Trinity College Dublin
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Evaluation of the Community Outreach Dementia Project Leitrim

HSE & GENIO DEMENTIA PROGRAMME

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

GENIO

EVALUATION OF THE COMMUNITY OUTREACH DEMENTIA PROJECT LEITRIM

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Project Overview

Project Name: The Community Outreach Dementia Project Leitrim (CODPL)

Project Site: Leitrim/Sligo
Project Lead: Siobhan McEniff, (then) Acting Director of Nursing, Our Lady's Hospital Manorhamilton (OLHM), Co Leitrim

Secondary Project Lead: Frank Morrison, Acting General Manager, HSE Sligo/Leitrim

Project Coordinator: Ruth Morrow, Advanced Nurse Practitioner

Project Officer: Aoife McPartland (June 2014 to June 2015 and December 2016 to May 2016), and Josephine Feeney (June 2015 to November 2015), both staff nurses from OLHM

Steering Group: Siobhan McEniff, Project Lead; Ruth Morrow, Project Coordinator; Mary Quinn, Discharge Liaison Officer; Aoife McPartland, Project Officer.

Roles and organisations on the consortium (See Appendix 1): (then) Acting Director of Nursing, OLHM; Acting General Manager, HSE Sligo/Leitrim; Discharge Liaison Officer, Sligo University Hospital; Advanced Nurse Practitioner, Leitrim; Dementia Advisor, Alzheimer's Society of Ireland; Staff Nurse, OLHM; Board Member, Family Carers Ireland (formerly the Carers Association); Consultant Psycho-Geriatrician, Psychiatry of Old Age; Home Care Manager, HSE Sligo/Leitrim; Team Coordinator, Psychiatry of Old Age; Registrar, OLHM; Area Manager, Family Carers Ireland (formerly the Carers Association) Sligo; Consultant Geriatrician, Sligo University Hospital; Spider Project, IT Sligo; Head of Research, IT Sligo; Assistant Director of Public Health Nursing; Informal carer of a person with dementia; and Manager, Ballagh Centre, Leitrim.

Project Award Scheme and Value: This project was awarded €100,000 'Innovation Funding' from Genio, a philanthropic organisation, as part of the HSE & Genio Dementia Programme 2013 Stream 2 funding for individualised supports in the community. Additionally the HSE provided €77,350 funding (benefit in kind), through the Leitrim consortium leading to a total funding of €177,350 for the project.

Project Start Date/Duration: 1st February 2014 – 31st May 2016

Website: www.genio.ie/dementia-community-projects

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Glossary of Terms & List of Abbreviations

Glossary of Terms

Dementia	A general term which describes a range of, generally progressive, conditions which cause damage to the brain, with damage affecting memory, thinking, language and the ability to perform everyday tasks.
Gatekeeper	A service provider who mediates or controls access to services and/or resources.
Home Help	Home help staff assist people to remain in their own home and to avoid going into long-term care. They support vulnerable people in the community who through illness or disability are in need of help with day to day tasks (e.g. essential personal care, washing, help at mealtime, etc.). Home services can be provided by the HSE or private agencies.
Informal Carer	A person who provides care to a person with dementia outside of the framework of organised, paid, professional work (e.g. family member, friend, etc.).
Integrated Care Pathway	A methodology for the mutual decision making and organisation of care for a well-defined group of patients (in this case, people with dementia) during a well-defined period. The aim of an integrated care pathway is to enhance the quality of care by improving patient outcomes, promoting patient safety, increasing patient satisfaction, and optimising the use of resources.
Multidisciplinary Team	A group of healthcare workers who are members of different disciplines, each providing specific services to patients, working on an interdisciplinary basis.
Nursing Home Support Scheme (Fair Deal Scheme)	A scheme of financial support for people who need long-term nursing home care to ensure that long-term nursing home care is accessible and affordable for everyone. The application process includes a care needs assessment and a financial assessment.
Quality of Life	A multidimensional evaluation of an individual’s person-environment organisation including social, psychological, physical and environmental domains and more usually limited to health status measurement in healthcare research.

Responsive Behaviour

Actions, words or gestures that can be used by people living with dementia as a means to communicate perspectives, needs and concerns of importance to them: for example, to communicate unmet physical or psychosocial needs or in response to a distressing environmental stimulus. Other terms that are sometimes used to refer to responsive behaviours include behaviours that challenge us, behavioural and psychological symptoms of dementia (BPSD), or more recently, distressed behaviours.

Service Provider

An individual providing care to a patient from the Health Service Executive, or non-statutory body/volunteer agency.

Service Users

Primarily refers to people who use dementia services as patients, and in some instances includes the informal carer.

Stakeholder

An individual involved in the conceptualisation, development, or implementation of the initiative, or an individual affected by the initiative (for example service providers, consortium members and service users).

List of Abbreviations

AHP:	Allied Healthcare Professional
CNS:	Clinical Nurse Specialist
CODPL:	Community Outreach Dementia Project Leitrim
DLO:	Discharge Liaison Officer
ED:	Emergency Department (A&E; Accident & Emergency)
FG:	Focus Group
FU:	Follow-up interview
GP:	General Practitioner
HCP:	Homecare Package
HSE:	Health Service Executive
ICP:	Integrated Care Pathway
LTC:	Long Term Care
MDT:	Multidisciplinary Team
OT:	Occupational Therapist
PCT:	Primary Care Team
PHN:	Public Health Nurse
POA:	Psychiatry of Old Age
PwD:	People with Dementia, Person with Dementia
QoL:	Quality of Life
RGN:	Registered General Nurse
SG:	Steering Group
SI:	Single Interview

Foreword

In 2012, as part of the wider HSE-Genio Dementia Programme, five sites around Ireland received funding to develop a range of community-based personalised supports which would enable people with advanced dementia to remain living in their homes for as long as possible. Two of these community sites took part in an evaluation study.

This report describes the evaluation of one of these community sites, the Community Outreach Dementia Project Leitrim (CODPL). The project aimed to support up to 30 people with advanced dementia and complex needs to remain living well at home for longer. The evaluation found that the project was successful in achieving this aim, with 29 of the 30 project participants remaining at home for at least the 12 weeks of the intervention and 15 of the 30 continuing at home after the 12 week intervention. The key support that enabled this was additional hours of personalised home support provided in either 'blocks' of hours or in other arrangements determined by the family carer in a way that allowed them take a break.

The evaluation found that the provision of this additional home support was very cost effective, as the cost was considerably less than the cost of nursing home care, the only other alternative to providing additional supports at home. However, the cost difference is not as great when the many hours of care provided by family are taken into account. This huge commitment on the part of families points to the need to ensure adequate support is available to family carers to enable them to continue providing care to their loved one.

These key findings, of the feasibility of supporting people with advanced dementia to remain at home through the provision of flexible, responsive and personalised home supports, and the cost effectiveness of this approach, are reflected in the findings of previous evaluations of other elements of the HSE-Genio Dementia Programme (Cahill, Pierce and Bobersky, 2014; O'Shea and Monaghan, 2016).

I would like to thank the participants for sharing their experiences and insights with the research team. Their contribution will feed directly into the future planning and development of community-based dementia services. I also wish to acknowledge the excellent work of the research team from Trinity College Dublin and the National University of Ireland Galway, led by Dr Anne-Marie Brady. We are grateful for the support of the Atlantic Philanthropies in funding this research.

We hope that these findings will inform the ongoing implementation of the National Dementia Strategy and will contribute to the momentum now evident in Ireland to enable people with dementia to remain living well at home and to support their family carers and communities.

Dr. Fiona Keogh,
Director of Research and Evidence, Genio
April 2017

Executive Summary

Introduction

The Community Outreach Dementia Project Leitrim (CODPL), based in Our Lady's Hospital Manorhamilton (OLHM) in Co. Leitrim, was one of several community projects funded by the Health Service Executive (HSE) and Genio Dementia Programme (Genio, 2015). It was designed to test out innovations in community care with a view to enabling people with advanced dementia and complex needs to remain at home longer and prevent unnecessary hospitalisation. At the same time, the project aimed to enhance home support for families through a 12 week intervention providing additional, flexible and responsive home care hours (including over-night respite and weekend cover) as well as telecare devices and other technologies. Dementia-specific educational initiatives were provided for service providers in the local area to improve their awareness and knowledge of dementia. The high level goal of the project was to improve the quality of life of people with dementia and their families. The CODPL is a positive example of learning in action, where objectives and corresponding interventions have been adjusted over time to respond to the needs arising in the community in a more effective way. During implementation the project's reach was progressively expanded to support people with advanced dementia in their transition from home to long-term care (i.e. the Nursing Home Support Scheme, also know as 'Fair Deal') as well as cases presented by the Public Health Nurse service as having outstanding needs, in particular in terms of carer burden. Thirty-five people with dementia and their carers benefitted from CODPL supports.

Evaluation Aims & Approach

Trinity College Dublin and the National University of Ireland, Galway were commissioned to evaluate this two year project (2014-2016) and its four components. An exploratory mixed method involving both quantitative and qualitative approaches was used to provide a comprehensive evaluation of the CODPL. The evaluation was underpinned by a framework called RE-AIM (Glasgow et al. 1999, Gaglio et al. 2013) which assessed project activity in terms of reach, effectiveness, adoption, implementation and maintenance.

The evaluation examined the project's processes as well as its outcomes, looking at three key aspects:

1. Experience of dementia care services
2. Economic analysis
3. Education, and awareness and knowledge assessment

Key Findings

Experience of the Person with Dementia

- Sample data revealed that project participants were a particularly vulnerable group, including older people (the average age was 86 years) at an advanced stage of dementia. They reported a moderate level of disability and poor quality of life (average QoL-AD score 27 out of a possible range of 13-52) at the beginning of the project, which continued to deteriorate as the disease progressed.
- A range of positive outcomes were achieved by the project for this group, including: enabling people with dementia at an advanced stage to remain at home for longer, facilitating early discharge from hospital and enhancing the quality of life of participants.
- Of the 30 participants who received project support, 29 continued to live at home during the project period. In addition, at least 15 of these people continued to live at home after the initial 12 week period of project support.

Experience of Families

- In most cases the families participating in the project acted as main carers for their relatives with dementia and described their caring burden as moderate to severe, indicating an urgent need for support. Some of the carers noted that this stress had a negative effect on their own health, which in turn affected their ability to look after their relatives. This burden was further compounded by a feeling of being constantly restricted (e.g. being unable to work) and a feeling of isolation.
- Beneficiaries received support from the CODPL in the form of additional individualised home support hours to complement and enhance standard HSE services, ranging from 5 to 202 hours (in 14 cases more than 144 hours of care were delivered). The project also provided respite options to assist carers in coping, but these were subsequently replaced with a more engaging type of support, where the project hours were used, where possible, to facilitate meaningful engagement of the person with dementia.
  The care requests made by beneficiaries were considered modest.
- Recognising and assessing the person with dementia and their family members as a unit of care facilitated the delivery of a more personalised service.
- Families reported their experience of the CODPL support as being very positive. The provision of additional home care hours was considered the greatest benefit in terms of relief of carer burden. They found the supports to be of good quality and valued the flexibility in delivery. However, they expressed some concern regarding sustaining support given the resource constraints within standard community care services.

Impact on Cost of Community Care

- The vast majority of care for people with dementia supported by the COPDL project was provided by family members at no cost to the HSE.
- The cost of all the community care services funded by the HSE, including the services provided by the COPDL project to complement families caring, ranged from €236 to €1,009 per week, with an average of €504 per week.
- Assuming that the net cost of long-stay residential care is €813 per week, for 27 of the 30 project participants the cost to the HSE of providing additional, flexible and responsive home care hours was lower than the cost of care in a long-stay residential setting and therefore represents a good use of resources.

Impact of Technology

- The uptake of assistive technology provided under the project was lower than anticipated as only six families made use of the Telecare packages.
- The findings are indicative of the limited application of such technology for persons with advanced stages of dementia.

Education and Training

- There was a high level of dementia awareness and knowledge among the service providers surveyed at the beginning of the CODPL. For this reason, the project educational initiatives were modest in scale and focused on complementing existing programmes.
- An education day, “Broadening Our Horizons”, and two “Life Story” workshops were run by the project with the objective of promoting a shift from task-orientated care towards more person-centred models of care. A total of 90 health care professionals were reached by these initiatives.
- The feedback received from participants was positive. Most of the attendants reported that they enjoyed the events and found the presentations of benefit, some suggested that they were able to apply the principles learned in their everyday practice.

Community Outreach Dementia Project Leitrim Facilitators

- The consortium and steering group established to provide high-level oversight to the project brought together hospital, primary care and dementia-specific service perspectives that, if nurtured, could help drive culture, policy and system change in service delivery.
- A key strength of the project was the capacity for problem solving and flexibility, including: provision of hours at short notice for crisis avoidance and rapid response; provision of respite hours to families at times when HSE home care services were quite restricted such as evenings, overnight, at weekends and over the Christmas break; re-allocation of unused budget from telecare to home care hours. This approach was highly valuable in optimising outcomes for people with dementia and their families.
- The project structures (project office, consortium and steering group) for the most part, were successful in working towards attainment of project objectives and fit with a case coordination approach. The Project Officer role was deemed particularly important.
- The Public Health Nurses were the first point of contact, and as such, the ‘face’ of services to persons with dementia living at home and family carers seeking support. Knowledge of the community and their constant presence meant that the Public Health Nurses were able to develop relationships and monitor and respond to changing circumstances in a timely manner.

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Community Outreach Dementia Project Leitrim Challenges

- Real world projects of this nature benefit from a built-in preparatory and set-up phase targeting engagement with all stakeholders and addressing required adaptations so that all are aware of and can respond to what the initiative entails.
- There was some delay in the involvement of the Public Health Nurse role, which had an impact on project development and roll-out.
- The gaps identified by the project in community care services for people with advanced dementia and their family carers were primarily a lack of flexibility in provision of home support hours and too few hours available. The project was successful in addressing these gaps using additional resources such that the total cost of care still remained less than the cost of a nursing home place for 27 of 30 participants.
- Embedding innovations into standard HSE services presents challenges for service providers at the levels of care delivery and administration, such as the ability to provide the flexibility evidenced as valuable to families through the project. The CODPL also highlighted important systemic issues within the wider health and social care context, such as the limited funding base for home care given the demand and the lack of availability of staff to provide home care.

Sustaining the Community Outreach Dementia Project Leitrim

- Embedding the project innovations into existing services proved to be challenging due to wider budgetary constraints within the health service and the resource limitations of existing community care services.
- In common with many parts of the country, home care agencies serving Leitrim have limited capacity to provide services and to facilitate flexibility in the provision of home supports due to the lack of appropriately trained staff. This wider issue needs to be addressed if the gains in this initiative are to be sustained.
- The project had developed and begun to implement a plan for the further development of dementia care services in the region, including a dementia education programme for home support staff; an education programme for Public Health Nurses; the adoption of the Zarit Burden Interview to assess carer burden (Zarit et al., 1985) as part of standardised assessment; and establishment of a ‘Cogs’ club (i.e. a service designed to help people with dementia to improve their memory and overall mental function through the use of Cognitive Stimulation Therapy). This was submitted to the HSE to inform future interventions beyond the life of this project.
- The sustainability of project gains must be considered in the context of broader national developments (e.g. development of an integrated care programme for older persons) and will require finding a balance between local community needs and sectoral constraints.

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RE-AIM Framework

REACH

- Success in reaching 35 People with Dementia and their associated informal carers.
- A key strength of the project reach was recognising the importance of informal carers and the provision of support to the same.
- The project reached most service providers, though this was delayed in some cases due to staff changeovers.
- The reach of the educational initiatives was modest but in keeping with the targets of the project.

EFFECTIVENESS

- The steering group, consortium and Project Officer role were each recognised as contributing to overall project effectiveness.
- Key aspects of the project which were effective in supporting informal carers and the Person with Dementia were: assessment of PwD and informal carer as a unit; quality of support provided; opportunity for informal carer to input on selection of hours; and flexibility in provision of supports.
- Under-utilisation of Telecare was indicative of limited application of such technology for people at advanced stage of dementia.
- Flexible deployment of home support hours was the most effective form of support provided by the project.

ADOPTION

- Positive changes implemented by the project but limited evidence of a shift in underlying assumptions and shared meanings across the service about dementia care and service delivery.
- The difficulty in sustaining care hours reflects national constraints on community care and was a challenge in project adoption.

IMPLEMENTATION

- Agencies involved in providing home care supports had limited capacity to meet the project’s ambitions for individualised and flexible supports such as providing home help in ‘out of hours’, at short notice or for unplanned events.
- Project structures positively contributed to successful implementation, though this was challenged by availability of staff to deliver community care.
- A case coordinator approach was viewed by stakeholders as a key contributor to the successful implementation of supports for people with advanced dementia and their carers.

MAINTENANCE

- Sustainability of project gains was constrained by the limitations of wider organisational resources and budgetary constraints.
- A cultural shift within the HSE is required in order for the project ethos, and a focus on individualising care with both the PwD and informal carer in mind, to continue.
- The sustainability of the project activities can only be considered in the context of national developments.
- The net increase in requirements for support for PwD and their carers as a consequence of changing demographics and levels of morbidity points to the need for an increase in public spending on community supports even to maintain their current levels. If the supports that were deemed to be important by carers and service providers alike in this project are to be maintained and extended across regions, a further net increase in community spending is needed. It may also be advisable to consider using existing supports in a different way (e.g. more flexible and personalised care).

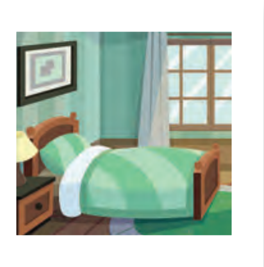
Recommendations for Enhancing Dementia Care

- The adoption of a person-centred approach to care that focuses on the relationship between the Person with Dementia and their families.
- The provision of additional, flexible and more responsive home support hours is a key action to enable the Person with Dementia to remain at home for longer and to support family carers. This is in line with the recommendations by the National Dementia Strategy for more flexible support.
- Facilitating and supporting more dementia-specific care coordination approaches to care within existing healthcare roles is important to enhance the quality of services provided to People with Dementia.
- Centralising the provision and coordination of community care and primary care services for People with Dementia might be beneficial as they often fall between the cracks of a range of services.
- For the effective implementation of Telecare it is essential to take account of appropriateness, purpose and timing for those living with advanced dementia and their families.
- Educational initiatives related to dementia must be embedded as part of ongoing educational programmes for service providers.
- A re-conceptualisation of the provision of community care services and a move away from a focus on physical care requirements would be required in order for the project outcomes to be maintained and for the project ethos to continue within standard health services.
- In line with best practices on quality implementation frameworks (Meyers et al., 2012), the experience from this project points to the importance of a substantial set-up phase for any future initiative of the complex and evolving nature of the Community Outreach Dementia Project Leitrim. This is essential to ensure preparedness in terms of resources, services and stakeholders and how they interface with one another. Similarly, the basis for monitoring and evaluation should be established at set-up point.

CODPL Key Achievements:

30 people with dementia and their families received additional, flexible and responsive home care support from the project

Family carers reported some highly positive experiences of the project, particularly in respect to the quality of support provided



For **10** participants the additional home care hours was sustained after the end of the project intervention and embedded into standard HSE supports

20 of the 30 participants continued to live at home for the full duration of the 12 weeks of support

90 health care professionals participated in the project educational and awareness raising initiatives

6 families benefitted from the Telecare package

For **27 of the 30** project participants the cost to the HSE of providing additional, flexible and responsive home care hours was lower than the cost of care in a long-stay residential setting

1. Introduction

1.1. Dementia Care in the Community

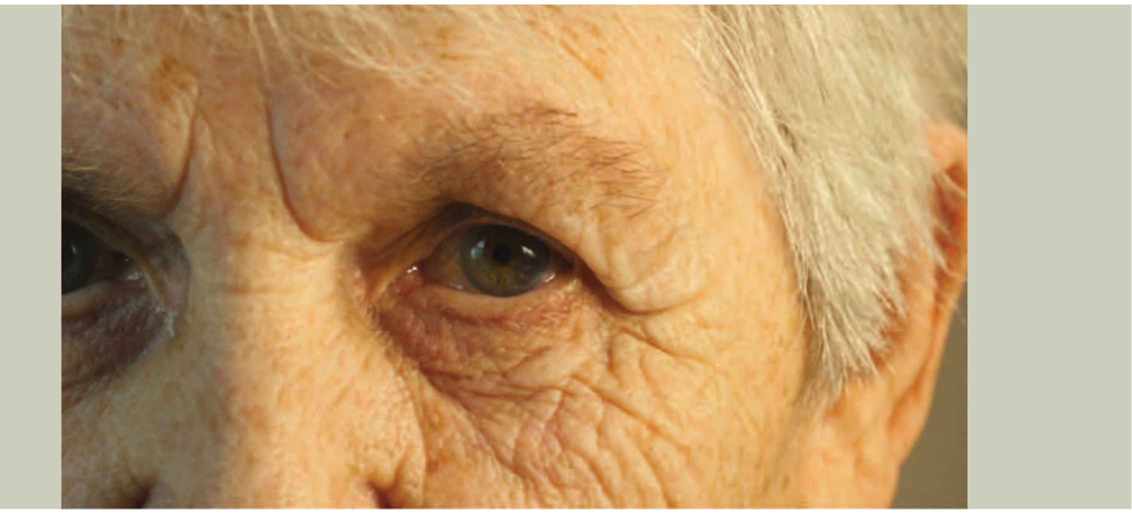
In Ireland, it is estimated that there are approximately 55,000 people living with dementia (Health Service Executive, 2016). Projections for the next thirty years suggest that the prevalence of the condition is due to increase steadily to reach a figure of up to 151,157 persons living with dementia in the country by 2046 (Pierce et al., 2014). This represents a significant social and economic challenge to society, policy and service delivery (Cahill et al., 2012). To address this growing concern in 2014 the Irish Government published a National Dementia Strategy (Department of Health, 2014), calling for a refocus of current service provision to address the needs of people with dementia and their carers in a more responsive manner. The priority actions identified by the Strategy include:

- Building awareness and understanding
- Facilitating timely diagnosis and intervention
- Introduction of integrated services, supports and care for people with dementia and their carers
- Strengthening dementia training and education
- Better leadership to guide change in practice

The need for integrated approaches applies to hospital as well as community care. Cognisant of the fact that the care requirements of people with dementia (PwD) change over time, integrated approaches allow service provision to be flexible yet seamless, with the central tenets of coordination, continuity and responsiveness (Woolrych and Sixsmith, 2013). Person-centred care, encompassing the personalisation and individualisation of services for PwD, is often seen as the ‘gold standard’ of dementia care. It consists of four key elements: 1) valuing PwD and their informal carers; 2) treating people as individuals; 3) looking at the world from the perspective of the PwD; and 4) a positive social environment for the PwD (Brooker, 2003). An important focus of person-centred care is the potential for communication and relationships to promote well-being in PwD (Downs, 2015). However, in a cross-country European examination of home care services for PwD, it was reported that while basic care needs are generally met, individualised care specific to the needs of the PwD is seldom provided (Bökberg et al., 2015).

Cahill et al (2012) estimated that, of the people in Ireland who are living with dementia, 26,000 were living at home and assumed that, for each of these people, four family members are affected. The shift towards community care, combined with the ageing population and increased prevalence of chronic conditions, results in an increased burden of care for informal carers (Champlain Dementia Network, 2013). An increasing focus on home-based rather than institutional care internationally is well reflected in Irish policy, though the supports to achieve this compare less well than in many other countries (OECD, 2011). For example, long term leave for informal caring is not available in Ireland on a statutory basis as is the case in some OECD countries (OECD, 2011). Thus, long-term informal carers are likely to give up employment to continue their caring role and the impact of this in terms of financial and emotional burden extends well beyond their care giving career (Cronin et al., 2015). In addition, research points to poor health and well-being among Irish informal carers (O'Sullivan, 2008, O'Brien, 2009). In terms of the economic impact of dementia in Europe, 56% of the €160 billion total cost estimate is represented by informal care (Wimo et al., 2011).

Public expenditure cutbacks have trickled down to PwD in the form of significant reductions in community care services, health and social care staff and health and social care infrastructure. The cost of dementia in Ireland has been estimated at just over €1.69 billion per annum, 48% of which is attributable to informal care provided by family and friends to those living with dementia in the community (Connolly et al., 2014). A further 43% is accounted for by residential long-stay care, while formal health and social care services contribute only 9% to the total costs of dementia. Increasingly, however, the burden on the acute care sector is being recognised (Cowdell, 2010, Nolan et al., 2006). People with a diagnosis of dementia tend to have a significantly longer length of stay in hospital than those without dementia, a finding that holds across a number of co-morbidities. Applying European prevalence data for dementia to patients in the acute care sector in Ireland, suggests that the estimated cost of this extended length of stay associated with dementia is almost €200 million per annum in Ireland (Connolly and O'Shea, 2013). Given these figures, the implementation of innovative, efficient and cost effective strategies that speak to national priorities in the area of dementia care and that can be replicated in other areas are essential to enhance dementia care.



1.2 HSE & Genio Dementia Programme

Genio is a Non-Governmental Organisation which works to bring together Government and philanthropy to develop, test and scale better ways of supporting people with disabilities, mental health difficulties and dementia to live full lives in their communities. The HSE & Genio Dementia Programme, developed incrementally since 2012 with assistance from the Atlantic Philanthropies and the HSE, supports the development of innovative service models to improve the range and quality of community based supports and services for PwD. Since 2011, innovation funding has been awarded to nine regional community-based projects focused on developing a range of personalised, flexible and responsive supports and services to help PwD to live well in their community for longer and three projects developing integrated care pathways in acute hospitals (Genio, 2015).

The experience and learning from each project is shared through a learning network with a view to supporting sustainability and scaling. The findings and ongoing learning contribute to building leadership in the dementia sector, and will inform public policy and investment in the area with a view to supporting the implementation of the Irish National Dementia Strategy (Department of Health 2014).

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In 2013 innovation funding was awarded to three projects to develop integrated care pathways in acute hospitals (St James's Hospital, Mercy University Hospital and Connolly Hospital) and five projects to develop personalised supports in the community (Louth, Kilkenny, Mallow, Roscommon and Leitrim). The Community Outreach Dementia Project Leitrim (CODPL) belonged to this latter group and aimed to establish enhanced supports for PwD and their carers in the community, as well as facilitating community 'inreach' and hospital 'outreach' linkages. Its target was to provide flexible and responsive support to approximately 30-40 persons with dementia who presented with more complex needs, and their families, in order to enable them to remain in their own home or similar setting for longer, preventing unnecessary hospital admissions.

In 2014, the authors of this report, under the leadership of Dr Anne-Marie Brady, were commissioned to evaluate the HSE and Genio Dementia Programme 2013, focusing on the three hospital sites and two of the community projects (Memory Matters in Kilkenny/Carlow and the Community Outreach Dementia Project Leitrim). This document reports the findings in relation to the CODPL.

2. Development of the Community Outreach Dementia Project Leitrim (CODPL)

The following project description represents the joint understanding of the Community Outreach Dementia Project Leitrim by the evaluation team, Project Lead and Project Officer as it unfolded. It provides an overview of pre-existing services in the area and the project's organisation. The CODPL aims are outlined followed by a description of the main project components.

The CODPL was based in Our Lady's Hospital Manorhamilton (OLHM), Co Leitrim. The North West of Ireland has the highest percentage of older people (aged over 65 years) nationally, with the majority in the Leitrim and West Cavan area, and also the highest projected increase in the number of older people of all the counties of Ireland (CSO, 2012b). In Leitrim/West Cavan 92% of older people live in rural areas (CSO, 2012b). This geographical distribution brings particular problems associated with rural poverty, social isolation and poor access to services (Connolly et al., 2012); all of these featured strongly in our evaluation interviews. Additionally, at 57.3% Leitrim has the highest dependency ratio of all the counties (range 43.3%-57.3%) (CSO, 2012a). While estimated dementia prevalence rates vary regionally across Ireland, at the time of project development the Local Health Office areas in the HSE West region recorded the highest rates. Each of the nine areas was believed to have at least 1% of its total population living with dementia (Cahill et al., 2012). In 2011, it was estimated that 411 people in county Leitrim had dementia (Pierce et al., 2014).

2.1. Local Community Services

A range of community services for people over 65 years were in place in the Sligo/Leitrim/West Cavan area prior to the CODPL project. An overview of these services is provided in the following table.

Table 1: Community Service Provision for the Elderly in the Sligo/Leitrim/West Cavan area

Community Hospitals	Provide rehabilitation, respite, assessment, convalescence, and intermediate care beds to older people with nursing and social needs, including all non-acute needs. Facilities: 1. **Our Lady's Hospital in Manorhamilton:** ▪ 35 older persons beds at admission ▪ Day hospital 3 days per week. Average monthly attendance 365 older people ▪ Cogs' day service[2] (a programme of activity, stimulation, music and fun for people with mild to moderate dementia) once a week. Average monthly attendance 52 2. **St. John's Hospital in Sligo** ▪ 26 bedded dementia unit ▪ Day hospital 5 days per week. Average monthly attendance 480 3. **St Patrick's Hospital in Carrick-on-Shannon** ▪ 18 bedded dementia unit ▪ Day hospital 4 days per week. Average monthly attendance 480
Community Nursing Units	1. Community Nursing Unit, Arus Breffni, Manorhamilton 2. Ballymote Community Nursing Unit 3. Arus Carolan Community Nursing Unit, Mohill
Community Day Centres and other services	3 x HSE Day Centres in North Leitrim (e.g. Arus Bhride which also has social housing units) Dunnally Day Care in Sligo, run by the Alzheimer's Society of Ireland (ASI) with HSE funding, provides 20 day care places Access to consultant-led geriatric and Psychiatry of Old Age (POA) clinics, and referral access to community psychiatric nursing
Community Voluntary Sector	43 Active Age groups. While the services in offer are not dementia-specific, they provide useful support for older people in the community Family Carers Ireland (formerly the Carers Association) supports informal carers with an outreach service including support groups, carers' clinics and phone access
Private Nursing Homes	2 in co. Leitrim - 110 beds in total 6 in co. Sligo - 296 beds in total

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[1] The dependency ratio refers to the number of people outside of the normal working age of 15-65 versus those who are in the working age range

[2] Cogs clubs are a service designed to help people newly diagnosed with dementia to improve their memory and overall mental function through the use of Cognitive Stimulation Therapy (CST). This involves activities aimed at stimulating different areas of the brain and is believed to be helpful in the treatment of people with mild to moderate dementia

The waiting times for nursing home placement under Fair Deal were 12 weeks at the time of project set up. While nationally efforts to reduce the waiting times for a nursing home placement under the Fair Deal Scheme have shown some success since 2014, average waiting times of 11 weeks were noted in 2015 against a Government target of four weeks (McEntee, 2016). However these times are mediated by a number of factors, including availability of beds for dementia-specific care and the requests of certain families in terms of location of a preferred nursing home. In addition, the processing of an application for Fair Deal and nursing home placement may not always result in an actual placement; this is the case, for example, when the PwD is deemed eligible but the carer chooses to defer placement. Thus, the waiting time for nursing home placement is not necessarily the main issue for carers. Nevertheless, it is well documented that the pressure on families caring for relatives with dementia is very significant. A crisis, whether it be related to carer health or the needs of the PwD, can trigger unscheduled admissions to hospital resulting in prolonged hospital stays and ultimately, nursing home placement.

2.2. Project Organisation

Siobhan McEniff, the (then) Acting Director of Nursing from Our Lady's Hospital in Manorhamilton (OLHM), Co. Leitrim, together with a small steering group was successful in securing funding from Genio to improve care for PwD in the Sligo/Leitrim area by delivering enhanced community supports. A consortium of stakeholders from statutory and voluntary bodies was formed to guide the project. Membership included the Project Lead and Project Officer as well as relevant representatives from the partner organisations (details in Appendix 1). Its purpose was to oversee the project and fulfilment of its objectives.

2.3. Project Aim and Objectives

According to established literature, people with dementia have high rates of acute hospital admissions and tend to enter long-term care early. The Community Outreach Dementia Project Leitrim (CODPL) attempted to address these issues by providing a pathway to care which did not rely entirely on the Acute Service and offering additional supports within the community.

Aim

The overall aim of the CODPL was to test innovative approaches to improve dementia care in the Leitrim/Sligo area. This was to be achieved through the delivery of a suite of individualised community-based supports for 30 persons with advanced dementia in order to enable them to remain at home for longer and prevent unnecessary hospitalisation. The final goal was to enhance the quality of life of target beneficiaries and their carers.

Objectives

The specific objectives were:

i. To enhance home supports for families through provision of additional flexible home care hours, including overnight respite, weekend cover and ‘block’ hours of care, and Telecare devices and assistive technology.
ii. To facilitate discharge from the OLHM Day Hospital via the provision of enhanced home supports, including additional hours of home care and Telecare devices and technology to support informal carers.
iii. To facilitate avoidance of hospital admission through the provision of hospital outreach services through the OLHM Day Hospital, and enhanced home supports.
iv. To improve awareness and knowledge of dementia among health professionals, and informal carers, in the community.
v. To provide training to health care professionals within the OLHM Day Hospital to improve the experience of patients with dementia under their care, and facilitate meaningful interaction with such patients.
vi. To improve the quality of life of PwD and their informal carers via meaningful interaction of service providers, carer respite, and increased awareness and knowledge of dementia among health care professionals in the area.

Originally the project intended to provide 12 weeks of support to people with advanced dementia in transition from home to long-term care, specifically those applying for the Fair Deal Scheme[3]. Evidence gathered during early project implementation suggested that assistance provided at the Fair Deal assessment-stage could be too late and might have limited added value for some PwD and their families. It was recognised that supports needed to be offered at an earlier stage in the community. As a result, the project's reach was progressively expanded to include PwD who were presented by the PHN service as having outstanding needs, in particular in terms of carer burden.

2.4. CODPL Project Components

To meet the project objectives the following supports were put in place:

Figure 1: Overview of CODPL Project Components

Each project component is described in detail in the following sections. The CODPL ran for two years, from February 2014 to May 2016. Figure 2 presents an overview of activities and relevant milestones during this period.

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[3] The Fair Deal Scheme, also known as the Nursing Home Support Scheme, is an HSE-supported initiative providing financial assistance for people who need long-term nursing home care (further details available at http://www.hse.ie/eng/services/list/4/olderpeople/nhss/).

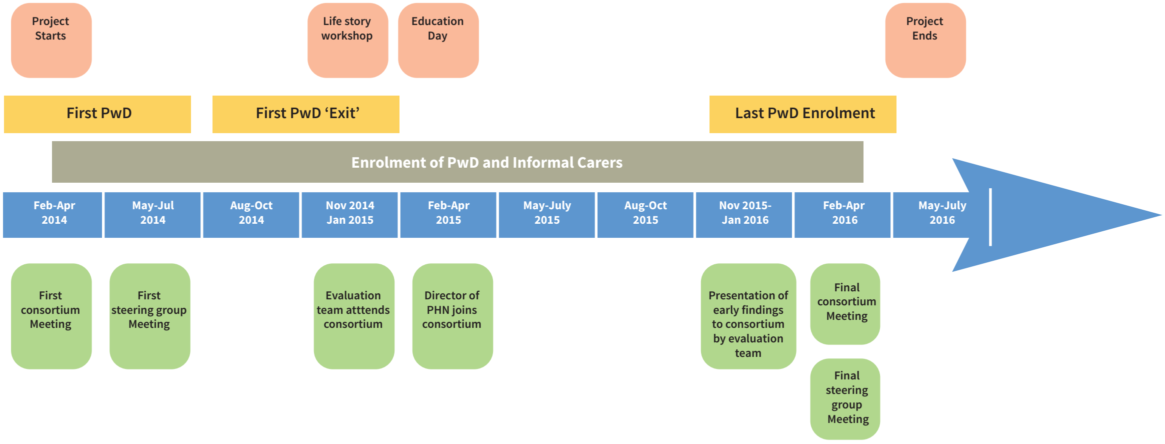


Figure 2. Overview of Project Activity and Milestones

2.4.1 Additional Home Support

The target of the project was to offer personalised home support to a total of 30 families in addition to home supports already in place, with a view to enabling PwD to remain at home for longer and prevent hospitalisation. This support was designed to last 12 weeks because the average wait between being approved for the Fair Deal programme and admittance to LTC was 12 weeks at the time the application for funding for the project was made. A suite of tools were used to assess families' suitability for the project (details in Appendix 2). The intended referral pathway is outlined in Figure 3.

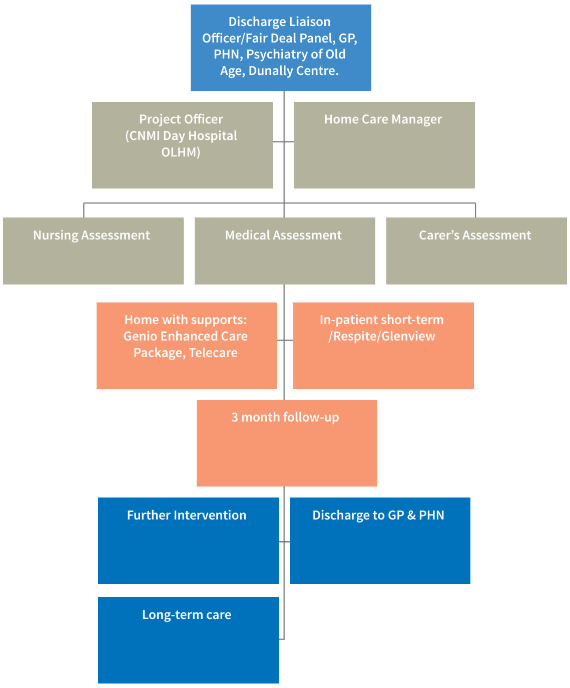


Figure 3. CODPL Referral Pathway (Provided by the Project)

EVALUATION OF THE COMMUNITY OUTREACH DEMENTIA PROJECT LEITRIM

While the proposed project referral pathway placed the Primary Care Team at the starting point, in reality, PHNs were the main source of referral and the main gatekeeper for the project at both time of entry to and exit into standard HSE supports. The total number of referrals made to the project for additional homecare supports was 59. Out of this figure 24 applicants did not meet the inclusion criteria and were referred back to the PHN for further input, leaving a total of 35 families who were enrolled in the project. Most of the referrals were from PHNs (54%) as shown in Figure 4. Further details are reported in Appendix 2.

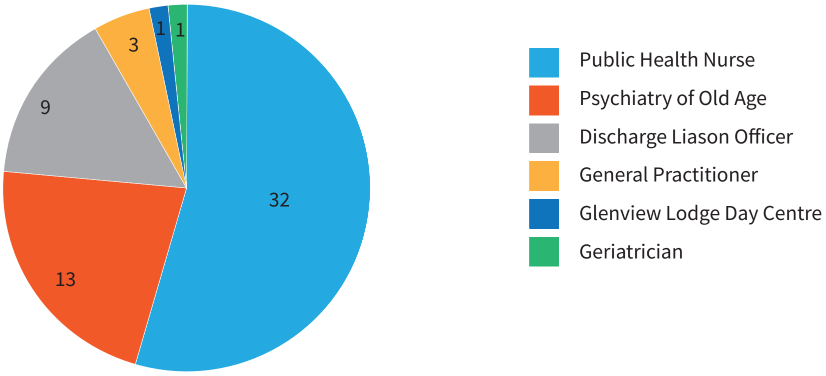


Figure 4: Sources of Referrals

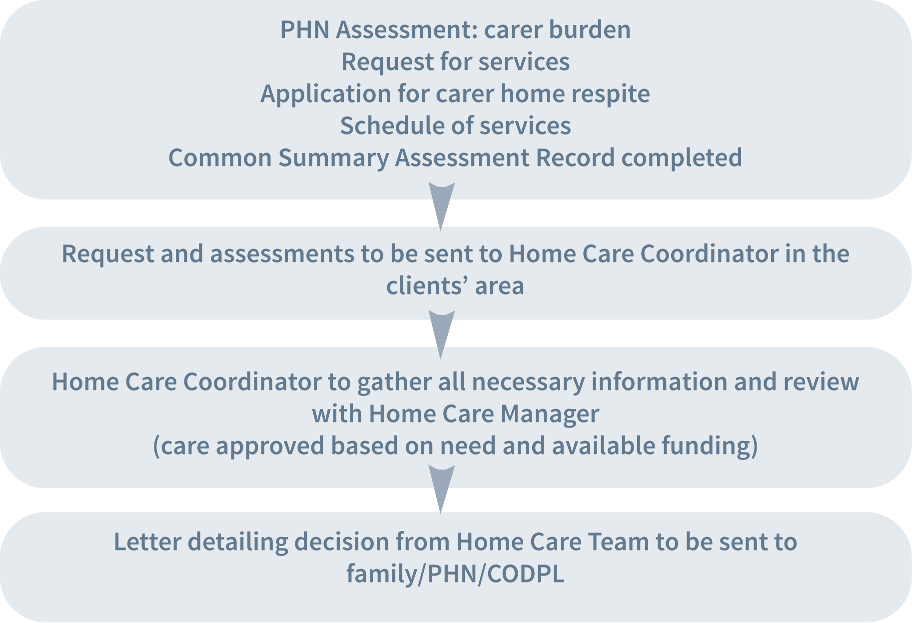
The important gatekeeper/coordinator role of the PHN in the assessment of need for, and delivery of, community based services has been highlighted nationally (Department of Health and Children, 2000, O'Shea and Monaghan, 2016) though it has been recognised that only a very small proportion of PwD living in the community receive any services from the PHN (O'Shea and Monaghan, 2016). Figures 5 and 6 illustrate the spread of referrals and enrolments across townlands and points to engagement of PHNs from across the project catchment area.

Figure 5:
Number of
Referrals by Townland

EVALUATION OF THE COMMUNITY OUTREACH DEMENTIA PROJECT LEITRIM

Figure 6:
Number of
Enrolments by Townland

The intended project exit pathway for the PwD and informal carer is outlined in Figure 7. As the project unfolded, the Project Officer contacted the PHN to complete a request for service applications for maintaining the support beyond the project intervention.



PHN Assessment: carer burden
Request for services
Application for carer home respite
Schedule of services
Common Summary Assessment Record completed

Request and assessments to be sent to Home Care Coordinator in the clients' area

Home Care Coordinator to gather all necessary information and review with Home Care Manager
(care approved based on need and available funding)

Letter detailing decision from Home Care Team to be sent to family/PHN/CODPL

Figure 7. CODPL Exit Pathway (Provided by project team)

As above-mentioned, learning from early project implementation allowed the team to refine plans and activities to increase value and relevance for the target beneficiaries. Among other things, there was a transition from offering a pre-set menu of services to a more responsive and individualised support package. From engagement with families it became clear that their interest was in receiving support at times that were most critical for them. These times differed from family to family, for instance for some it was at the weekend, while others preferred support in the evenings. Additionally, an anticipated overnight sitting service was replaced with a more engaging type of support, where the hours of enhanced care provided by the project were used, where possible, to facilitate meaningful engagement of the PwD. This included activities such as reminiscing, reading materials of interest and talking, as well as providing relief for the informal carer. These changes required deeper engagement with the PHNs to fully capture and address the needs of beneficiaries, and close collaboration with the relevant stakeholders. During implementation 2 PwD entered LTC and 3 died before project supports could be delivered, while 13 others entered LTC and/or died during the course of the 12 weeks. Figure 8 illustrates the participants' progress through the project, developed as per data provided by the project in May 2016.

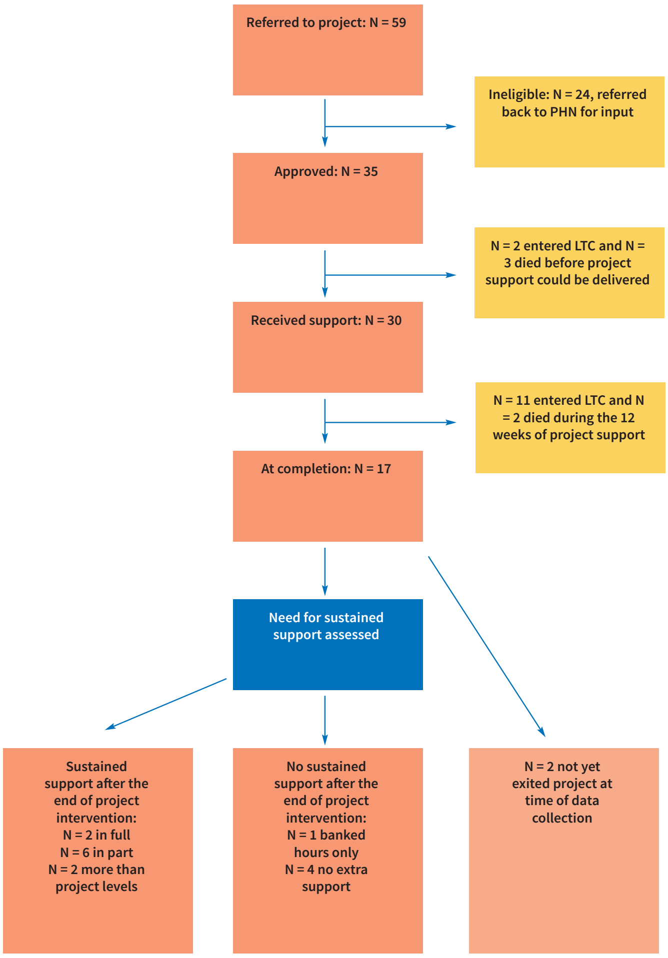


Figure 8. Flowchart of Participants' Progress through the Project

After the three months of project support were successfully delivered and participants returned to standard care, great effort was made, where relevant, to facilitate the continuation of this extra support within regular services, in full or in part. Of the 17 PwD who continued to live at home, 10 received the extra home support. The rest of the PwD either died or went into LTC in the period after the project ended (see Figure 8).

Table 2: Status of Home Care Support after the Project Intervention

	N	%
PwD went to Long-term Care or RIP	18	51.5
Received post-project additional home care support in full	2	5.7
Received post-project additional home care support in part	6	17.1
Received more hours than provided by project	2	5.7
No request for extra support	3	8.6
Banked hours – not for continuation	1	2.9
Extra support not continued	1	2.9
Not yet exited the project at time of data collection	2	5.7

2.4.2 Informal Carer Respite

De-Exeter house is a private and independent custom made facility in Termon, Co Donegal which provides residential respite and rehabilitation for stress, addiction, dual diagnosis and a wide range of mental health issues for up to eight clients at a time. Medical and psychological supports are available to clients 24 hours per day on site. The informal carers supported by the CODPL project were offered a respite stay at De Exeter House for up to three days. Where the informal carer accepted a respite period at the facility, then care for the PwD was arranged in their absence (as needed). A total of three informal carers utilised the De-Exeter House respite package.

2.4.3 Provision of Telecare and Assistive Technology

On entry to the project, the Project Officer, a Public Health Nurse (PHN) or an Occupational Therapist (OT) assessed all families for the need of 'Telecare' devices and assistive technology to facilitate them in their caring role. The available devices and technology were supplied by 'Tunstall' (a provider of personal, health and in-home care). The Project Officer provided testimonials and demonstrations of the devices at the time of assessing families to encourage uptake. PHNs and OTs were briefed on this technology so that they could also complete technology referrals. The 'Telecare' was for 'life-time' use by the families, and was not for removal following the end of the CODPL project.

The uptake of Telecare was low; a total of six families agreed to have Telecare packages put in place. This included: falls detectors (n=4); chair occupancy sensor (n=2); personal alarms (n=2); smoke alarm (n=1); carbon monoxide alarm (n=1); bogus caller button (n=1); bed occupancy sensor (n=1); medication dispenser (n=1); and door exit sensor (n=1).

2.4.4 Education

The Leitrim Education Day 'Broadening Our Horizons'
The Leitrim Education Day, 'Broadening Our Horizons', was held on the 30th April 2015 from 8.45am to 4pm. The targeted audience was health care professionals (mainly home helps and nursing staff), and informal carers of PwD who had been involved in the CODPL project. A training needs analysis was performed by the CODPL project team to determine the content of the day. The speakers included practicing medical, nursing and occupational therapy professionals, a PwD and an informal carer for a PwD. The topics covered were understanding dementia, end of life issues, managing responsive behaviours, assessments and medications, and a personal insight of dementia from the perspective of the PwD and an informal carer for a PwD. Attendance at the day offered category 1 National Midwifery Board of Ireland (NMBI) accreditation.

Sixty people attended the education day, the majority of whom were staff nurses with representation including: PHNs; clinical nurse managers; health care assistants/home help staff; 'befrienders'; informal carers of PwD who had been involved in the project; an occupational therapist; a social worker; and a psychologist.

The 'Life Story' Workshops
The 'Life Story' workshops were held at OLHM, and delivered by the team coordinator from Psychiatry of Old Age (POA), and an Occupational Therapist, and designed to provide health care professionals (including home helps and nursing staff who were working in the area) with knowledge and skills to engage in reminiscing activities and create a life story book with a PwD, with the support from the person's family and friends. The workshops also included content to inform the communication needs of a person with moderate to advanced dementia, person-centred care and living well with dementia. The workshops spanned an afternoon. The sessions were delivered using a combination of traditional teaching methods as well as interactive sessions, with examples of a memory box and life story book used and group work involving role paly to demonstrate responsive behaviour. Two life story workshops were held, the first session had eight attendees, and the second session 22 attendees.

2.5 Steering Group and Consortium

The internal governance arrangements for the project involved a steering group and a consortium. The steering group represented those who initially conceived the project. Members met regularly to discuss project referrals, 'day to day' progress and challenges, as well as oversee the implementation of the project and recommendations from the consortium. They generally met on a fortnightly basis, with meetings supplemented with phone and email contact when required.

The consortium was a gathering of key stakeholders, brought together through a memorandum of understanding. They met quarterly from the beginning of the project, with a total of nine meetings. Meetings were generally well attended. Some members of the consortium were invited to join at a later stage, for example an informal carer of a PwD and the Assistant Director of Public Health Nursing, who joined in February 2015. A feature of the consortium was its membership stability in that there was limited turnover of members as a consequence of members moving on to different roles and needing to be replaced.

3. Methodology of Evaluation (Overview)[4]

As outlined in Chapter One, the authors of this report were commissioned to evaluate the CODPL as part of a larger evaluation of the HSE & Genio Dementia Programme. The complexities concerning dementia care provision, alongside the capacity of the health system to respond, present significant challenges for any project seeking to improve care and support for the PwD and informal carers in the community. An evaluation of such projects requires attention to the set-up, implementation process, impact and sustainability. The evaluation methodology adopted for this project was informed by action research with its emphasis on context, relationship, process and outcome, and a well-established evaluation framework, RE-AIM (Glasgow et al., 1999, Gaglio et al., 2013).

3.1. Aims

1. To understand how individualised supports in the community for dementia can change and improve service delivery and outcomes for PwD and their families.
2. To explore the roll-out of individualised supports and alignment with implementation of the National Dementia Strategy.

3.2 Objectives

i. Examine the dementia journey for key stakeholders at baseline and following project implementation.
ii. Evaluate the applicability and evidence base (effectiveness/efficacy) of the initiative in line with current policy trends at national and international level.
iii. Assess contribution to quality of life and experience of participants including PwD, and their informal carers, agencies and healthcare professionals, and their degree of influence in developing the services.
iv. Evaluate the process of adoption and development, influence on dementia policy, and stakeholder cooperation and implementation of the initiative.
v. Evaluate the impact of implementation of the initiative on outcome measures as agreed with stakeholders for example improved access to/from services, care delivery and efficiency in service provision. Assessment of organisational, stakeholder and community engagement as indicators of sustainability of such services to support PwD and their informal carers.
vi. Compare costs of 'service as usual' to the costs of new approaches and initiatives.
vii. Make recommendations as to inform the implementation of the National Dementia Strategy and individualised community supports nationally.

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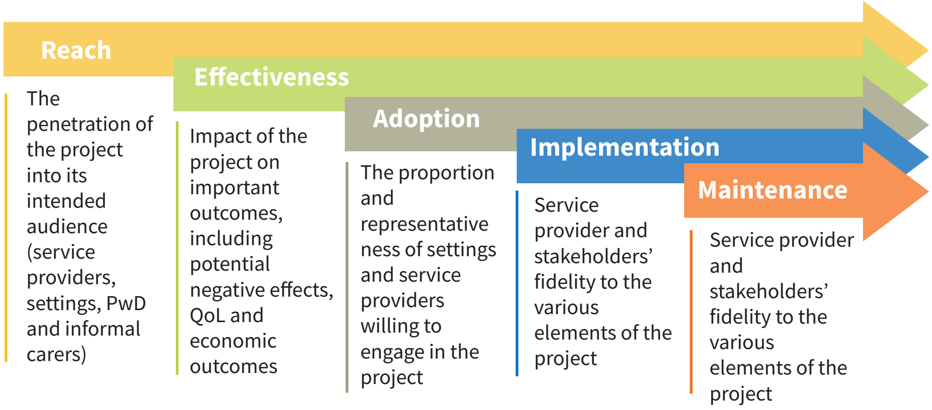
[4] For more detailed information, please see the accompanying methodology reference document

3.3 Evaluation Overview

The evaluation is underpinned by an evaluation framework called RE-AIM (Glasgow et al., 1999, Gaglio et al., 2013) which is briefly presented in Figure 9. Using this framework, project activity was evaluated in terms of reach, effectiveness, adoption, implementation, and maintenance. The framework was applied using exploratory mixed methods involving both quantitative and qualitative approaches.



Reach	Effectiveness	Adoption	Implementation	Maintenance
The penetration of the project into its intended audience (service providers, settings, PwD and informal carers)	Impact of the project on important outcomes, including potential negative effects, QoL and economic outcomes	The proportion and representativeness of settings and service providers willing to engage in the project	Service provider and stakeholders' fidelity to the various elements of the project	Service provider and stakeholders' fidelity to the various elements of the project

Figure 9. RE-AIM Framework Used in the Evaluation

There were three key aspects of this process-focused evaluation methodology, as outlined in Figure 10.

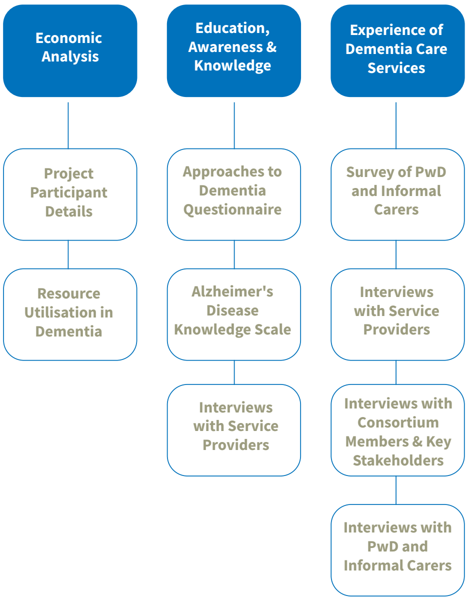


Figure 10. Overview of Evaluation Method

Table 3. Overview of Sample Sizes in Data Collection Stages

Participant Group/Source	Time 1	Time 2
Economic analysis	-	30[5]
Awareness and knowledge survey	60	-
Surveys of service users and informal carers	13	11
Interviews with service users and informal carers	7	8
Interviews with service providers (including consortium members & key stakeholders)	22	18

Figure 11 provides an overview of the timeline of data collection in relation to project activities.

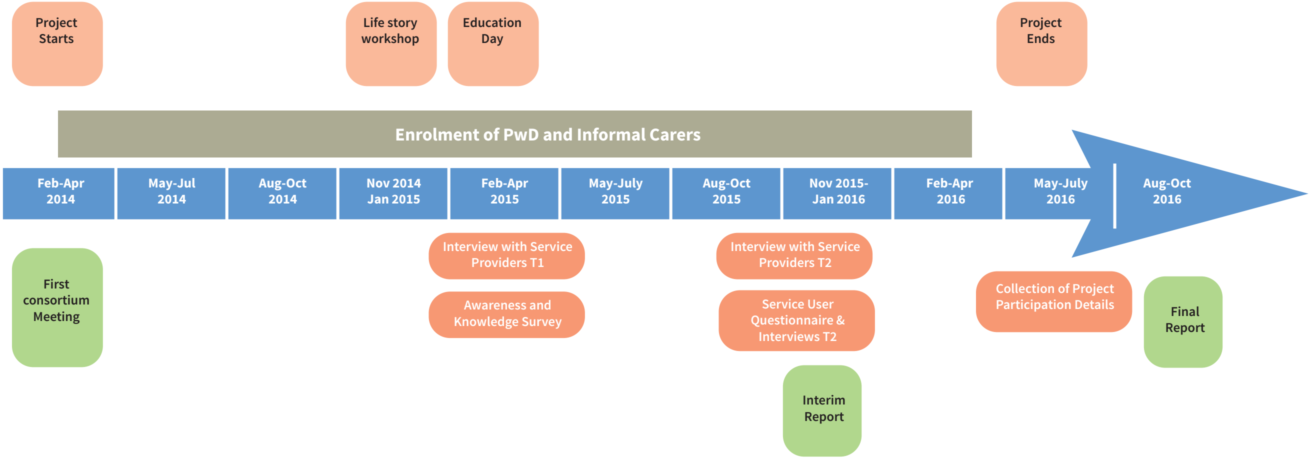


Figure 11. Timeline of Evaluation Data Collection and Project Activity

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[5] While 35 PwD were enrolled in the project, only 30 of these received home support hours as the five other individuals entered LTC and/or died before supports were implemented. The economic analysis is based on these 30 PwD.

4. Findings

This chapter presents the findings that emerged from the evaluation of the Community Outreach Dementia Project Leitrim and explores the degree to which the project achieved its intended objectives. The evaluation findings are presented in relation to the experience of the PwD as well as their families and informal carers. It explores the service provider perspective and describes outcomes from the educational initiative and costs of care.

Figure 12 outlines the various sub-sections within project outcomes.

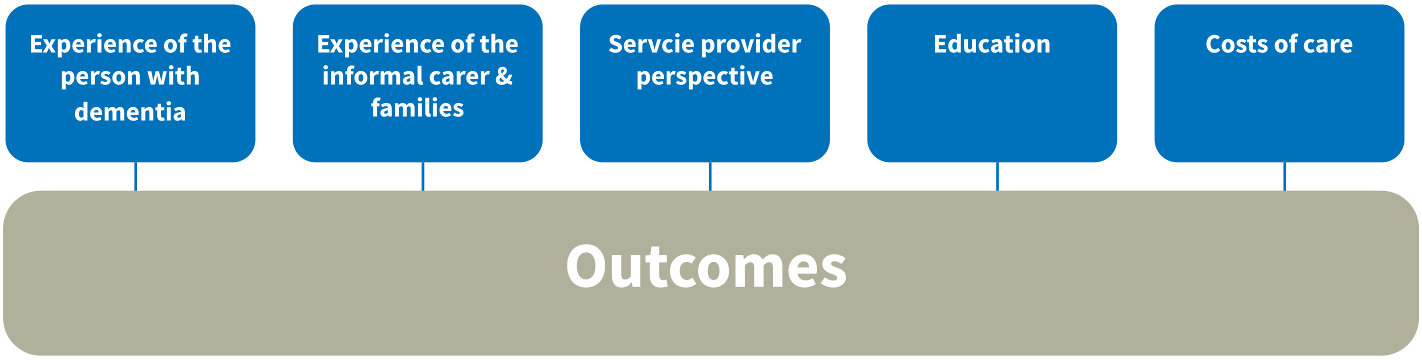

Figure 12: Overview of Project Outcomes

4.1 Experience of the Person with Dementia

The experiences of persons with dementia and their informal carers were gathered through a survey, and a number of interviews. The objective was to collect respondents’ views and opinions on community care in their location and assess the contribution of the project. Information on quality of life indicators and carer burden at the two time points was also recorded. A sample of 13 informal carers and 13 PwD participated in the baseline data collection, while a sample of 11 respondents from each group took part in the follow-up. Summary details are presented in Table 4.

Table 4: Demographics of Respondents at Baseline

Demographics of PwD sample at baseline	
Average age	87 years (range from 68 to 103 years)
Gender	Majority female (N = 11)
Dementia diagnosis	Alzheimer's Disease (N= 2) Vascular Dementia (N = 1) Lewy Body Dementia (N = 1) Mixed Dementia (N = 1) Multifractal Dementia (N = 1) Senile Dementia (N = 1) Not known (N = 6)
Living arrangements	Majority in own home (N = 10). Mostly alone (N= 5), or with spouse (N= 3) or children (N = 3)
Informal carer	Children (N = 8) Spouse (N = 2) Sibling (N = 1) Others (N = 2)
Average quality of life of the sample	Poor (average QoL-AD score 27 out of a possible range of 13-52)
Average level of disability of the sample	Moderate (average Barthel Index of Activities of Daily Living score 9 out of a possible range of 0-20)

The following table reports the scores of the Barthel Index (Collin et al. 1988) and illustrates some of the main difficulties encountered by the PwD in our sample in their day-to-day life.

Table 5: Barthel Index Scores of PwD at Baseline[6]

Barthel Index scores at baseline	
Grooming Need help with personal care	100%
Feeding Unable to feed alone or need help with cutting food etc.	72.7%
Moving from bed to chair Need help of one person to move from the bed to the chair	66.7%
Mobility Immobile or need help of one person to walk	58.3%
Dressing Unable to dress alone or need some help	91.7%
Stairs and Bathing Unable to walk up and down the stairs Unable to take a bath or a shower alone	91.7% 91.7%
Incontinence (regular or occasional) Bowels Bladder	58.3% 83.4%
Toilet use Unable to use the toilet alone or need help 90%	

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[6] 12 PwD responded to this part of the questionnaire

It is to note that during project roll-out the majority of informal carers outlined progressive deterioration in the PwD since enrolment, particularly in terms of mobility. Similarly, there was also a decline in the PwD's quality of life as measured by the QoL-AD (Logsdon et al., 1999), as illustrated in Table 6[7] . This kind of deterioration, common among PwD, was inevitably beyond the control of the project and affected implementation as the needs of the participants and their carers in many cases changed over the course of the project.

Table 6: QoL-AD Scores from Survey Data

	Mean Score	SD	Min	Max	N
Time One	27.0	3.2	22.5	31.5	9
Time Two	24.9	5.1	15.0	30.0	11

Nevertheless, the findings of the evaluation demonstrated that positive results were achieved by the project. Both service providers and informal carers strongly believed the project had enabled PwD to remain in their homes and avoid unscheduled hospital admissions. For example, one informal carer outlined: *"Those two days that I had that girl [home support worker] actually kept us all going. I would not have managed as long at all without her"* ([8]FU SI, LT03).

CASE STUDY[9] : Emily and Jane's Story

Emily is a woman in her 90s who has mixed dementia, which is at an advanced stage. Her daughter Jane, who is in her 60s, lives next door to her and has been caring for her mother for several years. Jane gets little support from other family members and has given up work to care for her mother. She described her burden caring for her mother as high level and felt that there was more and more to be done each day. She spoke about always feeling like she was on 'high alert'.

Emily was referred to the CODPL by the Public Health Nurse and was granted an additional 12 hours of home support provided during the day. These additional care hours were primarily used for supervision and assistance with transfers, but included also reminiscence therapy and social interaction. The main benefit reported by Jane was that it allowed her to go out to do her shopping and catch up on other important chores. The benefits to Jane were short-lived, however, as Emily's mobility deteriorated, so she had to remain in the house during these hours to assist the home help because of the requirement for two people for lifting and moving her mother.

When Emily left the project, 10 project hours were sustained. Jane paid privately to fund the additional 2 hours as she felt she could not continue to care without them. She spoke very positively about these hours and felt she could not have kept Emily at home as long as she did without the help provided. She said that the home support worker had a great connection with Emily and interacted well with her and that Emily's face lit up every time the worker came into the house. Jane stated that she would have been very worried about leaving Emily if she was not satisfied with the home help provided. Emily went into respite care in late 2015 and at this time it was recommended to Jane that Emily be considered for LTC. Due to the deterioration in Emily's mobility and her desire to have someone in the same room as her at all times, Emily entered LTC. Jane found this a very difficult decision and described the guilt she still feels because of this.

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[7] Total possible range of scores: 13-52. The difference between T1 and T2 was not statistically significant (t(7)=.77, p=.47, N=8).
[8] FU: Follow-up interview; SI: Single Interview; FG: Focus Group; LT0X: Unique participant identifier of informal carer; SG: Steering Group
[9] Pseudonyms are used to protect the identity of respondents

One of the key impacts of the project for the PwD related to the use of meaningful engagement: a person-centred approach to care which encourages active participation of the PwD while recognising that individual participation will vary, depending on abilities and personal histories (Harmer and Orrell, 2008). The project drew primarily from one private agency for home care support with staff trained in dementia care. The project team collaborated closely with the agency and were able to negotiate a bespoke dementia care plan to meet individual needs. The dementia-specific care plan devised for each participant was highlighted as a facilitator here (as it outlined proposed forms of engagement), as well as the use of block hours to enable the PwD to engage. Numerous informal carers outlined that the PwD enjoyed, and benefitted from, the interaction with home support staff. Meaningful engagement was complemented by 'matching' the PwD with an appropriate home support staff (e.g. pairing a PwD who enjoyed outdoor activity with a home support worker happy to engage in this activity) and both informal carers and service providers alluded to the strong relationships and bonds built between support staff and PwD. In addition, the multi-faceted components of respite hours were highlighted where meaningful engagement occurred alongside tending to physical care needs and home help duties.

> *"She [home support worker] would read her something out of a magazine…She would put on a programme that she liked on the TV, or they would listen to the radio or she would let her talk about times long ago. Then I also left a snack for my Mum and she also gave my Mum the snack. She put her on the toilet as well and she also would, Mum had a little open fire and she would have kept the fire going so there was a lot more than just a sitting service" (FU SI, LT06)*

Other positive impacts included facilitation of early discharge from hospital and enhanced quality of life for PwD. Some people who were referred but did not meet the project criteria, still benefited in the sense that, where possible, they were connected to personalised supports by referring them to the ASI dementia advisor and then referred back to PHN to access relevant services.

4.2 Experience of the Informal Carer and Families

Informal carer burden was a strong feature across stakeholder interviews over the course of the evaluation. For example, one service provider stated that: *"it's a very demanding role for a family member to take on and I suppose it can be a very wearing role for them"* (SI, OT I). A summary of survey findings, as relevant to informal carer burden (as well as informal carer QoL), is provided in Table 7. The numbers who completed the survey were too low to draw any definitive conclusions about project impact on informal carer health status or informal carer burden. The range of scores on the assessment of carer burden were quite substantial representing a broad range in the degree of burden experienced. The mean scores for informal carer burden at both time points (initial and follow-up) reflect a moderate to severe burden of care (scores between 41-60 indicate moderate to severe burden) (Zarit et al., 1985).

Interestingly, there was also a broad range of scores on the informal carer QoL tool. The mean scores reported here reflect minimal problems in informal carer QoL (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) (The EuroQol Group, 1990). Informal carer health status was scored from 'the worst health you can imagine' (0) to 'the best health you can imagine' (100) (The EuroQol Group, 1990), with mean scores here indicating relatively high QoL. In interviews however, some informal carers described the impact of stress on their health, and also outlined the ripple effect of their caring role on other family members e.g. the granddaughter of PwD suffering ill health as a result of stress. The impact of stress on informal carer health was highlighted at initial interview and this continued at follow-up interview. Co-existing with this, there were some positives of the caring role highlighted by informal carers, such as the learning of new skills and patience, gaining new insights, and becoming a better person.

Table 7: Summary of Survey Findings Related to Informal Carer Burden [10]

	Time Point	M	SD	Min	Max	N
Informal carer burden (Zarit carer burden; Possible range of scores 0-88)	Initial	40.5	12.3	14	60	11
	Follow-up	46.0	14.8	33	74	6
Informal carer QoL (EQ-5D-3L; Possible range of scores 5-15)	Initial	6.1	1.1	5	8	13
	Follow-up	6.3	1.3	5	9	10
Informal carer health status (EQ-5D-3L; Possible range of scores 0-100)	Initial	70.6	14.9	50	95	11
	Follow-up	64.0	20.1	30	90	10

While it would appear from the narrative data that the project reduced informal carer burden and enhanced informal carers' QoL, a significant impact did not emerge in the survey findings outlined above. However service providers and informal carers alike referred to the relief for informal carers provided by the project, which encompassed a number of different aspects, all linked to improving the QoL of PwD and their informal carers.

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[10] These scores derive from the PwD and informal carers' surveys implemented by the Evaluation Team. Baseline data were collected in the period Apr-Jul 2015; the follow up survey was carried out in the period Apr-Jul 2016.

Informal carers described satisfaction that their needs were being considered: *"The Genio project. That was the first I suppose sort of that we felt that something was being given to us to help us"* (FU SI, LT02). Providing informal carers with a break was emphasised as being of great significance: *"even that three or four hours of a break for that (informal) carer was just an absolute lifesaver"* (FU SI, SG II). The provision of these additional hours was described as *"a tremendous help"* (FU SI, LT02), *"like winning the lotto" (FU FG, PHN I), and one informal carer said "I thought I was in heaven"* (FU SI, LT03).

> *"I couldn't survive without it now, do you know if they pulled it…I wouldn't like to see the state of me if I hadn't had the good sleep that night, it wouldn't be great, but, you know. So it can be a life saver in that regard…The Project has been a lifesaver"* (FU SI, LT05)

Informal carers reported some highly positive experiences of the project particularly in respect to the quality of support provided. They referred to the home support staff who provided the additional respite hours as highly trained, trustworthy and flexible. They also described their own positive interactions with home support staff; for example, one informal carer outlined that she often chats to the home support staff member as she feels like she truly understands her situation. In line with this, a service manager emphasised the value of home support staff as a listening ear for informal carers. Another informal carer reported that she received feedback from the home support staff who cared for the PwD while she was out of the house which she found very valuable. Other positive experiences of informal carers included having an input into the selection of hours and continuity of care (i.e. the same 1-2 home support staff on a regular basis).

> *"I have to say that the ladies who came, were excellent, each of them. We were very, very pleased with them and they gave my mother great care when they were there" (FU SI, LT02)*

The significance of being able to provide additional personalised hours was highlighted in interviews: *"She [informal carer] had no other services at the weekend and to her those few hours…were a Godsend and she wouldn't have got them any other way"* (FU FG, PHN I). The respite hours provided by the project appeared to improve the quality of the time the informal carer spends with the PwD; *"Your other time then spent with that person can be more personal and more involved because you are not doing, doing, doing things all the time. Your quality of time with the person improves because you have time to sit and talk to them"* (FU SI, LT06). The project provided respite care in De Exeter House (see Section 2.4.2 for a description of this service) aimed at relieving informal carer burden. However, there were mixed views about the net benefit of this. One carer referred to the challenges in preparing to leave the PwD in order to spend a weekend away. Questions were also raised about the impact of a single weekend away, which alone, would be insufficient in resolving issues.

Though the dominant view among informal carers regarding the project support was positive, some expressed concern and anxiety regarding exiting the programme.

CASE STUDY[11] : Albert and Grace's Story

Albert (aged in his 60s) has dementia with significant comorbidities, and is cared for by his wife Grace (also aged in her 60s) at home. Grace has very little family support and says that "you don't get visitors once someone's got dementia" as she feels people are reluctant to engage with this illness. She is a particularly proactive informal carer in that she tries to remain up to speed with national policies on home care and family carers etc. and has initiated contact with befriending and day centre services for her husband.

Following referral by the PHN, Albert was enrolled in the CODPL and provided with 3 hours weekend home support per week focusing on relational care (social interaction and watching sports); hours not usually available through mainstream supports. This was an important source of social interaction for Albert, and Grace found this extremely beneficial in providing her with a break and an opportunity to have some time for herself as an escape from her caring duties. She described this as a little breather for herself, providing her with some headspace.

After 12 weeks of receiving these hours (the original planned timeline of support hours for the project), Grace received a letter to say that her hours were now finished. After contacting the home care manager and significant negotiation, the 3 hours were restored. Grace was told she had been allocated 144 hours through the project and that the support would continue until her allocated hours were utilised. Since enrolling in the project, Albert's condition has deteriorated significantly both in terms of mobility and communication. Grace has been told by her PHN that these hours will not be sustained once the 144 project hours are exhausted as there is a shortage of HSE home support hours available. She was very concerned that nothing would replace these when they were finished in the coming weeks. She expressed worry about the future deterioration of her husband's condition and the high likelihood that she would require significantly more support hours in the future, and was concerned that this would be compromised if she fought to have these extra three home support hours when she could be in greater need in the future. While Grace expressed satisfaction with individual service providers she encounters routinely, she reported dissatisfaction with the ability of community care services to respond to her and her husband's individual needs and experiences.

More broadly, informal carers also reported varied experiences of dementia care generally in the community. These centred on access to, and the inadequacy of, home support. Survey data indicated greater dissatisfaction among informal carers regarding community services between times one and two (see Table 8). This may be due to the reduced number of participants in the time two survey. It is also possible though that the greater dissatisfaction is related to the heightened anxieties expressed by informal carers in interviews about exiting the programme, or because of increased care needs due to the progression of dementia. Notably, at time one, 6/13 informal carers felt that the PwD would still be living at home even if they were not in receipt of assistance from community care services indicating a strong preference amongst informal carers to keep the PwD living at home.

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[11] Pseudonyms are used to protect the identity of respondents

Table 8. Survey Findings on Satisfaction with Dementia Care Services – N (%)[12]

	Time point	Very satisfied or satisfied	Neither satisfied nor dissatisfied	Very dissatisfied or dissatisfied	Don't know
Satisfaction with community care services provided to informal carer	Initial (N=13)	12 (92.3)	1 (7.7)	-	-
	Follow-up (N=7)	5 (71.6)	1 (14.3)	-	1 (14.3)
Satisfaction with community care services provided to PwDI	Initial (N=12)	5 (41.7)	3 (25.0)	4 (33.3)	-
	Follow-up (N=7)	1 (14.3)	1 (14.3)	5 (71.5)	-

Survey data also indicated that almost half of informal carers (6/13) felt that community care services do not give them enough help, whilst only 7/13 felt that they were given the right type of help from community care services (at time one). Accordingly, a sense of having to fight for supports was a common theme in interviews at both time points and this was associated with a feeling that informal carers were not respected or listened to, and were left feeling helpless and had no control over services. Among the barriers to accessing supports that were raised by informal carers were: rigid enforcement of rules which can prevent access to equipment and services; delays in processing of applications for services; lack of availability of home visits from service providers; and no flexibility in the provision of services.

CASE STUDY[13] : Sarah and Orla's Story

Sarah (aged in her 80s) has advanced dementia with limited communication and mobility. She has been cared for by her daughter Orla (aged in her 40s), who lives with her, for a number of years. Orla works full-time so she pays for a large amount of private home help hours while she is in work, with a small amount of hours provided by the HSE. She provides the majority of care to her mother and receives very little support in her caring role from other family members. She is up during the night most nights with Sarah. She described the amount of time that her caring role consumes and its impact on her ability to meet up with friends or socialise.

Following referral by the Public Health Nurse, Sarah was enrolled in the CODPL. Despite some initial reluctance on Orla's part to become involved in the project for a number of reasons (e.g. a desire to maintain a routine, a concern that it would involve in-patient care for her mother, and resistance to the idea of having a home support worker in the house while she was there), once the project hours commenced, she found them hugely beneficial. She was provided with 12 hours overnight home support once per week. This was not available through standard HSE supports. She spoke about this additional support keeping her sane and giving her the energy to get through the rest of the week when she was assured of one night's rest. While originally she used some of these hours to go out and socialise, as her mother's condition progressed and she found the caring role more draining, she used all of these hours for rest and sleep.

When Sarah exited the project, the 12 hours were sustained by the HSE. Orla spoke of the worry she feels at the possibility of these hours being taken away as she feels they are such a lifeline to her. Since originally enrolling in the project, Sarah's condition has deteriorated a lot in relation to her physical state and mobility, as well as her communication and her ability to recognise people. Orla has requested additional support hours from the HSE but had not received any at the time of the interview. She continues to care for Sarah at home.

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[12] These scores derive from the PwD and informal carers' surveys implemented by the Evaluation Team. Baseline data were collected in the period Apr-Jul 2015; the follow up survey was carried out in the period Apr-Jul 2016.

[13] Pseudonyms are used to protect the identity of respondents

Families were made aware at the outset that the project intervention was limited to twelve weeks only. Some fear of the additional project support hours being taken away was raised by informal carers across initial and follow-up interviews. Home care packages were referred to as a lifeline for service users but there are many links in a complex and fragile chain of home supports including informal and privately or publicly funded formal support, any one of which can be interrupted at any given time. Compounding this were the difficulties for informal carers in getting information about available services, and a sense of lack of transparency about what services were available and the relevant criteria for accessing them. An early activity of the Project Officer was to collate a list of services available for distribution to informal carers, and responses suggest that this may not have reached all informal carers or indeed been interpreted as particularly effective.

Informal carers also referred to what they perceived as a failure of the HSE to consider the whole picture and contexts for individual informal carers. Examples included one informal carer who was looking after two parents each with high dependency care needs. Instead of seeing the total picture in terms of caregiving burden, the informal carer reported that the HSE would only consider the PwD when assessing the need for services. Another example was provided by an informal carer who was told that a hoist should be used for moving the PwD but that this was not feasible when the informal carer was on her own with the PwD. This perceived lack of sensitivity to the lived reality of informal carers' needs was raised frequently by service providers and informal carers alike. Despite this, however, survey data demonstrated that 8/13 informal carers felt that community care services do consider the needs and preferences of the informal carer when making decisions about how to meet the needs of the PwD. Service providers and informal carers alike placed an emphasis on the need for the HSE in particular, to address what they perceived to be a poor recognition of informal carer support needs. Typically, one HSE manager highlighted the importance of looking after and supporting informal carers to sustain the informal carer for longer and delay the need for LTC. A number of informal carers suggested that an advocate for informal carers be put in place to support them and to represent them as needed. The currently available support for informal carers, in the form of training provided by Family Carers Ireland (formerly the Carers Association), was outlined as providing a valuable source of support to informal carers by one member of the HSE management team. This is confirms the preference for Family Carers Ireland as a home care support provider indicated in other sections of this report (Facilitators and Challenges), whereby it was felt that the additional services offered by this organisation were of great benefit to informal carers.

In regards to the experience of using assistive technologies, as previously mentioned the deployment of Telecare over the course of the project was less than anticipated. Both informal carers and service providers stated that, for most PwD and their families, Telecare was not relevant or appropriate at the time which it was offered due to the advanced stage of progression of the illness. While some of the informal carers suggested that they did not need Telecare or that it was not appropriate to their situation, over half (54%, N=7) reported that they already used some form of Telecare which they found useful. The most common forms of Telecare were smoke alarms (n=6), bed occupancy sensors (n=4) and carbon monoxide sensors (n=4).

Some barriers to uptake of Telecare, as reported by stakeholders, included paperwork involved and the communication around this process. Both PHNs and OTs perceived there to be a significant amount of paperwork involved in an application for Telecare. They expressed frustration when the application was unsuccessful or the equipment ultimately provided by the project was different to that requested. This had a negative knock-on effect whereby service providers reported then reducing the number of applications made. One positive of the use of Telecare was the effective training provided on this at the project outset which was valuable in providing knowledge around the use and applicability of various devices.

4.3 Service Provider Perspective

Indirectly, the project provided additional resources to service providers. For the Discharge Liaison Officer, access to project components supported transitioning patients to and from the acute hospital. Though difficult to prove, referral to the project may have helped prevent hospital admissions through, for example, provision of additional supports in a time of crisis. Similarly, the project provided GPs with an additional resource to offer informal carers in a time of need. The project enabled rapid access to the consultant geriatrician, the importance and benefits of which were highlighted by service providers in interviews. PHNs highlighted the benefits of the amount and quality of support for the PwD and carers at a time when getting additional supports through the 'normal channels' is very challenging.

Service providers outlined a number of services in development for older persons, potentially as a result of the project. This included a plan to develop a care pathway for PwD, plans to develop a Memory Clinic, as well as plans to extend day review for PwD to other hospitals, though it was unclear whether these plans were a direct consequence of the project.

4.4 Education

4.4.1 Awareness and Knowledge of Dementia

The awareness and knowledge levels of service providers in the area in which the project was active were assessed from February to April 2015 using the Approaches to Dementia questionnaire (Lintern, 2001) and the Alzheimer's Disease Knowledge Scale (Carpenter et al., 2009). A total of 60 surveys were returned that were mostly completed by individuals with a nursing background (n=39), although volunteers, informal carers and other dementia service providers also participated. Many of the service providers were working in their current jobs in excess of seven years, representing a highly experienced group in relation to dementia care. In addition, many had completed dementia-specific education programmes although these were mostly described as short courses of less than one day. This level of education was reflected in the respondents' perception of their own knowledge of dementia with most respondents suggesting that they had some knowledge (n=44) or were very knowledgeable (n=12) about dementia. The Approaches to Dementia Questionnaire demonstrated overall positive attitudes to PwD indicating that the individuals who completed the surveys were more likely to engage with the PwD and to see them as sentient beings (Lintern, 2001). Overall there was a relatively high level of dementia knowledge among the respondents with a mean score of 23.2 (maximum score 30)[14]. In particular, the scores in the 'Treatment and Management' and 'Caregiving' subscales specifically demonstrated positive attitudes towards PwD and the importance of person-centred approaches.

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[14] A number of questions were incorrectly answered by a relatively large number of people. For example, the item 'it has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease' within the risk factors subscale was incorrectly answered by 72% (n=42) of the respondents. However, these questions were rated as having a strong difficulty index.

4.4.2 Education and Training

The project's educational initiatives complemented other dementia-related awareness raising and education events (e.g. the National Dementia Education Programme (De Siún and Manning, 2010)) thus adding to the momentum of awareness raising across the region. While the awareness and knowledge surveys administered early in the project demonstrate reasonably good levels of awareness and knowledge about dementia, the education events sought to re-orientate staff to more person-centred models of intervention. It was not the intention of the project to offer educational programmes to compete with or replace already existing initiatives, but to create forums for challenging existing models of dementia care, to promote person-centred practices and to create an appetite for further learning. Two formal educational programmes were designed and delivered as part of the project. These were a Life Story Workshop and a one-day education event entitled 'Broadening our Horizons', both of which concentrated on advanced dementia. Much of the target audience were working with people who were further along in their dementia journey, supporting the need for concentrated education in this area. In line with the project aims and objectives, these programmes were underpinned by the desire to promote a more person-centred philosophy of care as advocated in the work of Kitwood (1997). This was described by the facilitators of the life story workshop as promoting a 'normal life' for PwD. Achieving this required service providers to be able to understand the PwD's life and to try to put themselves in their shoes. While the content of the 'Broadening our Horizons' education day was more diverse, similar values underpinned both events with the organisers hoping that attendees might be stimulated to pursue other more comprehensive dementia training programmes such as the National Dementia Programme (De Siún and Manning, 2010). Both of the programmes were open to all staff working in the area as well as informal carers.

The content included in 'Broadening our Horizons' considered the responses to a training needs analysis that was sent to 70 heath care professionals. Sixty people attended this event. An evaluation form was designed specifically for this education day by the evaluation team together with the CODPL project team (see accompanying methodology reference document). Generally speaking the day was positively evaluated with most of the attendants reporting that they enjoyed the day and found the presentations of benefit (the full evaluation can be accessed in the accompanying methodology reference document). Telephone interviews were also completed with five participants and they all supported the evaluation data with some suggesting that they were able to apply some of the principles they learned in their everyday practice.

Introducing life story work as a strategy for working with PwD spoke to some of the perceived knowledge and skills deficits highlighted in the training needs analysis. Two life story workshops were facilitated and 27 people attended. There was no formal evaluation of the workshops completed although telephone interviews were conducted with four participants a number of months later[15] . These participants spoke positively about the value of the workshop and referred to instances of implementing some of the strategies that were suggested. The strategies they used varied depending on the PwD, and participants spoke about the importance of getting to know the PwD and using strategies that suited the person's particular needs. While during the workshop they learned about different ways to incorporate life story work into their daily practices, they were encouraged not to follow a particular script and to be open and responsive to the PwD's unique needs. This approach was apparent in the interviews when the participants talked about the different ways they included life story work for different people. Rather than formalising the approach in a life story 'book', the participants were more likely to reminisce with the PwD using photographs or activities like knitting, which they found effective.

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[15] Attempts were made by the evaluation team to increase the number of telephone interviews.

One life story participant stated *"Well it's improved me as a nurse, like the importance of having simple memorabilia's, photos, having family involved. So anyway it benefited I feel the residents and their families like you know."* (Staff nurse)

Some challenges were highlighted in relation to the roll-out of educational initiatives. A number of service providers reported that they were either unaware of these educational initiatives, or were unable to attend, thereby indicating that these initiatives did not reach saturation. However, it is to remember that education was a relatively small part of the project. Some training for hospital staff was originally envisaged. Training for support workers was targeted and delivered, and a number of awareness raising events implemented. Additionally, the Project Officer provided informal individualised input as part of her ongoing monitoring and support duties. Those who did attend the education events, or who had spoken to colleagues who had attended these, reported positive feedback. Service providers viewed the full-day workshop as beneficial to service users for information and networking. While informal carers did attend both of the educational initiatives, their numbers were low and it is difficult to assess impact in this regard.

4.5 Cost of Care[16]

The basic question in any economic evaluation is whether the extra cost of a programme, technology or intervention is worth it when both the costs and the benefits of that intervention are considered. A positive outcome as regards an improvement in QoL and/or health may not be considered worthwhile if the costs of the intervention are considered very large. Conversely, a small improvement in a desired outcome might be considered beneficial if the cost of the intervention is very small.

The basic approach used in this evaluation is best described as a Balance-of-Care approach in which the total cost of living at home is compared to the cost of LTC (see O'Shea and Monaghan 2016 for more details on this approach). Costs were calculated first from a societal perspective and secondly from the perspective of the HSE.

As regards outcomes, a key objective of the project was to ease the burden on informal carers for a 12 week period so that the PwD could continue to live at home. The short-term nature of the intervention was explained to participants at the outset. Beyond the 12 week period the project hoped to embed a sufficient number of project hours into standard service so that some, if not all, of the PwD could continue to live at home in preparation for transition to long-term care. 29 of the 30 participants continued to live at home for the full duration of the 12 weeks of support. That represents 96% of the participants which is a significant achievement as regards a basic objective. The person who went into LTC before completing the project died shortly after entering LTC.

Was the expenditure on the project an efficient allocation of resources? This question can only be answered with reference to an alternative. In this case a reasonable alternative to consider is that the participants would have moved to LTC. One of the proposed inclusion criteria for being selected for the project was that the person had to have been approved for the Fair Deal programme (this inclusion criteria was relaxed during the course of the project). The reason that the project was designed to last 12 weeks was that the average wait between being approved for the Fair Deal programme and admittance to LTC was 12 weeks at the time the application for funding for the project was made.

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[16] A more detailed economic analysis is available in the accompanying document *Evaluation of the Community Outreach Dementia Project Leitrim & Memory Matters Community Dementia Project – Methodology Reference Document for Community Sites.*

As regards outcomes, taking into account the preferences of the PwD and their informal carer(s), the preferred outcome is that the PwD continues to live in the community rather than move to LTC. The limited available evidence suggests that society as a whole also prefers that people live at home. O'Shea and Kennelly (2008) found that, on average, people in Ireland were willing to incur higher taxation in order to fund a hypothetical care of the elderly programme that was similar in many respects to the actual programme introduced in Leitrim.

Firstly, considering the issue from a societal perspective, the total costs of living at home are considered and compared to the cost of LTC. Later, the costs incurred by the HSE are considered on their own (see accompanying methodology report for details of how the different costs were calculated).

Before the intervention, project participants received the following standard services from the public health system: home help service, public health nurse visits, and visits to day care centers. These were utilised in different degrees, and some persons also received assistance from the HSE to buy additional hours of home help services privately. The cost of these standard services ranged from €8.50 per week (person with no home support apart from an occasional visit by the PHN) to €752 per week.

In order to capture the full costs for a PwD to live at home, estimates of the monetary value of informal care and living expenses were also derived. These were then added to the cost of publicly provided services, together with the cost of the additional services delivered under the project. The resulting aggregate included HSE costs, project costs, project coordination costs, informal care, care purchased privately, as well as housing and personal consumption services. Summary statistics are provided in Table 9. The total cost of living at home per week varied from a minimum of €903 to a maximum of €1,781. The mean across the 30 participants was €1,247 and the median was €1,194. These figures are broadly consistent with the figures reported in O'Shea and Monaghan (2016) for another cohort of people in Ireland who also had dementia.

Table 9. Costs of living at home: Societal Perspective

Descriptive Statistics	Total Weekly Cost to Society of Living at Home
Minimum	€902.60
Maximum	€1,780.80
Range	€878.20
Mean	€1,247.40
Median	€1,194.10

The distribution of this data is shown in Figure 13.

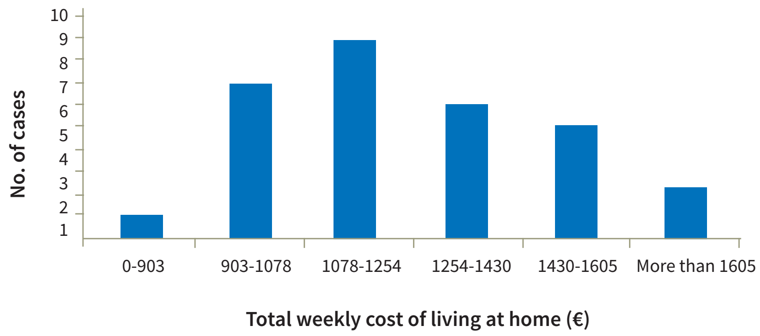

Figure 13: Costs of Living at Home: Societal Perspective

According to a report published by the HSE in 2016, there are three public nursing homes in Leitrim. The weekly cost of these nursing homes varied from €884 to €1,499. Initially the analysis assumed that the most expensive facility, a community hospital, was the most likely destination for this cohort given their advanced stage of dementia. If that community hospital was used as the relevant comparator, then the cost of living at home is cheaper for 28 of the participants. Since living at home is presumed to be preferable and it is almost always cheaper, it can be said that it is the better outcome.

The choice of comparator is critical. A simple average of the weekly cost of the three nursing homes in the county was used (€1,098). Had this number been used as the relevant comparator there would have been only 10 participants where the societal cost of living at home was cheaper than the average weekly cost of LTC.

The perspective taken so far is not necessarily the perspective that the HSE might take. The objective function of the HSE is focused solely on the costs that it incurs in providing home care services or in providing residential services in LTC. Therefore in this section only those costs incurred by the HSE are focused on.

The costs of all the services funded by the HSE including the cost of the services provided by the project were added. The costs ranged from €236 to €1,009 and the mean and median costs were €504 and €487 respectively, as shown in Table 10.

Table 10. Weekly HSE Costs

Descriptive Statistics	Weekly HSE Cost Including the Cost of Project Supports
Minimum	€236
Maximum	€1,009
Range	€774
Mean	€504
Median	€487

The distribution is shown in Figure 14.

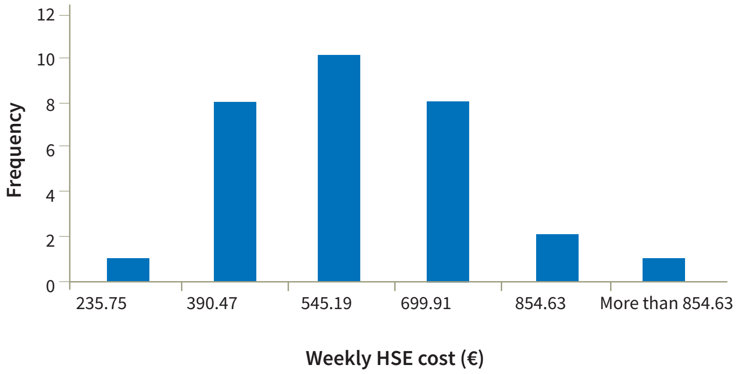

Figure 14. Weekly HSE Costs

Under the Fair Deal scheme, individuals are required to make a contribution towards the cost of their stay in LTC. According to a report on the Fair Deal Scheme (Department of Health, 2015), the average contribution by individuals towards their stay in public nursing homes was €285 in 2014. The net cost to the HSE of the average LTC was calculated as €1,098 minus €285 (= €813).

The net cost of the most expensive LTC facility was higher than the cost to the HSE of the services provided to the person at home. There were only three cases where the cost to the HSE of providing services to the person living at home was more expensive than the average cost of LTC; for the remaining 27 cases it was cheaper from the HSE perspective that the person lived at home. Previous work in this area has also found that the cost of LTC is generally higher for the HSE than the cost of keeping a person at home as long as the number of hours of home help and other social care services provided by the HSE to people living at home is limited.

One thing that is clear from this analysis is that there is no cheap option of caring for PwD who have a high level of dependency. It is almost always cheaper for the HSE that PwD are cared for at home by a combination of informal care (which costs the HSE nothing) and community-based healthcare services. When the issue is considered from a societal perspective, the conclusion depends on which comparator is used.

As mentioned above, the success rate in terms of people continuing to live at home while the project was running was very high (29/30). In many respects, that was to be expected as people would have anticipated a 12 week wait before being admitted to LTC. The more challenging question for the project is whether it had an impact beyond the life of the project itself. As described previously, the respite hours received under the project could be added to the hours of home care being received before the project. The precise number of respite hours added to the regular hours varied. As Figure 8 describes, there were quite a variety of outcomes realised by PwD in the project after it had been completed. Some had moved into LTC including a few who died there. Of the 15 PwD who exited the project and were living at home, 10 had at least some of the project hours mainstreamed.

Looking first at the cost to the HSE of these 10 people continuing to live at home it varies from as low as €186 per week to a high of €629 with a mean of €378. From the HSE perspective, it is clearly preferable that all of these people continue to live at home because it is less than the net cost to the HSE of LTC facilities.

If a societal perspective is adopted, the conclusion that can be drawn again depends on the comparator chosen. The total costs of living at home is higher than the cost of the most expensive LTC for only one participant while they are higher than the average cost of LTC for half of the 10 people whose hours were sustained.

It would be interesting to know whether there are identifiable factors that are correlated with ending up in LTC or continuing to live at home. These were very small groups and care must be taken when drawing strong inferences from such small samples. No differences were found between the group that ended up in LTC and the group that didn't.

It is a policy goal and also found consistently in consultations on policy and programme development in Ireland is that PwD and their families prefer that the PwD live at home as long as possible. The basic objective of ensuring that the PwD continued to live at home was achieved over the course of the project for all but one of the participants. That might have been expected but what is noteworthy is that at least fifteen people continued to live at home after the initial 12 week period of the project. That basic result indicates that the project has a significant and positive impact for that group.

From a cost perspective, whether the project is a success or not depends on the perspective of the analysis and on the comparator chosen. From the HSE perspective, the project was successful because it is almost always cheaper for the HSE for the person to live at home rather than in LTC. When the societal perspective is adopted the situation is not so clear. If the most expensive LTC is chosen as the relevant comparator then living at home is again almost always cheaper than LTC. But when the average cost of LTC is used as the comparator, LTC was the cheaper alternative for two thirds of the 30 people. The fact that the latter group continued to live at home during the project could well be considered a cost effective outcome if the value of staying at home exceeded the additional cost to society of them doing so.

4.6 Summary of Outcomes

Outcomes

- A range of positive outcomes were reported by/on behalf of PwD and their informal carers (e.g. enabling the PwD to remain at home for longer, facilitation of early discharge from hospital, enhanced quality of life for the PwD, and relief of pressure for informal carer).
- A number of gaps in community care services for PwD and their informal carers were highlighted both before and after the project e.g. the lack of flexibility in provision of home support hours within mainstream community care services.
- The basic objective of ensuring that the PwD continued to live at home was achieved over the course of the 12 weeks of the intervention for 29 of the 30 participants. In addition, at least 15 people continued to live at home after the initial 12 week period of support. This indicates that the project had a significant and positive impact for that group.
- From the HSE perspective, the project was successful because it is almost always cheaper for the HSE for the person to live at home rather than in LTC. When the societal perspective is adopted and the most expensive LTC is chosen as the relevant comparator, then living at home is almost always cheaper than living in LTC.
- While positive experiences of the educational initiatives were reported by service providers, it was not possible to measure the impact on practice as they were small in scale and not available to all staff.
- There was less than anticipated deployment of Telecare.

5. Project Facilitators and Challenges

The project had a number of structures designed to maximise facilitation for change. These included the consortium, the steering group and the Project Officer role. Other facilitators and challenges to the project are also outlined here. Figure 15 provides an overview of some important factors to take into consideration in the development of individualised supports in the community. Each factor is discussed in detail in the following sections.

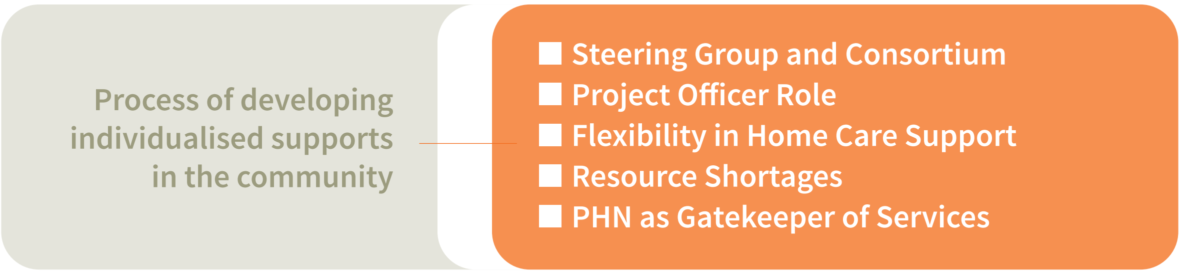

Figure 15. Process of developing individualised supports in the community

5.1. Steering Group and Consortium

The steering group had a shared historical knowledge around supports for PwD and their informal carers locally, including evolving support strategies over the years. This knowledge included previous and current practical supports for informal carers (including cash grants in the past) and the strengths and limitations of these. In hindsight, had the steering group membership included greater representation from primary care service providers (such as PHNs, GPs and OTs) this shared historical knowledge and experiences might have been further enhanced.

In terms of the working mechanisms of the group and how they impacted on the project process, steering group members highlighted the benefits of regular and frequent contact, taking responsibility for reviewing referrals and resolving crisis situations. Meetings were supplemented with additional phone and email contact where crisis or emergency situations arose. Of note, however, is that membership did not extend to PHN representation although the PHNs were a crucial gatekeeper in the project recruitment process and were pivotal in facilitating the continuation of additional home support for beneficiaries after the project intervention ended. Additionally, PHNs became more relevant as the project's scope changed to include PwD beyond the Fair Deal panel. PHNs were engaged with on each case by the Project Officer.

The importance of the consortium to bring together people from across different services (public, private and advocacy agencies) for the successful implementation of the project was regularly highlighted in the stakeholders' interviews. Despite its strong expertise, and perhaps as an indication of the complexity of sub-systems that characterise dementia support in the community, there were notable gaps in early representation, including GPs and PHNs. However, there were conflicting views about the level of awareness among GPs about the project.

The relatively late involvement of PHNs also resulted in early decision making that did not acknowledge particular concerns or experiences of PHNs and other service providers with whom PHNs work closely such as OTs. As a consequence, challenges emerged relating to the referral process with misalignment between those referred and the inclusion criteria set by the project.

The consortium members expressed interest in continuing to work together to further develop dementia care. However, without the framework of a project, the process, focus and intended goals of such continued engagement will need to be worked out.

5.2. Project Officer Role

In the stakeholder interviews, the Project Officer role was raised as a critical facilitator for project planning, development, set-up and roll-out in addition to being a 'go to' person for service users and providers alike. The set-up and structure of the role meant it was relatively free from the bureaucracy of other roles fixed within the HSE because the project had its own budget and governance structure. This was reported to limit the risk of complicated administrative procedures, which can delay decision making and the implementation of supports. The Project Officer was responsible for triaging referrals and completing the initial assessment prior to steering group review. This activity was essential to expedite the process and ensure timely enrolment. She also played an important part in coordinating and managing the project, as reported by the steering group.

The Project Officer played a critical role as a liaison between service users and service providers, and between different categories of service providers, and was able to facilitate communication and engagement between these stakeholder groups.

5.3. Flexibility in Home Care Supports

The initial plan for provision of home support hours was to prolong home care by 12 weeks for those awaiting LTC. Interviews with carers confirmed that many did not plan to proceed with a LTC for the PwD for a host of complex reasons (e.g. unwillingness to engage in Fair Deal process or a wish for the PwD to remain at home).
In-built flexibility was a particular feature of project development and was also the nature of project roll-out. The project was therefore able to facilitate a greater number of PwD and families than would normally be possible for within home care. The flexibility also enabled the home care service to intervene in crisis and emergency situations more easily. Three key elements stood out in reflecting the project's problem solving approach and flexibility. One was enrolment and provision of hours at short notice for crisis avoidance and rapid response. To support this, steering group members, particularly the Project Officer, made themselves available to service providers during and sometimes, outside working hours: *"I remember one case where a woman was just completely overburdened with her husband and on a Friday evening, and she just pulling her hair out and didn't know what to do, whereas we were able to get that, the service in where she was able to get a night's sleep"* (FU FG SG I). Another flexibility element was the provision of respite hours to families at times when HSE home care services were quite restricted such as evenings, overnight, at weekends, and over the Christmas break. This generated particularly positive feedback from informal carers. Importantly, this was a novel aspect of the project which differed from usual services. The final aspect of flexibility was the re-allocation of unused budget from Telecare to respite hours. This decision, made at consortium level, demonstrated effective problem solving and supported a personalised responsive orientation to meeting the needs of the PwD and informal carer.

The strength of the project's capacity for problem solving and flexibility, however, also posed a challenge of increased risk of confusion amongst service providers and key stakeholders whereby it was felt that *"they [project team] were constantly moving the goalposts"* without including those involved in the project (FG PHN I). This finding indicated a need to enhance communication where changes or amendments to care plan arrangements were made.

5.4. Resource Shortages

As above-mentioned the value and benefits of additional home support hours were acknowledged by project beneficiaries and service providers. The positive experiences of service providers in the project led to the suggestion of implementing this type of supports on a larger scale, with the possibility of extending services to those at all stages on the dementia journey and not just those at the advanced stage. However, a number of important considerations emerged during the project evaluation.

First of all, both steering group members and PHNs expressed a concern over the unforeseen inequity created as those recruited onto the project were provided with more home support hours than others in their locality who did not fit the criteria for enrolment but may have had equal, or indeed higher, need. This is a challenge when any initiative is being tested in real world settings, where roll out is not universal but is being tried with a small group. There were also some issues with the sources of home support hours. In addition to the HSE, home support workers for PwD in the region are supplied by a private agency, Family Carers Ireland and the Alzheimer's Society Ireland (ASI). The project linked with the private provider to off-set the shortage of home support staff in the other organisations. This was selected through a competitive tendering process as the project wished to source dementia-trained support workers (the private provider confirmed that their staff had received University of Stirling training). This collaboration had a number of advantages in terms of ensuring access to direct dementia support provision. However, Family Carers Ireland and the ASI provide more comprehensive services than the private agency, such as training, facilitating support groups, and information and advice for informal carers. It was felt that through the engagement of the private agency some of these "extras" might have been missed. Furthermore, PHNs raised a concern about communication issues with the staff from the private agency in relation to client status. This reflects the challenges of inter-agency reporting mechanisms across the public and private sectors.

While it is clear that the project put in place measures to provide adequate support to beneficiaries, some service providers outlined that the number of hours provided at initial roll-out were unrealistically high to be sustained at project exit. The PHN group reported that there were less hours requested and implemented as the project progressed, reflecting the learning around setting realistic care packages that had the potential to be sustained. In some cases, the hours deployed fell short of those applied for and this caused dissatisfaction among service providers and informal carers. It was unclear why this occurred, but it is likely that the steering group's assessment of need differed from the perceived need of the service user or individual service provider. Another issue was the limited availability of home care support hours at weekends, on bank holidays, in the evening time, overnight, at short notice and during holiday periods. Lack of support provision was highlighted in the initial interviews with carers. They reported additional pressures as a consequence of not having help with care at this times, and not being able to respond to family concerns/commitments. The project tried to address this need for more flexibility in the delivery of supports as feasible, but it was not always possible due to constraints in the availability of agency staff.

EVALUATION OF THE COMMUNITY OUTREACH DEMENTIA PROJECT LEITRIM

Moreover, as noted by service providers (particularly the PHNs) the feasibility of sustaining the extra home hours beyond the project intervention was affected by national systemic issues. These include, for example, the ongoing and increasing demand for hours; the provision of home support for physical needs only; national policy restricting the allocation of new care hours unless hours can be recycled; the inclusion of day centre hours in the calculation of support hours required resulting in reduction of home support hours given; inconsistency in the provision of hours; and challenges in getting increased provision even in cases of considerable deterioration in the PwD. Despite an undertaking had been given by HSE management to continue any hours deployed, as the project was ending it became clear to service providers that national restraints on HSE home care support budget were likely to impact on support provision across the region and the continuation of the additional support hours that arose from the project for some informal carers was uncertain. This was highlighted as a potential threat to caring for PwD as home. In this region, many people with dementia are located in very remote areas, and this further complicated the lack of home help staff. For the same reasons, some pessimism was evident among service providers in relation to sustaining a change from task-oriented home support, focused on physical care, to a more flexible arrangement with inclusion of informal carer respite.

The discussion presented in this section highlights some important considerations to keep in mind in the development of innovative approaches to dementia care in the community. These are summarised in Table 11.

Table 11. Dementia Care: Service Needs and Resource Constraints

Particular service needs	Resource Shortages
Dementia-specific case coordination function, and other dementia-specific service providers in community care Need for flexible home support Extension of services to all stages of dementia journey Move from task oriented home care towards relational care	Staff shortages in the community e.g. home support staff and Registered General Nurses (RGNs) Limited availability of home support hours evenings and

As reported in the table, a particular need identified by informal carers and service providers is a dementia-specific case coordinator function across existing service provider roles. This could also be a valuable component within a linked team approach to dementia care, encompassing regular team meetings with case review and case conferences.

5.5. PHN as Gatekeeper for Services

Informal carers, consortium members and PHNs highlighted the gatekeeping role of PHNs to services. This was seen as a core strength in that PHNs were the first point of contact, and as such, the 'face' of services for PwD living at home and informal carers seeking support. Knowledge of the community and their constant presence meant that the PHNs are able to develop relationships and monitor changing circumstances. Some informal carers who were interviewed referred to the importance of the PHN in stepping in to support informal carers and/or the PwD when needed. PHNs gave examples of going to considerable lengths to get support for informal carers who were under increasing stress from the pressures of caring.

However, PHNs also spoke at length about the pressures associated with their role including the heavy administrative load, added to which was the increasing number of patients being discharged from hospital with high dependency needs. Against this background of competing demands, it is difficult to prioritise times for regularly reviewing clients and ensure adjustment of hours when needed. PHNs reported being in the firing line and bearing the brunt of family frustrations in relation to dementia care services.

> *"It's almost like you've to change the whole way the public health nurse has been structured at the moment. They're trying to do everything and they can't… Their feeling is, they have no time to do, they are constantly filling in things. Applying for things, it always comes back to them and then they just get to the stage where they just can't. They just can't take on any more. And that's where we're at, at the moment. Because there's not enough resources"* (FU SI, PHN II)

Informal carers differed in their views of PHN support including the number of visits made to see the PwD. There were mixed views about the gatekeeping role of the PHN: *"You have no direct access to what's going on at all. It's all hidden away and you may get and you may not get and you won't what the reason is. They can give you any reason and how can you fight against that reason. So it's not at all transparent or clear what's happening"* (FU SI, LT01). While PHNs reported on the challenges in getting support for service users, some informal carers misinterpreted this as reluctance for PHNs to designate support hours. PHNs, expressed concerns about reports on budgetary constraints in home support provision and the implications for assessment and responding to needs of carers[17].

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[17] As a consequence of pressure on emergency departments in the first quarter of 2016, spending on home help and support packages increased in order to free up beds. This resulted in a reduction in expenditure later in the year in order to address over spending.

5.6. Summary of Project Facilitators and Challenges

Facilitators and Challenges

- The project structures contributed positively to project set-up and roll-out, with the Project Officer role deemed particularly important.
- The delayed involvement of the PHN role had an impact on project development and roll-out.
- Flexibility in provision of project supports was highly valuable in optimising outcomes for PwD and their informal carers.
- National resource constraints pose a challenge to embedding the project hours into standard home care services.
- Wider organisational and societal driving and restraining forces for the project and for the future development of similar projects are outlined, including for example health policy on home care packages and limited availability of staff in the community.

6 Discussion

The purpose of this chapter is to explore the wider implications for dementia care development that emerged from the findings of this evaluation, with focus on lessons learned and sustainability considerations.

6.1. Impact on PwD and Families' Experience

International research has highlighted the need to acknowledge the expertise of the informal carer and their need for support (Jamieson et al., 2014). There is little doubt that the project's focus on both the needs of the PwD and carer was central to its broad approval among carers and service providers alike.

The findings suggest that the additional hours provided by home support through the project were the most valuable feature of the CODPL. In particular, the perceived benefits were:

- **The positive effect of additional hours on informal carer burden.** Knowing that there was support available for i informal carers should they need it, also decreased the sense of burden as illustrated in the interviews with carers. Similar findings are reported elsewhere (Shanley, 2006).

- **The quality of the assistance provided:** the use of meaningful engagement and social interaction by project support workers, and the use and impact of dementia-specific care plans. Indeed, the importance of ongoing meaningful engagement is acknowledged as important to wellbeing (Killick, 2016).

The ability for PwD to remain at home for longer. In many instances where the PwD was transferred to LTC, the informal carers described regret and guilt that resonated strongly with findings from research elsewhere (Church et al., 2016). In other words, despite the fact that the PwD in this project were already known to be eligible for nursing home care and that project was about support in the interim period, the informal carers were still intent on avoiding a nursing home transfer if at all possible. The project facilitated this within its scope. An unanticipated finding that arose was the importance of the supports offered by the project to carers and PwD who though had advanced dementia were not previously assessed for Fair Deal. For these PwD and carers, their situation had reached crisis point and the project was well positioned to provide support. Though difficult to prove, it is very conceivable that for this group, the project prevented unscheduled admissions to hospital.

Participatory planning: the assessment of the informal carer and PwD as a unit of care contributed to the effectiveness of the project and carers highlighted this as a particular strength of the project. Consideration of the PwD and the informal carer as a dyad/unit in relation to care planning has been highlighted in the literature (Bloomer et al., 2014).

The provision of individualised and flexible support. It was clear that informal carers did not make excessive demands for additional support hours. In some instances, knowing that additional hours could be provided in the event of an emergency was sufficient, although there was a lack of confidence expressed about the actual provision of such supports as experienced by some informal carers. Informal carer input into the selection of hours, as well as flexibility in the provision of hours, were positively endorsed. It is recognised that informal carers are often excluded in decisions about care for the PwD (Jamieson et al., 2014), making it all the more significant here that the informal carer was invited to input in the selection of project hours. Furthermore, Springate and Tremont (2014) argued that given the unique predictors of carer burden, it is important to tailor interventions specific to the type of burden experienced. Flexibility in provision of support has also been highlighted as important elsewhere (Sutcliffe et al., 2015). For projects such as this, there are an inevitable tensions between striving to meet individual needs of carers and PwD and the realities of what is achievable. For a carer who is providing support to two people such as elderly parents, the threat of needing emergency support when one frail parent becomes ill is a real one. For other carers who are juggling competing demands, such as work outside the home and family commitments, the need for support at short notice is also likely.

That the COPDL project was small scale in terms of duration and the numbers of PwD reached and still managed to demonstrate these benefits is testimony to the importance of individualising supports for both carers and PwD. The small-scale nature of the project, with a dedicated Project Officer role in place to drive it, facilitated rapid progress and scope to adapt and respond to learning along the way. Despite its scale, the project illustrated the raft of stakeholders and services involved in supporting PwD in the community. The Project Officer role was crucial in that all of these were involved and their input optimised.

The complex interface between voluntary (not for profit), statutory and for-profit agencies adds further to the complexity of dementia care in the community. This meant that as the project evolved and adaptations were made, stakeholders and services were not always abreast with developments, a point that was raised in the service provider interviews. This again highlights the importance of the Project Officer role and speaks to particular challenges in maintaining communication and feedback networks in what is a complex service of public, private and voluntary agencies. Although a small initiative at one level, a communications strategy for the project might have been helpful in terms of improving feedback loops and speaking to the information needs of individual agencies (HIQA, 2012, Health Service Executive, 2016).

The project's impact on PwD and carers' experiences as listed above, added to the importance of the Project Officer's role, lends further weight to the need to support dementia-specific case coordination approaches to care across existing healthcare roles in order to enhance coordination and improve ability to respond in an individualised way to care needs at short notice. The fact that a small-scale project such as the COPDL should experience challenges in navigating through the raft of stakeholders and services involved in supporting PwD in a community, is further testimony to the value of a community-based dementia-specific case coordination function.

6.2. Maximising Use of Community Care Structures

The project structures positively contributed to effectiveness and successful implementation of activities. A number of considerations on specific elements are here presented.

The consortium included a strong representation from dementia-specific and related services. As such, members were well positioned to comment on strategies to develop capacity for respite care and identify scope for refining and adapting plans as the project moved into the early stages of implementation. Importantly, the consortium took an 'all of community' approach, with stakeholders from multiple sectors (including an informal carer), as recommended by the HSE & Genio programmes (Keogh et al., 2016) in harnessing existing community resources using on the ground strengths and resources to meet local and individual need (O'Shea and Murphy, 2014). Furthermore, a feature of the CODPL consortium membership was its stability throughout the project with minimal changes in membership. This increased potential for knowledge transfer and problem solving.

In general, the project was highly effective in achieving early engagement of service providers and representing public, voluntary and for-profit agencies that provide dementia support. The apparent lack of engagement of GPs with the project may be more nuanced than first appears. It is possible that the GPs may have been at least party to the referral process, given their close working relationship with PHNs. A further dimension to the level of GP engagement with the project may be related to the trend away from GP home visits. As a result, PHNs are more likely to be aware of the circumstances of informal carers and PwD. This reflects the changing nature of community care where the PHNs act as gatekeeper and the GPs are increasingly focused on clinical sessions (O'Kelly et al., 2016).

6.3. Assistive Technology

Under-utilisation of Telecare was indicative of limited application of such technology for persons with advanced stages of dementia and needs of carers (Cullen et al., 2016). This reflects the importance of both the potential usefulness of telecare in advanced dementia and assessing this through a feasibility framework such as that developed by Bowen et al. (2009) in order to capture applicability, acceptability, appropriateness, demand, adaptability, efficacy and integration.

6.4. Awareness and Education

The project steering group recognised that capacity building for staff could be helpful and the project therefore had a modest plan for education. There were significant challenges not least, the capacity of service providers and assessment of real impact. Nevertheless, they were positively evaluated and there was some evidence from the qualitative data that attendees applied some of the principles learned within their practice. As has arisen elsewhere (Irving et al., 2014), the importance of educational initiatives as an ongoing enterprise was highlighted and the project initiatives were viewed in that context, as complementing other initiatives while also raising awareness of the project's particular ethos. Having an informal carer and a PwD speak at the education day also supported the project's person-centred ethos. Of note, there were low numbers of home support staff who attended the educational initiatives, even though some of the sessions (e.g. Life Story workshop) was specifically for them. Home support staff are an important target group for an education programme due to their high level of contact with PwD, and it is important to facilitate their participation in dementia education programmes in the future.

6.5. Financial Considerations

It was evident that family support is core to successful tenure in the community and this is evidenced internationally (Prince et al., 2016). Care provided to support the family and informal carer must be responsive over time. More broadly, what the economic analysis suggested was that a relatively large number of PwD, even though deemed suitable for entry to LTC, could stay at home longer if home support increased in a way that best suits the informal carer, PwD and wider family.

One thing that was clear from this analysis is that there is typically no inexpensive option of caring for PwD who have a high level of dependency. It is typically cheaper for the health service that PwD are cared for at home by a combination of informal care (which costs the state nothing) and community healthcare services, though this does not consider the broader societal cost. The cost of care is subsidised considerably by informal care and therefore when there is scope within families to accommodate a person at home, the cost of care can be lower. However if circumstances are such that informal care is not available, the cost of care to the health service is likely to be higher in the community.

Another important consideration is the implication of looking at marginal or average costs. From the HSE perspective the marginal cost of community based services are much more tangible than the marginal cost of an additional person in LTC. In the former case, each additional hour of care has to be funded. As we have seen elsewhere, much of the care in practice was purchased from a private provider making the budget constraint very real and evident. That is not necessarily the case with LTC. Our comparisons have all been with the average cost of a place in a nursing home as that is the only information that is available. The fixed costs of a nursing home such as energy, maintenance, management etc. are likely to be significant in practice, which means that the marginal cost is likely to be much lower than the average cost. This may explain why the HSE in practice is often reluctant or unable to provide additional supports to people who might be able to live at home with some rather marginal extra care.

6.6. Summary of Key Learning

Notwithstanding the importance of the Project Officer role and the implications for dementia care in the community, the following key lessons have been collected from the project.

Summary of Key Learning

- Provision of additional, flexible and responsive home support hours was of the greatest benefit to informal carers in terms of support and relief of informal carer burden. In this regard, requests for additional support hours were relatively modest.
- The consortium and steering group brought together hospital, primary care and dementia-specific service perspectives that, if nurtured, could help drive cultural, policy and system change.
- The significance of the PHN as a gatekeeper for community care services was emphasised, with the breadth of their reach highlighted.
- It would be potentially beneficial to centralise the provision and coordination of community care and primary care services for PwD as they often fall between the cracks of a range of services.
- Telecare can be useful for people with dementia but its appropriateness, purpose and timing need to be carefully examined as the needs of people with dementia, and their carers, change as the illness progresses. Such assessment could be guided by feasibility frameworks such as that developed by Bowen et al (2009).
- Educational initiatives may be more effective if they are embedded as part of ongoing educational programmes for service providers. Dementia-specific training and education is recommended in the NDS and embedding such training in ongoing education programmes would be an effective strategy for wider reach in support of culture change.
- The cost of care is subsidised considerably by informal care and therefore when there is scope within families to accommodate a person at home, the cost of care can be lower. However if circumstances are such that informal care is not available, the cost of care to the health service is likely to be higher in the community.

In general, these learning points are consistent with the priority areas of the Irish National Dementia Strategy (Department of Health, 2014) and speak to the potential to deliver "person-centred flexible and responsive services" so as to advance the goal of delivering the "right care, in the right place at the right time" (p, 24).
In the CODPL there was significant evidence of adoption of the intervention within the targeted settings and among the relevant stakeholders. However, the project experience demonstrated that the re-conceptualisation of the culture and context of existing supports provided by the HSE towards a more person-centred, flexible and individualised approach requires further attention. For this re-conceptualisation, there would need to be evidence of:

- embedding different ways of working in terms of how home support staff work,
- the freedom and scope of informal carers, as well as PwD, to define their support needs, reflecting a shift in underlying assumptions and shared meanings across the service about dementia care and service delivery.

In the CODPL, as well as the other Dementia Programme sites, changes are already visible at local level, but it is essential to gain support at national level to embed these changes into standard practice and roll them out more widely. The learning from this project provides a useful basis for continuing or expanding this work and moving towards deeper cultural change.

6.7. Sustainability

This project was a demonstration and occurred in a wider service already acknowledged to be under-resourced, with rationing of community care and missed care an everyday occurrence (Phelan and McCarthy, 2016). Therefore the reality of rationing, which is an occurrence across the spectrum of health and social care services and structures nationally, did influence the allocation of home care. Consequently, there were tensions which inevitably arose between the spirit of CODPL's innovative responsiveness to informal carers' needs, and the reality of what was possible at the point of embedding project support into standard HSE services. The tensions went well beyond the HSE's budgeting constraints and extended into what was feasible in terms of integration with the pre-existing administrative operations within the HSE's community care service.

The degree to which the project could bridge the gap between its vision for supporting the PwD and informal carers, and the limitations of existing community services was affected by a number of factors. For example PHNs, among others, reported difficulty in getting HSE manager buy-in for sustaining supports beyond the project intervention. At a local level, the flexibility and deployment of home care is deeply influenced by national community care policy and decisions around this are widely reported in the national media[18]. This potentiates risk for conflicting information and uncertainty among key stakeholders seeking to achieve innovation in care at a local level. Because of the sense of uncertainty around sustaining project hours as part of standard services for some informal carers and the anxiety this caused, if these supports were to be rolled out on a larger scale, there would need to be a greater sense of security for informal carers. The pressures on home support budgets in terms of meeting demographic changes alone are significant (Care Alliance Ireland, 2016). The increased seasonal demands on acute care beds resulting in the increased community care expenditure to support the Winter Initiative Plan[19] means that the HSE has to re-balance its spending late in the year. Against this background of considerable funding pressures, it would seem unrealistic to expect service improvements involving additional supports with built-in flexibility for an out-of-hours component to be sustainable without corresponding increase in, and ring-fenced, funding. In addition, there would need to be a visible commitment to sustaining the additional supports for PwD and informal carers.

[18] As a consequence of pressure on emergency departments in the first quarter of 2016, spending on home help and support packages increased in order to free up beds. This resulted in a reduction in expenditure later in the year in order to address over spending Thus, what some service providers perceived to be cutbacks in support packages was reported as a 'rebalancing' of spending by the HSE. Regardless, mainstreaming of increased supports that the project provided was immediately under threat with PHNs reporting difficulties in arguing their case for PwD and the informal carer.

[19] The aim of the HSE's Winter Initiative Plan, is to adopt specific measures required to address the anticipated surge in activity and service demand during the winter months. This includes reducing the numbers of people waiting to be discharged from hospitals and who require specific supports and pathways to do so

Capacity issues also arose in respect of two inter-related key elements of the project's aspirations for individualised supports: the availability of home support staff to provide additional supports, and the ability to provide the flexibility evidenced as valuable to informal carers through the project. Innovative projects such as COPDL highlight the precariousness of existing support structures for dementia care in the community in terms of service capacity. Efforts to enhance supports towards more individualised care and support as reflected in the Irish National Dementia Strategy (Health Service Executive, 2014, Department of Health, 2014).

Future Plans

The CODPL project team developed and begun to implement a plan in order to continue to develop dementia care services in the region. Key components of this plan include:

- Implementation of dementia education for home support staff
- Development of a one day education programme for PHNs
- Use of the Zarit carer burden assessment tool (Zarit et al., 1985) as part of standard PHN assessment of PwD and informal carers
- Implementation of a ‘Cogs Club’ (a day long programme of activity, stimulation, music and fun for people with mild to moderate dementia)

Furthermore, as a positive reflection of the potential maintenance of project gains, service providers outlined a number of older person services that are in development and which have, in part, followed on from the project. This included, for example, a plan to develop a care pathway for PwD. However, it is not clear who will implement this plan now that the project has ended.

The sustainability of the project activities can only be considered in the context of national developments. To this end, there are a number of ongoing national policy and service developments that have particular relevance to health and social care delivery for older persons, and are important here given that the majority of PwD are older. Sustainability of the project innovation in terms of service delivery for PwD and their informal carers need to be considered within these developments. These include:

- National Dementia Office and Implementation plan for the National Dementia Strategy
- Integrated care programme for older persons (Health Service Executive, 2015a)
- The Single Assessment Tool for Services for Older People (Health Service Executive, 2015c)
- National Clinical Programme for Older People (Health Service Executive, 2013) which aims to support integrated care for older people and to support older people to live at home in the community
- The HSE National Service Plan (Health Service Executive, 2014, Health Service Executive, 2015b) which outlines a focus on integrated person-centred care for older people with complex needs.

Other national developments which must be considered include the greater emphasis on primary and continuing care, as well as an increased emphasis on collaborative working, and the developing model of home care. It remains to be seen how the sustainability plans of this, and similar, projects, will be impacted by national developments in the field.

6.8. Conclusion and Recommendations

The objective of the CODPL was to test innovative approaches to dementia care in the community. The analysis presented in this report shows that the realisation of this objective in practice is extremely complex due to the range of stakeholders involved and their capacity to respond to the project's needs. Particular challenges derive also from the wider systemic issues (and constraints) which affect home support services around the country.

Nevertheless, the additional home support provided through the project to PwD and their informal carers was certainly of value. Notably, the project did not make a vast addition to home care packages in terms of the number of additional hours delivered, but what was provided did make a substantial difference to beneficiaries in terms of quality of life and relief of informal carer burden. On the face of it, the degree of required support places pressures on community care services (public, voluntary and for-profit). However, in costs terms our economic analysis continues to support this model of home care.

On the basis of these considerations, the following recommendations emerge from our evaluation.

Recommendations

- The adoption of a person-centred approach to care that focuses on the relationship between the Person with Dementia and their families.
- The provision of additional, flexible and more responsive home support hours is a key action to enable the Person with Dementia to remain at home for longer and to support family carers. This is in line with the recommendations by the National Dementia Strategy for more flexible support.
- Facilitating and supporting more dementia-specific care coordination approaches to care within existing healthcare roles is important to enhance the quality of services provided to People with Dementia.
- Centralising the provision and coordination of community care and primary care services for People with Dementia might be beneficial as they often fall between the cracks of a range of services.
- For the effective implementation of Telecare it is essential to take account of appropriateness, purpose and timing for those living with advanced dementia and their families.
- Educational initiatives related to dementia must be embedded as part of ongoing educational programmes for service providers.
- A re-conceptualisation of the provision of community care services and a move away from a focus on physical care requirements would be required in order for the project outcomes to be maintained and for the project ethos to continue within standard health services.
- In line with best practices on quality implementation frameworks (Meyers et al., 2012), the experience from this project points to the importance of a substantial set-up phase for any future initiative of the complex and evolving nature of Community Outreach Dementia Project Leitrim. This is essential to ensure preparedness in terms of resources, services and stakeholders and how they interface with one another. Similarly, the basis for monitoring and evaluation should be established at set-up point.

As outlined in Chapter 3, the evaluation was underpinned by the RE-AIM framework (Glasgow et al., 1999, Gaglio et al., 2013). This framework was used to evaluate project activity in terms of reach, effectiveness, adoption, implementation and maintenance. The following table provides an overview of key learning from the evaluation in relation to each of the five RE-AIM dimensions. Highlighted here are the numerous successes of the project, challenges faced which impacted upon project gains, as well as broader concerns which may impact upon the sustainability of the project activities.

EVALUATION OF THE COMMUNITY OUTREACH DEMENTIA PROJECT LEITRIM

Table 12: RE-AIM Key Learning

REACH

- Success in reaching 35 People with Dementia and their associated informal carers.
- A key strength of the project reach was recognising the importance of informal carers and the provision of support to the same.
- The project reached most service providers, though this was delayed in some cases due to staff changeovers.
- The reach of the educational initiatives was modest but in keeping with the targets of the project.

EFFECTIVENESS

- The steering group, consortium and Project Officer role were each recognised as contributing to overall project effectiveness.
- Key aspects of the project which were effective in supporting informal carers and the Person with Dementia were: assessment of PwD and informal carer as a unit; quality of support provided; opportunity for informal carer to input on selection of hours; and flexibility in provision of supports.
- Under-utilisation of Telecare was indicative of limited application of such technology for people at advanced stage of dementia.
- Flexible deployment of home support hours was the most effective form of support provided by the project.

ADOPTION

- Positive changes implemented by the project but limited evidence of a shift in underlying assumptions and shared meanings across the service about dementia care and service delivery.
- The difficulty in sustaining care hours reflects national constraints on community care and was a challenge in project adoption.

IMPLEMENTATION

- Agencies involved in providing home care supports had limited capacity to meet the project's ambitions for individualised and flexible supports such as providing home help in 'out of hours', at short notice or for unplanned events.
- Project structures positively contributed to successful implementation, though this was challenged by availability of staff to deliver community care.
- A case coordinator approach was viewed by stakeholders as a key contributor to the successful implementation of supports for people with advanced dementia and their carers.

MAINTENANCE

- Sustainability of project gains was constrained by the limitations of wider organisational resources and budgetary constraints.
- A cultural shift within the HSE is required in order for the project ethos, and a focus on individualising care with both the PwD and informal carer in mind, to continue.
- The sustainability of the project activities can only be considered in the context of national developments.
- The net increase in requirements for support for PwD and their carers as a consequence of changing demographics and levels of morbidity points to the need for an increase in public spending on community supports even to maintain their current levels. If the supports that were deemed to be important by carers and service providers alike in this project are to be maintained and extended across regions, a further net increase in community spending is needed. It may also be advisable to consider using existing supports in a different way (e.g. more flexible and personalised care).

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Appendices

Appendix 1: Consortium Members for the CODPL

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Appendix 2: Sources of Referral

The following table provides further details on the sources of referrals, looking at total numbers and the specific distribution for the 35 patients formally enrolled in the project.

Source of Referral	**N**
All referrals (N=59)	
PHN	32
POA	13
DLO	9
GPs	3
Glenview lodge day centre	1
Geriatrician	1
Those enrolled only (N=35)	
PHN	23
Community mental health team	4
DLO	2
GP	1
Combination of PHN and DLO (PHN primary referrer)	1
Combination of PHN and DLO (DLO as primary referrer)	1
Combination of GP, PHN and community mental health team	1
Combination of community mental health team and PHN	1
Glenview lodge day centre	1

The suite of tools used to assess families' suitability for the project included: the Zarit Carer Burden Interview (for the informal carer) (Zarit et al., 1985), the Care Needs Assessment Pack in Dementia 'CareNap-D' (McWalter, 1996), the Mini Mental State Examination 'MMSE' (Folstein et al., 1975)/Montreal Cognitive Assessment 'MoCA' (Nasreddine et al., 2005), the Barthel Index (Mahoney and Barthel, 1965), the Geriatric Depression Scale 'GDS' (Yesavage et al., 1983), Pain Assessment in Alzheimer's Disease 'PAINAD' (Warden et al., 2003), the Falls Risk Assessment tool 'FRASE' (Nandy et al., 2004) and the Edinburgh Feeding Evaluation in Dementia Questionnaire 'EdFED Q' (Amella, 2007), among other tools. The referral of a family involved completion of various paperwork including the CODPL Referral Form, a Common Summary Assessment Referral 'CSAR' form[20] (Government of Ireland, 2009) and a schedule of services.

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[20] This is now being phased out as the Single Assessment Tool is in process nationally

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