining 128 had ceased. There were a variety of reasons why these packages had ceased, including:

- ➔ The person had deceased (89)
- ➔ The person was admitted to long-term care (31)
- ➔ The person was admitted to acute hospital (4)
- ➔ The HSE provided an alternative service after the package had commenced (4)

Applications for 44 people for a standard IHCP never commenced. The reasons for this are as follows:

- ➔ The person had deceased before commencement of package (10)
- ➔ The person was admitted to long-term care (10)
- ➔ The person was admitted to acute hospital (4)
- ➔ Person/family declined (4)
- ➔ The HSE provided an alternative service (2) or
- ➔ The HSE did not approve the package (12)

Of the 355 applications for a **dementia-IHCP**, 297 actually commenced and were active at some point between December 2014 and December 2017. The vast majority (95%; n=282) were for older persons with dementia (i.e. aged 65 and over) with 5% of recipients under 65 years of age (n=15). A further five applications were approved by the end of December 2017, but had not commenced at the completion of data collection (end December 2017).

Of the 297 dementia-IHCPs that had commenced, 148 were still active at the end of December 2017 and the remaining 149 had ceased. There were a variety of reasons why these packages had ceased, including:

- ➔ The person had deceased (79)
- ➔ The person was admitted to long-term care (63)
- ➔ The person was admitted to acute care (5)
- ➔ The HSE provided an alternative service after the package had commenced (1) or
- ➔ The person emigrated (1)

Applications for 53 people with dementia never commenced. The reasons for this are as follows:

- 24 applicants were admitted to long-stay residential care before the package commenced
- 14 applicants were deceased before the IHCP commenced
- Five applicants were admitted to acute hospital and

- In five cases the IHCP was refused by the person or their family.
- In five cases; one was not approved by the HSE and for each of the other four cases, the person was provided with an alternative service.

A total of 505 IHCPs were commenced through the period of the initiative; 208 standard-IHCPs (including a sub-group of 32 disability IHCPs) and 297 dementia IHCPs. These three groups are described in detail below.

Figure 6a: Status of IHCPs at the end of December 2017, by dementia-IHCPs and standard IHCPs

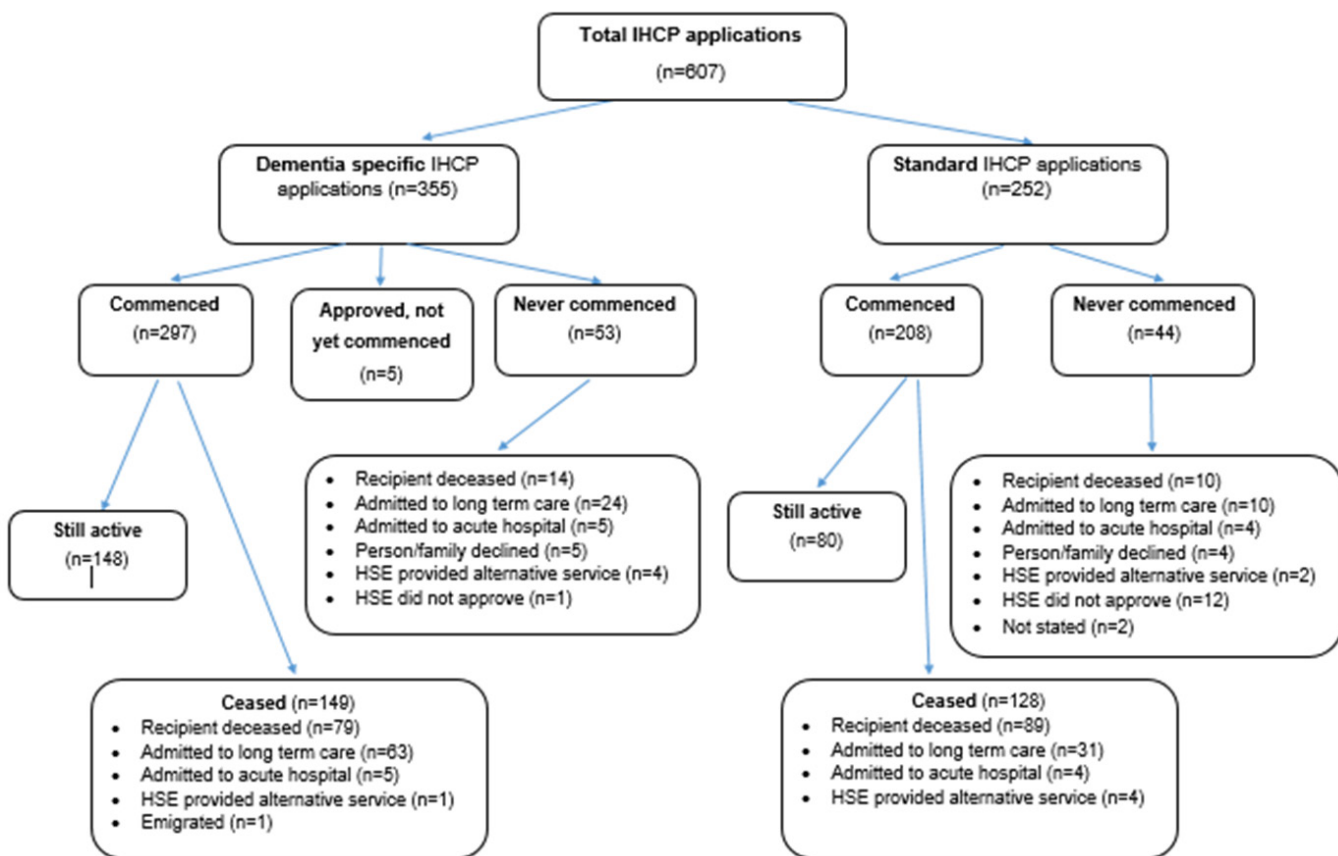
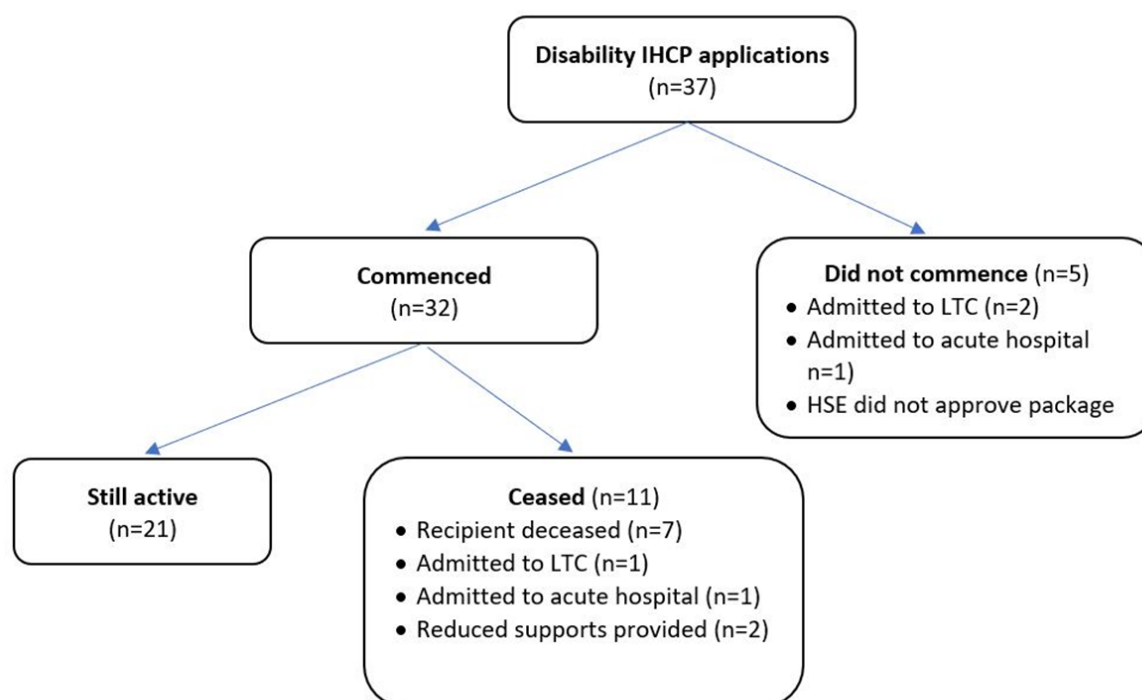


Figure 6b: Status of Disability-IHCP at end of December 2017



3.3.2 Standard IHCP recipients

A total of 208 Standard-IHCPs commenced and were active at some point between December 2014 and December 2017.

Profile of people in receipt of a standard-IHCP

- ➔ More women than men received Standard-IHCPs (56.3%).
- ➔ The recipients ranged in age at time of approval from 25 to 100 years with an average age of 74.7 years.
- ➔ Just over a third (34.6%) of those receiving a Standard-IHCP were 75-84 years of age and 15% were under 65 years
- ➔ Slightly less than half of recipients were married (48%), and the remaining either widowed (29.1%), single (17.9%) or separated/divorced (4.6%).

- ➔ Just under half of recipients of Standard-IHCPs were living with a spouse or partner (46.2%), one third were living alone (33%), 11.7% with a son/daughter and 3.5% with other family
- ➔ The mean Barthel Index² score of Standard-IHCP recipients was 5.8 indicating high levels of dependency. Most of this group had a maximum or high dependency level (89%), as indicated by their scores on the Barthel Index, with a minority (5%) recorded as either low dependency or independent
- ➔ 40.2% were cared for by a spouse or partner with the next highest proportion being cared for by an adult child (31.7%), then 'other family' (14.6%) and 9% had no informal carer

² The Barthel index is a scale used to measure performance in activities of daily living. It is usually administered by a clinician such as a nurse as part of the assessment for home care services. It is scored out of 20, with lower scores indicating increased disability or dependency.

- ➔ Almost half of carers reported that they provided at least 8 hours of care daily (46.8%), with more than a quarter (26%) providing the majority or complete care to the person
- ➔ The average number of home help or HCP hours in place prior to commencement of the IHCP was 9.6
- ➔ Most of the Standard IHCPs were allocated from 4 CHO areas; CHO 9, CHO 2, CHO 6 and CHO 4 which allocated 62, 41, 27 and 23 Standards-IHCPs respectively.
- ➔ Almost all (91.4%) of Standard-IHCP recipients were referred from an acute or community hospital with only 5.8% referred from the community. There were a small number of recipients referred from the National Rehabilitation Hospital (2.4%) and 0.5% from a nursing home.
- ➔ Most of those referred for a Standard-IHCP from acute hospitals had a maximum or high dependency level (89%).

3.3.3 Disability-IHCP recipients

People receiving Disability-IHCPs are a subgroup of people receiving Standard-IHCPs. Of the 208 Standard-IHCPs that commenced, 32 of these were for people with disabilities, the vast majority of whom are people with disabilities under 65 years of age.

Profile of people in receipt of a disability-IHCP

- ➔ A slightly greater proportion of women received Disability-IHCPs (53.1%).
- ➔ The recipients ranged in age at time of approval from 25 to 67 years with an average age of 47 years.

- ➔ Just over half (53.1%) of those receiving a Disability-IHCP were under 50 years of age
- ➔ Just under half of recipients were single (46.7%) while 36.7% were married, 6.7% separated, 6.7% widowed and 3.3% had their marital status recorded as 'other'.
- ➔ The living arrangements of recipients varied. The majority were living with a spouse or partner (38.7%), 19.4% with a son/daughter, sibling or other family member.
- ➔ 22.6% were living alone, 19.4% were living with 'other'
- ➔ The mean Barthel Index score of people receiving Disability-IHCPs was 6.8. The majority of disability-IHCP recipients (75.1%) had a maximum or high dependency level based on their scores on the Barthel Index
- ➔ The average number of home help or HCP hours per week in place prior to commencement of the IHCP was 6.7
- ➔ Most of the disability-IHCPs were allocated from three CHO areas; CHO 4 (31%%), CHO 6 (25%) and CHO 9 (31%%).
- ➔ The majority of Disability-IHCPs were referred from an acute or community hospital (81.2%), then from the National Rehabilitation Hospital (12.5%), one person was referred from the community and one person from a hospice.

3.3.4 Dementia-IHCP recipients

A total of 297 Dementia IHCPs commenced and were active at some point between December 2014 and December 2017.

The following brief case study provides an insight into the characteristics and care patterns of one of the Dementia IHCP recipients before and after admission to the

scheme, including information on their carer and the overall impact of the IHCP. Mrs M was referred to the Dementia-IHCP from the community and had severe dementia.

Case Example of Dementia-IHCP

Mrs M

Mrs M is an 84-year old widow who was diagnosed with dementia 4-6 years ago and lives alone in a city centre location. Her married daughter has been her primary carer for about three years, with siblings helping out, but most of the care falls to this one daughter, who lives about a 45-minute drive away. The woman's condition progressed to the point where she couldn't be left alone and needed high levels of supports with ADLs and hoisting. The daughter began staying over nights to the point where she was spending most of the time at her mother's home, with little opportunity to get home to her own house. The PHN visited regularly and in September 2016 made an application for home care supports. From this application, the woman was granted ½ hour twice a week in the mornings (Tues and Thurs) with two carers coming into the house each time for hoisting (total carer hours = 2 per week). This was the only home care support coming into the home before commencement of the Dementia-IHCP.

A short time later, following an illness and involvement of the GP, PHN and palliative care team, an application for an IHCP was made. A package of 42 hours was provided to cover support visits from two care workers visiting three times a day seven days a week for changing the woman in the morning (8-9 a.m.), to wash her and get her up and hoist her into a chair in the middle of the day (2-3 p.m.) and to change her and get her comfortable for the night (8-9 p.m.). Outside of this, the family provides the remainder of the care, to a level of approximately 90 hours per week. The daughter described the supports as 'wonderful supports', both those before and after the IHCP commenced.

The daughter spoke about the difference that the IHCP was having. The woman's wishes were 'always to remain at home' and the family are determined to honour their mother's wishes. The most important part of the IHCP is that it offers the family the supports to do this. They believe that the IHCP would not work for a person with dementia with this level of needs without family members being heavily involved. She spoke about how lovely it was to see her mother sitting in a chair even for a short amount of time each day. A significant benefit is that the IHCP allows the daughter to return home to have a full weekend at home, from Saturday morning until Sunday evening. A sibling is now willing to cover this time period now that personal care tasks are addressed. This is the first time in months that the daughter has been able to spend this amount of time in her own home with her family.

Profile of people in receipt of a Dementia IHCP

- ➔ More women (60.5%) than men received Dementia-IHCPs.
- ➔ The recipients ranged in age at time of approval from 51 to 101 years with an average age of 81 years.
- ➔ 40.1% of those receiving a Dementia-IHCP were 75-84 years of age and 5.1% were under 65 years.
- ➔ Over half of recipients were married (54%), with the remainder either widowed (36.2), single (8.6%) or separated/divorced (0.7%).
- ➔ Slightly more than one-third were living with either a spouse or partner (52.7%) or adult child (14.6%), while over one quarter were recorded as living alone (28.5%).
- ➔ The mean Barthel score for people receiving a dementia-IHCP was 6.6. The majority of people receiving a dementia-IHCP were recorded as having a maximum or high dependency level (79.1%), with a very small proportion (3.4%) categorised as having either low dependency or being independent.
- ➔ An adult child (43%) or a spouse/partner (41%) is most likely to be the principal informal carer of people receiving dementia-IHCPs. Siblings or other family members are the main informal care in approximately 10% of cases. A small proportion (2.4%) were recorded as having no principal informal carer.
- ➔ Carers reported that they provided at least 8 hours of care daily (58.2%), with more than one-third (35.7%) providing most or complete care to the person with dementia
- ➔ The average number of home help or HCP hours in place prior to commencement of the IHCP was 10.5
- ➔ Most of the dementia-IHCPs were allocated from three CHO areas; CHO 9, CHO 2, CHO 6, allocating 83, 49, and 34 IHCPs respectively (See Map 1).
- ➔ Over half of people receiving a dementia-IHCP were referred from acute or community hospitals (56.4%), with the next highest proportion referred from the community (41.8%). Very small numbers were referred either from a nursing homes (1%) or a psychiatric hospital (0.7%).
- ➔ Most of those referred for a Dementia-IHCP from acute hospitals had a maximum or high dependency level as measured by the Barthel Index (86.2%).

Figure 7: Supports in place prior to commencement of dementia-IHCPs

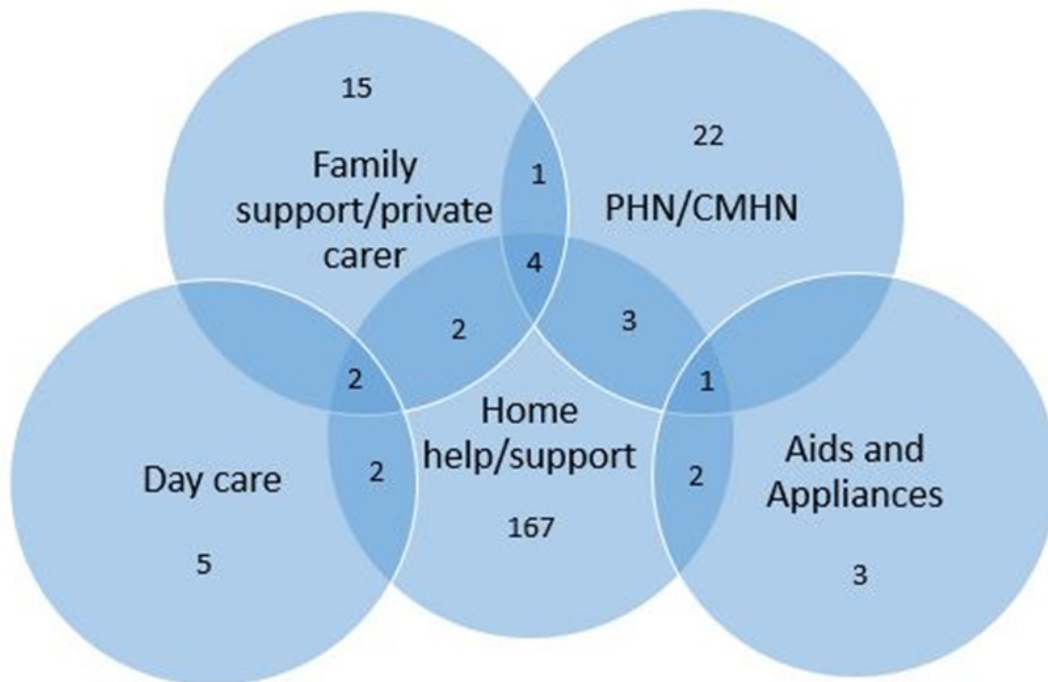


Figure 7 shows the supports in place prior to the commencement of the dementia-IHCPs. This data is recorded on the Common Summary Assessment Report (CSAR) which is the assessment completed at the time of application for the IHCP. The majority of this group were in receipt of low levels of home help/support (an average of 10.5 hour per week). A small number of people also had additional supports, including PHN/CMHN, day care, private carers, and aids and appliances. A small but significant number of people had no formal supports in place prior to the commencement of the Dementia-IHCPs, relying exclusively on informal care provision mainly from family members. The section on the CSAR for recording family support does not make a distinction between

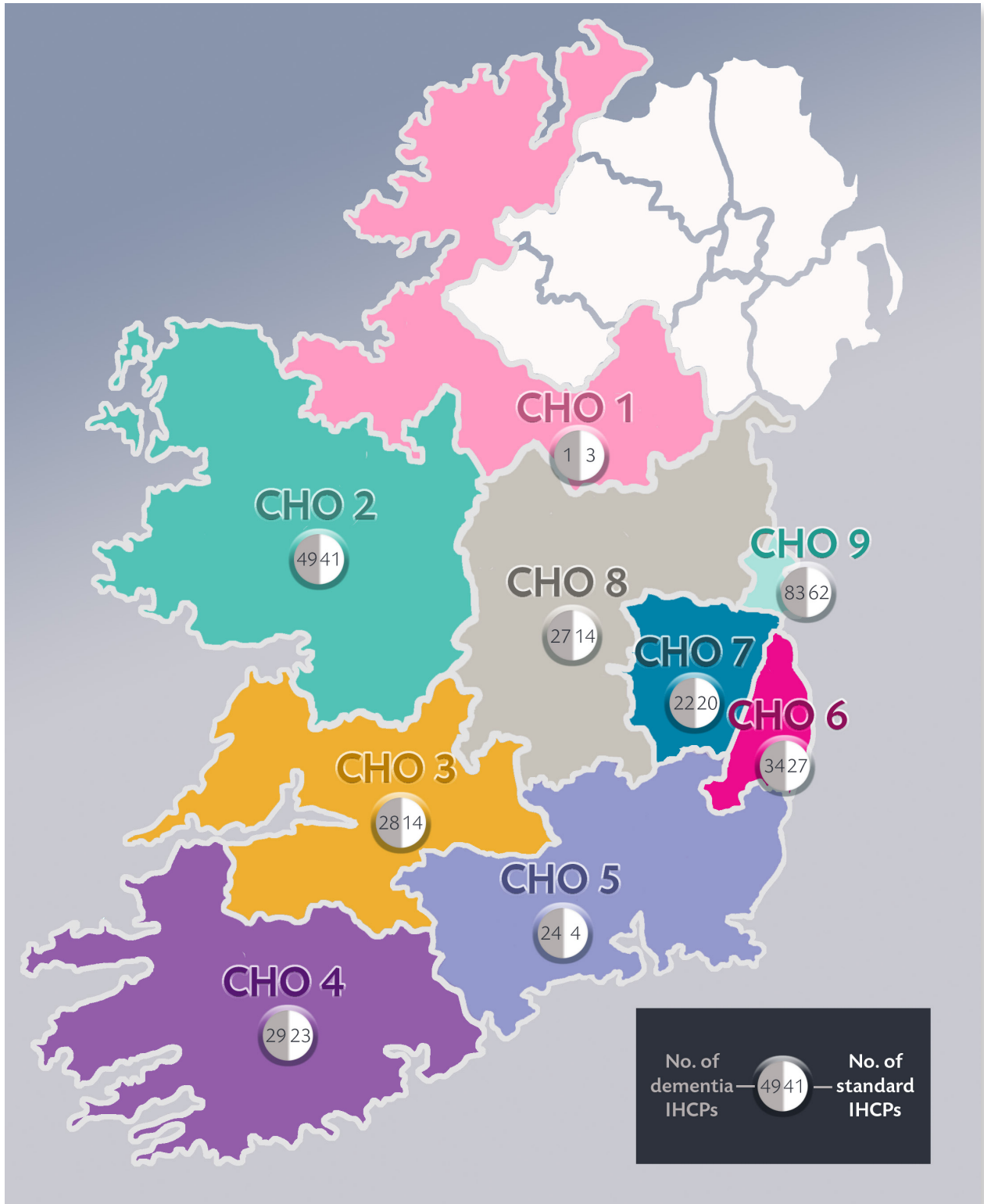
whether the family is providing care or paying for private care. The number of applicants for dementia-IHCPs recorded as having family support or a private carer is remarkably low and is unlikely to be an accurate reflection of the contribution that family carers are making to supporting people with dementia at home.

3.4 IHCPs by CHO areas

The number of dementia-IHCPs and Standard-IHCPs allocated between December 2014 and December 2017 by each of the nine CHO areas is shown in the map below (Figure 9).

Figure 9: Map showing number of dementia and standard IHCPs by CHO area

Report 1: Context, Recipients and Costs



There is a large variation between CHO areas with regard to the provision of IHCPs. There are several reasons contributing to the difference:

- ➔ When first introduced, the primary aim of the IHCP initiative was to facilitate timely discharge home from acute hospitals, for people with complex needs who required support greater than that typically available on a HCP. To this end, IHCPs were made available to in-patients in nine acute hospitals and their associated care pathways: University Hospital Galway, University Hospital Limerick, Waterford General Hospital, Our Lady of Lourdes Hospital, Drogheda, St Vincent's Hospital, Tallaght University Hospital, St James's Hospital, Beaumont Hospital and the Mater Hospital (the latter five of which are based in Dublin). For this reason, there are relatively high numbers of IHCPs in CHO areas in which these acute hospitals are located. No acute hospital was designated for IHCPs in two CHO areas, CHO 1 and CHO 8, which explains the relatively low numbers in these two areas.
- ➔ When the Initiative was being introduced, its operation commenced first in CHO 2 and CHO 9 and then soon after in CHO 4, CHO 6 and CHO 7. This phased implementation is the main reason for the greater provision of IHCPs in areas 2 and 9 compared to the others.
- ➔ A regional approach to the allocation of IHCPs was adopted following a review after about 18 months of operation. Thus, in September 2016, an attempt was made to rebalance IHCP allocation across the four regions (DNE, DML,

South and West), with a further rebalancing across CHOs within some regions coming later.

- ➔ In September 2016, the IHCP Initiative was refocused with the result that people with dementia living in the community were given as much priority as people in acute hospitals.

CHO 1: This CHO area was not initially included in the IHCP initiative, primarily because none of the acute hospitals selected for the initiative were in this area. A small number of packages were however provided to people living in the area.

CHO 2: University Hospital Galway is located here, which explains the relatively large number of IHCPs provided to people in Galway and surrounding areas. In addition, CHO 2 was one of two areas to first begin implementing the IHCP initiative in December 2014, and therefore had a longer time period over which IHCPs were provided.

CHO 3: University Hospital Limerick was designated for the roll-out of IHCPs in Limerick, North Tipperary and Clare.

CHO 4: In this area, the provision of IHCPs was restricted to Cork, with the initial focus on providing IHCPs to in-patients in Cork University Hospital to facilitate discharge home.

CHO 5: The implementation of the IHCP Initiative in this area started later than CHO 2 and CHO 9 and was largely confined to Waterford and to a lesser extent South Tipperary.

CHO 6: St Vincent's Hospital, Dublin was the acute hospital designated for IHCPs in CHO 6.

CHO 7: Tallaght University Hospital, Dublin was designated for the roll-out of IHCPs, although take-up was relatively low.

CHO 8: With no acute hospital in CHO 8 designated for IHCPs, the number of IHCPs provided in this area was initially low. Following a review of the regional allocation of packages, IHCPs were provided in CHO 8, but because of the time lag in introducing IHCPs into this area, the numbers did not reach the level of some other areas.

CHO 9: Two large acute hospitals, Beaumont Hospital and the Mater Hospital are located in this area, which covers North Dublin. Furthermore, the catchment area for the two hospital extends beyond CHO 9. CHO 9 was the second of the two CHO areas selected for the commencement of the IHCP initiative from December 2014.

3.5 Comparisons between standard and dementia IHCP recipients

The characteristics of all people receiving IHCPs are shown in Table 2 below, with a breakdown by those receiving dementia-IHCPs and standard-IHCPs.

Table 2: Characteristics of people receiving IHCPs, by All IHCPs, Dementia-IHCPs and Standard IHCPs

	All IHCPs (N=505)	Dementia-IHCPs (n=297)	Standard IHCPs (n=208)
Sex, n (%)			
Male	208 (41.3)	117 (39.5)	91 (43.8)
Female	296 (58.7)	179 (60.5)	117 (56.3)
Age, mean (SD), range	78.2 (12.1) 25-101	80.6 (8.9) 51-101	74.7 (14.9) 25-100
Age groups, n (%)			
<65 years	46 (9.1)	15 (5.1)	31 (14.9)
65-74 years	106 (21.0)	53 (17.8)	53 (24.5)
75-84 years	192 (38.0)	120 (40.4)	72 (34.6)
85-94 years	148 (29.3)	102 (34.3)	46 (22.1)
95+ years	13 (2.6)	7 (2.4)	6 (2.9)
Marital Status, n (%)			
Married	252 (51.9)	158 (54.5)	94 (48.0)
Widowed	162 (33.3)	105 (36.2)	57 (29.1)
Single	60 (12.3)	25 (8.6)	35 (17.9)
Separated/Divorced	11 (2.2)	2 (0.7)	9 (4.6)
Other	1 (0.2)	0 (0.0)	1 (0.5)
Principal Carer, n (%)			
Spouse/Partner	203 (41.1)	123 (41.7)	80 (40.2)
Adult child	189 (38.3)	126 (42.8)	63 (31.7)
Sibling	19 (3.8)	11 (3.7)	8 (4.0)
Other family member	41 (8.3)	20 (6.8)	21 (10.6)
Other	17 (3.4)	8 (2.8)	9 (4.5)
None	25 (5.1)	7 (2.4)	18 (9.0)
Living arrangements, n (%)			
With Spouse/partner	246 (50.1)	155 (52.7)	91 (46.2)
Alone	149 (30.1)	84 (28.5)	65 (33.0)
With son/daughter	66 (13.4)	43 (14.6)	23 (11.7)
With other family	14 (2.8)	7 (2.3)	7 (3.5)
With other	16 (3.3)	5 (1.7)	11 (5.6)
Barthel score, mean (SD)	6.3 (4.6)	6.6 (4.7)	5.8 (4.3)
Dependency level (BI), n (%)			
Maximum dependency	245 (50.3)	137 (46.9)	108 (55.4)
High dependency	159 (32.6)	94 (32.2)	65 (33.3)
Medium dependency	62 (12.7)	51 (17.5)	11 (5.6)
Low dependency	17 (3.5)	8 (2.7)	9 (4.6)
Independent	4 (0.8)	2 (0.7)	2 (1.0)
Referral Source, n (%)			
Acute hospital	324 (64.5)	145 (49.3)	179 (86.1)
Community hospital	32 (6.4)	21 (7.1)	11 (5.3)
National Rehabilitation Hospital	5 (1.0)	0 (0.0%)	5 (2.4)
Nursing home	4 (0.8)	3 (1.0)	1 (0.5)
Psychiatric hospital	2 (0.4)	2 (0.7)	0 (0.0)
Community	135 (26.9)	123 (41.8)	12 (5.8)

3.5.1 Statistical comparisons

Two sample, independent t-tests were conducted to determine if there was a statistically significant difference between the two groups (standard and dementia) on several characteristics. The two groups were similar in several important respects, for example, gender, marital status and proportion living alone, as there were no significant differences between the groups on these characteristics.

However, there were some significant differences between the groups. The dementia-IHCP recipients were significantly older than the standard group, which is not unexpected given that 15% of those in the standard group were younger people with disabilities; there were significantly fewer recipients aged under 65 years in the dementia group; and significantly more referrals came from the community for the dementia group. However, this last difference between the groups may be an artefact in the sense that the allocation processes changed during the IHCP initiative, with a decision made in 2016 to prioritise more referrals from the community for dementia-IHCPs in particular (see Figure 2).

3.6 Content and costs of IHCPs

The major component of all of the IHCPs was hours of care provided by home helps and home care workers and there is robust data on the amount of hours supplied. The number of hours provided by a standard IHCP ranged from 14 to 168 hours with a mean of 45 hours per week provided. For disability packages, the number of hours provided per week ranged from 28 to 168 hours with an average of 47.4 hours per

week. The number of hours provided by dementia-IHCPs ranged from 6 to 168 hours per week with a mean of 39 hours per week provided. It is clear that dementia package average hours were significantly less than standard or disability packages.

Most people in receipt of IHCPs had high or maximum levels of dependency. In such cases, our understanding from interviews with HSE staff is that the home care hours focused almost entirely on personal care tasks. In some of these cases, two home care workers were assigned where hoisting was required. This, in effect, halved the hours of care actually experienced by the person and family. For example, as illustrated in the case example in Box 3, a package of 42 hours which required two home carer workers to attend at each visit means that, in effect, the hours of care experienced by the person and family are 21. The need for two formal carers at visits is a significant cost driver. There seemed to be different practices around the country in terms of the circumstances where two carers were mandated and the extent to which a family member was permitted to provide the 'second pair of hands' (if they were willing and able).

For some cases, there was a move away from multiple, short task-oriented visits of home care workers towards blocks of hours, which may provide time for meaningful engagement with the recipient and/or an opportunity for a break for a family member. This appears to be particularly the case for recipients with lower dependency levels (approx. 15%). More detailed information on the typical content of IHCPs for people with dementia, is available from the in-depth sample of dementia-IHCPs, and will be provided in Report 2.

Public health nurses (PHNs) were the health professionals most frequently involved in the packages, in addition to home care workers. In most cases PHNs, community mental health nurses (CMHNs) and social workers were centrally involved in setting up the package. In some cases PHNs, CMHNs and social workers visited regularly once the package was in place. This was particularly the case for PHNs when nursing care was needed by the recipient. In many cases, however, PHNs were more generally available as required over the course of the IHCP. Occupational therapists (OTs), were also involved at the outset in the conduct of a home assessment and procurement of aids and appliances and occasionally a physiotherapist was also involved. As with the PHNs, the provision of services and supports by physiotherapists and other allied health professionals, where available, occurred on an 'as needed' basis. The other essential element of many IHCPs was the provision of a wide variety of aids and appliances, such as hoists, beds and wheelchairs and pads. Data on elements such as PHN and other health professional visits and the aids and appliances were not consistently collected for all IHCPs and so cannot be reported in detail. It should also be noted that general practitioners (GPs) are an essential care provider for older people. Their visits are considered part of care as usual and were not captured as part of the IHCP initiative. However, as part of the interviews undertaken for the in-depth sample of people with dementia, detailed data was collected on the use of all elements of the health and social care services and these will be reported in detail in Report 2.

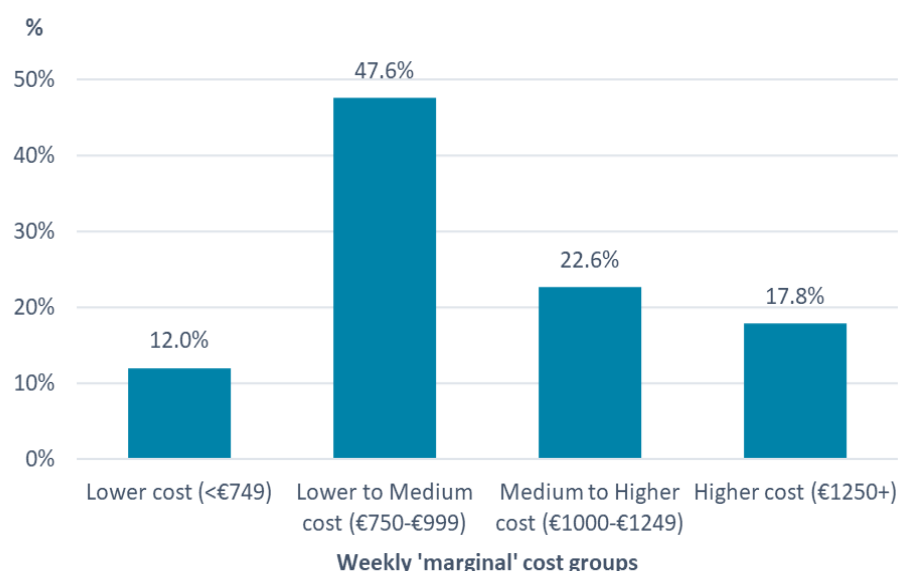
3.6.1 Costs of Standard-IHCPs

The costs of IHCPs are presented in the following sections. For each type of IHCP the weekly average cost is presented. This weekly average cost covers hours of care provided by home care workers (who can be home helps engaged by HSE and/or home care workers provided by approved private providers) provided under the IHCP. Other costs, including visits by PHNs and Allied Health Professionals and the costs of aids and appliances are not included in this average cost. The weekly average costs therefore refer to the home care costs generated by the IHCP only.

The costs of standard-IHCPs varies in each case depending on need and availability of services. The average weekly cost of a standard IHCP at the end of December 2017 was €1,024. The average weekly cost ranges from €399 to €3,500 with a median cost of €936. In order to assess the effect of outliers on the average weekly cost, a 1% trimmed mean was computed. This removes the top and bottom 1% of cases (i.e. the outliers). The trimmed mean was virtually the same at €1,012, €12 less than the full mean.

Figure 10 shows the distribution of standard-IHCPs according to four cost categories. It shows that just under half of the standard-IHCPs fall within the lower to medium average cost category of between €750 and €999 per week and the majority (60%) are less than €1,000 per week.

Figure 10: Average weekly cost of standard-IHCPs to end December 2017



3.6.2 Cost of Disability-IHCPs

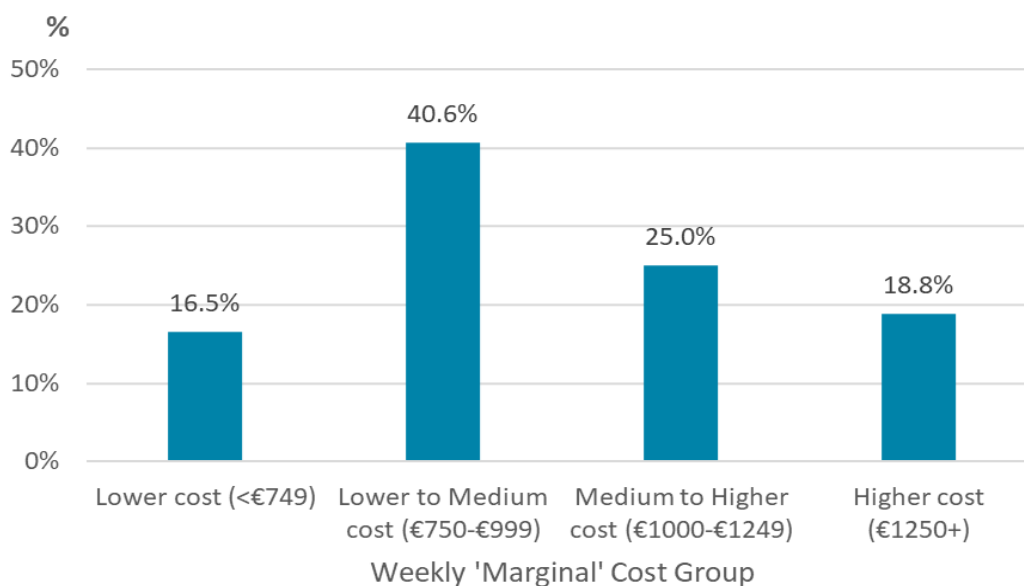
Table 3 shows the resource use for the 32 Disability-IHCPs. There was a lot of variation in the duration of Disability-IHCPs with the shortest lasting one week and the longest lasting 160 weeks (i.e. over three years) and more than 90% lasting one year or more. The average duration of disability-IHCPs to the end of December 2017 was 94 weeks.

Table 3: Resource use (hours per week) for Disability-IHCPs

Resource use	No. of Disability-IHCPs
Less than 30 hours	4
30-39 hours	8
40-49 hours	11
50-59 hours	6
60-69 hours	1
More than 70 hours	2

The average weekly cost of Disability IHCPs ranged from €559 to €3,500, with an average weekly cost of €1,137 (see Figure 11).

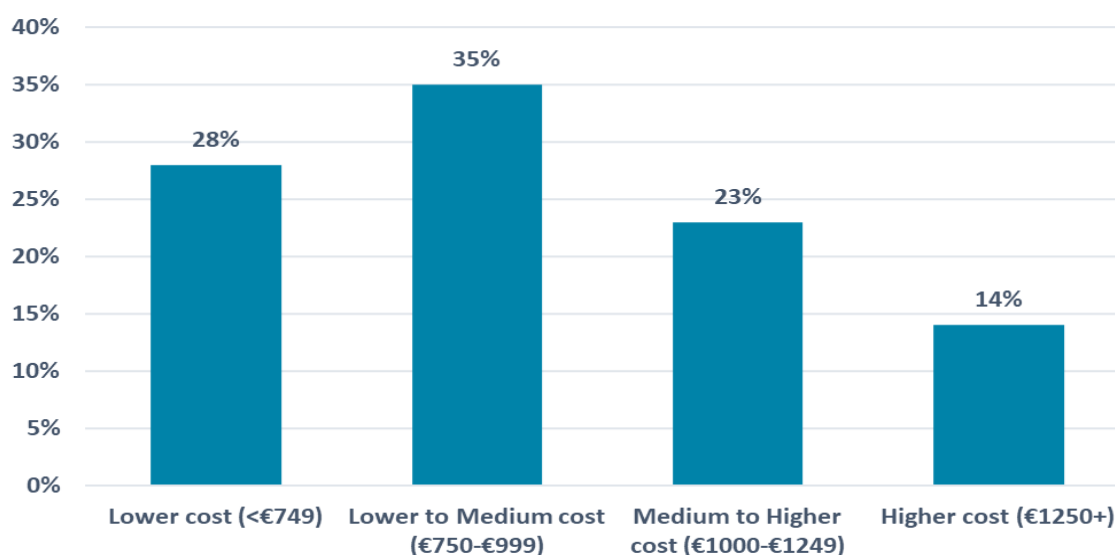
Figure 11: Average weekly cost of Disability-IHCPs to end December 2017



3.6.3 Costs of dementia-IHCPs

The costs of dementia-IHCPs were quite varied, with the average weekly cost ranging from €147 to €1,829. The mean weekly cost of a dementia-IHCP was €925. The average weekly cost of dementia-IHCPs is €99 lower than that of standard-IHCPs, which had a mean weekly cost of €1,024. The trimmed mean weekly cost of a dementia-IHCP (i.e. excluding the most extreme costs) was €917.

Figure 12 shows the distribution of dementia-IHCPs according to four cost groupings. It shows that the highest proportion of dementia IHCPs fall in the low to medium cost category of between €750 and €999 per week (35%) and overall, the majority (63%) are less than €1,000 per week. That means, however, that one third of dementia IHCPs were above €1,000 per week and that is before any account is taken of informal care provision.

Figure 12: Average weekly cost of dementia IHCPs to end December 2017

3.7 Detailed statistical analysis

A series of regression analyses were carried out in order to examine the following relationships:

- ➔ Hours of care per week received before the implementation of IHCP for standard IHCPs and dementia-IHCPs.
- ➔ Hours per week received following the introduction of IHCP for standard IHCPs and dementia-IHCPs.
- ➔ Average weekly cost of IHCP for standard IHCPs and dementia-IHCPs.
- ➔ Total costs (over duration of IHCP) for standard IHCPs and dementia-IHCPs.

The covariates available to us from the data are: living alone; gender; age at approval; marital status; referral setting; informal caregiving; and Barthel Index dependency. Of major interest to policy-makers are causal relationships that explain differences in

provision and costs between standard IHCPs and Dementia IHCPs. Standard regression methods assume the relationship between the outcome of interest and the covariates is linear, but this is not necessarily the case. A more robust comparison can be made by comparing recipients of dementia-IHCPs to recipients of standard-IHCPs with similar characteristics. One way to achieve this is to re-weight the recipients of standard-IHCPs, giving more weight to those recipients that are more similar in characteristics to the dementia-IHCP recipients. After re-weighting, the two groups will be very similar in terms of their covariates. Any remaining difference in outcomes is thus more plausibly attributable to receiving a dementia-IHCP rather than a standard-IHCP. This difference can be estimated using a weighted multiple regression analysis and interpreted as the average difference between a dementia IHCP recipient and a similar standard-IHCP recipient.

Since standard IHCPs tended to be of longer duration, we ran a further weighted analysis that accounted for differences in the duration of IHCPs, in which case the estimate can be interpreted as the average difference between a dementia-IHCP recipient and a similar standard-IHCP recipient in receipt of the IHCP for the same length of time.

3.7.1 Key regression results

The main regression results are as follows:

Relationship between hours of care per week received before the introduction of IHCP and Barthel dependency.

An examination of the relationship between hours of care per week received before the introduction of IHCPs and dependency for recipients of dementia-IHCPs and similar reweighted recipients of standard IHCPs showed that those who were classified as being independent (score of 20) on the Barthel index received significantly fewer formal hours of care per week before the award of the IHCP (9 fewer hours per week, $p < 0.01$) compared to individuals with a high/maximum dependency on the Barthel Index, controlling for the covariates described above.

Weekly hours of care for standard-IHCPs and dementia-IHCPs

An examination of the relationship between hours per week received as part of IHCP for recipients of dementia-IHCPs and similar recipients of standard IHCPs showed that individuals with dementia received significantly fewer hours per week (6.44 fewer hours, $p < 0.05$) than individuals without dementia, controlling for the covariates described above.

Average weekly cost of care for standard IHCPs and dementia-IHCPs

Related to this finding, as hours of care are related to cost, an analysis of the average weekly IHCP cost for recipients of dementia-IHCPs and similar recipients of standard IHCPs showed that individuals with dementia have an average weekly cost of €130.78 ($p < 0.01$) lower than individuals without dementia.

Informal care provision and formal care costs

Where carers provided 8-12 hours of care daily, IHCPs had an average weekly cost of €235.70 ($p < 0.01$) more than individuals whose carers provided >12 hours of care daily, controlling for the covariates. This means that where less informal care was available/provided, more formal IHCP hours were provided leading to higher costs.

For recipients whose carers provided 0-8 hours of care daily, the average weekly cost of the IHCP was €80.89 higher ($p < 0.05$) than for individuals whose carers provided >12 hours of care daily, controlling for the covariates. However, this group had lower average weekly costs, i.e. received less formal care, than recipients who received between 8-12 hours of informal care per day.

Costs and dependency

Not surprisingly, the analysis of dependency and its relationship to cost showed that reweighted IHCP recipients who have a low/medium dependency on the Barthel Index have a significantly lower average weekly cost (€82.24 lower, $p < 0.05$) than individuals who have a high/maximum dependency on the Barthel Index, controlling for the covariates.

3.8 Duration of Standard-IHCPs and dementia-IHCPs

The duration of both standard and dementia IHCPs varied greatly between recipients, with both groups having a range of one week to roughly three years in duration. We need to remember that this dataset was dynamic, that is, IHCPs started and finished at any point within the three year period of interest. A total of 148 dementia-IHCPs and 80 standard-IHCPs were still active when data collection ceased. In order for their duration to be calculated they were given an end point of 31.12.2017. More standard-IHCPs commenced earlier in the three year study period which means that on a straightforward comparison, the average duration of standard-IHCPs is longer than that for dementia-IHCPs.

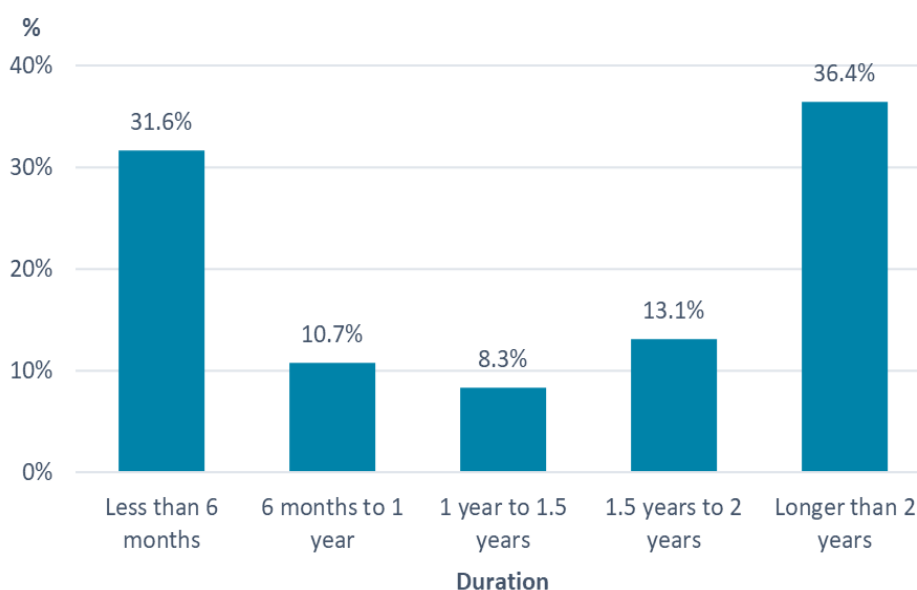
As well as the overall duration, of particular interest is the length of time on a package for those recipients who entered long-term care (LTC). For standard IHCPs, the average time of the package before entry to LTC

was 45 weeks (range 1-164 weeks) and for dementia-IHCPs was 36 weeks (range 1-128 weeks). For standard IHCPs, the average time of the package before death was 35 weeks (range 1-118 weeks) and for dementia-IHCPs was 36 weeks (range 1-146 weeks). Thus, IHCPs supported recipients to remain at home for an average of 9 months or more before entry to LTC. Thus, IHCPs supported recipients to remain at home for an average of 9 months or more before entry to LTC and for an average of at least 9 months before passing away.

Considering the overall packages, regardless of their end point, how long did they last? These findings are presented in figures 13 and 14 below.

The shortest standard IHCP to the end of December 2017 had lasted for one week while the longest package had been active for 154 weeks (i.e. almost three years). The mean duration of a standard IHCP over the course of the study was 68 weeks. Figure 13 shows that almost 60% of Standard IHCPs lasted for one year or more.

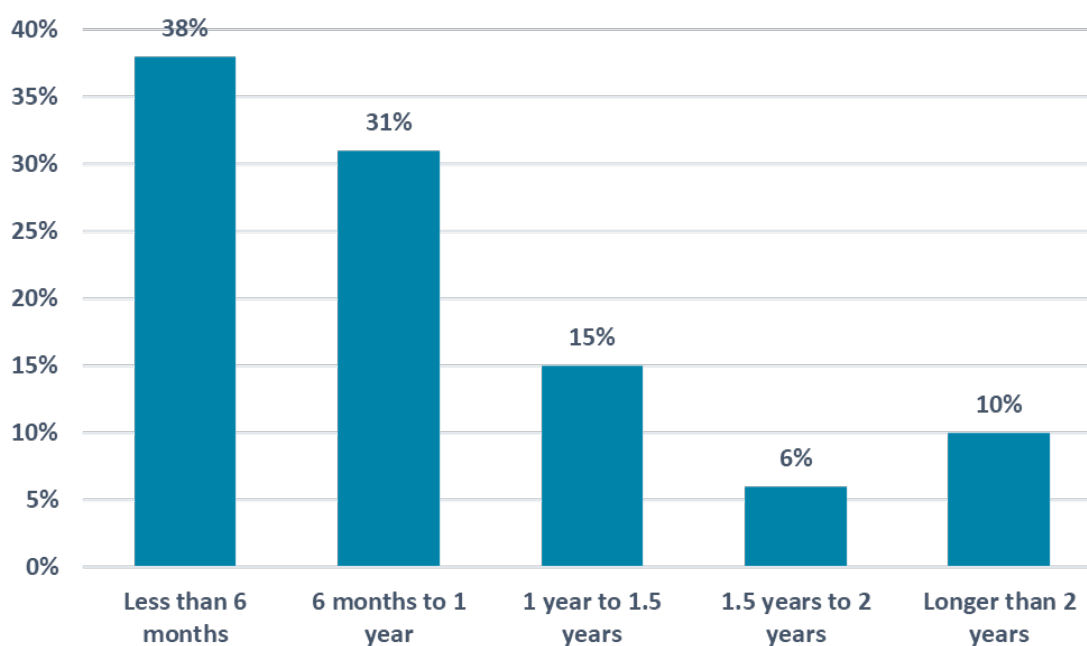
Figure 13: Duration of standard IHCPs to end December 2017



Similarly to the Standard-IHCPs, the shortest dementia-IHCP to the end of December 2017 had lasted for one week. In contrast, however, the longest dementia-IHCP had been active for 164 weeks (i.e. over three years) to the end of December 2017. The mean duration of a dementia-IHCP to the

end of December 2017 was 44.4 weeks, lower than the average duration of 68 weeks for a standard-IHCP. Figure 14 shows that nearly one-third of dementia-IHCPs lasted for one year or more. The reasons for cessation of IHCPs are presented in Figure 6a.

Figure 14: Duration of dementia IHCPs to end December 2017



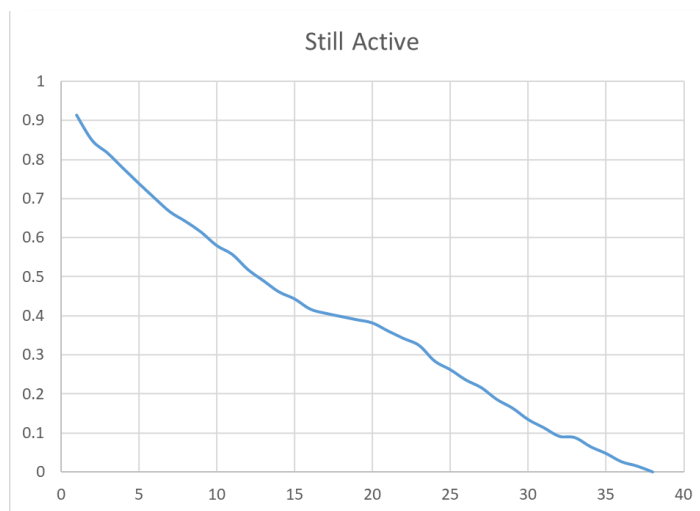
A key question for this evaluation and an important question for policy makers is how long older dependent people remain on IHCPs once they have started? The proportion of IHCP packages likely to be active in the future for a given population are shown in Figure 15 and Table 4 below. These estimates are based on a reweighting of the current dataset and show what could be expected from the roll-out of an intensive home care package programme for any number of older people in the future with similar characteristics to this cohort. For

example, after 12 months one can expect that about half of all packages (52%) will be active. The proportion of IHCP packages likely to be active after 24 months falls to almost a quarter (28%) and continues to fall to close to zero after 36 months. The decline in the proportion of people on IHCP packages over time is to be expected – people enter long-stay care or people die at home. What is reassuring is that IHCPs keep people at home for significant periods of time, as shown by the estimate that more than half of all recipients are likely to be on a package one year after it commences.

Table 4: Estimated proportion of active IHCPs by single month

Month	Estimated proportion of active IHCPs over time %
1	0.91
2	0.85
3	0.82
4	0.78
5	0.74
6	0.70
7	0.67
8	0.64
9	0.61
10	0.58
11	0.56
12	0.52
13	0.49
14	0.46
15	0.44
16	0.42
17	0.41
18	0.40
19	0.39
20	0.38
21	0.36
22	0.34
23	0.32
24	0.28
25	0.26
26	0.24
27	0.22
28	0.19
29	0.16
30	0.13
31	0.11
32	0.09
33	0.09
34	0.06
35	0.05
36	0.03

Figure 15: Estimated monthly proportion of packages active over three year period



3.9 Balance of Care: Cost Comparisons

As well as being beneficial in themselves to the recipients and their families, IHCPs are potentially an alternative to an acute hospital bed or to nursing home placement. These two options were used as comparators in order to benchmark the costs of the IHCP initiative.

Residential care 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 (HSE, 2018). Given the variation in nursing home costs across the country and in public or private settings, three costs were calculated: the average cost of public long-stay care nationally (€1,526), the average cost of private nursing home care in the Dublin area (€1,149), and the average costs of private nursing home care in the rest of the country (€909).

Acute care costs: In order to estimate the potential cost associated with acute care, the average cost of an acute hospital bed was obtained from HIPE (Health Care Pricing Office, 2017), which was €856 per night or €5,992 per week.

As noted above, the costs of both standard and dementia-IHCPs were quite varied; the average weekly cost of dementia-IHCPs ranged from €147 to €1,829, with a mean weekly cost of €925. Almost two-thirds of dementia-IHCPs (63%) had an average weekly cost of less than €999. This is very close to the average weekly cost of residential care. Thus, most dementia IHCPs were at least no more costly than residential care and all were significantly less costly than acute care.

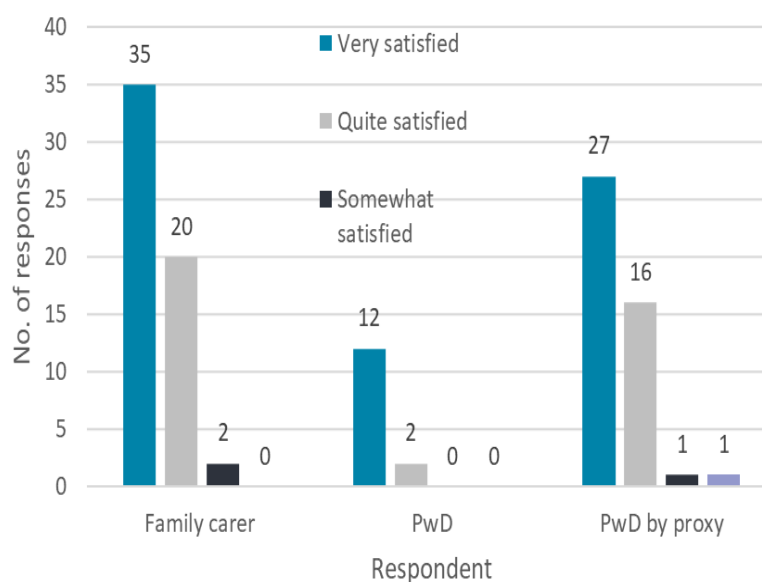
The average weekly cost of a standard IHCP was €1,024 and ranged from €399 to €3,500 with a median cost of €936. Sixty per cent of standard IHCPs had an average weekly cost of less than €999 per week. Although the average cost of standard IHCPs at €1,024 was slightly higher than the average weekly cost of residential care, most standard IHCPs cost approximately the same as residential

care and all, even the most expensive, were significantly less costly than acute care.

3.10 Satisfaction and Outcomes

As well as cost, the impact on the person and the carer is of central interest. The review questionnaires were used to gather information on the satisfaction of persons with dementia and family carer's with IHCPs and outcomes for them relating to the domains of individualised, effective, accessible, safe and sustainable. Review questionnaires for a total of 62 people with dementia were completed and returned, i.e. for 21% of people receiving a dementia-IHCP. Responses from people with dementia, family carers and the person with dementia by proxy (where the carer responds on behalf of the person) are shown in Figs 16 to 18. The figures show that, in the main, people supported by a dementia-IHCP were 'satisfied' or 'very satisfied' with the IHCP they are receiving. Most family carers and people with dementia reported that the person with dementia had enough or more than enough input into the design of the IHCP.

Figure 16: Satisfaction of people with dementia and family carers with dementia-IHCP



The majority (71%) responded that the packages were put in place either very quickly or with a little delay. Most carers (87%) felt that the person with dementia supported by the package was safe, and most respondents with dementia also felt safe. However, the

responses to a question relating to whether or not the package meets the person with dementia's needs showed that 29% of carers responded 'did not meet needs' or 'not very well'.

Figure 17: Input of person with dementia and family carer into the design of dementia-IHCP

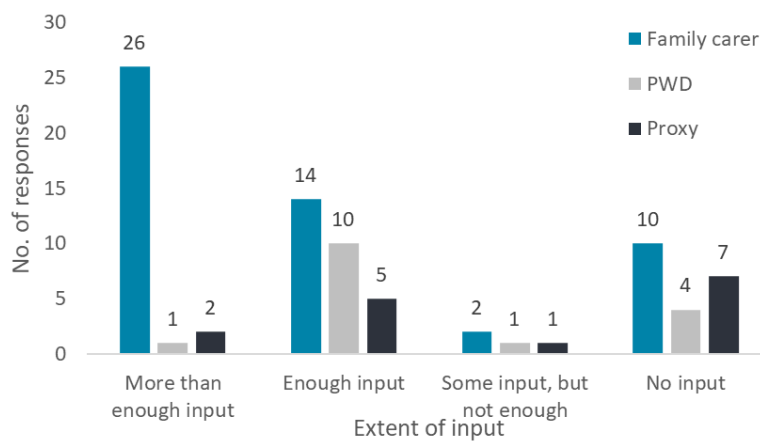
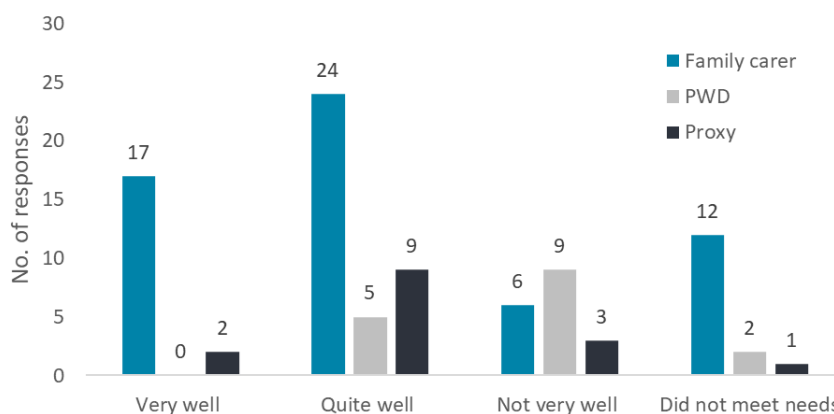


Figure 18: Dementia-IHCP meets the needs of person with dementia



The review questionnaire included an open-ended question, which gave the respondents an opportunity to comment briefly on anything else they would like to say about the IHCP. Of the 62 review questionnaires completed, 38 had comments; six from the person with dementia and 32 from the family carer. The comments from people with dementia were all positive, for example:

'It means being able to get out more and enjoy things I like'

'I would not be able to survive and function without the IHCP and my family would have to give up work to care for me'

'Very happy to have got it'

'It is a great support to have and the carers are wonderful'

The themes from the family carer comments and the frequency of each theme are shown in Table 5. The total frequency in Table 4 is greater than the total number of comments as some comments covered two themes. Most of the comments related to how the family could not keep the person at home without the package. There were several positive comments relating to satisfaction

with the IHCP and appreciation for having received it. There were also 11 negative comments about the private homecare provider agencies, mostly relating to a negative experience in general with the private home care agency and that the quality and lack of continuity of carers was unsatisfactory and needed to be addressed.

Table 5: Frequency of themes from family carer review questionnaire comments

Themes from family carer comments	Frequency	Sample comments
Inability to manage and keep person at home without the IHCP	9	<i>'The IHCP is essential to me to allow our family to care for our loved one at home'</i>
Satisfied with care provided and with care staff	7	<i>'I wish to thank all involved in the package for my husband. He and I are so happy with carer's- it has made us both so happy- thank you very much'</i>
Issues with private providers		
» General issue with the private agency	3	<i>'Happy with care provided but not happy with management of [private provider]. Communication and organization with management is lacking. Not informing family about roster changes causes family a lot of stress'</i> <i>'Not satisfied with the level of communication and skills of the contract care carers'</i>
» Continuity of carers	3	
» Management (lack of communication)	2	
» Roster and time changes	2	
» Lack of communication and skills among staff	1	
Need for more hours and support (more hours at night suggested)	4	
Appreciation for receiving the IHCP	4	
Concerns around funding for IHCPs	2	<i>'Due to financial constraints and manpower issues we were worried that it would stop and we would not be able to keep Dad at home'</i>
Quality of life of the PwD improved (do things they enjoy for example)	1	
Dissatisfaction with IHCP (due to package being postponed after it was active for a year)	1	

The responses to the questionnaire and the comments provide an insight into how much the support received is valued and what a difference it can make to the person and family. The in-depth study of 43 recipients

of dementia-IHCPs provided an opportunity to explore in much greater depth, the impact of the package on the person and the family and any other issues relating to the IHCPs. This quantitative and qualitative data will be covered in Report 2.

4. Discussion

The IHCP initiative has been successful in several ways. At a minimum, it has demonstrated the feasibility of caring for older people with complex needs at home, including people with dementia, if the necessary supports are put in place. It has also been used for enabling some younger people with disabilities to be cared for at home. When IHCPs were first initiated, it was not known for how long it might be possible to support people with complex needs at home, particularly following discharge from acute care. We now know that it is possible for people with complex needs to remain at home for significant periods of time. A reweighting of the dataset showed what could be expected from the roll-out of an intensive home care package programme for any number of older people in the future with similar characteristics to this cohort. For example, after 12 months it can be expected that about half of all packages (52%) will be active. The proportion of IHCP packages likely to be active after 24 months falls to almost a quarter (28%) and continues to fall to close to zero after 36 months. This demonstrates that IHCPs can keep people at home for significant periods of time. To our knowledge this is the first time that data such as this has been available in an Irish context. This data allows for the planning of service provision for cohorts with this level of need, considering both length of time and costs, to a level not possible heretofore.

4.1 Costs and effectiveness

The provision of IHCPs for older people with complex needs has been effective in a variety of circumstances; in urban and

rural settings; where the person has been discharged from an acute hospital, NRH or community hospital; where the person was at home but was at risk of entering long term care (LTC); for people with maximum and high dependency levels; for people with little or no family or informal care; and for people who were at the end of life. The cost of IHCPs is, on average, considerably higher than other forms of home care. However, the cost of these packages needs to be considered in the context of a continuum of care (this being one part - the higher end) and alternative ways and timeliness of intervening (for example, earlier in the trajectory of care). Both of these issues are considered in more detail below. While the average cost of IHCPs was high, the economic analysis has demonstrated that this approach costs substantially less than acute hospital care and is less costly for many, but not all, when compared to nursing home care. There are no arguments for keeping older people including those with dementia in acute beds if their acute care needs have been addressed and they can be safely looked after at home with a carefully designed IHCP.

The comparison with residential care alternatives is both interesting and complex. The average exchequer cost of weekly IHCPs are broadly equivalent to weekly residential care costs across the country. While it is important to point out that the cost calculation for care at home does not include family care costs, which have been shown to be significant for people on the boundary of residential care (O'Shea and Monaghan, 2016), keeping people at home is a viable financial alternative to nursing home care. Given the fact that people prefer to live at home rather than in residential care, IHCPs

have achieved this objective for the majority of people at no extra cost to the exchequer. There are some people who need more intensive home care than others to remain living in their own homes, requiring significant additional resources that lead the cost of the IHCP exceeding residential care alternatives. The cost benefit calculation for these people requires careful consideration. It may be that the additional costs generated are the price to be paid to meet the stated government policy objective of keeping people living at home for as long as possible and practicable. It may also be that additional costs are offset by the additional benefits of living at home compared to admission to nursing home care. For some people, however, keeping people living in their own homes may simply be too expensive relative to admission to nursing home care, with no additional benefits accruing to home care placement. In such cases, where costs are higher and benefits are no greater and maybe worse than residential care alternatives, IHCPs should be discontinued.

4.2 Personalisation

The aim of the IHCP initiative, to provide more personalised care, was only partially achieved. The content of the packages was additional home care hours, which were usually focused on personal care tasks. These hours are expensive and, in some cases, alternative supports may be more appropriate and lead to better outcomes. Personalisation of home care services is relevant to all IHCP recipients. However, most of what we now know about personalisation of IHCPs comes from dementia-IHCPs. Based on responses to the review questionnaire, there is some evidence of the involvement of the family

carer and, to a lesser extent, the person with dementia, in the formulation of dementia-IHCPs but about 17% of this subgroup reported little or no input into the design of the IHCP. However, interviews with staff revealed a strong appetite for and interest in providing a more personalised approach to care. However, a more systematic approach to implementation is required to provide the training and support needed for the health professionals involved in setting up and implementing IHCPs and for the home care workers who deliver the care. Excellent examples of personalised care for people with dementia were observed in the fieldwork for the in-depth study. However, existing processes and protocols (for example, highly risk averse practices) can create real barriers to providing personalised care. The personalisation of IHCPs is covered in much greater detail in Report 2 (Keogh et al. 2018) where qualitative data from a sample of dementia-IHCPs is reported and the implementation support required for this approach is addressed in Report 3.

It could be argued that if sufficient resources are provided it is possible to keep anyone at home. What is perhaps most valuable from the initiative and the evaluation, are the insights gained into how these packages work, or don't, under what circumstances they work well and what is needed within the wider system to implement the initiative most effectively. This is a question that will be addressed more fully in Report 2 (Keogh et al. 2018) but indications from this analysis and early findings from the process evaluation are that a belief that it is possible to support a person at home, coupled with a commitment to put it in place and make it work, on the part of both the relevant people in the health

system (hospital and community) and the family, are crucial. The question of ‘what is needed to make this happen most effectively’ is the subject of the programme of capacity building work across eight sites, ongoing since November 2016, and will be addressed in Report 3.

4.3 Targeting people at risk of inappropriate placement

A strong underlying rationale for the IHCP initiative was to offer a viable option for people who could be discharged from acute hospital care but who needed a high level of support to be at home and also to offer an option for people who were living at home but who were at high risk of entering nursing home care or an inappropriate acute hospital admission. LTC placement usually comes about when a person’s care needs exceed what can be reasonably provided in the community. The challenge is to define ‘what can be reasonably provided in the community’. This judgement can depend on not just the needs of the individuals but the array of services that may, or may not, be available in their area. The understanding of reasonable provision in the community also differs culturally (Pharr et al. 2014). Balance of care studies for older people have found that it is not just personal attributes such as age and medical needs that determine LTC admission, but other factors such as money management dependency (Greiner et al. 2014) and environmental factors such as a lack of transport which results in isolation and inability to perform essential tasks such as food shopping (Hollander and Prince 2002). Cepoiu-Martin et al. 2016 reviewed 59 studies to identify predictors of LTC

placement for persons with dementia in the community and found that greater dementia severity and older age increased the risk of LTC placement and that degree of functional impairment and caregiver burden were also important factors. A full understanding of the person including their preferences, physical environment and family circumstances, is required to determine the best setting for an individual. Categorising people by age bands (e.g. under or over 65 years) or other labels can sometimes create barriers in terms of the optimal provision for a person and their unique needs and circumstances.

The IHCP initiative seems to have been successful in targeting people who were at risk of inappropriate placement, either those remaining on inappropriately in acute care or those at home but at risk of LTC, as 83% had high or maximum dependency and 30% lived alone, both of which are predictors of LTC.

4.4 Feasibility

While the IHCP initiative has demonstrated the feasibility of caring for older people with complex needs at home, the question remains as to whether it is desirable to support people at home ‘at all costs’. Costs in this sense mean not just the financial cost but the emotional and psychological cost to the family and informal carers, as well as the cost to the person when home may not be the best place for their needs. There is often a complex set of factors unique to each person and set of family circumstances that need to be balanced.

From a wider societal point of view, given the demands on home care resources, there is not a limitless amount that can be provided to support an individual at home. There has

been discussion as to the upper limit of the IHCP, at approximately €1,500 and how this amount could support several other people with lower needs. These are the decisions that are continually made in the provision of any health or social care service – what are the optimal limits for different services?

The allocation of hours within an IHCP is not an exact science. There is no precise formula that can tell you how many hours of additional formal care are needed to keep people living at home. And it is hours that ultimately determine the cost of the package. Therefore, if one is concerned about relative costs, one way to reduce the cost of IHCPs is simply to reduce the average amount of hours provided per package. For example, the cost of an IHCP could be arbitrarily set at 50% of the alternative residential care cost for the person receiving the package. Or it could be set, more generously, but still less favourably, at 75% of the residential care option. The point is that there are choices that can be made to influence resource allocation to community-based care, depending on judgements about need, equity and coverage. Setting weekly IHCP rates at some percentage of weekly nursing home costs would lead to more people receiving packages, *ceteris paribus*. However, the provision of IHCPs needs to be considered as part of a continuum of care. The timely provision of care, which responsively changes to changing need, is also important. Both of these issues are considered below. Irrespective of payment rates and coverage, expanding IHCPs will require additional funding, which will have to be new money rather than taking resources from the Nursing Home Support Scheme. People will still need nursing home beds, irrespective of the success of IHCPs in keeping people living at home for longer.

This evaluation cannot provide a definitive answer to the question of optimal funding limits for different services, although scenarios have been presented and questions to be considered have been posed. However, we now know more about what is probably the upper limit in terms of home care provision, in intensity, cost and the needs of the person. What emerged in the course of the initiative is that there wasn't a huge demand for this very high level of support – the significant demand for home care was at a lower level in terms of hours and intensity.

An important contribution of the initiative is that it has demonstrated that intensive home care is an option for some people being discharged from acute hospital, or who wish to remain at home, but it is not necessarily the desired option for every older person or their family. It does offer an opportunity for some families who wish to respect the wishes of their loved one to remain at home to be facilitated to try this. It can provide some time for the person and family to explore options outside of an immediate crisis or simply to come to terms with changing needs and the resultant need for another care setting. However, these additional potential benefits of the time provided by an IHCP were not often recognised as such and were not often used to discuss future options.

4.5 Timing

A related point is the timing of the provision of an IHCP. Interviews with both providers and families indicated that intervening at the point of hospital discharge is 'too late' – that families are burnt out and the hospital admission has highlighted the demands of the care they have been providing and

can no longer provide. This is certainly the case for some but obviously not for all, as 65% of all IHCP recipients were discharged from hospital home with the package. This points to the importance of options being available for older people and families. With appropriate support, many families are willing to care for the person at home, often for considerable periods of time (up to three years for some in this cohort) and at a high level of need. This finding has important implications for the implementation of the Capacity Review, in terms of the interdependence between hospitals and home care in the most efficient operation of both but also in terms of providing the best option for the older person and their family.

This was a dynamic initiative which changed over time in response to evolving national eligibility criteria and feedback from the implementation of the first year or so of IHCPs. The criteria for the provision of an IHCP broadened to prioritise packages which could support older people at home, particularly people with dementia. A hospital admission can mark a transition to poorer health for an older person since declines in functional and cognitive health can persist after hospital discharge (Martin and Cruz-Jentoft 2012). For people with dementia, the question of timing is even more pertinent as, once admitted to hospital, people with dementia fare worse than those without dementia, with functional and cognitive decline and also with a greater likelihood of discharge to a nursing home and higher mortality rates (Sampson et al. 2009, Manning et al. 2014, De Siun et al. 2014). Where a person with dementia has a reduced or total loss of mobility and becomes incontinent as a result of a lengthy

stay in hospital, this change can determine their pathway to discharge to a nursing home rather than home. The feedback that was coming from health professionals in the community was that there were people who could be maintained at home if significant levels of support could be provided, but that these individuals would be admitted to a nursing home or hospital imminently without more support. Intervening when the person was still at home seemed to work well and 30% of all IHCPs were for people who were at home.

The question of timing is related to cost as discussed above. For all three client groups, it may be more cost-effective and produce better outcomes to intervene earlier and provide lower levels of support that gradually increase as the person's needs increase. This was beyond the scope of this evaluation but is worth consideration for future study.

4.6 Continuum of home care

Related to the issue of the timing of provision is the concept of a continuum of care. IHCPs are an important part of that continuum, which was unavailable heretofore. The limit in terms of who could be supported at home, was determined by the upper limit of home care hours available at the time of the introduction of IHCPs, i.e. the upper limit of a home care package, typically €525 per week.

The desirable state for the provision of home care (or home support services as they are now called), is that a continuum of hours is available, from a relatively low level to the level seen in IHCPs, with no discontinuities in terms of 'packages' or budgets. The assessment process for the allocation of hours would be a simple unified process and

the funding similarly would be from a single budget. Criteria would be transparent and provision would be clearly related to need. In order to work effectively, both the recipients and those allocating the hours need to have confidence in the system – in particular, that changing needs will be responded to. Work under way within the HSE on the implementation of the Single Assessment Tool and the harmonisation of budgets for home help and HCPs are very welcome moves in the right direction. The new home care scheme being developed by the DoH could provide a legislative underpinning for an effective continuum of care. However, there is also potential to undermine this approach through eligibility rules which create discontinuities and unintended gaps between different schemes (for example home care and NHSS).

The lower threshold can be set depending on the resource available, i.e. one way of rationing the resource if it is insufficient is to restrict the availability to those with higher needs. However, it is essential that the consequences of this are recognised in potentially higher costs, where people on the boundary of care cannot access home care and end up in more expensive settings as a consequence (Tucker et al. 2016).

In terms of discharge from hospital the requirement for home care may need to be at the level of IHCPs for some, but not for all. It should address the need – with this need not just being defined by professionals but by the person and family. As the initiative was rolled out, limits were changed in response to what was being learned. The adjustment of the lower limit in particular, meant that IHCPs could potentially be provided more cost effectively, as people who needed lower levels of care were eligible for packages.

4.7 Carers

There are 168 hours in the week. Even if 30 hours of state-funded care are provided and allowing for six hours unbroken sleep per night (which may not be the case), families are still providing almost 100 hours of supervision and care per week, either directly themselves or using a combination of their hours and funding private home care hours. The importance of family carers to the overall health and social care system in Ireland cannot be underestimated. The majority of carers are willing to provide care for the older person or person with dementia or a disability, but they are not able to do this alone. Many are paying for care out of their own means, but there are limits on this as well. The availability of flexible, responsive and reliable support is key for family carers. The different eligibility criteria for home care and nursing home care can create gaps and unintended consequences in terms of where care is provided and where costs fall. This can influence care choices in ways that may not necessarily lead to the best outcomes for the person. Great care will be required in the creation of the eligibility criteria for the new home care scheme to avoid these potential pitfalls. Greater detail on the experience of family carers is provided in Report 2.

4.8 Standardisation and equity

The HSE is conscious of differences in level of service practices around the country and so there is a strong emphasis on trying to standardise service provision and practice. It is recognised that this is important for reasons of equity, so that individuals have the same opportunity to access services when necessary. The way in which standardisation

has been approached is through the standardisation of process (e.g. SOP) and the communication of this from the centre to local management. However, there are several very significant challenges in trying to standardise provision nationally. In spite of many years of effort, management structures and many elements of service vary nationally. This is a wider HSE issue and not unique to older persons' services. This system issue is overlaid on environmental differences such as transport links, geography, local cultural issues and so on. In this context, attempting to achieve standardisation through a national process may not be the most effective route. An alternative approach may be to standardise the outputs and outcomes to be achieved, the governance around resource use and effective tools for resource allocation and outcome monitoring. In this way desired outcomes can be achieved and people can work locally using their resources in the best possible way to achieve these outcomes.

4.9 Implementing initiatives in a complex system

The degree of complexity within the health and social care system was very striking. The data collected on the IHCP Initiative shows that it has been and continues to be an evolving initiative, with numerous contextual factors influencing its development and delivery over the three-year timescale covered by this report. Evidence in this report shows, for example, the many initiatives underway and the complex networks within which personnel work. Complexity was not an issue specifically mentioned by many staff interviewees, but it was clear from the descriptions of the

initiative, the amount of different personnel involved, in different settings and the need to coordinate across numerous divisions and private providers, while carrying on 'the day job' and working to implement other clinical practice or organisational changes, that the capacity of staff to implement any initiative is compromised. That said, the degree of commitment and energy that staff brought to this task was also noteworthy. Carefully planned efforts were required on an ongoing basis across many levels, divisions and care settings within the HSE to progress implementation, as well as engagement with voluntary and private sector organisations, and perhaps most importantly service recipients and their families. However, implementation capacity and more specifically, implementation expertise, is an issue for the HSE as an organisation when considering the introduction of any new initiative.

Several barriers to implementation were identified. Communication within such a complex system is understandably a challenge, particularly when the initiative was evolving and changing. However, communication is recognised as an important factor for the effective implementation of any new initiative. There is evidence that effective communication within an organisation enhances the success of implementation (Greenhalgh et al. 2004). A significant challenge to implementation is the availability of home care workers. Since 2016, there has been a marked decrease in the availability of home care workers. This problem is not unique to Ireland and studies have shown that the turnover of staff in the private care sector is common due to insufficient rates of pay and low status and valuation of staff (Prince,

Prina, and Guerchet 2013). However, this is a significant practical limitation within the home care system if any scaling up of home care is envisaged in the near future. A more detailed analysis of facilitators and challenges will be presented in Report 2.

It is important to recognise the essential role in this evaluation of a common, national dataset that measured more than outputs. Datasets, and the infrastructure to support their collection and storage are generally at a very poor stage of development in the health service. This is not unique to Older Persons' Services and is recognised as a gap to be addressed (Health Information and Quality Authority 2014). The importance of shifting to a stronger focus on better outcomes for older people and that these are measured on an ongoing basis had previously been emphasised by the NESF Project Team on Care for Older People (NESF 2005). The availability of reliable data on both outputs and outcomes is essential for the future development of home care and wider services in Ireland.

4.10 Conclusion

A significant strength of the IHCP initiative was that it was delivered to a wide range of people with complex needs in a wide range of areas and circumstances. In this sense, the initiative really tested the limits of home care as an option for people with complex needs. Over 500 benefited from the initiative, many for six months or longer. This total included almost 300 people with dementia, 176 older people with complex needs and 32 people with disabilities. As part of a programme

of investment from the DoH, HSE and the Atlantic Philanthropies to support the implementation of the NDS, there was a particular focus on testing the feasibility of IHCPs for people with dementia and complex needs and learning from this implementation experience. The learning from the initiative is already changing how home care is designed and delivered so that more people can benefit. The unique insights and findings from this evaluation offer Irish evidence from real world conditions that can be used in the DoH review of home care to transform how home care is delivered into the future.

5. 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. **Family carers in this study significant amounts of care hours and many also funded private care.** While home care is a vital support, 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, and could help to minimise the need for home care, or at least its intensity, following discharge home.
7. **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.
8. **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* .
9. **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.

10. **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.

Abbreviations

ADLs:	Activities of Daily Living
ASI:	Alzheimer Society of Ireland
CHO:	Community Healthcare Organisation
CI:	Cognitive impairment
CMHN:	Community Mental Health Nurse
CSAR:	Common Summary Assessment Record
CSO:	Central Statistics Office
DML:	Dublin Mid-Leinster
DNE:	Dublin North East
DOH:	Department of Health
ED:	Emergency Department
EHRC:	Equality and Human Rights Commission
GP:	General Practitioner
HCP:	Home Care Package
HSE:	Health Service Executive
ICPOP:	Integrated Care Programme for Older People
IHCPs:	Intensive Home Care Package
LTC:	Long-term care
NCPOP:	National Clinical Programme for Older People
NDS:	National Dementia Strategy
NDSIP:	National Dementia Strategy Implementation Programme
NESF:	National Economic and Social Forum
NHSS:	Nursing home Support Scheme
NRH:	National Rehabilitation Hospital
OT:	Occupational Therapist
PHN:	Public Health Nurse
QOL:	Quality of Life
QOL-AD:	Quality of Life in Alzheimer's Disease
RUD:	Resource Utilization for Dementia
SD:	Standard Deviation
SOP:	Standard Operating Procedure
UK:	United Kingdom
WHO:	World Health Organization
ZBI:	Zarit Burden Interview

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Appendix 1: IHCP Indicators Framework

Key Performance Indicators for the monitoring of Intensive Home Care Packages (IHCPs)

Overview

- Section 1:** Provides an introduction to the context and the development process for the framework.
- Section 2:** Describes the seven domains in the framework which were used to develop the Key Performance Indicators (KPIs).
- Section 3:** Describes the data collection items and processes that will be used to collect the information to create the KPIs.

Section 1: Context and development process for Indicator framework

Context

The HSE and Atlantic Philanthropies have jointly developed a programme with the aim of improving the care and wellbeing of people with dementia by supporting a National Dementia Strategy Implementation Programme (NDSIP). This programme has several inter-related strands, one of which relates to the provision of integrated services and supports to enable people with dementia to continue to live at home and have a better quality of life. The activities relating to this outcome include the provision of Intensive Home Care Packages for people with dementia and the development, in collaboration with Genio, of performance indicators to ensure quality and to monitor progress against agreed outcomes.

Development of the framework and indicators

This document presents a framework for the monitoring and evaluation of Intensive Home Care Packages (IHCPs). This framework and indicators have been developed by a group of senior HSE managers of Older Persons services and Genio staff.

This draft document will be sent to key personnel who will be involved at different stages of the IHCP process as part of a consultation process. Feedback from this exercise will be incorporated into the final KPI framework.

The process for obtaining the information for the KPIs will be piloted in order to test the feasibility of the process and refine the questions. Feedback will be obtained and changes will be incorporated into a final version to be used to across the sites as the IHCPs are rolled out.

How the framework will be used

The outcome which is being sought through the delivery of IHCPs is that older people will receive integrated services and supports that will enable them to remain at home with a good quality of life or return from hospital to home with a good quality of life. However, the manner in which these supports are developed and delivered is important so that they are carefully tailored to each person and their unique circumstances, also known as 'individualised'.

A framework was developed to assist in measuring progress towards achieving these outcomes. This framework has seven domains as follows:

1. Individualised
2. Effective
3. Efficient
4. Equitable/Accessible
5. Safe
6. Fit for Purpose
7. Sustainable

In order to ensure the perspectives of the person and their family carers carry as much weight as the organisational concerns, the KPIs under these domains were developed to reflect the perspectives of three stakeholders: the person, the carer and the wider service provision system (i.e. the HSE). A matrix in figure 1 below maps out how these domains relate to each stakeholder.

Under each domain and for each stakeholder, a number of outcomes have been agreed and from these outcomes a set of indicators has been developed to measure the extent to which these outcomes are achieved or not.

It is envisaged that these indicators will be used to measure the quality of all IHCPs to be rolled out. As Genio has a specific role in monitoring the 500 dementia specific to be delivered under the NDSI Programme, there will be a more detailed process around these IHCPs which will be done in two ways:

1. Collection of a core indicator set on all 500 IHCPs from the providers. An audit of a random selection of cases will be conducted to ensure data quality.
2. An in-depth evaluation of a sample of circa 80 recipients of IHCPs (person and carer) to obtain more detailed qualitative information as well as other quantitative information.

Consultation with different groups will be carried out and modifications made based on feedback.

An excel spreadsheet is being piloted to test a common agreed data set across all the sites. This will form the dataset for the KPIs. The logistics of the process are being worked out so that there is no duplication and to limit the burden on those collecting the data as much as possible.

Two short Genio questionnaires are to be completed by the person in receipt of the IHCP and for the family carer after the IHCP has been in place for a short while. This will help to understand the experience of the IHCP for both and what improvements could be made.

Section 2: KPI Framework

Individualised

IHCP is designed around the needs and wishes of the person and family

- Person/family involved in planning/design of IHCP
- Relevance to person/family needs
- Responsive and flexible

Effective

IHCP delivers the best possible outcomes

- Outcomes for person
- Outcomes for family
- Outcomes for commissioner

Efficient

Resources are used to provide the most effective IHCP in the most appropriate setting

- Available resources are used to maximum effect to provide the most effective IHCP packages
- IHCPs are provided in a timely and responsive fashion

Equitable/Accessible

- Access is based on need
- Process is accessible/easy and efficient

Safe

IHCPs are provided in a safe manner

- Users are protected from harm
- Safe interventions and supports are provided

Fit for Purpose

IHCPs provided are individualised and are compliant with relevant standards

- Compliance with standards
- Provider knowledge and skill
- Support individualised approach

Sustainable

Provision of IHCPs can be maintained and scaled up.

- Financial sustainability
- Capacity and competence of IHCP providers
- Assurance for older people and family around care provision

Indicators for these domains have been developed based on the three key stakeholders in the process; the end user, i.e. the person supported by an IHCP, their family/carer and the commissioner, i.e. the HSE. Not all domains are relevant to all stakeholders and this is mapped in the table below. The KPIs describe potential indicators for these three levels of analysis; the person, the family and the HSE, as displayed below in Figure 1.

Figure 1: Matrix of KPI domains by stakeholders

Domain of Quality	Individualised	Effective	Efficient	Equitable	Safe	Appropriate	Sustainable
<i>Level of Analysis</i> Person supported by IHCP	✓	✓		✓	✓	✓	✓
<i>Level of Analysis</i> Family Carer	✓	✓		✓	✓	✓	✓
<i>Level of Analysis</i> HSE	✓	✓	✓	✓	✓	✓	✓

Section Three: Master List of all KPIs	Reference for detail
1. NO. OF PEOPLE IN RECEIPT OF AN IHCP	(1P-1)
2. % OF RECIPIENTS INVOLVED IN THE DESIGN OF IHCP AND/OR FAMILY CARERS RATING OF INVOLVEMENT OF THE PERSON SUPPORTED BY AN IHCP	(1P-2)
3. % OF RECIPIENTS WHO RATE THEIR NEEDS/WISHES AS MET BY IHCP	(1P-3)
4. % OF RECIPIENTS WHO ARE SATISFIED WITH THE IHCP PROVIDED	(1P-4)
5. % OF RECIPIENTS WHO RATE THEIR IHCP AS SUPPORTING CHOICE AND CONTROL FOR THE PERSON	(1P-5)
6. % OF FAMILY CARERS SATISFIED THAT THEIR NEEDS AND WISHES WERE ADDRESSED IN THE DESIGN OF THE IHCP	(1F-1)
7. % OF FAMILY CARERS WHO FEEL THAT THE IHCP IS TAILORED TO THE NEEDS OF THE PERSON SUPPORTED BY AN IHCP	(1F-2)
8. % OF FAMILY CARERS WHO ARE SATISFIED WITH THE IHCP PROVIDED	(1F-3)
9. % OF RECIPIENTS WHOSE IHCP WAS REVIEWED	(1O-1)
10. % OF IHCPs WITH A KEY WORKER ASSIGNED	(1O-3)
11. % OF RECIPIENTS WHO INDICATE AN INCREASE OR MAINTANCE OF QUALITY OF LIFE	(2P-1)
12. % OF FAMILY CARERS WHO RATE THE IHCP AS EFFECTIVE IN HELPING THEM TO CARE FOR THE PERSON SUPPORTED BY AN IHCP	(2F-1)
13. % OF RECIPIENTS DISCHARGED FROM ACUTE HOSPITAL TO IHCP	(2O-1)
14. % OF RECIPIENTS AT LPF WHO TOOK UP IHCP	(2O-2)
15. TIME WHICH THE PERSON SUPPORTED BY THE IHCP SPENT IN HOSPITAL PRIOR TO IHCP (IF REFERRED FROM ACUTE HOSPITAL SETTING)	(2O-3)
16. AVERAGE COST OF IHCP PER PERSON	(3O-1)
17. % OF RECIPIENTS WHO EXPRESS SATISFACTION WITH THE PROCESS OF OBTAINING AN IHCP	(4P-1)
18. % OF RECIPIENTS WHO WERE SATISFIED WITH THE WAITING TIMES IN THE PROCESS	(4P-2)
19. % OF RECIPIENTS WHO WERE SATISFIED WITH AVAILABILITY OF INFORMATION	(4P-3)
20. % OF FAMILY CARERS WHO EXPRESS SATISFACTION WITH THE PROCESS OF OBTAINING AN IHCP	(4F-1)
21. % OF FAMILY CARERS WHO WERE SATISFIED WITH THE WAITING TIMES IN THE PROCESS	(4F-2)
22. % OF FAMILY CARERS WHO WERE SATISFIED WITH INFORMATION PROVIDED	(4F-3)
23. AVERAGE WAITING TIME FOR IHCP	(4O-1)

24. GEOGRAPHICAL LOCATION OF EACH IHCP	(4O-2)
25. % OF PERSONS WITH HIGH LEVEL OF NEEDS	(4O-3)
26. % OF RECIPIENTS WHO FEEL THAT THERE IS AN APPROPRIATE LEVEL OF SAFETY PROVIDED BY THE IHCP	(5P-1)
27. % OF FAMILY CARERS WHO FEEL THAT THERE IS AN APPROPRIATE LEVEL OF SAFETY PROVIDED BY THE IHCP	(5F-1)
28. % OF SERIOUS SAFETY RELATED INCIDENTS RECORDED	(5O-1)
29. % OF RECIPIENTS WHO ARE CONFIDENT IN THE ONGOING PROVISION OF IHCPs	(7P-1)
30. % OF FAMILY CARERS WHO ARE CONFIDENT IN THE ONGOING PROVISION OF IHCPs	(7F-1)
31. % OF IHCPs ALLOCATED TO EACH AREA	(7O-1)
32. SUSTAINABILITY OF IHCPs (E.G. COST-EFFECTIVENESS, SPECIFIC BUDGET, PROVISION IN SERVICE PLACE, PLAN FOR ROLLOUT OF IHCPs, WORKFORCE PLANNING, PUBLIC INFORMATION ETC.)	(7O-2)

Figure 2: IHCPs Process - Flow Diagram

Stage 1:
Identification process

Stage 2:
Assessment process

Stage 3:
Local level application/
approval process

Stage 4:
Regional level application
/approval process

Stage 5:
Implementation process

Stage 6:
Review process

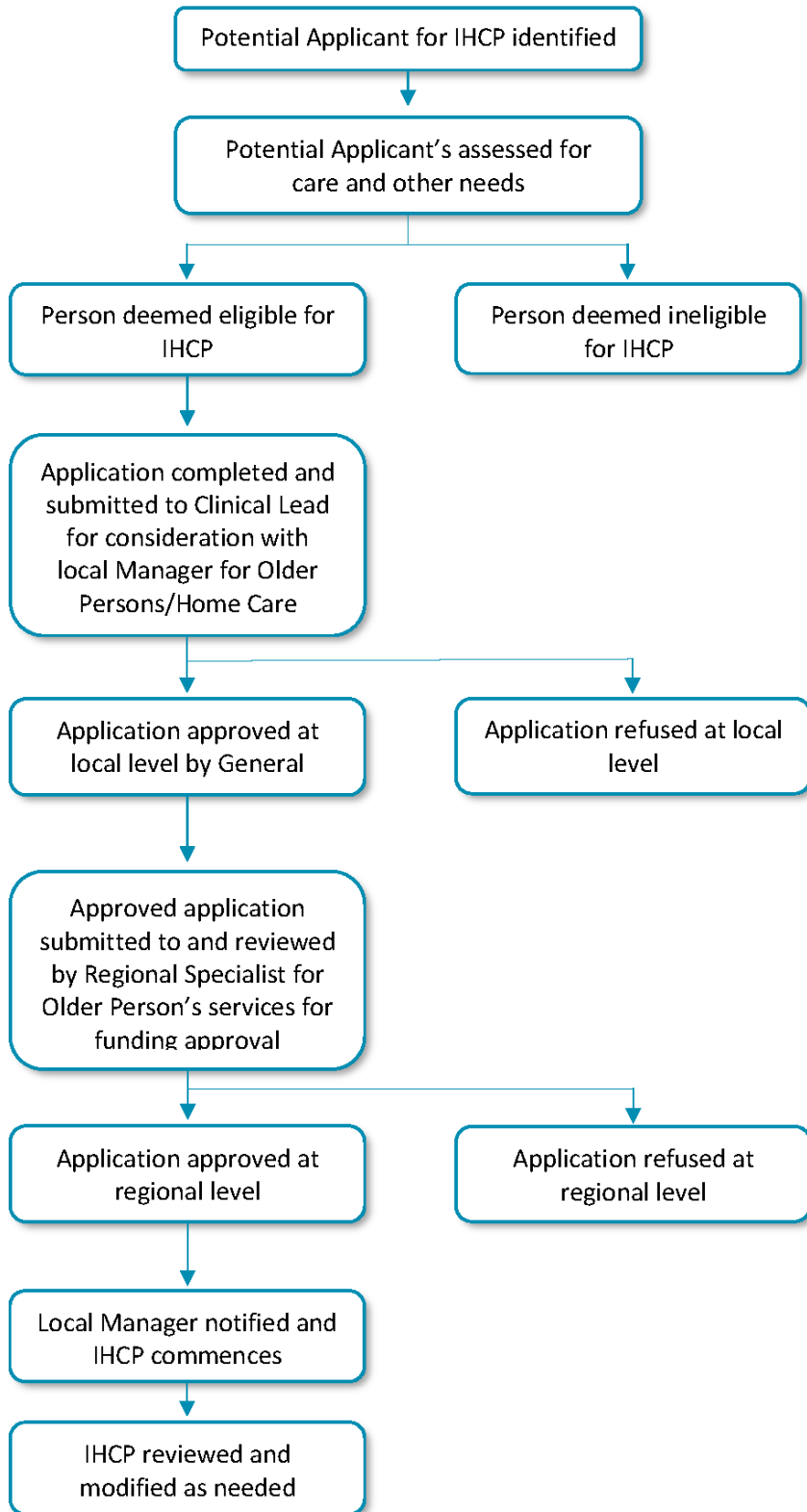


Figure 2: IHCPs Process - Flow Diagram (Continued)

ACTIVITIES

Stage 1: Identification process

- Persons likely to be in need of IHCP identified

Stage 2: Assessment process

- Assessment of need carried out by multidisciplinary (MDT) clinical team, i.e. joint hospital/community MDT or community MDT
- CSAR completed by clinicians (**Record of baseline supports, dependency level needed for KPIs**)
- Other assessments completed, as needed, and reports written
- Individualised plan of support designed around person's needs and wishes (**Recorded for KPIs**)
- Schedule of services drafted based on care plan and client input

Stage 3: Local level application/approval process

- Application compiled (i.e. HCP form, CSAR and any health professional reports, Care Plan, Schedule of Services) (**Date application signed needed for KPIs**)
- Application forwarded to local Home Care Managers/Designated Community Service Manager using existing established channels
- Care Plan/Schedule of Services reviewed by MDT
- Key worker identified and recorded
- Care Plan/Schedule of Services agreed and recommended by MDT to Clinical Lead
- Review Date agreed by Clinical Lead (**Needed for KPIs**)
- Checklist for compliance completed and signed
- General Manager reviews, signs and recommends to the Regional Specialist.
- A time limited interim IHCP may be enacted in crisis response situations whilst awaiting full approval

Stage 4: Regional level application/approval process

- Locally approved application (i.e. HCP application, CSAR and other health professional reports, Care Plan, Schedule of Services, checklist including cost calculator and quote from external provider) forwarded to Regional Specialist for review (**Regional application date needed for KPIs**)
- Specialist approves funding based on schedule of services/costs and completes approval form

Stage 5: Implementation process

- Approval form returned to the designated manager in the CHO.
- IHCP commences and Specialist notified of commencement date (**needed for KPIs**)

Stage 6: Review process

- A review of IHCP is conducted after supports have been in place (normally at about 4-6 weeks after commencement)
- IHCP modified as needs emerge within the review process
- Review reports sent to Regional Specialist for Older Person's Services
- As part of the review process, the person and their family member each completes a short questionnaire about their experience with IHCPs to date (**needed for KPIs**)

Stage 7: Cessation of IHCP

- Regional office is notified of any IHCPs that cease and the reason for cessation (**needed for KPIs**)

Appendix One: Complete list of all Key Performance Indicators for IHCP

1. DOMAIN- INDIVIDUALISED: IHCP IS DESIGNED AROUND THE NEEDS AND WISHES OF THE PERSON THAT IT SUPPORTS AND THEIR FAMILY/CARER			
Analysis Level	Outcome	KPI	Stage of Data Collection
1P. INDIVIDUAL ANALYSIS	EACH PERSON SUPPORTED BY AN IHCP HAS AN IHCP TAILORED TO THEIR NEEDS AND WISHES	1P-1. NO. OF PEOPLE IN RECEIPT OF AN IHCP.	APPROVAL STAGE
		1P-2. % OF RECIPIENTS INVOLVED IN THE DESIGN OF IHCP AND/OR FAMILY CARERS RATING OF INVOLVEMENT OF THE PERSON SUPPORTED BY THE IHCP	Q 1 AT REVIEW STAGE AND/OR Q3C IN FAMILY CARER QUESTIONNAIRE
		1P-3. % OF RECIPIENTS WHO RATE THEIR NEEDS/WISHES AS MET BY IHCP	Q 2 AT REVIEW STAGE
		1P-4. % OF IHCP RECIPIENTS WHO ARE SATISFIED WITH THE IHCP PROVIDED	Q 12 AT REVIEW STAGE
		1P-5. % OF RECIPIENTS WHO RATE THEIR IHCP AS SUPPORTING SELF-AGENCY	Q3 AT REVIEW STAGE
1F. FAMILY CARER LEVEL	IHCPs ARE TAILORED TO INCLUDE THE WISHES OF THE FAMILY/CARERS AS WELL AS THE PERSON SUPPORTED	1F-1. % OF FAMILY CARERS SATISFIED THAT THEIR NEEDS AND WISHES WERE ADDRESSED IN THE DESIGN OF THE IHCP	Q 5C AT REVIEW STAGE
		1F-2. % OF FAMILY CARERS WHO FEEL THAT THE IHCP IS TAILORED TO THE NEEDS OF THE PERSON SUPPORTED BY THE IHCP	Q2C AT REVIEW STAGE
		1F-3. % OF FAMILY CARERS WHO ARE SATISFIED WITH THE IHCP PROVIDED	Q13C AT REVIEW STAGE
1O. ORGANISATION LEVEL	IHCPs ARE TAILORED TO EACH PERSON'S NEEDS AND REFLECT THE PERSON'S WISHES AND THE WISHES OF THE FAMILIES/CARER	1O-1. % OF RECIPIENTS WHOSE IHCP WAS REVIEWED	REVIEW STAGE
		1O-2. % OF RECIPIENTS WHO WERE REVIEWED AND HAD THEIR FEEDBACK USED IN REVISED IHCP (IF REVISED)	Q7 AND Q11C AT REVIEW STAGE
		1O-3. % OF IHCPs WITH KEY WORKER ASSIGNED	APPROVAL STAGE
2: DOMAIN - EFFECTIVENESS : THE IHCP PROVIDED DELIVERS THE BEST POSSIBLE OUTCOMES			
Analysis Level	Outcome	KPI	Stage of Data Collection
2P. INDIVIDUAL LEVEL	QUALITY OF LIFE IS IMPROVED OR MAINTAINED FOR THE PERSON SUPPORTED BY THE IHCP	2P-1. % OF IHCP RECIPIENTS WHO INDICATE AN INCREASE OR MAINTAINANCE OF QUALITY OF LIFE	Q 5 & 6 AT REVIEW STAGE
DOMAIN - EFFECTIVENESS (continued)	IHCPs ARE PROVIDED THAT SUPPORT THE FAMILY/CARER TO CARE FOR THE PERSON SUPPORTED BY THE IHCP	2F-1. % FAMILY CARERS WHO RATE THE IHCP AS EFFECTIVE IN HELPING THEM TO CARE FOR THE PERSON SUPPORTED BY IT	Q6C AT REVIEW STAGE

20. ORGANISATION LEVEL	IHCP INCREASES THE AMOUNT OF TIME THE PERSON CAN REMAIN AT HOME INSTEAD OF LTC AND/OR FACILITATES THE DISCHARGE OF THE PERSON FROM HOSPITAL	20-1. % OF IHCP RECIPIENTS DISCHARGED FROM ACUTE HOSPITAL TO IHCP	ASSESSMENT STAGE
		20-2. % OF IHCP RECIPIENTS AT LPF WHO TOOK UP IHCP	ASSESSMENT STAGE
		20-3. TIME WHICH THE PERSON SUPPORTED BY THE IHCP SPENT IN HOSPITAL PRIOR TO IHCP (IF REFERRED FROM ACUTE HOSPITAL SETTING)	ASSESSMENT STAGE
3. DOMAIN - EFFECTIVE: RESOURCES ARE USED TO PROVIDE THE MOST EFFECTIVE IHCP IN THE MOST APPROPRIATE SETTING			
Analysis Level	Outcome	KPI	Stage of Data Collection
3P. INDIVIDUAL LEVEL	None at this level		
3F. FAMILY CARER LEVEL	None at this level		
3O. ORGANISATIONAL LEVEL	RESOURCES ARE USED TO PROVIDE THE MOST EFFECTIVE IHCP IN THE MOST APPROPRIATE SETTING	3O-1. COST OF IHCPs PER PERSON (TAKING INTO ACCOUNT THE EFFECTIVENESS INFORMATION)	APPROVAL STAGE/ REVIEW STAGE (IF ANY CHANGES MADE TO PACKAGE)
4. DOMAIN - EQUITABLE: ACCESS IS BASED ON NEED AND THE PROCESS IS ACCESSIBLE AND EFFICIENT			
Analysis Level	Outcome	KPI	Stage of Data Collection
4P. INDIVIDUAL LEVEL	PROCESS OF ACCESSING IHCP IS UNDERSTANDABLE AND STRAIGHTFORWARD FOR THE PERSON SUPPORTED BY IT.	4P-1. % OF RECIPIENTS WHO EXPRESS SATISFACTION WITH THE PROCESS OF OBTAINING AN IHCP	Q 8 AT REVIEW STAGE
		4P-2. % OF RECIPIENTS WHO WERE SATISFIED WITH WAITING TIMES DURING THE PROCESS	Q 9 AT REVIEW STAGE
		4P-3. % OF RECIPIENTS WHO WERE SATISFIED WITH AVAILABILITY OF INFORMATION ON THE IHCP	Q 10 AT REVIEW STAGE
4F. FAMILY CARER LEVEL	PROCESS OF ACCESSING IHCP IS UNDERSTANDABLE AND STRAIGHTFORWARD FOR THE FAMILY CARER	4F-1. % OF FAMILY CARERS WHO EXPRESS SATISFACTION WITH THE PROCESS OF OBTAINING AN IHCP	Q 9C AT REVIEW STAGE
		4F-2. % OF FAMILY CARERS WHO WERE SATISFIED WITH THE WAITING TIMES DURING THE PROCESS	Q 10C REVIEW STAGE
		4F-3. % OF FAMILY CARERS WHO WERE SATISFIED WITH INFORMATION PROVIDED ON IHCP	Q 8C AT REVIEW STAGE
Analysis Level	Outcome	KPI	Stage of Data Collection
DOMAIN - EQUITABLE (continued) 4O. ORGANISATION LEVEL	IHCPs ARE PROVIDED ON AN EQUITABLE BASIS BASED ON NEEDS OF THE PERSON SUPPORTED BY THE IHCP.	4O-1. AVERAGE WAITING TIME FOR IHCP	REVIEW STAGE
		4O-2. GEOGRAPHICAL LOCATION OF EACH IHCP	APPROVAL STAGE
		4O-3. % OF PERSONS WITH HIGH LEVEL OF NEEDS CORRELATED WITH OVERALL WAITING TIME TO IMPLEMENTATION OF IHCP	REVIEW STAGE

5. DOMAIN - SAFETY: IHCPs ARE PROVIDED IN A SAFE MANNER				
Analysis Level	Outcome	KPI	Stage of Data Collection	
5P. INDIVIDUAL LEVEL	EACH PERSON IN RECEIPT OF AN IHCP IS ACCORDED AN APPROPRIATE LEVEL OF SAFETY	5P-1. % OF RECIPIENTS WHO FEEL THAT THERE IS AN APPROPRIATE LEVEL OF SAFETY PROVIDED BY THE IHCP	Q 4 AT REVIEW STAGE	
5F. FAMILY CARER LEVEL	FAMILY/CARER FEELS THAT IHCP IS SAFE FOR THE PERSON SUPPORTED BY IT	5F-1. % OF FAMILY CARERS WHO FEEL THAT THERE IS AN APPROPRIATE LEVEL OF SAFETY PROVIDED BY THE IHCP	Q 4C AT REVIEW STAGE	
		5F-2. % OF FAMILY CARERS WHO FEEL THAT THE SAFETY CONCERNS OUTLINED AT THE DESIGN STAGE WERE ADDRESSED BY THE IHCP PROVIDED.	REVIEW STAGE	
5O. ORGANISATION LEVEL	IHCPs PROVIDED ENSURES THAT ITS USERS ARE SAFE AND THAT RISK IS MINIMISED	5O-1. % OF SERIOUS SAFETY RELATED INCIDENTS RECORDED WITHIN THE IHCPs PROVIDED	ONGOING	
		5O-2. % OF IHCPs WHICH SPECIFICALLY ADDRESS IDENTIFIED INDIVIDUALISED SAFETY ISSUES	APPROVAL STAGE	
		5O-3. % OF IHCPs WHICH HAVE SAFETY ELEMENTS REVIEWED OVER THE COURSE OF IHCP	REVIEW STAGE	
6. DOMAIN - FIT FOR PURPOSE: IHCPs PROVIDED ARE INDIVIDUALISED & COMPLIANT WITH RELEVANT STANDARDS				
Analysis Level	Outcome	KPI	Stage of Data Collection	Analysis Level
6P. INDIVIDUAL LEVEL	None at this level			
6F. FAMILY CARER LEVEL	None at this level			
6O. ORGANISATION LEVEL	IHCP ARE DELIVERED WHICH COMPLY WITH RELEVANT QUALITY STANDARDS THOSE DEVELOPING IHCPs HAVE RELEVANT SKILLS AND TRAINING	This will be collected in conjunction with the HSE		
7. DOMAIN- SUSTAINABILITY: PROVISION OF IHCPs CAN BE MAINTAINED AND SCALED UP				
Analysis Level	Outcome	KPI	Stage of Data Collection	
7P. INDIVIDUAL LEVEL	PEOPLE SUPPORTED BY THE ihcp ARE CONFIDENT THAT THE IHCP WILL BE AVAILABLE FOR AS LONG AS THEY NEED IT.	7P-1. % OF IHCP RECIPIENTS WHO ARE CONFIDENT IN THE ONGOING PROVISION OF IHCP AT THE REQUIRED LEVEL	Q 11 AT REVIEW STAGE	
7F. FAMILY CARER LEVEL	FAMILY/CARERS ARE CONFIDENT THAT THE IHCP WILL BE AVAILABLE LEVEL FOR AS LONG AS THEY NEED IT.	7F-1. % OF FAMILY CARERS WHO ARE CONFIDENT IN THE ONGOING PROVISION OF IHCPs AT THE REQUIRED LEVEL	Q 12C AT REVIEW STAGE	
7O. ORGANISATION LEVEL	IHCPs BECOME AVAILABLE TO THE TARGET GROUP IN THE EIGHT AREAS AND IN OTHER SUBSEQUENT AREAS IN A SUSTAINABLE MANNER.	7O-1. NO. OF AREAS OFFERING IHCPs.	APPROVAL	
		7O-2. % SUSTAINABILITY OF IHCPs	ONGOING	

Appendix 2: Information in IHCP workbook on Persons in receipt of IHCPs

Characteristics of IHCP recipients	Characteristics of IHCPs
Age	Duration
Sex	Reason for cessation, if relevant
Marital status	Resource use approved
Main information carer	Hours of care provided
Living arrangements	Other elements (e.g. nursing care)
Dependency level (Barthel Index ¹)	Aids and appliances
Geographical location (CHO, LHO area)	Economic costs
Referral Source (Community, Acute hospital)	Weekly costs
	Total costs

¹The Barthel Index is a simple to administer tool for assessing a person's ability to self-care and undertake activities of daily living. It is a tool that is commonly used by HSE staff conducting assessments for home care.

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