An Evaluation of the Consumer Directed Home Care Pilot Project in Community Healthcare Organisation 3.

Amanda Phelan, Alice Duggan, Gerard Fealy & Deirdre O' Donnell

ACKNOWLEDGEMENTS

The authors gratefully acknowledge the following:

- The Health Service Executive, for funding this study and for their ongoing support throughout the research process.
- Eilís Lawlor (JustEconomics) for undertaking the economic analysis of the Consumer Directed Home Care pilot project.
- All those who gave generously of their time to participate in the research, including care providers, care recipients, family carers, public health nurses, national informants and the CDHC Steering Group and Project Team. Without their participation, the study would not have been possible.

Table of contents

Figures

Tables

Glossary

Approved Home Care Provider: Any home care provider included on the HSE list of approved providers following the tender for home care services. The term approved provider is used in the report.

Formal Care: Professional care provided by the State (HSE), for-profit home care service providers or not-for-profit home care service providers. Formal care may be paid for by care recipients, family members or the State.

Health Service Executive Home Support Services: As of January 2018 HSE-funded home help services and home care packages are being amalgamated so that home care for older people will operate as a single funded service called “home support services”.

Informal Care: Unpaid care provided to care recipients by family members, friends of neighbours.

CHAPTER 1
INTRODUCTION

1.1 Background

Home care packages (HCP) were introduced in Ireland in 2006 as a way of maximising care in the community setting, with the objectives of supporting older people to live at home, supporting carers to care, reducing inappropriate admissions to acute care, facilitating timely discharge to community settings, and reducing pressures on emergency services (HSE, 2010). The HCP Scheme provided additional resources to deliver enhanced home care in addition to the traditional Home Help Service that had evolved over many years. Since 1st January 2018, home help services and the home care package scheme have been amalgamated and are now referred to as Home Support Services. Home support services are an important pillar in the health care system and the recent Sláintecare Report (Houses of the Oireachtas, 2017a) has prioritised their expansion, with an additional with €120 million allocated for the first five years of plan implementation. Yet, as noted by the Health Service Executive (HSE) Submission to the Dáil Committee on the Future of Health Care (HSE, 2017a), there is a need to focus on 'building a sustainable service model capable of meeting unmet need together with increasing demand'.

In Ireland, home care for older people is delivered in a myriad of ways, which include services organised and provided directly by HSE-employed staff, services delivered on behalf of the HSE by private (for-profit) and voluntary (not-for-profit) home care providers; informal home care delivered by family members/friends and client-funded private home care services (delivered by home care providers or by individuals employed by the client directly). There is no legislation governing home support services and the service is currently not independently regulated or inspected. The Department of Health is currently engaged in a detailed process to determine what type of home support scheme is best for Ireland. This process will consider the future design of both the funding and regulation systems for these crucial services (Healy, 2017).

For CHO 3, primary care services are delivered by 41 primary care teams in 11 networks to a population of 380,000 people in counties Limerick, Clare and North Tipperary (HSE, 2017b). Within the healthcare system, the focus of the service is to provide a continuum of care, which meets the needs of the individual person, through a person-centred, coordinated approach. Such an approach is concerned with two key issues: the ease with which a person can access and utilize different healthcare services to meet their needs, and the quality of the outcome of their journey through these services (Healy, 2017).

For person-centred coordinated care to be successful, it requires services to be scaffolded around the individual, their families and carers (Phelan *et al*., 2017). It also requires carers and care recipients acting as partners in care, strong leadership, clarity of purpose and outcomes, and a culture in which both the care recipient and the carers are empowered (Health Information & Quality Authority [HIQA], 2012; Healy, 2017). This translates to better outcomes, better experiences of care and ongoing support of staff to be enabled to deliver better care (HSE, 2016). Additionally, financial rectitude is paramount in the provision of home care; for example, the cost of HSE-funded home care for older people in Ireland is significant, currently representing an expenditure of €373 million (HSE, 2017c). In Community Healthcare Organisation (CHO) 3, for example, the 2017 service plan anticipated 1,107 home care packages for older people, with 933,000 home help hours (HSE 2017b). In the 2018 Service Plan, the targets for the Home Support Service are set out in terms of hours to be delivered and client numbers in receipt of home support (HSE, 2017d).

As the complexity and demand for publicly funded home support increase, the HSE has engaged in a multi-focused Reform Programme, which includes a number of initiatives (Healy, 2017). One of these is the Consumer Directed Home Care (CDHC) pilot programme, which aligns with care frameworks, such as the 10-Step Integrated Care Framework for Older People and the recent statement and definition of person-centred coordinated care (Phelan *et al.*, 2017).

1.2 Policy on older persons' care in Ireland

Several policy and strategy documents have been published in Ireland, with the aim of meeting the needs of an ageing population with increasingly complex care needs. However, coherence between legislation, policy and implementation is essential (Mangan, 2017). While there is an abundance of strategies and policy statements, there is a lack of accompanying innovation and action (Browne, 2017).

The *Healthy Ireland Strategic Framework for Improved Health and Wellbeing (2013-2025*) states that healthy ageing is crucial to achieving the goals of Healthy Ireland (Department of Health [DoH], 2013a). It makes specific reference to partnerships, strategies and initiatives that aim to support older people to maintain, improve or manage their physical and mental wellbeing. Among the goals of the *National Positive Ageing Strategy* (Department of Health, 2013b) is the goal 'to enable people to age with confidence, security and dignity in their own homes and communities for as long as possible' (p.21). This strategy also recognises the importance of a continuum of responsive services, which are flexible to people's changing needs and preferences as they age. The National Carer's Strategy (Department of Health, 2014) emphasises the importance of including carers in decisions relating to the person that they are caring for, as well as supporting carers to care and remain healthy themselves.

The *Assisted Decision-Making (Capacity) Act* (Government of Ireland, 2015) is pertinent to individuals who may have limited decision-making capacity due to, for example, cognitive impairment. It provides for people to be supported and mandates the expression of their will and preferences (Browne, 2017). Although this Act was not yet fully implemented at the time of writing this report, it provides a legal basis for greater autonomy and self-determination for those with reduced capacity for decision making, which may have implications for the planning and delivery of care services for population groups, such as older people. Central to this legislation is the emphasis on individual's will, preference, values and beliefs, which are fundamental components of person-centred care approaches.

Within the HSE, a multifaceted Reform Programme has been undertaken. This is consistent with a pattern observed across many European countries; the models of care for older people are being broadly reassessed and redesigned (Mazars, 2016) to reflect changing needs as demographic shifts occur. Under these reforms, there is an increasing focus on person-centred, integrated care, which means that all services work together in a well-coordinated way around a person's assessed needs. The aim of integrated care is to facilitate people's easy navigation of healthcare services and to provide quality outcomes for patients (Healy, 2017; Phelan *et al*. 2017). The HSE is developing standardised models and care pathways to support integrated care. Among these are the National Clinical Programme for Older People (NCPOP) and the Integrated Care Programme for Older People (ICPOP) (HSE, 2017e; 2017f).

The ICPOP aims to shift the delivery of care away from acute hospitals towards community-based, planned and coordinated care, through the development and implementation of integrated services and pathways for older people with complex health and social care needs. Under this programme, the HSE has developed a 10-step integrated care framework for older people. Two of these steps are person-centred care planning and service delivery and enabling older people to live well in the community. One of the actions undertaken in support of the ICPOP is the implementation of a Consumer Directed Home Care (CDHC) pilot programme in CHO 3. CDHC was trialled as a new way of enabling choice and control in care delivery, in keeping with the principles of empowerment and autonomy inherent in person-centred care. Successful person-centred, coordinated care requires a scaffolding of services around the individual, their families and carers (Phelan et *al*., 2017). It also requires a partnership approach between carers and care recipients, strong leadership, clarity of purpose and outcomes, and a culture of empowerment for carers and care recipients (HIQA, 2012; Healy, 2017).

The CDHC pilot programme is closely aligned with the integrated care framework and the principles of person-centred, coordinated care. Moreover, this care involves a systems-based approach, in which coordination and operationalisation of the CDHC needs to be aligned at the level of the HSE and the approved provider, in order to have a direct impact on the older person's care experience. This is consistent with the approach recommended by the King's Fund (2013) in its *House of Care* report (Coulter, Roberts & Dixon 2013), which places the care recipient at the centre of the commissioner-provider interface and provides the framework for collaboration of care underpinned by personalised commissioning.

By devolving decisions to care recipients and their families about the way home care is organised and provided, CDHC introduces personalisation to the way in which care is commissioned. The intention is that this will improve outcomes for clients through a process of disintermediation wherein providers and care recipients are directly linked. In addition, it should replace the previous monopsony (i.e. where there was only one principal buyer, the HSE) who purchased approximately 55 percent of their total €373 million funding from external providers in 2017. In theory, this should improve choice and competition. However, for these benefits to be realised, certain conditions would need to be in place, such as the creation of a real market with genuine choice between providers. This means that a plurality of providers is necessary to avoid creating a private sector monopoly i.e. where there are many buyers but effectively one provider. CDHC is also dependent on cohesive systems in which support, care planning and the attitude of the care provider are fundamental to its success (Cash, Moyle & O' Dwyer 2017).

1.3 Community Healthcare Organisation 3

The CDHC was piloted in older person care in CHO 3, which is composed of three local health offices (LHOs), Clare, Limerick and North Tipperary/East Limerick, and has a population of 379,327 (HSE, 2017b). CHO 3 is served by 41 primary care teams in 11 networks. There were three pilot sites for the CDHC pilot project in CHO 3, Ballynanty, North Clare and Thomond. The profile of the population in the pilot areas indicates that those aged 65 years and older accounted for between 13.6 percent and 18.7 percent of the population in their respective areas (Table 1a) and that the social profile of the population in the pilot areas comprised large populations that are categorized as disadvantaged or highly disadvantaged (Table 1b).

Table 1a Age profile of the pilot population aged 65 years and older (Health Atlas Finder, 2017)

Nationwide	**CHO 3**	**Ballynanty**	**North Clare**	**Thomond**
13.3%	14.6%	13.6%	18.7%	18%

Table 1b Level of social deprivation HP index (Health Atlas Finder, 2017)

	Nationwide	**CHO 3**	**Ballynanty**	**North Clare**	**Thomond**
Marginally above average	26.8%	27.4%	6.4%	32.2%	29.8%
Marginally below average	25.3%	27.3%	14.8%	29.9%	25.0%
Disadvantaged	15.0%	16.0%	25.7%	13.4%	12.0%
Very disadvantaged	5.8%	6.4%	28.8%	2.9%	3.8%

In one pilot area, Ballynanty, over half of the overall population (54.5%) is categorised as disadvantaged or highly disadvantaged. In all of the pilot areas, approximately one fifth or less of the population attended third-level education and in Ballynanty, less than 5 percent attended third-level education (Table 1c).

Table 1c Level of education in the pilot population (Health Atlas Finder, 2017)

	Nationwide	**CHO 3**	**Ballynanty**	**North Clare**	**Thomond**
Primary education or lower	8.1%	8.2%	20.0%	8.9%	5.2%
Third-level education	18.5%	16.3%	4.9%	19.1%	21.8%

The goals of service provision in CHO 3 are:

- To provide fair, equitable and timely access to quality, safe health services; foster a culture of honesty, transparency, compassion and accountability.
- To manage resources in a way that delivers best health outcomes, improves people’s experience of using the service and demonstrates value for money.
- To promote health and wellbeing in all activities undertaken by CHO 3.
- To engage, develop and value the workforce.

These goals are common across the four service divisions of CHO 3, namely health and wellbeing, primary care, mental health and social care. The Social Care Operational Plan

(HSE, 2017f) encompasses programmes and services for older people, including home care services. The social care ethos of CHO 3 is 'supporting our fellow citizens to live a life of their choosing to the greatest extent possible' (HSE, 2017b, p.2). Among its stated priorities are:

- Rolling out the integrated care programme (HSE, 2017b, p.47).
- Maximising the potential of older people, their families and local communities to maintain people in their own homes and communities, while delivering high quality residential care when required.
- Reforming our services to maximise the use of existing resources and developing sustainable models of service provision with positive outcomes for service users, delivering best value for money (HSE, 2017f, p. 1).

Tables 1d and 1e summarise the numbers of home care packages and home help hours, respectively, delivered in CHO 3 for the period 2011 to 2016. The tables indicate that there has been a rise in the number of home care packages and home help hours both of which have been rising since 2013. These provide the context, in terms of home care service provision for older people, in which the CDHC pilot project was implemented.

Table 1d Home Care Packages in CHO3 (2011-2016)

LHO	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**
Clare	131	134	132	126	248	287
Limerick	442	465	385	406	433	498
North Tipp/East Limerick	208	186	203	191	269	243
CHO Total	**781**	**785**	**720**	**723**	**950**	**1,028**

Table 1e Home Help Hours in CHO3 (2011-2016)

LHO	**2011**	**2012**	**2013**	**2014**	**2015**	**2016**
Clare	178,319	168,342	187,619	195,278	212,098	223,580
Limerick	390,782	380,455	364,543	387,381	387,485	389,776
North Tipp/East Limerick	323,739	320,429	308,839	312,855	349,491	347,031
CHO Total	**892,840**	**869,226**	**861,001**	**895,514**	**949,074**	**960,387**

1.4 The Consumer Directed Home Care (CDHC) Pilot Project

In examining the approach to the delivery of publicly funded (HSE funded) home supports for older people, as set out in the Social Care Division Operational Plan of 2014, the HSE concluded that a review of home support services should be undertaken. Mazars Consulting was engaged to undertake the review, which included a desktop examination of models across other jurisdictions. One of the approaches identified was the Consumer-Directed Care (CDC) approach (Mazars, 2016), which was operating in Australia. During 2014-2015, in discussions with external home care providers in the context of service delivery and evolving approaches to tendering arrangements, the HSE undertook to establish a pilot project to examine the feasibility of introducing a CDC approach, modelled for the Irish context, with effect from late 2018. CHO 3 accepted the request to undertake the pilot project, given its urban and rural demographic profile, as well as the mix of service providers in the area, which included HSE providers, not-for-profit providers, and for-profit providers. Planning commenced for the Consumer-Directed Home Care (CDHC) Pilot Project in December 2016. The project was initiated in April 2017 in CHO 3, in three pilot sites, Ballynanty, North Clare and Thomond.

The target group for the CDHC pilot project was persons aged 65 years and older. However, in exceptional circumstances other clients could be considered on a case-by-case basis. Clients had the choice whether they wish to participate in the pilot or not. Due to the unique and urgent home care requirements of end-of-life clients, the pilot was not deemed suitable for such clients.

Participation in the CDHC pilot was enabled after assessment by the Public Health Nursing Service. Referrals were accepted from any source, including healthcare professionals, members of the designated primary care teams (PCTs), the Community Intervention Team, the Discharge Coordinators from the University Hospital Limerick (UHL) group, and self-referrals from individual older people, family, or extended support network. The main sources of referral in the initial stage of the referral process were the acute setting, via the CDHC Clinical Lead (this role was assigned as a specific part of the CDHC pilot project), and Primary Care, through the public health nurse (Figure 1.1). Assessment was conducted using the Single Assessment Tool (SAT) (HSE, n.d.) in the case of the acute hospital and the Common Summary Assessment Record (CSAR) (HSE, 2009) in the case of the community.

The planning process required confirmation from the public health nurse (PHN), discharge coordinator or nursing home manager that the client/prospective care recipient was willing to be part of the CDHC, could administer their care, or otherwise has the necessary support to do so. Upon referral, clients were provided with CDHC information leaflets.

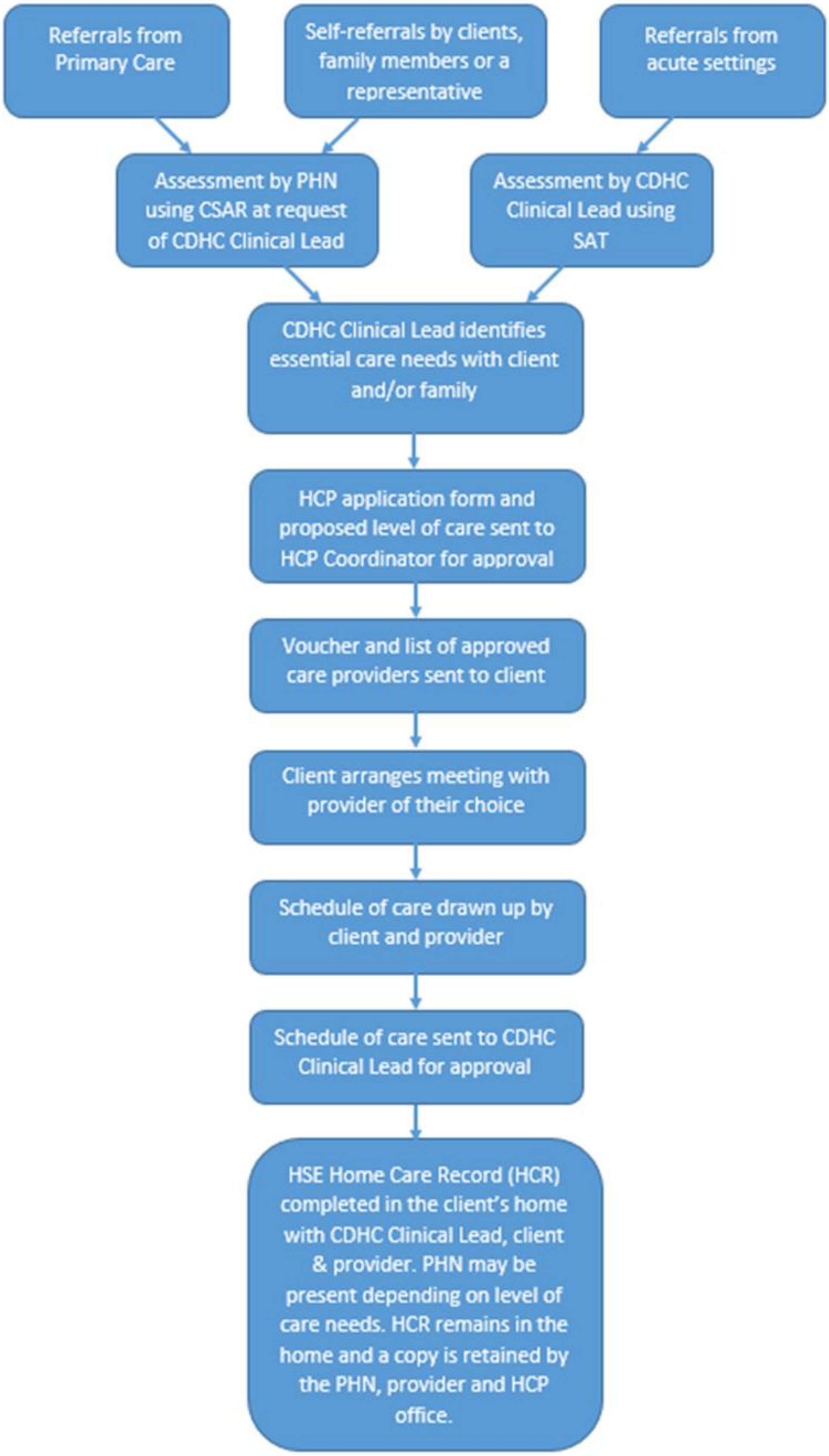


Figure 1.1 CDHC operating procedure from referral to approval of the schedule of care

During an initial home or in-hospital visit, the CDHC Clinical Lead explored with the client and/or family how they wished to arrange their care. This included how the care is best used to complement existing family and social supports. The CDHC Clinical Lead also identified any essential care needs that must be met by the HSE-funded care provided by an approved provider through the CDHC. The way in which these essential needs must be met was also specified. A care need becomes essential if the client cannot perform it unassisted, and the carer from the approved provider is the only person available to assist at a particular day or time. Once essential care needs were provided for, the non-essential tasks required by the client could then be included in a flexible manner. Following assessment, a Home Care Package Application form was sent to the Home Care Package Coordinator for approval, along with the proposed level of care (Figure 1.1). The level of care recommended was based on the client's assessed care needs and the number of hours required to support those needs.

Upon approval, the client received a HSE-funded voucher, stating the monetary value of their assessed need which could be delivered within available resources. The value of the voucher was calculated based on the client's assessed care needs as well as the times at which care was required, and the limit of the available resources for the Home Support Service. The value was calculated based on an average cost using an automated tool. The client was given a list of HSE-approved Home Care Providers, so that they could directly arrange their CDHC Provider Schedule of Care with the provider of their choice. Although the rates charged by providers differ, the times at which these rates change are standard: from 08:00 to 22:00 Monday to Saturday, the normal rate is charged, from 22:00 to 08:00 there is a night-time rate, and the third rate is for Sunday and Bank Holidays which follows the same time changes for day and night rates.

Once the client received the CDHC voucher, they then arranged to meet with their chosen care provider and agreed the CDHC Provider Schedule of Care. This Schedule demonstrated that the essential care requirements were met, and that the client's wishes were respected. However, the care planning process required that the flexibility and choice offered by the CDHC should not lead to adverse medical, physical or social risks to the client.

Once agreed and signed by both parties, the CDHC Provider Schedule of Care was then sent to the CDHC Office for review and approval by the Clinical Lead. If the Clinical Lead was not satisfied that the client's needs would be met by the proposed schedule of care, the care plan was returned to the home care provider, with an outline of the deficits in the plan.

Once amended, the CDHC Provider Schedule of Care plan was resubmitted for final approval. The CDHC service could not commence until the CDHC Clinical Lead approved the CDHC Provider Schedule of Care. Once approved, the care plan in the HSE Home Care Record was completed in the client's home with the CDHC Clinical Lead, client and provider. The PHN may be present depending on the level of care required. The Home Care Record is a folder containing the client's care plan, an attendance log for carers and contact details for the client's family, GP, etc. It remained in the client's home and a copy is retained by the PHN and Home Care Package Office.

If a client had a concern relating to the home support service, this was brought to the attention of the Home Care Provider in the first instance. Any concerns which could not be resolved between the client and the provider directly were reported to the CDHC Office. The Clinical Lead reviewed the client's care need after the first month and on a three-monthly basis thereafter to ensure that the assessed needs were appropriately supported; however, identified needs could be reviewed at any time at the request of the client, the family, a primary care team member or the home care provider, where a change in need or circumstance is identified.

Introducing and validating new programmes in the delivery of health care are essential elements of clinical governance, fiscal transparency and decisions to adapt and sustain initiatives on a national basis. Essentially, healthcare systems are tasked with proactive quality improvement of services, delivered to all clients, which are person centred, safe, effective and which result in better health and wellbeing (HIQA, 2012; HSE, 2016). This is consistent with the five key goals of CHO 3, namely, promoting health, fostering a culture for the modern era, engaging our workforce, managing resources effectively and providing fair access (HSE, 2017b).

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

According to the 2016 census in Ireland (CSO, 2017a), there were 637,567 people aged 65 years and over living in Ireland. The majority of older people live at home (94.7%), with 156,799 living alone (CSO, 2017a). People at any age may live with a disability, but age is a risk factor – 224,388 people over 65 years report a disability (CSO, 2017b). The ageing of the Irish population is projected to continue over the coming decades and with a larger proportion of older people in the population, there will be a larger care demand to meet care requirements (Wren, 2009).

Since the planned reorientation of healthcare in Ireland to primary healthcare and continuing focus on community-based care (Houses of the Oireachtas, 2017a), there is a determined emphasis on keeping people in their homes and delivering care on a localised basis. Consequently, the increasing demographic shift in ageing necessitates a concurrent examination of policy implementation, funding systems and care service provision for older people. The CDHC pilot project represents an initiative to enable older people to have more choice in care delivery and, in the absence of the availability of HSE direct services, older people can select the approved service provider and times and days of home support hours and services which best meet their and their carers' preferences.

2.1 Home care service provision in Ireland

Genet *et al*. (2012) refer to home care sectors rather than systems, as they are usually fragmented and variable. This is reflective of the inconsistencies of current home care provision in Ireland. Formal services are organised and delivered through a complex mix of public, not-for-profit and for-profit agencies, alongside a significant level of informal care delivery. In addition, there is a lack of standardisation of care services across Ireland; for example, there are different care delivery arrangements within different CHO geographic areas.

Home care or community-based care is generally favoured by older people for reasons relating to comfort and independence (Doyle & Timonen, 2008; Donnelly, O'Brien, Begley & Brennan, 2016), and has long been stated by successive governments as the priority for care of older people in Ireland. However, the current situation in Ireland reveals a disjointedness between policy and reality, as care provision is biased in favour of residential care (Hanly & Sheerin, 2017). This bias is evident in government spending; in 2014, €345 million was spent on home care services, as compared with almost €1 billion on residential care services (O'Shea, 2017a).

The prioritisation of residential care for older people is perpetuated by the inadequacies of the home care system. Hospital discharges are can be delayed due to service or resource unavailability, long waiting lists for required care and an insufficient number of home support hours. People may also be compelled to enter residential care facilities, not based on their choice, but because of lack of timely access to appropriate community and home care supports (Browne, 2017; Roe, O'Halloran & Normand, 2016). Furthermore, although a statutory scheme exists for residential care services for older people (Nursing Home Support Scheme [NHSS]/Fair Deal Scheme), there is no equivalent scheme for home care services (Healy, 2017).

2.2 Nursing Home Support Scheme (NHSS)/Fair Deal Scheme

Approximately 22,000 older people currently receive support under the NHSS (Browne, 2017). Eligibility for support under the scheme is assessed by a HSE multidisciplinary team, and the use of the Standardised Assessment Tool (SAT) (HSE, n.d) is being phased in. Residents contribute towards the cost of their long-term residential care, which is calculated according to means-test criteria outlined in legislation, and the remainder of the cost is covered by the State (Citizens' Information, 2016).

The provision of access to nursing homes for older people, regardless of their financial means, as well as the legislative basis of the NHSS, represents a distinct bias towards residential care. However, the scheme is not without its limitations. The fee negotiated by the state only provides for "bed and board" and nursing care for residents (Browne, 2017, p.6). Facilitating individuals' wishes and preferences is not prioritised in fees and there is no provision for therapies or special equipment. People must sign legally binding contracts with care providers, which may be difficult to understand, and there are no formal linkages between the Health Information and Quality Authority (HIQA) and the price negotiation system (Browne, 2017). Complex needs may not be adequately considered, and social activities are associated with additional charges, which may be unaffordable for people whose only income source is the Non-Contributory Pension. The NHSS has also been criticised for its application process, which may be burdensome for applicants, and for the administration costs associated with means-testing. Issues of equity and discrimination have also been raised; critics of the NHSS scheme question why people should be treated differently due to their age, condition or care setting, given that acute care for the general population is funded by general taxation with minimal cost sharing (O'Shea, 2017a).

Irrespective of the scheme's practical or philosophical fallibility, there is a clear financial bias towards the Fair Deal Scheme, which is indicative of the high priority given to nursing home care in Ireland (O'Shea, 2017a). There is less clarity regarding the funding decisions for home and community care services. Although these services are favoured in public debate and political rhetoric, they continue to be undermined by poor financial provision (Hanly & Sheerin, 2017).

2.3 Home support service (formerly Home Help services and Home Care Packages)

The HSE is responsible for the delivery of publicly-funded home support services for older people in Ireland, as well as for issuing tenders for contracts to private or not-for-profit providers who wish to deliver publicly-funded home supports on behalf of the HSE. As of January 2018, the HSE-delivered traditional Home Help (HH) service and the Home Care Package (HCP) scheme have been amalgamated and are now referred to as Home Support Service. Almost 50,000 people avail of these services (Healy, 2017). In addition the HSE delivers Intensive Home Care Packages (IHCP), which are separately funded.

The Home Support Service provides personal and/or essential domestic care to dependent people to support them to live at home and are intended to complement informal care. The purpose of the Home Support Service is to maximise people's ability to remain at home, through the reduction of inappropriate admissions to acute care, facilitation of timely discharge from acute hospitals, and reduced pressure on emergency departments (HSE, 2010). The Intensive Home Care Package scheme is designed to enable people with very high levels of dependency and complex needs to remain in their homes rather than entering residential care (Healy, 2017). Home Support Services and IHCPs are HSE-funded and therefore free of charge to the client under the public health system. They are important and effective in enhancing the quality of life of community-dwelling people with high levels of dependency (Browne, 2017).

However, despite the benefits of the Home Support Service for Older People, access to these services can be difficult. Community Healthcare Organisations (CHOs) of which there are 9, are allocated capped budgets for Home Supports for Older People, meaning that there can be waiting lists across the networks (O'Shea, 2017a). There is no standardised assessment process for home support in place across the system. However, the recent development and adoption of the SAT (HSE, n.d.) aims to address consistency in care needs assessments and eligibility (HSE, 2017c). The nationwide roll out of the SAT was part of the HSE National Service Plan for 2017.

The absence of any legislative foundation for home care equates to a lack of statutory entitlement and protection, leaving state-funded home care services vulnerable to cuts when public resources are constrained (O'Shea, 2017a). This affects public perceptions of risk, uncertainty and continuity of care, which may play a role in the emphasis on residential care for older people with long-term care requirements. Community-based care is considered insecure, difficult to integrate and susceptible to budgetary constraints and cuts, whereas residential care is associated with greater certainty, particularly for older adults who may have complex care needs (O'Shea, 2017a). The redress of the current prioritisation of residential care for older people in Ireland requires a significant and tangible change in the provision of home care and community supports.

The emergence of the private home care sector in Ireland is relatively recent, and it remains unregulated (Hutchinson, 2013), despite recommendations for regulation from the Law Reform Commission (Law Reform Commission, 2011). The lack of regulation raises concerns regarding accountability, quality assurance and training and skills of private home care service providers (Doyle & Timonen, 2008). It also contributes to inconsistencies in resource allocation and service delivery, and acts as a barrier to any reorientation of the service model (O'Shea, 2017a; Department of Health, 2017a; Healy, 2017; Murphy, Whelan & Normand, 2015).

2.4 Informal home care

In Ireland, and in most EU countries, informal carers provide an average of 60 percent of the total required home care (Timonen, Doyle & O'Dwyer, 2012; O'Shea, 2017a; Garms-Homolova, Naiditch, Fagerstrom *et al*., 2012). In many countries, high levels of informal care provision serve to compensate for inadequate or absent formal care services. Nevertheless, the contribution of informal carers in providing the majority of the care is essential, regardless of the level of professional care provided in a home care sector.

Depending on the valuation approach used, informal care provision in Ireland has been valued at between €2.1 and €5.5 billion (Hanly & Sheerin, 2017). However, this value is seldom fully acknowledged in policy-making, due, in part, to a tendency to emphasise paid work as more important than unpaid work.

Supports for informal carers in Ireland are mainly provided through direct income supports, which are based on different eligibility criteria. There is a means-tested carer's allowance or a newer type of social insurance benefit, which depends on employment-related eligibility criteria. For carers who may be in receipt of other social welfare payments, there is a half carer's allowance (Hanly & Sheerin, 2017). Full time carers may be eligible for the carer's support grant – formerly the respite care grant – from the Department of Social Protection, which is an annual payment of €1,700 per person being cared for. If a person employs a carer for him/herself or on behalf of a family member, they can claim the tax relief on the cost of that care (Barry, 2010). There is also a home carer's tax credit, which may be available to married couples or civil partners where one partner works in the home caring for a dependent person (Office of the Revenue Commissioner, 2017). In 2017, the Government introduced additional supports for carers in receipt of the carer's allowance, whereby they were eligible for a free General Practitioner Card and were also eligible to avail of new respite services (Department of Health, 2017b).

The legislation underpinning these supports is the *Carer's Leave Act (2001)* (Hanly & Sheerin, 2017) under which employees are entitled to unpaid leave to provide full-time care for a dependant up to a maximum of 104 weeks (Department of Employment Affairs & Social Protection, 2017). However, these supports are not reflective of the market value of the labour provided by informal carers and do not equate to payment for caring (Rodrigues, Schulmann, Schmidt, Kalavrezou & Matsaganis, 2013).

According to the 2016 census (CSO, 2017b), 195,263 Irish people identified themselves as carers. Of these, 60.5 percent were female, and 52.7 percent were between the ages of 40 and 59 years. The age group with the biggest increase in people identifying as carers was 85 years and over, whose numbers rose from 1,318 to 1,776. These figures are noteworthy, indicating as they do, that an enormous burden of care is borne by informal carers, particularly those in the older old age bracket.

As the ageing of the population continues, a reduction in the number of potential carers is predicted, due to population changes and the increased participation of women in the labour force. This will require an enhanced response from the State, in terms of the provision of home care for older people (O'Shea, 2017a). There is always a danger that activities lacking explicit quantifications and valuations are commonly ignored by policy-makers, and the State has been slow to acknowledge the need for complementarity in care provision (Hanly & Sheerin, 2017; O'Shea, 2017a). Acknowledgment of the economic value of unpaid caring is essential. For a sustainable model of care, formal care must be adequately incentivised and compensated, while also providing support to informal carers who wish to participate in the labour market. This equates to significant government investment in formal care as well as income supports for informal carers (Hanly & Sheerin, 2017).

2.5 Financing home support services in Ireland

General taxation is the primary source of finance for publicly funded (HSE funded) home support service in Ireland, through the General Fund, which is allocated to the Department of Health in the annual budget (Timonen, Doyle & O'Dwyer, 2012). Ninety-seven per cent of formal home care is publicly funded despite the mixture of public, for-profit and non-profit providers (Murphy, Whelan & Normand, 2015).

There is a growing acknowledgement of the importance of home care services for older people as part of the broader health system. This has been reflected in the prioritisation of the expansion in home care service in the recent Sláintecare Report (Houses of the Oireachtas, 2017a). The HSE 2017 National Service plan reports a €26.7 million or a 3.6 per cent increase in funding for services for older people compared with 2016. However, it was noted by the HSE Submission to the Dáil Committee on the Future of Health Care (HSE, 2017a) that sustainability must be a central focus in planning any service model, so that it will be 'capable of meeting unmet need together with increasing demand'.

In the context of increasing demand and unmet need, the dominant model of home care service provision remains fragmented and supply-driven, with primacy afforded to the needs of service providers rather than those of care recipients (O'Shea, 2017a). A reorientation of the model towards sustainable service provision will require greater integration and responsiveness to the needs of services users. In this context, it is worthwhile to consider international perspectives and approaches to home care provision.

2.6 International approaches to home care service provision

Approaches to long-term care vary widely between countries. Models differ according to the demand for care, the provision of informal and formal care and the extent to which they rely on public or private provision (Costa-Font & Zigante, 2014). The nature and level of support for informal carers is variable across countries (Table 2a). Income supports are the most common means of supporting informal care, although there is some variation as to the amount paid, duration of payment and the payment recipient. For example, Germany and Austria provide support primarily through cash benefits to carers, whereas in Scandinavia, care provision is considered the State's responsibility, so public provision of care services is more commonplace than cash benefits (Rodrigues *et al*., 2013). Almost 80 percent of

European Union countries offer statutory leave arrangements for the care of dependent relatives (Rodrigues *et al*., 2013).

Table 2a International models of care provision (Ilinca, Leichsenring & Rodrigues, 2015).

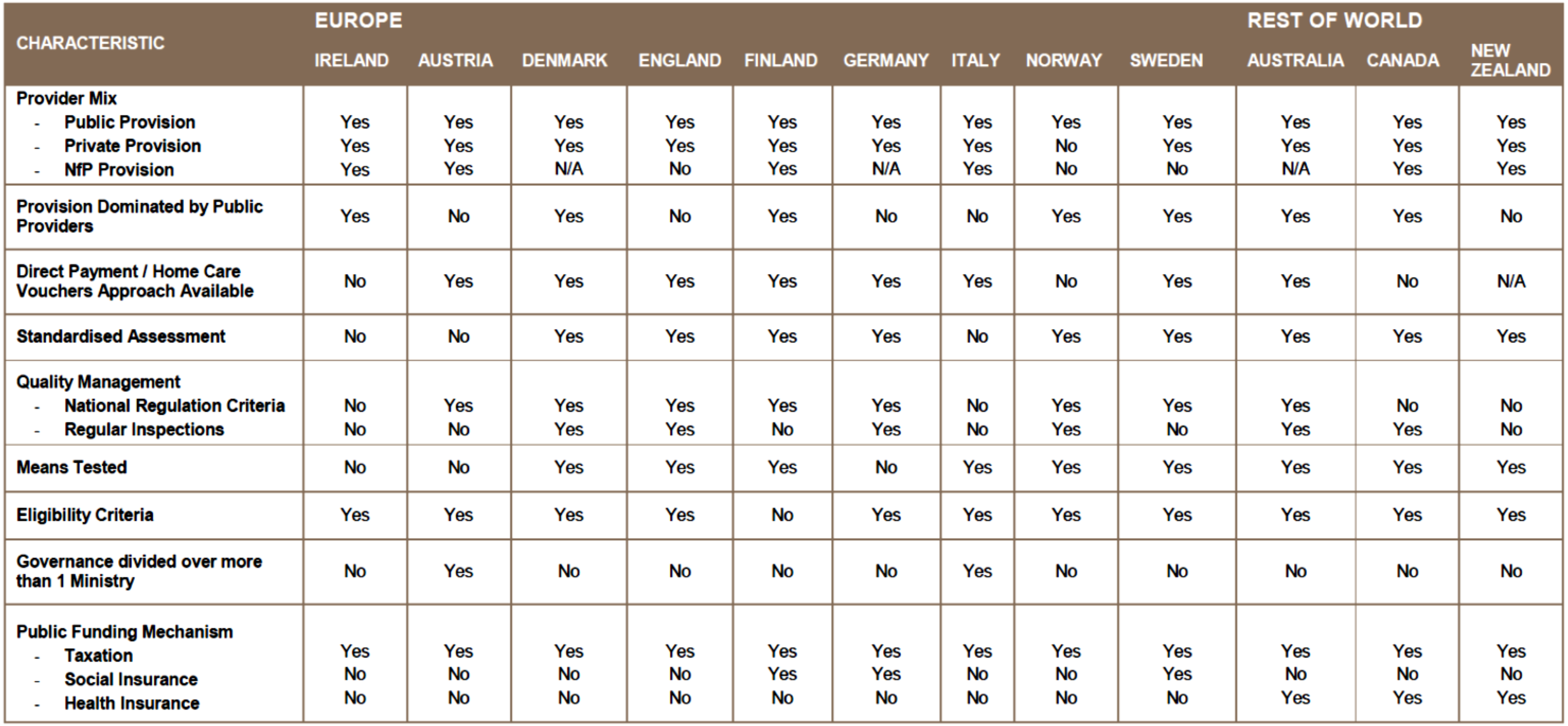
	Demand for care	Provision of informal care	Provision of formal care	Countries
Standard care mix	High	Medium/low	Medium	Germany, Austria, France, United Kingdom
Universal-Nordic	Medium	Low	High	Sweden, Denmark, Netherlands
Family-based	High	High	Low	Spain, Italy, Greece, Portugal, Ireland
Transition	Medium	High	Medium/low	Latvia, Poland, Hungary, Romania, Slovakia, Czech Republic

Governance approaches to the provision of informal care vary and are classified by Genet *et al*. (2012) as a three-part typology: ‘framework’, ‘centralized’ and ‘laissez-faire’. According to Genet *et al*.’s (2012) typology, Ireland has a ‘laissez-faire’ approach, whereby the Government has a somewhat light-touch role in home care regulation. Centralised governance involves the Government playing a major role in producing broad regulations for home care provision. Framework governance has a high level of decentralised decision-making and a national vision for home care and is the most common in Europe (Genet *et al.*, 2012).

Funding for formal homecare services usually comes from a combination of sources, including general taxation, social insurance or care insurance schemes, co-payments or private donations. The involvement of different national and local bodies in funding systems is also variable between countries. Contributions from care recipients to formal public home care services range from fixed co-payments, to means-tested co-payments, to universal services that are free of charge to all citizens. Means-tested co-payments are typical in most European countries (Genet *et al.*, 2012).

In a review of home care service provision in fifteen countries, Mazars (2016) compared the provision with those of Ireland, against nine characteristics that included the provider mix whether the service was means tested, the eligibility criteria, and the funding mechanism (Table 2b). As demonstrated in the table, Ireland lacked any standard assessment for home care and did not offer any form of personalisation approaches, nor was home care subject to regulation. In addition, the funding mechanisms through either health or social insurance differs in various countries, which has an inevitable impact on fiscal availability for service provision.

Table 2b Comparison of international models of home care service delivery (Mazars, 2016)



CHARACTERISTIC	EUROPE									REST OF WORLD		
	IRELAND	AUSTRIA	DENMARK	ENGLAND	FINLAND	GERMANY	ITALY	NORWAY	SWEDEN	AUSTRALIA	CANADA	NEW ZEALAND
Provider Mix												
- **Public Provision**	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
- **Private Provision**	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
- **NfP Provision**	Yes	Yes	N/A	No	Yes	N/A	Yes	No	No	N/A	Yes	Yes
Provision Dominated by Public Providers	Yes	No	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	No
Direct Payment / Home Care Vouchers Approach Available	No	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	N/A
Standardised Assessment	No	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Quality Management												
- **National Regulation Criteria**	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No
- **Regular Inspections**	No	No	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes	No
Means Tested	No	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Eligibility Criteria	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Governance divided over more than 1 Ministry	No	Yes	No	No	No	No	Yes	No	No	No	No	No
Public Funding Mechanism												
- **Taxation**	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
- **Social Insurance**	No	No	No	No	Yes	Yes	No	No	Yes	No	No	No
- **Health Insurance**	No	No	No	No	No	No	No	No	No	Yes	Yes	Yes

2.7 What is consumer-directed care and why is it being considered?

Table 2b illustrates that a ‘direct payment/home care vouchers’ approach is widely adopted across Europe. This is an iteration of ‘consumer-directed care' (CDC), a model of care that is being introduced in many western countries (Low, Yap & Brodaty, 2011). The term has no universally-agreed definition and is often used interchangeably with terms such as personalisation of care, individual funding, individual budgets, direct payments, self-managed care and cash-for-care (Laragy & Allen, 2015).

The rationale for CDC is based on a critical view of traditional, agency-directed long-term aged care services, in which autonomy is restricted and individuals’ capacity for self-determination is reduced (Kodner, 2003). CDC forms part of a movement towards the de-medicalisation and de-institutionalisation of care services for older people, which aims to provide alternatives to long-term residential care and facilitate people to remain in their homes. A consumer-directed approach to home and community care is based on empowering people with physical dependencies by giving them greater choice and control over their personal care, thereby maximising their autonomy (Coleman, 2001). This approach to care is aligned with the HSE’s focus on person-centred care and in the broader integration of person-centred coordinated care (Phelan *et al.*, 2017). Enabling the person’s preference for care provider and the timing of care delivery is based on the principle of individual choice.

CDC is not a single care delivery design, but a range of models which differ according to the way in which decision-making and control are distributed between the care recipient and the care service provider. Models also vary in terms of functional and financial eligibility of care recipients, services offered, benefit limits, hiring restrictions, administrative structures and funding sources (Table 2c).

Table 2c Models of consumer-directed care (Kodner, 2003).

Professionally-monitored models	Professionally-assisted models	Cash models
Care recipients are in control of hiring/firing workers	Care recipients make decisions about hiring/termination, scheduling and supervision	Clients periodically receive cash payments
Care recipients are guided by care managers	Eligibility is assessed by a care manager	Clients have full discretion as to its use for goods and services that they deem essential
Care managers monitor adherence to an approved care plan	A care manager approves service hours	Optional professional counselling may be offered

Methods of payment also vary between models, from client-managed cash payments, to cash payments with the assistance of a fiscal agent, to vouchers, which represent direct payment by the public authority (Kodner, 2003).

2.8 Potential benefits of CDC

Despite some variation in all three models, the care recipient, or their representative, is afforded greater influence and control, and they rely less on case managers in care agencies (Laragy & Allen, 2015). Consumer-directed care has been framed as a response to increasing managerialism in health and social care, in which the views of service users are frequently marginalised, and most decision-making power rests with service providers (Low, Chilko, Gresham, Barter & Brodaty, 2012). Proponents of CDC have also suggested that CDC may promote the development of diversity in local care economies by creating competition (Tyson, 2008).

Findings from research on personalisation of services for people with learning disabilities have found that well-implemented personalisation can have positive impacts on people's lives (Sims & Cabrita Gulyurtlu, 2014). Similarly, research on CDC-type programmes for older people in Canada, the United Kingdom and the United States has demonstrated positive outcomes, including greater independence, greater continuity of care, longer life expectancy and higher life satisfaction (Stainton, Boyce & Phillips, 2009; Lord & Hutchinson, 2008; Glendinning, Challis, Fernez *et al*., 2008; Foster, Dale & Brown, 2007). It has also been noted that CDC-type programmes may yield positive outcomes for informal carers (Moran, Arksey, Glendinning *et al.*, 2012).

2.9 Potential challenges of CDC

Outcomes

The evidence regarding the outcomes for recipients of CDC is somewhat equivocal. For example, there have been mixed reports of outcomes from CDC-type programmes in the United Kingdom, which are referred to using the term ‘self-directed support’ and are largely defined by personalised budgets (PBs). PBs form part of the United Kingdom’s ‘personalisation agenda’, which has been widely applied across different areas of social care. Despite reports of positive outcomes of personalisation, it has been reported that, when compared to care for younger adults, older adults did not greatly benefit from PBs (Woolham & Benton, 2013). Furthermore, despite evidence that CDC can increase satisfaction with care and community service use, there is little evidence to show that it has a positive effect on clinical outcomes, when compared with case management (Low, Yap & Brodaty, 2011). In addition, the CDC model assumes consumers can and wish to choose, which may not always be the case (Torres *et al*. 2015).

An explicit aim of the CDHC is to foster independence, choice and control by shifting power from the HSE to service users. This promotes what has been described as ‘self-governance’ (Newman *et al*. 2009) (p.548) and reduces the need for more managerial, traditional forms of governance. In practice, however, self-governance runs risks not only of abuse and exploitation, but also of more inequality of service provision as more assertive service users are better able to negotiate better quality care from their chosen provider.

Newman *et al.* (2009) observe that self-governance depends on “longer-term capacity building supported by user-led peer and other community organisations, effective mechanisms for information-sharing and meaningful participation, co-production processes and developing skills for decision-making and management among a wide range of civil society actors” (p.548). They point out that these factors are time-consuming activities that require high levels of skill. However, as Glendinning (2002) has pointed out, these do not tend to be included in performance and regulatory regimes, which tend to focus on shorter-term delivery of easily measurable targets.

A common thread underlying critiques of home care measurement is the lack of common metrics for care quality. However, much work has been done to improve the quality of performance monitoring in health and social care in recent years. The Scottish Government provides an overview of some methods for outcomes monitoring (Community Care Providers Scotland (CCPS), 2010). This includes the use of technological solutions like Carista, which can be used for monitoring all aspects of social care, for example, ensuring that people are receiving the right number of care hours, and more sophisticated outcomes monitoring (CCPS, 2010). This is in addition to social care inspections that are carried out by regulatory bodies like the Care Quality Commission.

Low pay is endemic in the home care sector, (Grimshaw and Carroll, 2006) along with insecure employment arrangements, such as zero-hours contracts (Migrant Rights Centre Ireland [MRCI], 2015), and all of these factors influence the turnover of workers. An investigation by Her Majesty's Revenue and Customs (HMRC, 2013) in the UK, found that half of all care home workers were not being paid the minimum wage, once things like travel time between appointments were considered. Cost pressures and a tight labour market are believed to have impacted on care quality. One immediate impact of failure to pay for travel between appointments is that care workers report leaving appointments early, with some reports that time spent on caring activities was as short as 15 minutes (Unison Scotland, 2014).

Inequalities

CDC is based on a greater level of involvement for service-users, as well as greater choice and control over the care they receive. However, despite the broadly positive connotations of the term 'service-user involvement', it can have different interpretations with divergent ideological underpinnings. Slasberg and Beresford (2016) caution against welcoming the personalisation agenda without adequately and rigorously appraising the evidence. They propose that a misleading narrative has been constructed around personal budgets in the United Kingdom and argue that it perpetuates a two-tier care system, in which the bottom tier – almost 90 per cent of people – have not experienced any beneficial transformation to the care they receive.

Service user movements have been concerned with democratisation and the redistribution of power. Governments and service providers, on the other hand, may consider service user involvement from a managerialist/consumerist perspective, focusing on consultation with service users for information gathering and market research purposes, without any intention to reconfigure the distribution of decision-making power (Beresford, 2009). Governments may be receptive to CDC because costs associated with home care agencies and care managers may be reduced or even eliminated (Kodner, 2003).

There is some evidence from the United Kingdom that individual budgets, an expanded form of the CDHC, have had positive impacts, including increased care recipient choice and control, continuity of care worker, and the ability to reward some family carers (Moran *et al*.

2012). However, these benefits were not universal. In the same study, older people reported anxieties about the responsibility of organising their own support and managing their budget. Moran *et al.* (2012) found that for older people to benefit fully from these schemes, they may need access to help and advice in planning and managing their budget. Furthermore, it is unlikely that a market-based model can provide real choice and control to all people. This gives rise to questions of whether and for whom choice equates to control (Fawcett & Plath, 2014). People with limited resources, limited access to information and limited support to make informed choices can be further marginalised by a market-based system (Wells, 2010; Laragy & Allen, 2015).

Socioeconomic inequalities and inequities are often exacerbated in later life, meaning that those with the greatest need for care are also the least likely to be able to provide for their own care. Fine (2013) notes that the recognition of individual need inherent in the personalisation of care must also be extended to those who provide informal care. Consideration of how gender affects care needs in later life is essential, given women's historical position of disadvantage in the labour market, the higher chance that women will be widowed and live alone, and the greater likelihood that women will take on an informal carer role (Lloyd, 2010). The individualised focus of CDC can be viewed through a positive lens, as being aligned with person-centred care (Phelan *et al.,* 2017). However, considering the inequalities and inequities, the individualised responsibility of CDC may also pose challenges to equitable care provision (Ferguson, 2007).

Practicalities

Although the changes associated with personalisation may be well-intentioned, the practicalities of implementation may present challenges (Baxter, Rabiee & Glendinning, 2013). Spicker (2013) argues that CDC may not always be effective, given the difficulty of matching people with resources. Complex needs and the time-consuming nature of coordination mean that mismatches are inevitable. Claims about financial savings resulting from personalisation have been refuted for ignoring the infrastructural support necessary to enable people to access and use personalised services (Beresford, 2009).

Adapting to a new mode of service delivery takes time and requires more than just procedural change (Laragy & Allen, 2015). Good communication between local authorities and service providers, ongoing feedback and monitoring of outcomes for older people are all important features of well-implemented personalisation programmes (AgeUK, 2010). The provision of appropriate supports for older adults to adjust to and navigate personalised programmes has been identified as an essential feature of CDC (AgeUK, 2010)

2.10 Accountability and risk

Ensuring accountability and quality of care is also a concern (Tilly, Wiener & Cuellar, 2000; Kodner, 2003). This concern is linked to a perceived potential for CDC to increase risk to vulnerable people who are already at risk of abuse or neglect (Social Care Institute for Excellence, 2010). Traditional, agency-based home care may be considered safer as there may be a higher level of professional training and monitoring (Matthias & Benjamin, 2003). This is particularly pertinent for older adults with dementia, as they are at a higher risk of abuse and neglect than their peers (Tilly, 2007). However, it has been suggested that family ties, social support, language compatibility and care provider turnover are important factors in understanding elder abuse, and these may not be intrinsic to a specific model of care (Matthias & Benjamin, 2003).

Fine's (2013) analysis of the individualisation of care concludes that dichotomous understandings of CDC as good or bad are misguided. It is important to acknowledge the validity of concerns about the potential use of personalisation to restructure care provision as a market, or to justify welfare cutbacks. Notwithstanding these concerns, its potential to provide new opportunities beyond the narrow scope of current models of care service provision, and to redefine care practices around the needs of care recipients (Fine, 2013; Ottmann, Laragy, Allen & Feldman, 2011), are also valid. Spicker (2013) cautions that the case for personalisation must be argued and proven in the context in which it is applied, hence the importance of comprehensive, 360-degree evaluation. Likewise, taking into account O'Shea's (2017a) observations on the public perception of risk in home care provision, there may be a concern regarding carers' ability to compensate for possible reductions in formal care delivery (Torres et al. 2015).

A wider view of governance measures would address the health of the social care sector and its workforce, alongside outcomes for patients. In the United Kingdom, where social care has been outsourced to the private sector since the 1970s, the sector is experiencing extreme difficulties due to a lack of funding. A report on domiciliary care finances (Opus Restructuring & Company Watch, 2017) found that the home care industry is lossmaking, and of 2,581 United Kingdom care companies, a quarter were at risk of insolvency and 69 had shut in the previous three months. Local authorities in the United Kingdom have experienced ten years of severe budget cuts, which have been passed on to sectors like home care (Glendinning, 2012). Under these pressures, the United Kingdom local authorities have negotiated large block contracts to achieve economies of scale. This has depressed the wages of carers and also left areas of the country vulnerable to a loss of service. For example, in 2017, Cleeve Link Homecare collapsed, leaving local authorities struggling to find care for almost 500 older and vulnerable people (Plimmer, 2017). Provider markets are relatively unstable and there is high turnover of both providers and care workers, which is impacting on the quality of care (Glendinning, 2012).

2.11 Conclusion

The chapter has considered the context of older person care in Ireland, in relation to both residential care and care in the community. In considering care delivery, a review of international models has enabled a comparison of the care of older people in Ireland with that of other countries. The move to a client-directed care delivery model has been framed under different models in different countries and there are contingent relationships to both health care structures and funding of home care. This is an important consideration, in terms of transferability of CDC to Ireland. However, the principal component of the model is to facilitate a method of care that creates the optimum potential for client choice and enables care delivery to be built around care needs.

All systems of care delivery involve some element of risk and person-directed care might not necessarily give rise to any greater or any fewer risks (Manthorpe, 2012). However, a key message from the literature is that personalisation is not a panacea for improving care outcomes. Evidence from the United Kingdom, for example, indicates that severe budget pressures have led to poor quality commissioning and the undermining of the workforce provider market, with resultant implications for the quality of care. These can be avoided by linking commissioning and unit costs with the outcomes from care work for the care recipient, their family and the carers themselves (National Programme for Third Sector Commissioning, 2009). The development of a governance framework that incorporates an auditing of service and care is central to this and should be aligned with wider concerns about the potential sources of poor governance.

CHAPTER 3

STUDY DESIGN

3.0 Introduction

The aim of the study was to examine the quality and effectiveness of the CDHC pilot project, with reference to experiences of care recipients and care providers, service fidelity, clinical outcomes, governance and financial sustainability. The study objectives were identified according to Moore *et al.*'s (2015) framework for evaluating complex interventions. They are listed below:

- To assess programme fidelity, i.e. to assess whether the CDHC pilot project was implemented as planned.
- To assess the quantity of the programme, i.e. to assess whether the CDHC pilot project was sufficient to attain the intended outcomes.
- To investigate the modality of the CDHC pilot, i.e. to investigate how the pilot was operationalized.
- To assess the reach of the CDHC pilot, i.e. to assess who participated in the pilot project.
- To identify any challenges in CDHC pilot implementation process.
- To examine contextual issues (local and external), which acted as facilitators or barriers to the pilot project's successful implementation.
- To examine the relative efficiencies of CDHC and the traditional model of service delivery.

3.1 Target population and sampling strategy

The target population for the evaluation included the full range of stakeholders involved in the CDHC pilot project in CHO 3. This included the following: care recipients; informal/family carers of care recipients; approved providers, including for-profit and not-for-profit providers; members of the CDHC Steering Group and Project Team, PHNs in CHO 3; and representatives from groups involved in informing and planning national policy for older person home care services, including the HSE, the National Community Care Network (NCCN) and Home and Community Care Ireland (HCCI).

3.2 Data collection methods

The design of this evaluation study was based on the triangulation of research methods. Triangulation provides multiple sources of information while counteracting the limits inherent in a single source. An advantage of triangulation is the blending of research methods to enable findings that are underpinned by dissonance, convergence, and complementarity (Erzerberger & Prein, 1997).

The study design involved a combination of data collection methods, incorporating descriptive questionnaires with qualitative investigation of stakeholder experiences of the CDHC pilot programme. A third aspect of the study design was an economic review of the CDHC, conducted by a health economist. Stakeholder consultation was a primary feature of the research design and facilitated the inclusion of a range of perspectives on the CDHC pilot programme. The combination of various sources of information to examine the same phenomenon allowed for a thorough, comprehensive evaluation (Jick, 1979), thereby enhancing the validity of the study findings (Hussein, 2009) (Figure 3.1).

We designed and administered four self-report stakeholder experiences questionnaires (SEQ) as follows: SEQ-1 for care recipients, SEQ-2 for family carers, SEQ-3 for the approved providers and SEQ-4 for the CDHC Steering Group and Project Team. The stakeholder experiences questionnaire (SEQ-1) measured variables related to the care recipients' experiences of self-rated health and self-reported independence with activities of daily living (ADLs) and instrumental ADLs, knowledge about and decision making around the CDHC service uptake, the care services provided by the service provider, and the care recipient's satisfaction with the service. The SEQ-1 also measured the care recipient's demographic characteristics.

The SEQ-2 measured variables related to the care recipient's family carer, including variables linked to the relationship and role in caregiving, knowledge and decision making around the CDHC service, self-rated health, experiences of the service, including satisfaction. It also measured family carer demographic characteristics. The SEQ-3 measured variables related to the service provider's demographic characteristics, such as service location, staffing levels, rates of pay and the range and content of home care services provided to the client/home care recipient in the pilot service. The SEQ-4 was a brief questionnaire administered to the members of the CDHC Steering Group and Project Team and gathered information on their professional and disciplinary background, and their role and level of involvement with the pilot project.

To complement data from the self-report questionnaires, we also conducted focus group discussions and individual interviews among a purposive sample of key informants and stakeholders, including the care recipients, family carers, the approved providers, PHNs, the CDHC Steering Group and Project Team and national informants. We conducted each data collection event using best-practice evidence for the conduct of qualitative data collection and according to pre-prepared topic guides. The focus group discussions and interviews were directed towards the various stakeholders' role in and experiences of programme. The aim was to provide rich and nuanced information. The data collection methods and sources of data are summarised in Figure 3.1.

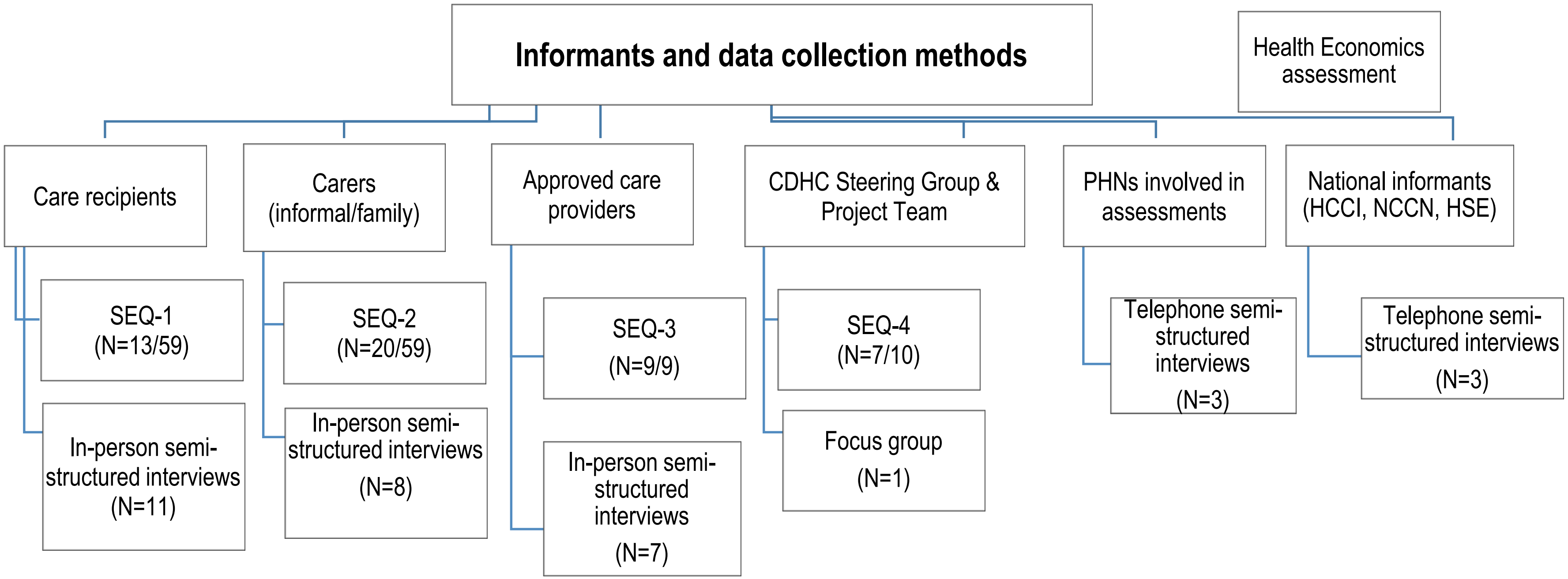


Figure 3.1 Data sources and data collection methods

3.3 Data collection procedures

We invited care recipients to participate in face-to-face, semi-structured interviews to discuss their experiences of the CDHC service. The interviews were conducted in the care recipients' homes.

We also invited family carers to participate in semi-structured interviews, and a member of the research team travelled to meet them at a location of their choosing. We conducted a focus group discussion with the CDHC Steering Group and Project Team, using best practice methods of group moderation and facilitation to enhance participation and data generation.

We conducted a total of seven face-to-face semi-structured interviews with the representatives from the Approved providers to elicit their views and experiences of delivering the service. We also conducted three semi-structured telephone interviews with PHNs to discuss their experiences of participating in the CDHC pilot. Similarly, three semi-structured telephone interviews were conducted with representatives from groups involved in informing and planning national policy for older person home care services (HSE, NCCN & HCCI). Each interview and focus group discussion was conducted using a topic guide. We engaged the services of a health economist to conduct an economic assessment of the service. The assessment was conducted using de-identified data provided by the HSE.

The HSE acted as gatekeeper and facilitated access to potential participants. To recruit the care recipients, we wrote to a total of 59 care-recipient-family-carer dyads inviting them to participate in the evaluation study, through the offices of the HSE. The 59 individuals had been assessed as eligible to receive care under the CDHC pilot programme. The HSE discovered subsequently that one client had died in in the previous days, thus the sample was then 58 individuals.

We followed up our initial letter of invitation with a postal pack which contained the following:

- An introductory letter inviting care recipients and their family/informal carers (if present and involved) to participate in the study
- Two separate, colour-coded participant information leaflets for care recipients and family/informal carers
- Two separate, colour-coded 'expression of interest' slips for care recipients and family/informal carers
- One family carer questionnaire (SEQ-2)

- Three stamped return envelopes addressed to the Research Team at University College Dublin.

The postal packs were compiled by the UCD Research Team, sealed and sent to the HSE, where they were addressed and posted to the care recipients' home address. The care recipients who were interested in participating in the study were invited to complete the expression of interest slip, including their phone number, and return it to the Research Team using a prepaid envelope.

Fourteen care recipients returned the expression of interest slip and were contacted by a member of the Research Team. They were given the option of completing SEQ-1 by telephone or face-to-face and the Research Team also invited the care recipients to participate in an interview. In total, 13 care recipients completed SEQ-1.

The Research Team targeted a maximum number of 15 interviews with care recipients. This sample size was considered adequate to provide sufficient in-depth and nuanced evaluative information (Bryman, 2012). Interviews were arranged on a first-come, first-served basis. Of the 13 care recipients who completed SEQ-1, 11 agreed to participate in a semi-structured interview.

Family carers were invited to complete the SEQ-2 and return it by post in a pre-paid envelope. They were also given the option of completing the questionnaire by telephone with a member of the Research Team, although no family carer opted to do this. We also invited family carers to participate in semi-structured, in-person interviews. Interested family carers were invited to return the expression of interest slip to the Research Team. In total, 8 interviews were conducted with family carers.

Nine care providers participated in the CDHC pilot programme and all were informed of the evaluation study in advance of its commencement. The HSE invited each of the nine providers to nominate a representative from their respective agency to complete SEQ-3 and participate in a semi-structured interview on behalf of their agency. Using an e-mail communication with a URL link, we administered the SEQ-3 online to all 9 service provider agencies and all nine completed the questionnaire. A total of seven face to face semi-structured interviews was conducted with care providers.

We invited the members of the CDHC Steering Group and Project Team (N=10) to complete SEQ-4 and participate in a focus group discussion. A total of seven completed and returned the SEQ-4 questionnaire and eight participated in the focus group discussion.

Public health nurses who were involved in assessing the care needs of care recipients were recruited from each of the three pilot sites in CHO 3, two urban and one rural. We recruited the PHNs by inviting their Director or Assistant Director of Public Health Nursing to nominate them and to invite them to contact a member of the Research Team. In the event, a total of three PHNs were interviewed. We also recruited participants from the national bodies representing private and voluntary homecare service providers, as well as one HSE representative involved in informing and planning national policy on home care for older people. A letter of invitation to participate in a semi-structured telephone interview was sent to the three organisations. A representative from each national organisation self-selected and contacted the Research Team. A total of three interviews was conducted with representatives of these national bodies.

3.4 Data analysis

Data obtained from the four SEQs were handled and analysed using SPSS Version 20.0 (SPSS Inc. Chicago IL). We calculated frequency distributions, measures of central tendency and measures of variability to summarise the data.

All interviews and the focus group were digitally recorded and transcribed by a professional transcriber. Returned transcripts were then anonymised and were inputted into NVivo 11 ©, a computerised qualitative data management programme. All of the interview and focus group data were handled as a single data set. We used Braun and Clarke’s (2006) thematic approach to data analysis to explore the data and identify patterns. Thematic analysis focuses on identifying, analysing and reporting emergent themes (Braun & Clarke, 2006). This involved a careful examination of each transcript using a six-step data analysis procedure, as outlined in Table 3a:

Table 3a Thematic analysis process (Braun & Clarke, 2006)

Step	Activity
1. Familiarisation with the data	The entire data set was read through on numerous occasions to immerse the researchers in the data
2. Coding	Initial coding involves the production and collation of patterns related to experiences of the CDHC programmes
3. Searching for themes	Codes were examined for potential themes and these were reviewed as representing the narratives of the participants
4.Reviewing themes	Initial themes were reviewed and refined to ensure they met the research objectives.
5. Defining and naming themes	Themes were built up using detailed analysis of each theme which enabled a coherent description of the theme.
6. Writing up	This final stage involved the integration of the data and contextualising within the literature

3.5 Health economics assessment

Health economics aims to examine efficiency, effectiveness, behaviour and value in the delivery of and service use in healthcare. It is described as 'the application of economic theory, models and empirical techniques to the analysis of decision making by individuals, health care providers and governments with respect to health and health care' (Morris, Devlin & Parkin, 2007) (p.2). The health economics assessment represented an initial analysis of the CDHC pilot database. The aim was to better understand the economics of the CDHC and to assess other quantitative variables such as the time taken between assessment and care delivery and how these vary by providers, location and so on. The analysis was based on the following research questions:

1. What are the costs of the CDHC programme?
2. How do costs vary by provider and location? Are there outliers influencing the average costs?
3. What are the savings to the HSE from outsourcing the identification of carers to the approved provider?
4. What is the average length of time between assessment and care delivery? How does this vary by provider and location? Are there outliers influencing it?

An anonymised database was passed to Just Economics, a company specialising in health economics, in January 2018 for analysis. Details were provided on key variables such as geography, provider and number of care hours, which could then be compared with cost.

A time motion study was carried out by HSE staff to measure the amount of staff time that was spent identifying suitable providers. Time motion studies are used to measure organisational changes brought about by an intervention, such as staff time spent on specific tasks, efficiency or productivity improvements. Self-administered activity diaries are one of the main methods available for capturing data on time use (Crosbie, 2006). Activity diary research involves the recording of a log of how people allocate their time during the day, often focusing on particular activities pertinent to the research. Staff were asked to record the length of time that they were spending under the traditional model on sourcing care for participants. These data were used to calculate the value of time saved to the HSE. From a total economic perspective, this does not represent a ‘saving’ as such, since the task is passed on to the client who has to expend time and expense to identify their own care provider. Nonetheless, it does free up time within the HSE to devote to other activities and may offset some of the cost increases.

A brief review of the literature on the economics of personalised care was carried out. This examined best practice in measurement and governance issues to ensure that care quality is not compromised, that the market remains vibrant and sustainable with real choice for clients and that inequalities of provision do not arise due to differential market power of actors.

3.6 Ethics

The study was subjected to full ethical review and received approval from University College Dublin’s (UCD) Human Subject (Sciences) Ethics Committee (LS-17-118 Phelan). The study complied with international law and ethical best practice. All of the research team were Garda vetted as required for research with vulnerable adults (UCD Human Resources, 2013).

Potential respondents were informed that there was no obligation to participate and that participation or non-participation would not impact on level or quality of their care. They were reassured that their participation would be confidential to the Research Team. Any data collected from the research were accessible only by the Research Team. The data were stored on an encrypted file in a password-protected computer which, during analysis, were accessible only to the Research Team. Any hard copy material was stored in a locked cabinet to which only the UCD researchers had access. None of the questionnaires recorded names or other identifying characteristics and each questionnaire had a unique code. The provision of separate return envelopes for completed SEQ-2 and expressions of interest in focus groups ensured that informal carers could not be linked to their survey data.

Regarding the data collection by interviews and focus group, only the anonymity of the care recipients and their informal carers could be assured. For the approved providers, PHNs, representatives of national-level groups and the CDHC Steering Group and Project Team, the numbers were drawn from small populations and were self-selected. Therefore, there is the potential for participant identification. However, the research team took every reasonable precaution to mitigate this risk and participants were fully informed of this risk. Any identifying material within the transcripts was de-identified and each individual participant was given a code. The CDHC Steering Group and Project Team narratives are presented as voices within the focus groups, rather than individual coding.

3.6.1 Study governance

The Research Team met with the CDHC Steering Group and Project Team (HSE) on three occasions over the duration of the evaluation project, on November 22nd 2017, February 2nd 2018 and February 21st 2018. The Research Team also attended two meetings at which the approved provider agencies were present, on November 22nd 2017 and February 21st 2018. At the final meeting with the CDHC Steering Group and Project Team (HSE) and the approved provider agencies, the research team invited any final relevant submissions to be forwarded to the research team. One submission on behalf of HCCI was received. This was reviewed and relevant points incorporated into the study. The HSE were kept informed of the progress of the evaluation at regular intervals.

CHAPTER 4
QUALATATIVE FINDINGS

4.0 Introduction

The qualitative data collection involved 32 semi-structured interviews; with 11 care recipients, 8 family carers, 7 individuals representing approved providers, 3 PHNs , and 3 representatives from groups involved in informing and planning national policy for older person/home care services, (including the HSE, the National Community Care Network (NCCN) and Home and Community Care Ireland (HCCI)). The length of interviews ranged from 9 minutes 44 seconds, to 1 hour 10 minutes. A focus group (duration 1 hour 29 minutes) was also conducted with the CDHC Steering Group and Project Team. Data were collected from January 9th 2018 to February 12th 2018. This chapter presents the findings from the qualitative data analysis, while chapter five presents the findings from the questionnaire data and the economic analysis.

The key codes to interviews are as follows:
CR: Care recipient
C: Carer (family/informal)
P: Approved providers
PHN: Public health nurse
NR: National representatives
FG: CDHC Steering Group and Project Team (focus group)

The qualitative data were analysed according to Braun and Clarke's thematic analysis, described as 'a method for identifying, analysing and reporting patterns (themes) within data' (2006) (p.79). Five main themes emerged, each with related subthemes. These are presented in Figure 4.1. Themes were inter-related and focused on the micro levels (understanding and using the CDHC system), the meso levels (administrative process and governance) and the macro level (national issues pertaining to the CDHC pilot).

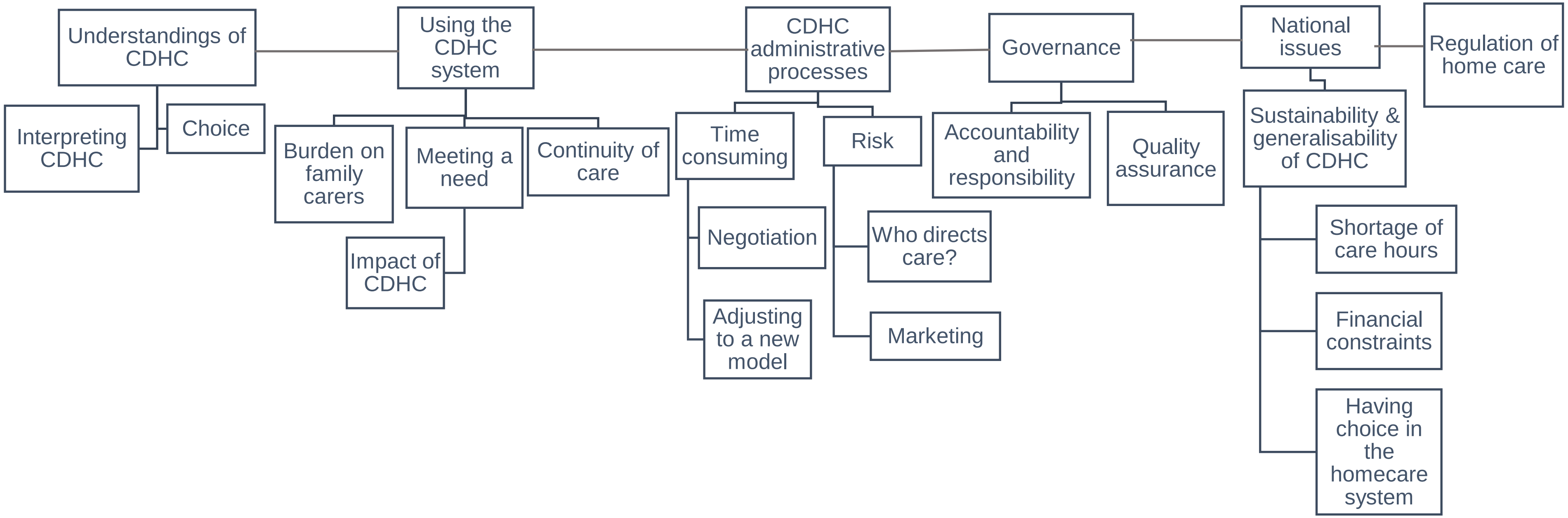


Figure 4.1: Themes and subthemes in the qualitative data

4.1 Understandings of consumer-directed home care (CDHC)

Understandings of CDHC focused on two main areas: how CDHC was interpreted, and the central aspect of choice. Choice emerged as a theme through references to the idea of choice, flexibility and choice, experiences of choice and the contingency of choice with particular reference to capacity, advocacy and geography.

4.1.1 Interpreting CDHC

It was noted that CDHC was open to different interpretations. General understandings of the CDHC model varied across different participant groups. Providers observed that this lack of clarity was aggravated by a global non-standardised approach to CDHC:

> "Obviously it's very clear that, you know, CDHC probably means different things to different people… it is different things in Australia for instance, Germany, whatever – right? So in this context, obviously, it's hard. This is meant to be a pilot programme which is then meant to help influence maybe national policy, right. So, what I don't see built into it is any discussion around what actually CDHC is or should be." (P3)

It is unsurprising, therefore, that this lack of standardisation led to a number of informants pointing to confusion around the exact meaning of the CDHC in the context of the pilot project:

> "I don't think there's a clear sense of what it (CDHC) is yet. I don't think we've been given that." (P1)

Consequently, the processes of the pilot were also considered unclear by some participants:

> It's (CDHC) very muddied, in my eyes, and I still haven't got that clarity through the pilot … are we delegating the care via the client or is it the client delegating the care to the provider? … for me it's very complicated." (FG)

Yet, in terms of its conceptual approach and core aim, other participants appeared more confident in their understanding of the term as it applied to the consumer directed care:

> "CDC is where you give choice, you give a responsibility, you give authority to a family, not only to pick the choice of provider, but look at the

> length of the shift, look at the times, look at the availability, look at the availability of family members to fill in the gaps.” (NR1)

Although the breadth of the concept of CDC was acknowledged, there was also a recognition that this pilot project was specifically concerned with delivery of care within the older person’s home – that is to say, care delivery within a specific setting was a defining feature of the pilot project:

> “What we have been tasked with in this pilot is to provide consumer directed home care, so we are still providing home care and I think that that’s key, we’re not providing consumer directed care … we’re still providing home care … It has to be directed within the home.” (FG)

The perspectives of care recipients and informal/family carers also revealed varying levels of understanding and clarity. Most participants were aware of the CDHC as a “new scheme that came out” (C6). It is important to consider the perspectives of care recipients and informal/family carers in light of the fact that the majority were not in receipt of care services prior to participating in the CDHC pilot project.

Some participants suggested that they did not know what to expect at the beginning of their participation in the CDHC pilot. Taking into account that the majority were first time home care consumers, this lack of familiarity was reasonable:

> “I suppose I didn’t really know what was happening. You wouldn’t know what was going to happen first.” (CR11)
> “I had no idea what the carer would do for me, I had no idea because I’d heard people talk about ‘oh they just come in and give you your medication or if you need a shower and, you know, maybe ready your lunch’ and that’s all I knew, I had no idea” (CR2).

4.1.2 Choice

Despite some suggestions of obscurity and confusion around the definition of CDHC, the notion of choice in terms of provision and limitations, emerged from the interviews. This was inherent in narratives on the idea of choice, the experience of choice and the conditions within which choice was navigated, such as capacity, the presence of advocacy and geographical location.

4.1.2.1 The idea of choice

The idea of giving greater choice to clients and families about the sourcing and arrangement of home care was considered unarguably positive by providers:

> “Who couldn’t welcome families getting choice?” (P1)
> “Everybody wants consumer choice, there's nobody out there that doesn’t want consumer choice.” (P3)

The positive connotations of choice were elaborated. It was recognised that the older people receiving care had a lifetime of autonomous decision-making and that this should not change in home care arrangements. The degree of satisfaction with care provision was considered enhanced by such independent choice:

> “It gives them (older people) autonomy, it gives them choice, it gives them I suppose a degree of independence. These are all adults that would have had jobs, had lives, probably reared families and kids … strong people, and it is good for them as older individuals to have this autonomy and … even be involved in it, and not just be told because the HSE are paying for it, we’ll decide, so that is good. It's more dignified and … usually if someone makes a choice to go with something they are going to be happier with it because it's your own choice, it's like picking out an outfit, you’re going to prefer something you pick yourself than something someone else picks for you.” (P7)

Within the context of making the autonomous choice was the associated responsibility, which was referenced in descriptions of CDHC:

> “You (consumer) sign off that you’re taking responsibility. And you take that responsibility, with choice.” (P6)

By extension, participants also noted that choice may be a burden for some, who may not be able to manage the integral conditions of possibility of choice:

> “I think some people cope better with structure … sometimes too much choice, people can’t cope often with that, do you know what I mean?” (P5)

Moreover, it was noted that the demands of making this choice deterred some people from taking up the CDHC. For example, in the CDHC Steering Group and Project Team, it was observed that when the CDHC voucher remained unused, the reason could be that such choice was challenging:

> “One individual, when we did make contact with him, he didn’t want the CDHC, he did feel the onus of responsibility was too much.” (FG)

4.1.2.2 Flexibility and choice

It was observed that the current tender for delivery of home care services incorporates an element of consumer choice insofar as the care recipient’s preference for a particular provider is facilitated in cases where care cannot be provided by HSE staff:

> “You have consumer choice under the current process … the service user is meant to be asked ‘Do you have a preference for one of the approved providers?’, and if so the case is offered to that approved provider. After that, it's only if they then don’t have a preference or don’t make a choice then it goes out in to a random selection among the approved providers.” (P3)

It was also suggested that flexibility should be an important feature of CDHC, and should enhance choice. One provider further observed a more nuanced interpretation of choice which extended beyond who and when, as detailed below:

> “The client choice is really only about times and who. And to me client choice must be about ‘it’s my choice that it’s this type of care’.” (P1)

The flexibility around clients’ ability to direct how time is used, once essential care needs have been met, was understood as a key feature of CDHC, in order to create a “patchwork quilt of a care plan that works for your granddad and by extension works for ye (you) (client and family).” (P6)

However, the extent to which this flexibility in choice could be exercised within the pilot was considered limited. Choice was considered restricted focusing on clinical need or the assessment of the PHN. Some activities demanded they should be completed at a particular time of the day as indicated below:

> “The choice could be so restricted around what the clinical needs or the public health nurse’s opinions are. That’s understandable too. I’m not criticising them, I’m just saying. But the choice could be restricted severely by basis of well, your mum needs her medication in the morning and the evening. That’s an hour, okay. So where’s the choice now?” (P6)

One provider questioned the value of placing the onus of arranging care placed on the older person and/or their family. It created additional bureaucratic burdens and it could be considered that this effort could result in minimum differences in the care delivery process:

> “If you accept, as a model, that this core time is core and essential, then you're only talking about a few minutes here and there … why invent a whole new level of complexity and pressure back on the consumer to have to make all of these decisions, contact all of these different companies, do these different assessments for the sake of really only being able to influence five or ten minutes of your care time?” (P3)

For some providers, it was noted that issues of choice and flexibility of CDHC must be kept within limits, as constant changing and renegotiating of care arrangements would be untenable from a management and organisational perspective:

> “Some people’s view of person-centred and customer-centred and customer choice can get taken to the extreme, … but like there’s flexible and flexible … I think the CDHC thing is just the initial flexibility … what care company they want in, what organisation, do they want a female, do they want a male, kind of pick the time, it's initial flexibility, it's not on-going continuous flexibility and change of carers.” (P7)

Thus, although care was negotiable, some structure and degree of regularity was essential from a pragmatic point of view:

> “Yes negotiate. You can’t just kind of say ‘Oh look I want that hour and this hour and that hour and everything… hours all over the place.’ They have to kind of have a structure and have an idea where you’re coming from and where you need them.” (CR2)

4.1.2.3 Experiences of choice

Not all care recipients described having actively chosen their care provider as part of the CDHC pilot. Some reported being assigned a particular provider: “We were told [provider name]” (CR10), while others reported being contacted by a provider: “[Provider name] contacted me.” (CR2)

Other participants reported a more active role in arranging their own home care. This demonstrated the ability to be an agency for self in care organisation:

> “You got a sheet with a list of the resource...with the people (providers) and then you also...then information as to what it was all about. So it was really up to yourself to decide who you were going to take.” (CR8)

However, although the navigation of the process was based on the concept of choice, some participants interpreted the process as complex. In some instances, the process may have involved finding an available provider to deliver the care, rather than the active exercise of making a choice:

> “It seemed awfully complicated, but in any case we got that sorted out … that you’d go through the various agencies until you got somebody free to come out.” (C8)

For some, choice was a case of random selection “we really just took a chance.” (C6) Others described a more pragmatic “process of elimination.” (CR5)

Care recipients and family carers described how they navigated contact with the providers and how a decision to engage a provider occurred. This could be based on both being able to actively engage with the provider and the perception of professionalism demonstrated:

> “One of them (providers), I left a message and nobody phoned me back, so I thought, well, forget that one. And then another lady I didn’t find as professional as this one.” (CR9)
> “Some of them didn’t answer the phones, some of them didn’t respond to an email, which was amazing really, so we eventually went with a group called [provider name].” (C1)

Participants also reported basing their choice on a sense of connection and comfort with the provider:

> "I just felt they were very nice." (C4)

An initial review of the provider company names could influence the care recipient's choice. For instance, one care recipient reported being dissuaded from one provider and attracted to another based on the name, and a sense of identifying more with a particular provider:

> "It was just the name that put me off. Psychologically I think I'm 20, you know that way … I thought it reflected people that'd be bedridden … I thought that [provider name] sounded much more positive, I thought that the name for the first one didn't sound positive." (CR8)

However, despite having the ability to choose which provider delivered their care, the ability to actually access choice could appear less important to care recipients and their families than the simple fact of receiving care. What matters was that care was delivered:

> "I could choose and I could change if I wanted to, this was saying you had a kind of a choice, but I mean she's very good … as far as possible they would try and suit me. But as yet it hasn't occurred, it hasn't mattered a lot to me" (CR2).
>
> "I might not have been able to get a carer that soon if I hadn't gone with it (CDHC)" (CR7).
>
> "*And would you find it good that you were the one that was able to make the choice of which one you wanted and the hours?* (Researcher)
>
> Yeah … I kind of picked… it was Wednesday that was suiting me. Well, really it made no difference". (CR11).

This sentiment was echoed by other participants in the study. For instance, in the focus group with CDHC Steering Group and Project Team participants, it was observed that people's primary focus was receiving care, rather than having a choice of who provides care:

> "Sometimes the older people don't necessarily care where they get it (care). It is the getting of it that makes them feel that the care is provided, rather than having all of these choices" (FG).

4.1.2.4 Choice is contingent on other factors

The contingent nature of choice was frequently mentioned by participants. Choice could be rendered under particular conditions. Thus, choice is a mediated activity, dependent on its conditions of possibility. In the previous section, we noted that a decision to engage with the CDHC could be related to the desire to have choice. Other factors which impact on choice were the capacity to make an informed decision based on the choices available, the need for some to have assisted, supported or representative decision making and the availability of services within various geographical locations.

Capacity

Capacity was discussed in the context of being able to make the choice to engage in CDHC and was described in two ways. Firstly, capacity was constructed as the cognitive ability to engage with the decision-making and subsequent follow through required by the CDHC. Secondly, capacity was associated with being sufficiently inclined and empowered to engage with the programme.

It was noted that, because the CDHC was a choice based option, if the capacity to make the choice was severely compromised, then, choice becomes challenging. In describing CDHC, one provider stated:

> “It’s only a model that can be pursued where people have the capacity or autonomy to make decisions” (P1).

This perspective was common among the approved providers and HSE staff and it was noted that several factors may influence decision-making capacity, including cognitive ability and more general levels of confidence and self-efficacy. In the excerpt below, the PHN noted the compromised capacity of one older person and also that choice is dependent on self or family agency being positively disposed towards and able to execute the CDHC:

> “There was an elderly lady with dementia. And being cared for by mostly her daughter in-law and they didn’t seem to have the kind of initiative to actually phone the agencies” (PHN1).

Participants remarked that the agency to participate in the CDHC did also involve understanding and being able to engage with the voucher system and that not every care recipient would have this ability:

> "The capacity and the ability and the wherewithal to pursue the voucher and understand it" (FG).

There was some variation in uptake between the pilot sites – one in particular had very low numbers. There was a perception that the inclination to participate could be associated with disadvantage:

> "That area where we had low uptake, it is a recognised area, disadvantaged on all sorts of levels" (FG).

This area was described by a participant as potentially experiencing challenges in their ability to follow up on the organisation of care:

> "Quite under-privileged and I felt they didn't have the capacity to orchestrate the hours themselves in contacting the companies themselves so that's the one disadvantage and the downfall" (PHN3).

Advocacy

In cases where the care recipient may not be empowered or have the capacity or desire to engage with the CDHC, the involvement of a family/carer could facilitate care recipients' choice:

> "For some families, if they do have somebody who can do the organising for them … it will work. But if there's an elderly patient living on their own and if they've nobody to make the phone calls for them and make the decision for them, to help them to make decisions, it makes it a bit more difficult I think" (PHN3).

Therefore, it was suggested that there should be an advocate or an intermediary for older people who may not have access to support (e.g. from a family member) when making decisions about their care or negotiating their care arrangements under CDHC. This was particularly relevant in the context where the older person may find the whole process overwhelming, as suggested below:

> "There does need to be a voice for some elderly people because I think a lot of them will say … 'oh God, that's a lot of hassle, they're after handing

> me a list, I can’t be ringing all of those people, it’s just too much, I’ll do without it’ ” (P2).

A concern was raised for the potential of assessed care needs to go unmet, if a care recipient did not have appropriate support or considered the input required from them to be too great:

> “If there was nobody there to advise the client, in some instances, the voucher was left on the mantelpiece” (NR3).

Yet, if family or friends were not available to assist, it was also made clear that any possible intermediary or advocate would need to be independent and impartial:

> “I think it's important then that whoever supports them, in making that decision is not from a biased background” (P3).

The need for an advocate or intermediary was also related to an “absolute fear of complaining about the service you currently have” (P1). It was suggested that older people in receipt of home care services can be vulnerable and may not have the confidence to express dissatisfaction with services for fear of losing them, thereby implying a need for an advocacy or intermediary service to support people through CDHC.

Geography

The three study pilot areas included both rural and urban locations where geography could impact on the operationalisation of choice. The extent of a person’s choice in relation to their care provider and care arrangements could differ and/or be curtailed depending on where that person resided:

> “Maybe down the country areas where there’s minimum providers there would be very little choice or in some cases there might be only one or none that could provide that care. And that would be the problem with the CDC type of thing that the client may have no choice but to take someone that they mightn’t be happy with” (NR3).

The restriction of choice and limited availability of care staff was also described by care recipients, who noted restrictions in relation to both staffing and activity type:

> "They (providers) hadn't the staff. And they won't come up … for a half an hour to put on my stockings in the night, I don't expect them" (CR4).

In some instances, participants perceived their distance from the providers' location as a means of ruling out potential care providers. There was a sympathetic awareness of potential travel that staff may have to engage in, which may also suggest a reluctance on the part of the care recipient to assert their wishes and investigate the ability of the provider to meet their needs:

> "The list came but … I said sure they're all too far away from me, you know, to be, I couldn't be expecting them to come out of [Town 1] up here or from [Town 2] up here" (CR2).

4.2 Using the CDHC system

Using the CDHC involved a voucher system and its use was articulated as a subtheme. This could represent a burden on the care recipient and/or family. However, this theme also supported a subtheme of how the CDHC could meet the need of the consumer, and how such care impacted on both care recipients and carers. A strong final subtheme pointed to the desire for continuity of care within the CDHC.

The question of whether the vouchers issued to care recipients represented a monetary amount or a number of care hours was posed by a number of providers. The perception was that the voucher represented a monetary amount equivalent to a certain number of care hours, which was not manipulable to account for provider travel costs. This was cited as a constraint on providers' ability to supply care, particularly in rural areas:

> "They're (CDHC client) isolated and say you've €200, we can provide ten hours or nine hours, whatever it is … but we can't get to you because we can't, we need you to pay travel. They'll say well, can you give me six hours and take three of those hours to pay your staff travel, I can't do that. Under this, we can't" (P1).

Even in the event of availability of formal carers, the length of time and cost of travel could prohibit service delivery:

> "We don't have the carers to go there and, if we did and really wanted to cover, that money is nearly gone on mileage" (P2).

Care recipients and informal/family carers did not report any significant difficulties in dealing with the voucher. However, their comments also revealed mixed understandings of the CDHC system, and of whether they had been allocated an amount of money or a number of hours:

> "I got a letter then from the HSE to say I'm allowed two hours a week … oh no, there was no money. I never have anything to do with money which is great … I don't see anything, a voucher or anything, just sign this form" (CR2).

Some participants did not speak about the voucher at all, and described a more prescriptive model of organising care, based on hours. Thus, on assessment, it was the amount of care time that remained foremost in their perception of the CDHC programme:

> "The HSE really agreed that my husband would get two hours a day" (C7).

Equally, there could be a general lack of clarity on the exact mechanism by which the care was being financed:

> "The care service, right? They're actually paid by the health board, are they?
> *Yes.* (Researcher)
> Yeah, okay. That's all I wanted to know" (C5).

4.2.1 The burden on family carers

It was suggested that the level of flexibility facilitated by the model of CDHC implemented in the pilot might not adequately acknowledge the burden of care borne by family/informal carers. For example, if the older person's care required two people to safely engage with the care activities, carer relief could be minimal:

> "If someone needs to be gotten up in the morning, and [continence] pads changed and [person] showered, and it's a two-person call where often it's the family carer and one of our workers, so it's not even, you know, it's not even a break for them. It's literally they need to be there anyway … if it's just clinical needs, you know … it doesn't help the person who's in the home doing the caring". (P1)

One family carer voiced similar concerns. In the excerpt below, they describe being satisfied with the care received by their family member, but their experience of the CDHC had not been flexible enough to relieve the general burden on the family carer:

> “The system and the package doesn’t do anything for me, personally … maybe it works very well for someone who would have a daughter coming into them every evening … one size doesn’t fit all. The home care is excellent, I must say that, but the home help is not available at all. Things like, simple things like drying up or washing a few dishes, doing a little bit of hoovering” (C7).

However, other family carers described a different experience regarding the accommodation of their needs. It was recognised that caring for the carer was an important aspect of assessment:

> “In fairness to the nurse in question, she was also stressing “Look, it’s not just dealing with [my wife], we’ve got to think of you as the carer. Who’s looking after the carer?” (C2).

Moreover, selecting the distribution of hours by the older person, in consultation with the carer, enabled hours to be also suited to carers. The scope for the CDHC pilot “to offer a bit more flexibility, like block hours or care relief and those sort of things” (FG) was noted as a particularly positive aspect, and one which would not be available through traditional home care service delivery. An example was given of a case in which the family were able to arrange care to suit their needs:

> “Use the hours in a block setting and be able to you know, the carers to be able to get a break”. (PHN2)

This facility within the CDHC pilot was seen as a unique advantage as opposed to the existing model of home care service provision:

> “From a home care package setting that isn't really something that they're able to provide, because they don’t seem to have the hours to be able to give that sort of a home respite” (PHN2).

> "If somebody needed a block of hours that could be organised for them and that isn't the case really with the normal home help that we would have" (PHN3).

4.2.2 CDHC met a need

Care recipients were aware that engaging in the pilot programme would facilitate timely access to the services they required:

> "Obviously there's less waiting" (CR2).

In some cases, the knowledge that the access to care would be quicker through CDHC appeared to be a significant motivation for uptake:

> "I might not have been able to get a carer that soon if I hadn't gone with it. They're setting up a new pilot scheme or something." (CR7).

This was reflected in the perspectives of the CDHC Steering Group and Project Team. There was an acknowledgement that staff could explicitly state the quicker access to home care:

> "Rather than me thinking that you have the capacity and ability to actually pursue this for yourself. It's about 'Look, if you go this way you'll get what you need.' … access is key." (FG)

It was also suggested that the delivery of hours and the meeting of needs through CDHC was a significant contribution to clients' satisfaction with the CDHC:

> "They're delighted with the help that they're getting because they're the hours that they need, you know." (PHN2).

As indicated in the previous section, for some families, the flexibility of scheduling of care in CDHC allowed for the accommodation of care recipients' and the carers' needs. This feature was seen as differentiating the CDHC pilot from the traditional Home Care Package system:

> "One particular gentleman that has, you know, got ten hours over the week, as more like a sitting service to give his wife a break or whatever

> … and to me we would never have got that type of call through Home Care Package.” (P5).

4.2.3 Impact of CDHC on care recipients and family carers

Generally, clients and their families reported high levels of satisfaction with the care services they were receiving through the CDHC pilot. This could tap into a whole new quality of life dimension for the carer:

> “It has really enhanced his (care recipient) living. And I never realised the impact, as being his primary carer as well, I didn’t realise how much it would free up my time, and how important it would be for me. And I couldn’t say enough goodness about it.” (C3).

Family carers described the activities they could engage in, which positively impacted health:

> “This has given me back, you know, the ability to be able to go for my walk in the mornings, which keeps me healthy, mentally and physically, to do that.” (C1).

Care recipients also noted that the receipt of care services had benefits for their family members:

> “I feel better for [family carer], he doesn’t have as much to do. He used to do all that” (CR9).

Care recipients and family members were keen to point out how responsive and accommodating the care provider staff were. Frequently, they said that the carer would do “anything” asked of them:

> “Whatever we nearly ask her to do, she will do … When she comes, sometimes now [care recipient] might feel like getting out of bed, and if she gets out of bed she’ll go up and help her get washed, and dressed, and they’ll come down here and they’ll have a cup of coffee, and they’ll swap their stories, and whatever else. And being honest, she might say “I’ll peel a few potatoes. Do you want me to vacuum the floor?” … All that

> personal help. If it’s a fine morning, she’ll get her into the wheelchair, take her for a walk, and all that sort of stuff” (C5).

Care recipients frequently mentioned having very positive relationships with carers. This could impact on coping strategies and positive mental health:

> “One particular friend is always saying to me, she said “You never get depressed. How did you never get depressed, you know?” … But I will put a good bit of it down to this particular girl.” (CR8).

Despite such positive impacts, some carers felt additional time from the CDHC was needed:

> “I think it's brilliant. But it's still not enough.” (C1).

Family carers noted the value of extra care hours in terms of quality of life, for themselves and their family members in receipt of care:

> “I know the constraints, but an extra few hours would be worth an awful lot to me. … I can definitely tell you they’re not enough … I’ve got to look at it for myself. I would love to have the extra time, and at the same time, if there was somebody here for that little bit of extra time, you’d have [care recipient] to talk to somebody different”. (C5)

Equally, care recipients expressed a desire for supplementary care hours, particularly if social isolation was a feature.

> “I’d love to get the weekends, I've no one at the weekends because family are all away now.” (CR4).

4.2.4 Continuity of care

Care recipients and families were mostly satisfied with the continuity of care; the majority of care recipients reported having the same carer almost all the time, unless she/he was sick or on holidays. Continuity of care was also considered important by family members as this was based on the existing positive relationship with the person providing formal care:

> "I don't want anybody else except her. Because she has built up a relationship, she has a relationship with her before and I don't want to bring anybody else in." (C4).

However, one care recipient had experienced a high turnover of staff, which she found bothersome due to the lack of sustained relationships, although there was no fault with the individual carers or the services provided.

> "They're very good and all that but like I have a girl today and I won't have her again until next Tuesday and I'll have somebody else another day. Now it's alright and I'm not too bad but in the beginning I found that very frustrating … it's alright now, I kind of know them all, but at the same time you're just getting used to someone and someone else comes." (CR10).

4.3 CDHC administrative processes

The CDHC administrative process was spoken of by the participants in relation to its potential to be time consuming, how people had to negotiate care, issues with adjusting to a new model, risks in delivering the CDHC and marketing and advertising.

4.3.1 Time consuming

Providers suggested that the administrative processes associated with the CDHC pilot were time-consuming and repetitive. This was evidenced through an increased number of visits required from providers:

> "It's more time consuming. It's taking pretty much three physical visits from my nurse. It's taking at least two visits from the HSE … adding toing and froing, a lot of 'tennis' going on." (P6).

Such increased visiting was considered duplicating work and it was noted that expanding the current administrative burden on a national level would not be feasible:

> "Very convoluted. You're duplicating on stuff" … scale that up to a national project … it actually becomes ineffective, inefficient and costly." (P1)

Although not a major challenge in terms of workload burden, the additional input was also echoed by the PHNs involved in the pilot:

> “There was a little bit more work involved in the initial assessment, initial referrals pathway.” (PHN2)

4.3.2 Negotiation

In the CDHC, the assessment and devising of care plans had a greater element of negotiation than a traditional home care package due to the client’s and/or family members’ higher levels of involvement and influence and the need to start the service from scratch rather than having detailed referrals from the traditional system:

> “…the referrals that come through from Home Help and Home Care Package, they’re quite detailed when they come to us, … whereas with the CDHC you kind of went in a little bit blind, because you didn’t have the information from the HSE before you went out, it was the families giving you the information … I probably invested a lot more time into the clients of CDHC trying to establish what exactly the care plan will be and the hours and stuff than I probably would have done if it was, if it had been a prescriptive kind of Home Care Package” (P5).

It was also noted by providers that the CDHC model would involve more time to negotiate, which could curtail the ability to accept additional business:

> “[CDHC involves] negotiating and not getting business, you know, at the end of the day. So that has the potential to push up the cost of the care that’s being provided, you know” (P3).

4.3.3 Adjusting to a new model

However, it was noted that challenges and “teething problems” (P7) were inevitable with any new initiative and that a period of adjustment to a new operating procedure must be allowed. Related to this was the idea that the implementation of CDHC would require a change of mentality. This reflected a power shift, as the choice of when and by whom care was delivered was the remit of the person themselves:

> “It's about moving and exploring towards new ways of thinking … we need to maybe loosen some of the grip we have over how we assign services and assign them to days and times.” (NR2)

This departure from the comfortable and usual power of control was noted to be transformative and could pose difficulty in adjusting to a new model of care delivery:

> "Letting go from a more prescriptive model of delivery of care is hard to do and I think that has been true in our case, that the letting go has been a difficult process for us." (FG)

The idea of "letting go" was linked to a perceived potential need for the HSE to place more trust in providers to fulfil complex care needs:

> "At what point the HSE can trust that an agency is going to fulfil and meet the needs of the person, because we've always been used to being involved in the care plan where there's a high level of complexity and … so it's a change in mind-set." (FG)

It was also suggested that losing this power of control involved trusting people's ability to engage and navigate care:

> "People are well able to choose their chosen nursing home and they're well able to navigate … a very, a much more difficult process and are well able to do it, but whereas when it comes to home care we're presuming that they won't have the ability to do it." (FG).

One of the participants representing a national organisation described home care as an undervalued sector, perceived as providing basic activities, rather than making a substantial contribution to health:

> "The problem up to now, in terms of integrated care and home care is, the hospital consultants, the GPs, and every one of the rest of the healthcare system don't trust home care. They don't trust it. Because, they see it as just lighting the fire, doing a bit of housekeeping, and not really adding to the health and wellness of the older person." (NR1)

There was a suggestion that implementation of CDHC on a broader scale would require a concurrent promotion of public awareness and understanding. This was considered in the context of changed perspective on having a choice of the negotiation of home care:

> "A national push on it, some sort of promotion about information on how to access homecare" (P1).

Drawing on the complex nature of residential care, a suggestion was made that there is a low level of full public understanding of the Nursing Home Support (Fair Deal) Scheme, and that it should be ensured that information about home care would be clear, accessible and have accessible information supports:

> "If statutory homecare was rolled out, and CDHC was rolled out in the similar vein that Fair Deals is rolled out … I am still trying to get to grips around Fair Deals and the 20% and then there's the 30% … it is baffling … it's just paper after paper after this per cent and this is for – I just think it needs to be clean, put a campaign on the telly and say the state are now … the Irish Government have decided to introduce homecare. This is what it means to you. If you have this, this is what will happen. If you've this… And if you've any questions, please phone or contact this number." (P1)

4.3.4 Risk in CDHC

Linked to the devolution of power related to home care, it was suggested that CDHC might pose certain risks. For example, it was suggested that when care is directed by the consumer, essential activities such as personal care may be usurped by household tasks. Alternatively, the family may decide the priorities which may clash with professionals' assessment of care needs:

> "There's a risk then that it would conflict with the professionals' direction, … there's still risk that personal care will get a lower priority than domestic duties … there's also the risk then that the family will go a different direction to the professional and I think for greater dependencies, the risk is even greater." (FG)

Consequently, it was considered a challenge of the CDHC to balance clients' needs with their wishes (and those of their families) to direct their care in a certain way, while also acknowledging the importance of professional direction of care.

Another risk mentioned by participants was the potential for the system to be manipulated.

> “The HSE have to be careful from point of view of providers taking advantage … Some people will argue - well why should it matter because you know you're getting €200 voucher a week and you know, why doesn’t the service user just use that whatever way they want in terms of whatever they get. And there's an element of, that’s okay up to a certain point, but does that service user understand that by the way, today you're telling him he can have, you know, eight hours of service for that, does that person understand that by the way if he goes to another provider he could get nine or ten hours for it …. ” (P3)

This was echoed by the CDHC Steering Group and Project Team, who spoke of providers being in a position of power in the delivery of care, and this power could mean that they assume a role of directing the care rather than being consumer directed:

> “The paranoia … around that potential manipulation for the advantage of the provider … that it’s more provider-directed than consumer-directed” (FG).

Maintaining a component of the CDHC model which ensures that essential needs are met was considered a buffer against the risk of this kind of manipulation:

> “If that core requirements disappears in the future under CDHC and it's total free choice then the concern is that it's not the actual service user maybe who is actually making the final decision” (P3).

4.3.5 Marketing and advertising

The CDHC model was viewed as promoting a competitive market for providers, whose focus would be to extend market share:

> “[CDHC] increased competition amongst existing providers to attract the clients.” (NR3)

In this regard, risks were perceived in relation to clients’ choices being influenced more by marketing than the quality of the service, as well as the potential effect of larger providers on small and medium-sized companies:

> "It will come down to the organisation who've the biggest marketing budget and then that will determine service user choice … whoever has the biggest advertising budget gets the business which doesn't necessarily mean they're going to get the best service, and secondly if it does result in the smaller and medium sized companies exiting the market I think that will be poorer for the service users at the end of the day." (P3)

4.4 Governance

Governance was a strong concern, particularly within the CDHC Steering Group and Project Team focus group and the provider interviews. Governance was considered to comprise of issues related to general governance, with other sub-themes related to accountability, responsibility and quality assurance.

4.4.1 General governance

Amongst the CDHC Steering Group and Project Team, there were mixed perceptions of the situation regarding governance of the CDHC pilot. Some members felt that there was greater governance in the traditional method of home care delivery:

> "The supports that come with the traditional method at the moment are not there with the consumer-directed method … There's an awful lot more governance of the traditional method. You're ringing out all the time." (FG)

Others felt that the level of governance in CDHC was complex:

> "Even for us it's very convoluted … it's extreme, in some cases." (FG)

There was a suggestion that different levels of governance might be appropriate for clients with different levels of dependency. There was a proposal that governance should be based on a pragmatic approach with trust being placed in the person in receiving the care:

> "Where you have somebody with a low level of need who is supported to live at home in the community with a minimal level of input and personal care or for their incidental needs and that kind of thing, that do they require the same level of governance?, do you have to have three people gathering and meeting to decide a care plan with that kind of thing? …

> there is a whole issue around not only just the trusting of the provider to do what they're supposed to do but there is a need for a level of trust that the client will understand their own needs and how they'd like to provide them" (FG).

The tender process was noted as a significant governance mechanism, which would cover any potential future implementation of CDHC. It was noted that planned implementation of local audit teams can enhance current systems, yet it was noted that a national regulation approach was needed:

> "Any external providers that would be part of a delivery of CDHC going forward would have gone through the tender process and be committed to the standards that apply and it's through that that we would be introducing our first approach to CDHC, it would be tied into our tender arrangement … monitoring of those arrangements through audit teams that are introducing at the local general management of service level arrangement that we have in place with those providers, so a number of elements to the oversight of it … but it's a work in progress … pending the regulation to the whole care service in its entirety." (NR2)

4.4.2 Accountability and responsibility

Participants spoke of issues of accountability and responsibility for care. This was a concern for stakeholders. The devolution of power to the consumer also raised questions relating to who was accountable for care delivery when external providers were negotiating care with people, rather than the HSE:

> "Where does the accountability lie at the end of the day?" (FG).

Concern about accountability was a particular theme in the focus group with the CDHC Steering Group and Project Team. The responsibility of the HSE to fulfil a duty of care to clients was mentioned:

> "We have a duty of care to these clients and they have been referred to us and we have to ensure that their needs have been met" (FG).

Fulfilling a duty of care included clarifying the accountability of the HSE under the CDHC model:

> “There’s a big delegation issue there for me, are we delegating it to the provider directly, indirectly via the client or is it the client that’s delegating it to the provider and where are we legally then from an accountability point of view?” (FG).

Providers wondered whether the CDHC represented a delegation of responsibility by the HSE as the organisation of care was now the remit of the consumer, and the provider delivers care with a somewhat sporadic and remote governance system:

> “Is this a delegation thing? Where that admin, that PHN set up, all of that, the phone call to the agency, just all that gets either moved to the family carer to do the phone calls to the agencies and the agencies then go in, do the set-up, do the care plan, this is what we’re delivering, send that to the HSE, and the HSE audit that. They pop in every couple of months or they, you know, they pick a random house, but it’s not, they’re not as hands-on on the governance side” (P1).

A question was raised about who would benefit from a delegation:

> “That, to me, as a citizen, would be worrying. If I was a businessman, it would be great” (P1).

It was suggested that less input for the HSE would enable provider agencies to engage in more profitable business practices:

> “If this was a business, … you could get it as lean as you want, you could run margins up and get it as clean as possible, but I question that is pure private services and … it shouldn’t be that industry … it’s not a product” (P1).

Similar queries were raised among the CDHC Steering Group and Project Team. There was some differing of opinion regarding the ability of clients to take responsibility for the services they are receiving under CDHC, particularly if they were dissatisfied with the service. Some participants in the focus group suggested that if the HSE no longer fulfilled an intermediary role between client and provider, this could foster greater autonomy for the client and empower them. However, others expressed concern about the vulnerability of clients, suggesting the HSE provided a safety buffer:

> "If the comfort blanket of the HSE isn't there, like for example if I had somebody coming in to do ironing for me on a Thursday and I came home from work and I found half a basket of ironing was done only, well next week when she turned up I would kind of, 'Well, actually Mary, I thought the understanding was that I would get the full basket done every week'. Whereas I think as long as the HSE remains the intermediary we are looking at each other kind of saying, 'well, would you have the conversation with them?' and they're looking at us kind of saying, 'well, would you not have the conversation?'
> *That's the point, who has the conversation then?* (Other focus group participant)
> Yes, the client should be empowered to have the conversation. They are directing it. (FG)

The suggestion that not all clients and/or families could be responsible for managing their own home care was reflected by a family carer, who noted the challenges of addressing difficulties or concerns:

> "This (responsibility of care organisation) will be very difficult for some people" (C1).

However, the family carer could have the confidence and capacity to express their difficulties and negotiate the appropriate provision of care for their family as demonstrated in the narrative below:

> "I had managed staff in the past and so it didn't bother me to say it to her, I said, 'No you must stick to the time that we gave you', you know because we had other people slotted in, family members into the other times you know. So she tried to change it a few times and then she'd say, 'Oh your brother said, it was okay', and I said, 'Well you answer to me, you know and I'll tell you if it's okay and it's not okay to change your hours, we put a lot of time into this and this is, we narrowed it down to this, this is what we want', and it was great to have [CDHC Clinical Lead] as a backup, you know what I mean?" (C1).

Despite having a high level of confidence and capacity to deal with this issue, this family carer still expressed the feeling of security that came with having the support of the Clinical

Lead, implying the importance of this role in facilitating clients and families to take responsibility for their care.

Along with the issue of who is responsible, participants expressed different perspectives on who should be responsible for ensuring that care is delivered to those who need it. Some expressed the view that the family should hold a significant level of responsibility for the care of their relatives, and that the traditional, more prescriptive model of care delivery does not reflect that:

> “They (HSE) take a lot of choice away from the family, and almost, the families are just bystanders, and they’re not really involved in the care. Which is, in my view, a bad thing, because then families nearly say, we’re entitled to this care and the HSE must do this and it must do that’, whatever. And it wrongly takes a lot of the responsibility away from a family in caring for their own mother or father (NR1).

Those who held this view noted that the CDHC changes the balance of responsibility. It was seen as a way of “allowing families that bit more choice but also more responsibility” (P6). Others were of the view that the State has a basic responsibility to provide care to those who need it:

> “In circumstances where an agency can’t, or a family can’t, that person should not go without care for three to four months … there should be an onus, a responsibility, it’s an ethical thing, that the State should step in. The State have said this person is entitled to €500 worth of care” (P1).

The responsibility of the HSE for ensuring appropriate and conscientious care delivery was reiterated by a national informant, who emphasised the HSE are the funding body in an unregulated industry that does require a level of clinical governance:

> “…the holders of the public purse in an environment that’s not legislated or regulated”. They are “authorising a level of public funding” and “still would need to have oversight of the delivery of that service in a reasonable way” (NR2).

This was echoed by the CDHC Steering Group and Project Team, with reference to financial governance:

> "We do need to maintain financial governance. We can't just hand the voucher over and say 'Give us €500 a month', and let them off, we can't do that either … we have accountability for public money" (FG).

Providers also recognised that the accountability for the service will be traced to the source of funding (i.e. the HSE):

> "I empathise hugely with the HSE because they have the responsibility of once the HSE stick their sticker on the door of a house, straight away, no matter what happens, it's to the HSE people are gonna come" (P6).

In this context, it was considered understandable that the HSE would want to maintain a certain level of governance and oversight, despite some delegation of responsibility:

> "I would be rightly concerned if I had to give away all control and yet be held accountable for one service being given at the end of the day" (P3).

4.4.3 Quality assurance

Governance was also considered in terms of ensuring services met a high standard. The CDHC Steering Group and Project Team spoke of how they provided some oversight into the care quality in the CDHC. This involved a monthly contact and a three monthly review, while it was noted that the HSE contact details were provided to the people participating in the CDHC, so they could access assistance in the event of problems arising:

> "I suppose, from the project that we did, the governance was there, you know. As per national guidelines we would have gone back monthly, and I suppose the contact details [of the HSE] would be there and you would be reviewing it three-monthly and I suppose there would have been a certain amount of trust and also that they would know how to access and come back if there was an issue" (FG).

There was also a degree of uncertainty expressed as to the exact mechanism of quality assurance. It was noted that the current community front line staff, such as PHNs, were not able to fulfil this function due to workload. Again, this quality assurance was lacking in the context of an absence of national care standards and regulation for community care:

> "The public health nurses are not in any way shape or form have the time or the capacity within their workload to do the quality standard piece which you know if they're not going to be able to do it and HIQA standards or HIQA are not in place to provide that, who is going to do that if this CDC is part of the 2018 tender going forward?" (NR3)

Providers pointed out their existing quality assurance procedures which were delivered under their internal quality assurance mechanisms and this was linked by one provider to having a health professional background:

> "We have directors of care over, governing us, we have policies and procedures, we have audits, all our staff are supervised. I'm also a nurse so I would oversee the care plans, keeping an eye on the carers, that they know what they're doing, that they're following procedure … that's being looked at all the time anyhow. That doesn't change with CDHC." (P2).
>
> "There would be regular reviews and obviously the documentation and all the rest of it" (P5).

It was suggested that the HSE could relax their governance procedures after initial provider approval. Approval meant that the standards of quality were existing within the provider's organisation and were demonstrated. Consequently, internal provider systems could continue to assure this:

> "Fundamentally, [we] have the client at best place. If they (HSE) believe that and they check up on that, well then why can't we just go off and do all this ourselves? Do you know, like what's the barrier?" (P6)

However, this opinion was not shared by all providers. An opposing perspective was that the higher level of oversight provided by the HSE is essential to maintaining the high levels of internal governance within agencies:

> "I don't think it's the place for an agency to stand over the governance … any of the agencies that are on are very high standard of governance and tracking calls and tracking hours and complaints procedures and all of that's there, but I suppose the reason it's there is because you're being watched." (P1)

4.5 National Issues

Within the narratives of the stakeholders, particularly the formal care staff (Approved providers and HSE), there was a recognition of the impact of the national context on policy and on extending the CDHC. This theme was sub-divided into a shortage of care staff, a shortage of care hours and care delivery financial constraints. In addition, there was some consideration of how the CDHC could be rendered sustainable and replicable.

4.5.1 Shortage of carers

The national shortage of care staff was a recurring theme throughout the interviews, across all stakeholder groups, and is an important contextual factor in delivery of home care services. Recruitment was a particular concern of the providers:

> “We have a crisis nationally with just being able to get homecare staff.” (P1)
> “I think that’s a national issue, there isn’t enough carers, there isn’t enough providers to provide really.” (P4)

The shortage of staff was noted as being more severe in rural areas:

> “We’re rural and we have issues with getting carers.” (PHN1)

Recruitment challenges could be linked to the conditions of employment, for example, as formal carers travel to people’s homes, the ease of travel was considered important, for example, in relation to the roads to be travelled:

> “People sometimes make the choice and they say, “Well, I’ll work in [County 1] rather than in [County 2] where the roads are bad” (P4).

Coordinating carers with appropriate geographical workload was also noted by a provider as a challenge to the efficient delivery of care. It was recognised that formal carers require hours of work and if this is not forthcoming, then they will not just wait around:

> “It's very hard to get people and then we get the people for a while and then there's no case. And then you know, so these people like are not I'm just going to wait around, like you know.” (P3).

The gender of carers can also be a factor to be considered in the coordination of clients and staff. A shortage of male carers, in particular, was noted as a challenge to the arrangement of some cases:

> “We did have an issue where a male carer … went to get a better job, so there was a panic as to, now, where all of his clients would be looked after. Now it happened another male carer was taken on, thanks be to God” (FG).

Care recipients and their families were also aware of the shortage of care staff and also the close scheduling of calls which could translate to trying to leave one house a little early to arrive at the next call on time. Some care recipients noted that this led to clients’ care being rationed:

> “Short-changed here, and short-changed at the other end … you can’t be instantly here, and instantly there” (CR5).

They also reported the effects of this shortage on the level of flexibility that could be offered to them through CDHC, thus counter-acting the concept of 24/7 care options:

> “Well, this agency couldn’t give us weekends because they didn’t have the staff and that seems to be a big problem for agencies, they don’t have the staff you know.” (C1)

In considering the feasibility of scaling up CDHC, the dangers of universally implementing CDHC as the only model of service delivery were alluded to. It was suggested that this could potentially exacerbate the shortage of care staff and make a major challenge inherent in recruiting staff:

> “There’d be a higher demand for homecare workers that would lead to a workforce shortage because if you put everybody under this model, that means that the HSE don’t have to provide care and all those carers are taken out of the equation, so there could be an increase in business alright but that would lead to workforce shortages, it's hard enough to attract carers at the moment, we feel that with this model it will be even worse” (NR3).

The CDHC Steering Group and Project Team discussed the shortage of care staff in relation to the CDHC pilot, a central idea of which is "going to the market" (FG). This aims to improve care quality by giving choice, but staff shortages were also experienced in using private providers:

> "The quality of care and all sorts of things. That hasn't proven to be the case, I think, because we have gone to the market … we still have a lack of carers, we still have people waiting a long time for carers to be available." (FG)

The "rates of pay and terms and conditions" (NR3) were cited as influences on the availability of care staff and it was observed that Ireland was not alone in experiencing these challenges:

> "The international research shows that the issues around equality of employment with some care agencies also contributes to the lack of presence in the market" (FG).

The unpredictable and precarious nature of employment in this sector was described by one provider, who gave an example of when a client is hospitalised. This translated to a gap in work for formal carers and posed a challenge in sustaining guaranteed work:

> "I had one there recently, and there's about 15 hours there and there's three home helps going in. And I had to make the call, I suppose I had to make the call to the relatives to see exactly what was happening because I had home helps who were without work. Some of them were 12 hours down, you know, in the week, which is substantial." (P4)

4.5.2 Shortage of hours of home care

The underfunding of the home care sector was also alluded to in terms of a shortage of hours. Participants suggested that the shortage of traditional HSE derived hours of home care accelerated attempts to promote the CDHC voucher system:

> "A limitation on the traditional availability of home help hours definitely pushed us forward to encourage families to activate the voucher." (FG)

Consequently, the CDHC pilot was perceived as having provided care hours which would not otherwise have been accessible:

> “We can see where hours are needed but then when we go back to the drawing board and look for the hours … I suppose that’s always been a struggle as to getting the hours or putting the argument forward for a client. Funding is a big issue as you know yourself with them things. So I think maybe I personally think I wouldn't have got as many homecare packages if the CDHC wasn’t involved.” (PHN1)

4.5.3 Financial constraints

The fact that the home care sector is under resourced financially was frequently mentioned. In this context, participants questioned the extent to which choice and flexibility could really be facilitated under an expanded CDHC model and also what was the advantage in terms of choice if core needs were always the greatest financial expenditure in any system delivered:

> “The HSE doesn’t have the budget to give €200 to somebody to say, ‘By the way use that now as you see fit’, it just doesn’t because the demand for the service is greater than the supply right, and therefore the HSE must ensure that the care needs are met and I think 85% of the budget, 90% probably has to go to meet those core needs and therefore how much extra choice are you really, really going to get them for a completely brand new model.” (P3)

The practicality of implementing a new model of home care delivery, in a context where demand is greater than supply, was questioned. Such practicality was related to finite resources:

> “In an ideal world everybody would have free homecare when they needed it and it would include X, Y and Z and quality of life and all the rest of it. If I was a civil servant sitting on the other side of the table I would say … that’s nonsense. We can’t afford, we cannot afford … the basic service that we have at the minute, we can’t afford it but you’re saying up your game?!’ (P1)

It was also suggested that the financial constraints on the sector could have implications for governance, as audits cost money and human resources, and the demand for service delivery will always take precedence in the context of fiscal limitations:

> “The audit side of it is always going to play second fiddle right because the pressure is going to be on to deliver the frontline service.” (P3)

Furthermore, it was reported that the cost of delivering home care services is likely to continue to increase:

> “The cost of delivering homecare, the cost for us goes up year on year, staff, wage increases.” (P1)

The model was perceived as being more expensive by the CDHC Steering Group and Project Team:

> “I suppose it is more costly for the HSE. It is working out a lot more costly, even when you’re looking at all those visits, and mileage, it is more costly for the HSE to administer this, and to pay for it as well.” (FG)

4.5.4 Sustainability of CDHC

The feasibility of implementing CDHC on a wider and more long-term scale was a point of uncertainty.

> “Sustainability is the main issue … It’s fine for a pilot, but …” (FG)

It was noted that during the pilot, there were very high levels of involvement by the CDHC Project Team.

> “There’s been a lot of handholding you see … we really pushed families to activate that voucher.” (FG)

The role of the Clinical Lead was considered central to the implementation of the project:

> “It was very focused project … we’ve been really lucky to have a very dedicated coordinator whose worked extremely well like with all of us …

> our role as community nurses is so broad and her role was very, very specific.” (PHN1)

The support of the CDHC Project Team was considered especially important in cases where a client may not have had family support to engage in CDHC:

> “You do rely heavily on relatives to make that choice and to make that phone call. But it would seem to me if there are cases like that, the co-ordinator, the CDHC coordinator, are chasing them.” (P4)

This support was greatly appreciated by care recipients and families, as evidenced by the following quote from a family carer:

> “It was great to have the coordinator come out and sit down and do the care plan and I don’t think you get that with the home help you know … everything just went so smoothly because of that girl.” (C1)

Most care recipients stated that if they ever had a problem with their care arrangements, they would contact the CDHC Clinical Lead. Participants suggested that the level of support provided by the Clinical Lead was crucial to the project’s success. There was some doubt as to if/how the project could proceed, be scaled up or sustainable without this level of involvement and support:

> “In the pilot scheme, we had the clinical lead … and between the two of us it’s worked really well and they’ve accepted it. But if that link isn’t there going forward, if it’s just going to be a company, I don’t know what the plan is.” (P2).

In the broader context of an ageing population, concern was also raised about the ability of CDHC to meet the demand for home care:

> “The demographics … I was looking at it recently and I thought my calculator’s broken, I couldn’t be right in this figure, but my calculation was off the top of my head that between, since 2006 until now, the older population has increased by 36% … so if we just think about that, in ten years’ time ... how is this model going to be flexible enough and sustainable enough to continue to meet that level of demand?” (P1)

4.5.5 Generalisability

The small size of the pilot was often referred to by participants, and was suggested as a possible limitation to the generalisability of findings from the pilot project to broader populations and settings:

> “It's very hard to get an overall view from such a small sample … It's just surprising the very small number that were chosen for a pilot study and at that again the smaller numbers that took up, you know the pilot study, for the HSE and the Department of Health to base a future tender or a future model of homecare delivery of such a small number is absolutely astounding now to be honest.” (NR3)

It was also suggested that there are other stakeholders whose views would be relevant to the wider implementation of CDHC, but whose voices were not included in the evaluation:

> “The implications or the consequences of this pilot are they extend way beyond social care or community care … so if you look, it’s hospitals, it somebody, it’s primary care. … There’s much more voices here involved in this than we’re going to hear as part of this evaluation.” (P1)

This was considered an important point regarding the replicability and scaling up of the CDHC.

4.5.6 Having choice in the home care system

It was recognised that supporting choice within the home care system itself was paramount. There appeared to be a consensus that the CDHC could never exist as the only model of home care service delivery in Ireland:

> “The voucher system then would be an option you know to deal with cases where the client does want to take or have control and we would still need to have the other mechanisms of service delivery” (NR2).

It was acknowledged that the CDHC may not be suitable for all persons in need of home care services, and it was suggested that it might be a more appropriate model for clients with less complex care needs:

> “There are a cohort actually it suits very well … I think CDHC works better for the less dependent clients, versus the higher-dependency clients.” (FG)

The practicalities of defining eligibility for CDHC were considered a challenge:

> “One of the key challenges I think will be defining the, who we can offer it to and what are the criteria for perhaps including people without being too patriarchal about it. ” (NR2)

Some of these challenges were explored by the CDHC Steering Group and Project Team. There were discussions about “thresholds” and “categories” (FG) concerning levels of need, capacity and ability to engage in CDHC. However, the true relevance of such thresholds or categories could become less meaningful if external factors, such as support systems (family, community) were not taken into account:

> “I think there’s a bit more to the level of need piece insofar as I would think you can’t globally say that the level of need, we’ll say if you were to use SAT, a complication of it, we’ll say a high level of need to the client. But if they have other support systems in place and you have two level 5s and this Level 5 doesn’t and this Level 5 does, it’s generally the case that both Level 5s, because they’re a Level 5, are not considered for inclusion, do you know what I mean, that there should be certain other triggers.
>
> *I mean there are always variables in, every case is individual I suppose but kind of general guidance*” (other focus group participant) (FG).

The above quote describes the limitations of using “level of need” as an inclusion or exclusion criterion for the CDHC. The example given is that two clients may be assessed as having the same level of need (level 5), but the reality of their care needs may vary depending on the level of family or community support available to them. The first speaker suggests that there should be other criteria which identify a person as suitable for the CDHC. The second speaker suggests that general guidance would be helpful but that variability in individual cases must also be acknowledged.

The CDHC Steering Group and Project Team pointed to the importance of ensuring that a pathway would exist between CDHC and traditional home care service delivery, in the event that a person's needs or capacity changed and CDHC was no longer the most appropriate model for them:

> "I think it needs to be very clear that there's a clear pathway that you can revert back to traditional model." (FG)

4.5.7 Regulation of home care

The need for regulation of home care in Ireland was considered significant and this view was expressed by representatives of the Approved providers and national informants. There was a sense that the introduction of home care regulation is overdue:

> "The important point from a national point of view is we don't have national homecare regulations which is incredible. I remember years ago being promised homecare [regulation] in 2016. Homecare regulation and I remember thinking 2016? Are you crazy? That's so far away! We still don't have it." (P1)

Comparisons were drawn with residential care, which is regulated and monitored by HIQA:

> "HIQA can go into the nursing home and they have the kind of you know the checklist and everything they check, and then they can write a report. That is not in our business at the moment." (NR3)

The aspects of home care which need to be subjected to standardisation and audit were numerous:

> "We do need standards for home care in Ireland, we absolutely need it. We've been calling for many years to have an independent authority, like HIQA has to do with nursing homes, to come in and actually implement both standards and audit the standards for home care in Ireland … in terms of quality, training of carers, the quality of the supervision, quality of how to deal with complaints, whatever." (NR1)

It was also noted that regulation of the home care sector would have benefits for care recipients and their families, who could be more assured that standards are upheld and this could relieve the burden of choice:

> “Confident that they can actually get a provider who is regulated or licenced, and that they won't have to have concerns or as many concerns as they might have now of choosing a provider.” (NR2)

4.6 Conclusion

This chapter has provided rich narratives which underpin the five themes within the qualitative data. While the participants identified positive aspects of the CDHC, there was a myriad of issues which required further consideration. It was recognised that the CDHC operated at a systems level where direct service delivery was impacted by understandings of the term and the fostering of true choice at a micro-level. Within a meso-level, issues were identified related to engaging with the system and the administrative apparatus which support its delivery. Finally, the macro-level themes acknowledged that the operation of the CDHC was dependent on broader concerns related to staff, finances, enabling sustainability, supporting choice in homecare and having regulation of home care.

CHAPTER 5

STAKEHOLDER QUESTIONNAIRES AND ECONOMIC ANALYSIS

5.0 Introduction

In this chapter, findings are presented from the descriptive stakeholder experience questionnaires (SEQ-1, SEQ-1, SEQ-3 & SEQ-4), as well as the economic analysis of the CDHC pilot project.

5.1 Care providers' questionnaire (SEQ-3) analysis

5.1.1 Demographic Information

All nine care approved providers who were approached to complete the survey returned a completed questionnaire. All of the CHO service areas were serviced by the approved providers. Three of the approved providers employed nursing staff and three approved providers also employed care assistants with a FETAC qualification less than level 5. All nine approved providers employed care assistants with a FETAC qualification greater than level 5.

5.1.2 Areas serviced by the providers

Table 5a: Areas serviced by the approved providers (N=9)

	Percentage (N=9)	Frequency
County Clare	77.8%	7
County Limerick and Limerick City	77.8%	7
North Tipperary/East Limerick	44.4%	4

5.1.3 Categories of home care staff

Table 5b: Categories of home care staff employed by the approved providers (N=9)

	Percentage (N=8)	Frequency
Nurses	33.3%	3
Care assistants (QQI/FETAC 5+)	100%	9
Care assistants (QQI/FETAC <5)	33.3%	3

5.1.4 Staffing

The average number of total home care staff employed by the nine approved providers nationally is 862 ranging from a minimum of 75 staff to a maximum of 4,050. An average of 724 of the home care staff employed by the approved providers have QQI/FETAC level 5 and above qualification which equates to an average mean percentage of 88% across the 9 providers.

5.1.5 Hourly rates of pay across staff categories

Table 5c: Average hourly rate of pay for home care staff across the approved providers (N=9)

	Average hourly rate of pay (min, max)
Nurses	€22.25 (12.5, 25.00)
Care assistants (QQI/FETAC 5+)	€12.01 (10.00, 13.50)
Care assistants (QQI/FETAC <5)	€11.56 (10.00, 12.50)

5.1.6 Services provided through the CDHC pilot

All of the approved providers who responded to the questionnaire offer home help (light housekeeping, laundry, meals etc.), companion care (company etc.) as well as personal home care (medications, washing/dressing etc.) to CDHC clients. Three of the approved providers indicated that they offer additional services. One approved provider indicated that they offer any service specified under the client's care plan. A further approved provider indicated that they offer driving services, collecting prescriptions and support to attend medical appointments. A third approved provider indicated that they offer dementia, disability and hoist care services.

5.1.7 Hourly rates for home care services offered through the CDHC programme

The approved providers were asked what were their hourly rates for home care services offered through the CDHC pilot. The hourly rates charged for CDHC customers across all nine approved providers were in line with the 2016 homecare tender rates.

5.1.8 Client engagement with the providers through the CDHC pilot programme

The number of clients contacting the approved providers to engage home care through the CDHC programme ranged from 0 to 12 with an average of 5 clients across all 9 approved providers. Two of the approved providers were not engaged to deliver home care through the pilot programme. On average, 559 hours of home care were delivered to 48 CDHC clients across the 9 approved providers and this ranged from 0 hours in two approved providers to 1,961 hours from one approved provider. This total number equated to an average of 35 hours of care per week delivered to 48 clients under the CDHC programme across all 9 approved providers who responded to the survey. This weekly average ranged from 0 hours to a maximum of 101 hours per week. Across all 9 approved providers, 5,030 hours of care were delivered through the CDHC programme. A total of 30 hours of home care services provided through the CDHC programme were delivered by a nurse. The vast majority of the CDHC care hours were delivered by a care assistant

5.1.9 Service delivery to clients through the CDHC pilot

The approved providers indicated that they offer home care services 24 hours a day, seven days a week including bank holidays and weekends. Of the 7 approved providers who have been engaged by clients through the CDHC programme the average majority of the care hours (74%) are delivered between 8am and 5pm. No care hours are delivered through the CDHC programme between 12 and 8am.

Table 5d: Percentage of care hours delivered through the CDHC pilot programme at different time periods

	Average %	Min %	Max %
Percentage of CDHC care hours delivered at the weekend (Saturday and Sunday)	9%	0%	20%
Percentage of CDHC care hours delivered between 8am and 5pm	74%	12%	90%
Percentage of CDHC care hours delivered between 5pm and 12am	8%	0%	25%
Percentage of CDHC care hours delivered between 12am and 8am	0%	0%	0%

The 7 approved providers who were engaged by clients to deliver care through the CDHC programme provided a full range of personal care (medications, washing/dressing), home help (light housekeeping, laundry, meals) as well as companion care.

Table 5e: Percentage frequency by which services are provided to clients under the CDHC programme by approved providers (N=7)

	Yes	No
Shopping for food, prescriptions and clothes	71.4	28.6
Preparing meals	100	0
Doing routine jobs around home (washing dishes, sweeping floors, putting out the bins)	100	0
Personal laundry and ironing	85.7	14.3
Prompting clients to take medicines at the right times	28.6	71.4
Washing and dressing the care recipient	100	0
Assisting the care recipient to get in and out of bed	85.7	14.3
Assisting the care recipient to get to and use the toilet	100	0
Assisting the care recipient to cut up and eat food	85.7	14.3
Assisting the care recipient with recommended exercises, activities or therapies	57.1	42.9
Supporting the care recipient in applying for any benefits and advice they might be entitled to	14.3	85.7
Assisting the care recipient with pet care	28.6	71.4
Transporting the care recipient to shops and appointments	28.6	71.4
Transferring and positioning of care recipients	85.7	14.3

While 86 percent of the approved providers (n=6) indicated that there is capacity for the clients partaking in the CDHC pilot programme to pay for additional care hours (in addition to their voucher provision) none of the clients had done so.

5.1.10 Cost of travel

None of the approved providers who responded to the survey (N=9) indicated that they charged the care recipient for the cost of travel to their home, additional to the cost of direct care service provision. One of the approved providers indicated that they did have an upper limit on the distance a care worker can travel to deliver care to a client under the CDHC programme and this upper limit was 13 kilometres.

5.2 Care Recipients Questionnaire (SEQ-1) Analysis

5.2.1 Demographic Information

Of the 59 people who were approached to participate in this evaluation study, 13 completed the questionnaire with a member of the research team either face-to-face or via telephone. This represents a 22 percent response rate. The majority of the respondents (92%) were aged 76 years and older and the remaining 8 percent were aged between 55 and 75 years. Of the 13 respondents to the questionnaire, 77 percent were female and 62 percent were living in County Clare. The remaining 38 percent were living in County Limerick or Limerick City. Figure 5.1 illustrates the breakdown of respondents' educational attainment. The majority of respondents (46%) had obtained a third level qualification.

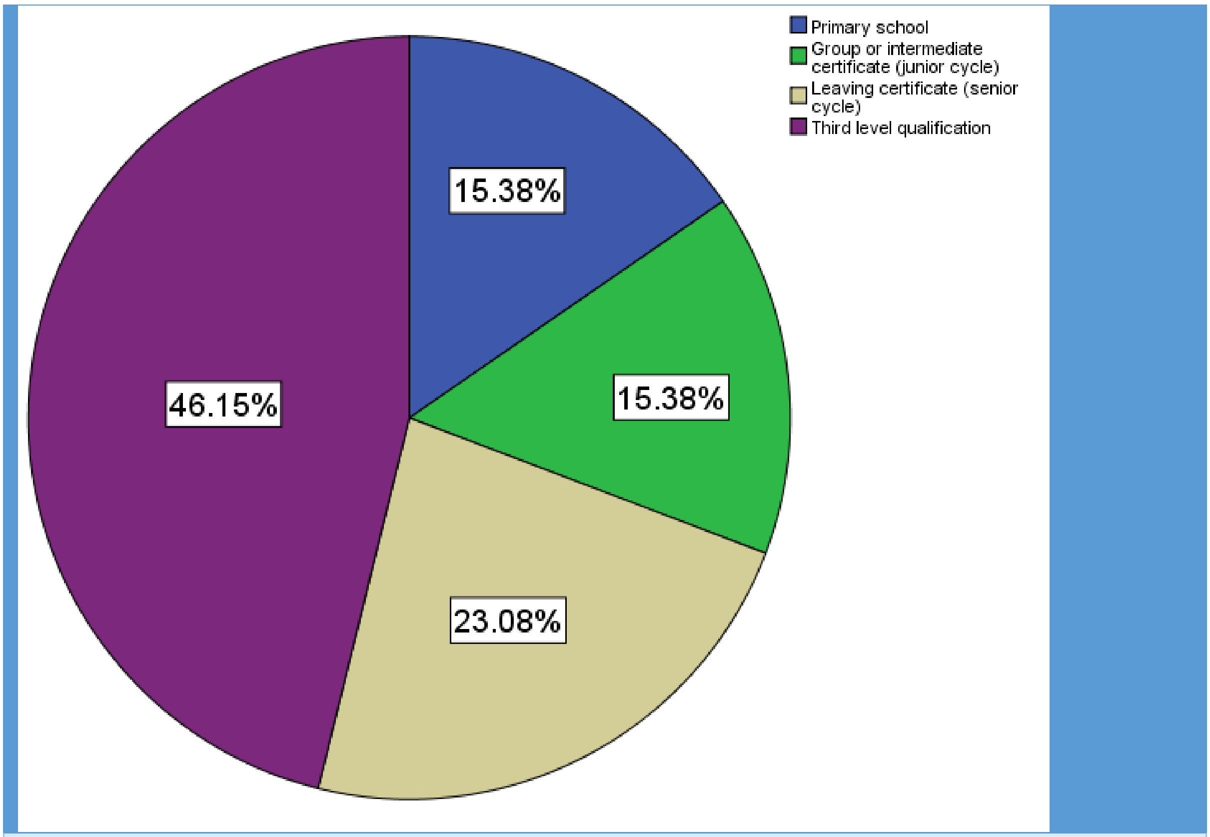


Figure 5.1: Respondents' Self-Reported Highest Level of Educational Attainment (N=13)

5.2.2 Self-Reported Health

All 13 of the questionnaire respondents reported that they had a long-term illness, health problem or disability that has lasted for the past 6 months. A minority (23%) noted that they had attended an emergency department between 1 and 3 times in previous 6 months to receive care. The remaining 77 percent had not attended an emergency department in the 6 months prior to completing the questionnaire. The respondents were asked to rate their general health in the 4 weeks prior to completing the questionnaire using a five point Likert scale ranging from excellent to very poor. The majority of the respondents (38%) rated their general health as fair with the next most frequent response being good (23%). Figure 5.2 below illustrates the distribution of respondents according to their self-reported general health evaluations.

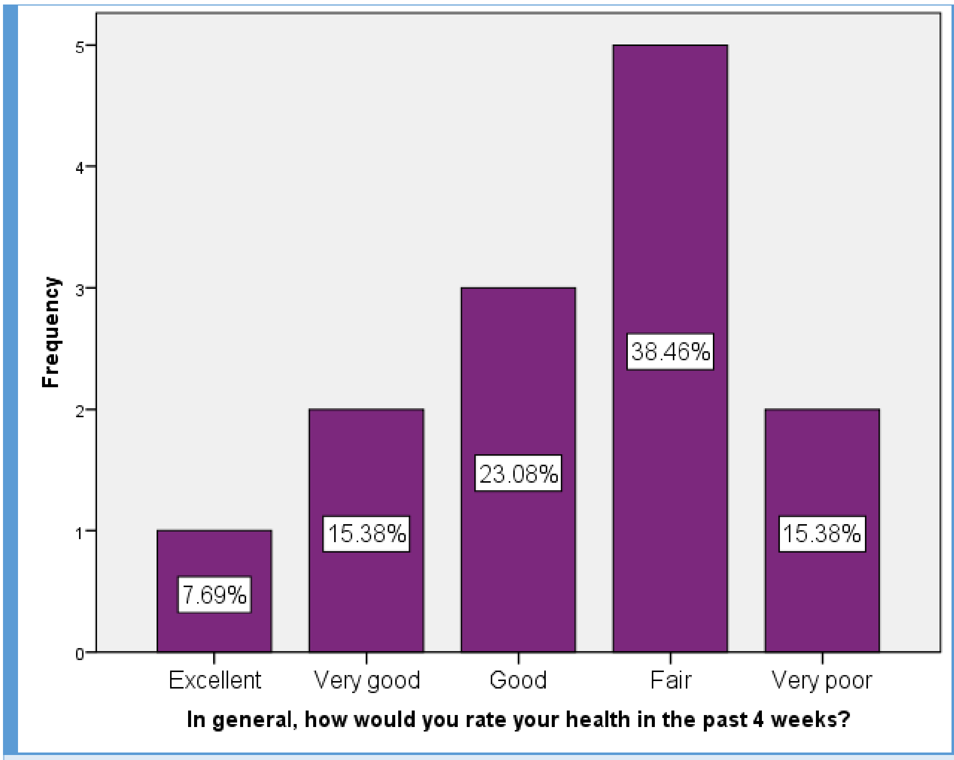


Figure 5.2: Distribution of respondents according to their self-rated general health in the 4 weeks prior to completing the survey (N=13)

The respondents (N=13) were asked about their activities of daily living in order to assess their self-rated care needs. Table 5f below provides the distribution of their responses as to their ability to undertake ten activities of daily living.

Table 5f: Distribution of responses according to self-reported ability to undertake activities of daily living (N=13)

Activity of Daily Living	Yes	No
Are you able to go shopping for food and clothes without any help?	30.8%	69.2%
Are you able to prepare your own meals without any help?	46.2%	53.8%
Do routine jobs around your home (washing dishes, sweeping floors, putting out the bins) without any help?	38.5%	61.5%
Take your medicines in the right doses and at the right times without any help?	76.9%	23.1%
Use public transport or drive yourself for routine journeys?	38.5%	61.5%
Wash and dress yourself without any help	61.5%	38.5%
Get in and out of bed without any help	92.3%	7.7%
Move about your house without any help (walking aid, walking stick allowed)	84.6%	15.4%
Get to and use the toilet without any help	100%	0%
Cut up and eat your food without any help	84.6%	15.4%

5.2.3 Evaluation of the CDHC Pilot Programme

5.2.3.1 Setting up home care under the CDHC pilot

All 13 of the respondents to the evaluation survey took up the option to receive their home care through the CDHC pilot programme. For 46 percent of the respondents this was the first time they had engaged home care services. Prior to receiving home care through this pilot programme, 23 percent received care delivered by a family member and friend or a neighbour. A further 15 percent received less than 3 hours per week of care from a professional home carer prior to participating in the pilot programme. Figure 5.3 below illustrates the distribution of respondents according to their care arrangements prior to participating in the pilot programme.

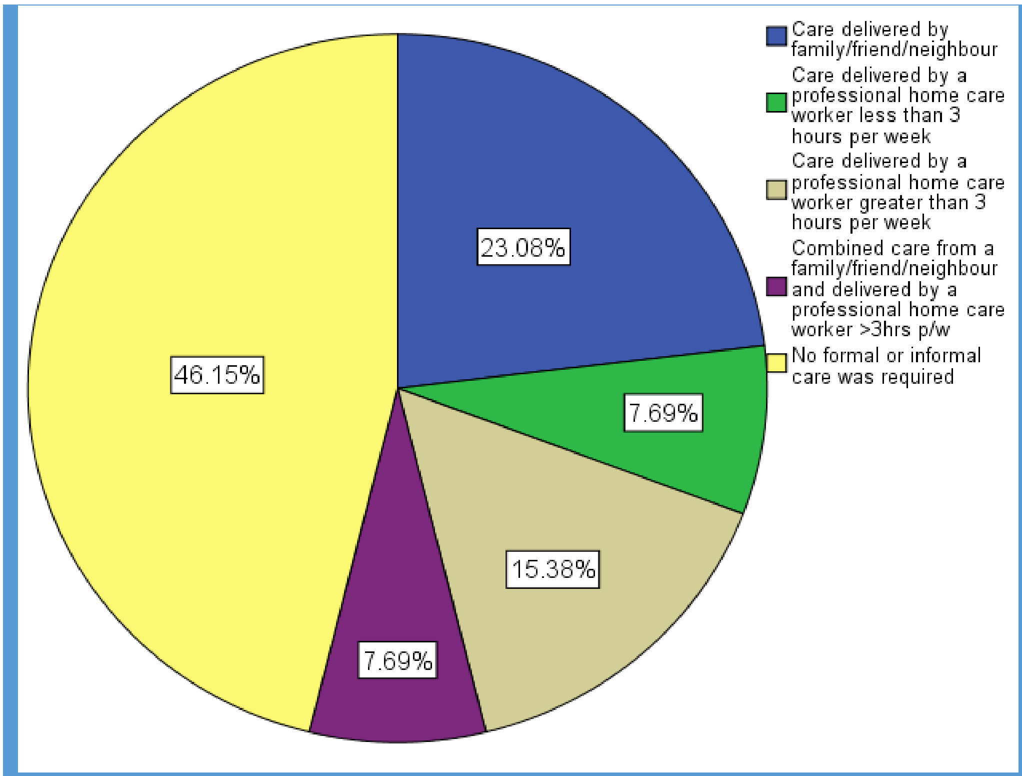


Figure 5.3: Distribution of respondents according to their home care arrangements prior to participating in the CDHC pilot programme (N=13)

The majority of the respondents (46%) indicated that they first heard about the pilot CDHC programme through their public health nurse. A further 39 percent were referred to the programme upon discharge from hospital and 15 percent heard about the pilot through their general practitioner or another healthcare professional. 33 percent of the respondents indicated that they found the ‘voucher system’ for arranging care under the CDHC pilot difficult to understand and 67 percent had no difficulty understanding the system. 46 percent of the respondents researched and found the care provider themselves and further 46 percent indicated that a family member or friend undertook the research to find the care provider. The overall majority of the respondents (92%) said that they had received enough support and accessible information to assist with arranging their home care through the CDHC ‘voucher system’. The majority of respondents (46%) found an approved provider using the ‘voucher system’ for arranging home care within 1-2 weeks of receiving their voucher and a further 31 percent identified their approved provider within one week of receiving their CDHC voucher. Figure 5.4 below shows the distribution of respondents according to how long it took for them to identify an approved provider from the point of receiving the voucher through the CDHC pilot.

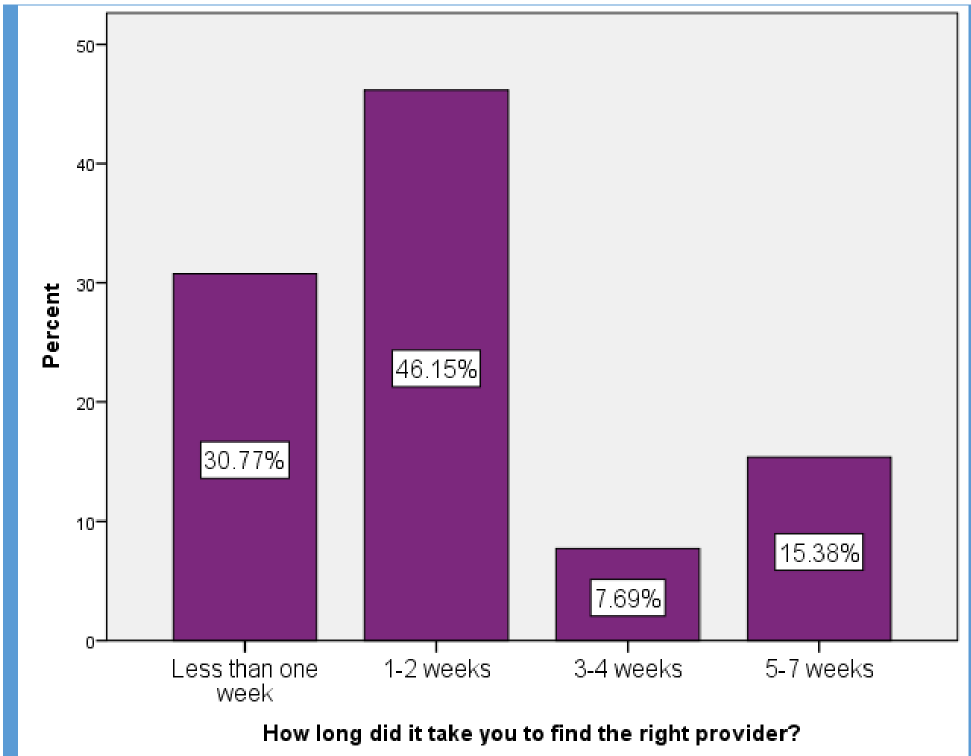


Figure 5.4: Distribution of respondents according to how long it took them to identify an approved provider from the point of receiving their CDHC voucher (N=13)

5.2.3.2 Evaluating the experience of care under the CDHC pilot

The overall majority of the respondents (92%) indicated that the voucher they received following their assessment for the CDHC pilot programme was sufficient to allow them to purchase enough care to meet their weekly need. All of the respondents redeemed the full monetary value of their voucher every week and a majority of them (85%) were very satisfied with the range of care services offered by the approved providers participating in the CDHC pilot. Table 5g displays the percentage frequency with which different care activities were reported by the respondents as being performed by the approved providers under the CDHC pilot programme. The most frequently cited activity performed by the home carer provided under the CDHC pilot was doing routine jobs around the home (92%) followed by preparing meals (46%) and personal laundry and ironing (46%).

Table 5g: Distribution of responses according to activities of daily living with which CDHC carer assists (multiple activities selected) (N=13)

Activity of Daily Living	Yes	No
Shopping for food and clothes	38.5%	61.5%
Preparing your meals	46.2%	53.8%
Doing routine jobs around your home (washing dishes, sweeping, putting out the bins)	92.3%	7.7%
Your personal laundry and ironing	46.2%	53.8%
Prompting you to take your medicines at the right times	30.8%	69.2%
Washing and dressing	30.8%	69.2%
Getting in and out of bed	7.7%	92.3%
Moving about your house	7.7%	92.3%
Getting to and using the toilet	0%	100%
Cutting up and eating your food	15.4%	84.6%
Assisting you with recommended exercises, activities or therapies	23.1%	76.9%
Supporting you in applying for any benefits and advice you might be entitled to	0%	100%
Transporting you to shops and appointments	30.8%	69.2%

The respondents were asked to assess whether all their care needs were currently being met by the carer provided under the CDHC pilot programme using a five point Likert scale ranging from strongly agree to strongly disagree. The majority of the respondents (69%) strongly agreed that all their care needs were being addressed and a further 15 percent agreed. Figure 5.5 below illustrates the distribution of respondents according to their assessment as to whether all their care needs were being addressed.

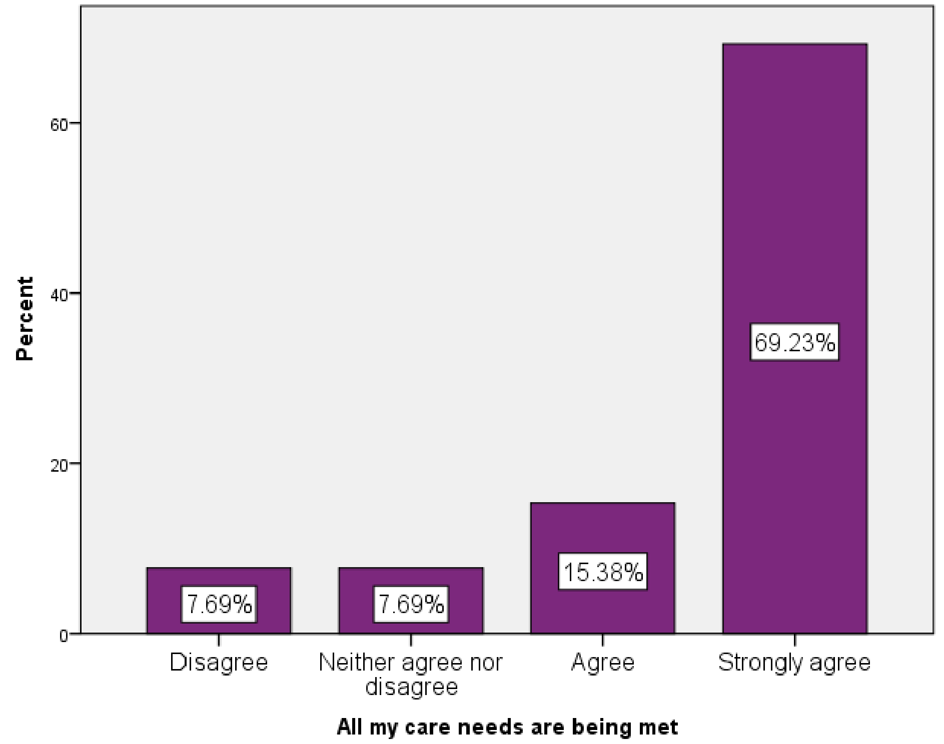


Figure 5.5: Distribution of respondents according to their assessment as to whether all their care needs were being addressed under the CDHC pilot programme (N=13)

Using a five point Likert scale ranging from strongly agree to strongly disagree the respondents were asked to assess the general quality of care they have received under the CDHC pilot and whether there is enough choice in the care provision to fit around their own weekly activities/preferences as well as activities of their family/friends or neighbours involved in their care. The majority of respondents (78%) strongly agreed that they were happy with the quality of care they have received. 62 percent strongly agreed that there was enough choice in care provision to suit their own weekly activities or preferences. 54 percent strongly agreed that there was enough choice to suit their family/friends/neighbours involved in their care. Table 5h shows the distribution of respondents according to their level of agreement with these three evaluation items.

Table 5h: Distribution of respondents according to Likert scale responses to three evaluation statements (N=13)

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I am happy with the quality of care I have received	0%	0%	0%	23.1%	76.9%
There is enough choice in the care provision to fit around my weekly activities/preferences	0%	0%	7.7%	30.8%	61.5%
There is enough choice in the care provision to suit those family/friends/neighbours involved in my care	0%	0%	23.1%	23.1%	53.8%

Using a Likert scale ranging from strongly agree to strongly disagree the respondents were asked to evaluate whether the approved provider responsible for delivering their home care under the CDHC pilot programme was prepared to be flexible in the care arrangements. 54 percent of the respondents strongly agreed that the approved provider organisations were prepared to be flexible with a further 46 percent agreeing. The majority of the respondents (92%) indicated that if they became dissatisfied with the quality of care they receive under the pilot programme they would know who to contact to tell their concerns to.

Since participating in the CDHC pilot programme 92 percent of the respondents indicated that less than two different approved providers have provided them with care services. A further 8 percent of the respondents had received care from between two and four different approved providers while participating in the pilot. The majority of the respondents (92%) have received care from less than five different home care workers with 8 percent receiving care from between five and ten different home care workers. All of the survey respondents indicated that they have met the same carer enough times to build a good relationship with them and all of them indicated that they would recommend participating in the CDHC pilot to a friend.

5.3 Family Carers' Questionnaire (SEQ-2) Analysis

5.3.1 Demographic Information

The 59 people who were offered the opportunity to participate in the CDHC pilot programme were asked to identify a family carer (including a friend or neighbour) who may have been instrumental in assisting them to establish home care under the pilot programme. A total of 20 family carers returned a completed evaluation questionnaire through the post. The majority of these family carers were women (70%) and 50 percent indicated they were a spouse/partner of the CDHC care recipient. A further 35 percent indicated they were the care recipient's son or daughter. Of the 20 family carers who responded, 80 percent indicated that they were the primary source of non-professional care for the CDHC care recipient. Figure 5.6 illustrates the distribution of respondents according to their age.

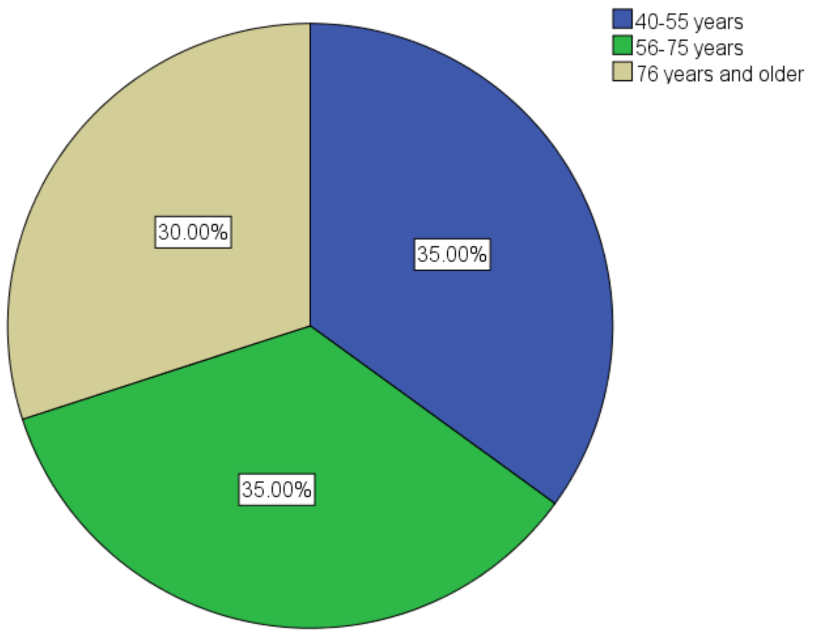


Figure 5.6: Distribution of family carers according to age (N=20)

The majority (45%) of the respondents indicated that they have provided family care or support to the CDHC recipient for between 3 and 5 years and a further 35 percentage had delivered family care or support for less than 3 years. Figure 5.7 below illustrates the distribution of respondents according to how long they have been providing family care or support to the CDHC care recipient.

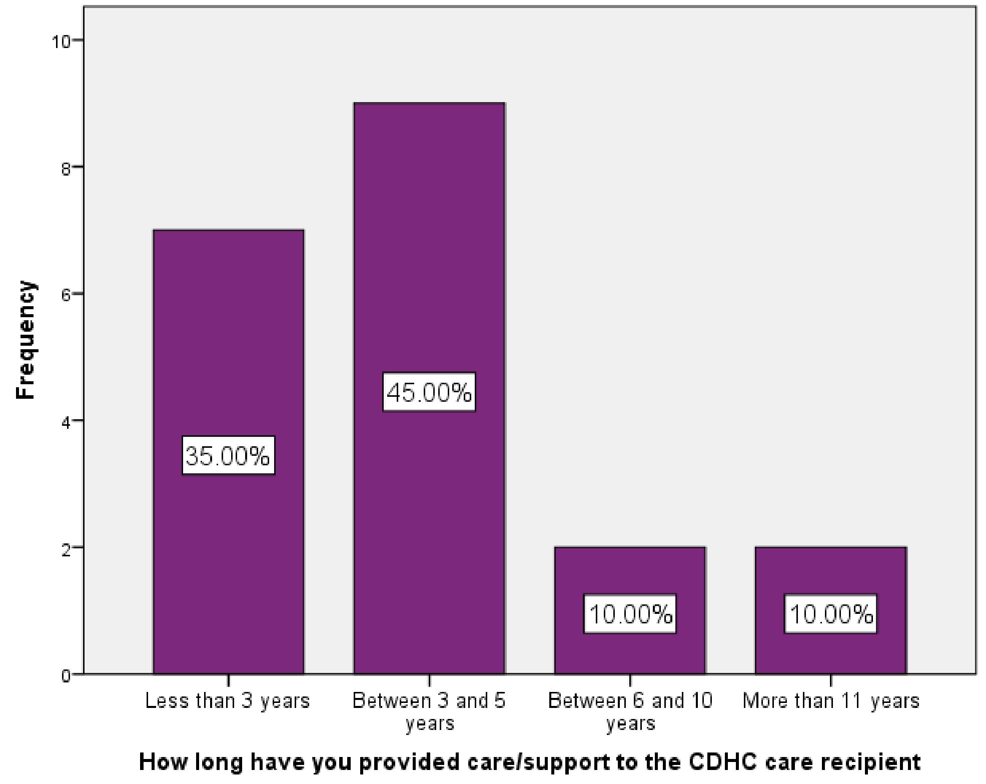


Figure 5.7: Distribution of respondents according to how long they have been providing family care or support to the CDHC care recipient (N=20)

5.3.2 Employment and health status

The majority of the respondents (60%) indicated that they were retired with a further 20 percent indicating they were employed part-time (less than 30 hours per week). A total of 15 percent of the respondents were employed fulltime and 5 percent indicated they were self-employed. Of the 20 respondents to this questionnaire, 37 percent indicated that they had a long-term illness, health problem or disability that had lasted 6 months or more. The respondents were asked to rate their general health in the 4 weeks prior to completing the questionnaire using a five point Likert scale ranging from excellent to very poor. The majority of the respondents (45%) rated their general health as good with the next most frequent response being very good (25%). Figure 5.8 below illustrates the distribution of respondents according to their self-reported general health evaluations.

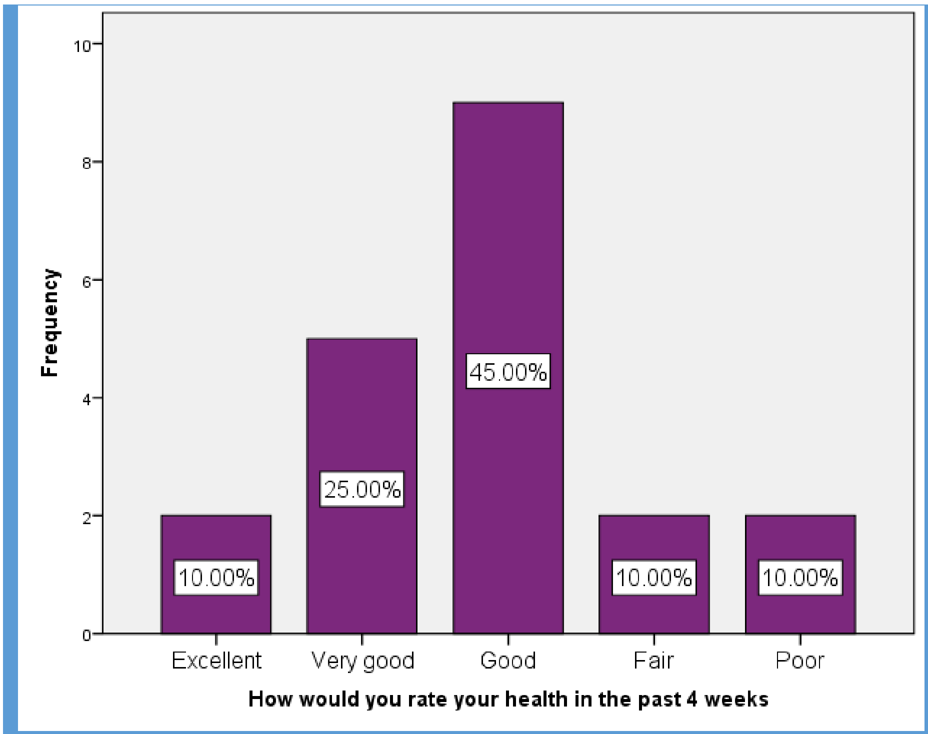


Figure 5.8: Distribution of respondents according to their self-rated general health in the 4 weeks prior to completing the survey (N=20)

5.3.3 Evaluation of the CDHC Pilot Programme

5.3.3.1 Impact of CDHC on family care hours

The majority of the respondents (47%) indicated that prior to the care recipient participating in the CDHC pilot programme, their home care was delivered by family or friends. A further 20 percent of respondents indicated that the care recipient didn’t receive any formal or informal care prior to participating in the CDHC pilot programme. Prior to participation in the CDHC pilot programme, a majority of the respondents (58%) provided more than 15 hours of care per week to the care recipient. A further 26 percent of the respondents provided 3-7 hours of care per week to their family member prior to the CDHC pilot programme. Figure 5.9 illustrates the distribution of respondents according to how many hours of care per week they provided to the care recipient prior to the CDHC programme.

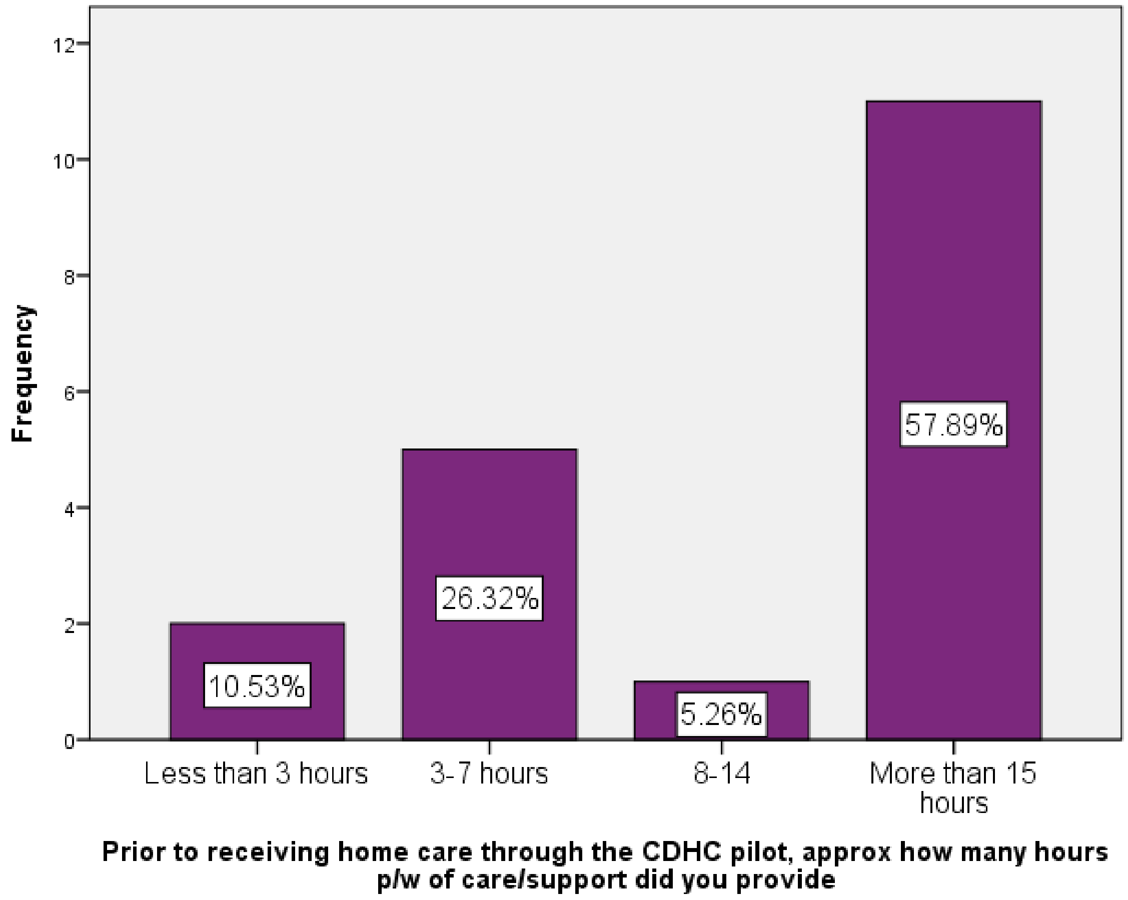


Figure 5.9: Distribution of respondents according to how many hours of care they provided to the care recipient prior to participation in the CDHC pilot programme

Following participation in the CDHC pilot programme, 53 percent of the respondents indicated that they provided more than 15 hours of care per week to the care recipient. A further 21 percent indicated that they provided 3-7 hours of care to the care recipient since participation in the CDHC pilot programme. Figure 5.10 illustrates the distribution of respondents according to how many hours of care they provide to the care recipient since participation in the CDHC pilot programme.

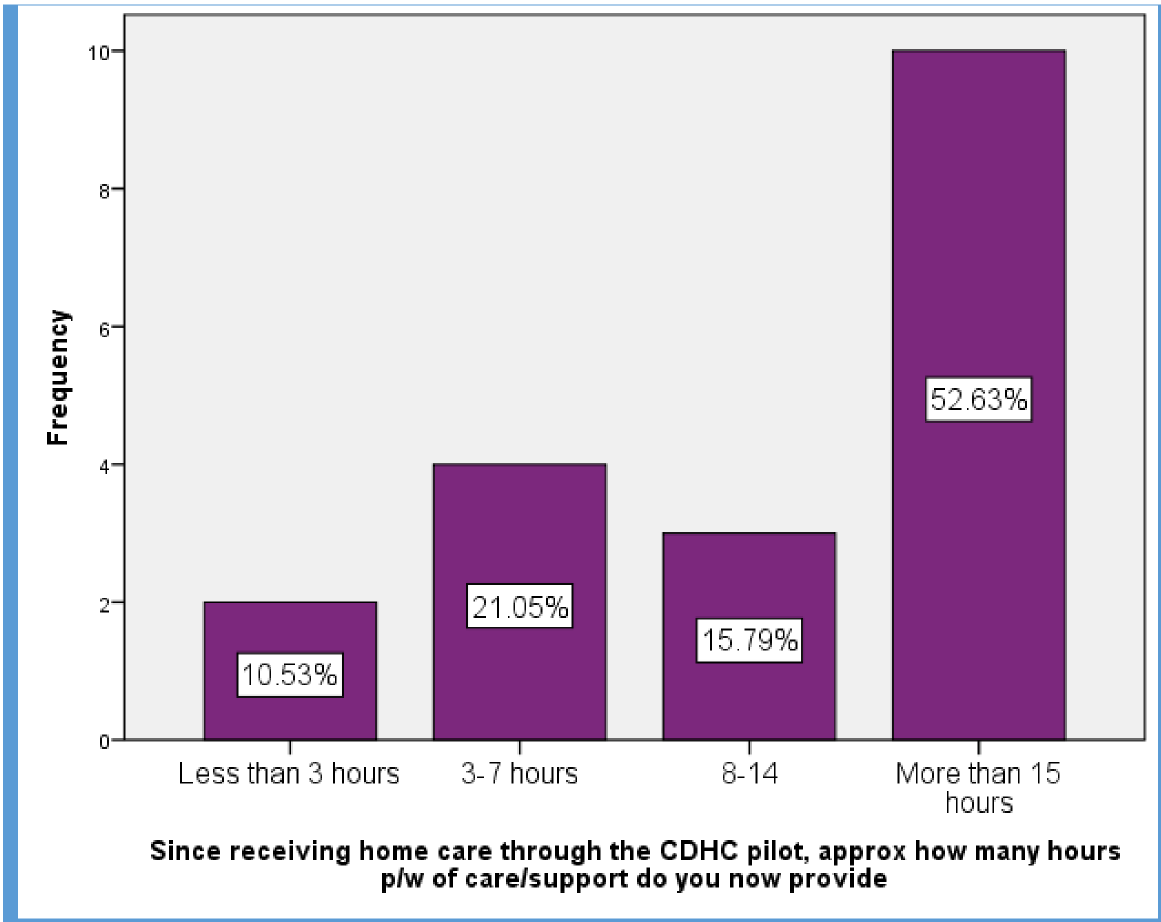


Figure 5.10: Distribution of respondents according to how many hours of care they provided to the care recipient since participation in the CDHC pilot programme

5.3.3.2 Setting up home care under the CDHC pilot

The majority of the respondents (80%) indicated that they assisted the CDHC care recipient to make the decision to participate in the pilot program. All of the respondents (N=20) indicated that they had enough support and accessible information to assist them in arranging home care through the voucher system. A majority of the respondents (35%) indicated that it took less than one week to find the right approved provider under the CDHC pilot programme a further 23 percent indicated that it took between 3 and 4 weeks. Figure 5.11 illustrates the distribution of respondents according to how long it took to find the right care provider under the CDHC pilot programme.

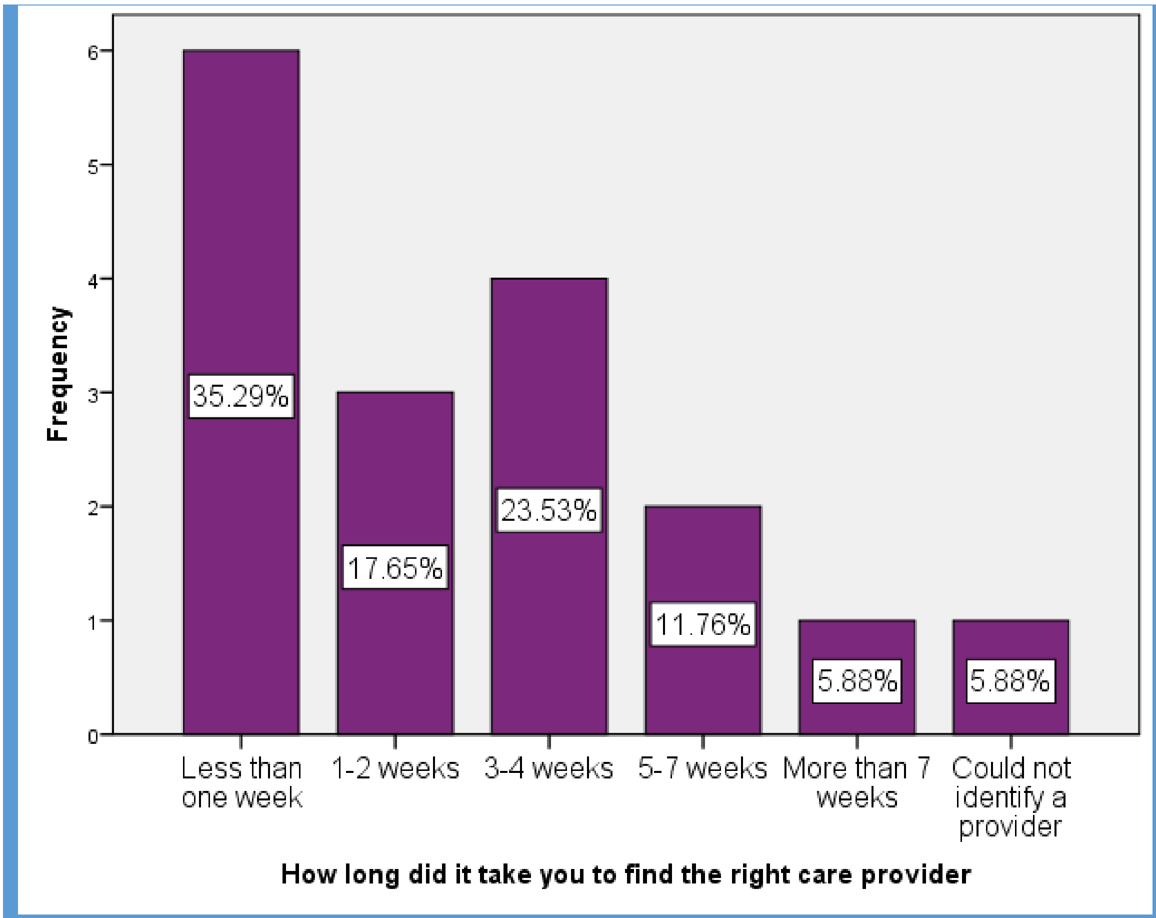


Figure 5.11: Distribution of respondents according to how long it took to find the right approved provider under the CDHC pilot programme (N=17, Missing = 3)

A majority of the respondents (62%) indicated that the voucher was sufficient to purchase enough care to meet the care recipients' weekly need. A further, 37 percent indicated that it was not enough to meet weekly need. All of the respondents indicated that the full monetary value of the voucher was redeemed every week.

5.3.3.3 Evaluating the experience of care under the CDHC pilot

The respondents were asked to rate their level of satisfaction with the range of care services offered by the care providers participating in the CDHC pilot programme using a five point Likert scale ranging from very satisfied to very dissatisfied. A majority of the respondents (70%) indicated that they were very satisfied with the range of services. Figure 5.12 illustrates the distribution of respondents according to their level of satisfaction with the range of services.

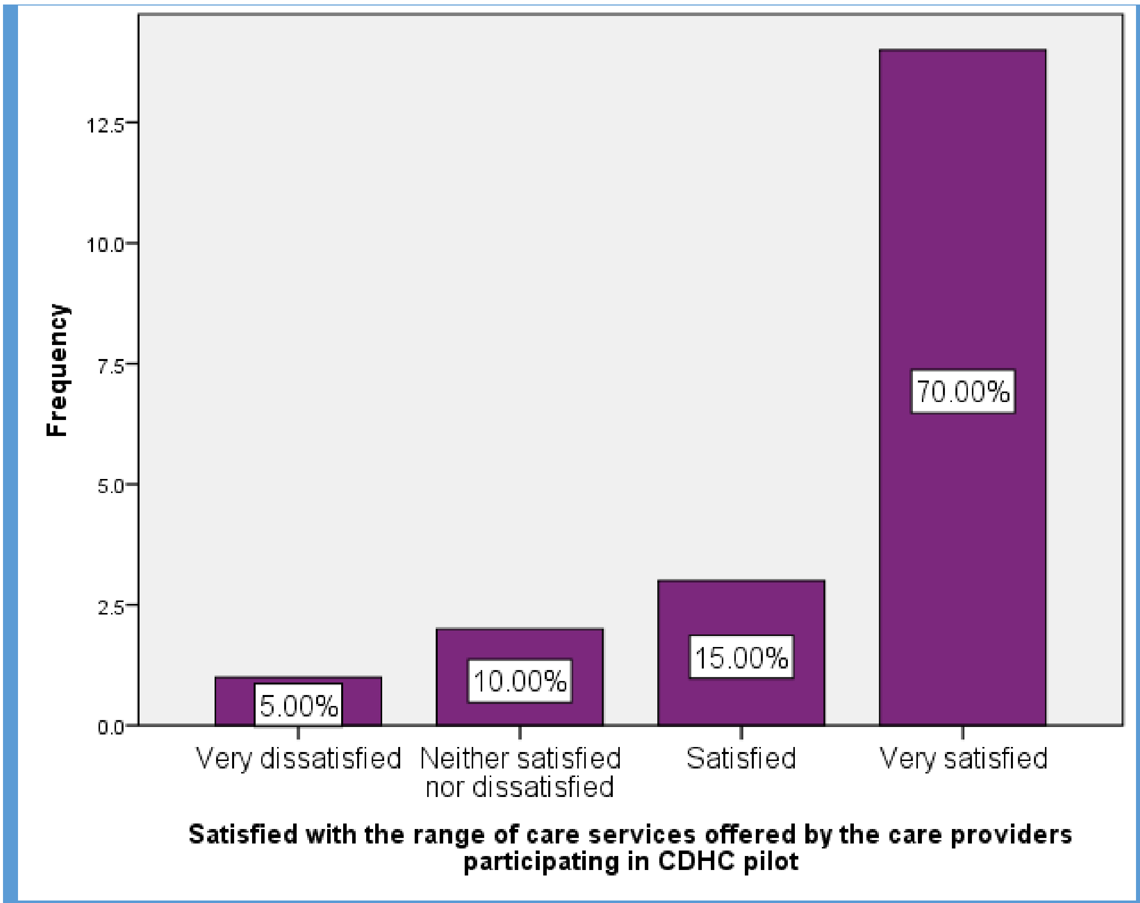


Figure 5.12: Distribution of respondents according to how satisfied they are with the range of services offered by the approved providers participating in the CDHC pilot programme (N=20)

The respondents were asked to indicate their level of satisfaction with the quality of care delivered by the professional home care worker under the CDHC pilot programme using a five point Likert scale ranging from very satisfied to very dissatisfied. 74 percent of the respondents indicated that they were very satisfied with the quality of care and a further 21 percent were satisfied. All of the respondents indicated that if they became dissatisfied with the quality of care they would know who to contact to report their concerns. A majority of the respondents (82%) indicated that the care recipient had additional care needs which were not currently being addressed by the CDHC home carer.

Using a five point Likert scale ranging from strongly agree to strongly disagree, the respondents were asked to rate their level of agreement to a sequence of statements assessing the impact participation in the CDHC pilot programme has had on them personally. A total of 53 percent agreed that their levels of stress and anxiety about the care recipient has decreased since participation in the CDHC programme. A further, 65 percent agreed that they feel more supported in their caring role and 35 percent strongly agreed that they feel more optimistic about their family member's ability to live independently. Furthermore, 55 percent agreed that they have more time to do things that they enjoy, additionally 35 percent agreed that they have more time for work or for other caring roles and 50 percent agreed that they do not have to travel as much to take care of their family member since participation in the CDHC pilot programme. Table 5i indicates the distribution of respondents according to the five point Likert scale for each of the impact items.

Table 5i: Distribution of respondents according to the five point Likert scale for each of the items assessing the personal impact of participation in the CDHC pilot programme (N=18, Missing =2)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
My levels of stress and anxiety about my family member/neighbour/friend has decreased	0%	5.3%	21.1%	52.6%	21.1%
I feel more supported in my caring role	0%	0%	5.6%	72.2%	22.2%
I feel more optimistic about my family member's/friend's/neighbour's ability to live independently	5.0%	15.0%	20.0%	25.0%	35.0%
I have more time to myself to do things I enjoy	5.0%	0%	20.0%	55.0%	20.0%
I have more time for work and/or for my other caring roles	5.6%	5.6%	27.8%	38.9%	22.2%
I do not have to travel as much to take care of my family member/neighbour/friend	5.6%	0%	27.8%	55.6%	11.1%

Since participating in the CDHC pilot programme 85 percent of the respondents (N=20) indicated that less than two different care organisations have provided their family member with care services. A further 15 percent of the respondents indicated that their family member received care from between two and four different care providers while participating in the pilot. All of the respondents indicated that their family members have received care from less than five different home care workers. All of the survey respondents indicated that they would recommend participating in the CDHC pilot to a friend.

5.4 Findings from questionnaire with CDHC Steering Group and Project Team (SEQ-4)

The CDHC Steering Group and Project Team are comprised of 10 people. 7 responses to SEQ-4 were received. All 7 respondents to SEQ-4 were HSE employees. 5 respondents had prior experience of sitting on a similar HSE Group and/or Project Team, 2 did not. Table 5j displays the disciplinary backgrounds of the respondents.

Table 5j: Disciplinary backgrounds of SEQ-4 respondents

Disciplinary background	Number of respondents
Nursing	5
Social work	0
Medicine	0
Allied Healthcare Professional (OT, SLT, Physio)	1
Other (please specify)	1

The role specified under "other" was home help coordinator. All respondents reported having experience of home care service delivery prior to sitting on the CDHC Steering Group and Project team. A range of experiences was described, including direct delivery of nursing and home care services, and varying levels of management and coordination of these services. Table 5k below shows the percentage of their professional time that respondents dedicated to the CDHC pilot project.

Table 5k: Percentage of professional time dedicated to the CDHC pilot project

Estimated percentage of professional time dedicated to CDHC pilot project	Number of SEQ-4 respondents
Less than 5%	1
Between 6-15%	5
Between 16-20%	0
Greater than 20%	1

5.5 Economic analysis

This analysis aimed to better understand the economics of the CDHC pilot programme and assess other quantitative variables, such as the time taken between assessment and care delivery and how these vary by providers, location and so on.

The analysis was based on the following research questions:

1. What are the costs of the CDHC programme?
2. How do costs vary by provider and location? Are there outliers influencing the average costs?
3. What are the savings to the HSE from outsourcing the identification of carers to the client?
4. What is the average length of time between assessment and care delivery? How does this vary by approved provider and location? Are there outliers influencing it?

An anonymised database was provided to the health economist in January 2018 for analysis. This included information on geography, approved provider and number of care hours, which could be compared with cost.

5.5.1 Describing the dataset

The database entries were split into two locations: urban (n=24) and rural (n=32). A second key variable is the approved provider of care services. There were six included in the analysis: Provider 1 (n=8), Provider 2 (n=9), Provider 4 (n=14), Provider 5 (n=6), Provider 6 (n=10) and Provider 8 (n=3). Most clients were referred by Public Health Nurses (72%) or Community Registered General Nurses (18%).

There were also five cases where the approved provider was not identified due the client, or their families not contacting or choosing an approved provider, or a lack of available carers. In addition, several potential clients declined to participate in the CDHC. If we take these five and the additional two who declined earlier in the project, we have a total dropout of 7 from a sample of 58, or a dropout rate of 12 percent. However, this is likely to underestimate the numbers that will decline the CDHC, or for whom it will not be suitable. In discussion with the HSE, it emerged that some clients were not able to negotiate the acquisition of care by themselves, perhaps because of mental health issues or a lack of skills. A finding from this pilot therefore is that the CDHC can only ever be optional as it will not suit every client. The average number of hours approved was 7.55. However, this ranged from 1 hour for some clients to 17.5 hours.

5.5.2 The costs of CDHC

The mean cost for the CDHC voucher is €167.27. There is a skew to the left within the dataset, due to some high cost outliers increasing the average. The median is therefore lower than the average at €137, and the range is €23 to €502. This suggests that the more intensive care needs are also costlier to deliver. Generally, packages of care of 10 hours or under are often delivered on a Monday to Friday basis. Over 10 hours ‘generally’ includes Sunday as a care day option. If Sunday hours are believed to be required, that number of hours are factored into the voucher value. This may be because Sunday rates are paid at a higher rate and these are most likely included.

Across the board, the average number of hours recommended to the HCP coordinator for approval was higher than those approved (7.59 vs 7.16). For most clients there was no difference in recommended and received hours but for a small number there was a difference, sometimes as high as 6 or 7 hours less than what was recommended. Where more care is provided, this was following a review of client’s needs. Care was increased following approval from the HCP coordinator. The recommended figure was from the first assessment. The Pilot did not record private hours purchased by families outside the CDHC.

There were also a few examples of where more care was provided than the amount recommended to the HCP coordinator. This reflected situations where the client was found to have higher care needs at review and number of care hours was increased accordingly. A second area of interest is the costs by location and approved provider. The average cost was also higher in rural compared with urban locations (€179 compared with €150 respectively), which may reflect a higher degree of care needs. The value of the voucher is the same regardless of the approved provider, as it is based on nominal hours required following an assessment of individual client need. When we compare the cost per hour by Approved provider we see quite a bit of difference in the values. However, these averages take Sunday hours into account and are therefore not necessarily comparable with each other i.e. the value may be higher because there are more Sunday hours.

Table 5l: Average voucher value by approved provider

Approved Provider	**Average voucher**
Provider 4	€225.90
Provider 6	€146.05
Provider 2	€125.06
Provider 5	€209.25
Provider 1	€142.57
Provider 8	€186.83

5.5.3 Costs of matching clients with providers

A potential saving for the HSE comes from freeing up of staff time from not having to source carers for clients. To estimate this, an informal time and motion study was conducted. Staff were asked to record the length of time that they spend on sourcing care for those not in the CDHC pilot. These data were used to calculate the value of time saved to the HSE. From a total economic perspective, this is not a ‘saving’ as such, as the task is passed on to the client, who must expend time and expense to identify their own approved provider. Nonetheless, it does free up time within the HSE to devote to other activities.

The results suggest that for straightforward cases, staff spend an average of 0.5 hours sourcing carers. However, for more complicated cases, this time is greater. We have used these data to estimate the HSE savings from the pilot. Based on the numbers with Home Care packages in 2017, we estimate an annual saving of approximately €27,000. Table 5m details the calculations.

Table 5m: Calculation of estimated annual saving to HSE based on pilot

Variable	**Value**
Total number of clients	1149
Total after dropout	1011
Proportion with high needs	26%
Estimate of time on high needs	1 hour
Estimate of time on low needs	0.5 hours
Salary estimate (Home Care Package Coordinator ADPHN)	€68,049
Number of annual hours spent (high needs)	263
Number of annual hours spent low needs)	374
Total number of hours expended on identifying care	637
Average number of hours in year	1610
Proportion of time spent in year	0.4
Total saving	€26,924

There are several assumptions underpinning this calculation. Based on the pilot data, we estimate that 26 percent of clients have high needs (using more than 10 hours of care as a proxy). We know that these cases are more time consuming but do not have an estimate, so we assume that it takes a full hour to access care for them. Our estimate of the average number of hours in a year is based on a 35 hour week and six weeks of holiday. The salary cost includes national insurance. Finally, the drop-out rate of 12 percent is based on the dropout from the pilot but may be an underestimate.

The figures only include Home Care Packages. However, if we extend the analysis to Home Help, we find a further potential saving of €22,951, or a total saving of €49,875. This is based on 1,171 Home Help clients in 2017 with a salary estimate based on the cost of a Home Help Coordinator (Grade VI).

The costs identified here may still underestimate the time spent identifying approved providers. For example, it does not take into account any additional follow-up required e.g. where care is not available, and approved providers need to be communicated with regularly. A more formal time motion study would be required to make a fuller estimate of savings.

5.5.4 Time from approval to care delivery

One feature of the CDHC is that the client is responsible for finding their own care. One variable of interest is therefore whether this meant it takes longer to find care. We do not have a direct comparison for this, so can only report on the time taken through the CDHC. The mean (average) number of days from approval to care delivery is 87. The median is 80, again suggesting some higher outliers are pulling up the average. This varied by location (104 days in rural areas and 70 days in urban areas). The median for urban is lower suggesting a few high outliers, which if removed would widen the gap between urban and rural further.

Table 5n: Time between HSE care approval and delivery by location

Location	Mean time difference (days)	Median time difference (days)
All	87	80.5
Urban	70	62
Rural	104	99

There is quite a bit of variation by provider (from 115 days and 57). However, this may relate to rural locations for clients of approved provider 4 compared with approved provider 2. In discussions with the HSE, it was pointed out that this is not necessarily the fault of the approved provider. It may relate to a lack of haste on the part of the recipient, or for rural locations may relate to approved providers needing to travel further to meet with care recipients.

Table 5o: Time difference between care approval and delivery by provider

Approved Provider	Mean time difference (days)	Median time difference (days)
Provider 4	115.47	112.00
Provider 6	100.80	102.50
Provider 2	57.22	102.50
Provider 5	66.17	69.00
Provider 1	85.13	81.50
Provider 8	86.00	N/A

However, this merits further investigation, especially given risks of social isolation for older people in rural locations. It would be useful to understand what causes the delays in people finding care and where waits are long, what can be done to minimise it. A test of the CDHC going forward is whether introducing more competition into the home care market increases the availability of carers and reduces these time delays.

5.6 Conclusion

In conclusion, across all nine providers who participated in this study 5,030 hours of home care were delivered to clients participating in the CDHC pilot programme. This total number of hours equates to an average of 35 hours of home care per week delivered to CDHC clients. The vast majority of these CDHC care hours were delivered by care assistants and 74 percent were delivered between 8am and 5pm.

The vast majority of care recipients who completed the evaluation questionnaire were aged 76 years and older (92%) and were female (77%). All of the 13 care recipient respondents reported that they had a long-term illness, health problem or disability that had endured for at least the 6 months prior to completing the survey. However, the majority (61%) rated their general health as either fair or good. For nearly half of the care recipient respondents (46%) the CDHC pilot programme was the first time they had engaged professional home care services. A further significant group of the care recipient respondents (23%) had received home care delivered by a family member, friend or neighbour prior to engaging with the CDHC pilot programme.

The overall majority of the care recipient respondents (92%) said that they had received enough support and accessible information to assist with arranging their home care through the CDHC 'voucher system'. All of the respondents redeemed the full monetary value of their voucher every week and a majority of them (85%) were very satisfied with the range of care services offered by the approved providers participating in the CDHC pilot. The most frequently cited activity performed by the home carer provided under the CDHC pilot was doing routine jobs around the home (92%) followed by preparing meals (46%) and personal laundry and ironing (46%). The majority of the care recipient respondents (84%) strongly agreed or agreed that all their care needs were being addressed and were happy with the quality of care they have received (78%). All of the care recipient respondents indicated that they have met the same home carer enough times to build a good relationship with them and all of them indicated that they would recommend participating in the CDHC pilot to a friend.

A total of 20 family caregivers returned a completed evaluation survey through the post. The majority of these family caregivers were women (70%). Spouses as well as sons or daughters made up the vast majority of the family caregivers who responded to this survey (85%). Of the 20 family caregivers who responded, the overall majority (80%) indicated that they were the primary source of non-professional care for CDHC care recipient and they assisted the care recipient to make the decision to participate in the pilot program. All of the family caregiver respondents indicated that they had enough support and accessible information to assist them in arranging home care through the voucher system.

The vast majority of the family caregiver respondents (95%) were very satisfied or satisfied with the quality of care delivered to the care recipient. However, a majority (82%) indicated that the care recipient had additional care needs which were not currently being addressed by the CDHC home carer. A significant number of the respondents (53%) agreed that their levels of stress and anxiety about their family member had decreased since participating in the CDHC programme. Furthermore, a majority (65%) agreed that they feel more supported in their caring role and strongly agreed (35%) that they feel more optimistic about their family member's ability to live independently. All of the survey respondents indicated that they would recommend participating in the CDHC pilot to a friend.

It is expected that the CDHC will broadly be cost neutral for the HSE. The cost of the voucher should be comparable with the tendered price of care and although there is much variation by geography and provider, these are to be expected and tend to be driven by things like the number of Sunday hours. The one area of potential saving is from freeing up staff time from not having to source care. This is in effect a transfer of cost from the HSE to the client, or their family but it is a saving from the HSE's perspective. The saving from not having to source care for the pilot is, of course, small so we have generalised to the mid-West based on data for those on Home Care Package and Home Help services in 2017. What we found was potential annual savings of €26,924 and €22,951 respectively. However, these may underestimate the costs, as they are mostly reflective of less complex cases.

CHAPTER 6
DISCUSSION

6.0 Introduction

This chapter presents a discussion of the findings and limitations of the study. The aim of this study was to evaluate the quality and effectiveness of the CDHC pilot project, in terms of care recipient and care provider experiences, service fidelity, clinical outcomes, governance and financial sustainability. The objectives of the study were:

- To assess programme fidelity, i.e. to assess whether the CDHC pilot project was implemented as planned.
- To assess the quantity of the programme, i.e. to assess whether the CDHC pilot project was sufficient to attain the intended outcomes.
- To investigate the modality of the CDHC pilot, i.e. to investigate how the pilot was operationalised.
- To assess the reach of the CDHC pilot, i.e. to assess who participated in the pilot project.
- To identify any challenges in CDHC pilot implementation process.
- To examine contextual issues (local and external), which acted as facilitators or barriers to the pilot project's successful implementation.
- To examine the relative efficiencies of CDHC and the traditional model of service delivery.

As detailed in previous chapters, the qualitative findings are broadly classified under five main themes: understandings of CDHC, using the CDHC system, CDHC administrative process, governance and national issues. What follows is a presentation of the relationships between these themes and the findings from the analysis of the questionnaires, as well as the relevant literature and knowledge accrued internationally relating to home care service delivery for vulnerable adults.

6.1 Variability of conceptualisation of CDHC

The understandings of CDHC were found to vary within and between stakeholder groups consulted as part of the evaluation. This is reflective of trends in international literature, in that "consumer-directed care" is not a monolithic concept (Gill, McCaffery, Cameron, Ratcliffe, Kaambwa *et al.*, 2016). Rather, it refers to a collection of approaches with variable distributions of decision making and control between the consumer and care service provider. Approaches to consumer directed care may also vary according to services offered, functional and financial eligibility of clients, restrictions on hiring, sources of funding and administrative structures (Kodner, 2003; Genet *et al.* 2013). Whatever the iteration of consumer-directed care, all models are underpinned by certain core principles – empowerment, choice, control and autonomy for persons receiving care (Coleman, 2001; Newman *et al.*, 2009; Cash *et al.*, 2017). A CDHC approach also enables care purchasing outside the traditional public health care system (Laragy & Allen, 2015).

The findings from this study demonstrate that choice and flexibility were central tenets of the model of CDHC implemented in the pilot project. However, differing perspectives on the meaning of CDHC revealed a level of obscurity around its conceptualisation. Members of the CDHC Steering Group and Project Team expressed a clarity of understanding and specified that this project was about home care, as opposed to a broader concept of consumer-directed care without particular regard to setting. However, approved providers reported less clarity, and understandings among care recipients and families were also varied.

A particular point of obscurity seemed to relate to whether the CDHC model was based on hours of care of a monetary amount. This was particularly evident from the perspectives of care recipients and families, most of whom described the allocation of their care in terms of hours, rather than money. Since home care has been historically understood as a system of allocating hours, it is understandable that the adoption of a funding model would involve an adjustment period. Part of this adjustment would relate to shifts in mentality and attitude – a point made by participants in the evaluation. Participants representing stakeholders involved in the planning and delivery of care services noted that the redistribution of decision-making and influence in CDHC represents a considerable challenge due to the inherent need to relinquish a degree of control. These challenges of adjusting and changing mind-sets are documented in previous research, which observes that adjusting to new models of service delivery requires more than just procedural change and can be a slow process (KPMG, 2012; Laragy & Allen, 2015).

What appears to emerge from these findings is that any future approach to CDHC would require greater clarity and transparency around the definition and operational procedures of the model. This learning is aligned with findings from research in the United Kingdom, which has found that well-implemented personalisation programmes must have a very strong focus on good, continuous communication between local authorities and service providers, and ongoing feedback from service users (AgeUK, 2010; Gill *et al.*, 2016).

In line with the ethos of CDHC programmes, the centrality of the principles of choice and flexibility in the CDHC are borne out by the findings in this study. However, with regard to programme fidelity, not all care recipients reported actively choosing their approved providers, which suggests a level of departure from the planned implementation of the pilot. An important point to note here is the contingent nature of choice. The variety of care recipient experiences regarding choice in the CDHC requires a consideration of some contextual factors.

6.2 Supply of care

6.2.1 Formal care

The most significant prerequisite for choice is supply. Within the context of the findings, a total of 5,030 hours were delivered by the nine approved providers in the CDHC study. Although the majority of care was delivered by health care assistants, a common theme from consultation with all stakeholders was the national shortage of formal carers, and the geographical variation in the availability of carers. It was pointed out that, particularly in rural areas, a client’s choice of provider might be severely restricted, due to the limited availability of services in their area. In such cases, participants questioned the extent to which CDHC is beneficial to clients, in that they take on the burden of responsibility for organising their own care, but they do not have the positive element of choice to balance this. This finding speaks to the tension between entitlement and access to health services whereby access to health and social care is determined not just by eligibility but also dependent on type, volume and geographical location of services (Palfrey, 2000; Burke, Normand, Barry & Thomas, 2016). It is noted in the literature that there are challenges to the facilitation of choice and flexibility inherent in CDHC in a resource-constrained sector e.g. matching cases with care staff in a manner that respects the preferences of the care recipient (Spicker, 2013). This evaluation revealed that, in the context of the CDHC pilot, meeting the preferences of some clients was rendered difficult by a shortage of male carers and was constrained by the limited availability of home care workers in rural locations. Concern regarding shortages of care workers is not unique to Ireland. For example, Plimmer (2017) points to the challenges in sustaining adequate staff levels, and in times of economic crisis, public services may struggle.

The length of time between approval of care and the commencement of care delivery was found to vary in the economic analysis, and it was noted that this may relate to lack of haste on the part of the recipient, or for rural locations, it may relate to providers needing to travel further to meet with care recipients. However, this merits further investigation, especially given risks of social isolation for older people in rural locations and the potential costs to them of sourcing their own approved provider. A test of the CDHC going forward is whether introducing more competition into the home care market increases the availability of carers and reduces these time delays, as is outlined in literature that supports CDC models (Tyson, 2008).

It was noted by participants that the nature of employment in this sector can be unpredictable or precarious, particularly when the economic recovery offers many alternative employment opportunities (Migrant Rights Centre Ireland [MRCI], 2015). Pembroke, Wickham and Bobek (2017) note that many employees in the home care sector in Ireland are employed under 'if and when' arrangements, where there is no guarantee of regular weekly hours. Precarious working arrangements in the home care sector lead to a high turnover of staff and this can impact on the quality of care (Pembroke *et al.*, 2017). It is also documented in the literature from the United Kingdom that low pay and insecure working arrangements are endemic in home care (Grimshaw & Carroll, 2006).

It could be suggested that CDHC represents an admirable move away from a supply-driven model of home care, towards a model which is more responsive to the needs, wishes and preferences of service users, as advocated by O'Shea (2017b). However, an important particularity of the context in which this CDHC pilot was conducted relates to a Labour Court agreement regarding home care services, which requires that HSE direct service provision is considered before the option of using approved external providers is implemented (HSE, 2016b). This means that care must be delivered by HSE-employed staff where they are available. Consequently, if CDHC were to be implemented nationally, access to CDHC would be predicated on shortages of HSE-employed home care staff, thus perpetuating this supply-driven model or, at least, limiting the ability of the client to choose which home care pathway they follow, since CDHC could only be offered as an option for people in cases where care could not be provided by HSE staff. Access to CDHC would also vary greatly on a geographical basis, as some CHOs have more severe shortages of HSE home care staff.

6.2.2 Informal care

Within the care recipients' questionnaires, almost a quarter of the care recipients had required support from informal carers prior to engaging with the CDHC. The high turnover and/or lack of availability of employed carers can restrict choice and also increase the burden on families to provide informal care for their relatives. Fine (2013) notes that the flexibility and personalised nature of CDHC should accommodate the needs of the family as well as the care recipient. In this respect, experiences of family carers who participated in the evaluation varied – some reported minimal relief and improvement to their personal wellbeing, and suggested that the flexibility of the CDHC was not sufficient to benefit them alongside the care recipient. This was reiterated in the analysis of the family caregiver questionnaires which found that CDHC pilot had minimal impact on the hours of care or support provided by the family carer to the care recipient. This perspective was echoed by some other stakeholders, including approved providers, who noted especially the potential for the CDHC to increase the burden on family carers, as they may be responsible for the negotiation of care arrangements. This may be a particular issue in the context of declining cognition as a family member may be expected to assume more input over time, and this can potentially cause tensions in family relationships (Cash *et al.*, 2017). However, other family carers in the CDHC evaluation reported significant benefits to their personal lives, in terms of increased free time and feelings of relief. This mixture of experiences and evaluations by family carers is broadly reflective of the ambivalence of the literature on experiences of consumer-directed care. Although the individualised nature of care through CDHC can be perceived as being in alignment with person-centred care (Phelan *et al.*, 2017), it is also important to note that the transfer of responsibility can be a burden for some, and can render equitable care provision more challenging (Ferguson, 2007). Thus, it is important that individuals can choose the extent of the control they wish to exercise (Cash *et al.*, 2017).

6.3 Capacity

Many of the findings contained an underlying idea of capacity. It was conceptualised in three different ways: capacity of resources, capacity in terms of a person's agency and ability to engage, and cognitive capacity.

6.3.1 Access to resources

The scope for delivering care hours in blocks under the CDHC pilot was a significant contributor to the experiences of reduced stress and improved quality of life described by family carers. PHNs reported that this type of care delivery was particular to the pilot – it would have been very unlikely that the arrangement of hours in blocks would have been possible through the traditional system of allocation of home care packages. Access to home care packages via the existing system can be difficult, due to the fact that CHOs are allocated capped budgets. This results in waiting lists across primary care networks (O'Shea, 2017b). There was an acknowledgement by members of the CDHC Steering Group and Project Team, PHNs and care recipients that the presentation of the CDHC pilot as a quicker route of access to care services may have influenced the uptake in the CDHC pilot.

As the population continues to age, the demand for care will increase (MRCI, 2015). Therefore, a concurrent increase in attention and funding for the sector is required. Research has demonstrated the impact of austerity on reduction in health resources and the transferring of cost of health onto individual households in Ireland particularly in the area of home care service delivery (Burke, Thomas, Barry & Keegan 2014). The need for additional investment in home care service delivery was identified by participants in the research, and this has been reflected in the Sláintecare report (Houses of the Oireachtas, 2017a). It should also be noted that the Citizens Assembly recently called for an increase in funding to the home care sector (Citizens' Assembly, 2017). Increased funding has been allocated to services for older people and the home care sector, and the streamlining of the home help and home care services is also underway as part of the move towards a single funded home support service. This will result in the creation of services that are more accessible to service users by simplifying application processes and easing transitions between changed levels of services as assessed needs change (DoH, 2017c). Despite this increase in funding and procedural change, the imbalance of funds between home support services and residential care services for older people has not been redressed. Approved providers, national informants and the CDHC Steering Group and Project Team emphasised the importance of home care as an element of a sustainable response to growing demand and unmet needs of an ageing population. This echoes the HSE's submission to the Dáil Committee on the Future of Health Care, which emphasised supply and sustainability of services (HSE, 2017a).

6.3.1.1 Financial sustainability

The findings from the economic analysis of the CDHC pilot suggest that, from the HSE's perspective, it is largely cost neutral, as the cost per hour is limited to rates agreed in the tender process for home care services. There is a potential area of saving for the HSE in that staff spend less time sourcing care for CDHC clients. Based on the economic analysis of the pilot, the potential saving is small, although it must be acknowledged that most of the clients on the CDHC pilot had low dependency levels. As such, the organisation of their care was generally not too complex. Therefore, this may not reflect broader patterns of time spent organising care. It is possible that this saving would be greater if more complex cases were included, but a conclusive remark cannot be made on this issue based on the sample studied and the data analysed in the evaluation of the pilot programme.

It is also important to note that, although this can be considered a saving by the HSE, the cost of sourcing care is not eliminated. It is merely transferred to the client. Equally, the input of the CDHC coordinator was influential in accommodating schedules, however, this would not be a role generalisable to national roll out. Thus, there could be similar HSE staff inputs in articulating the CDHC. These observations must be considered alongside the findings regarding care recipient and families' experiences of the CDHC pilot, particularly the mixed responses of family carers in relation to the burden they experience.

6.3.2 Capacity of care recipients and families

Participants in the evaluation also discussed capacity in terms of the capacity of individuals and families to make choices. PHNs and members of the CDHC Steering Group and Project Team spoke of clients' and families' capacity to engage in CDHC in terms of confidence, wherewithal and initiative. It was noted that potential clients possessed these characteristics to varying degrees. This points to the importance of acknowledging and respecting the fact that not all consumers can and wish to make a choice about the delivery of their care (Torres *et al.*, 2015).

Within the care recipient responses in the questionnaire, most stated their age as over 76 years, with a long term illness of over six months duration. This concurs with data from the Irish census which demonstrates age as a risk factor for disability (CSO, 2017b). However, most of the care recipients who took part in the pilot programme had relatively low levels of dependency and did not have diminished cognitive or decision-making capacity. Furthermore, the findings from SEQ-1 revealed that 46.15 percent of care recipients had a third level qualification, and a further 23 percent had completed senior cycle second-level education. This demonstrates a relatively high level of educational attainment among those who took up the option to receive care through CDHC. Conversely, there was notably low uptake in one of the pilot sites, which is a recognised area of social and economic deprivation. While the evaluation could not conclusively capture the underlying reasons for the dearth of referrals from the socioeconomically disadvantaged area or higher dependency groups, it was suggested by participants that CDHC may not be suitable or appealing for people with limited resources and support to make informed choices. This observation is supported by literature which points to the potential for consumer-directed care to exacerbate inequalities. Socioeconomic disadvantage can accrue across the life course, and the inverse care law stipulates that those with the greatest need for care in later life can also be least likely to be able to provide for their own care, and this is exacerbated in contexts where medical or social care is most exposed to market forces (Hart, 1971). They may also be less assertive and less well able to negotiate their own care, resulting in further inequity (Wells, 2010; Laragy & Allen, 2015; Newman *et al.*, 2009). The findings did show varying levels of assertiveness among those who opted to participate in the CDHC pilot – some care recipients and families were more willing and able to actively engage and negotiate with approved providers in terms of directing the care. Similarly, it was suggested that referrers (e.g. PHNs) may have assessed a client's suitability for CDHC based on their perceptions of clients' levels of assertiveness or capacity. However the data do not provide clarity on the exact criteria by which clients' suitability was assessed.

The network of support available to a care recipient may enhance their capacity to engage in CDHC and make choices about their care. The findings demonstrate that CDHC was perceived as potentially challenging for older persons who might have limited family or other social support. A concern was raised around the possibility that such individuals might not follow up on the arrangement of their care. During the CDHC pilot, the CDHC Clinical Lead and Project Team liaised closely with clients and followed up on arranging care if there was a delay. Prgomet *et al.* (2017) also note a high level of engagement by coordinators in consumer-directed care, compared with other care delivery systems. This underlines the need for an intermediary support or advocate for clients who may not have the support of family, neighbours or friends, in order to enhance the capacity of clients to engage in CDHC and protect against the risk of missed care. The provision of this type of support has been identified as an essential feature of consumer-directed care in research from the United Kingdom (AgeUK, 2010). Otherwise, CDHC has the potential to marginalise the needs of people who require additional support and information to engage with the programme (Cash *et al.*, 2017).

6.3.3 Cognitive capacity

The idea of capacity also relates to individual cognitive and decision-making capacity. The suitability of CDHC as a model of care delivery for older adults with cognitive impairment is an important point to consider. The majority of clients receiving care through the CDHC pilot did not have cognitive impairments. A small number of cases did have varying levels of cognitive impairment; in these cases the importance of a network of support for the care recipient to engage in CDHC was evident. Although it is yet to be fully implemented, the *Assisted Decision Making (Capacity) Act* (Government of Ireland, 2015), sets out a legal framework through which individuals' will, preference, values and beliefs must be identified and respected, with the aim of increasing self- determination and autonomy for those with reduced decision-making capacity. The principles of CDHC appear to align with those enshrined in the *Assisted Decision Making (Capacity Act)*. It has been demonstrated that consumer-directed care for people living with dementia may increase care satisfaction, but has little impact on care outcomes (Low & Fletcher, 2015). In relation to people with dementia in the Irish context, it is important to consider the Adult Safeguarding Bill (Houses of the Oireachtas, 2017b), which recommends that adults who experience social vulnerability should have a statutory entitlement to an independent advocate. This reinforces the idea expressed above, that the provision of advocacy/support services should be an integral part of CDHC, in acknowledgement of the variability of individual capacity to engage with such a system, particularly in the absence of adequate family support or in cases of cognitive impairment.

6.4 Experiences of care recipients and families

The findings revealed largely positive experiences of services received through CDHC. This is supported through the responses in the care recipients' questionnaires, where 92 percent stated they had received enough support. The majority of care recipients and families reported good relationships with approved providers, continuity of care, and improvements in quality of life. Ninety two percent of care recipients reported having received care from less than two approved providers and less than five different home care workers since engaging in the CDHC pilot. This reflects findings from research on consumer-directed care which documents positive outcomes in terms of continuity of care and life satisfaction (Stainton, Boyce & Phillips, 2009; Lord & Hutchinson, 2008; Foster, Dale & Brown, 2007; Prgomet *et al.*, 2017; Cash *et al.*, 2017).

Care recipients' accounts of their experiences mostly focused on descriptions of the care needs with which they are assisted, and positive reports of their relationships with carers from the approved providers. Upon further probing about the specificities of CDHC, it was common for care recipients and family carers to express favourable opinions of the principles of enhanced choice, flexibility and autonomy. However, the majority of care recipients who completed SEQ-1 had not been in receipt of professional home care services prior to receiving care through CDHC – 23 percent had been receiving care from a family member/friend/neighbour and 46 percent did not require any formal or informal care prior to participating in the CDHC pilot. Hence, the ability of respondents to compare CDHC with the existing model of service delivery was limited.

The processes of identifying a provider and arranging care were not found to be particularly problematic – 67 percent of care recipients had no difficulty understanding the CDHC system, while 33 percent found it difficult to understand the voucher system. 92 percent of respondents reported receiving adequate support and accessible information to assist with arranging their care. In light of this finding from the questionnaire, it is important to note that the support of the CDHC Clinical Lead was highly appreciated and mentioned in the majority of interviews. The vital enablement role of such a coordinator is also noted in other studies. (Day, Thorington, Summons, Van Der Riet, Hunter *et al.*, 2016; Gill *et al.* 2017).

All of the care recipients and family carers who completed SEQ-1 and SEQ-2 said that they would recommend participating in CDHC to a friend. However, it is difficult to deconstruct these positive responses, and establish whether they relate specifically to the unique features of CDHC, or whether their satisfaction relates to timely access to services and the meeting of needs, without particular concern for the mechanisms or pathways by which access was gained. For example, although the ethos of CDHC programmes can receive public support, one study demonstrated that of the 35 percent of people who demonstrated interest in such a programme, only 10 percent used the model (Ottman, Allen & Feldman, 2009). Equally, a study by KPMG (2012) demonstrated a low level of interest in CDHC from older people already in receipt of traditional home care services. The importance of acknowledging the possibility that the positive responses related to access, rather than the ability to choose and direct one's care, was echoed by some PHNs and members of the CDHC Steering Group and Project Team. Previous literature has also notes that the choice and autonomy enabled by consumer-directed care might be less highly valued by older adults, compared with other groups, for example, younger people with disabilities (Woolham & Benton, 2013).

6.5 Experiences of stakeholders involved in service delivery and planning (HSE & approved providers)

The time-consuming nature of the bureaucracy of CDHC pilot programme was a common theme, particularly from approved providers, who noted an increased administrative burden. This is reflected in literature which acknowledges the challenges of the practical implementation of personalised or consumer-directed care (Baxter, Rabiee & Glendinning, 2013; Spicker, 2013). The procedural change involved in the CDHC was a central focus of the approved providers' interviews, with particular reference to duplication of administrative processes and less prior knowledge of a care recipients needs before the initial visit.

This is related to the fact that CDHC represents a departure from a more prescriptive model of service delivery, and a move towards greater empowerment of care recipients and families to direct care. As such, it requires a relinquishing of control by the HSE which was noted as a potential challenge by approved providers and members of the CDHC Steering Group and Project Team. However, the possibility that the challenges would become more manageable after a longer adjustment period was also noted, given the relatively short duration of the pilot project. This has been documented in previous research which notes that implementing consumer directed care involves more than procedural change (Laragy & Allen, 2015).

Despite perceived potential difficulties of adopting a new model of care delivery, it was also noted that CDHC aligns with existing HSE programmes, including the National Clinical Programme for Older People (HSE, 2017e) and the Integrated Care Programme for Older People (HSE, 2017f). In keeping with the plan for creating integrated care pathways, the CDHC Steering Group and Project Team emphasised that the CDHC would need to be seamless with the traditional model of service delivery, to allow for changing care needs and client preferences.

6.6 Risk, accountability and governance

While the principles of self-determination and autonomy which underpin CDHC were positively regarded by the majority of participants, concern was also expressed by participants about potential risks posed by this model of service delivery. One such risk was the idea that the greater control afforded to the care recipient could result in the prioritisation of domestic tasks over personal care needs, thus compromising care quality. It was also suggested that there could be an imbalance of power in the relationship between approved provider and care recipient, with the result that the provision of care could be arranged to suit the approved provider rather than the care recipient. These themes of quality of care and accountability are common concerns in the literature on consumer-directed models of care (Kodner, 2003; Tilly, Wiener & Cuellar, 2000). The redistribution of power inherent in CDHC has been noted as a means of reducing the need for managerial forms of governance in favour of “self-governance” (Newman *et al.*, 2009). However, more traditional forms of governance are typically considered to have higher levels of monitoring and may be considered safer (Matthias & Benjamin, 2003) in comparison with self-governance, which creates obscurity around the locus of accountability, and may leave older people vulnerable to exploitation or abuse.

The CDHC Steering Group and Project Team reported a high level of governance in the CDHC pilot, due to the ongoing involvement of the Clinical Lead, and the fact that the providers had to meet specific criteria in order to become HSE-approved. Such engagement has been observed elsewhere in the literature regarding consumer-directed care (Prgomet *et al.*, 2017). It was suggested that the role of the CDHC Clinical Lead was indispensable to the success of the project, particularly from a governance perspective. The fact that many care recipients and families cited the CDHC Clinical Lead as the person they would contact with any questions or problems about the programme points to the importance of the role within the project. There was some uncertainty expressed as to whether this role would be sustainable in the event of a wider scale implementation of CDHC, and if not, the exact mechanism by which the same high level of governance and quality could be sustainably assured was perceived to be unclear. The forthcoming introduction of HSE Audit Teams represents a significant development in home support governance mechanisms.

Given that CDHC is based on consumer choice, it was noted by participants that its introduction as a model of service delivery could increase competition between approved providers to attract clients. Critiques of consumer-directed care have made similar observations, and point out that service-user involvement can be viewed from a consumerist perspective, whereby the consultation and negotiation between client and care provider is used for market research purposes and decision-making power is not redistributed (Beresford, 2009). In this context, another possible risk is the manipulation of care recipients' choice through targeted marketing. In 2008, the Australian Law Reform Commission noted issues in relation to risk in direct marketing to people in the community, particularly those with cognition challenges as this may manipulate decisions. In particular, it was noted that direct marketing can be frightening for older people (Australian Law Reform Commission 2008). Within the Irish Data Protection Commissioner's reports, there have been case studies on data protection breaches by various agencies and these include direct marketing via email, post, telephone and SMS. The balancing of risk and benefit is a challenge of consumer-directed care - one study in Australia suggested that choice could be influenced by care provider recommendations, yet enabling client choice was considered to enhance continuity of care (Prgomet *et al.*, 2017).

6.7 Regulation of home care

The absence of regulation in the home care sector in Ireland has a bearing on the issues discussed above in relation to risk, accountability and governance. It may be one of the most important contextual issues to this research, and has been noted as a barrier to the reorientation of service delivery (O'Shea, 2017b; Department of Health, 2017a; Healy, 2017; Murphy, Whelan & Normand, 2015). Despite recommendations from the Law Reform Commission in 2011 for home care regulation, it has still not been introduced. The urgent need for regulation was emphasised by approved providers and members of the CDHC Steering Group and Project Team, and was reflected by national informants. The lack of regulation of home care has an effect on public confidence in home care services, and contributes to the enduring bias towards residential care (O'Shea, 2017b). Regulation has been 'an increasingly important part of the political toolbox in European healthcare systems that are funded by taxation' (Saltman, 2012, p. 821). In providing robust regulatory standards, consumers can be assured of confidence in homecare provision and can source their choice of care from State-approved providers. Although the HSE in CHO 3 are developing quality-based audits of home care, independent regulation removes any conflict of interest and ensures standards within public, not-for-profit and for-profit providers. However, within an open market, regulation should also consider marketing standards in terms of direct advertising to individuals.

6.8 Limitations

There are some limitations of this study which arise from issues around the quantity and reach of the CDHC pilot project. The number of older people who took part in the pilot was relatively low, meaning that the potential sample size for the evaluation was small. Furthermore, recruitment from within this small population was relatively low. The implications of this are most pertinent to the questionnaire data, in that the small sample size restricts the extent to which findings can be generalised beyond the study sample.

There was a disproportionately low level of representation from the socioeconomically disadvantaged pilot site. Since the pilot project only dealt with older people, it is not possible to make assertions about the suitability of CDHC for other populations e.g. younger people with disabilities. The majority of the older people to whom care was delivered through the CDHC pilot had capacity. In this context, it is not possible to comment on the suitability of CDHC as a method of delivering care to people with diminished or impaired capacity, particularly those without the support of another person (e.g. family/friend/neighbour). Due to the scope of the pilot, the potential for generalisable conclusions to be made from the evaluation is restricted.

From the perspective of the research design, participants' self-selection could be considered a limitation. When participants self-select, the decision to participate may reflect some inherent bias in the traits of the participant (Bryman, 2012). For example, those who chose to participate in the research may have had a particularly strong opinion. It must be acknowledged that self-selection does not necessarily provide a comprehensive or representative picture of the opinions of a population. Although invitations to participate were sent to anybody who was assessed as eligible to receive care through the CDHC, no responses were received from those who opted not to take part in the pilot project. As a result, the range of perspectives included in the evaluation is narrower than anticipated.

CHAPTER 7

CONCLUSIONS & RECOMMENDATIONS

7.0 Introduction

This chapter presents the conclusions drawn from this study, and proposes some recommendations. The aim of this evaluation was to examine the quality and effectiveness of the CDHC pilot project, with reference to experiences of care recipients and care providers, service fidelity, clinical outcomes, governance and financial sustainability. The evaluation was based on a number of objectives, which targeted certain components of the pilot that were considered important, including quantity, reach, modality, fidelity, challenges, contextual issues and cost.

7.1 Conclusions

As noted in the previous chapter, the small number of care recipients involved in the pilot programme is a limitation, as are the lack of input from those who chose not to activate the vouchers issued to them, and the low uptake from older people in the socioeconomically disadvantaged pilot site. Similarly, most of the care recipients who partook in the pilot programme had relatively low levels of dependency. The scope of the evaluation does not allow for explanation of these trends in the referrals to the CDHC pilot. They reflect an imbalance in the reach of the programme and make it difficult to comment on the applicability or suitability of CDHC for older persons with higher dependency levels or more complex care needs. Furthermore, they point to a need for guidelines for identification and referral of suitable clients.

Empowering care recipients and enabling greater choice, flexibility and autonomy in care organisation and delivery was a central focus of the CDHC pilot. Regarding the fidelity of implementation, it was noted in the findings that there was some variation in terms of the level of choice and flexibility exercised and experienced by care recipients and their families through the pilot project. This may have been due in part to an apparent lack of clarity as to the exact definitions and processes involved in CDHC, as well as some difficulty on the part of the HSE in adjusting to the different distribution of control and responsibility in CDHC, as compared with the traditional model of service delivery. Other challenges included the increased administrative burden to approved providers, as well as the geographical variation in the availability of carers.

The findings from this evaluation may inform future action taken in this area of policy, but should be interpreted with a cautious approach to inferring sustainability and replicability of the programme in other contexts. The high level of commitment and ongoing involvement from the CDHC Project Team, particularly the Clinical Lead, were significant facilitators to the successful implementation of the pilot project, particularly with respect to governance and quality assurance. A service for advocacy/support of care recipients under CDHC was considered essential, and sustainable provision for such a role would be necessary in the event of any future modifications or implementation of a CDHC model.

Regarding the cost of CDHC, the economic analysis demonstrates that the CDHC approach is largely cost neutral for the HSE, and there may be a small saving to the HSE due to the transfer of responsibility for care organisation to the client. Any potential saving is important in the context of the requirement for the HSE, as a public body, to manage costs in a resource limited environment in order to ensure it obtains equivalent value for public funding allocated through CDHC as it does from the other service delivery mechanisms, as this will be a requirement to ensure its sustainability. However, it is noted that the input of a dedicated CDHC coordinator may not be feasible for a national roll out, which may neutralize any cost saving.

The national shortage of carers and the challenges inherent in accessing home care hours through the home help/home care package schemes are important contextual factors to the implementation of this pilot. Hence, the CDHC may have been viewed as a means by which to access necessary services in a timely manner, and this must be acknowledged as a possible influence on care recipients' positive evaluations of the pilot.

If a CDHC model were to be implemented on a wider scale, this would occur in the context of the Labour Court agreement, which ensures a balance of public and private service while also allowing for the provision of choice of care for the users of the home support service. The agreement stipulates that home care hours must be directed to HSE-employed staff before considering any other options. This agreement means that CDHC could only be offered to clients as an option in circumstances where care hours could not be delivered by HSE-employed staff.

The absence of regulation in the Irish home care sector compounds some of the concerns relating to CDHC, including accountability, quality assurance and training and skills of private home care service providers. As previously discussed, without the implementation of regulations and standards in home care services, any reorientation of the model of service delivery is hindered (O'Shea, 2017b; Department of Health, 2017a; Healy, 2017; Murphy, Whelan & Normand, 2015).

While this evaluation has examined the local issues in CHO 3 and, by extension, some national issues, the introduction of the CDHC on a wider scale would require careful consideration of issues within each local context. The CDHC pilot project was evaluated in the context of the amalgamation of the Home Help Services and Home Care Packages into the Home Support Services; it is suggested that the CDHC is not a suitable model for the universal delivery of home support services – rather, it could only exist as an option available to people depending on their level of need, capacity (individual or with family support) to engage with the system, and resources available to provide care. Careful consideration needs to be given to the suitability and appropriateness of the CDHC to service users. For example, the responsibility may be too high for people that do not or cannot give informed consent, end of life clients and those upon whom the CDHC places an unfair burden. The CDHC should also be seamlessly integrated with the existing model of service delivery so that, should a client's needs change over time, they can always revert to receiving care through a model in which they bear less responsibility.

7.2 Recommendations

Based on the evaluative evidence from the review of the CDHC pilot programme, the Research Team offers some recommendations, which are contextualised below using quotes from previous chapters.

The transfer of responsibility can be a burden for some, and can render equitable care provision more challenging (Ferguson, 2007). Thus, it is important that individuals can choose the extent of the control they wish to exercise (Cash et al., 2017) (p.115).

PHNs and members of the CDHC Steering Group and Project Team spoke of clients' and families' capacity to engage in CDHC in terms of confidence, wherewithal and initiative. It was noted that potential clients possessed these characteristics to varying degrees. This points to the importance of acknowledging and respecting the fact that not all consumers can and wish to make a choice about the delivery of their care (Torres et al., 2015) (p. 117) … It was suggested by participants that CDHC may not be suitable or appealing for people with limited resources and support to make informed choices. (p. 117).

- It is recommended that CDHC could not be implemented as the universal method of home support service delivery. However, the CDHC model of home care is a viable model of care, provided that it is part of a larger infrastructure of home care support, that includes care provided directly by the HSE and not-for-profit providers.

- The CDHC model of care should meet criteria of fidelity and acceptability from the perspective of care recipients and their family carers, and this should be monitored on an ongoing basis through formative evaluations, including user satisfaction.
- It is recommended that those positive elements of CDHC, including choice and flexibility, where feasible, should be incorporated into existing home support services.
- It is recommended that the traditional model of home support service delivery is maintained, with the inclusion of choice of care provider, where that choice is available.

It was also noted that CDHC aligns with existing HSE programmes, including the National Clinical Programme for Older People (HSE, 2017e) and the Integrated Care Programme for Older People (HSE, 2017f). In keeping with the plan for creating integrated care pathways, the CDHC Steering Group and Project Team emphasised that CDHC would need to be seamless with the traditional model of service delivery, to allow for changing care needs and client preferences (p.121).

- The complementarity of CDHC with existing home support service provision arrangements in Ireland must be considered.

It could be suggested that CDHC represents an admirable move away from a supply-driven model of home care, towards a model which is more responsive to the needs, wishes and preferences of service users, as advocated by O'Shea (2017b) (p.114).

Upon further probing about the specificities of CDHC, it was common for care recipients and family carers to express favourable opinions of the principles of enhanced choice, flexibility and autonomy … [However] the importance of acknowledging the possibility that the positive responses related to access, rather than the ability to choose and direct one's care, was echoed by some PHNs and members of the CDHC Steering Group and Project Team (p. 119-120).

- It is recommended that certain positive elements of CDHC including choice and flexibility could be incorporated into existing home support services.

There is a tension between entitlement and access to health services whereby access to health and social care is determined not just by eligibility but also dependent on type, volume and geographical location of services (Palfrey, 2000; Burke, Normand, Barry &

Thomas, 2016). It is noted in the literature that there are challenges to the facilitation of choice and flexibility inherent in CDHC in a resource-constrained sector e.g. matching cases with care staff in a manner that respects the preferences of the care recipient (Spicker, 2013) (p.113). This is against a background of the ageing of the Irish population projected to continue over the coming decades and with a larger proportion of older people in the population there will be a larger care demand to meet care requirements (Wren. 2009) (p.18)

- It is recommended that the design and implementation of any future model of CDHC gives due regard to pragmatism and capacity in the context of constrained home support service resources.

The findings from this study demonstrate that choice and flexibility were central tenets of the model of CDHC implemented in the pilot project. However, differing perspectives on the meaning of CDHC revealed a level of obscurity around its conceptualisation (p.112). In this context, it is important that there are standard definitions and understandings of the CDHC.

- It is recommended that the definition, nature and purpose of any future model of CDHC must be made clear and transparent for all stakeholders involved in its implementation. This should include a promotion of public awareness.

The time-consuming nature of the bureaucracy of CDHC pilot programme was a common theme, particularly from providers, who noted an increased administrative burden. This is reflected in literature which acknowledges the challenges of the practical implementation of personalised or consumer-directed care (Baxter, Rabiee & Glendinning, 2013; Spicker, 2013). The procedural change involved in CDHC was a central focus of the providers' interviews, with particular reference to duplication of administrative processes and less prior knowledge of a care recipients needs before the initial visit (p.120).

- It is recommended that the operational processes implemented in the CDHC pilot project are re-examined to maximise efficient use of time, material and human resources. Such operational processes should be underpinned by appropriate governance frameworks.

Similarly, it was suggested that referrers may have assessed a client's suitability for CDHC based on their perceptions of clients' levels of assertiveness or capacity. However the data do not provide clarity on the by which clients' suitability was assessed (p.118).

- It is recommended that clearly defined guidelines are further considered and developed to determine client suitability for CDHC.

It was suggested that the role of the CDHC Clinical Lead was indispensable to the success of the project, particularly from a governance perspective … There was some uncertainty expressed as to whether this role would be sustainable in the event of a wider scale implementation of CDHC, and if not, the exact mechanism by which the same high level of governance and quality could be sustainably assured was perceived to be unclear (p.122).

- Given that the role of the CDHC Clinical Lead was confined to the pilot project and would not be replicated and sustained in the event of national implementation of CDHC, it is recommended that due regard and support should be given to the vital role of the public health nurse in the operationalisation and monitoring of home support services, particularly in light of their role in overall case management.

The forthcoming introduction of HSE Audit Teams represents a significant development in home support governance mechanisms (p.122).

- The HSE Audit Teams are a critical mechanism for managing accountability, clinical governance, quality assurance, patient safety and data protection across the CHO area; accordingly, such teams should have oversight of key performance indicators and their national alignment. This should apply equally to all means of home support services provision, including any future model of CDHC.

The absence of regulation in the home care sector in Ireland has a bearing on the issues discussed above in relation to risk, accountability and governance. It may be one of the most important contextual issues to this research, and has been noted as a barrier to the reorientation of service delivery (O'Shea, 2017b; Department of Health, 2017a; Healy, 2017; Murphy, Whelan & Normand, 2015). Despite recommendations from the Law Reform Commission in 2011 for home care regulation, it has still not been introduced. The urgent need for regulation was emphasised by providers and members of the CDHC Steering Group and Project Team, and was reflected by national informants (p.122).

- Independent regulation of the home care sector should be instituted, as advocated by the Law Reform Commission (2011) and the Citizens'

Assembly (2017). This would provide an objective and standardised framework with which to assure quality and care standards.

In the Irish context, it is important to consider the Adult Safeguarding Bill (Houses of the Oireachtas, 2017b), which recommends that adults who experience social vulnerability should have a statutory entitlement to an independent advocate. This reinforces the idea expressed above, that the provision of advocacy/support services should be an integral part of CDHC, in acknowledgement of the variability of individual capacity to engage with such a system, particularly in the absence of adequate family support or in cases of cognitive impairment (p.119).

- It is recommended that an independent advocate may be considered as a resource for care recipients who may not have the support of a family member or significant other person to engage with home support services, including any future model of CDHC.

Another possible risk is the manipulation of care recipients' choice through targeted marketing. In 2008, the Australian Law Reform Commission noted issues in relation to risk in direct marketing to people in the community, particularly those with cognition challenges as this may manipulate decisions. In particular, it was noted that direct marketing can be frightening for older people (Australian Law Reform Commission 2008). Within the Irish Data Protection Commissioner's reports, there have been case studies on data protection breaches by various agencies and these include direct marketing via email, post, telephone and SMS (p.122).

- Home care providers should not engage in direct marketing of their services, such as soliciting, junk mailing, cold-calling and door stepping, to those in receipt of a home support service. This is to ensure the protection of vulnerable adults.

REFERENCES

Abbott, D. & Marriott, A. (2012). Money, finance and the personalisation agenda for people with learning disabilities in the UK: some emerging issues. *British Journal of Learning Disabilities, 41*, 106-113. DOI: 10.111/j.1468-3156.2012.00728.x.

AgeUK (2010). *Personalisation in practice: lessons from experience. Making personal budgets, support planning and brokerage work for people in later life.* Retrieved 4 December 2017, from https://www.ageuk.org.uk/documents/en-gb/for-professionals/care/personalisation_in_practice-lessons_from_experience.pdf?dtrk=true.

Australian Law Reform Commission (2008) *Australian Privacy Law & Practice.* Retrieved 15 March 2015, from https://www.alrc.gov.au/publications/26.%20Direct%20Marketing/direct-marketing-vulnerable-individuals#_ftn179.

Barry, U. (2010). Elderly care in Ireland: provisions and providers. UCD School of Social Justice Working Papers Series, 10(1):1-34. Dublin: University College Dublin. Retrieved 20 March 2018, from http://researchrepository.ucd.ie/bitstream/handle/10197/2083/Barry-EGGEIrelandeldercare-2010.pdf?sequence=3.

Baxter, K. Rabiee, P. & Glendinning, C. (2013). Managed personal budgets for older people: what are English local authorities doing to facilitate personalized and flexible care? *Public Money & Management, 33*(6), 399-406. DOI: 10.1080/09540962.2013.835998.

Beresford, P. (2009). Whose personalisation? *Soundings, 40*. Retrieved 1 December, from http://www.compassonline.org.uk/wp-content/uploads/2013/05/CTP48Beresfordpersonalisation1.pdf.

Braun, V. & Clarke, B. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Brookes, N., Callaghan, L., Netten, A. & Fox, D. (2015). Personalisation and innovation in a cold financial climate. *British Journal of Social Work, 45*, 86-103. DOI: 10.1093/bjsw/bct104.

Browne, M. (2017). *Responding to the challenges and opportunities of an ageing population: how long-term care and support is currently provided in Ireland. Presentation to Citizens'*

Assembly, 10th June. Retrieved 4 December 2017, from https://www.citizensassembly.ie/en/Meetings/Dr-Michael-Browne.pdf.

Bryman, A. (2012). *Social research methods 4th edition*. Oxford University Press: Oxford.

Burke, S., Normand, C., Barry, S. & Thomas, S. (2016). From universal health insurance to universal healthcare? The shifting health policy landscape in Ireland since the economic crisis *Health Policy V.120* (3), 235-240. DOI: 10.1016/j.healthpol.2015.12.001

Burke, S., Thomas, S., Barry, S., Keegan, C. (2014). Indicators of Health System Coverage and Activity in Ireland during the economic crisis 2008-2014 – From 'more with less' to 'less with less'. *Health Policy V. 117*(3), 275-278 DOI: 10.1016/j.healthpol.2014.07.001.

Cash T., Moyle W. & O'Dwyer S. (2017). Relationships in consumer-directed care: An integrative literature review, *Australasian Journal on Ageing, 36*(3), 193-204.

Central Statistics Office (2017a). *Census of Population 2016-Profile 3 An Age Profile of Ireland.* Retrieved 14 December 2017, from http://www.cso.ie/en/releasesandpublications/ep/p-cp3oy/cp3/.

Central Statistics Office (2017b). *Census of Population 2016 – Profile 9 Health, Disability and Carers.* Retrieved 12 December 2017, from http://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9cr/.

Citizens' Assembly (2017). *Second Report and Recommendations of the Citizens' Assembly: How do we best respond to the challenges and opportunities of an ageing population?*
Retrieved 15 March 2018 from https://www.citizensassembly.ie/en/.

Citizens' Information (2016). *Nursing Homes Support Scheme.* Retrieved 4 December 2017, from http://www.citizensinformation.ie/en/health/health_services/health_services_for_older_people/nursing_homes_support_scheme_1.html.

Coleman B. (2001). *Consumer-directed services for older people.* Washington, DC: AARP Public Policy Institute.

Community Care Providers Scotland (2010). An outcomes approach in social care and support. Retrieved 18 February 2018, from http://www.ccpscotland.org/wp-content/uploads/2014/01/outcomes-briefing.pdf.

Costa-Font, J. & Zigante, V. (2014). *Long Term Care Coverage in Europe: A Case for Implicit Insurance Partnerships. Working paper no.37.* Retrieved 30 November 2017, from https://pdfs.semanticscholar.org/80b0/4061c3c49657dc5e69329842a538b83d4446.pdf.

Coulter A., Roberts S. & Dixon A. (2013) *Delivering better services for people with long term conditions.* King's Fund, London. Retrieved 30 November 2017, from https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/delivering-better-services-for-people-with-long-term-conditions.pdf.

Crosbie, T. (2006). Using activity diaries: some methodological lessons. *Journal of Research Practice, 2*(1). Retrieved 10 February 2018, from http://jrp.icaap.org/index.php/jrp/article/view/22/42.

Data Protection Commissioner (2018) *Case Studies.* Retrieved 15 March 2018, from https://www.dataprotection.ie/docs/Case-Studies/945.htm#Postal.

Day J., Thorington A.C., Summons P., Van Der Riet P., Hunter S., Maguire J., Dilworth S., Bellchambers H., Jeong S., Haydon G., Harris M. & Higgins I. (2017). Home care packages: insights into the experiences of older people leading up to the introduction of consumer directed care in Australia, *Australian Journal of Primary Health* 23(2) 162-169.

Department of Employment Affairs and Social Protection (2017). Carer's support grant (formerly called respite care grant). Retrieved 12 December 2017, from http://www.welfare.ie/en/Pages/respite.aspx.

Department of Health (2012). *National Carers' Strategy.* Retrieved 13 December 2017, from http://health.gov.ie/wp-content/uploads/2016/02/National-Carers-Strategy.pdf.

Department of Health (2013a). *Healthy Ireland: a framework for improved health and wellbeing 2013-2025.* Retrieved 13 December 2017, from http://health.gov.ie/wp-content/uploads/2014/03/HealthyIrelandBrochureWA2.pdf.

Department of Health (2013b). National Positive Ageing Strategy. Retrieved 13 December 2017, from http://health.gov.ie/wp-content/uploads/2014/03/National_Positive_Ageing_Strategy_English.pdf.

Department of Health (2017a). *Improving Home Care Services in Ireland – Have your say!* Retrieved 29 November 2017, from http://health.gov.ie/wp-content/uploads/2017/07/Home-Care-Consultation-Detailed-Version.pdf.

Department of Health (2017b). *Health Ministers Announce New Supports for Carers & People with Disabilities.* Retrieved 14 December 2017, from http://health.gov.ie/blog/press-release/health-ministers-announce-new-supports-for-carers-people-with-disabilities/.

Department of Health (2017c). *HSE National Service Plan 2018 – Increased Supports for Older People and Streamlining of Home Support Services.* Retrieved 9 March 2018, from http://health.gov.ie/blog/press-release/hse-national-service-plan-2018-increased-supports-for-older-people-and-streamlining-of-home-support-services/.

Donnelly, S., O'Brien, M., Begley, E. and Brennan, J. (2016). *"I'd prefer to stay at home but I don't have a choice" Meeting Older People's Preference for Care: Policy, but what about practice?* Dublin: University College Dublin. Retrieved 5 December 2017, from http://researchrepository.ucd.ie/bitstream/handle/10197/7670/IASW.AGE_ACTION.ASI.UCD_Research_Report_on_Care_of_Older_People_2016.pdf?sequence=1.

Doyle, M. & Timonen, V. (2008). Breaking the mould: new trajectories in the domiciliary care of older people in Ireland. *International Journal of Social Welfare, 17,* 324–332.

Fawcett, B. & Plath, D. (2014). A national disability insurance scheme: what social work has to offer. *The British Journal of Social Work, 44*(3), 747-762. DOI: 10.1093/bjsw/bcs141.

Erzerberger, C., & Prein, G. (1997). Triangulation: Validity and empirically based hypothesis construction, *Quality and Quantity, 31*, 141-154.

Ferguson, I. (2007) 'Increasing User Choice or Privatizing Risk? The Antinomies of Personalization', *The British Journal of Social Work 37*(3), 387-403.

Fine, M.D. (2013). Individualising care. The transformation of personal support in old age. *Ageing and Society, 33*(3), 421-436. DOI: 10.1017/S0144686X11001310.

Foster, L., Dale, S., & Brown, R. (2007). How caregivers and workers fared in cash and counseling. *Health Services Research, 42*(1), 510–532. DOI:10.1111/j.1475-6773.2006.00672.x.

Garms-Homolova, V., Naiditch, M., Fagerstrom, C., Lamura, G., Melchiorre, M.G., Gulacsi, L. & Hutchinson, A. (2012) Clients in Focus. In N. Genet, W. Boerma, M. Kroneman, A. Hutchinson & R.B. Saltman (Eds) *Home care across Europe: current structure and future challenges.* http://www.euro.who.int/__data/assets/pdf_file/0008/181799/e96757.pdf.

Genet, N., Boerma, W.G.W., Kringos, D.S., Bouman, A., Francke, A.L., Fagerström, C., Melchiorre, M.G., Greco, C. & Devillé, W. (2011). Home care in Europe: a systematic literature review. *BMC Health Services Research, 11*, 207, http://www.biomedcentral.com/1472-6963/11/207.

Genet, N., Boerma, W., Kroneman, M., Hutchinson, A. (2012). *Conclusions and the way forward.* In N. Genet, W. Boerma, M. Kroneman, A. Hutchinson & R.B. Saltman (Eds) Home care across Europe: current structure and future challenges (pp.105-122).

Genet, N., Boerma, W., Kroneman, M., Hutchinson, A. & Saltman, R.B. (2012). *Home care across Europe: current structure and future challenges.* UK: World Health Organization. Retrieved 30 November, 2017 from http://www.euro.who.int/__data/assets/pdf_file/0008/181799/e96757.pdf.

Genet, N., Boerma, W., Kroneman, M., Hutchinson, A. & Saltman, R.B. (2013). *Home care across Europe: case studies.* Utrecht: World Health Organization. Retrieved 30 November 2017, from https://www.nivel.nl/sites/default/files/bestanden/Home-care-across-Europe-case-studies.pdf.

Gill L., McCaffery N., Cameron I.D., Ratcliffe J., Kaambwa B., Corliss M., Fiebig J. & Gresham M. (2017) Consumer Directed Care in Australia: early perceptions and experiences of staff, clients and carers, *Health and Social Care in the Community,* 25(2), 478–491.

Glendinning, C. (2002). Partnerships between health and social services: developing a framework for evaluation. *Policy & Politics, 30*(1), 115-127.

Glendinning, C. (2012). Home care in England: markets in the context of under-funding. *Health & Social Care in the Community, 20*(3), 292-299.

Glendinning, C., Challis, D., Fernez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. & Wilberforce, M. (2008). *Evaluation of the Individual Budgets Pilot Programme: Final Report.* University of York, York: Social Policy Research Unit.

Government of Ireland (2015). *Assisted Decision Making (Capacity) Act.* Retrieved 13 December 2017, from http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html.

Grimshaw, D. & Carroll, M. (2006). Adjusting to the national minimum wage: constraints and incentives to change in six low-paying sectors. *Industrial Relations Journal, 37*(1), 22-47. DOI: 10.1111/j.1468-2338.2006.00388.x.

Hanly, P. & Sheerin, C. (2017). Policy paper: valuing informal care in Ireland: beyond the traditional production boundary. *The Economic and Social Review, 48*(3), 337-364. file:///C:/Users/Programme%20Office/Downloads/773-2053-1-PB.pdf.

Hart, J.T. (1971) The Inverse Care Law. *The Lancet 297*(7696), 405-412. DOI: 10.1016/S0140-6736(71)92410-X

Health Atlas Finder (2017a). *Health Atlas Finder - Area Profile CSO Census 2016 (de facto) - Community Healthcare Organisation (CHO) - Population Total.*

Health Atlas Finder (2017b). *Health Atlas Finder - Area Profile CSO Census 2016 (de facto) - Community Healthcare Organisation (CHO) - Population Total: CHO 3: Clare, Limerick, Tipperary N.*

Health Atlas Finder (2017c). *Health Atlas Finder - Area Profile CSO Census 2016 (de facto) - Primary Care Team Area (PCT) - Population Total: Ballynanty.*

Health Atlas Finder (2017d). *Health Atlas Finder - Area Profile CSO Census 2016 (de facto) - Primary Care Team Area (PCT) - Population Total: North Clare.*

Health Atlas Finder (2017e). *Health Atlas Finder - Area Profile CSO Census 2016 (de facto) - Primary Care Team Area (PCT) - Population Total: Thomond.*

Health Information and Quality Authority [HIQA] (2012). *National Standards for Safer Better Healthcare.* Retrieved 10 March 2018, from https://www.hiqa.ie/system/files/Safer-Better-Healthcare-Standards.pdf

Health Service Executive (n.d.) *Single Assessment Tool (SAT).* Retrieved 10 March 2018, from https://www.hse.ie/eng/services/list/4/olderpeople/sat/.

Health Service Executive (2009). *Common Summary Assessment Record (CSAR).* Retrieved 10 March 2018, from https://www.hse.ie/eng/services/list/4/olderpeople/nhss/csarguidancedocument.pdf

Health Service Executive (2010). *National Guidelines and Procedures for Standardised Implementation of Home Care Packages*. HSE: Dublin.

Health Service Executive, (2016a). *Framework for improving quality in our health service (Part One Introducing the Framework).* HSE: Dublin.

Health Service Executive (2016b). *Standard Operating Procedure (SOP) for The Provision of High Quality, Enhanced Home Support and Personal Care Services for Older People, to Complement Existing Community Services*. HSE: Dublin.

Health Service Executive (2017a) *Submission on the future of healthcare.* Oireachtas: Dublin.

Health Service Executive (2017b) Mid-West-CHO 3 Operational plan. HSE, CHO 3. https://hse.ie/eng/services/publications/serviceplans/Service-Plan-2017/Operational-Plans-2017/CHO-3-Operational-Plan-2017.pdf

Health Service Executive (2017c). Social Care Division Operational Plan. http://www.hse.ie/eng/services/publications/serviceplans/Service-Plan-2017/Operational-Plans-2017/Social-Care-Operational-Plan-2017.pdf

Health Service Executive (2017d). National Service Plan 2018. Retrieved 21 March 2018, from https://www.hse.ie/eng/services/publications/serviceplans/national-service-plan-2018.pdf

Health Service Executive (2017e). National Clinical Programme for Older Persons. Retrieved 13 December 2017, from http://www.hse.ie/eng/about/Who/cspd/ncps/older-people/

Health Service Executive (2017f). *ICP for Older Persons*. Retrieved 13 December 2017, from http://www.hse.ie/eng/about/Who/cspd/icp/older-persons/

Healy, P. (2017). *Long-term support and care: facilitating independent living. Current practices in Ireland – how to access the system.* Delivered to the Citizens' Assembly June 10 2017, retrieved 28 November 2017, from https://www.citizensassembly.ie/en/Meetings/Pat-HealyPaper.pdf.

Her Majesty's Revenue and Customs [HMRC] (2013). *National Minimum Wage compliance in the social care sector HMRC: An evaluation of National Minimum Wage enforcement in the social care sector over the period 1st April 2011 to 31st March 2013*. Retrieved 10 February 2018, from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262269/131125_Social_Care_Evaluation_2013_ReportNov2013PDF.PDF.

Houses of the Oireachtas (2017a). *Sláintecare Report*. Oireachtas: Dublin.

Houses of the Oireachtas (2017b). *Adult Safeguarding Bill.* Oireachtas: Dublin.

Hussein, A. (2009). The use of Triangulation in Social Sciences Research: Can qualitative and quantitative methods be combined? *Journal of Comparative Social Work.* Retrieved 10 March 2018, from http://journal.uia.no/index.php/JCSW/article/view/212/14.

Hutchinson, A. (2013). Ireland. In N. Genet, W. Boerma, M. Kroneman, A. Hutchinson & R.B. Saltman (eds). *Home care across Europe: case studies.* Utrecht: World Health Organization. Retrieved 30 November 2017, from https://www.nivel.nl/sites/default/files/bestanden/Home-care-across-Europe-case-studies.pdf.

Ilinca, S., Leichsenring, K. & Rodrigues, R. (2015). *From care in homes to care at home: European experiences with (de)institutionalization in long-term care. Policy Brief.* European Centre. Retrieved 30 November 2017, from https http://www.euro.centre.org/data/1449741582_83911.pdf.

Jick, T. D. (1979). Mixing Qualitative and Quantitative Methods: Triangulation in Action. *Administrative Science Quarterly, 24*(4), 602-611.

Kodner, D.L. (2003). Consumer-directed services: lessons and implications for integrated systems of care. *International Journal of Integrated Care, 3*(2). DOI: http://doi.org/10.5334/ijic.80.

KPMG (2012). *Evaluation of the consumer-directed care initiative. Final Report*. Department of Health and Ageing, Canberra.

Laragy, C. & Allen, J. (2015). Community aged care case managers transitioning to consumer directed care: more than procedural change required. *Australian Social Work, 68*(2), 212-227. DOI: 10.1080/0312407X.2014.991337.

Law Reform Commission (2011). Legal aspects of professional home care (LRC-105-2011). Retrieved 4 December 2017, from http://www.lawreform.ie/_fileupload/Reports/r105Carers.pdf.

Lloyd, L. (2010). The individual in social care: the ethics of care and the 'personalisation agenda' in services for older people in England. *Ethics and Social Welfare, 4*(2), 188-200. DOI: 10.1080/17496535.2010.484262.

Lord, J., & Hutchison, P. (2008). Individualized funding in Ontario: Report of a provincial study. *Journal of Developmental Disabilities, 14*(2), 44–53.

Low L.F. & Fletcher J. (2015) Models of home care services for persons with dementia: A narrative review, *Psychosocial & Ethical Aspects of Dementia*, 27(10), 1593-1600.

Low, L.F., Yap, M. & Brodaty, H. (2011). A systematic review of different models of home and community care services for older persons. *BMC Health Services Research, 11*(93). http://www.biomedcentral.com/1472-6963/11/93.

Low, L.F., Chilko, N., Gresham, M., Barter, Brodaty, H. (2012). An update on the pilot trial of consumer-directed care for older persons in Australia. *Australasian Journal on Ageing, 31*(1), 47-51. DOI: 10.1111/j.1741-6612.2011.00572.x.

Mangan, I. (2017). *Opportunities in retirement: perspectives from civil society.* Paper delivered to the Citizens' Assembly, Dublin. 8 July 2017. Retrieved 4 December 2017, from https://www.citizensassembly.ie/en/Meetings/Ita-Mangan-Age-Opportunity-Paper.pdf.

Manthorpe, J. & Samsi, K. (2012). 'Inherently risky?': personal budgets for people with dementia and the risks of financial abuse: findings from an interview-based study with adult safeguarding coordinators. *British Journal of Social Work, 43*(5), 889-903.

Matthias, R.E. & Benjamin, A.E. (2003). Abuse and neglect of clients in agency-based and consumer-directed home care. *Health & Social Work, 28*(3), 174-184.

Mazars (2016). *Health Service Executive – Services for older people. Activity & resource review: home care services*. Retrieved 23 November 2017, from http://www.lenus.ie/hse/bitstream/10147/621444/1/Activity.pdf.

Migrant Rights Centre Ireland [MRCI] (2015). *Migrant Workers in the Home Care Sector: Preparing for the Elder Boom in Ireland.* Retrieved 11 March 2018, from https://www.mrci.ie/wp-content/uploads/2015/09/Migrant-Workers-in-the-Home-Care-Sector-Preparing-for-the-Elder-Boom-in-Ireland.pdf.

Moore, G.F., Audrey, S., Barker, M., Bond, L, Bonell, C., Hardeman, W., Moore, L., O'Cathain, A., Tinati, T., Wight, D. & Baird, J. (2015). Process evaluation of complex interventions: Medical Research Council guidance. *BMJ, 350.* DOI: 10.1136/bmj.h1258.

Moran, N., Arksey, H., Glendinning, C., Jones, K., Netten, A. & Rabiee, P. (2012). Personalisation and carers: whose rights? Whose benefits? *The British Journal of Social Work, 42*(3), 461-479. DOI: 10.1093/bjsw/bcr075.

Moran, N., Glendinning, C., Wilberforce, M., Stevens, M., Netten, A., Jones, K., Manthorpe, J., Knapp, M., Fernandez, J., Challis, D. & Jacobs, S. (2013). Older people's experiences of cash-for-care schemes: evidence from the English Individual Budget pilot projects. *Ageing & Society, 33*(5), 826-851. DOI: 10.1017/S0144686X12000244.

Morris S. Devlin N. & Parkin D. (2007) *Economic analysis in healthcare.* Wiley & Sons, Chichester.

Murphy, C.M., Whelan, B.J. & Normand, C. (2015). Formal home-care utilisation by older adults in Ireland: evidence from the Irish Longitudinal Study on Ageing (TILDA). *Health & Social Care in the Community, 23*(4), 408-18. DOI: 10.1111/hsc.12157.

National Programme for Third Sector Commissioning (2009). A better return: setting the foundations for intelligent commissioning to achieve value for money. New Economics Foundation. Retrieved 18 February 2018, from http://b.3cdn.net/nefoundation/6059c7f32debc02156_dem6iys0l.pdf.

Newman, J., Glendinning, C. & Hughes, M. (2009). Beyond modernisation? Social care and the transformation of welfare governance. *Journal of Social Policy, 37*(4), 531-557. DOI: 10.1017/s0047279408002201.

Office of the Revenue Commissioners (2017). *Home carer tax credit.* Retrieved 12 December 2017, from https://www.revenue.ie/en/personal-tax-credits-reliefs-and-exemptions/health-and-age/home-carer-credit/qualifying-for-home-carer-tax-credit.aspx.

Opus Restructuring LLP & Company Watch (2017). *Domiciliary care finances.* Retrieved 21 February 2018, from http://www.opusllp.com/wp-content/uploads/2017/03/DOC-170317-NRH-domiciliary-care-finances-report-v2.pdf.

O'Shea, D. (2017a). *What is it like to age in Ireland? What are the opportunities?* Paper delivered to the Citizens' Assembly, Dublin. 10 June 2017. Retrieved 4 December 2017, from https://www.citizensassembly.ie/en/Meetings/Dr-Diarmuid-O-Shea-Paper.pdf

O'Shea, E. (2017b). *Funding Long-Term Care in Ireland.* Paper delivered to the Citizens' Assembly, 11 June 2017. Retrieved 30 November 2017, from https://www.citizensassembly.ie/en/Meetings/Prof-Eamon-O-Shea.pdf.

Ottmann G., Allen J., Feldman P. (2009) *Self-Directed Community Aged Care for People with Complex Needs: A Literature Review*, Melbourne, Uniting Care Community Options and Deakin University.

Ottmann, G., Laragy, C., Allen, J. & Feldman, P. (2011). Coproduction in practice: participatory action research to develop a model of community aged care. *Systemic Practice and Action Research, 24*(5), 413-427. DOI: 10.1007/s11213-011-9192-x.

Palfrey, C. (2000). Key Concepts in Health Policy and Planning. Macmillan Press: Houndsmills: Hampshire.

Pembroke, S., Wickham, J. & Bobek, A. (2017). *The social implications of precarious work project: the nature and extent of precarious work in Ireland.* Retrieved 10 March 2018, from https://www.tasc.ie/download/pdf/the_nature_and_extent_2.pdf.

Phelan, A., Rohde D., Casey M., Fealy G., Felle P., Lloyd H. & O'Kelly G. (2017). *Patient narrative project for person centred co-ordinated care*. UCD, IPPOSI & HSE: Dublin.

Plimmer, G. (2017). UK home care industry 'on the brink of collapse' says report. *Financial Times*: London.

Prgomet M., Douglas H.E., Tariq A., Georgiou A., Armour P. & Westbrook J.I. (2017). The Work of Front Line Community Aged Care Staff and the Impact of a Changing Policy Landscape and Consumer-Directed Care, *British Journal of Social Work,* 47(1), 106-124.

Rodrigues, R., K. Schulmann, A. Schmidt, N. Kalavrezou and M. Matsaganis, (2013). *"The Indirect Costs of Long Term Care", European Commission, Research Note 8/2013.* Retrieved 29 November 2017, from file:///C:/Users/Programme%20Office/Downloads/2013-SSM_RN8_long%20term%20care_final.pdf.

Roe, L., O'Halloran, A. & Normand, C. (2016). The evaluation of the Older People Remaining at Home (OPRAH) Project: a mixed methods study. *Age and Ageing, 45*, ii1-ii2. DOI: 10.1093/ageing/afw159.3.

Saltman, R.B. (2012). The role of regulation in healthcare, *British Medical Journal, 344*(821). DOI: 10.1136/bmj.e821.

Sims, D. & Cabrita Gulyurtlu, S.S. (2014). A scoping review of personalisation in the UK: approaches to social work and people with learning disabilities. *Health and Social Care in the Community, 22*(1), 13-21. DOI: 10.1111/hsc.12048.

Slasberg, C. & Beresford, P. (2016). The false narrative about personal budgets in England: smoke and mirrors? *Disability and Society, 31*(8), 1132-1137. DOI: 10.1080/09687599.2016.1235309.

Social Care Institute for Excellence (2010). At a glance 31: enabling risk, ensuring safety: self-directed support and personal budgets. Retrieved 12 December 2017, from https://www.scie.org.uk/publications/ataglance/ataglance31.asp.

Spicker, P. (2013). Personalisation falls short. *The British Journal of Social Work, 43*(7), 1259-1275. DOI: 10.1093/bjsw/bcs063.

Stainton, T., Boyce, S. & Phillips. C.J. (2009). Independence pays: a cost and resource analysis of direct payments in two local authorities. *Disability & Society, 24*(2), 161-172. DOI: 10.1080/09687590802652439.

Tilly, J. (2007). *Consumer-directed, home and community services for adults with dementia.* Retrieved 29 November 2017, from https://www.alz.org/documents/national/Consumer_Direction_issue_brief_2007.pdf.

Tilly, J., Wiener, J.M. & Cuellar, A.E. (2000). Service programs in five countries: policy issues for older people and government. *Generations, 24*(3), Social Science Premium Collection, 74-83.

Timonen, V., Doyle, M. and O'Dwyer, C. (2012) Expanded, but not regulated: ambiguity in home-care policy in Ireland. *Health and Social Care in the Community, 20*(3): 310-318.

Torres, J. M., Kietzman, K. G., & Wallace, S. P. (2015). Walking the Line: Navigating Market and Gift Economies of Care in a Consumer-Directed Home-Based Care Program for Older Adults. *The Milbank Quarterly,* 93(4), 732–760.

Tyson, A. (2008) ‘Service Providers and Commissioners’ in C. Poll, and S. Duffy (eds) *A Report on In Control’s Second Phase Evaluation and Learning 2005-2007.* London: In Control Publications. Retrieved 12 December 2017, from http://www.in-control.org.uk/media/55944/in%20control%20second%20phase%20report%20.pdf.

Unison Scotland (2014). Scotland – it’s time to care. A survey of Scotland’s homecare workers. Retrieved 9 February 2018, from http://www.unison-scotland.org.uk/socialwork/timetocare.pdf.

University College Dublin Human Resources (2013). *Garda vetting policy – faculty and staff.*

Wells, P. (2010). A nudge one way, a nudge the other: libertarian paternalism as political strategy. *People, Place & Policy Online, 4*(3), 111-118. DOI: 10.3351/ppp.0004.0003.0004.

Woolham J. & Benton, C. (2013). The costs and benefits of personal budgets for older people: evidence from a single local authority. *The British Journal of Social Work, 43*(8), 1472-1491. DOI: 10.1093/bjsw/bcs086.

Wren, M. (2009). Long Term Health & Social Care. In Layte R. (ed) *Projecting the impact of demographic change*. Retrieved 29 November 2017, from https://www.esri.ie/pubs/JACB200961.pdf.