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Evaluation of the Connolly Hospital Dementia Pathways Project

HSE & GENIO DEMENTIA PROGRAMME





EVALUATION OF THE CONNOLLY HOSPITAL DEMENTIA PATHWAYS PROJECT

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EVALUATION OF THE CONNOLLY HOSPITAL DEMENTIA PATHWAYS PROJECT

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.

Dementia Champion

An individual who promotes a more person-centred approach to dementia care, helps raise awareness of the challenge of dementia, and advises and instructs front-line staff on psychosocial interventions and best practice.

Family/Informal Carer

A person who provides care to a person with dementia outside of the framework of organised, paid, professional work (for example, family member, friend, etc.).

Formal Carer

Used to describe numerous categories and levels of professional service providers and caregivers, providing care to people with dementia.

Governance

Policies, guidelines and systems that are in place.

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.



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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 family/informal carer.

Special

A Special is an observation service provided to a patient or patients within the hospital to ensure their safety. This may be provided on a one-to-one or cohort basis where one special is allocated to a number of patients.

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 drivers and service users).





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List of Abbreviations

AHP:	Allied Health Professional
AMAU:	Acute Medical Assessment Unit
CNM:	Clinical Nurse Manager
DDCB:	Dementia/Delirium Care Bundle
DNS:	Dementia Nurse Specialist
DRG:	Diagnosis Related Group
ED:	Emergency Department (A&E; Accident & Emergency)
FG:	Focus Group
GP:	General Practitioner
HCA:	Health Care Assistant
HPO:	Healthcare Pricing Office
HSE:	Health Service Executive
ICP:	Integrated Care Pathway
LTC:	Long Term Care
MASS:	Memory Assessment and Support Service
MDT:	Multidisciplinary Team
NHSS:	Nursing Home Support Scheme
OT:	Occupational Therapy/Therapist
PHN:	Public Health Nurse
POA:	Psychiatry of Old Age
PRN:	Pro Re Nata, as needed
RGN:	Registered General Nurse
SI:	Single Interview
SLT:	Speech and Language Therapy/Therapist





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Project Overview

Project Title:	Connolly Hospital Dementia Pathways Project
Project Site:	Connolly Hospital and catchment area (extending to Dublin North West, South Meath and North Kildare)
Project Lead:	Dr Siobhán Kennelly, Consultant Geriatrician, Connolly Hospital and Local Health Office, Dublin North West
Dementia Nurse Specialist:	Ms Susan O'Reilly
Consortium Name:	Connolly Dementia Consortium
Project Award Scheme and Value:	A HSE and GENIO Dementia Programme 2013 grant to the value of €500,587 from the Integrated Care Pathway's grant stream of the innovation funding was awarded.
Project Start and End:	April 2014 - April 2018 (inclusive of a critical level of activity from April 2015 onwards with the commencement of the Dementia Nurse Specialist, and a no cost extension to September 2018 to complete environmental changes)
Period of Grant:	4 years



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Foreword

More than a quarter of inpatients in acute hospitals in Ireland have dementia and the costs of caring for people with dementia in hospital are significant. There is no doubt that people with dementia will at times need to be admitted to hospital. However, they can experience the acute hospital setting as disorientating and stressful, and research shows that they tend to have poorer care outcomes, longer duration of stay and are at greater risk of admission to residential care compared to similarly aged people without dementia.

In 2012, as part of the HSE & Genio Dementia Programme, supported by the Atlantic Philanthropies, three acute hospitals in Ireland received funding to develop integrated care pathways (ICPs) for people with dementia in order to improve dementia care delivery; enhance the overall experience of care for people with dementia within the acute setting; and make access to and discharge from the acute hospital as seamless as possible. All three acute hospitals took part in an evaluation study. While the development of ICPs for dementia care are currently advocated internationally, there is limited evidence in terms of the experiences of and contribution and impacts of ICPs to dementia care. These three projects are among the first of their kind in the Republic of Ireland. The related learning in terms of the project process and outcomes findings have much to offer to the scant evidence base that currently exists.

This report describes the evaluation of one of these three acute hospitals, the Connolly Hospital Dementia Pathways project based in Connolly Hospital, Blanchardstown, in partnership with local community services. The project had a number of important aims: 1. reduce the negative effects associated with hospitalisation for people with dementia through appropriate avoidance of acute hospital admissions, 2. reduce the length of stay in the hospital through supported discharge, and 3. improve the hospital experience of the person with dementia through early detection, person-centred care, and a dementia-friendly environment. In order to drive the development and implementation of the ICP, the project developed key services and roles, as well as drawing upon existing services within the hospital and community.

The evaluation found that the Connolly Hospital Dementia Pathways project made significant progress in terms of dementia care integration and development within the hospital and the community. The project successfully developed an ICP for people with dementia which encompassed a number of important components including, for example, a Dementia/Delirium Care Bundle. The project consortium, its subgroups and designated project personnel, i.e. Dementia Nurse Specialist (DNS) and Dementia Link Nurse, facilitated the ICP development and implementation. The DNS, whose role was a hybrid of project management and Clinical Nurse Specialist succeeded, together with the project consortium, in promoting person-centred care within the hospital.

To further enhance the experience of people with dementia in the hospital, environmental changes were made to a number of areas within the hospital. An environmental audit conducted as part of the evaluation found the transformation to be consistent with dementia-friendly hospital design, enhanced person-centred care and impacted on the wider hospital environment and staff. A key component of the project was dementia education and awareness-raising across the hospital and community and a range of educational initiatives, underpinned by person-centred approaches, were provided. The evaluation showed evidence of increased awareness of dementia and the education programmes were positively evaluated.



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I would like to thank the participants for sharing their experiences and insights with the research team. It is hoped that their contribution will feed directly into the future planning, development and integration of acute hospital and community 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 Prof Anne-Marie Brady. We are grateful for the support of the Atlantic Philanthropies in funding this research. We continue to work closely with the HSE and National Dementia Office and hope that these findings will help inform the ongoing implementation of the National Dementia Strategy and will contribute to making the provision of care and support to people with dementia and their families, across both acute hospital and community settings, more responsive and personalised.

Olivia Cosgrove, Genio
October 2018





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Executive Summary

Introduction

The Connolly Hospital Dementia Pathways project led by Dr Siobhán Kennelly was funded through a grant by the Genio Trust with the support of The Atlantic Philanthropies and the HSE. The project aimed to: 1. reduce the negative effects associated with hospitalisation for people with dementia through appropriate avoidance of acute hospital admissions, 2. reduce the length of stay in the hospital through supported discharge, and 3. improve the hospital experience of the person with dementia through early detection, person-centred care, and a dementia-friendly environment. The project aimed to develop key services and roles, as well as utilise existing services within the hospital and community to drive the development and implementation of an Integrated Care Pathway (ICP) for people with dementia and their carers. The project ran for three years, from April 2015 to April 2018 (with a no cost extension until September 2018 to complete environmental changes). Some preparatory work was completed prior to the official start date of the project which coincided with the commencement of the Dementia Nurse Specialist (DNS) role. The project's main objectives were to:

- I. Develop an ICP for people with dementia with a clear governance framework between acute hospital and community services,
- II. Improve the experience of the person with dementia and their family carer through early identification of patients with dementia, key clinical guidelines, person-centred care and a dementia-friendly environment,
- III. Provide out-patient care for people with dementia,
- IV. Provide education across the community and acute hospital to enhance the care and treatment of people with dementia.

To achieve its aims, the Connolly Hospital Dementia Pathways project incorporated a number of components including:

- An ICP for dementia care, including a Memory Assessment and Support Service,
- Dementia-friendly environmental changes,
- A range of dementia education and awareness raising activities, and
- Project-specific roles.

Trinity College Dublin and the National University of Ireland, Galway were commissioned to evaluate this three year project (2015-2018).

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Evaluation Aims & Approach

The aims of the evaluation were to:

1. Understand how ICPs can change and improve service delivery and outcomes for people with dementia and their families,
2. Explore the roll-out of integrated care pathways and their alignment with implementation of the Irish National Dementia Strategy (Department of Health, 2014).

The specific objectives of the evaluation were to:

- 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 and its outcomes in line with current policy trends at national and international level,
- iii. Assess the contribution of the project to quality of life and experiences of participants, including people with dementia and their family carers, agencies and healthcare professionals, and their degree of influence in developing the services,
- iv. Evaluate the process of adoption and development of the initiative, the influence of the initiative on dementia policy, and stakeholder cooperation and implementation of the initiative,
- v. Evaluate the impact of implementation of the Connolly Hospital Dementia Pathways project on outcome measures as agreed with stakeholders,
- vi. Make recommendations so as to inform the implementation of the National Dementia Strategy and the roll-out of integrated care pathways nationally.

An exploratory mixed methods approach involving both quantitative and qualitative approaches was used to provide a comprehensive evaluation of the Dementia Pathways project. An evaluation of such projects requires attention to the set-up, implementation, process, impact and sustainability of initiatives. Therefore, the evaluation was informed by an action research approach and 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.





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Key Findings

Connolly Hospital Dementia Pathways Project Impact and Outcome Findings

- While there was increased identification of delirium through the use of the 4AT tool, this was predominantly within the Emergency Department (ED) setting only. The PINCH ME tool proved successful, where used, for the prevention and management of delirium.
- While the project's focus was not intensively within ED the project did impact on the improvement of dementia care through the ICP in the ED, for example through accelerated assessment. Further improvements are required, for example improved recording and communication of 4AT assessment.
- The Dementia/Delirium Care Bundle (DDCB), and the personal profile therein, was viewed positively by service providers and service users alike and resulted in numerous positive impacts on patient care as well impacting positively on the service provider role.
- The newly developed Memory Assessment and Support Service (MASS) enabled integration and continuity of care to be provided to service users. In addition, the MASS provided a more resource-intensive and therefore beneficial service to people with dementia and their family carers. It also supported hospital avoidance in a number of cases.
- The project roles, in particular the DNS role, were critical for the success of the project. Both service providers and service users spoke highly of the DNS role and its positive impact. Staffing challenges in the recruitment and retention of the dementia link nurse were highlighted as a major difficulty in enhancing integration of care.
- The project evaluation interviews and the hospital organisation, ward organisation and patient case note audits indicated movement towards enhanced integration of dementia care between the outset of the project and its endpoint.
- The positive impact of the environmental changes implemented as part of the project was evident in interviews with service providers and service users, in particular the environmental changes implemented in the Care of the Older Person ward.
- The majority of respondents of the awareness and knowledge survey at follow-up had attended at least one project training session.
- The majority of survey respondents had a positive attitude towards people with dementia at both timepoints and while on average there was a good level of dementia knowledge among respondents at both timepoints, there was a degree of variability among staff indicated by the spread in the range of responses.
- A range of formal and informal education programmes were delivered to all staff, which were based on their roles and perceived needs within the hospital and community. These were positively evaluated and plans have been made to continue and expand upon many of the educational programmes from within existing resources. There is more emphasis on the standard education programmes and bespoke approaches such as telementoring will be implemented when specific need arises.
- Throughout the interviews with staff, there was evidence of increased dementia awareness and the provision of more person-centred dementia care.
- Many of the staff mentioned the DNS as the key driver of the education programmes and that their success could be attributed to her knowledge, expertise and passion.



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Connolly Hospital Dementia Pathways Project Process Findings

- The project consortium was reported on positively by stakeholders. The multidisciplinary composition of both the consortium and working groups was seen as critical in the overall success of these groups and, by consequence, the project. However, changeover of members was a challenge due to staff turnover and staff changing positions.
- Four project facilitators were identified which supported the project process and achievement of its outcomes. These were:
 - Management support,
 - Existing network of supports and parallel developments,
 - Project drivers,
 - Flexibility.
- Five overarching challenges were found to have impacted on the project over its time line. These were:
 - Resource pressures, including impediments to patient flow,
 - Process of diagnosis,
 - Integrating the project into the acute care setting,
 - Difficulty in impacting and assessing change,
 - Communication gaps.
- The project facilitators were active over the course of the project and were found to counterbalance the challenges.

Connolly Hospital Inpatient Activity Analysis Findings

- The total number of cases discharged with a diagnosis of dementia increased from 348 to 614 between 2014 and 2017. All of this increase was due to an increase in the number of cases with a secondary diagnosis of dementia.
- The proportion of cases admitted from Long Term Care (LTC) and discharged to LTC both increased between 2014 and 2017.
- Overall, length of stay declined significantly between 2014 and 2017. However, the various sub-categories examined showed contrasting trends in length of stay. Length of stay decreased significantly for people admitted from home for example, but increased significantly for cases admitted from LTC.
- Length of stay was generally higher for people with dementia than for people without dementia who had received the same primary diagnosis. But the difference in length of stay was not always statistically significant.
- Overall, costs of the cases with a diagnosis of dementia fell significantly between 2014 and 2017. This was particularly the case for people with a secondary diagnosis of dementia.
- Costs fell between 2014 and 2017 in all of the various sub-categories that were examined.



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Recommendations for Enhancing Integrated Dementia Care

On the basis of the project evaluation findings, a number of recommendations, specific to the project, are proposed for enhancing integrated dementia care. Furthermore, this report is one of a series of evaluations and the cumulative learning from these has also suggested a number of broader recommendations.

Project-Specific Recommendations

- A regional centre for dementia diagnosis, with a central database accessible by individual services and healthcare providers would be beneficial to improve the diagnosis journey for service users and improve communication between service providers and settings.
- Sufficient project lead in time is recommended to refine project objectives, for project planning and to complete the necessary groundwork for the commencement of project roles.
- Given the unexpectedly long length of time and the complexity of processes involved in implementing project changes, it is recommended that an increased period of time is allocated to plan and implement similar projects in the future.
- Project leadership and a team of project drivers (including Dementia Champions) is invaluable to the success of such projects.
- Working in tandem with community-based services is very onerous and requires dedicated leadership for future projects.
- Additional business support/project support would have been very valuable in progressing the project and is recommended that such support is built into the planning of future projects.
- There is a need for ongoing information and education for service users including, for example, a comprehensive guidebook on dementia and an overview of the likely timeline of the progression of the condition.
- Providing a follow-up information workshop/session for families following diagnosis would be beneficial.
- Development of ongoing in-depth comprehensive assessments for service users whereby they would be reviewed by a number of relevant healthcare providers and allied health professionals to assess them in a more holistic way is recommended.



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Broader Evaluation Recommendations

- The person with dementia and their individualised needs should at all times be central to innovations to enhance integrated dementia care.
- To achieve meaningful impact, a dementia-friendly orientation needs to be embedded in the strategic objectives and operational planning of an organisation.
- A whole organisation approach to the integration of dementia care is advocated with involvement of key multi-level and inter-departmental stakeholders with the power to leverage support and facilitate required actions.
- Innovation in integrated dementia care requires clear governance and visionary leadership, and such leaders require dedicated resources to support dementia care development.
- A consortium approach is recommended for projects designed to design, test and implement innovations to develop integrated dementia care.
- Inter-sectoral involvement is required where innovations in dementia care are designed to cross the continuum of care. Such involvement should focus on developing collaborative networks and the setting up of effective in-reach out-reach communication systems between those involved.
- Innovations in dementia care (for example, ICP development) and dementia-friendly environmental design are time intensive and require extensive planning inputs to include process mapping of the journeys of people with dementia, evidence review and stakeholder consultation.
- Associated projects need to factor in sufficient lead-in time to devising related interventions and the planning activities involved should be viewed as sub-components of the overall intervention.
- Innovations in dementia care, such as ICPs, require ongoing point of care support through dedicated dementia-specific roles which are highly visible and whose role-holders have expertise in complex dementia care.
- Where dementia-specific roles are shown to have a positive impact, there needs to be commitment and resources to continue them if gains in dementia care integration are to be maximised and built upon.
- When introducing innovations such as ICPs, both opportunistic and dedicated education programmes aimed at enhancing dementia knowledge and awareness contribute to the overall level of staff preparedness. Therefore, sustainable dementia education programmes should be available for all service providers who are involved with people with dementia and such education should retain a strong person-centred focus.
- So as to maximise learning for current and future projects, there is a need to in-build parallel participatory evaluation of the processes involved in projects to develop integrated dementia care in addition to measuring outcomes. Evaluations should additionally plan to extend beyond the end-point of an individual project so as to evaluate for any ongoing impact over time.
- Consideration should be given to embedding dementia-specific key performance indicators and audit metrics into quality assurance systems to monitor ongoing organisational performance relating to dementia care integration.



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RE-AIM framework Applied to the Connolly Hospital Dementia Pathways Evaluation

REACH

- The MASS reached a high number of people, with an increase in the number of referrals to the service over the course of the project, and the reach is further extended through phone support.
- The DDCB was implemented for patients with dementia, delirium and/or who were acutely disorientated, meaning that a significant proportion of patients on the Care of the Older Person ward were reached over the course of the project).
- The DNS role reached a very high number of service providers and service users in the acute care setting as well as in community care through the MASS.
- The environmental changes within the Care of the Older Person ward were achieved but the reach extended beyond the project aims, influencing environmental design decision throughout the hospital (for example, toilet signage and paint colours).
- Though it was difficult at times for staff to be released to attend training, the total number of staff who attended project training was substantial (for example, 64% of staff surveyed had attended project training). The recipients of education and training initiatives were hospital wide, although there was some focus on particular wards and departments in particular the Care of the Older Person ward, the day hospital and the ED.
- The reach of project education extended beyond the hospital boundaries through the MASS and Regional Education Centre, Connolly Hospital.
- The incorporation of project education into whiteboard sessions greatly improved ease of access to education for a number of staff categories though this method was not used within all areas of the hospital.

EFFECTIVENESS

- There were a number of positive impacts on patient care (for example, a move away from the focus on the medical model of care) resulting in better care outcomes for patients.
- The MASS facilitated provision of dementia-specific services with less pressure on resources than other ambulatory care services, leading to improved care outcomes for those who attended the service.
- Increased detection of delirium was reported and consequently, delirium was more effectively prevented and managed.
- Staff endeavoured to facilitate accelerated treatment for people with dementia or delirium in the ED. This also involved the use of the MASS for rapid access assessment as an alternative to the ED.
- The DDCB speaks to the strategic goals of the organisation (for example, priorities for safety and person-centred care).
- There were a number of positive outcomes of the personal profile (for example, reduction of responsive behaviours, facilitation of conversation between staff and patient).
- Service providers and service users alike reported on the positive impact on the quality of dementia care of the project roles, in particular the DNS role.
- The effectiveness of environmental changes was contingent upon the project education initiatives which formed an important foundation for engagement with improved facilities.
- An array of positive effects of the project's environmental changes were reported, including, for example, a reduction in responsive behaviours among patients in the Care of the Older Person ward.
- A positive attitude towards people with dementia and good level of dementia knowledge was evident among staff at project base-line and follow-up.



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- The effectiveness of the education programme was contingent upon the DNS as the primary driver of same.
- There were many references to the positive impact of the education programme on patient outcomes, for example a move away from medication as the first line of treatment to more person-centred approaches.
- The projects impact on outcomes had a number of important facilitators including management support, an existing network of supports (including core services in place and collaborative working), parallel developments, project drivers, and project flexibility.
- A number of challenges to the project impact on outcomes were identified including resource constraints, the process of diagnosis of dementia, integrating the project into an acute care setting with competing priorities, difficulty in impacting and assessing change, and communication gaps.
- The total number of cases discharged with a diagnosis of dementia increased from 348 in 2014 to 614 in 2017.
- Overall, length of stay declined significantly between 2014 and 2017 and costs of the cases with a diagnosis of dementia fell significantly between 2014 and 2017.

ADOPTION

- The penetration of the project into community care settings was not as significant as originally planned.
- The project was facilitated through collaborative working across wards and departments within the hospital, between the MASS and the acute hospital, between the community and the hospital, and between the project itself and other ongoing developments and projects (for example, Frailty project).
- Use of the 4AT was limited to the ED and Acute Medical Assessment Unit (AMAU).
- All who completed project training received the 4AT and PINCH ME tools.
- The DDCB was rolled out in one ward only; significant education and environmental changes also took place on this ward.
- The involvement of various staff groups in project activities varied depending on the initiative, for example, nursing staff were more heavily involved in the roll-out of the DDCB, than doctors.
- The positive impact from the hospital areas and departments chosen to be involved in the project's environmental changes are likely to increase the uptake and implementation of similar changes across the hospital.
- The project consortium and subgroups were multidisciplinary, and in the case of the consortium, included both the hospital and community perspectives.

IMPLEMENTATION

- It was unclear whether all aspects of the DDCB were implemented in their entirety by staff due to the difficulty in auditing each aspect of the DDCB in real time.
- The DDCB was enhanced by the DDCB subgroup through a test and refine process, to the overall benefit of the development of the DDCB.
- The education programme was adapted as needed to meet the needs of hospital staff and this flexibility was viewed positively.
- The project education raised awareness of dementia which consequently increased understanding and motivation to provide more effective care.
- The flexibility of the project team in project planning and roll-out was important to overcome challenges and impact the greatest level of change in dementia care and the integration of care. The project evolved from original plans and certain aspects and components were adapted as new learning emerged.



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MAINTENANCE

- Given the positive impact of environmental changes implemented and the recognition of same by hospital staff, it is likely that the principles of dementia-friendly design will be used in any future hospital environmental works.
- The ability of the education programme to draw upon existing programmes and resources was an important strength and indicator of the potential for sustainability.
- There was an emphasis on maintenance of education initiatives among hospital staff, with the need for a driver highlighted in order for gains to be maintained.
- The need for systems change for the sustainability and embedding of the project was emphasised.
- A number of strong indications for maintenance of various project components were identified, including for example, the existence of a network of project drivers.
- The development of an Integrated Care Team, including the DNS role and a number of other multidisciplinary stakeholders and the recruitment of Clinical Nurse Specialist and Advanced Nurse Practitioner roles in dementia points towards maintenance of project gains as well as further progression and development of dementia care into the future.



EVALUATION OF THE CONNOLLY HOSPITAL DEMENTIA PATHWAYS PROJECT

Connolly Hospital Dementia Pathways Project Key Achievements:



There was a move towards **enhanced integration of care** for people with dementia within the hospital and through the **provision of enhanced ambulatory care** in the Memory Assessment Support Service.

The project was successful in improving **prevention and management of delirium**, design of a **personal profile document**, and implementation of a **Dementia/Delirium Care Bundle** within one ward of the hospital.



The **Dementia Nurse Specialist** role was critical in implementing change to enhance care for patients with dementia, delirium and other cognitive impairments.

A suite of **education and training programmes** were provided, with many of these planned to be continued and/or expanded.



There were very positive **environmental changes** with indications of plans to support continuance of changes.

Project success was contingent upon **the project roles and Consortium**, a number of **project drivers** and the **flexibility** of the project team.



Management support and an existing network of supports and parallel developments were key factors in advancing activities relating to the **integration of dementia care**.



EVALUATION OF THE CONNOLLY HOSPITAL DEMENTIA PATHWAYS PROJECT

1. Introduction

1.1 Dementia Care in Acute Hospitals

In Ireland, it is estimated that there are approximately 55,000 people living with dementia (Health Service Executive, 2016a; Pierce and Pierse, 2017). Projections for the next thirty years suggest that the prevalence of the condition is due to increase steadily to approximately 151,157 persons living with dementia by 2046 (Pierce *et al.*, 2014). This represents a significant social and economic challenge to society, policy and service delivery (Cahill *et al.*, 2012) if the well-being of those living with dementia is to be supported.

The Irish National Dementia Strategy (Department of Health, 2014) was published in 2014, calling for a refocus of service provision to address the needs of people with dementia and their family carers in a more responsive and individualised manner. The priority actions identified by the strategy included:

- 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, and
- Better leadership to guide change in practice.

Cognisant of the fact that the care requirements of the person with dementia and family carers change over time, the strategy centralises the integration of dementia services. Integrated approaches allow service provision to be flexible yet seamless, with the central tenets of co-ordination, continuity and responsiveness (Woolrych and Sixsmith, 2013). The need for an integrated approach to dementia care applies across the continuum of care. However, the acute hospital as a context for experiencing and delivering dementia care has been identified as a dementia care setting of particular concern.

It is suggested that up to 29% of people in acute Irish hospitals may have dementia (Department of Health, 2014; Timmons *et al.*, 2015) and the cost of additional days of hospital admission due to dementia has been estimated to be in excess of €199 million per annum (Connolly and O'Shea, 2015). The acute hospital setting is often perceived as a disorientating and stressful place by and for people with dementia, and international research has indicated that negative hospitalisation experiences can lead to cognition and functional ability declines (Suarez and Farrington-Douglas, 2010; Hung *et al.*, 2017). The reasons for this are multifactorial. For example, the acute hospital is fast-paced, with a predominant task and illness orientation which can be challenging for people with dementia, as their needs are frequently complex (Borbasi *et al.*, 2006; Moyle *et al.*, 2011). Research has further identified the inadequacy of the hospital as a dementia care environment (Nolan *et al.*, 2006; Nolan, 2007), with poor understanding of the needs of people with dementia, insufficiencies in communication and disconnects between the acute hospital and other health and social care settings (Daly *et al.*, 2013), each impacting negatively on people with dementia. For a multiplicity of reasons, it is not surprising that people with dementia in the acute setting are reported to have poorer care outcomes, a longer duration of stay compared to people without dementia of a similar age, higher mortality and a greater risk of admission to residential care (Mukadam and Sampson, 2011; Department of Health, 2014). The Irish National Audit of Dementia Care in Acute Hospitals (De Siún *et al.*, 2014) revealed a



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number of gaps in dementia service provision, specifically: 94% of the hospitals surveyed did not have a dementia care pathway for people with dementia, only 36% of people with dementia were subject to an assessment of function and only 43% had a standardised assessment of cognition status recorded in their clinical records.

As these research findings clearly identify, there is a need to enhance dementia care delivery within the acute hospital setting so as to enhance the overall experience of care for all concerned as well as to improve clinical outcomes and well-being for people with dementia. It has also been suggested that the facilitation of a positive dementia care experience more broadly extends to the personal attributes of those delivering care, as well as the associated organisational, environmental and contextual factors (Scerri *et al.*, 2015). To this end, the needs of both the person with dementia and family carers require consideration (Bloomer *et al.*, 2016), as do the experiences and perspectives of formal carers. In addition to dementia care development within the acute hospital, if truly integrated care is to be achieved, there is a simultaneous need to enhance in-reach and out-reach between the acute care setting and primary, community and continuing care. Attention on integrated care in dementia is timely, given the focus on, and developments arising from, the National Clinical and Integrated Care Programmes (Health Service Executive, 2017a, 2017b). In particular, the Integrated Care Programmes aim to “provide person-centred, co-ordinated care to service users in a seamless manner across the health and social care spectrum, improving quality and putting patient outcomes and experiences at the centre of everything” (Health Service Executive, 2016b p.1). The concepts inherent in this aim are consistent with the underpinning principles of person-centred dementia care.

An integrated care pathway (ICP) is a type of structured care methodology which formalises anticipatory patterns of care processes (Davis, 2005) and multidisciplinary team working to help a patient with a specific condition or symptom set to move progressively towards positive outcomes (Campbell *et al.*, 1998; Middleton *et al.*, 2001; Allen *et al.*, 2009). To this end, ICPs are tools which map clinical and administrative activities for those professions caring for individuals with particular diagnostic conditions (Irving and McGarrigle, 2012). There is an increasing use of ICPs for dementia in the acute care context (O'Sullivan *et al.*, 2017). In the presence of dementia, such pathways are advocated as a means to centralise the focus on the needs of the person living with dementia as well as to improve both multidisciplinary and multi-agency communication and collaboration (Middleton *et al.*, 2001; Irving and McGarrigle, 2012). By streamlining processes, breaking down barriers between teams and capitalising on a more rational use of existing resources, ICPs may also increase the quality and efficiency of care (Rees *et al.*, 2004). According to Rotter *et al.* (2010), ICPs also contribute to a reduction of in-hospital complications, with some of the studies reviewed reporting decreased length of stay and lower costs. As evident from these considerations, ICPs may improve various aspects of acute care, producing beneficial effects not only for patients, but also for service providers and the wider healthcare system (Wolfs *et al.*, 2011; Loughlin & Brown, 2015).

While the Irish National Dementia Strategy (Department of Health, 2014) has set the overarching framework to support change and innovation in the delivery of care for people with dementia, the translation of national priorities into local practice will require time, together with proactive and innovative approaches at hospital level. Integrated models of care can help contextualise broader national policy to local circumstances through an increased focus on local factors such as service availability, geography and population structure (Irving and McGarrigle, 2012). However, Samsi and Manthorpe (2014) highlight that the concept of an ICP can be interpreted in different ways in terms of reach, scope and the stakeholders involved. This has implications for ICP design, as there is no ‘one-size-fits-all’ solution. Therefore, ICP development must reflect local needs and resources. There are also a number of practical considerations to take into account such as financing, the integration of patient records into a shared system and bringing together different disciplines which might have their own individual ways of working (Wolfs *et al.*, 2011). The findings of a recent literature review have suggested that the evidence base on the utilisation of ICPs specifically



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for dementia care is scarce and further research is needed to determine their effectiveness (O'Sullivan *et al.*, 2017). This report presents the findings of a study evaluating the development and implementation of a dementia-specific ICP to enhance service delivery and outcomes for people with dementia and their families.

1.2 HSE & Genio Dementia Programme

Genio is an Irish-based non-profit organisation, specialising in social service transformation. They work with government and philanthropy to support people in leading self-determined lives, such as those living with dementia, mental health difficulties, disabilities and people experiencing homelessness. The Health Service Executive (HSE) & Genio Dementia Programme developed incrementally since 2012 with assistance from the Atlantic Philanthropies and the HSE, supporting the development of innovative service models to improve the range and quality of community and hospital-based services for people with dementia. Since 2011, innovation funding has been awarded to nine regional community-based initiatives and three projects in acute hospitals (HSE and Genio, 2016).

In the hospital sector, funding was awarded in 2013 to projects in Connolly Hospital, Dublin, St. James's Hospital, Dublin, and Mercy University Hospital in Cork to develop ICPs for people with dementia. The projects aimed to reduce inappropriate admissions, accelerate supported discharges and enhance collaboration with community-based health and social care supports, as well as ensure that the person with dementia's journey into and out of acute care is appropriately planned and managed (HSE and Genio, 2016).

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

In 2014, the authors of this report were commissioned to evaluate the HSE & Genio Dementia Programme 2013, focusing on the three hospital sites and two of the community projects (Memory Matters in Carlow/Kilkenny and the Community Outreach Dementia Project Leitrim). This document reports the evaluation findings in relation to the Connolly Hospital Dementia Pathways Project. Under this initiative Connolly Hospital and key stakeholders in the community joined forces to establish more integrated and responsive services for people with dementia.





EVALUATION OF THE CONNOLLY HOSPITAL DEMENTIA PATHWAYS PROJECT

2. Connolly Hospital Dementia Pathways Project – An Overview

2.1 Introduction

The Connolly Hospital Dementia Pathways project, led by Dr Siobhán Kennelly, was funded through a grant by the HSE and Genio Trust with the support of The Atlantic Philanthropies and the HSE. The project ran for three years, from April 2015 to April 2018 (with a no cost extension to complete environmental changes until September 2018), though some preparatory work was completed prior to the official start date which coincided with the commencement of the Dementia Nurse Specialist (DNS) role. This chapter provides an overview of the project as it unfolded over the timeframe of the project.

2.2 Connolly Hospital Dementia Pathways Project Setting

Connolly Hospital, located in Blanchardstown in Dublin, serves a population of 331,000 and has one of the fastest growing catchment areas in the country (HIQA, 2013). The catchment area for the hospital covers the communities of West Dublin, North Kildare and South Meath. It is a public hospital run by the Health Service Executive and has 205 acute beds and 53 day beds providing a range of specialist in-patient, out-patient and day care, diagnostic and support services. Approximately 3145 people with dementia live in the catchment area if the dementia prevalence rate estimate of 0.95% for Leinster is applied (Pierce *et al.*, 2014).

The hospital provides a range of services for older people:

- Hospital level services,
- Out-reach/in-reach team,
- Community level services.

2.2.1 Hospital Level Services

There were a number of hospital level services for older people in existence prior to project commencement, which were expanded and enhanced to enable and advance the work of the project. These included a Consultant Geriatrician working across the hospital and community, ambulatory care through the Holly Day Hospital, and rehabilitation services. There was some access to mental health services for older persons through the Ash ward (psychiatric ward) for patients in the Dublin North West area when referred to the Psychiatry of Old Age team.



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2.2.2 Out-Reach/In-Reach Team

There are 26 nursing homes with approximately 1800 residents in the catchment area of the hospital. The Liaison Medicine for the Elderly team was established in 2008 to provide specialist in-reach/out-reach services to patients in these nursing homes. It is a link between primary care providers and the hospital team which extends secondary care provision to frail elderly older people at the location that is most appropriate to them. The team includes a Geriatrician, a Clinical Nurse Specialist (CNS) and administrative support.

In 2013, Connolly hospital introduced a Clinical Case Manager for older persons which covers the Dublin catchment area of the hospital. This service aims to ensure that older people with complex needs receive the necessary clinical and social supports that enable them to maintain their health and independence. The focus of this role is on older people in domiciliary, non-nursing home settings.

2.2.3 Community Level Services

A number of community-based services are accessible locally to people with dementia. The local area provides access to support services from the Alzheimer Society of Ireland (ASI) including an Alzheimer's Day Centre and an ASI Café to support family carers. There is also access to the community services of a HSE Primary Care Team network, Home Care Packages, and respite care. Access to mental health services for older persons are also available.

Five off-site beds were made available to the Community Geriatrician in St Mary's Community Nursing Unit for assessment and rehabilitation prior to project commencement. Admissions were made here with the aim of early intervention and acute hospital avoidance. Patients referred to this unit had full access to medical, nursing and MDT care in an environment that was conducive to their needs. While this was not a formal part of the project, it was instrumental in providing an alternative to acute hospital admission in an appropriate setting.

A key element of the pathway for Connolly Hospital was the integration and expansion of these services in line with the development of dementia-specific services.





EVALUATION OF THE CONNOLLY HOSPITAL DEMENTIA PATHWAYS PROJECT

2.3 Aims of the Project

The Connolly Hospital Dementia Pathways project aimed to reduce the negative effects associated with hospitalisation for people with dementia through appropriate avoidance of acute hospital admissions, reducing the length of stay in the hospital through supported discharge and improving the hospital experience of the person with dementia through early detection, person-centred care, and a dementia-friendly environment. The project aimed to develop key services and roles, as well as utilise existing services within the hospital and community to drive the development and implementation of an ICP for people with dementia and their carers. The project's main objectives were to:

- I. Develop an ICP for people with dementia with a clear governance framework between acute hospital and community services,
- II. Improve the experience of the person with dementia and their family carer through early identification of patients with dementia, key clinical guidelines, person-centred care and a dementia-friendly environment,
- III. Provide out-patient care for people with dementia,
- IV. Provide education across the community and acute hospital to enhance the care and treatment of people with dementia.

2.4 Project Organisation and Consortium

The project consortium was led by the project lead, Dr Siobhán Kennelly, and DNS, Susan O'Reilly, specifically employed by the project. The project was governed by a consortium of key stakeholders. The consortium brought together a number of stakeholders and those with the knowledge and experience to contribute to the development and implementation of an ICP for people with dementia in Connolly Hospital. The consortium met on a regular basis, approximately four times per year. Consistent with a consortium approach to the planning and development of innovations in integrated and personalised approaches to dementia care (Keogh *et al.*, 2016), members were identified in response to the ongoing goals and activities of the project. The consortium included a Geriatrician, hospital management, Psychiatry of Old Age (POA), Community Older Person's Services, a GP, DNS and other key stakeholders as required. Consortium membership was affected by staff changeover with staff moving to different positions, as well as staff resignations and retirements, though the number of consortium members was maintained through replacement of departing members. However, the changeovers inevitably had an impact on the ability of the consortium to provide effective support to the project.

Project activities consisted of four priority action areas; integration, person-centred care, education and environment. The implementation of activities and goals associated with each of these work streams was led by a subgroup of key stakeholders identified as being instrumental to the successful completion of project activities. Subgroups were elected from within the consortium and responsibilities were assigned in line with individual expertise and based on individual preferences for tasks.

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2.4.1 Communicating the Change

A number of leaflets were developed by the project to provide information and guidance for service users and service providers:

- Living Well with Dementia: providing an array of relevant information including, for example, keeping active, expressing emotions, staying connected and keeping routines,
- Communicating with People with Dementia,
- Connolly Hospital Dementia Pathways Project: Providing information for people with dementia and their families,
- Person-centred care guide to the Dementia/Delirium Care Bundle.

The project vision was regularly communicated through posters, ezines, public information sessions, informal and formal interviews and open days. This was also used by the project as an opportunity to obtain stakeholder views.

2.5 Project Components

The project used and built upon existing structures within the older persons services, for example, the Medicine for Older Persons team (including home ward), Case Managers for Older Persons, Nursing Home Liaison Teams, Older Persons Frailty Teams. The key components of the project are given in Figure 1 below. Each of these components are described in the sub-sections that follow.

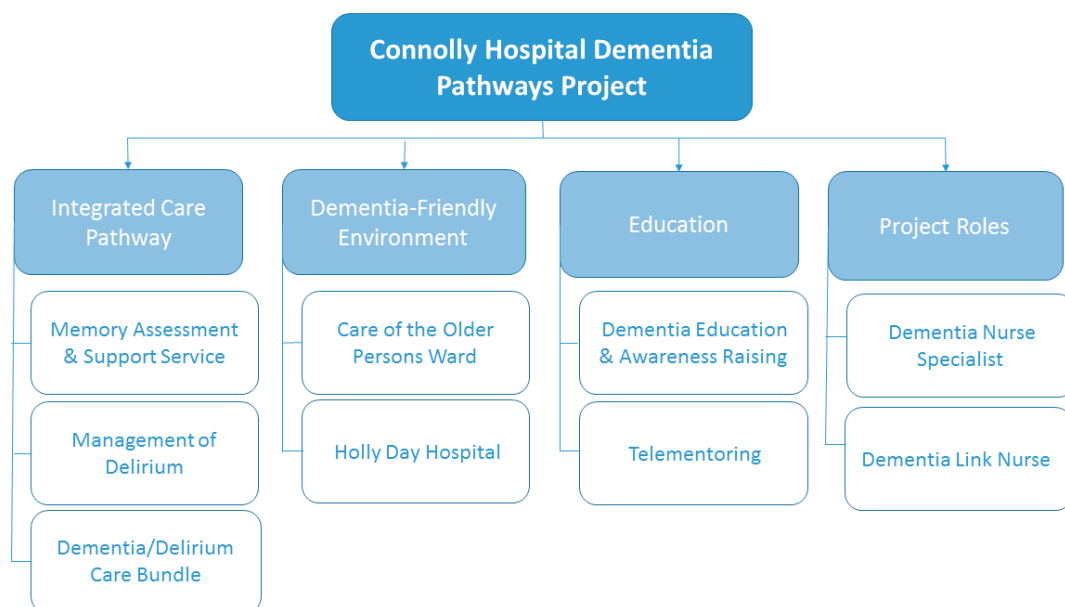


Figure 1. Key Project Components



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2.5.1 Development of the Integrated Care Pathway

The ICP aimed to support people with dementia as they transition from the community to the hospital and vice versa. The following were the key elements of the ICP:

- Development of the MASS to provide ambulatory care to people with dementia and their family carers, and offer a rapid access alternative to the Emergency Department (ED), as appropriate,
- Identifying and assessing people with dementia in the community and putting in place care strategies to prevent hospital admission/ED visits,
- Providing dementia-specific support to meet the individualised care needs of people with dementia when in hospital,
- Improving quality of care and implementing strategies associated with minimising known complications for people with dementia in the hospital and ED,
- Providing follow-up support for people with dementia following an acute episode of illness, and to promote health and well-being, preventing further deterioration or complications from illness.

The Community Liaison Medicine for the Elderly service and case management roles supported the ICP development by providing assessments and care in the community where possible to avoid hospital admission. Together with the MASS and project roles, this improved in-reach and out-reach links between hospital and community.

The development of the ICP was led by the DNS who played a key role in driving the creation and implementation of the ICP policy framework and the Dementia Delirium Care Bundle. Process mapping was conducted in the early stage of the project. The pre-project care journey is presented in Figure 2. The following were the key findings of the process mapping:

- Emphasis on task-oriented care,
- Variations in care given,
- Variations in assessments carried out between wards and medical teams,
- Little emphasis on person-centred communication,
- Poor evidence of behaviour support,
- Poor evidence of pain assessment, end of life planning, meaningful activities and maintenance of independence on the wards,
- No evidence of delirium screening, prevention, identification or management,
- First point of entry to the hospital, in most cases, was through the ED.

The DNS used 10 patient charts to retrospectively track the patients' experience from the community to the hospital and back into the community, in relation to services and supports pre and post-admission. Informal and formal interviews were held with people with dementia and their families. Key staff in the hospital and community (nursing, medical, support staff, estates, infection control, health and social care professionals) were consulted with about their experiences of services for people with dementia and provided input on areas for improvement.

The revised care journey, as developed by the project team, is provided in Figure 3. Using a practice development approach and Plan-Do-Study-Act (PDSA) cycles, subgroups were set up for each priority action area.

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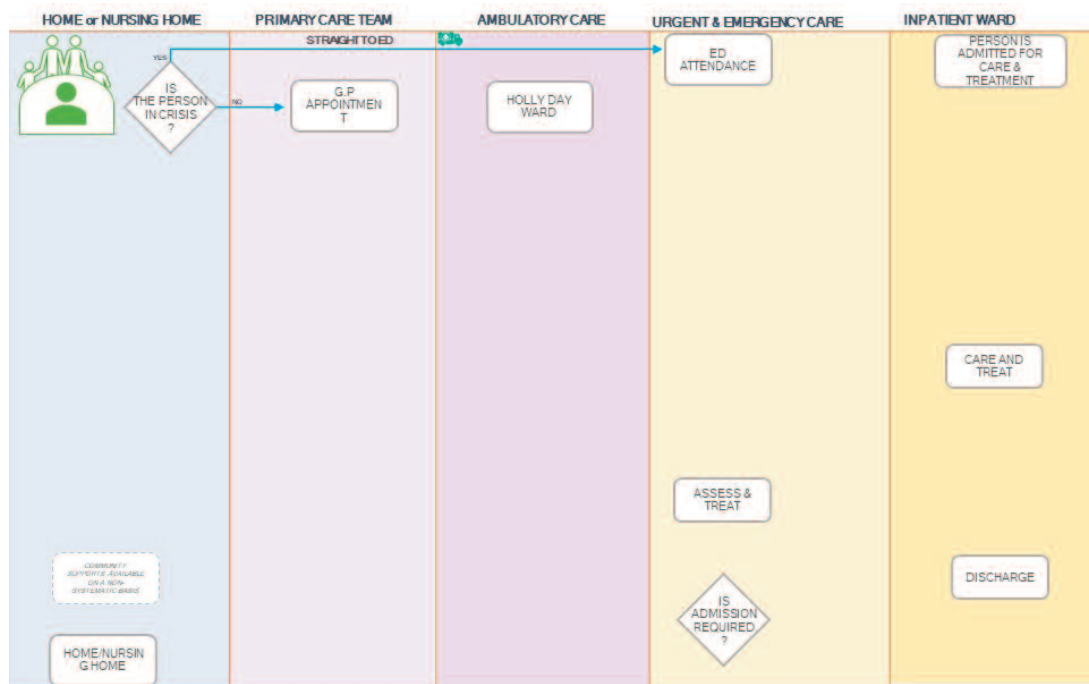


Figure 2. Pre-Project Care Journey¹

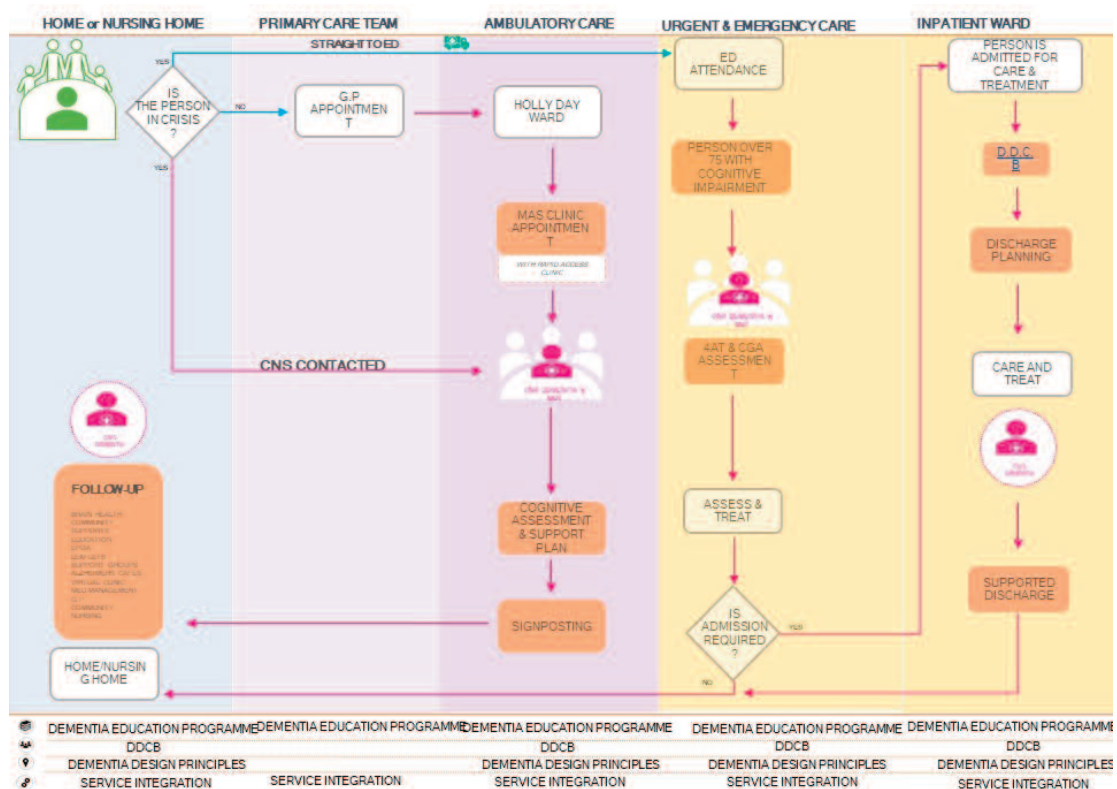


Figure 3. Proposed Care Pathway Developed by Project²

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2.5.1.1 Memory Assessment and Support Service

A Memory Clinic was set up in 2014 for patients with a new referral of memory loss. The project re-orientated this to the MASS in 2015. The weekly Memory Clinic was extended to offer a second nurse-led clinic which included formal cognitive assessment and medical review on the first visit, followed by discussion of diagnosis and feedback and support on the second visit. See Figure 4 for an overview of referral pathways in and out of the MASS.

Referral Pathways to/from the Memory Assessment & Support Service



Figure 4. Referral Pathways for the MASS ³

Approximately 2-3 first time assessments and 2-3 follow-up reviews were conducted per clinic, with additional time for unscheduled appointments. For new referrals with no diagnosis of dementia, assessments took place over two days: day one focused on initial consultation and assessment by the DNS and the Registrar, where needed, and day two included, for example, brain scans and other assessments by the Consultant, Registrar and DNS, as well as disclosure of diagnosis and signposting to supports. The MASS clinics were held on Mondays, Thursdays and Fridays. The Monday clinic focused on reviews, diagnosis and referrals from other Memory Clinics. The Thursday clinic focused on a nurse-led service (with support from doctors) including physical examination and medication review. Finally, the Friday clinic focused on patients with complex medical needs as well as referrals from the Frailty Team within the ED.

³ Figure provided courtesy of the project.



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The MASS was a key element of the ICP and allowed for specific pathways of care for people with dementia through the provision of multidisciplinary care. Where needed, referral to other services from the MASS included end of life care, emergency respite for carer crisis, and acute nursing support through the community intervention team Clinical Case Manager for Older Persons. Reasons for referrals included: dementia; delirium; other cognitive vulnerability; responsive behaviours; discharge planning and support. A significant number of referrals were in-patient referrals who required additional assessment and/or support through the MASS. Such referrals were identified by hospital staff, primarily OTs but often others including the DNS. The MASS clinic served a number of important functions including:

- Early supported discharge,
- Admission avoidance,
- Clinics twice weekly with links to the Frailty Clinic,
- Linking with MDT and other specialties.

A virtual clinic was established in June 2016 as part of the MASS. This was operated by the DNS and interaction between the DNS and patients was primarily over the phone. This served as an important link between the hospital and patients between appointments/in-patient stays. Through this service, the DNS was able to assess patient well-being and progress of any new treatments or medications, and conduct assessments over the phone. Where the patient and their circumstances remained stable, a follow-up appointment with the virtual clinic could be made. In cases where intervention was required, information on appropriate support services was provided (for example, Alzheimer Society of Ireland, Alzheimer's Cafés), an appointment was made for the patient to attend the MASS or a referral was made to the appropriate service or team (for example, to the Public Health Nurse (PHN) to seek increase in Home Care Package). The DNS consulted with other services and teams where necessary (for example, GP, Consultant, PHN). This service reduced the caseload within the MASS as patients didn't need as much intervention.

The Clinical Case Manager in the community played an important role in the MASS (and also in the project planning and application stage) and had an active caseload of approximately 60 patients at any one time. Her role included:

- Identifying frail or vulnerable patients in the hospitals outpatient clinics and following up to ensure they received relevant supports (for example, Alzheimer's Café, day hospitals, Home Care Package),
- Supporting family carers and trying to support the person cared for to remain at home for as long as possible,
- Where relevant, assisting the patient to be admitted to the hospital bypassing the ED,
- Conducting regular patient reviews,
- Receiving referrals from the MASS.

In 2017, the MASS dealt with 101 crisis cases. Of these 101 cases, 95 were managed through re-scheduled appointments, community referrals, the Primary Care Team, Home Care Package and/or respite referrals, successfully avoiding acute hospital admission. Further information on services provided by the MASS in 2017 is provided in Table 1. Over the lifetime of the project, the MASS developed into a hub which supported many of the elements of the ICP.



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Table 1. MASS Services Provided in 2017

Service	Number
In-patient assessment/review/supported discharge	372
MASS clinic assessment/review	480
New diagnosis	106
Crisis/appropriate acute hospital avoidance	101
Virtual review clinic	333

2.5.1.2 Assessment and Treatment of Delirium

The 4AT (see Appendix 1) was introduced in the ED and Acute Medical Assessment Unit (AMAU) as a means of identifying patients with delirium. Early identification of delirium was an important goal of the project: the 4AT and the Single Question in Delirium (SQiD)⁴ were used to identify patients with symptoms of delirium. Where delirium was identified using one or both of these tools, the staff member searched for underlying causes in order to manage the delirium using the PINCH ME tool (see Appendix 1) which outlines possible causes and management of delirium, and was introduced as part of the project. The presence of delirium was also recorded in the patient's notes to be used as a prompt to initiate the DDCB for the patient at ward level.

2.5.1.3 Dementia/Delirium Care Bundle

The DDCB was devised to encompass patients with delirium and other cognitive impairments as well as dementia in order to capture a greater number of patients for whom the DDCB would be beneficial including patients with symptoms of dementia but without a formal diagnosis. The project focused implementation of the DDCB in one ward (Care of the Older Person) so the numbers were lower than initially planned but this focus was deemed important to determine what worked in practice and to ensure organisational buy-in to the project aims. A subgroup was formed in January 2017, with representation from nursing and a range of Allied Health Professionals (AHPs), to develop the DDCB. An algorithm for activation of the DDCB (see Figure 5) was developed which provided an overview of the DDCB elements and activities. A guidance document for use of the DDCB was also developed (see Appendix 2).

4 The SQiD is the following question directed to the patient's relative or carer: 'Do you feel that [patient's name] has been more confused lately?'

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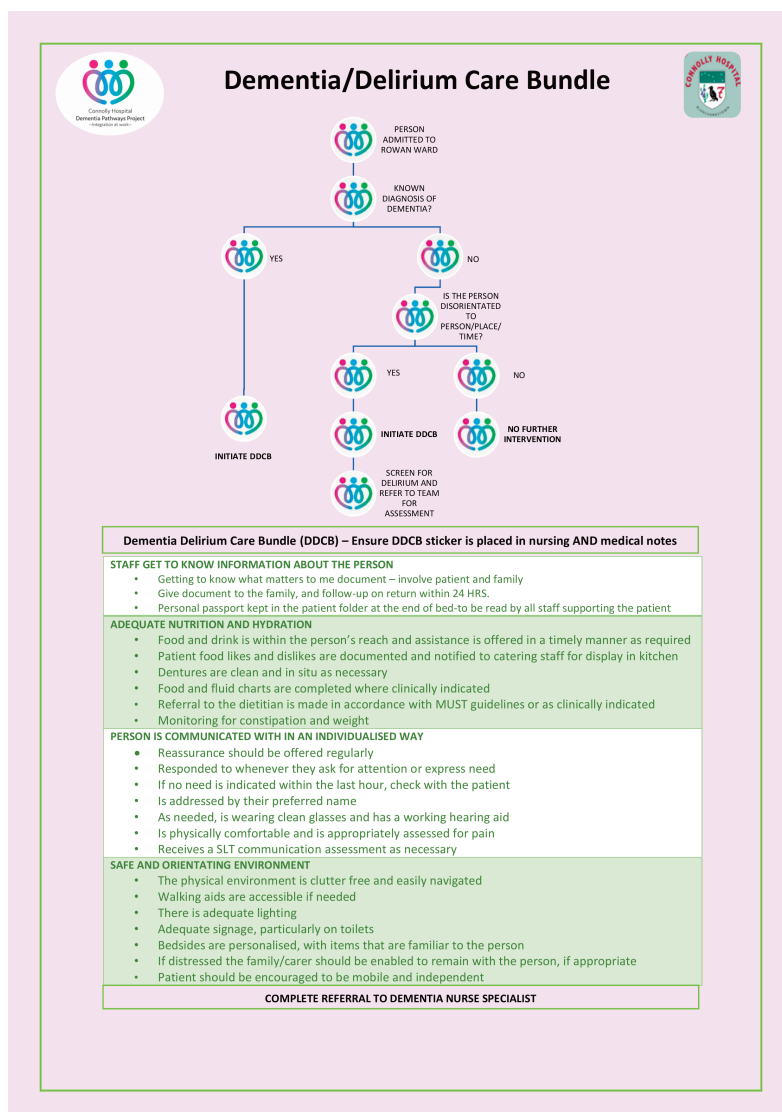


Figure 5. DDCB Algorithm⁵

The DDCB was designed to be quickly and easily implemented, and require no additional documentation. The triggers/prompts for implementation of the DDCB were a diagnosis of dementia and/or disorientation to person, place and time. The prompt to assess for disorientation was included in the nursing assessment document so no extra documentation was required. The main elements of the DDCB, all supported by person-centred guidelines, were; knowing key information, personalised communication, adequate nutrition and hydration, and dementia-friendly environment. Implementation of the DDCB commenced in July 2017.

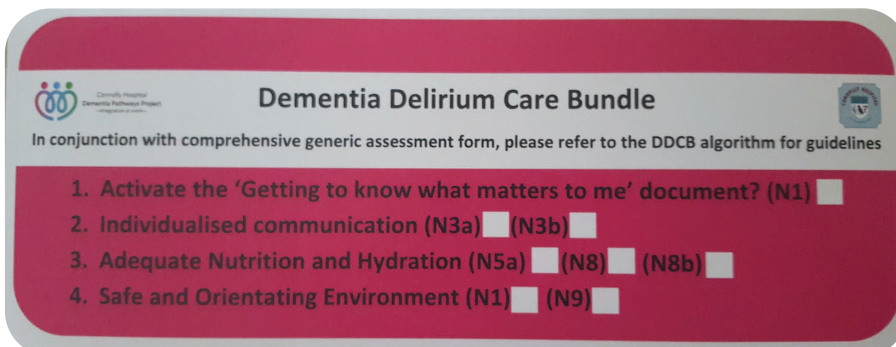
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Knowing key information about the person encompassed a number of elements including the 'Getting to know what matters to me' tool; the personal profile document used by the project. This document aimed to provide information about the person with dementia including medical and social care details so that service providers had key information to help facilitate person-centred care within 24 hours of admission. This document was selected following a review of the relevant literature, and consultation with the patient council, local Alzheimer's Café, people with dementia and their families and hospital staff. The document was completed by either the person with dementia and their family, the DNS or hospital staff. A prompt for completion was included in the nursing care plan (see Appendix 3).

Policy and clinical care guidelines were developed on adequate nutrition and hydration of the person with dementia and were underpinned by person-centred behavioural management principles. National guidelines on nutrition and dementia (Irish Nutrition and Dietetic Institute, 2016) were consulted. The hospital's committee on nutrition and hydration was also consulted with, and was fed into by the project in a reciprocal way. Protected mealtimes were established on the Care of the Older Person ward as part of the project. As per Figure 5, staff engaged in a number of relevant activities. Patient likes and dislikes were included on a specialised whiteboard in the catering department for all patients from the Care of the Older Person ward.

The DNS (and the dementia link nurse while in place) logged contact details of people with dementia, in conjunction with the person with dementia and their family carer. Communication networks were developed to ensure early contact with the DNS where required. Whiteboards on wards allowed for communication between staff about the patient, for example, dietician and catering staff. Though whiteboards were in use prior to the project, their function was expanded to include a platform for on-site dementia awareness raising and education for staff. As per Figure 5, individualised communication with the person was facilitated using a number of different techniques.

The project logo (developed by the project) was printed on magnets and these were used to discretely identify people with the DDCB in place by placing a magnet on the patient information board at the nurses' station. A paper version of the logo was also placed bedside. Two project stickers were also used for those who had the DDCB in place. One of these was placed on the patient's nursing care plan (see Image 2) and the other on the patient's medical notes, whereby existing documentation was used to accommodate the DDCB. These served a dual purpose in highlighting patients with cognitive vulnerability as well as prompting activation of the DDCB. They also helped promote awareness of cognitive vulnerability as many patients requiring the DDCB may not have had a formal diagnosis of dementia.



The image shows a project sticker titled "Dementia Delirium Care Bundle". It features a header with logos on the left and right. Below the title, it says "In conjunction with comprehensive generic assessment form, please refer to the DDCB algorithm for guidelines". The main body of the sticker contains a numbered list of four items, each followed by a checkbox:

1. Activate the 'Getting to know what matters to me' document? (N1) ☐
2. Individualised communication (N3a) ☐ (N3b) ☐
3. Adequate Nutrition and Hydration (N5a) ☐ (N8) ☐ (N8b) ☐
4. Safe and Orientating Environment (N1) ☐ (N9) ☐

Image 1.
Project Sticker Used for
Nursing Care Plan⁶



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A resource pack for the DDCB was situated at the nurses' station in the ward in which the DDCB was used. This included the DDCB algorithm, practical tips and useful information when helping people with dementia and their families, relevant project documents (for example, the DNS referral form and personal profile document), handouts from whiteboard education sessions, and other relevant leaflets and documents.

As part of the improved communication processes of the DDCB, a customised invitation to physiotherapy (see Appendix 4) was developed by a member of the DDCB subgroup. This was followed up with dementia education for hospital porters. This invitation was later adapted to be used by OT. These were designed to improve communication between the patient and the porter, and to provide clear, concise dementia-friendly information to the patient. While development of these invitations was not part of the Dementia Pathways project, they complemented the DDCB and the project objectives. These were reported on positively by service providers.

A safe and orientating environment was ensured using a number of different techniques, as indicated in Figure 5. This included, for example, maintaining a clutter free environment with a focus of encouragement for the person with dementia to be mobile and independent. As outlined in Section 2.5.2, a number of adjustments were made to the hospital environment to not only improve care for those in receipt of the DDCB, but for all patients.

The DDCB was audited in early 2018 by the DNS, the Clinical Nurse Manager (CNM) of the Care of the Older Person ward and a physiotherapist. Three methods of audit were used; interview, document check and observation. Improvements were shown in person-centred care planning; for example, in relation to the use of the personal profile document and staff knowing key information about the person, delirium prevention and identification, and assessment and management of pain. Some deficits were reported in relation to identifying the person's preferred means of communication and their likes and dislikes in terms of nutrition and hydration. At the time of reporting, these were being addressed at an organisational level through a number of mechanisms, including the Nutrition and Hydration Group, the Falls Committee and the Core Care Plan for people with communication difficulties. Furthermore, pre-audits of the DDCB in another ward were complete at the time of reporting, with plans to roll-out the DDCB to this ward in the near future.

2.5.2 Dementia-Friendly Environment

A dedicated subgroup was formed in 2015 with responsibility for implementing environmental changes in designated areas of the hospital to create a sustainable, dementia-friendly environment and reduce the risk of falls, improve continence and help maintain functioning. Represented groups included Speech and Language Therapy (SLT), Occupational Therapy (OT), Physiotherapy, Medical Social Work, CNMs, as well as environmental management. Subgroup members contributed to the national steering group to develop guidelines for dementia-friendly design in acute hospitals, run by the National Disability Authority. Each member shared their learning from the subgroup to try to achieve systemic change and adoption of dementia-friendly design principles across the hospital.

The project funded an OT role (part time) for a six-month period whose remit included work on the environmental aspect of the project. All environmental changes were designed, drawing on universal dementia-friendly design principles with the primary function of enhancing the patient experience for people with dementia. The project used a change model point of view for environmental change. Staff needed education to understand the change and

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for it to be sustained; therefore, environmental changes occurred in tandem with project education. Plans for environmental change were informed by consultation with people with dementia. This was in the form of informal interviews with people with dementia and their family carers as well as a suggestion box for service users located in the Care of the Older Person ward, beside proposed plans for the environmental changes which explained the reasoning behind the proposed changes.

The environmental changes were targeted at the Care of the Older Person ward and Holly Day Hospital. These areas underwent dementia-friendly changes to interiors, furniture and bathrooms. A dementia-friendly day room (solarium) was re-designed on the care for the elderly ward (see Image 2 for a photo of the room before changes and Image 3 for photos of the room after changes). This included:

- Change of layout and furniture to appear more homely,
- Introduction of tea and coffee making facilities for families,
- Use of recessed shelves to include books, a plant and other homely items,
- Paint and flooring changed with incorporation of colour to aid orientation for the person with dementia,
- Introduction of a curved wall to provide a separate smaller seating area,
- Walled enclosed cupboards included on curved wall,
- Clock with date and time to aid orientation for the person with dementia,
- Replacement of window blinds with curtains,
- Addition of extra controls for lighting and sockets to make these easily inactive where required.



Image 2.
Solarium Prior to Environmental
Changes⁷

⁷ Image provided courtesy of the Project Team



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Image 3. Solarium After Environmental Changes⁸

Prior to the project, this room was primarily used for clinical and MDT meetings. A Standard Operating Procedure was developed for the use of this room and importantly, it was highlighted that priority for use of the room is to be given to patient activities and unrestricted access for people with dementia and/or families.

Other key changes to the Care of the Older Person ward to aid orientation and way finding for the person with dementia included:

- Improvement of signage with large signs for key areas (with pictures) including the nurses station and toilets (see Image 4),
- Use of bright colours in door recesses to highlight these (see Image 5), with yellow used for all toilet door recesses,
- Inclusion of a clock with time and date in all single rooms and shared bed bays,
- Use of navy toilet seats on all toilets within the ward,
- Change of colour of handrails and skirting on the corridor to make these more easily differentiated from the wall.



Image 4. Nurses' Station with Improved Signage and Decluttering⁹

⁸ Image provided courtesy of Genio.

⁹ Image provided courtesy of Genio.

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Image 5. Coloured Recesses¹⁰

Further environmental changes are planned for this ward including changing the pictures displayed on the corridor and introduction of vinyl wallpaper on the corridor wall and day room door.

People with dementia and their family members were encouraged to personalise the bedside as part of the project. This included bringing photographs or other mementos or personal items from home to display on the patient's wall area or bedside. The project team, through consultation with people with dementia and their family carers in informal interviews, discovered this would be a more meaningful environmental change than having an abstract identifier above or beside the patient's bedside.

Environmental changes were also implemented as part of the project in the MASS, the ED and the AMAU. In the MASS, improved signage was implemented where large signs were used with both text and images to indicate key areas such as toilets, consultant rooms and the reception desk. The no cost extension to the project to complete environmental changes in the MASS) included the addition of an extra nurses' station as well as the renovation of space to accommodate a permanent office for the DNS and the Integrated Care Team (implemented following the evaluation timeline).

Environmental changes in the ED and AMAU were primarily in the form of improved signage. Two ED bays (located close to the nurses' station) were also altered using dementia-friendly design principles in conjunction with a person with dementia. These ED bays now include a clock with date and time, have improved signage (to and from the toilet), include a coloured vinyl on one of the walls, and have been made less "clinical". Toilet signage was altered across the hospital in the form of a large sign which included an image of a toilet.

Targeted educational initiatives were a key element of the project to ensure the cultural changes needed to sustain the dementia-friendly environment initiatives were achieved. These initiatives are outlined below.

¹⁰ Image provided courtesy of Genio.



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2.5.3 Education

Education was a major component of the project, which ranged from dementia awareness to Dementia Champion training. All staff in the hospital who had patient contact were targeted to receive some level of dementia education depending on their role. An overview of the education programmes delivered is contained in Table 2.

Table 2. Overview of Education and Training Programmes

Name of Education Programme	Duration	Number of staff
Dementia Awareness	1 hour	570
Acute Care Training	4 hours	102
National Dementia Programme	2 days	207
Dementia Champion Training		23

The overall aim of the education programme was to drive cultural change throughout the hospital and community setting using educational initiatives that focused on understanding the person with dementia and providing person-centred care. An education subgroup was formed to oversee the dementia education component of the project. Within the formal educational programme, there was an emphasis on using existing dementia education programmes, such as from the National Dementia Programme and Dementia Champion Training. While there were four main formal components of the education programme, the initiative was supplemented with informal and opportunistic educational sessions that were delivered in response to individual need throughout the hospital and community, but in particular in the Care of the Older Person ward and the day hospital (where the MASS is located).

In addition, a series of short education sessions known locally as ‘whiteboard sessions’ were delivered. These were sessions where all staff in a particular ward or department would come together and a 10-15 minute education session focusing on an aspect of dementia care would be discussed. These were used to provide information about key aspects of dementia care such as person-centred care, or updates about the project such as the introduction of new documentation. In this way they worked as both an education and communication tool and were delivered at a time when most staff were on the ward or department. Where necessary, the whiteboard sessions included all staff including support staff. For example, in the implementation of the DDCB, catering staff on the ward were invited to attend. Brief informal education sessions (including whiteboard sessions) covered a range of topics including:

- What is dementia,
- How to communicate with people with dementia,
- De-escalation techniques,
- Management of responsive behaviours,
- Person-centred care,
- Various aspects of the DDCB including the personal profile document,
- Delirium and the PINCH ME protocol.

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Furthermore, telementoring was developed between the hospital and local nursing homes to allow shared learning and discussion of complex cases, and were facilitated by a multidisciplinary panel. The purpose of these was to explore complex cases similar to a case conference but with an emphasis on dementia care coupled with a particular issue that was occurring at the time. Telementoring sessions commenced in June 2015 and continued on a regular basis until March 2017. They were approximately one hour in duration and software was used, whereby all participants could see and hear each other on their PC/laptop. A number of local nursing homes participated as well as the project lead, the DNS, and the community liaison. Each nursing home had between one and seven participants. Other healthcare professionals were included as needed, for example a GP. Each telementoring session had a different topic whereby cases were discussed and education and information on the topic was provided. Session topics included:

- Responsive behaviours in dementia and medication use,
- Medication reconciliation,
- Antibiotic use in the nursing home,
- Diabetes in the nursing home resident,
- Epilepsy and seizures,
- Falls and bone health in the nursing home,
- Responsive behaviours in residents,
- Depression/anxiety in the nursing home resident.

Other informal or opportunistic teaching sessions revolved around implementation of the DDCB. For example, recognising and managing delirium using the 4AT and PINCH ME assessment tools which were mostly delivered on a one-to-one basis and emerged in the context of the person with dementia/family carer dyad. Finally, there were some hospital wide activities that were held to raise awareness of the Connolly Hospital Dementia Programme and dementia generally, including a seminar to launch the project and a skills fair.

2.5.4 Project Roles

The DNS and Dementia Link Nurse roles, outlined further below, were important in the development of out-reach and in-reach for the project. The DNS role, in particular, was critical in the development and roll-out of the project.

2.5.4.1 Dementia Nurse Specialist

The DNS, a qualified nurse with extensive experience in dementia, was appointed in April 2015 for a three year period. This multi-faceted role encompassed clinical work, consultancy, education, research, environmental changes, project management and administration. She was the clinical point of contact for people with dementia and their family carers in the acute hospital and MASS, and played a pivotal role on each of the project subgroups. Importantly, the DNS role included project management encompassing a number of critical activities, for example, project planning, implementation, financial overview, and reporting to the project funder. A selection of other DNS activities are provided in Table 3.



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Table 3. Selection of DNS Activities

Integration	Person-centred care
<ul style="list-style-type: none"> ■ Patient assessments (in-patients and out-patients) ■ Patient reviews (subject to assessment) and MDT case reviews ■ Care planning ■ Cognitive assessments ■ Follow-up support for people with dementia who have returned home from the hospital ■ Relevant patient follow-up activities including referrals to community services and provision of information and support for the wider care team ■ Acting as a point of contact for people with dementia and their family carers ■ Family meetings/support, liaison, and speaking to families where required ■ Linking with nursing homes for support and providing support to LTC service providers following a patient's discharge from hospital ■ Offering advice and support to service providers on individual patients ■ Acting as a link between nurses and doctors ■ Discharge planning support 	<ul style="list-style-type: none"> ■ Formation of the DDCB subgroup and membership of same ■ Contributing to the development and roll-out of the DDCB ■ De-escalating patients and role modelling de-escalation strategies to staff ■ Promotion of person-centred compassionate dementia care at all levels of contact with the person
Education	Environment
<ul style="list-style-type: none"> ■ Staff training ■ Educating and empowering service providers to engage in dementia-friendly care ■ Increasing the visibility of dementia information (for example, leaflets and posters) ■ Acting as a point of contact for any staff member seeking input or advice on dementia care ■ Post-diagnostic supports and signposting 	<ul style="list-style-type: none"> ■ Formation of the environment subgroup and membership of same ■ Steering group member for the National Guidelines for Dementia Friendly Hospital Design



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The DNS acted as a point of contact for the Dementia Link Nurse (and later, the project OT), the Community Case Manager for Older Persons, Community Mental Health Nurse for Older Persons and the Liaison Geriatric Services for people with dementia.

The DNS played a key role in the integration of services between the hospital and the community. This included:

- Setting up an Alzheimer's Café in a local area,
- Carer education sessions in a local nursing home,
- Regular case meetings with community partners,
- Guest speaking at a number of community initiatives to raise dementia awareness,
- Organising education initiatives for community-based staff,
- Developing links with other hospital and community sites with similar goals.

The project funded some administrative support from MCO Projects Ltd for the DNS for an approximate nine month period on an as-needed basis (1-2 days per week). Tasks which were completed by the administrative support included the development of a database of attendees of education sessions, assistance in operation of project subgroups, and the drafting of relevant documentation following consultation with the project consortium.

2.5.4.2 Dementia Link Nurse

The dementia link Registered General Nurse (RGN) role commenced in May 2015 on a two-day-week basis as a replacement for a dementia link PHN role which was in place for a number of months prior to January 2015, during the planning and set-up stage of the project. There was a significant delay in finding a suitable replacement for the dementia link PHN role. The aim of the dementia link nurse role was to support people with dementia in the community and prevent crises which may lead to unscheduled admissions. Upon referral from a GP or PHN or other healthcare professional (in conjunction with a GP), the dementia link nurse conducted a site visit to perform a needs assessment with a view to pre-empting any escalation of care. The dementia link nurse also followed up people with dementia after discharge from the hospital to provide follow-up advice and support. She sought emergency referrals for people with dementia who required prioritisation for review with geriatric medicine or community mental health services for older people. Where indicated, the dementia link nurse referred the individual to the MASS for ambulatory care. She attended one MASS clinic per week. She also liaised with the MDT community in the hospital. She contributed to the development of a referral pathway from the PHN or Community RGN to the hospital. She also identified dementia education needs and opportunities for dementia care training in the community. This role ceased in late August 2016 though the role activities continued to an extent through other consortium members within community roles, such as the Clinical Case Manager who worked closely with the MASS. In addition, several months subsequently, the project funded an OT role (part time) for a six-month period whose remit included acting as a community link and developing a form of cognitive rehabilitation in the community.

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2.5.5 Overview of Project Activities and Milestones

Figure 6 presents a timeline overview of the key project components and activities described in the previous sections.

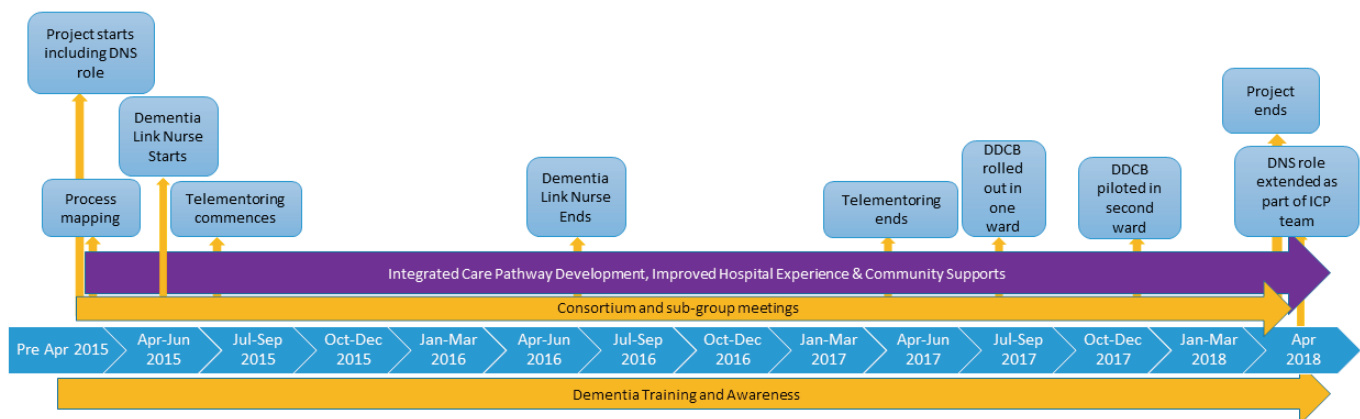


Figure 6. Overview of Connolly Hospital Dementia Pathways Project Activity

2.6 Summary

The Connolly Hospital Dementia Pathways project aimed to develop and deliver enhanced integrated care for people with dementia. This chapter provided an overview of the project components and the timeline across which they unfolded. The following chapter describes the methodology that was used to underpin the evaluation of the project.



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3. Methodology of Evaluation (Overview)

3.1 Introduction

As outlined in Chapter 1, the authors of this report were commissioned to evaluate the Connolly Hospital Dementia Pathways project 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 person with dementia. An evaluation of such projects requires attention to the set-up, implementation process, impact and sustainability of the initiatives. To this end, the evaluation methodology adopted for the project reported here, was informed by action research with emphasis on context, relationship, process and outcomes, and is underpinned by the well-established RE-AIM evaluation framework (Glasgow *et al.*, 1999; Gaglio *et al.*, 2013).

3.2 Aims

The aims of the evaluation were to:

1. Understand how integrated care pathways can change and improve service delivery and outcomes for people with dementia and their families,
2. Explore the roll-out of integrated care pathways and their alignment with implementation of the Irish National Dementia Strategy (Department of Health, 2014).

3.3 Objectives

The specific objectives of the evaluation were to:

- 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 and its outcomes in line with current policy trends at national and international level,
- III. Assess the contribution of the project to quality of life and experiences of participants including people with dementia and their family carers, agencies and healthcare professionals, and their degree of influence in developing the services,
- IV. Evaluate the process of adoption and development of the initiative, the influence of the initiative on dementia policy, and stakeholder cooperation and implementation of the initiative,
- V. Evaluate the impact of implementation of the project on outcome measures as agreed with stakeholders,
- VI. Make recommendations so as to inform the implementation of the National Dementia Strategy (Department of Health, 2014) and the roll-out of integrated care pathways nationally.

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3.4 Methodology Overview

The evaluation was underpinned by an evaluation framework called RE-AIM (Glasgow *et al.*, 1999; Gaglio *et al.*, 2013) which is briefly presented in Figure 7. Using this framework, project activity was evaluated in terms of reach, effectiveness, adoption, implementation, and maintenance. The framework was applied using an exploratory mixed methods approach. This form of research involves the collecting, analysing and integration of quantitative and qualitative data to capitalise on the respective strengths of both approaches (Lieber and Weisner, 2010; Bryman, 2012; Doyle *et al.*, 2016). Mixed methods research was considered appropriate as it is a means to investigate “complex and multi-faceted research problems” (Doyle *et al.*, 2009 p. 175) and can “facilitate a greater understanding of complex human phenomena that exist in healthcare research in addition to allowing the patient’s voice to be heard” (Doyle *et al.*, 2016 p. 633).

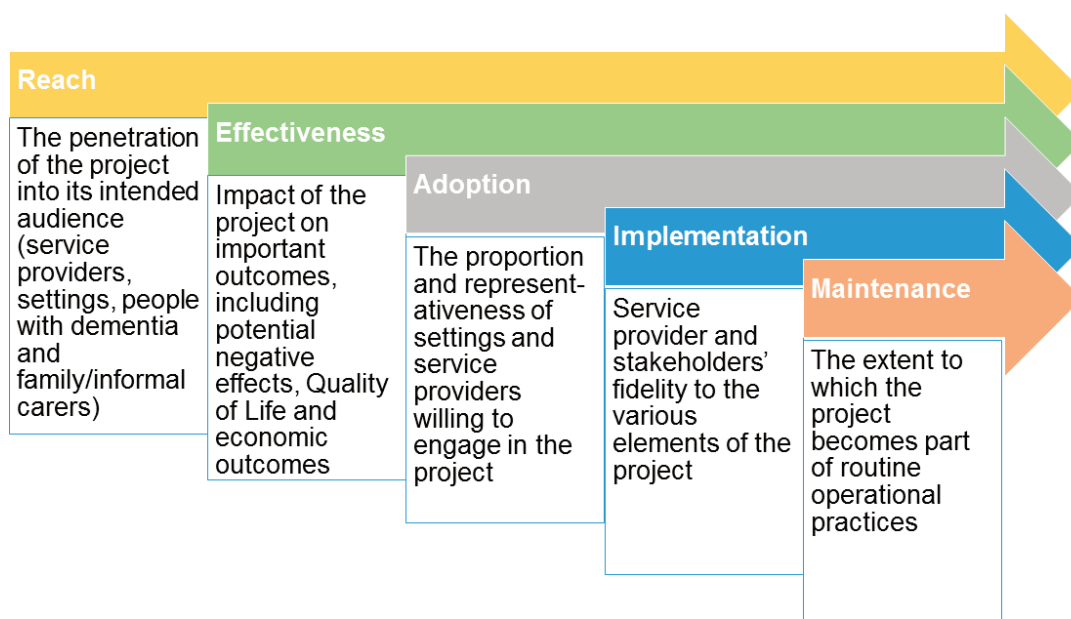


Figure 7. RE-AIM Framework Used in the Evaluation

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There were four key aspects of the evaluation methodology, as outlined in Figure 8.

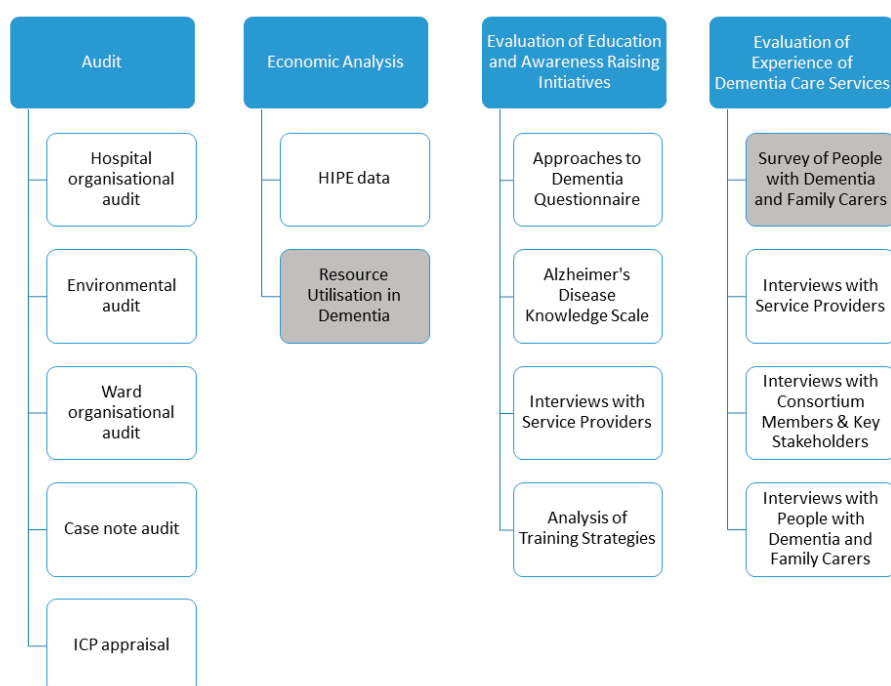


Figure 8. Overview of Evaluation Method¹¹

Data collection for the evaluation occurred at three main time points, early on in the project timeline (Time 1 [T1]/baseline), at a mid-stage of the project where there was a peak level of project activity (Time 2 [T2]) and towards its end (Time 3 [T3]/follow-up). Of note, because T1 data collection took place over a number of months, some of this data was collected a number of months after the project had started and as such, T1 data reflects the 'early in-project status' as opposed to pre-project status. In order to capture the process related details of the project as they unfolded, additional data were collected on an ongoing basis. A purposeful sampling strategy was adopted to identify participants (Palinkas *et al.*, 2015), with ethical approval granted by Trinity College's Faculty of Health Sciences Ethics Committee and the Connolly Hospital Research Ethics Committee (REC). The total number of participants involved in each stage of data collection is provided in Table 4.

¹¹ It was not possible to include data sources shaded in grey in the evaluation due to very limited amount of such data that it was possible to collect. This included data from the Resource Utilisation in Dementia tool (Wimo *et al.*, 1998).



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One of the evaluation aims was to understand how ICPs can change and improve service delivery and outcomes for people with dementia and their families. Despite extensive efforts and the use of a gatekeeper in the research site, the number of family carers recruited was small and it was not possible to interview people with dementia at T1 or T2. While limited, the data from the interviews with family carers was very informative in terms of the experience of dementia in the hospital and within the MASS, though it is important to bear in mind that views experienced by this sample may not represent the range of experiences of all family carers of people with dementia. Impacting on the recruitment of people with dementia and their family carers was the availability of potential participants fulfilling the evaluation study inclusion criteria¹² and the complexity of individual and care circumstances surrounding potential participants during hospital stays.

Table 4. Overview of Sample Sizes in Data Collection Stages

Participant Group/Source	Time 1/Baseline	Time 2	Time 3/Follow-up
Economic analysis	HIPE data for 2014 – 348 cases	-	HIPE data for 2017 – 614 cases
Awareness and knowledge survey ¹³	134	-	105
Surveys of service users and family carers	4	-	-
Interviews with service users and family carers	3	-	8 (3 focusing on inpatient and 5 focusing on MASS experience respectively)
Interviews with service providers (including consortium members & key stakeholders)	33	16	18



¹² People with a primary or secondary diagnosis of dementia, and their family carers, who were identified by a gatekeeper as being well enough to take part in the evaluation. These service users and their families needed to be in receipt of care from Connolly Hospital and willing to participate in the evaluation study.

¹³ Awareness and knowledge survey data was collected by the Connolly Hospital Dementia Pathways Project team.

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Figure 9 provides an overview of the timeline of data collection in relation to project activities.

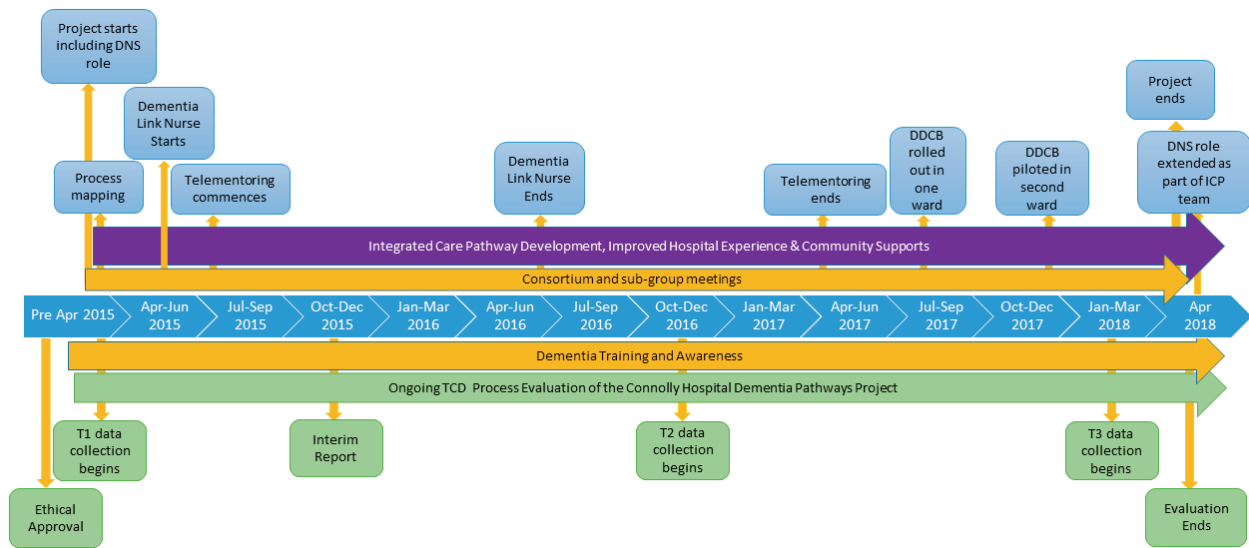


Figure 9. Overview of the Timeline of Project Evaluation Data Collection in Relation to Connolly Hospital Dementia Pathways Project Activities

3.5 Summary

This chapter provided a brief overview of the methodology used to inform the conduct of the Connolly Hospital Dementia Pathways project evaluation. The findings of the evaluation are reported in the following three chapters:

- Chapter 4 - Connolly Hospital Dementia Pathways Project Impact and Outcome Findings,
- Chapter 5 - Connolly Hospital Dementia Pathways Project Process Findings,
- Chapter 6 - Connolly Hospital Inpatient Activity Analysis.



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4. Connolly Hospital Dementia Pathways Project Impact and Outcome Findings

4.1 Introduction

This chapter presents the findings that emerged from the evaluation of the Connolly Hospital Dementia Pathways project relating to the impact of the project components. These findings are presented with reference to:

- The integration of dementia care,
- The physical environment,
- Dementia education and awareness.

4.2 Integration of Dementia Care

As demonstrated in Chapter 2, the Connolly Hospital Dementia Pathways project contained a number of elements that aimed to enhance the integration of dementia care within the hospital both for in-patient and out-patients, as well as on discharge from the hospital into the community. Evidence to inform the evaluation of the project in terms of these elements was obtained from multiple sources at T1/baseline, T2 and T3/follow-up, as well as over the course of the project. The evaluation findings in relation to the integration of dementia care are presented with reference to:

- Integration of dementia care – ICP for dementia,
- Integration of dementia care - project roles,
- Overall integration of dementia care.

4.2.1 ICP for Dementia

It was reported that the development and roll-out of the ICP for dementia has had a number of positive impacts on patient care resulting in better care outcomes for patients. This related to:

- A move away from the focus on the medical model of care towards person-centred care,
- Change in how staff interact with people with dementia,
- Increased linkage of patients with the MASS and local Alzheimer's Café and other support services,
- Reduction in use of antipsychotic medication for management of responsive behaviours,
- Some reduction in the use of specials on the Care of the Older Person ward through both the increased use of GLOBE (General Levels of Observation But Extra) care/cohorting and the use of the DDCB,
- Less stressful working environment for staff,
- Increase in focus on person-centred care at weekly CNM meetings.

There was acknowledgement that the impact of the project on care in the community was not as significant as initially hoped, primarily due to the lack of continuity in the Dementia Link Nurse role. The individual components of the ICP will be considered and discussed in the sub-sections that follow.



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4.2.1.1 Memory Assessment and Support Service (MASS)

While initially the MASS began as a Memory Clinic to cohort people with complex memory problems or in need of diagnosis, it evolved over time and in response to need, providing a more focused and targeted response through the use of a case management approach. The MASS became a hub for integration, early access to assessment and diagnosis and post-diagnostic supports, as well as incorporating a rapid access ambulatory service for people living with dementia and their families. The ability of the MASS to provide specialised dementia assessment to a cohort of patients and dementia-specific supports was a unique opportunity as the provision of supports previously would have been in the form of generic ambulatory care:

“It wasn’t that we didn’t have anything, okay, but it’s just it was all-comers, we saw a patient with dementia, then a patient with Parkinson’s, then a patient with osteoarthritis and then a patient with all three...whereas I suppose, what putting a service like this in place is that you can have a much more kind of targeted approach and that definitely is better. It’s I think particularly good for patients at an earlier stage in their diagnosis who weren’t suited to coming to the generic kind of clinics” (SI T3 Project Team 1).

The ability of the MASS to contribute to continuity of care between the ambulatory care and acute care environments was emphasised. Other highlighted benefits included the ability to provide: more time to patients, an advocacy service for patients, increased information and supports, a dementia-specific point of contact, and a follow-up service through the DNS. The increased amount of time available for patients meant that the MASS was able to provide a space for sensitive conversations which were unlikely to take place elsewhere and was able to facilitate a more flexible structure to appointments (for example, meeting with the person with dementia, meeting with the family carer, and then meeting with both together). This investment of time and resource was viewed very positively:

“That all just takes time but if you do it properly you save. It is a well worthwhile investment. It means a huge difference in terms of the messages that they go away with and the kind of security that they feel they have around the information that they’ve given and that they feel you have heard the full story” (SI T3 Project Team 1).

An unanticipated benefit of the MASS was the opportunity for enhanced specialised education which it provided to a number of staff categories including registrars, GPs, Non-Consultant Hospital Doctors, and Psychology students. The increased education levels coupled with the growth in dementia awareness amongst hospital and community staff was linked to an increase in referrals to the MASS over the course of the project.

The value of the MASS as a point of contact for families and an access point for support services for families was highlighted:

“It’s hard for a person to navigate their way through the health service and through all these different departments and things. So having a point of contact where the family can ring...and say look we’re having this issue, is there any way around it. Like it makes the family kind of more relaxed I think as well...And we kind of know who to ring and how to go around things as well. So it takes that kind of stress away from the family that they’re trying to navigate their way through an acute service when they have someone to care for as well.” (SI T3 Service Provider 1).



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The MASS was seen as serving as a more familiar and less intimidating environment for people with dementia and their family carers in comparison to the acute hospital. This was attributed to families seeing the same familiar faces at each appointment, as well as the low number of service users attending each clinic. Service users commented on the positive atmosphere of the MASS and they felt it was calm and they reported enjoying the more relaxed and interactive layout to the waiting area which encouraged engagement with other service users.

The range of supports provided by the MASS was highlighted and effort was made to be individualised and person-centred in the referral to/provision of services. Notably, while some felt that they were provided with, linked with or referred to adequate supports by the MASS, others highlighted that they did not receive sufficient support in this regard. The particular benefit of linking in with families by phone and providing phone support and/or conducting assessments over the phone was also highlighted. The way in which appointments were organised so that the person with dementia and family carer could be spoken to both separately and together, as needed, was reported on positively by service users as providing dignity and respect to the person with dementia, giving the family carer the opportunity to ask questions more openly, as well as facilitating the telling of a more accurate story.

An important objective of the MASS was admission avoidance and the MASS was seen as contributing positively to reducing the need for hospital admission by a number of key stakeholders including members of the project team (see case example 1). The MASS also facilitated hospital admission, where required, and when this occurred, admission often bypassed the ED.

Case Example 1: Hospital Admission Avoidance¹⁴

Seán, who has a diagnosis of dementia, had had a number of repeat admissions to another hospital. He showed evidence of delirium during each of these admissions and this had a negative impact on Seán, as well as his family members. His family were stressed, felt burnt out and did not feel adequately knowledgeable to manage some of Seán's more recent care needs such as his refusal to eat and drink. His family felt at crisis point when they contacted the DNS by phone seeking an admission to Connolly Hospital. At the MASS clinic, Seán's family were able to outline their needs and discuss and agree goals of care. Through attendance at the MASS, a number of supports were put in place in order to support Seán to remain cared for at home and prevent another hospital admission. This included the provision of palliative care services for Seán. The MASS clinic liaised with Seán's GP to discuss treatment and management options for his care. Follow-up support was provided to the family by the DNS. In this way, a hospital admission was avoided at this time.

The DNS role was spoken about very positively by service users, in particular her accessibility. This included being provided with a contact number for the DNS when leaving the MASS. Even in cases where service users did not need to contact the DNS or access the MASS in crisis situations, it was highlighted that the reassurance that this service was available was very positive (see Case Example 2). However, two other service users reported challenges in terms of communication.

¹⁴ This case example (which uses a pseudonym) was constructed based on interview data from a MASS service provider.



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Case Example 2: Service User Experience of the MASS¹⁵

Joseph is being cared for by his wife Maureen and his daughter Lucy. Joseph is 84 and has a diagnosis of dementia. Following a holiday abroad, Lucy felt that her father was disorientated and very confused. She spoke to the GP about her concerns and the GP referred Joseph to the MASS.

Lucy attends the MASS every 4-6 weeks with her father. She reported that the staff are fantastic and she described them as helpful, patient and understanding. Joseph enjoys going to the MASS as well and *“he likes when they make a fuss of him”*. The staff are familiar with Joseph’s background and day-to-day life and routines and speak to him about this when he attends the clinic.

The MASS provided advice and support to Lucy including information on power of attorney. They also helped her understand dementia and the different kinds of dementia. She felt that both she and Joseph are included in interactions and discussions when they attend the MASS. She also felt that there is a good connection between the GP and MASS in that Joseph’s GP is kept aware of his treatment and management of care at the MASS. One of the features of the MASS reported on most positively by Lucy was its accessibility if a crisis occurs:

“They’re very good and at least as I said to my mother, at least I know that if, if my dad took really bad that I could bring him up there to the hospital. That I could bring him there and tell them and ask for their advice and they’d help. And not have to go through A&E and all of that. So that is fantastic to know that that it’s there... I can ring [the DNS] and you know ask her advice.”

The importance of providing support to people with dementia and their family carers in the period following diagnosis was highlighted by one service provider and to this end, early support and diagnosis was a key activity within the MASS. This was also highlighted as a positive development by other stakeholders who highlighted the contrast in support that is provided following a diagnosis in the MASS in comparison to a diagnosis which is provided by a GP with minimal follow-up in terms of supports. As reported by the project team, the project’s preference was for service users to receive a diagnosis within the MASS where there is a defined pathway for diagnosis and support. Interestingly, one service user outlined that while some information was provided at the time of diagnosis, there is a need for post-diagnosis information and support for the person with dementia and their family carer 1-2 weeks following diagnosis when they *“have absorbed the diagnosis”*. To this end, two service users reported feeling left to their own devices when researching support, information and relevant education courses in the period following diagnosis of dementia.

The MASS also ran a number of outreach education sessions for people with dementia and their family carers. One service user shared their experience:

“They had a drop in thing. Now I couldn’t go, but my mother went and my brother... And they went to it and my mother said, it was brilliant she said... because [education session instructor] listened to us. Like they were telling what my Dad is like and what’s it like living there and whatever. And the different advice and different services... They felt really good coming away that they had learned so much... And my mother said, like you know we understand now about my Dad and you know what’s happening” (SI T3 MASS Service User 1).

¹⁵ This case example (which uses pseudonyms) was constructed based on interview data from a MASS service user. Some details have been changed to protect confidentiality and anonymity.



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Another service user reported that while they were informed that education sessions would be accessible, further information did not materialise. Service users emphasised the need for ongoing education and information for service users.

The input longitudinally of the MASS to patients and their family carers was described as waxing and waning depending on the stage of the dementia care journey and individual needs. As reported by the project team, the MASS developed to operate a maintained caseload whereby people were discharged from the service to other services where appropriate. This occurred through regular case conferences between members of the MASS team informed by consultation with people with dementia and their families. The length of time between appointments was highlighted as something that needed to be addressed by two MASS service users. The period between reviews was normally six months and in some instances three times per year, however it was suggested that in the case of rapid deterioration, that reviews should be given on a much more regular basis.

Because the function of the MASS expanded and evolved from project start to end, and the number of service users increased, potential issues in terms of volume and traction were highlighted. This related, at least in part, to the lack of a clear evidence-based model of the continuation of services for service users i.e. whether service users should receive intense supports in the post-diagnostic period or should receive ongoing supports through the MASS.

The function of the MASS interacted well with other services and teams within the hospital. For example, the Frailty Team liaised with the DNS on a regular basis and worked collaboratively with her to improve the journey of care for many people with dementia. This included, for example, the Frailty Team contacting the DNS for referral of a patient to the MASS for a formal diagnosis of dementia.

Suggested improvements to the MASS by service users included:

- Addition of a coffee shop/café area to the MASS or Holly Day Hospital,
- Providing service users with a comprehensive guidebook on dementia and an overview of the likely timeline of the progression of the disease, where possible,
- Better linkage and communication between GP services and the MASS,
- Providing a follow-up information workshop/session for families following diagnosis.

Another important suggestion was to develop an ongoing in-depth comprehensive assessment for service users whereby they would be reviewed by a number of relevant healthcare providers and AHPs (for example, doctors, nurses, physiotherapist, SLT, OT) to assess their progress and/or deterioration in a more holistic way than in the more brief assessment which occurred through routine attendance at the MASS:

“They’re not seeing the true person. If they had them for a day, over there doing things, they’d be able to monitor and say, God [person with dementia] is really progressing well, or he has deteriorated since I last saw him...You cannot assess somebody with dementia in a room, for fifteen minutes, or ten minutes” (SI T3 MASS Service User 2).



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4.2.1.2 4AT and Management of Delirium

At T2, it was reported that delirium was being increasingly detected as a result of the use of the 4AT in the ED and AMAU. It was highlighted that the introduction of new paperwork and guidelines for the identification and management of delirium in the ED was initially met with some resistance. The links between the Frailty team and the MASS were reported on positively where, for example, a follow-up appointment would be arranged in the MASS for a patient to attend following their in-patient stay.

“He’ll (member of Frailty Team) come to us (MASS team) and say, and he has done in the past, only last week, come and said oh there was a lady had fallen down the stairs. Really bad back pain but it had been x-rayed and everything was fine. But she was really agitated and hadn’t been diagnosed in the past. But wouldn’t come, wouldn’t stay so we thought well let’s go out and see her. So we went out to see her. And she certainly has probably a frontotemporal dementia. But she would’ve just gone home in the past” (SI T2 Service Provider 1).

It was highlighted by one service provider that the 4AT had been introduced as a pre- and post-surgery screening tool to detect delirium post-surgery but that otherwise there was minimal use of the 4AT outside of the ED and AMAU and the Frailty Team, though the PINCH ME tool was in use in some areas.

It was reported that the DNS regularly spoke to staff and educated them on the use of the PINCH ME tool. Nurses and AHPs reported positively on their use of this tool and found it beneficial in their day-to-day roles. While the project aimed to provide the PINCH ME and 4AT laminated tools to all staff within the hospital, at the time of reporting, only those who had completed project training and education had received these.

4.2.1.3 ED experience

At T1, the ED experience for people with dementia was highlighted as being particularly difficult due to the shortage of staff in the ED and an array of environmental challenges. These environmental challenges included:

- Lights on constantly making it difficult to differentiate night from day/sleep time from waking time,
- Limitations on space,
- High noise levels and busy environment.

The tendency of some people with dementia to wander was highlighted as a particular difficulty within the ED given the layout of the ED, which has two entrance and exit points. Nursing staff outlined that they tried to place people with dementia in bays which were visible from the nurses’ station however this was not always possible. It was suggested that a quiet designated assessment area for people with dementia within the ED would be highly beneficial.

As part of the project and the focus on person-centred care, ED staff endeavoured to provide accelerated treatment to people with dementia or delirium who would be likely to find the ED environment more distressing. This included, for example, priority for transfer to the AMAU, admission to the hospital, or for emergency respite. The Frailty Team was an important facilitator of this accelerated care management. Accelerated treatment sometimes involved the use of the MASS for rapid access assessment as an alternative to the ED.



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4.2.1.4 Dementia Delirium Care Bundle (DDCB)

It was intended that the implementation of the DDCB would result in a cultural change in the provision of dementia care among staff in the Care of the Older Person ward through a move away from task-oriented care and increased awareness of dementia among families of people with dementia and community service providers. This cultural change occurred in part through encouraging staff to think differently when assessing patients with dementia and managing their care.

Nursing staff, who described themselves as “*instrumental*” in the roll-out and use of the DDCB, were very positive about its use and were seen by others to have embraced the use of the DDCB. The nursing role in the DDCB included:

- Triggering activation of the DDCB (as per the algorithm),
- Distributing the personal profile document to families for completion,
- Inserting DDCB stickers on the nursing notes and medical notes,
- Placing the project magnet on the patient board for those with the DDCB activated,
- Making a referral to the DNS, where required,
- Activating and implementing the required components of the nursing care plan, as per the DDCB algorithm,
- Conducting additional patient assessments, for example, Abbey Pain Scale (Abbey *et al.* 2004),
- Informing any new recruit or agency Healthcare Assistants (HCAs) about the DDCB and the use of the personal profile document.

It was highlighted that the DDCB may be activated for a patient at a whiteboard session if a patient was admitted with confusion but the DDCB was not immediately activated. It emerged that the activation of the DDCB was rarely as a result of patient information from the ED, for example, 4AT score; however where the patient was identified as agitated or confused by ED staff in their notes, this would result in an increased likelihood that ward staff would activate the DDCB.

Given the recognition that a significant proportion of patients who demonstrate symptoms of dementia do not have a diagnosis of dementia, it was perceived as important to develop the algorithm for the DDCB to include a range of cognitive impairments including delirium. Another positive outcome of the DDCB was the rapid identification of patients losing weight as a result of the use of food charts and monitoring of weight.

The importance of the HCAs in the day-to-day implementation of the DDCB was highlighted by nursing staff who felt awareness and education of dementia in this staff group was very high. For example, it was reported that HCAs have a close relationship with patients as a result of their use of the personal profile document together with spending a large amount of time with patients:

“They get to know the patients a lot more than we do... And you know they do, they do care for the patients. You can see that from them, they’re very caring with their patients” (FG T3 Service Provider 3).

The involvement of doctors in the DDCB was also felt to be positive and the function of the DDCB stickers as a reminder that the patient has/may have a dementia diagnosis for doctors and other staff was highlighted as valuable. This may trigger, for example, a referral to an OT by the doctor or highlight that dementia appropriate communication strategies need to be used with this patient:



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“They (medical team) would recognise from the sticker that this patient has a cognitive impairment. So you can see the difference, the way they speak with them. Their body language, everything is different, they take on board that this patient has a memory issue. And that they need a little bit more attention” (FG T3 Service Provider 3).

Demonstrating the value and benefit of the DDCB to staff was found to facilitate the DDCB and reinforce staff participation:

“I think if you work with people every day and then you see something that works well, then you can’t help but kind of buy into it, do you know that way? Because if this was a project that I actually found didn’t really benefit people, was quite cumbersome for us as [AHP category] to get involved with, which it hasn’t been at all, then I’d be kind of singing a different tune. But I think because I think it has affected what we do positively it’s easy to get on board with it. And then you want to do more. Because once you start making changes then you start seeing all these other changes that you want to make as well” (SI T3 Subgroup Member 1).

There was minimal additional workload and time investment for staff as it was designed such that small modifications would impact positively on the provision of care. This was a key consideration of the DDCB subgroup when developing the DDCB, particularly in regards to the workload of nursing staff as the majority of the responsibility to complete the various activities within the DDCB lay with them. The significance of the DDCB in meeting the individual needs of the organisation (for example, priorities for person-centred care and safety) and the various stakeholders was emphasised:

“I always think about what matters to people; what matters to me, what matters to the patients, what matters to you, what matters to the organisation, what matters to the [management]? And the only way you are going to get change is by understanding what matters to people and actually helping them in some way. So in actual fact what matters to organisations at the minute is risk, person-centred care, safety, falls, all of those things. And in actual fact this dementia delirium care bundle could meet everybody’s needs. Their needs for safe and orientating environment for making sure that people don’t have delirium. Making sure that people don’t have an increased length of stay so they are all things that we are looking at in relation to this dementia delirium care bundle” (SI T3 Project Team 2).

Other important strengths of the DDCB which were highlighted included:

- Designing and refining through ‘trial and error’ of the DDCB such that it could be easily integrated into care as usual,
- Developing the DDCB through close collaboration with key stakeholders,
- Interdisciplinary involvement,
- All aspects of the DDCB were evidence based and supported by policies, procedures and guidelines,
- Developing education specifically around the DDCB and its development and roll-out in order to inform and educate staff and bring them on board.



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The use of the project magnet and DDCB stickers were reported on very positively as facilitating communication and highlighting where the DDCB was in place:

“Because we do keep it quite well (keep the patient board updated with project magnets), it does work very well as a communication tool on the ward...I think it is a brilliant idea and like I said in the beginning, it’s being aware of who’s activated. And even at your quick glance of the board, you may see that symbol beside someone. And that symbol now is quite synonymous with a certain number of steps that you might have to take” (SI T3 Subgroup Member 1).

While there was initially some concern that the project magnet may label patients, the neutral nature of the project logo used and the education on dementia provided to staff, meant that implementation of the magnet was perceived as very positive. This magnet system was highlighted as particularly beneficial for AHPs and staff who are non-static on the ward (for example, porters and medical teams) to be aware of who is activated on the care bundle and to provide individualised care accordingly. It was also emphasised as beneficial in alerting to additional needs such as assistance with feeding etc. More broadly, use of the project logo on the magnet and across all of the project outputs was viewed as also providing continuity and increasing awareness of the project and its activities. In addition, the stickers were viewed very positively as a prompt for implementation of individualised care and as specific reminders for care activities which needed to be completed as a result of activation of the DDCB.

It was unclear whether all aspects of the DDCB were implemented in their entirety by staff due to the difficulty in assessing and monitoring each aspect of the DDCB. For example, the DDCB outlines that if a patient has not indicated any need within the last hour, then the staff member should check with the patient if they require anything. Nursing staff outlined that because of their high level of patient contact, particularly in multi-bedded rooms, patients were being checked on an ongoing basis though this may not always have been in the form of the nurse communicating directly with the patient. Other aspects of the DDCB, such as the completion of assessment tools or the monitoring of hydration, were found to be easier to monitor as they were recorded in the patient chart.

Nursing staff outlined how the DNS provided ongoing regular whiteboard and informal education sessions to keep them abreast of any new information in relation to the DDCB. She also routinely visited the ward and checked in with staff to check if they had any queries or required any support, particularly in the initial roll-out stage of the DDCB. This high level of contact and education with the DNS resulted in minimal usage of the DDCB resource pack by nursing staff. Importantly this education and support of staff also helped to ensure that the continuation of the DDCB following project end was not dependent upon the DNS only.

The use of personalised bedsides appeared to be one aspect of the DDCB which was not fully implemented. HCAs reported that the use of personalised bedsides was being seen “to an extent” and some service users reported that they had not been informed about this. The promotion of a clutter-free environment, which was a component of the DDCB, was reported positively on as it reduces the risk of falls.

At the time of reporting, it was planned to incorporate discharge planning in the DDCB and a literature review had been completed for this. This will build in family meetings from early on in the admission.



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4.2.1.5 Personal Profile Document

At T1 (baseline), the personal profile document was not in routine use and assessing and interacting with the patient while missing vital patient information such as that available on the personal profile was seen to be “*an uphill battle*.” (FG T1 Service Provider 4) The personal profile document was described as humanising the person again after they have been categorised and “*put into gowns*” (FG T2 Service Provider 2) on admission to the hospital. HCAs felt that they could get to know the person through the use of the personal profile. Specific examples of the use of the personal profile document are provided in the box below.

“We would have had a gentleman and he had responsive behaviours but it was always in the morning time when he woke up, right, but in actual fact from filling in the personal passport and realising that this man actually never got up at home until half past ten, if you left the man in the bed ‘til half past ten he actually, there wasn’t a bother...But the staff actually changed their routine. So like one thing that we’d always say is that people with dementia can’t adapt to us, we have to adapt to them” (SI T2 Project Team 2).

“It could be just something simple, like that they just want their teddy bear or they just want something from home, or a photograph or something. So it just gives them information as well. It’s not always about giving them medication if they’re agitated...So it’s just small little things that they can put on a bit of music or they like to read a book, or read the magazine. Just the small little things that let us know that the patient’s likes and dislikes” (FG T3 Service Provider 3).

“I would definitely always check the green folder before you go into someone. Because if you can have a chat... But if you can just intertwine it (the intervention) with a chat about home, or about the dog, or the family, or past work, I think it definitely goes a lot smoother...And going you know, building that conversation in between your therapy interventions” (SI T3 Subgroup Member 1).

Other benefits of the personal profile document outlined by hospital staff included:

- Providing comfort to the family by enabling their involvement in personalisation of care,
- Acting as a prompt for conversation,
- Enabling the service provider to shift the focus of the patient when they were distressed or reduce agitation or upset,
- Ensuring patient information is readily available without the need for handover,
- Being able to call the person by their preferred name.

The importance of outlining the purpose of the document to families and ensuring that it is completed with sufficient detail was emphasised. Notably, it was outlined that while informing families about the project and the personal profile document, staff also sought their views on whether the document would be beneficial and whether any other additional information should be added to it.

Service users’ reports on the use of the personal profile were mixed. For example, one family carer reported that it was used in the care of her mother and was something which was very beneficial, particularly due to the large amount of HCAs interacting with her mother while another reported completing the personal profile for her mother but did not see evidence that it was used by service providers.



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4.2.1.6 Sustainability of ICP Related Changes

It was felt that the project philosophy and principles of person-centred care were embedded within the MDT and consequently, ICP related changes were likely to be sustained. The importance of sustaining the projects activities, particularly the ICP related changes, was emphasised by interviewees as they were seen as vital and changes which could not afford to be lost. The difficulty in maintaining momentum for a project within the HSE following cessation of project funding was highlighted as a potential challenge though the importance of the endeavour and the associated care and cultural changes arising from it were emphasized in terms of the growing population of older people.

It was evident that staff had been educated and empowered to engage in project activities, including for example activation of the DDCB, on an ongoing basis:

“Every patient is treated, if it’s a case that we think there’s a delirium, dementia, we activate the care bundle. We don’t need to ring [the DNS]. We know, we’ve been educated enough to know that it’s our responsibility to activate it” (FG T3 Service Provider 3).

4.2.2 Project Roles

The project lead (Section 4.2.2.1), as well as two project-specific roles, the DNS (Section 4.2.2.2) and the Dementia Link Nurse (Section 4.2.2.3), were introduced within the context of the project to facilitate the integration of dementia care. The DNS role was primarily hospital-based and the Dementia Link Nurse role was primarily community-based.

4.2.2.1 Project Lead

The project lead was viewed very positively by other consortium members and it was felt that she “*is always there to answer any questions*” (SI T1 Consortium 1). Her ability to foresee potential issues and challenges was remarked positively upon, as well as her passion to integrate hospital and community care. She was seen as the primary “*driver*” of the project in the project planning stage and in the initial stage of the project prior to the commencement of the DNS role. She was also recognised as an important driver for the project at the project end stage in working towards sustainability of project gains. Due to the Project Lead taking on additional responsibilities towards the end of the project, an additional case manager became involved with the MASS demonstrating project responsibility.



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4.2.2.2 Dementia Nurse Specialist (DNS)

The significance of the DNS role as a hybrid of project management and CNS was emphasised as unique and ultimately critical in the success of the project. The role of the DNS was viewed positively by an array of service providers including consortium members, AHPs, nursing staff and a range of other hospital staff. The role was described as “invaluable” (SI T3 Service Provider 1). The role of the DNS in the provision of education was referred to, in relation to her provision of brief education/whiteboard sessions as well as on-the-ground education and support to staff. As outlined further in Section 4.4.2, she endeavoured to provide education to staff at every available opportunity and in this way was perceived as very hands on. Accordingly, staff felt that she was both helpful and accessible:

“She’s always available, very helpful and you know, somebody that you will depend, will get back to you and get something done and that is something that’s really that’s needed badly” (SI T3 Key Stakeholder 2).

The DNS developed important ways of linking in with relevant stakeholders, for example, she invited the Alzheimer Society of Ireland dementia advisors to come in and work within MASS for a clinic. It was felt that “[The DNS] definitely really has opened an awful lot of peoples’ eyes” (FG T2 Service Provider 2) in relation to dementia education and awareness. Some hospital staff and consortium members referred to the two-way relationship which they have with the DNS where they each provide advice and input to each other’s care provision.

The significance of the role as being an identified point of contact for hospital staff and external service providers was emphasised and it was felt that this single point of contact structure improves service provision for service providers with a knock on positive impact for service users:

“[DNS] herself was lovely and very nice and a lovely manner and very respectful and very much giving mum dignity and respect. Like I could not fault them whatsoever, from that perspective... I think it’s definitely important to reference her. Because she does an amazing job down there. And she was, I think the most important element was that again that they showed dignity and respect to my mum. I think that it’s vitally important” (SI T3 MASS Service User 3).

One key stakeholder attributed the success achieved by the DNS in bringing staff on board and enabling staff to see the value of the role, to the DNS being very clinically active within the hospital. Another interviewee attributed this to her passion and enthusiasm. The DNS’s positive impact on staff was further validated by her nomination of a “best CNS” award by student nurses. The DNS’s background and experience in dementia care (including formal educational qualifications in dementia) and education were acknowledged as important strengths for her ability to fulfil the role effectively, and also to establish credibility amongst staff on the ground.

There was evidence of the growth in knowledge and visibility of the DNS role over time in the interview data including, for example, acknowledgement by AHPs that there was an increased uptake and involvement of the DNS. AHPs commented on the impact of the DNS role on referral, for example, some reported an increase in referrals while others noted a decrease in referrals with the DNS as a first point of contact.

The role evolved over time as the DNS educated and empowered hospital staff to provide enhanced care to people with dementia. It was suggested that the implementation of the DDCB facilitated this empowering of other staff. It was suggested that this education and empowerment resulted in improved management of responsive behaviours by staff (for example, through the use of psychosocial intervention) and a decrease in the use of medication to manage



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responsive behaviours (mentioned at T2 by a MASS service provider). Behavioural charts were in use to record and review responsive behaviours in the Care of the Older Person ward in order to understand patterns and triggers to better manage these behaviours.

The importance of the project and more broadly, changes in service provision, relying too heavily on one person or being person dependent, was emphasised. It was felt that the realisation that the project could not rely on the efforts of one single individual/role took quite some time. Recruiting the DNS role for the project took a significant amount of time as well and this delay resulted in a later than planned start date for the project and an increased length of time spent in project planning stage. This was viewed positively in hindsight by the project team who felt that this lead in time provided an opportunity to conduct the necessary groundwork and develop and refine the project plan. The commencement of the DNS role was described as “a huge turning point” (FG T2 Service Provider 2) for the project in implementing changes and improving quality of care and dementia awareness.

The role of the DNS in the data from service users was somewhat less clear in comparison to her impact on the day-to-day roles of service providers. Of the three inpatient service users interviewed, only two had had contact with the DNS, though the third may have interacted with the DNS but been unaware of her role. The fragmentation of information systems was highlighted as causing difficulty in the integration of care and the ability of the DNS to link in with MASS service users if they became inpatients:

“What we don’t have, for example, is an information system that automatically flags a person up as being somebody that we know so we’re always relying on a relative to call or, you know, that we know that something kind of has happened from that point of view...It’s very challenging” (SI T3 Project Team 1).

The high level of support which the DNS received from hospital staff (within the day hospital, the Care of the Older Person ward, and from consultants and other staff throughout the hospital) from the outset of her role was seen as an important facilitator for the role and for the roll-out of the project. The very good working relationship between the DNS and the Chief Executive Officer (CEO) was remarked upon in interviews. The DNS’s approach at the outset was to introduce herself to all the relevant teams (and relevant community care providers through site visits) and to consult with staff in order to understand their needs and gaps in service provision in order to provide supports accordingly. Reports from the project team were that this approach worked to ensure that staff were aware of the DNS role and understood its relevance in order to access this support accordingly. The DNS also linked in with Nurse Practice Development at an early stage in order to work with them and keep them abreast of the development of the education programme. Linking in with existing resources and consulting with staff facilitated a smooth transition of the DNS role into the hospital environment. It was suggested that the small scale of Connolly Hospital (in comparison to other larger hospitals) made it easier to establish links with relevant contacts and supports such as Psychiatry Liaison, Diabetes Nurse Specialist, Community Liaison team etc. The value of linking in with the Cork-IDEAS dementia project team in Mercy University Hospital as well as providers of Memory Clinics in a number of other hospitals, was emphasised as valuable in gaining insight and experience for the role. Other actions which facilitated the role of the DNS included:

- Demonstrating a willingness to help staff (for example, providing advice and support as needed) and working collaboratively to benefit each other,
- Providing ongoing role modelling and education to staff,
- Setting realistic and accurate expectations about the support that would be provided by the role.

There were concerns expressed (at T1 and T2) over the high workload of the DNS:



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“I think that she is, for one person it’s an awful lot of work. And I wonder how long, my concern would be how much more she can take on before she’s starts diluting her service...It’s such a specialised service that if all of a sudden you’ve taken on so much. You wonder then is the essence of it being lost, you know” (SI T2 Service Provider 1).

It was suggested that the role’s multi-faceted function (Involvement with the ICP in the hospital, development and roll-out of education programmes, project management, and provision of ambulatory care in the MASS) would potentially necessitate more than one person to cover the entire workload adequately. Indeed, this was recognised by the project team and consequently they implemented some project support in order to relieve the administrative burden on the DNS by providing the project support with specific focused tasks to do (for example, development of project leaflets) as well as some consultancy support to assist with the project management aspects of the project and other specific tasks (for example, project logo design). Importantly, one member of the project team felt that the project would have benefitted from a greater level of business support, ideally available from within the hospital. There was also additional support, in the form of an OT (as outlined in Sections 2.5.2 and 2.5.4), to move forward the work of the project in the areas of environmental change and community linkages. It was suggested that the use of a hospital-based OT for this community-based role was a challenge in the integration of care and connection with community services.

4.2.2.3 Dementia Link Nurse

The importance of being able to provide support in the community through the Dementia Link Nurse role was highlighted by service providers. Other benefits of this role highlighted by interviewees included:

- Complementary role to the Clinical Case Manager,
- Working close with those in the early and moderate stages of dementia, not necessarily linked in with other services as they have not faced crisis point,
- Being an important point of contact for both service providers and service users,
- Potential career pathway for community RGN,
- The ability to provide cognitive screening and assessment in the persons own environment (seen as preferential),
- Collecting collateral information about patients to ensure they are able to attend MASS appointments.

The lack of continuity in the timeline of this role (challenges to recruitment and retention) and between this role and the DNS was highlighted as a major challenge to the role. Limited support available, including community leadership, for the Dementia Link Nurse initially was also highlighted as a challenge to the role. The requirement for an improvement in the process for primary care needs, for example, greater linkage and collaborative working between the GP and PHN, to facilitate the link nurse role was highlighted. While it was outlined that the Dementia Link Nurse could link in with the Primary Care Team and other community care providers (Physiotherapy, OT, Social Worker etc) during clinical meetings, it was felt that there would be difficulty in getting buy-in from all attendees that the link nurse is a member of the primary care team. The logistical difficulty in organising such meetings was also alluded to.



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Despite the challenges in the provision of the Dementia Link Nurse role and the early cessation of this role, it was felt by the consortium that the project still positively influenced change in the community. This was facilitated through other consortium members within community roles as well as the funding of a short-term OT role as part of the project, and the Clinical Case Manager working closely with the MASS.

4.2.3 Overall Integration of Dementia Care

To evaluate the integration of dementia care practice within the hospital, current practice was compared to international best practice using tools from the Irish National Audit of Dementia Care in Hospital (De Siún *et al.* 2014).¹⁶ The evaluation encompassed an audit of 20 patient case notes, an organisational audit, and ward organisational and environmental audits of two hospital wards¹⁷ at baseline and follow-up. The audit tools include criteria relating to assessment and screening of dementia, the presence of dementia-sensitive policy, guidelines and systems, staffing, dementia-related communication and information, support and training for staff involved in delivery of care to people with dementia, and the physical environment itself (Section 4.3). Collectively, the audit tools provide an indication of dementia care at the point of admission to hospital, during admission and at the point of discharge.

4.2.3.1 Hospital Organisational Audit

The hospital organisational audit examined structures, policies, processes and positions relevant to the care, treatment and support of people with dementia in a general hospital. Table 5 provides a summary of changes to the findings of the hospital organisational audit from baseline to follow-up, a number of which demonstrate the potential to enhance the integration of care for people with dementia.



¹⁶ The evaluation team received full permission to use the INAD (DeSiún *et al.*, 2014) tools.

¹⁷ The in-patient ward audited had 28 beds and the day hospital audited had four consulting rooms.



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Table 5. Summary of Changes to Hospital Organisational Audit from Baseline to Follow-up

Governance	Baseline	Follow-up
A care pathway for patients with dementia is in place	In development	Yes
A senior clinician is responsible for implementation and/or review of the care pathway	Yes	Yes
The management team regularly reviews information in which patients with dementia can be identified in relation to:		
■ Readmissions	No	Yes
■ Delayed Discharge/Transfers	No	Yes
■ In-hospital falls and the breakdown of immediate causes	No	Yes
Nursing staff have access to a recognised process to record and report risks to patient care if they believe ward staffing is inadequate	Yes	Yes
Delivery of Care¹⁸		
Protected mealtimes are established in all wards that admit adults with known or suspected dementia	No	Yes
Assessment of Dementia and Mental Health Needs¹⁹		
There are policies or guidelines in place to ensure that patients with dementia or cognitive impairment are assessed for the presence of delirium at presentation	In Development	Yes ²⁰
There are policies or guidelines in place to ensure that patients with dementia or cognitive impairment with behaviour changes suggesting the presence of delirium, are clinically assessed by a healthcare professional who is trained and competent in the diagnosis of delirium	In Development	Yes in Development
There are systems in place to ensure that where dementia is suspected but not yet diagnosed, this triggers a referral for assessment and differential diagnosis either in the hospital or in the community	No	Yes
There is a policy or guideline stating that an assessment of mental state is carried out on all patients over the age of 65 admitted to hospital	No	No
There is a protocol in place governing the use of intervention for patients displaying violent or challenging behaviour, aggression and extreme agitation, which is suitable for use in patients who present with behavioural and psychological symptoms of dementia	In Development	Yes
There is a section or prompt in the general hospital discharge summary for mental health diagnosis and management	No	Yes

18 All questions answered yes at baseline apart from those reported in this section.

19 All questions answered yes at baseline apart from those reported in this section or where developments have involved the ICP for Dementia established by the project.

20 In place but development and roll-out were ongoing at the time of reporting.



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Discharge and Transfer Policies		
Information about discharge and support is made available to patients and their relatives	Yes	Yes
The discharge policy specifies that this information is made available to patients and their relatives on admission	Yes	Yes
The transfer policy states that transfers should take place during the day	No	Yes
The transfer policy states that relatives and carers should be kept informed of any moves within the hospital	No	Yes
Information		
There is a formal system in place for gathering information pertinent to caring for a person with dementia	No, In Development	Yes
The pro-forma prompts staff to approach carers or relatives to collate necessary information	N/A	Yes
Recognition of Dementia		
There is a system in place across the hospital that ensures that all staff in the ward or care area are aware of the person's dementia or condition and how it affects them	No, In Development	Yes
There is a system in place across the hospital that ensures that staff from other areas are aware of the persons' dementia or condition whenever the person accesses other treatment areas	No, In Development	Yes
Training, Learning and Development		
There is a training and knowledge framework or strategy that identifies necessary skill development in working with and caring for people with dementia	No, In Development	Yes
Staff induction programmes include dementia awareness	No, In Development	Yes
Dementia awareness training provided in the last 12 months:		
■ for Doctors	No	Yes
■ for Nurses	No	Yes
■ for Healthcare Assistants	No	Yes
■ for Allied Healthcare Professionals	No	Yes
■ for support staff	No	Yes
Training on how to support people with hearing/visual impairments in the last 12 months:		
■ for Doctors	No	No
■ for Nurses	No	No
■ for Healthcare Assistants	No	No



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Training on how to assess capacity provided in the last 12 months:		
■ for Doctors	No	Yes
■ for Nurses	No	Yes
■ for Healthcare Assistants	No	Yes
Training on communication skills for people with dementia provided in the last 12 months:		
■ for Doctors	No	Yes
■ for Nurses	Yes	Yes
■ for Healthcare Assistants	Yes	Yes
Training on approaches to behaviour that challenges including management of aggression and extreme agitation provided in the past 12 months:		
■ for Doctors	No	Yes
■ for Nurses	No	Yes
■ for Healthcare Assistants	No	Yes
Training on assessing risk whenever the use of restraint or sedation is considered provided in the past 12 months:		
■ for Doctors	No	Yes
■ for Nurses	No	Yes
■ for Healthcare Assistants	No	Yes
Involvement of people with dementia and carers and use of their experience is included in the training for ward staff	No	Yes
Resources Supporting People with Dementia		
Specialist assessment and advice can be obtained from:		
■ Speech and Language Therapist	N/A	Yes
■ Dietician	N/A	Yes
■ Occupational Therapist	N/A	Yes
There is access to an interpreting service which meets the needs of people with dementia in the hospital	No	Yes
Liaison Psychiatry		
The hospital provides access to a Liaison Psychiatry Service which can provide assessment and treatment to adults throughout the hospital	Yes	Yes
The Consultant Psychiatrist specialises in the care and treatment of older people	No	Yes
Psychiatry Liaison Service in the hospital regularly provides routine mental healthcare to working age adults and to older people	No	Yes
All healthcare professionals who are part of the liaison psychiatry service have dedicated time to provide the service	No	Yes
Liaison Psychiatry of Old Age		
The hospital provides access to a liaison POA service which can provide assessment and treatment to adults throughout the hospital	No	Yes
Geriatric Medicine		
No change in answers to this section from T1 to T3. At T1, Yes was answered to all relevant questions.		



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4.2.3.2 Ward Organisational Audit

The ward organisational audit²¹ gathered information on staffing levels, support, service availability and provision of information to support the care of people with dementia in an acute Care of the Older Person ward (which includes a stroke unit) and a day ward. This day ward, which provides ambulatory care, serves to assess and out rule/diagnose dementia and offer supports post-diagnosis, as well as links with community services to ensure appropriate support for people with dementia and their families. These wards were selected as they underwent significant changes as part of the project.

At baseline both wards had nursing shortages. By follow-up, both wards had been allocated additional staffing. The day hospital had been allocated an additional 1.5 WTE nursing posts, but the HCA post had been removed. While the Care of the Older Person ward continued to have a shortage of 3.5 WTE nursing posts, the ward had been allocated an additional six HCA posts. Both wards had agreed minimum staffing levels, which were met on all shifts at follow-up, and systems were in place to review these staff numbers and skill mix. Where required, nursing vacancies were filled by a combination of internal pool and agency staff, while HCA vacancies were filled by agency staff, and systems were in place to monitor use of internal pool and agency staff. All wards had administrative support on weekdays at baseline and follow-up, however access to administrative support on the Care of the Older Person ward at weekends had been withdrawn at follow-up.

At follow-up, both wards had implemented arrangements for cover to allow staff to attend training for dementia. Nursing staff and HCA staff on both wards had access to clinical supervision, guidance from Dementia Champions and access to peer support. While access to reflective practice, appraisal and mentorship were not implemented on either ward, management of the Care of the Older Person ward expressed interest in reflective practice for staff at follow-up. Access to faith-specific support for staff was available at baseline, but was not available at follow-up.

Both the day hospital and Care of the Older Person ward audited had 24/7 access to Geriatrician services. Pharmacy, physiotherapy infection control, tissue viability and palliative care services were available to both units Monday-Friday (daytime). At both timepoints, the Care of the Older Person ward had access to liaison psychiatry, POA, OT, social work, dietetics, and SLT Monday-Friday (daytime). While the day hospital did not have access to these services within the hospital, referral pathways were in place for those patients who required these services in the community.

At both timepoints, each ward had access to written, pictorial or verbal information about ward routines, hospital complaints procedures and how healthcare information would be shared with carers. Although information about advocacy services was not available at baseline, by follow-up, this had been implemented on both units.

The day hospital does not provide meals to patients attending the service, however, the Care of the Older Person ward operated protected mealtimes and had systems in place to ensure adequate staffing at both time points.

Patients' personal and healthcare information was shared in both wards, usually verbally during nursing handover or in writing in the nursing notes and care plans. At both timepoints, there was a system in place on both wards to communicate specific behavioural or communication needs for people with dementia. The personal profile document introduced as part of the project facilitated a comprehensive handover of personal information, as well as information related to behavioural and communication needs. Interview data however pointed towards some challenges in handover and communication (Section 5.3.2).

²¹ The ward and environmental audits were completed by a Clinical Nurse Manager with a researcher from the evaluation team.



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4.2.3.3 Patient Case Note Audit

The case note audit²² was conducted on the records of patients with a primary or secondary diagnosis of dementia who were admitted to the hospital for at least five days. The case note audit gathered information on assessments conducted during admission, discharge planning and coordination, and referral to specialist services. Healthcare records were identified by the Hospital In-Patient Enquiry (HIPE) data and through the assistance of the DNS and examined at baseline (n=20) and follow-up (n=20). The mean age of patients reviewed in the audit was similar at baseline (78.7; SD = 9.3) and follow-up (83.4; SD = 7.2; p=0.06) and more than half of patients were female at each timepoint (baseline: 75%; follow-up: 60%). The mean length of stay in the hospital was 45 days at baseline (range = 6-298; SD = 73.1) and 63 days at follow-up (range = 5-336; SD = 80.9) in the charts reviewed, however this difference was not statistically significant ($t(34) = -0.680$; $p = 0.501$). Of the twenty case notes audited at follow-up, four (20%) remained inpatients at the time of the audit.

At both time points, the majority of cases were admitted from their own home (baseline: 60%; follow-up: 70%). However, the number of those admitted to the hospital from residential care was higher at baseline (40%) than follow-up (25%). Of the cases who were discharged by the time of the audit, similar proportions were discharged to their own home (baseline: 40%; follow-up: 37.5%) or residential care (baseline: 50%; follow-up: 50%) at each timepoint. Of those admitted from their own home at either timepoint, more than one quarter were discharged to residential care (baseline: 25%; follow-up: 36%). Although a greater number of cases were discharged to residential care at follow-up, the average length of admission for those admitted from home and discharged to residential care was significantly lower at follow-up (96 days; SD = 24.2; range = 69-118 days) compared to baseline (166 days; SD = 114.35; range = 97-298 days).

Table 6 presents a summary of some of the key findings of the patient case note audit at both timepoints. At baseline, a number of strengths were identified including the comprehensive nature of multidisciplinary assessments for pressure sore risk, pain and continence. Between baseline and follow-up, the implementation of the DDCB was mixed between and within wards; improvements in the frequency of assessments were noted for mobility, nutritional status and functioning. While some improvements were noted in relation to collateral history documenting the nature of dementia progression and loss of function, other aspects required further intervention, particularly assessments for the presence and duration of cognitive decline, current mental status, recent changes in behaviour and mood and symptoms of delirium. Notably, not all cases audited were selected from the ward where the DDCB was implemented, though the audit findings here were mixed between and within wards.

²² Two researchers from the evaluation team conducted the case note audit. In order to ensure reliability of responses a sub-sample of charts (10%) was cross-checked.



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Table 6. Overview of Findings from 20 Patient Case Note Audits at Baseline and Follow-up

	Baseline		Follow-up	
	%	N	%	N
Comprehensive Geriatric Assessment				
Compliance with multidisciplinary assessments:				
Mobility	80%	16	95%	19
Nutritional status	55%	11	95%	19
Pressure sore risk	100%	20	100%	20
Presence of pain	90%	18	95%	19
Continence needs	95%	18	90%	18
Functioning	80%	16	95%	19
Problem list recorded	100%	20	100%	20
Medical history recorded:				
Mental health history	90%	18	85%	17
Co-morbid conditions	100%	20	100%	20
Collateral history recorded:				
Presence of cognitive decline	40%	8	50%	10
Duration of memory problems	40%	8	35%	7
Nature of dementia progression	40%	8	60%	12
Evidence for loss of function	45%	9	60%	12
Assessments recorded:				
Mental status test	50%	10	5%	1
Behavioural changes indicative of delirium	0%	0	5%	1
Recent changes in mood	5%	1	5%	1
Behavioural/psychological symptoms of dementia	20%	4	20%	4
Antipsychotic medication				
Number of people with dementia prescribed/administered anti-psychotic medications during admission	50%	10	55%	11
% of whom had a prescription for antipsychotic medication prior to admission	60%	6	73%	8
% of whom had a prescription for PRN antipsychotic medication	50%	5	64%	7
% of those above who were administered PRN antipsychotic medication	100%	5	71%	5
Referral to services				
Liaison Psychiatry	10%	2	30%	6
Psychiatry of Old Age	25%	5	25%	5
Geriatric Medicine ²³	35%	7	25%	5
People with dementia requiring social work assessment	45%	9	85%	17
% of whom received assessment	100%	9	100%	17
% of whom received formal care provision assessment	100%	9	93%	14
% of whom received a home safety/environment risk assessment	29%	22	75%	9

23 Patients who spent the most time during the admission on a Care of the Older Person ward and thus did not require referral to a geriatrician at T1 (25%; n=5) and T2 (56%; n=10)



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Palliative care				
Resuscitation status documented	30%	6	25%	5
Referred to palliative care	5%	1	5%	1
Discharge				
Number of cases with symptoms of delirium during admission	44%	8	7%	1
% of those whose delirium symptoms were summarised for discharge	25%	2	0%	0
Number of cases with behavioural and psychological symptoms of dementia during admission	50%	9	14%	2
% of those whose behavioural and psychological symptoms of dementia were summarised for discharge	33%	3	100%	2
Number of eligible cases where discharge plan was initiated within 24 hours	29%	5	0%	0
Named discharge co-ordinator in discharge plan	71%	12	50%	7
Appropriate place of discharge and support needed discussed with:				
Person with dementia	13%	2	71%	10
Family carer	53%	8	93%	13
Consultant	53%	9	86%	12
Multidisciplinary team members	53%	9	93%	13
Identified support needs documented	25%	2	100%	9
Cause of cognitive impairment summarised	17%	3	21%	3
Record keeping				
Organisation and ease of locating dementia-related documentation in patient record:				
Well organised	0%	0	0%	0
Adequately organised	15%	3	25%	5
Poorly organised	50%	10	65%	30

There was a noteworthy change in the frequency of discussions about the appropriate place of discharge with the person with dementia (baseline: 13%; follow-up: 71%) and the family carer (baseline: 53%; follow-up: 93%), possibly pointing towards a cultural change as a result of the project. In relation to the use of antipsychotic medications, at baseline, 50% of the people with dementia were prescribed such medications, of whom 60% had a pre-admission prescription. At follow-up, 55% were prescribed anti-psychotic medication, of whom 73% had a pre-admission prescription. Between baseline and follow-up, fewer of those who were prescribed PRN anti-psychotics (baseline: 50%; follow-up: 64%) were administered such medications on a PRN basis (baseline: 100%; follow-up: 71%).



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4.3 The Physical Environment

An environmental audit was conducted in the same two wards of the hospital as the ward organisational audit to ascertain environmental modifications completed in the course of the project. It should be noted that the planned changes to the physical environment focused primarily on one of these wards, with a small amount of environmental changes also implemented in the day hospital audited (as outlined in Section 2.5.2). The environmental audit gathered information about characteristics of the physical environments that are known to impact on those living with dementia (including orientation, accessibility and promotion of independence). The audit revealed a number of gaps in the suitability of the ward environment for people with dementia at baseline. In particular, there were shortcomings in orientation and way-finding cues in the ward environments, with an absence of distinct colour schemes and signage in both wards. Clocks were visible from the bed to all patients in both wards at both timepoints, and calendars were made visible to patients in both wards at follow-up (baseline: 1/2; follow-up: 2/2). In interview data, the use of clocks with time and date in the ED and AMAU, as well as the Care of the Older Person ward was commented upon positively by hospital staff as beneficial to both staff and patients, and one staff member commented that a family carer had queried where to source one when her family member was being discharged from the hospital. With regards to the bed space, messages from relatives and personal objects, including self-care items, were visible to people with dementia in the Care of the Older Persons ward where this was possible.²⁴

The baseline audit suggested some appropriate environmental practices for people with dementia in the day hospital, including plain, non-slip, subtly polished floors. As per audit findings, in both wards at baseline, toilet doors carried signs and toilet and bathroom doors were of a different colour to the walls, which is believed to be useful for older people with sight difficulties, especially if affected by dementia (Pollock 2003, Cunningham 2006). Toilet signage was significantly improved however at follow-up through both the use of text and image signage. The improved toilet signage across the hospital were viewed very positively by hospital staff in interviews. The audit data also demonstrated that call or alarm buttons were visible and in reach in the toilet or bathroom in both wards (baseline: 2/2; follow-up: 2/2).

A number of environmental changes took place between timepoints. Toilets were visible from the bed space in both wards at follow-up (baseline: 0/2; follow-up: 2/2). Signage was erected to support people with dementia to locate toilets (baseline: 0/2; follow-up: 2/2) and facilities within the bathroom, including soap, bins and hand-dryers (baseline: 0/2; follow-up: 2/2). The signage changes in the MASS and the Care of the Older Person ward were viewed very positively by hospital staff in interviews. One MASS service user commented that increased signage for the MASS within the main hospital would be beneficial.

Toilets and bathrooms were big enough to allow for the provision of assistance with using the toilet in both units at both timepoints, and in the in-patient ward audited, bathrooms were big enough for assisted bathing, and facilities were available to support people with dementia's choice about bathing or assisted bathing.²⁵

Between baseline and follow-up, a number of environmental changes took place to promote the independence of people with dementia. At follow-up, all people with dementia were visible to staff (baseline: 1/2; follow-up: 2/2) and offered space where active patients could walk and remain visible to staff (baseline: 0/2; follow-up: 2/2). Both wards were able to provide mobility equipment (baseline: 1/2; follow-up: 2/2) and hearing aids to people with dementia (baseline: 0/2; follow-up: 2/2).

²⁴ The day ward audited does not have patient bed spaces or rooms.

²⁵ The day hospital audited does not routinely provide bathing facilities for patients.



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It was noted that the implementation of environmental changes took longer than originally envisaged and this was associated with the complex and multi-component nature of implementing changes within the organisational structure of the HSE:

“Everything takes three times longer that you think it will and has five times more paperwork, bureaucracy and, you know, all of the stuff that goes with it” (SI T3 Project Team 1).

There were also delays associated with a re-tendering process. It was suggested that a lot of these processes could have been expedited through the use of project management and through the use of “inside knowledge” (SI T3 Key Stakeholder 4) from the outset. The inclusion of the paid OT role to assist in the environmental change strand of the project, though positive, was seen as very challenging as it was not in place until the majority of planning and decision making had been completed.

There was some concern initially from staff in the ED to environmental changes as they felt patients may be left longer within a cubicle if it is deemed to be dementia-friendly. The importance of education alongside the planning and roll-out of environmental changes was highlighted in relation to staff understanding of the importance of changes implemented and to facilitate cultural change. Flexibility in the planning and implementation of changes was highlighted as important by interviewees. For example, when it proved unworkable to paint walls within the ED as it would result in closure for 48 hours, it was decided to use a coloured vinyl on the wall instead.

The various changes to the corridors in the Care of the Older Person ward, including the change in colour of hand rails and skirting, was viewed positively:

“The hand rail was the same colour as the wall. So if you had diminished eyesight, you wouldn’t be even drawn to it. You’d be struggling to find it. But now even in your peripheral vision you can see it and easily place your hand on it. So the hand rail is distinguishable and then the colour of the skirting delimits the wall, floor interface so people feel guided along. So yeah that is working well, for little cost” (SI T3 Subgroup Member 2).

It was noted that the changes in skirting colour would be implemented across the hospital in the future. The use of photographs of the local area with descriptive text along the corridor were remarked upon positively by one family carer who reported that her mother enjoyed spending time looking at these. The use of coloured recesses for patient rooms was viewed extremely positively by both service users and service providers as being bright and happy and also as serving an important function in terms of orientation and navigation. For example, one family carer commented:

“The colour changes on the doors that’s, I mean something so simple, is so effective...You know, these small changes do make a huge difference...and they don’t cost a million” (SI T3 Inpatient Service User 1).

It was reported as being helpful in directing patients back to their room as the colours are more clearly understood than room numbers. It was noted that the angled reveals on the doors were an important facilitator in the use of the coloured recesses:



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“We were lucky in a way that those reveals on the door entries, they’re angled both up and down the corridor. So wherever you’re approaching you can see the room. The problem is they’re too narrow and they get damaged by the beds getting in now, but that’s another day’s solution” (SI T3 Subgroup Member 2).

The use of yellow recesses for all toilets was, again, reported on very positively as they stand out and make it easier for the patient to find, as well as be directed to. Hospital staff remarked that implementation of the colour coding of rooms and toilets and other environmental changes in the ward prompted conversations between staff and families about dementia-friendly design principles, as well as dementia care more broadly.

The implementation of the solarium in the Care of the Older Person ward was discussed by the majority of interviewees. The large size of the room was remarked upon as facilitating the creation of rooms within the room. The orientation of the room (facing south) and looking out upon some trees and greenery were other positive attributes of the room which complemented the re-purposing of the room. The completed solarium was described as brilliant, easy, helpful, amazing, and patient-centred. It was noted that a number of patients now spent a significant amount of time in the solarium and enjoyed their time there. The change in function of the room from a staff meeting room to a patient-based space was also viewed very positively. The calming effect of the room on patients was noted whereby the solarium is now an available space for patients to wander into and to spend time in to avoid boredom and to get away from the busy ward environment:

“They have somewhere to go, they’re not being, we’re not trying to keep them on the ward. And trying to keep them, coming out of other patients rooms. Because you know, a lot of the patients, they get bored, they’ve nowhere to go. And we have to keep telling them, no you can’t go there, you can’t go there. You were telling them all the time, you can’t, you know, because the ward is so busy. There’s nowhere for them to, there was nowhere for them to go. This is a bit of kind of like an escape from the wards” (FG T3 Service Provider 3).

The function of the room as somewhere to walk to, somewhere to have a chat and a cup of tea with a patient, a place for patients to escape to, a distraction for patients, and a quieter environment for patients, was remarked positively upon. It was described as providing “normalisation of life in a place that’s not normal” (SI T3 Key Stakeholder 4). It was outlined that the solarium serves as a space for patient interaction also. Staff outlined a number of specific examples where the solarium had resulted in positive changes in patients’ behaviour:

“The difference in that gentleman we had, he loved it here. Before the room was even done he loved it. He was in here with meetings with the doctors. Before it was even painted he loved it. When the room was painted he even loved it more. So it was great for him, his behaviour. The difference in his behaviour- there was less need for medication” (FG T3 Service Provider 3).

Case example three provides another example on the positive impact of the solarium. While one inpatient service user reported very positively on the solarium, another had not visited the solarium with her mother as yet due to her mother being acutely unwell, and the other reported she was unaware of the solarium and had never been to it.



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Case Example Three: Use of the Solarium²⁶

Mary-Ann is 77 and has a diagnosis of dementia. She has been an inpatient in the Care of the Older Person ward for the past 9 months. Mary-Ann routinely became very confused which resulted in her becoming hostile to hospital staff which they found difficult to respond to. She was described as “*extremely highly strung*” and “*extremely violent*.” HCAs reported that since the solarium has been opened as a patient-centred space, Mary-Ann’s behaviour has changed immensely and “*now all she wants to do is sit beside you and she’ll chat away*.” She enjoys spending time in the solarium each day and feels at home there. She enjoys cleaning and spends time each day cleaning and tidying the different areas of the room. The solarium was viewed very positively by hospital staff as providing a safe space for Mary-Ann to spend time and engage in activities which provided occupation and enjoyment.

The training on dementia-friendly design (given by the University of Stirling) organised by Genio and a follow-on Skype session which a number of the subgroup members attended was viewed extremely positively and seen as influential in shaping the development of the design changes within the project. Consultation with service providers in other hospitals and care settings where dementia-friendly design changes had been implemented was also reported as being beneficial whereby subgroup members visited other relevant sites and discussed the pros and cons of changes implemented in order to draw upon the most beneficial aspects of these changes. The shift in focus of the original proposed plans for environmental signs was viewed positively as this change facilitated the implementation of change in areas which was most impactful. The use of universal design principles was also highlighted as being very beneficial by a number of interviewees as changes benefitted not only people with dementia, but all service users. It was noted that the hospital was part of a national group on the development of guidelines for design for acute care during the course of the project (Grey *et al.* 2018); the DNS was part of the steering group while the environmental subgroup also contributed to the work of the steering group. This parallel development proved beneficial for the project. The multidisciplinary nature of the subgroup was remarked upon positively, including for example, representatives from Estates, Infection Control and Environment. This was seen as beneficial in complying with relevant policy and procedure, as well as driving and maintaining change.

The importance of significant culture change and relevant education in the successful utilisation and sustainability of environmental changes was highlighted whereby it was felt that unless staff are informed about and understand the function and benefits of changes implemented, “*what you’ve got is a very pretty room that isn’t actually benefitting people with dementia*.” (SI T2 Project Team 2)

²⁶ This case example (which uses a pseudonym) was constructed based on focus group interview data



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4.4 Dementia Awareness and Education

4.4.1 Awareness and Knowledge of Dementia

The awareness and knowledge levels of staff in Connolly Hospital as well as community-based service providers²⁷ were assessed by the Dementia Pathways project team, through a baseline survey conducted in the period May – September 2015 and a follow-up survey conducted from March – June 2018. Analysis at both time points was conducted by the evaluation team.

The awareness and knowledge surveys were administered by the DNS. A total of 134 staff completed ‘The Approaches to Dementia’ questionnaire (Lintern and Woods, 1996) and the ‘Alzheimer’s Disease Knowledge Scale’ (ADKS) questionnaire (Carpenter *et al.*, 2009) at baseline and 105 at follow-up. A profile of the overall surveys’ respondents is presented in Table 7. Calculation of response rates is not possible given that an un-recordable number of people were requested to take part in the surveys. As pre and post samples were not matched, the findings are presented using percentage changes.

Table 7. Sample Size and Demographics Baseline

	Baseline	Follow-up
Total no. of respondents	134	105
Gender	78% female	83% female
Mean age	40 years (range 22-63 years)	42 years (21-63 years)
Job roles		
Staff nurse	23 (17.2%)	33 (31.4%)
Allied Health Professionals ²⁸	20 (14.9%)	11 (10.5%)
Clinical Nurse Manager (CNM)	17 (12.7%)	23 (21.9%)
Administrative	15 (11.2%)	9 (8.6%)
Doctor	15 (11.2%)	2 (1.9%)
Healthcare Assistant HCA	11 (8.2%)	11 (10.5%)
Clinical Nurse Specialist	4 (3.0%)	3 (2.9%)
Student nurse	2 (1.5%)	3 (2.9%)
Other ancillary and support staff	27 (20.1%)	10 (9.6%)

²⁷ While a small proportion of community-based service providers completed the survey at both baseline and follow-up, the majority of participants were hospital staff.

²⁸ Including OTs, physiotherapists, dieticians/clinical nutritionists, social workers, and SLT.

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Fifty seven percent (n = 76) of the 134 staff surveyed at baseline and 50% of the 105 (n = 52) surveyed at follow-up, had worked in their current job for more than seven years. The cohort was therefore a very well experienced group. Staff were asked to self-rate their own knowledge of dementia on a scale of 1 to 10²⁹ and the majority at both baseline (72%, n = 95/132) and follow-up (61%, n = 63/104) perceived that they had some knowledge. While the percentage that perceived they had very good knowledge, increased from baseline (16%, n = 21/132) to follow-up (35.6%, n = 37/104) these numbers were small and it should be noted again that the respondents were not matched. Eighty eight (n = 92/105) percent of staff at follow-up felt confident of their ability to care for a person with dementia.

Almost two thirds (63.5%, n = 66/104) of staff surveyed at follow-up had attended project training. The most commonly attended project training was the National Dementia Programme (n = 39), one hour dementia awareness training (n = 25), and brief dementia/delirium education sessions (n = 17). Of those who had attended project training and education, seventy percent (n = 45/64) reported that they felt very confident in applying what they had learned in their work.

The Approaches to Dementia Questionnaire (Lintern and Woods, 1996) comprises two scales which explore the respondent's hope for people with dementia and their life and the recognition of personhood. The higher the score, the more positive the attitude to dementia or the higher the level of awareness.

The 19 items are scored on a scale from 1 to 5 and can be divided into two sub-scales:

- 'Hope' factor; based on 8 items with a maximum score of 40,
- 'Recognition of Personhood' factor; based on 11 items with a maximum score of 55.

According to Lintern (1996), higher scores in the Hope sub-scale suggest that staff are more likely to engage with the person with dementia (for example, explaining or giving information, provision of choice etc.) when they are caring for them. In the Personhood sub-scale, higher scores are indicative of staff perceptions of the person with dementia as an individual and 'sentient being' (Lintern, 2001 p.70). The majority of respondents demonstrated a positive attitude towards people with dementia in both survey rounds. In addition, there were improvements in the mean scores in both the Hope subscale (M = 29.2; +6.2%) and the Personhood subscale (M = 49.7; +8.8%) indicating more hope and better recognition of personhood at follow-up. An overview of the summary scores is presented in Table 8. While there is an overall improvement in the scores at follow-up, this should be interpreted with caution as the participants were not matched.

Table 8. Approaches to Dementia Questionnaire Summary Scores

	Baseline		Follow-up		% Change
	N	Mean (SD)	N	Mean (SD)	
Hope sub-scale (possible score 8-40)	125	27.5 (5.2)	101	29.2 (4.3)	+6.2%
Personhood sub-scale (possible score 11-55)	127	45.7 (4.3)	100	49.7 (4.6)	+8.8%
Total Score (possible score 19-95)	123	73.0 (7.7)	99	79.0 (7.5)	+8.2%

29 This was a self-reported rating system based on a scale from 1 to 10, categorised as follows: 'I know nothing at all' (scores 1 to 3); 'I have some knowledge' (scores 4 to 7); and 'I am very knowledgeable' (scores 8 to 10) as per Carpenter *et al.* (2009).

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When looking at the mean scores of staff at close contact with people with dementia (Table 9), namely nurses and HCAs, compared to those of staff with limited exposure to people with dementia, there was a positive change in approaches to dementia for both groups between baseline and follow-up, with particularly good results among ancillary and support staff. It is worth noting, however, that there was little difference between the two groups mean scores at either baseline or follow-up.

Table 9. Approaches to Dementia Scores by Staff Category

Total Scores by staff category (possible score 19-95)	Baseline		Follow-up		% Change
	N	Mean (SD)	N	Mean (SD)	
Nursing staff and HCAs	59	74.7 (6.6)	74	78.7 (7.4)	+5.3%
Ancillary and support staff	64	71.5 (8.3)	27	79.9 (7.8)	+11.7%

The Alzheimer's Disease Knowledge Scale (Carpenter et al., 2009) is a 30 item questionnaire which has been widely used to measure the respondents' knowledge of dementia across five areas:

- Life Impact (3 questions),
- Risk factors (6 questions),
- Symptoms (4 questions),
- Treatment and Management (4 questions),
- Care-giving (5 questions),
- Course (4 questions),
- Assessment and Diagnosis (4 questions).

Each correct answer is awarded a mark up to a maximum total score of 30, with higher scores indicating better knowledge of dementia. Results are summarised in Table 10.³⁰



³⁰ The sample size of the HCA group was relatively small at both timepoints so results should be interpreted with caution.

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Table 10. Alzheimer's Disease Knowledge Scale Summary Scores

ADKS ³¹	Time point	All staff		Professional categories					
				Staff Nurses		CNMs		HCAs	
		N	M (SD)	N	M (SD)	N	M (SD)	N	M (SD)
Life Impact (possible score 0-3)	Baseline	122	2.5 (0.6)	19	2.7 (0.5)	15	2.5 (0.7)	11	2.3 (0.5)
	Follow-up	95	2.4 (0.6)	31	2.4 (0.6)	22	2.5 (0.5)	9	1.6 (0.7)
Risk Factors (possible score 0-6)	Baseline	120	3.7 (1.2)	18	3.4 (0.9)	16	3.8 (1.5)	10	3.7 (1.3)
	Follow-up	94	3.9 (1.2)	31	3.7 (1.2)	23	3.8 (1.0)	7	3.6 (1.0)
Symptoms (possible score 0-4)	Baseline	121	3.3 (0.9)	19	3.4 (0.8)	16	3.8 (0.5)	11	3.1 (1.0)
	Follow-up	95	3.5 (0.7)	32	3.7 (0.5)	22	3.6 (0.6)	9	3.7 (0.5)
Treatment & Management (possible score 0-4)	Baseline	121	3.3 (0.9)	19	3.5 (0.7)	16	3.4 (0.6)	11	2.7 (1.0)
	Follow-up	94	3.6 (0.6)	30	3.6 (0.7)	23	3.6 (0.5)	9	3.2 (0.7)
Caregiving (possible score 0-5)	Baseline	125	3.8 (1.1)	20	3.7 (1.0)	16	3.8 (0.8)	11	3.0 (1.3)
	Follow-up	96	4.2 (0.9)	32	4.0 (1.1)	22	4.4 (1.1)	9	3.9 (1.2)
Course (possible score 0-4)	Baseline	121	2.8 (1.0)	19	3.1 (0.9)	15	3.1 (1.0)	9	2.8 (0.4)
	Follow-up	91	3.0 (0.9)	28	3.2 (0.8)	22	2.8 (1.0)	9	2.9 (0.9)
Assessment & Diagnosis (possible score 0-4)	Baseline	125	3.3 (0.8)	20	3.4 (0.7)	16	3.4 (0.7)	11	3.3 (0.6)
	Follow-up	97	3.7 (0.5)	32	3.7 (0.5)	23	3.8 (0.4)	8	3.3 (0.7)
TOTAL (possible score 0-30)	Baseline	111	22.6 (3.8)	15	23.4 (2.6)	15	23.8 (3.4)	9	20.9 (3.1)
	Follow-up	84	24.2 (2.8)	27	24.0 (2.6)	20	24.2 (2.4)	7	22.0 (3.0)

As illustrated in Table 10, on average there was a good level of dementia knowledge among respondents at both baseline (M = 22.6) and follow-up (M = 24.2), which are similar to other studies using the same survey (Carpenter *et al.*, 2009; Smyth *et al.*, 2013) but the spread in the range of responses (baseline: 12-28; follow-up: 17-29) is indicative of some degree of variability. The similarity between mean scores at both baseline and follow-up is likely reflective of the fact that the sample was not matched. In regards to the knowledge sub-scales, there were mixed trends in scores across staff categories and between the two time points. However, in most cases these differences were not particularly marked.

31 Red indicates decrease in scores between timepoints.



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4.4.2 Connolly Hospital Dementia Pathways Education and Training Initiatives

4.4.2.1 Overall Approach to Education and Training Initiatives

As outlined previously, the overall aim of the education programme in Connolly Hospital was to support a culture change within the hospital and community sites, which would improve the overall experience of care for the person with dementia. This meant that the education programmes focused on helping the participants to understand the real life experiences of people with dementia and to see the world through their eyes. It also meant a move away from task-orientated practices towards more holistic and person-centred care. The education programme sought to help staff to approach the person with dementia in a different way:

“But that’s really you know, dementia care it’s all about approach. It’s all about you know seeing the person differently. It’s all about changing the way you do things. You know and that it’s not task-orientated care. And that it can’t be to a rigid routine. That we have to adapt to people with dementia. Rather than them having to adapt to our systems and routines and whatever else” (SI T2 Project Team 2).

While the education and training initiatives were hospital wide, there was some focus on particular wards and departments in particular the Care of the Older Person ward, the day hospital and the ED. There was recognition that staff working within the acute sector might need dementia education that was different to staff working in long term care or in the community and this was considered in the design of the programme. In addition, it was perceived that the needs of staff for dementia education within the acute hospital setting had not been as visible as in other areas:

“I think you know, just in terms of the pathway itself being there at the frontline. The education piece has been huge. And I think what we probably have been able to do is kind of tailor our educational piece more around the needs for staff who are working in the acute hospital setting. Which I think mightn’t necessarily have been quite as visible before. And it is quite a different set of needs, to maybe staff who are engaging with people in either nursing homes or in the community” (SI T2 Project Team 1).

The education component of the project was overseen by an education subgroup but the primary driver of the initiative was the DNS who was responsible for implementing the education as well as other aspects of the project. The DNS was afforded considerable autonomy over the education programme and this contributed to the success of the initiative. While there was some emphasis on traditional classroom teaching programmes, there was a strong emphasis on in-vivo teaching which was ‘hands on’ and was immersed within the real world experiences of the person with dementia which were more likely to be remembered and repeated by the participants. This meant that every interaction with a person with dementia and a staff member offered an opportunity to ensure that the educational messages could be reiterated, reinforced and embedded within dementia care practices. In addition this approach offered an opportunity to role model appropriate caring behaviours which could be mirrored. Furthermore there was recognition that individuals learned in different ways and traditional didactic approaches were not suitable for everyone:



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"I think something that's didactic often times goes over somebody's head whereas if you're actually showing and they can actually see, God that works, you know what I mean, that's after working now, this man is much more settled now, they're reading the newspaper, you know, he's drinking his 7Up, do you know what I mean, and it's just, I suppose that's I think the biggest thing that we've done in Connolly Hospital" (SI T2 Project Team 2).

The importance of learning in this way was highlighted and it was felt that this type of learning facilitates a culture change amongst staff which was of particular importance in terms of sustainability of project impacts as *"unless you change that culture....it'll (education) be gone when you're gone"* (SI T2 Project Team 2).

The education sessions were kept very practical in nature and group work was used to help the participants to reflect on commonly encountered situations that were drawn from clinical experiences. In addition, to make it more applicable to the needs of the participants, strategies such as question and answer sessions were used. To reflect the multidisciplinary nature of dementia care and the breadth of the project, different professionals were asked to present and they delivered sessions on their areas of expertise with an emphasis on the provision of strategies to assist with real world scenarios. This also provided a diversity of perspectives which also meant that the delivery of the programmes did not become too burdensome for one individual:

"Like in fairness we're kind of all linked in together. And we all try and do; well I try and actually involve everybody in the education piece. Because I think that it's great to get other people's perspectives. And everybody has, I mean you can't be an expert in everything. But people have all different perspectives, you know and it's great. And people then don't get bored with hearing my voice (Laughs) you know what I mean. And particularly for the two days. There's no way you could stand up there and just do slides for two whole days. Nobody would get anything out of it" (SI T2 Project Team 2).

There was a sense that while there were different elements to the project, they could not be viewed in isolation and the education programme helped to bring them together in a cohesive and coherent way. In addition, the education programme was responsive to the needs of the participants and emerging issues that were affecting people with dementia within the hospital and community sites:

"And then I suppose they have to be flexible. So if it's a case that somebody with a frontotemporal dementia or a Lewy body dementia is on one of the wards, what we do is we'd do a session on that" (SI T2 Project Team 2).

Furthermore, there was an emphasis on making individuals feel more confident when caring for people with dementia and helping them to recognise that the needs of people with dementia are best addressed using more holistic approaches. There was also an emphasis on drawing from existing programmes like the National Dementia Programme which was delivered in conjunction with the regional Nurse Education Centre based at Connolly Hospital. These were adapted to suit the specific needs of the staff however, it was more difficult to get staff released for these as they were longer in duration and required a larger time commitment from staff. Shorter education sessions were more successful in terms of staff release and facilitating attendance, especially the ones that were completed on the ward. There were many references throughout the interviews to the whiteboard sessions that took place on a regular basis throughout the hospital but especially on the Care of the Older Person ward. These fifteen-minute sessions augmented the longer more formal education pieces or provided some education to those staff who were unable to attend due to staff shortages.



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Throughout the hospital, there were many training initiatives happening at the same time as the Dementia Pathways project. This meant that the initiatives associated with the project had to compete with other training programmes. Therefore, the designers of the education programme had to develop strategies to make it stand out from other training and to make it easier for staff to attend. Therefore, the dementia education provided needed to be based on the needs of both hospital and community sites to make sure that staff seen it as a necessary component of their professional development and learning. One of the strategies to achieve this was to ‘split’ the two day National Dementia Programme with day two being delivered two weeks after day one. In between, the participants had homework and a kind of buddy system was used to ensure that the participants were able to support each other. Practical exercises were also given:

“But in between those two days then they have homework. So they have something that they want to stop and start and share. And they have to do that within their own. So we try and get two people from each area. So that they can do it together like in a buddy system kind of. They have an environmental observation just to see what it’s like. Even we get people up on the acute ward to just stand still, for literally thirty seconds and listen to the noises that are around. And how that would be for somebody with dementia. And that’s all about changing awareness, about changing you know” (SI T2 Project Team 2).

4.4.2.2 Telementoring

Telementoring was developed between Connolly Hospital and local nursing homes to allow shared learning and discussion of complex cases. The feedback about the telementoring sessions was very positive and there was consensus that they were a good opportunity to discuss complex cases or specific dementia care issues in a more convenient and timely way. There was also anecdotal evidence that the sessions prevented admissions as issues affecting people within the nursing homes could be resolved and strategies were put in place to prevent their reoccurrence. Despite its success, there were difficulties in terms of managing the technical aspect of the innovation as well as the availability of staff in the nursing homes and other service providers, for example, GPs, and these led to their cessation in March 2017.

4.4.2.3 Dementia Champion Training

As part of the educational initiative, a number of Dementia Champions were trained and for the most part, the course was positively evaluated by the participants. There was some discussion about how detailed the course was and some of the participants didn’t anticipate how much work was involved. In addition, the blended approach of the course was criticised as there were some difficulties accessing and resolving IT issues with the online course interface. Furthermore, some of the participants felt that the programme was quite academic and that there should be more emphasis on therapeutic interventions with the person with dementia:

“I think maybe less of the policies and more of the therapeutic would have been better for us, like we’re all practical more than clinical, it’s more the hands on stuff really. I know there is other modules more therapeutic but say one module dedicated within the 12 weeks didn’t seem enough” (FG T1 Dementia Champions).



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Despite this, the course was seen as a positive experience with the interdisciplinary aspect of the course being welcomed as it provided the opportunity to learn about dementia care from different perspectives. While the course provided a lot of information and learning that was considered useful, there was a sense that there was a lack of clarity about the role of the Dementia Champion and what the participants would be doing when they were finished the course. This was reflected in different practices among the Dementia Champions depending on the areas where they worked. For example, some were involved in educating other staff within their respective departments, whereas others were involved in more advocacy work with the person with dementia and their family. The participants described this work as ‘self-directed’ and there didn’t appear to be a coherent vision about the role of the Dementia Champions in terms of the Dementia Pathways project. However, there was consensus that the main focus of the role was to increase the awareness and visibility of people with dementia throughout the hospital and the Dementia Champions were driving this process within their respective areas.

4.4.2.4 Impact of Education and Training Initiatives

Interviews with hospital staff revealed that generally staff were open to the education programmes and supported it when they could. In addition, there were many references to positive feedback about the education programmes and how the participants enjoyed and benefited from it. It was suggested that the education component of the project was the most important as it raised awareness of dementia throughout the hospital which consequently increased understanding and motivation to provide more effective care:

“The biggest benefit? I’d say has been the training, the education, and the awareness, and the understanding of, of this condition called dementia. I think that the training has been just invaluable, and I think that there is a huge awareness and understanding out there, and I think, so that is why I think the staff are motivated now too” (SI T2 Consortium 10).

However, there were many references to inability to attend due to short staffing within the hospital, especially the ED. Many of the interviewees talked about the use of the video ‘Barbara’s story’ (Guy’s and St Thomas’ NHS Trust Foundation 2014) and how effective it was. They made reference to the little things that could make all the difference to the person with dementia who is in hospital. For example, one interviewee made reference to the video and how it brought home the importance of being present with the person with dementia and taking things at a more gentle pace to accommodate their condition:

“...Just shows you how little changes can make such a difference, just stopping and explaining to the person why they are here and just reassuring them, a bit of reassurance which you wouldn’t think about in any other day, just quickly admitting the person, getting them to the ward but little things like even leaving the curtain open for the person to see out and see what’s going on instead of closing them off like this person in the video, she just wanted to see what’s going on. Little things like that” (FG T1 Service Provider 5).

There was also positive feedback about the longer education sessions and although it was perceived that there was a lot of content, it was described as informative and insightful. Feedback about the dementia education that was provided as part of the initiative included, for example:

“It was very, there’s a lot on it, like it’s very informative, very what would you say? It’s helpful. Yea it is, like it’s a lot to learn, as I say, we didn’t know as much. And it just, it really ourselves in their shoes and do you know. And the way we need to help them to, when they are agitated, instead to say come on go to bed and relax. No just sit down, have a conversation, try to understand what’s going on. I think it’s really helpful” (FG T3 Service Provider 3).



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Another point that many hospital staff took away with them from the education sessions was to try and put yourself in the person with dementia's shoes and that many of the negative experiences for people with dementia emerged from poor communication between the carer and the person:

"So just putting yourself in their shoes. And remember that the patient is in here, they may be frightened, you're coming and you're just, you know, coming at them, they don't know who you are. You're a stranger and we can't forget that they may be frightened. And that's their way of hitting out, is maybe just, pushing your way in. That was kind of it for me I suppose. Just remembering that the person is a human. At the end of the day they're somebody's parent, a family member. And we have to remember at the end of the day" (FG T3 Service Provider 3).

In addition, there were references to the whiteboard sessions and how effective they were for the staff. Hospital staff described how these were delivered on an as-required basis and like the other education programmes were delivered by the MDT. The whiteboard sessions were described as 'brilliant' as they helped to identify approaches that were being adopted to care for patients with either dementia or delirium and they made sure that all staff on the ward were aware of them. The importance of repeating the education sessions (described by one project team member as "constantly driving"), in particular the whiteboard sessions and brief education sessions, in order to reinforce the information and ICP activities was emphasised.

In terms of the impact of the education initiatives, there were many references throughout the interviews to the increased awareness of dementia throughout the hospital and community sites. A reduction in the usage of "confusion" in patient notes was reported whereby the terms cognitive impairment and delirium were being used in its place as a result of increased understanding amongst staff. There were also references to how staff who attended the training became more conscious of the person with dementia rather than just dementia as an illness. There was particular reference to increased awareness of the experience of dementia and there appeared to be a greater understanding of how the acute care environment might negatively impact on that experience. For example, one staff member talked about how moving a person with dementia from ward to ward can have a negative effect and the awareness that a more stable environment is preferential:

"We are much more aware now that moving patients is very bad, they go to Beech [ward] short stay and then they are moved upstairs and I'd say they could be moved five or six times" (T1 FG Service Provider 6).

Hospital staff talked about how there was more of a discussion about dementia and delirium and that they were more aware of approaching people with dementia in a different way as well as recognising when approaches were not suitable. There was discussion during the handover and at the whiteboard sessions about the best ways to approach and care for people with dementia and the increased general awareness of people with dementia in the hospital:

"Just in relation to their awareness of different things. And even staff now we'll say, you'll hear them at the whiteboard or whatever. At the handovers as well. But you'll hear them and they'd say, you know such and such a person. And he had, you know, hit out or whatever it would be. But it was because of A, B and C do you know what I mean. It was because of how he was approached. And if that had of happened differently that would've had a different outcome. So definitely, I can see it and just people becoming more aware of dementia. And you know even that they have to watch out for delirium. Even that they have to watch out for, you know constipation, the things that they have to watch out for. So people are I think much more aware" (SI T2 Project Team 2).



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There were also references to changes in practices to assist people with dementia that emerged in direct response to the education programmes. For example, one staff member, despite scepticism, decided to give people with dementia food on a different coloured plate:

"I was saying to them last time about even the simple thing when that lady spoke about food, that, how they (people with dementia) lose their taste and about putting the food on a different coloured plate and they would eat more and I was a bit sceptical and I went away and I actually bought disposable plates and we tried it and all the staff said 'Oh My God, I can't believe, they're eating the porridge in a red bowl'" (FG T2 Service Provider 2).

The emphasis on person-centred approaches, which were focused on throughout the education programmes, allowed staff to be flexible and imaginative in the provision of care to people with dementia. This was described by one staff member as "going with the flow", meaning that a one size fits all approach is not appropriate in dementia care and that staff had to be responsive to the persons needs at that particular time:

"We have one nurse and she actually, has started; now again it doesn't work with everybody, but she has started singing. Because sometimes singing actually helps. Sometimes with people with dementia singing works. So she's actually found that it really works, she actually does catheterisations and that it works. That people are distressed and you're almost distracting them with a song that they love. And you have the procedure done. So people are really changing, definitely up in [Care of the Older Person] ward as well" (FG T2 Service Provider 2).

Family carers reported positively on hospital staffs' ability to manage responsive behaviours as well as to take the person with dementia's likes and dislikes into account. This demonstration of person-centred care can be attributed, at least in part, to the project's educational initiatives. In addition, there were references to a move away from medication as a first line of treatment to other more person-centred approaches. These were credited to increased understanding and awareness of dementia but other factors such as the environmental modifications contributed to the change in care practices. For example, having a quiet and comfortable room to bring the person with dementia to while engaging with them was also seen as important. While increased awareness of dementia was at the core of project, recognising delirium and differentiating between delirium and dementia was also an important part of the education programmes:

"And it's also as well, delirium and dementia, it's also how to differentiate. If someone comes in and they may not be, we've seen patients come in, very delirious. And we think straight away they have a cognitive impairment. And then when we activate the care bundle and we see when they're treated, when the proper PINCH ME, 4AT tool is activated. And then when they have the treatment that the patient totally reverts back to normal, as in normal as they were fully compos mentis. And it was just we know then it was just a delirium, that they don't have a cognitive impairment, they don't have an actual diagnosis of dementia. So it kind of helps us to differentiate" (FG T3 Service Provider 3).

There were many references to the DNS and there was recognition that much of the success of the educational initiatives were down to her commitment, passion and expertise in dementia care:

"Yeah, and then [name] gave us stuff to read and like I would talk to [name] every day and, so. I suppose she's so passionate about it and it kind of rubs off on the rest of us. I think it is what [name] and the whole project are bringing about is pure awareness, and changing mindsets of staff, and I think that that is what it is all about" (SI T2 Consortium 10).



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4.4.2.5 Challenges to Education and Training Initiatives

The most common challenge discussed by hospital staff was difficulty being released from their ward or department to attend the training. For many of the individuals who attended the education programmes, they attended in their own time. Some hospital staff talked about how it was easier to attend the education programmes if you were not working in the ED or AMAU. This was perceived as unfortunate, especially as many of the patients with dementia were admitted through the ED and therefore spent time there prior to being admitted. Strategies were incorporated to facilitate attendance such as the provision of tea/coffee and something to eat so that staff did not have to be released for a break in addition to being released for the training. Another strategy involved reducing the training programme from four to three hours to facilitate attendance. One way that hospital staff suggested might also improve attendance was to have protected time for staff to attend training events. In addition, another staff member suggested that the training programmes for dementia care should be mandatory given how common dementia was throughout the hospital:

“Well they should probably be compulsory with the age group. I think so, because it needs to be everybody. Everybody including Healthcare Assistants, it should be compulsory because the age of patients coming to the hospital are getting older and so dementia is really an older age condition. With the population living a lot longer it’s going to be more prevalent so why not make it compulsory?” (FG T1 Service Provider 4).

In addition, an interviewee suggested linking the training to Continuing Professional Development (CPD) points might encourage staff to attend training as well. Another issue that emerged was awareness of the education programmes and a number of hospital staff interviewed suggested that they had not attended because they did not know they were on. They suggested that they would have attended had they known about them and recognised the importance of education in this area. This was attributed to email distribution lists and that not all staff had a hospital email address that they could be contacted on. Furthermore, there was a sense that the management style on the ward or department was influential in determining attendance at the training programmes and some were more likely to facilitate staff attendance than others:

“I never had any training when I was in [hospital area], it was never mentioned. But since I went to the [other hospital area] we have an excellent CNM who you now have, who will tell you everything that’s going on and she’d say oh [interviewees name] such and such a thing would you be interested. And that helped” (FG T2 Service Provider 7).



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4.4.2.6 Sustainability of Education and Training Initiatives

Throughout the interviews with the key stakeholders who designed and implemented the education programme, there was an emphasis on sustaining the educational initiatives once the project was complete. There was recognition that there needed to be a driver and without one, sustainability of the programme might be difficult. In particular, the ward-based and informal educational approaches might be difficult to maintain without a driving force behind them, in particular the DNS role:

“Not without having a CNS, you know that you know in dementia. We don’t you know, I’m trying to think what format would the sessions be, if it weren’t run. It would have to be maybe by senior staff nurse, at ward level, unless there were link nurses or something like that. The link nurses could then potentially maintain the momentum. But unless you’ve got some driving force that’s very difficult to sustain. So I would think that the continued resource of having a CNS in dementia would be required to sustain it” (SI T3 Key Stakeholder 1).

However, there was recognition that the regional centre for nurse education was an asset in terms of the sustainability and agreement had been reached to continue delivering the National Dementia Education Programme. However, these programmes were not, as yet, integrated into the practice development educational calendar in the same way as other programmes such as medication management and pressure ulcer prevention and this might be a challenge to their sustainability. Furthermore, the lack of a driver to encourage attendance at these programmes, might also impede their mainstreaming into the future. However, in the absence of a central driver such as the DNS, the Dementia Champions might fulfil some of this role by, for example, supporting project awareness and education programmes within their area of work, or conducting education sessions.

One of the key sustaining features of the project was the increased awareness of people with dementia throughout the hospital and this would lead to increased awareness for the need for dementia education including refreshers for those who had already attended. There was also acceptance that other areas within dementia care, such as intellectual disability and mental health, also needed to be targeted and provided for. However, despite the challenges that existed in terms of sustaining the educational component of the initiative, there was confidence that the programmes would be sustained. In addition, the key people involved in ongoing education and practice development were involved in the initiative and would play a central role in helping to sustain the education programme. Further discussion on the sustainability of the education and training initiatives is provided in Chapter 7.



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4.5 Summary of Connolly Hospital Dementia Pathways Project Impact and Outcome Findings

- While there was increased identification of delirium through the use of the 4AT tool, this was predominantly within the ED setting only. The PINCH ME tool proved successful, where used, for the prevention and management of delirium.
- While the project's focus was not intensively within ED the project did impact on the improvement of dementia care through the ICP in the ED, for example through accelerated assessment. Further improvements are required, for example improved recording and communication of 4AT assessment.
- The DDCB, and the personal profile therein, was viewed positively by service providers and service users alike and resulted in numerous positive impacts on patient care as well impacting positively on the service provider role.
- The newly developed MASS enabled integration and continuity of care to be provided to service users. In addition, the MASS provided a more resource-intensive and therefore beneficial service to people with dementia and their family carers. It also supported hospital avoidance in a number of cases.
- The project roles, in particular the DNS role, were critical for the success of the project. Both service providers and service users spoke highly of the DNS role and its positive impact. Staffing challenges in the recruitment and retention of the dementia link nurse were highlighted as a major difficulty in enhancing integration of care.
- The project evaluation interviews and the hospital organisation, ward organisation and patient case note audits indicated movement towards enhanced integration of dementia care between the outset of the project and its endpoint.
- The positive impact of the environmental changes implemented as part of the project was evident in interviews with service providers and service users, in particular the environmental changes implemented in the Care of the Older Person ward.
- The majority of respondents of the awareness and knowledge survey at follow-up had attended at least one project training session.
- The majority of survey respondents had a positive attitude towards people with dementia at both timepoints and while on average there was a good level of dementia knowledge among respondents at both timepoints, there was a degree of variability among staff indicated by the spread in the range of responses.
- A range of formal and informal education programmes were delivered to all staff, which were based on their roles and perceived needs within the hospital and community. These were positively evaluated and plans have been made to continue and expand upon many of the educational programmes from within existing resources. There is more emphasis on the standard education programmes and bespoke approaches such as telementoring will be implemented when specific need arises.
- Throughout the interviews with staff, there was evidence of increased dementia awareness and the provision of more person-centred dementia care.
- Many of the staff mentioned the DNS as the key driver of the education programmes and that their success could be attributed to her knowledge, expertise and passion.



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5. Connolly Hospital Dementia Pathways Project Process Findings

5.1 Introduction

This chapter presents the overall learning from the project process-related findings that emerged from the evaluation of the Connolly Hospital Dementia Pathways project. These findings are presented with reference to the:

- Function and impact of the Connolly Hospital Dementia Pathways Project consortium,
- Factors impacting on the implementation of the project.

5.2 Function and Impact of the Connolly Hospital Dementia Pathways Project Consortium and Subgroups

The setup of the consortium (See Chapter 2, Section 2.4) prior to project commencement (a condition of the grant application was that the consortium had to be in place) was seen as very important and beneficial in the planning and development of the project. The consortium was reported on positively by a number of its members. For example, one member reported enjoying setting it up and working as a part of it, and felt that it was a fantastic opportunity to improve dementia care. Another member reported that it was well supported and well organised with good representation from key stakeholders. The Project Lead's existing working relationships with a number of key stakeholders and relevant services was an important facilitator in forming the consortium and inclusion of an array of relevant members. The composition of the consortium as well as the various project subgroups as multidisciplinary and encompassing a range of key stakeholders was seen to be very important in the consideration of all perspectives and the development of plans and activities which would seamlessly integrate into existing systems and operations and meet the needs of all relevant service providers and service users. The multidisciplinary nature of the subgroups was highlighted as generating lengthy feedback and discussion but this was viewed as worthwhile. It was hoped that the important links formed on the consortium with community services could be built upon further in the future.

One challenge highlighted in the function and impact of the consortium was in relation to changeover of members. This was also an issue in the DDCB subgroup and within the environment subgroup. It was highlighted however that staff changeover is a reality of the modern healthcare system. This changeover resulted in delays in terms of re-outlining aims and objectives of the consortium or subgroup, and re-discussing topics and plans. It was highlighted that in some cases the project became less of a priority for consortium members where their role changed and they were diverted into other projects and ceased consortium membership.

Consortium meetings were reported as being a forum to gain an overview of the project activities and progress, and acted as an “*anchor*” to return to while members work on various project activities between meetings, and to gain insight on “*the bigger picture*” as well as communicating the project vision in an accessible and relatable way (SI T2 Consortium 9). The consortium was highlighted as providing an opportunity to keep the project on track and discuss the aims and objectives of the project and how these were being achieved, including adaptation to the planned activities of the project and rationale for this. The consortium did not meet very frequently and this was related in part to the difficulty in regularly assembling consortium members given the demands on them. Though consortium

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members recognised the importance of the project, they were not always in a position to attend all consortium meetings due to time constraints and other commitments. The importance of bringing a large number of members on board as well as continually re-energising members was outlined. Another factor related to the infrequency of meetings of the consortium, was the high workload associated with, and as a result of, each meeting. To this end, the need for the dedication of time and resources for the management of the consortium was highlighted. The infrequency of consortium meetings served to ensure that meetings were focused and that consortium members went away with an update on project activities as well as focused pieces of work to manage before the next meeting. The development of a number of project subgroups was also important in reducing the need for very frequent consortium meetings as the subgroup structure ensured a focused division of work, though the inclusion of numerous subgroups did involve an increased workload for the DNS in attending and managing meetings.

There was support for the project and project activities from an array of service providers both within and outside of the hospital. The inclusion of both the hospital and community perspective on the consortium was seen as very important in developing an integrated care model. The Project Lead ensured that consortium members had capacity to sign off on changes, where relevant, such that the consortium could implement changes when agreed. The inclusion of a number of “drivers” of dementia care on the consortium was also stressed to prevent the responsibility of implementing change falling to one or two individuals. The initial difficulty in “selling” the project to consortium members and hospital staff was delineated whereby the value of the project in resolving day-to-day issues related to dementia care was emphasised.

5.3 Factors Impacting on the Implementation of the Project

5.3.1 Factors Facilitating the Implementation of the Project

A range of factors facilitating the implementation of the project were identified in the evaluation. An overview is provided in Figure 10.

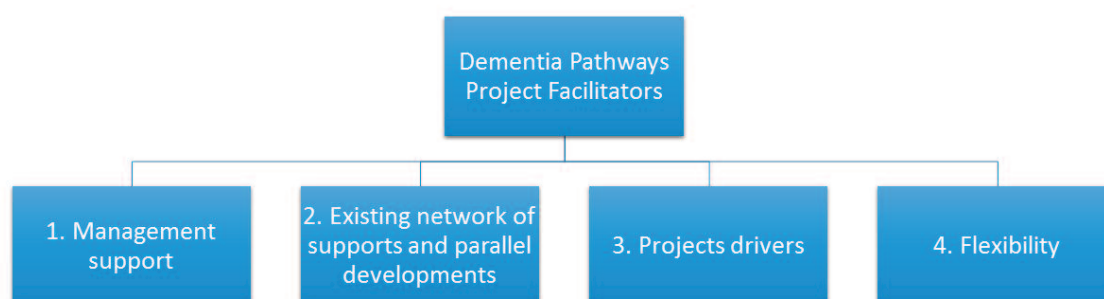


Figure 10. Connolly Hospital Dementia Pathways Project Facilitators

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1. The importance of **management support** and leadership by example in the change process was emphasised by interviewees. Management stakeholders involved in the project included hospital management, nursing management, education management and clinical services management. Specific tangible support from hospital management included the co-funding of environmental changes. The involvement of a number of representatives of hospital management and stakeholders in senior positions on the consortium reflected managements buy in to the project. This was beneficial in terms of the consortium's ability to sign off on project decisions and changes at a senior level:

"I think what fundamentally what the consortium meant was that we were able to get I suppose a very high level sign off on the project itself, be able to kind of engage with hospital management and they've been very supportive. And the same with management structures in the community. And once you kind of had that imprimatur there, it definitely made it easier for us to engage with other people. And I think that's for us, that's kind of been a big thing" (SI T2 Project Team 1).

Importantly, the enthusiasm and level of engagement of all staff was remarked upon and this was also an important facilitator for the project and complemented the management support. This management and staff support was complemented further by support from the project funder who facilitated access to relevant training and education for the project team, as well as meetings with other sites which were developing ICPs concurrently.

The significance of nursing leadership as a facilitator of the implementation and sustainability of the project was emphasised. It was highlighted that sustainability of the involvement of the medical team was more difficult to ensure given the high level of changeover of non-consultant hospital doctors and the finite lifespan of consultants. Therefore the value of nurse leadership was particularly important, and the engagement of Nurse Practice Development with the project had important implications in this regard.

2. The project was developed from a strong foundation whereby there was an **existing network of inter-related supports** already in place. This was further complemented by the project location and a number of **parallel developments** which facilitated the project implementation. These are presented in Table 11.



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Table 11. Overview of Existing Supports and Parallel Developments

Location	Core services in place
<ul style="list-style-type: none"> ■ High proportion of over 65s population in project location and a high prevalence of dementia, meaning staff had a good baseline level of experience of caring for people living with dementia. ■ Location of the project in an acute hospital with ability to manage people with dementia's medical needs as well as their dementia care needs. ■ Nurse Practice Development on site and strong linkage to same (for example, in the development of project policies and documentation). ■ Long stay unit on site with ability to legally detain people where required. ■ Holly Day Hospital on site with strong links with in-patient services and the ability to act as a "hub" for the project. 	<ul style="list-style-type: none"> ■ Enthusiastic and interested staff ■ Care of the Older Person services. ■ Assessment for GLOBE (supervisory) care on admission to the hospital. ■ Access to rehabilitation. ■ Discharge coordination team with promotion of early supported discharge. ■ Geriatric lead in care within the hospital and a strong interest in Medicine for the Elderly. ■ Development in 2008 of community liaison team. ■ Community intervention team in place.
Collaborative working	Parallel developments
<ul style="list-style-type: none"> ■ Good MDT communication systems in place where the majority of staff are familiar with each other due to the size and scale of hospital. ■ Established out-reach links. ■ Links and collaborative working relationship with Clinical Case Manager. ■ Established relationship with radiology with regular meetings. ■ Collaborative working with community-based stakeholders and the completion of the project proposal through collaboration. ■ Linkage with key stakeholders in education and training. ■ Relationship with POA (and consortium membership) with day hospital based on site. ■ Quarterly meetings between community and hospital managers in place prior to project commencement. ■ Collaborative working with HSE Services for Older Persons through, for example, the navigation hub, and representation of HSE Services for Older Persons on the consortium. 	<ul style="list-style-type: none"> ■ Development of the Frail Elderly project. ■ Protected meal times in place throughout the hospital. ■ Development of a therapy room on the Care of the Older Person ward during the course of the project provided access to a therapy room which could be accessed via walking rather than using a wheelchair and a porter transfer. ■ An organisational management of care project conducted during the course of the project which aimed to focus resources on ensuring all patients were ready for mealtimes and received adequate assistance with eating, where required, impacted positively on the project as it fitted with one of the DDCB goals of providing adequate nutrition and hydration. ■ A parallel campaign running for communication in dementia on the Care of the Older Person ward which facilitated the collaborative development of a leaflet on communication in dementia. ■ Introduction of dementia link nurses within the hospital.



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The way in which the MASS worked collaboratively with the Clinical Case Manager during the course of the project was reported on positively and served as a facilitator to the success of the MASS. The DNS and Clinical Case Manager routinely discussed cases and provided advice and support to each other, as well as working collaboratively (for example, conducting joint home visits). This demonstrated good integration and collaboration of services which was described as “very very strong” (SI T3 Key Stakeholder 4).

Care provision for people with dementia was reportedly better resourced for those patients being cared for by a Geriatrician or in Care of the Older Person wards than those within general wards or under other consultants. The availability of additional services and supports in the Care of the Older Person ward, for example a large proportion of static AHPs, made it easier to implement the DDCB and other aspects of the ICP within this ward. The location of large project signage at the ward entrance was viewed as beneficial in raising awareness of the project and informing patients and their families that staff are actively informed in promoting optimum dementia care. The high prevalence of dementia, delirium and cognitive impairment on this ward meant that the DDCB was active for a significant proportion of patients at any one time resulting in an expedited “settling in” period for the DDCB, i.e. this enabled staff to quickly become familiar with the DDCB and its various components as they were regularly used. Conversely, the lower prevalence of dementia in other wards was highlighted as a potential challenge of bringing the DDCB to other wards within the hospital. Another potential challenge for the roll-out of the DDCB to other wards was the larger number of teams and staff working within other wards. At the time of reporting, the project team planned to implement the DDCB across other wards within the hospital, for example, pre-auditing of the DDCB on another ward was completed. It was highlighted that the success of the implementation of the DDCB on the Care of the Older Person ward would make it easier to implement in other wards as the system of care was in place.

3. The level of success of the project was contingent upon not only the project roles, as discussed in Section 4.2.2, but also upon a number of important **project drivers** including Dementia Champions within the hospital. The importance of strong leadership and drivers for the project was recognised by the consortium from the outset:

“It prolongs its life, you know that’s what makes it tick, you do need key people, you need drivers. You need a good driver and you need key lead people and I think that will bring the other, the rest of the team on because I think when you’re introducing something new it takes a time to bed in. But you do need the drivers, you need people to invest in it and you know be supportive of it... That’s how people come on board when they see a bit of enthusiasm for something” (SI T1 Consortium 5).

It was evident that the Dementia Champions were passionate about the improvement of dementia care service provision within the hospital, and that all had a high level of interest and motivation in the area. Many of the Dementia Champions were members of the project subgroups and contributed to the development and roll-out of project activities, as well as supporting project activities and promoting project awareness within their area of work. A member of the project team attributed the formation of the environmental subgroup to the motivation and interest of Dementia Champions. Some Dementia Champions also conducted project education sessions. As part of Dementia Champion training, participants completed change projects. These projects, both directly and indirectly, supported the project. Project examples included the development of an invitation to physiotherapy, and the development of a poster on communicating with people with dementia. Dementia Champions also acted as a voice for dementia advocacy and a resource for patients and staff within their respective areas of work. The project team spoke very positively about the introduction of the Dementia Champions in terms of the support they provided to the project but also in terms of the timing of their introduction, as prior to project commencement such that there was a foundation of support and drivers built for the project. Other examples of important drivers included nursing

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management in areas of high project activity as well as individual hospital staff who exhibit excellence in dementia care service provision, for example, a HCA keeping a selection of magazines to provide to patients to read where appropriate.

4. An important learning outcome was the importance of **flexibility** in project planning and roll-out. The project team acknowledged that the project evolved somewhat from original plans and certain aspects and components were adapted, as needed, to overcome challenges and impact the greatest level of change in dementia care and the integration of care. The project's focus of implementing the DDCB on one ward only rather than across the entire hospital within a feasibility approach, was viewed very positively by hospital staff as a means of trialling and perfecting a model which could then be rolled out to other wards. This was part of the project team's flexible approach to the planning and implementation of the project whereby original aims, objectives and plans were amended, as needed, to impact the greatest level of change.

Flexibility in hospital structures and procedures was also a facilitator for the project. For example, hospital staff referred to their ability to:

- Provide meals outside of usual set meal times,
- Provide meals to patients in the solarium rather than at their bedside,
- Provide light snacks such as cereal and toast to patients outside of meal times,

Furthermore, one family carer referred to staff as being very flexible in allowing her to visit the person with dementia outside of visiting time. Hospital staff outlined that this flexibility often worked to their benefit as the family member may assist the person with feeding etc which benefits all stakeholders.

5.3.2 Factors Challenging the Implementation of the Project

A number of issues were identified as challenging the implementation of the project. Figure 11 provides an overview.

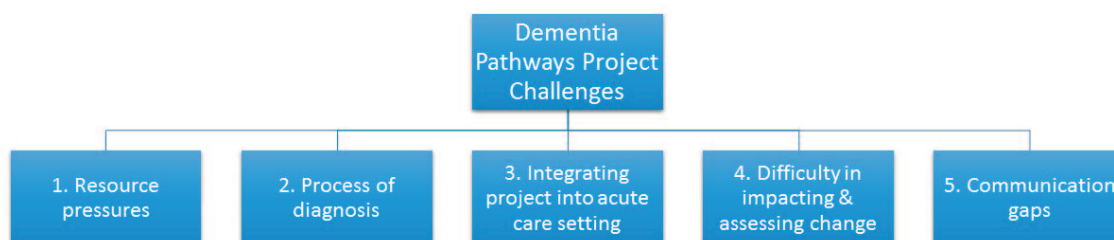


Figure 11. Connolly Hospital Dementia Pathways Project Challenges



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1. The resource pressures existing within the hospital as well as within the community were outlined as significant challenges to the implementation of the project. Shortages in community care have a direct impact on acute care, for example, there may be an inability to discharge a person from hospital if adequate care and support is not available in the community. In regard to community care, some interviewees felt that funding is overly focused on LTC and the Nursing Home Support Scheme (NHSS) instead of community care (for example, day centres and respite services) and home care services. The inequity in the availability of community services across different areas was also highlighted. The long waiting lists to access resources in the community were seen as a challenge to the provision of community care and it was reported that funding for community care services has not increased in a number of years despite increasing demand. It was highlighted that access to dementia-specific home care workers, as well as dementia-specific respite places would be of great benefit. It was also highlighted that resources need to be provided earlier in the dementia care journey to prevent carer exhaustion and crisis. The need for increased access to psycho-geriatric care in the community and within local LTC was also highlighted.

Meeting the needs for supporting nutrition at mealtimes was a concern for staff and family carers alike. There appeared to be staff shortages in some areas within the hospital. Challenges in accessing allied health as well as assistance with nutrition and toileting needs were highlighted by service providers and service users:

“We encourage families to kind of; it’s a big focus of ours. If families say, can we come in outside visiting time, I would say absolutely, you can come in at meal times, you know. To ensure that your, you know mum or dad, uncle; aunt whatever is being fed properly. Because unfortunately, we don’t have enough staff to feed every single patient at the exact time” (SI T3 Service Provider 8).

Difficulty in sourcing the required number of specialising staff, lack of access to services (for example, Physiotherapist) outside of Monday-Friday, and shortages of staff in community nursing were also highlighted in interviews. Pressure on non-staff resources outlined during the course of interviews by hospital staff and/or family carers included, for example, the need for increased use of pressure mats to reduce patient falls and limited access to electronically adjustable beds.

One resource pressure highlighted as a challenge to the implementation of the project was impediments to patient flow. Hospital staff acknowledged that there were a proportion of patients who had been in-patients in the hospital for a number of months, and a small number in excess of two years. Difficulties moving patients from the hospital to an appropriate setting were highlighted. In the case of patients with responsive behaviours, it was reported that it can be difficult to find LTC placement with patients remaining in hospital until suitable placement is found. Furthermore, it was felt that, at times, some LTC facilities were not adept to manage responsive behaviours and/or did not have the resources to manage the care needs of people with advanced dementia. The limited number of LTC facilities with resources to provide one-to-one specialising, where needed, was also highlighted as an impediment. The Nursing Home Support Scheme process was seen as involving a lot of bureaucracy and being overly lengthy. Service users reported delays in the processing of Fair Deal applications and the implementation of funding to nursing homes, where one family carer was told on the day of placement to LTC that the funding had not been approved. Other issues which resulted in impediments to patient flow which were highlighted by interviewees (service users and service providers) included:



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- Delays in processes such as ward of court or power of attorney,
- Difficulties in social circumstances or family circumstances of the person with dementia,
- Waiting on Home Care Package implementation or difficulties in implementing Home Care Packages due to staff shortages,
- Complexities and challenges in management of care resulting in repeat presentations to the ED and/or admissions to the hospital,
- Families reluctant to have their loved one discharged from the hospital and moved to LTC,
- Catchment area issues.

The MASS attempted to counter-balance these delays in transitioning to LTC where possible by, for example,

- Working with families to complete the paperwork for admission to LTC while the person with dementia is living at home so that when they are admitted to hospital, the process has already commenced, or
- By supporting the family with the provision of respite care prior to admission to LTC to avoid admission to the acute care environment.

2. The process of a diagnosis of dementia was highlighted as a challenge to the implementation of the project. The impact of a diagnosis for the person with dementia and their family, and the consequential difficult nature of this interaction for service providers was highlighted:

“Sometimes it’s hard breaking this news to them as well, you know. Even though they may have some idea what’s going on, the families. But when they’re actually told that this is the dementia and that it’s not going to improve. Sometimes it’s like a death to some people you know” (SI T1 Consortium 7).

Service providers outlined that often, while they are aware from the clinical notes and patient observation, that a patient has symptoms of dementia, the patient and their family may be unaware of a potential diagnosis of dementia or cognitive impairment. Difficulty in establishing the person’s baseline condition and subsequently diagnosing in the acute setting was highlighted at T1. Importantly, a member of the project team outlined that the project did not aim to improve the number of diagnoses being made in the acute hospital as she felt that a referral to the MASS where a diagnosis could be made following testing and assessment, with time for discussion with the person with dementia and their family carer, was more suitable. One service user felt that the delay in diagnosing her husband with dementia (as a result of initially being told there was no issue and then as a result of referral between different services) had a negative impact on his long term outcomes. It was noted that use of the DDCB with patients and their families who had not received a dementia diagnosis but where staff recognised behaviours and symptoms associated with dementia, sometimes prompted a difficult conversation between staff and families. Staff endeavoured to provide clarity that the DDCB was in use for a variety of patients and not just those with a diagnosis of dementia, as well as highlighting, in cases of delirium, that symptoms were reversible.

Sometimes, people with dementia do not wish to, or do not feel ready to disclose their diagnosis to family and this was highlighted as causing problems for service provision within the MASS. The need for greater public awareness and understanding for dementia was alluded to, to overcome issues relating to disclosure of a dementia diagnosis. Recent public campaigns such as “Understand Together” were referred to as contributing to greater public awareness. It was also highlighted that the dementia can sometimes be masked by the individual, making a diagnosis quite difficult.



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3. Integrating the project into an acute care setting was, at times, a significant challenge for the implementation of the project whereby the hospitals primary function to manage physical health needs proved difficult. In the acute care setting, often the priority is for those who are medically unwell and these needs are prioritised and therefore the condition of people with dementia may decline during a long term stay in the acute hospital particularly when there is limited availability of activity or cognitive stimulation. It was highlighted that the focus is on patient safety and physical health rather than their overall wellbeing, with the same value not placed on social care and interpersonal interaction as in LTC settings.

Limited space to walk or wander and limited access to outdoor spaces or activities were also highlighted as challenges within the acute care environment. It was highlighted that the management of bed flow is prioritised based on medical need (for example, isolation because of infection status, requirement of a bed in a specialised ward) rather than a consideration of the impact of multiple transfers on the individual patient. The disorientating nature of the changeover of staff and patients for people with dementia was also highlighted. Use of single rooms for people with dementia was seen as isolating and potentially disorientating. While it was evident that the project had made very positive changes in terms of improving the physical environment in a number of areas within the hospital for people with dementia, it was acknowledged that there is still “a long way to go” (SI T3 Subgroup Member 1).

The lack of stimulation and activity for hospital in-patients was outlined to be a challenge in the implementation of the project. This was related to the primary focus of the acute hospital on physical health needs. It was suggested that this reduced stimulation may result in cognitive decline, reduction in independence, reduction in hope and/or increase in responsive behaviours. Suggested activities included, for example, music therapy, listening to the radio, colouring or reading with the assistance of a HCA (where required). One family carer remarked that their family member participated in a reminiscing group for a number of weeks while an in-patient and felt this was extremely positive.

4. The difficulty in impacting and assessing change due to an at times, fragmented system was highlighted:

“There are some fundamentals in the system that are really flawed and really hinder your ability to kind of look at impact in terms of the way we capture information about patients, especially in ambulatory care settings. So outside of HIPE we have nothing that actually kind of talks to how we describe what that part of the patient journey is and that’s the same in the community with, like it’s all manual, it’s either all recorded on an Excel Spreadsheet if that’s how you’re trying to do it but we have no, you know, information management systems or business management systems that actually enable us to kind of really test what it is that you’re actually trying to do” (SI T3 Project Team 1).

The register of patients compiled as part of the MASS was one small step in combatting this challenge.

One of the key learning points for the project was the length of time taken to impact process change. It was also highlighted that there is mixed evidence on the impact of various elements of the ICP, such as the DDCB, on important outcomes such as length of stay, together with a difficulty in measuring accurate outcomes, making it difficult to assess whether the project has had a significant impact on care delivery.

The huge amount of groundwork required for the planning and implementation of project changes and the difficulty in accurately reflecting the extent and value of this work was emphasised. It was suggested that qualitative



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evaluation may be the best way to assess project impact though it was emphasised that much of the project impact will take years to be tangibly evident. It was acknowledged that the project had commenced a change movement and made significant progress in developing an ICP for dementia and improved dementia care in terms of a feasibility approach, but that further change was required to embed the changes and extend these to other areas and wards within the hospital.

The difficulty in measuring and quantifying project outcomes, such as admission avoidance, was outlined:

“It’s so difficult to quantify what you do. Because like even for me I could phone a family and [the DNS] could be exactly the same. And you could be an hour on the phone. But actually that hour may stop that person coming to A&E. Another family could be an hour on the phone and they’d still bring them to ED. So it’s so multi factorial isn’t it? And I think sometimes you know it’s very hard to identify exactly what was the thing that maybe. Or what was the single thing that helped reduce their length of stay, you know. So it’s very difficult to measure. I think sometimes you’re stuck with things like patient satisfaction and at least if you know that that’s coming back quite positive, you’ve something to work on. But it’s really difficult, isn’t it?” (SI T2 Service Provider 1).

5. At T1, one family carer outlined that he has to keep reminding hospital staff about his mother’s diagnosis of dementia while another outlined that she had to keep reminding staff about important specific care needs for her mother (for example, allergy, and method of administering medication). These **communication gaps** still appeared to be evident, at least to some extent, at T3:

“What we were trying to say to the nurses, at that point and the care assistants and the food people and everybody, was that Mammy needs prompting you know what I mean. She won’t ask to go to the toilet but if you ask her she will come, so you have to sort of start thinking for her. So we had to learn this new way of dealing with her. So then we’d say it to one nurse and then we’d say it to another. And then everyday we’d see different faces. And then it was after a week or two, then we realised that messages weren’t getting passed on, you know, and nobody knew anything” (SI T3 Inpatient Service User 2).

The high number of hospital staff, namely Doctors, Nurses and HCAs, in contact with any one patient was highlighted as a potential challenge to optimum communication and continuity of care. One family carer also felt this was particularly problematic in cases where the person was disorientated or had symptoms of dementia. The difficulty in accessing the person with dementia’s Doctor was also highlighted by family carers at T3, one of whom outlined that information about care was only provided to the person with dementia by the Doctor and was not passed on to the family carer.

At T1, the challenge of gaining information about their family member from nursing staff was highlighted as it was unclear which nurses were allocated to provide care to the person with dementia. Importantly, two of the family carers at T3 reported that it was very positive to have a sign in place for each patient showing who their nurse is for that day, making it easier for family carers to access information about the person with dementia.



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The need for greater support and information for people with dementia and their families was alluded to by both service providers and service users. This was highlighted, for example, in the transition from acute care to LTC where it was felt that increased liaison with family is required as well as further guidance in relation to the NHSS. Carer burden was evident amongst family carers at both timepoints. For example, two of the family carers at T3 had given up work to care for the person with dementia while another had changed his work schedule to care for the person with dementia. Family carers reported a focus on the person with dementia rather than the family carer's need, alluding to undervaluing of the unique relationship between the person with dementia and family carer. This compounded the need for greater support and information for family carers.

The leaflets developed by the project were referred to as providing a source of information for families. While there was not much reference to use of project leaflets by hospital staff during interviews, it emerged that the information leaflet for people with dementia and their families is used regularly. One family carer, eloquently reported on the profound impact which her husband's dementia had on their relationship and outlined that there is a need for practical information for family carers to help them prepare for and come to terms with these changes:

"There's no affection now, or holding hands, or remembering your birthday or things like that. And that's so hard. But at least if you know it and if they were to tell you that; 'now he's not going to be able to tell you he loves you, or there'll probably be no holding hands, or cuddles, or he won't remember your birthday or he won't remember Valentine's.' Just to tell you these things, not that you just find out on your own. It's to prepare you for it. Like I found that extremely hard to deal with, extremely hard. But nobody said to you '[Name], this is going to happen. He won't remember, you know.' So this is what's needed do you know...The practical stuff, I mean we all know he's going to get worse; it's not going to get better. So we know that. But they need to prepare you for things like that in the early stages...It's to prepare for these things. Practical, practical day to day things, do you know. You know a year down the road he mightn't be able to feed himself. To tell you that you know, his eating habits will get very messy, to prepare you for that. But it's not there, it's not there" (SI T3 MASS Service User 2).

It was highlighted at T1 that people with dementia often arrive to the ED without information or documentation about their level of mobility or dietary needs which proves challenging for hospital staff. Difficulty assessing or interacting with patients from LTC who attend the ED without a carer or LTC service provider present was also highlighted. When a personal profile document is used this is very helpful and aids communication and provision of care. The need for baseline patient information for surgery and post-operative care was also emphasised.

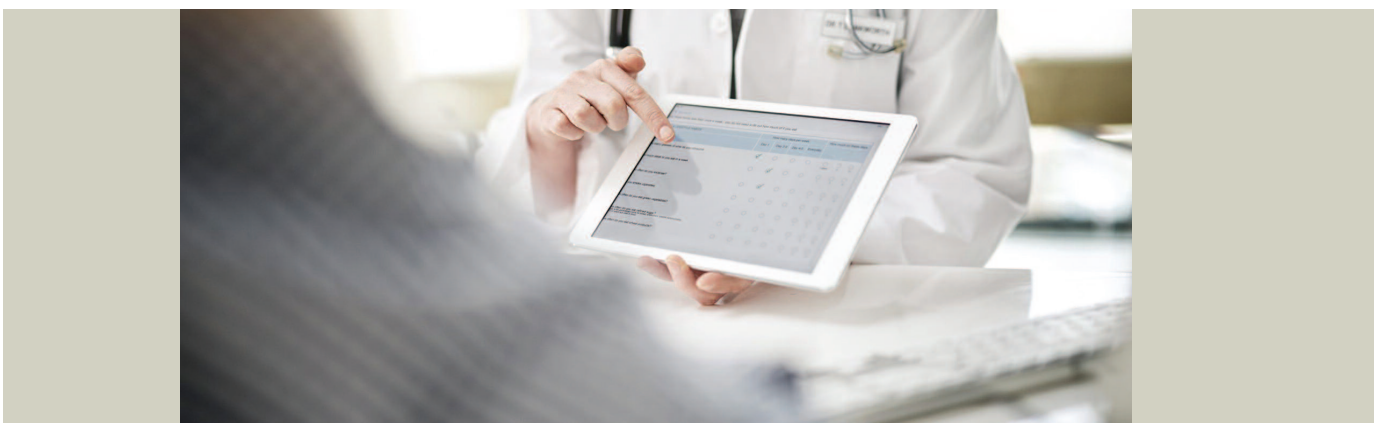
At T1, it was outlined that there is sometimes a failure to consider the bigger picture whereby services and departments work parallel to each other rather than in tandem. This had a consequential effect for service users whereby family carers were sometimes given conflicting information from different service providers dealing with different aspects of their family members care. This challenge was also reported by family carers at T3. There were some other issues reported by family carers, for example, not being adequately updated on changes to patient care and care planning.

At T2 differences in practice across wards within the hospital (for example, use of an alphabetical patient list) was highlighted and this inconsistency in practice and care indicated poor communication between wards and departments, and consequently challenged the implementation of the project.

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5.4 Summary of Connolly Hospital Dementia Pathways Project Process Findings

- The project consortium was reported on positively by stakeholders. The multidisciplinary composition of both the consortium and working groups was seen as critical in the overall success of these groups and, by consequence, the project. However, changeover of members was a challenge due to staff turnover and staff changing positions.
- Four project facilitators were identified which supported the project process and achievement of its outcomes. These were:
 - Management support,
 - Existing network of supports and parallel developments,
 - Project drivers,
 - Flexibility.
- Five overarching challenges were found to have impacted on the project over its time line. These were:
 - Resource pressures, including impediments to patient flow,
 - Process of diagnosis,
 - Integrating the project into the acute care setting,
 - Difficulty in impacting and assessing change,
 - Communication gaps.
- The project facilitators were active over the course of the project and were found to counterbalance the challenges.





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6. Connolly Hospital Inpatient Activity Analysis

6.1 Introduction

This section of the evaluation focuses on data concerning inpatient cases discharged from Connolly Hospital in 2014 and 2017. Data on all patients who were discharged from Connolly Hospital with either a primary or a secondary diagnosis of dementia in 2014 and 2017 was obtained from the HIPE office at Connolly Hospital. This data was combined with information from the Healthcare Pricing Office (HPO) to compute individual level costs for all the cases in the dataset. More details about the data sources, definitions and methodology can be found in Appendix 5. The analysis covers three broad issues: source of admission and destination of discharge, length of stay, and inpatient costs.

The reason that the 2014 data was analysed is that the evaluation set out to identify some key indicators with regard to people diagnosed with dementia in a full calendar year as close as possible to the start of the project. While some elements of the project were initiated in 2014, most of the important changes did not begin until 2015 so it was reasonable to consider 2014 data as pre-intervention baseline.

Ideally, waiting until a full year of data is available after an intervention has ended before analysing the impact of the intervention would be preferable. In this case however, since the project did not end until September 2018 that would have meant waiting until data from 2019 was available. That data will probably be available around April 2020. One of the evaluation recommendations is that the methods employed in this section should be used at that stage to get a more comprehensive picture of the impact of the programme.

For pragmatic purposes, the most useful year of analysis for this evaluation was 2017 as it was the most recent year for which a full year of data was available. However, it is important to recognise that many of the effects of the project will not have been evident by 2017. Additionally, there were so many extraneous factors that affect the data analysed that it is unrealistic to expect a priori that there would be significant changes in key outcomes over such a short period. Even if a significant change in a key variable such as length of stay was identified, it should not be solely attributed to the project under evaluation. The only conclusions that can be drawn from an analysis of the inpatient data were therefore necessarily tentative and should be considered more as possible findings rather than definitive ones.

Most of the analysis concerns length of stay and costs. These variables were not normally distributed and, in what follows, the two-sample Wilcoxon rank-sum test is used with a 5% significance level to compare changes in a range of variables between 2014 and 2017. A considerable number of patients were discharged more than once in each year so the number of cases in the data set is larger than the number of patients. The basic unit of analysis is the case rather than the patient unless otherwise specified.

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6.2 Discharges

Table 12 contains a breakdown of the number of cases and patients in 2014 and 2017. In 2014, Connolly Hospital discharged a total of 291 patients and 348 cases with a diagnosis of dementia. Two hundred and forty seven patients had a single discharge, while 44 patients had between two and four discharges. Single discharges accounted for 71% of cases while the 44 patients with multiple discharges accounted for 29% of the cases. In 2017, Connolly Hospital discharged a total of 481 patients and 614 cases with a diagnosis of dementia. Three hundred and eighty six patients had a single discharge, while 95 patients had between two and five discharges. Single discharges accounted for 62.9% of cases in 2017 so there was an increase of 8.1% in the proportion of cases accounted for by multiple discharges in 2017.

Table 12. Cases and Patients Discharged with Dementia

Number of discharges	Number of patients		Number of cases		Percent of cases (%)		Cumulative percent of cases (%)	
	2014	2017	2014	2017	2014	2017	2014	2017
1	247	386	247	386	71.0	62.9	70.9	62.9
2	34	70	68	140	19.5	22.8	90.5	85.7
3	7	14	21	42	6.0	6.8	96.6	92.5
4	3	9	12	36	3.5	5.9	100.0	98.4
5	0	2	0	10	0.0	1.6	-	100.0
Total multiple	44	95	101	228	29.0	37.1		
Total	291	481	348	614	100.00	100.00		

The increase in the number of cases from 348 to 614 (an increase of 76.4%) is by far the largest increase in the number of dementia cases in the three hospitals that participated in the HSE and Genio dementia programme. There was only a small increase in the number of cases between 2014 and 2015 so most of the increase has occurred in the past two years. There was no change in the number of cases where the primary diagnosis was dementia so all of the change is due to increases in the number of cases with a secondary diagnosis of dementia. Much of the increase is concentrated in a small number of specific Diagnosis Related Groups (DRGs) respiratory infection where the number almost doubled and urinary tract infection where the number more than trebled. It is worth noting that the number of cases with these and other common DRGs in older people who did not have dementia also increased significantly between 2014 and 2017. The increase between 2014 and 2017 may reflect changes in coding practice and referral practice over this time period. It may also be due to exogenous increases in the incidence of dementia due to the ageing population that are obviously beyond the control of the hospital.



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6.3 Readmissions

There were 44 discharges in 2014 where the patient had previously been discharged in 2014. In 27 of these cases (61.4%), a patient was re-admitted to Connolly Hospital within 30 days of their previous discharge. There were 95 discharges in 2017 where the patient had previously been discharged in 2017. In 42 of these cases (44.2%), a patient was re-admitted within 30 days of their previous discharge. The decrease in the proportion of cases in which a patient was re-admitted within 30 day was not statistically significant ($z = -0.8143$, $p = 0.4155$).

6.4 Admission Source

The majority of people diagnosed with dementia were admitted from home but there was a large shift towards admissions from LTC (including nursing homes, convalescent homes or other long stay accommodation) between 2014 and 2017 (Table 13). In 2014, patients were admitted from home in 220 cases (63.2%), while patients were admitted from LTC in 114 cases (32.8%). In 2017, patients were admitted from home in 325 cases (52.9%), while patients were admitted from LTC in 264 cases (43%).

The proportion of cases where patients were admitted from home decreased by 10.3% between 2014 and 2016 ($z = -3.09$; $p = 0.002$) while the proportion of cases admitted from LTC increased by 10.2% ($z = 3.12$; $p = 0.002$).

Table 13. Admission Source

Admission source	Number of cases		Percent of cases		Cumulative percent of cases	
	2014	2017	2014	2017	2014	2017
Home	220	325	63.2	52.9	63.2	52.9
LTC	114	264	32.8	43.0	96.0	95.9
Others	14	25	4.0	4.1	100.0	100.0
Total	348	614	100.0	100.0		

6.5 Medical Card

A majority of cases in both years involved people with medical cards. In 2014, 85.6% of cases involved patients with medical cards, while in 2017, 82.7% of cases involved patients with a medical card. The increase in the proportion of cases where the patients had a medical card was not statistically significant ($z = -1.17$; $p = 0.24$).

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6.6 Patient Death

In 2014, 14.9% of cases (n = 52) with a diagnosis of dementia resulted in death while in 2017, 11.4% (n = 70) cases resulted in death, a decrease of 3.5%. The decrease was not statistically significant ($z = -1.59$; $p = 0.11$).

6.7 Discharge Destination

In 2014, patients were discharged to home in 144 cases (41.4%) and to LTC in 130 cases (37.4%) (Table 14). In 2017, patients were discharged to home in 214 cases (34.9%) and to LTC in 294 cases (47.9%). These two destinations accounted for 82.7% of discharge destinations in 2017, an increase of 4% compared to 2014 ($z = 1.52$; $p = 0.13$). The increase in the proportion of cases discharged to LTC is statistically significant ($z = 3.16$, $p = 0.001$). Most, but not all, of that increase is accounted for by declines in the proportion of discharges going home.

Table 14. Discharge Destination

Discharge destination	Number of cases		Percent of cases		Cumulative percent of cases	
	2014	2017	2014	2017	2014	2017
Home	144	214	41.4	34.9	41.4	34.9
LTC	130	294	37.4	47.9	78.7	82.7
Death	52	70	14.9	11.4	93.7	94.1
Others ³²	22	36	6.3	5.9	100.0	100.0
Total	348	614	100.0	100.0		

6.8 Admission Source and Discharge Destination

Table 15 shows the breakdown of cases by admission source and discharge destination for three specific categories – cases admitted from and discharged to home; cases admitted from home and discharged to LTC; and other combinations. The cases that resulted in death have been excluded from this table.

Table 15. Admission Source and Discharge Destination

Admission source	Discharge destination	Number of cases		Percent of cases		Cumulative percent of cases	
		2014	2017	2014	2017	2014	2017
Home	Home	142	209	48.1	38.6	48.0	38.4
Home	LTC	33	64	11.2	11.8	59.1	50.2
LTC	LTC	95	224	32.2	41.3	91.2	91.4
Others		26	47	8.8	8.6	100.0	100.0
Total (Excluding Death)		296	544	100.00	100.00		

In 2014, 48.1% of these cases were admitted from, and discharged to, home. This proportion decreased to 38.6% in 2017 ($z = 2.68$; $p = 0.007$). This was almost exactly balanced by an increase of 9.1% in the proportion of cases that were admitted from, and discharged to, LTC. In 2014, 11.2% of cases had home as the admission source and LTC as the discharge destination. The comparable figure in 2017 was 11.8% of cases.

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6.9 Primary Diagnosis

As noted earlier, there were twenty two cases in both years where the primary diagnosis was dementia. This represented 6.3% of the total in 2014 and 3.6% in 2017. The decrease of 2.7% in the proportion of cases where the diagnosis of dementia was primary was not statistically significant ($z = -1.95$; $p = 0.05$).

6.10 Length of Stay

The HIPE data records the length of stay for each case. Length of stay ranged from 1 day to 343 days in 2014. The mean length of stay was 29.6 days, while the median was 9 days (Table 16). In 2017, length of stay ranged from 1 day to 244 days. The average length of stay was 20.4 days, while the median was 8 days. There was a statistically significant decline in length of stay between 2014 and 2017 ($z = -2.1$; $p = 0.04$).

Table 16. Mean and Median Length of Stay, 2014 and 2017, All Cases

Year	Number of case	Mean length of stay (days)	Median length of stay (days)
2014	348	29.6	9.0
2017	614	20.4	8.0

6.10.1 Length of Stay: Primary and Secondary Diagnosis

In both years, the length of stay was significantly longer for cases where the primary diagnosis was dementia ($z = -2.08$, $p = 0.04$ for 2014; $z = -4.4$, $p = 0.00$ for 2017). There was a large increase in the length of stay for cases with a primary diagnosis between 2014 and 2017 but this increase was not statistically significant (Table 17). The large decline in length of stay for cases with a secondary diagnosis of dementia between 2014 and 2016 was statistically significant ($z = -2.04$; $p = 0.04$).

Table 17. Length of Stay by Diagnosis of Dementia

Diagnosis	Number of case		Mean length of stay (days)		Median length of stay (days)	
	2014	2017	2014	2017	2014	2017
Primary	22	22	43.1	53.2	26.0	45.5
Non-primary	326	592	28.7	19.2	8.0	7.0
Total	348	614	29.6	20.4	9.0	8.0

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6.10.2 Length of Stay: Single and Multiple Discharges

As mentioned earlier, a multiple discharge case refers to a patient who had at least two discharges in a given year whereas a single discharge case refers to a patient who was discharged just once in a particular year. The mean and median lengths of stay were higher for single cases than multiple cases in both years (Table 18). Length of stay for both type of cases fell between 2014 and 2017, significantly so for single cases ($z = -2.3$; $p = 0.02$) but the change for multiple cases was not significant ($z = 0.5$; $p = 0.6$).

Table 18. Length of Stay by Number of Discharges

Discharges	Number of case		Mean length of stay (days)		Median length of stay (days)	
	2014	2017	2014	2017	2014	2017
Single	247	386	35.4	24.1	10.0	8.0
Multiple	101	228	15.4	14.0	6.0	7.0
Total	348	614	29.6	20.4	9.0	8.0

6.10.3 Length of Stay: Admission Source and Discharge Destination

There were contrasting trends concerning length of stay and the two main sources of admission, home and LTC. Length of stay decreased significantly between 2014 and 2017 for people admitted from home ($z = -2.51$; $p = 0.01$) while length of stay increased significantly for people admitted from LTC ($z = 2.45$; $p = 0.01$) (Table 19).

Table 19. Length of Stay by Admission Source

Admission Source	Number of case		Mean length of stay (days)		Median length of stay (days)	
	2014	2017	2014	2017	2014	2017
Home	220	325	40.9	28.7	15.0	12.0
LTC	114	264	7.8	10.1	4.0	6.0
Others	14	25	29.9	20.2	14.5	5.0

As noted above, the two main discharge destinations were home and LTC. Length of stay declined between 2014 and 2017 in both cases but the decline was not statistically significant in either case ($z = -1.5$ and $p = 0.13$ for people discharged to home and $z = 0.24$ and $p = 0.81$ for people discharged to LTC). Length of stay for cases discharged to home was not different from length of stay for cases discharged to LTC in either year ($z = -0.36$, $p = 0.72$ in 2014; $z = 1.52$, $p = 0.13$ in 2017) (Table 20).

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Table 20. Length of Stay by Discharge Destinations

Discharge destination	Number of cases		Mean Length of Stay (days)		Median Length of Stay (days)	
	2014	2017	2014	2017	2014	2017
Home	144	214	19.9	15.9	9.0	7.0
LTC	130	294	37.7	24.2	6.0	8.0
Others	22	36	40.1	13.0	14.5	7.5

Summary statistics on length of stay by admission source and discharge destination is contained in Table 21. There was a large and significant decline in length of stay between 2014 and 2017 for cases admitted from home and discharged to LTC ($z = -3.85$; $p = 0.0001$). There was a large and significant decline in length of stay between 2014 and 2017 for cases admitted from, and discharged to, LTC ($z = 2.18$; $p = 0.03$). The decline in length of stay for cases admitted from, and discharged to, home was not significant ($z = -1.59$; $p = 0.11$).

Table 21. Length of Stay by Admission Source and Discharge Destination

Admission source	Discharge destination	Number of cases		Mean Length of Stay (days)		Median Length of Stay (days)	
		2014	2017	2014	2017	2014	2017
Home	Home	142	209	20.1	16.0	9.0	7.0
Home	LTC	33	64	120.1	68.1	114.0	61.5
LTC	LTC	95	224	8.1	10.6	4.0	6.0

6.10.4 Length of Stay for People With, and Without, Dementia

The final issue examined is to compare the length of stay for people with dementia to people without dementia for a number of DRGs. The three DRGs that were most common as primary diagnoses for people with dementia were E62A and E62B (Respiratory Infection) and L63A (Urinary Tract Infection). The comparison group was people aged 65 or older who were discharged with one of these DRGs but without a diagnosis of dementia.

In the case of the Urinary Tract Infection DRG, mean and median lengths of stay were longer for people with dementia than for people without dementia in both years (Table 22 and 23). The difference in length of stay was statistically significant in 2017 ($z = -2.28$; $p = 0.02$) but not in 2014 ($z = -0.79$; $p = 0.43$).

For the respiratory infection DRGs, the evidence was mixed. Mean length of stay was longer in both years for both of the DRGs for people with dementia but the median length of stay was sometimes longer, and sometimes shorter, for the people with dementia compared to people aged over 65 without dementia. The only case where the difference was statistically significant was that of E62B in 2017 where the length of stay was longer for people with dementia ($z = -2.82$; $p = 0.001$).



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Table 22. Length of Stay of Cases With, and Without, a Diagnosis of Dementia, 2014

DRG	DRG description	Cases	Mean length of stay (days)	Median length of stay (days)
Diagnosed with dementia				
E62A	Respiratory infection	32	16.0	7.0
E62B	Respiratory infection	20	12.4	4.0
L63A	UTI	24	33.0	7.5
Not diagnosed with dementia				
E62A	Respiratory infection	98	13.6	8.0
E62B	Respiratory infection	86	8.8	4.0
L63A	UTI	52	13.5	5.0

Table 23. Length of Stay of Cases With, and Without, a Diagnosis of Dementia, 2017

DRG	DRG description	Cases	Mean length of stay (days)	Median length of stay (days)
Diagnosed with dementia				
E62A	Respiratory infection	63	15.2	7.0
E62B	Respiratory infection	17	8.7	7.0
L63A	UTI	76	21.3	8.5
Not diagnosed with dementia				
E62A	Respiratory infection	279	13.4	8.0
E62B	Respiratory infection	74	4.2	3.0
L63A	UTI	154	11.6	7.0

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6.11 Patient Cost

The HPO calculates a casemix cost for every DRG in the classification system that they use. That cost was assigned to any patient who has been in hospital within a range that the HPO has classified as normal for that DRG. The HPO has also designed algorithms to calculate costs for outliers – patients who are discharged either before the minimum, or after the maximum, number of days allowed for in any given DRG. Further details are available in Appendix 5 which contains a number of examples. The inpatient costs of every case in 2014 and 2017 were assigned using this method. Costs could not be calculated for 4 cases in 2017 as the casemix data was missing for the DRGs in question.

In 2014, patient costs ranged from €202 to €139,752 (Table 24). The mean cost was €14,338, while the median was €9,268. In 2017, patient costs ranged from €632 to €129,660. The mean cost was €10,820, while the median patient cost was €5,782. The mean and median costs in 2017 were €3,518 and €3,486 lower than in 2014, a difference that was statistically significant ($z = -4.81$; $p = 0.00$). The difference between the average and median costs in each year indicates that there were a small number of patients with very high costs.

Table 24. Mean and Median Patient Costs, All Cases

Year	Number of cases	Minimum	Maximum	Mean (€)	Median (€)
2014	348	202	139,752	14,338	9,268
2017	610	632	129,660	10,820	5,782

6.11.1 Patient Cost: Primary and Non-Primary Diagnosis

As explained in detail in Appendix 5 the relatively high cost of the cases with a primary diagnosis of dementia is mainly due to a change in the classification system used in 2017. The figures that are most comparable in Table 25 are those with a secondary diagnosis of dementia and there was a significant decline in costs for that group between 2014 and 2017 ($z = -5.4$; $p = 0.00$).

Table 25. Patient Cost by Diagnosis of Dementia in 2014 and 2017

Diagnosis	Number of cases		Mean patient cost (€)		Median patient cost (€)	
	2014	2017	2014	2017	2014	2017
Primary	22	22	12,328	21,362	12,520	20,026
Non-primary	326	588	14,474	10,426	9,268	5,565
Total	348	610				

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6.11.2 Patient Cost: Single and Multiple Discharges

Mean and median patient costs were significantly higher in both years for single discharge cases than for multiple discharge cases ($z = 3.84$, $p = 0.00$ in 2014; $z = 3.12$, $p = 0.00$ in 2017). There was a significant decline in costs for single discharges between 2014 and 2017 ($z = -4.2$; $p = 0.00$) and a statistically insignificant decline in costs for cases involving multiple discharges between 2014 and 2017 ($z = -1.61$; $p = 0.11$) (Table 26).

Table 26. Patient Cost by Number of Discharges

Discharges	Number of cases		Mean patient cost (€)		Median patient cost (€)	
	2014	2017	2014	2017	2014	2017
Single	247	382	16,343	12,208	9,268	7,065
Multiple	101	228	9,436	8,495	6,224	5,441
Total	348	610				

6.11.3 Patient Cost: Admission Source and Discharge Destination

Table 27 contains costs for cases admitted from home and from LTC in both years. Costs of cases admitted from LTC were significantly lower in both years than costs of cases admitted from home ($z = 3.5$, $p = 0.00$ in 2014; $z = 3.03$, $p = 0.002$ in 2017). Costs fell in both years for both cases admitted from home and cases admitted from LTC ($z = -3.37$, $p = 0.00$ for admissions from home and $z = -2.34$, $p = 0.02$ for cases admitted from LTC). A similar pattern was evident when cases were distinguished by discharge destination – costs were lower for cases discharged to LTC than for cases discharged to home and costs fell in both categories between 2014 and 2017. See Table 28 for details.

Table 27. Patient Cost by Admission Source

Admission Source	Number of cases		Mean patient cost (€)		Median patient cost (€)	
	2014	2017	2014	2017	2014	2017
Home	220	324	16843	13249	9565	6594
LTC	114	261	9380	7516	6461	5441
Total	334	585				

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Table 28. Patient Cost by Discharge Destination

Discharge destination	Number of cases		Mean patient cost (€)		Median patient cost (€)	
	2014	2017	2014	2017	2014	2017
Home	143	210	9831	8458	6907	5402
LTC	128	285	17491	12123	9268	5847
Total	271	495				

When cases were classified by admission source and discharge destination it was found that costs in all three categories were significantly lower in 2017 than in 2014 (Table 29). Cases admitted from, and discharged to, home had lower costs than cases admitted from home and discharged to LTC ($z = 6.51$, $p = 0.00$ in 2014 and $z = 7.5$, $p = 0.00$ in 2017). Similarly, cases admitted from home and discharged to LTC had significantly higher costs than cases admitted from, and discharged to, LTC ($z = 6.3$, $p = 0.00$ in 2014 and $z = 7.5$, $p = 0.00$ in 2017).

Table 29. Patient Cost by Admission Source and Discharge Destination

Admission source	Discharge destination	Number of cases		Mean patient cost (days)		Median patient cost (days)	
		2014	2017	2014	2017	2014	2017
Home	Home	142	208	9893	8480	6929	5402
Home	LTC	33	64	40108	27442	36896	20026
LTC	LTC	95	221	9634	7686	6477	5441





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6.12 Summary of Connolly Hospital In-patient Activity Analysis Findings

- The total number of cases discharged with a diagnosis of dementia increased from 348 to 614 between 2014 and 2017. All of this increase was due to an increase in the number of cases with a secondary diagnosis of dementia.
- The proportion of cases admitted from LTC and discharged to LTC both increased between 2014 and 2017.
- Overall, length of stay declined significantly between 2014 and 2017. However, the various sub-categories examined showed contrasting trends in length of stay. Length of stay decreased significantly for people admitted from home for example but increased significantly for cases admitted from LTC.
- Length of stay was generally higher for people with dementia than for people without dementia who had received the same primary diagnosis. But the difference in length of stay was not always statistically significant.
- Overall, costs of the cases with a diagnosis of dementia fell significantly between 2014 and 2017. This was particularly the case for people with a secondary diagnosis of dementia.
- Costs fell between 2014 and 2017 in all of the various sub-categories that were examined.





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7. Discussion

7.1 Introduction

This chapter considers the findings of the evaluation of the Connolly Hospital Dementia Pathways project and the considerations pertaining to sustaining project gains. This chapter will be presented with reference to the following sub-sections:

- Discussion,
- Sustainability of project gains,
- Considerations related to the evaluation findings,
- Conclusion and recommendations for enhancing integrated dementia care.

7.2 Discussion

The Connolly Hospital Dementia Pathways project aimed to: 1. reduce the negative effects associated with hospitalisation for people with dementia through appropriate avoidance of acute hospital admissions, 2. reduce the length of stay in the hospital through supported discharge and 3. improve the hospital experience of the person with dementia through early detection, person-centred care, and a dementia-friendly environment. To achieve its aims, the Connolly Hospital Dementia Pathways project incorporated a number of components including: the development of an ICP for dementia care, dementia-friendly environmental changes, out-reach/in-reach activities, including project-specific roles and the MASS, and a range of dementia education and awareness raising activities. The project team conducted extensive work in the four core areas of the project; integration of care, person-centred care, dementia-friendly environment and education. The MASS was a key success of the project in terms of integrating dementia care and providing continuity of care for people with dementia and family carers. Through the resources of the MASS and the flexibility of the DNS role, enhanced ambulatory care, rather than traditional out-patient care, was provided. This included, for example, the virtual clinic and the facility for service users to access the DNS by phone outside of clinic times. The DDCB proved highly beneficial to both service users and service providers, with a huge amount of buy-in evident from staff. The decision to pilot and refine the various components of the DDCB on the Care of the Older Person ward before rolling it out to other wards was beneficial and an efficient use of resources to determine what worked in practice and to ensure organisational buy-in to the project aims. The environmental changes implemented, particularly in the Care of the Older Person ward, were very successfully and an important outcome of the project. The use of project education initiatives to increase dementia awareness and knowledge among staff in order to change the culture of care and provide a strong foundation for the development of other project areas, was critical.

The objectives of the Connolly Hospital Dementia Pathways project were aligned with a number of the priority areas of the National Clinical and Integrated Care programmes for Older People operated within the HSE and the Irish National Dementia Strategy (Department of Health, 2014). For example, the strategy highlights the need for integrated services, supports and care for people with dementia and their family carers. The development of the MASS by the project was responsive to this priority area. Further priorities identified in the National Dementia Strategy are dementia training and education, dementia-friendly acute care environments, clarity in care pathways



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for all concerned and seamless transitions in care. As demonstrated in both the project description (Chapter 2) and the evaluation findings (Chapters 4-6), the activities within the Connolly Hospital Dementia Pathways project centralised all of these elements and sought to introduce innovations to achieve lasting and meaningful developments in terms of dementia care integration.

The project was particularly timely given the ongoing national review and reform of older persons' services, as well as the growth in political and policy focus on dementia. The further development of services for older adults in the primary and secondary care settings is a key objective of both the Integrated Care Programme for Older Persons (Health Service Executive, 2017b) and the National Clinical Programme for Older People (Health Service Executive, 2013). The development of integrated services and pathways for those with complex care requirements, such as those living with dementia, is fundamental to this aim. The necessity for dementia-specific ICPs which facilitate "*the right care and support, in the right place and at the right time*" is identified within the Irish National Dementia Strategy (Department of Health, 2014 p. 25). Dementia-specific ICPs are crucial in order to provide effective person-centred care for the person with dementia, including personalised supports (Irving and McGarrigle, 2012). However, there is limited evidence of the potential contribution and impacts of ICPs to dementia care, despite international advocacy for the development of them. The Connolly Hospital Dementia Pathways project is one of the first in the Republic of Ireland to develop and introduce an ICP for dementia care along with two other HSE and Genio funded projects (Chapter 1, Section 1.2). The combined learning from the evaluation of the Connolly Hospital Dementia Pathways Project alongside the other two projects has the potential to expand the currently limited evidence base as well as providing information and key points of learning to other settings intending to implement similar developments.

The evaluation of the Connolly Hospital Dementia Pathways project demonstrated that it was successful in developing an ICP and by project end had successfully implemented this within a small number of wards/areas within the hospital. Consideration of the project's ICP, and its impact and usage within the project site, demonstrates that it compares well with the purpose of ICPs described in Chapter 1. It further demonstrates compatibility with many of the defining criteria as outlined in the Integrated Care Pathways Appraisal Tool (West Midlands NHS, 2006 as cited by Great Ormond Street Hospital for Children NHS Foundation Trust, 2010), particularly in relation to it being an ICP and its development. There was significant evidence to demonstrate its use in practice, however, as would be expected, this was confined to the ward areas defined by the project. The project took place in the context of a strong network of supports and services for older people in the hospital and local community setting, and the size and structure of the hospital facilitated positive change in dementia care through the project. The evaluation provided evidence that a degree of streamlining of dementia care had occurred within acute care in the hospital as well as ambulatory and community care (through the MASS). There was also evidence of raised awareness of dementia and the person-centred needs of those living with dementia. While there was less than anticipated progress in the community aspects of the project, there was appreciable progress in terms of: development of a care bundle for those with dementia or delirium, setup and refinement of the MASS, leadership in dementia care through the DNS role, dementia-friendly environmental changes, and raising knowledge and awareness of dementia within hospital staff. Notably, there was a large amount of positivity amongst staff for the project changes.



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It was recognised by numerous stakeholders (see Chapters 4 and 5) that the project could not, and should not, rely on a single person in order to roll-out the initiative or maintain project gains. In line with this view, a consortium approach was employed, as advocated by Keogh and Pierce (2017), whereby a group of individuals, agencies and organisations came together with the agreed goal of supporting the development of an ICP for dementia. It was acknowledged however, that the DNS role was crucial to the success of the project. In order to ensure wider staff and organisational buy-in, cultural change and the empowerment of staff (including the consortium) in dementia education, awareness and service provision is required such that each staff member feels a sense of responsibility to provide an optimum level of care for people with dementia. The multidisciplinary nature of both the consortium and the project subgroups was an indicator of staff buy-in and this was noted as being particularly valuable in planning, adapting and rolling out the various components of the project. Considerable investment of human resource time, in particular through the DNS role, is evident in the work to date and further adoption and implementation of the proposed ICP will require strategic championing at all levels within the organisation.

In summary, the evaluation demonstrated that the Connolly Hospital Dementia Pathways project made significant gains in terms of dementia care integration and development within the hospital. The project objectives and implementation aligned with existing structures and resources within the hospital and community so as to maximise the project gains. The significance of buy-in from multiple levels of stakeholders and all categories of service providers has been emphasised. Also highlighted was the need to continue to roll-out the ICP to other wards and areas within the hospital. Some facilitators shown to be key to the achievement of outcomes such as those incorporated in the Connolly Hospital Dementia Pathways project included:

- A sufficient lead in time and planning phase,
- Strong project leadership with visibility on the ground and expertise in dementia care,
- Positive staff attitude towards project activities and person-centred dementia care,
- Collaborative working across project areas,
- Ongoing management and organisational support for project components during implementation.

A number of these factors are consistent with aspects of the steps of effective implementation science outlined by Meyers *et al.* (2012). To facilitate process learning, the implementation and evaluation processes should operate in tandem with each other. Changes which occurred beyond the timeframe of the project and whether gains achieved were maintained are not wholly evaluated here due to the timeframe of the evaluation. This could potentially be addressed by implementing and embedding an ongoing process examining key indicators, such as dementia care auditing metrics, or length of stay and costs. It would be valuable to continue to analyse and evaluate evidence such as length of stay and patient costs over time in order to form a better view of whether project outcomes will be maintained into the future.

This discussion has outlined key considerations in terms of the Connolly Hospital Dementia Pathways project findings. However, while the gains achieved in terms of dementia care integration have been highlighted, issues relating to their sustainability and further development also require consideration.



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7.3 Sustainability of Project Gains

The importance of the project and the care and cultural changes arising from it are relevant in terms of the growing population of older people. Connolly Hospital HIPE data showed a 20% increase in the number of people over 65 years admitted for inpatient care over the three years of the project with similar increases in the number of people living with dementia presenting for admission (based on HIPE data and Department of Health estimates of one in four hospital admissions being people living with dementia). For the project to be effectively sustained and embedded, systems change (for example, a national mandate for the widespread implementation of dementia-specific roles) is required rather than simply one or two project-linked roles. Relevant resources, including roles, should be embedded and included within service plans.

Activities and developments which had taken place and are facilitators for the sustainability of project gains and activities included:

- The existence of a network of project drivers, including the Dementia Champions,
- The integration of a number of project activities into the policies, procedures, protocols and guidelines (PPPGs) for the hospital, for example, the personal profile document has been embedded into the nursing care plan, and the PINCH ME and educational initiatives have been incorporated into PPPGs and promoted by Nurse Practice Development.

It was felt that given that the MASS is now well established within the hospital and has established administrative and clerical support that it will continue to operate without issue into the future and is seen as part of business as usual. Furthermore, it is planned to expand the range of services and supports offered through the MASS to include additional therapies and resources for people with dementia and their families. The operation of the MASS in close collaboration with other services and corresponding referral pathways in to and out from the MASS is very positive in terms of sustainability as it has been built within a strong network of supports. The project team outlined that the MASS will continue to develop as a hub for excellence in dementia care including, for example, the commencement of the Integrated Care Team.

Most of the education has taken/takes place through the regional nurse educational centre and is resourced from the RCSI hospital group which indicates the potential for sustainability as existing resources can be used to continue these education sessions. Accordingly, it is likely that all dementia education will be absorbed into the local training calendar. It was confirmed during interviews that there will be continued release of staff to attend dementia education and training. The project team outlined that plans had been made to continue and expand upon many of the educational programmes from within existing resources. The continuation of a DNS or CNS for dementia role was highlighted by interviewees as critical for sustaining dementia education into the future.

In early 2018, the development of an Integrated Care Team commenced through the support of the hospital management team to ensure availability of enhanced ambulatory care for people with dementia. At the time of reporting, an OT role had commenced and it was planned to have a social worker and physiotherapist as part of this team in the near future. The DNS had been made a permanent member of this team. Furthermore, Connolly Hospital had been approved for an ANP dementia post as well as a CNS dementia post. It is anticipated that both posts will be filled later in 2018/2019. There will be a lot of collaboration between these roles and the DNS role, with all of these roles crossing boundaries between the hospital and the community and working as part of the



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Integrated Care Team. The ANP role will be based in the hospital with a significant out-reach remit. The primary focus of the CNS will be in-patients within the hospital while the primary focus of the DNS will be MASS service users, though there will be a lot of crossover between these roles. This is in line with recent recommendations that one whole time equivalent DNS role should be in place for every 300 annual hospital admissions of people with dementia each year (Griffiths et al., 2015). The no cost project extension to complete environmental changes in the MASS (not included in the analysis above as it occurred following evaluation data collection) included the addition of an extra nurses' station as well as the renovation of space to accommodate a permanent office for the DNS and the Integrated Care Team (implemented following the evaluation timeline). Furthermore, it was planned to also include assessment by OT and social worker in the assessment process within the MASS clinic following implementation of the team.

While it was suggested that the consortium may continue to meet into the future in their continuation of the improvement of dementia care, there were no plans in place to this end at the time of reporting. However the hospital did plan to continue with the use of dementia-friendly and universal design principles in the future renovation, re-decoration and re-painting of other areas of the hospital in the future, for example, use of colour contrast hand rails and skirting, yellow recesses for all toilet doors and the use of navy toilet seats. At the time of reporting, there were plans to develop another hospital ward replicating the environmental changes included in the Care of the Older Person ward within the project as well as the inclusion of a dementia-friendly garden. Indirectly, as a result of the project and associated networking and discussion, a regional dementia network forum was established which the Project Lead is a member of.

7.4 Considerations Relating to the Evaluation Findings

Overall, the findings of this evaluation demonstrated positive impacts in terms of the integration of dementia care between the project outset and its conclusion. However, they should be interpreted in light of the following considerations:

- While it was originally intended to complete interviews with both the person with dementia and their family carer, the reality of this stage of data collection meant that it was not possible and/or suitable to include the person with dementia in the interview. In some cases the person with dementia was an in-patient in the hospital and/or not well enough to participate.
- The evaluation ended at the point of the agreed end date of the project and as such, it is not possible to comment on ongoing impacts of the project on dementia care locally into the future.



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7.5 Conclusion and Recommendations for Enhancing Integrated Dementia Care

This report presented the findings of the evaluation of the Connolly Hospital Dementia Pathways project, which aimed to develop and deliver enhanced integrated care for people living with dementia within the project setting. On the basis of the findings of the project evaluation, a number of recommendations specific to the project are proposed for enhancing integrated dementia care. Furthermore, this report is one of a series of evaluations and the cumulative learning from these has also suggested a number of broader recommendations to enhance the provision of integrated dementia care within hospital and community settings nationally.

Recommendations

Project-Specific Recommendations

- A regional centre for dementia diagnosis, with a central database accessible by individual services and healthcare providers would be beneficial to improve the diagnosis journey for service users and improve communication between service providers and settings.
- Sufficient project lead in time is recommended to refine project objectives, for project planning and to complete the necessary groundwork for the commencement of project roles.
- Given the unexpectedly long length of time and the complexity of processes involved in implementing project changes, it is recommended that an increased period of time is allocated to plan and implement similar projects in the future.
- Project leadership and a team of project drivers (including Dementia Champions) is invaluable to the success of such projects.
- Working in tandem with community-based services is very onerous and requires dedicated leadership for future projects.
- Additional business support/project support would have been very valuable in progressing the project and is recommended that such support is built into the planning of future projects.
- There is a need for ongoing information and education for service users including, for example, a comprehensive guidebook on dementia and an overview of the likely timeline of the progression of the condition.
- Providing a follow-up information workshop/session for families following diagnosis would be beneficial.
- Development of ongoing in-depth comprehensive assessments for service users whereby they would be reviewed by a number of relevant healthcare providers and allied health professionals to assess them in a more holistic way is recommended.

Broader Evaluation Recommendations

- The person with dementia and their individualised needs should at all times be central to innovations to enhance integrated dementia care.
- To achieve meaningful impact, a dementia-friendly orientation needs to be embedded in the strategic objectives and operational planning of an organisation.
- A whole organisation approach to the integration of dementia care is advocated with involvement of key multi-level and inter-departmental stakeholders with the power to leverage support and facilitate required actions.
- Innovation in integrated dementia care requires clear governance and visionary leadership, and such leaders require dedicated resources to support dementia care development.



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- A consortium approach is recommended for projects designed to design, test and implement innovations to develop integrated dementia care.
- Inter-sectoral involvement is required where innovations in dementia care are designed to cross the continuum of care. Such involvement should focus on developing collaborative networks and the setting up of effective in-reach out-reach communication systems between those involved.
- Innovations in dementia care (for example, ICP development) and dementia-friendly environmental design are time intensive and require extensive planning inputs to include process mapping of the journeys of people with dementia, evidence review and stakeholder consultation.
- Associated projects need to factor in sufficient lead-in time to devising related interventions and the planning activities involved should be viewed as sub-components of the overall intervention.
- Innovations in dementia care, such as ICPs, require ongoing point of care support through dedicated dementia-specific roles which are highly visible and whose role-holders have expertise in complex dementia care.
- Where dementia-specific roles are shown to have a positive impact, there needs to be commitment and resources to continue them if gains in dementia care integration are to be maximised and built upon.
- When introducing innovations such as ICPs, both opportunistic and dedicated education programmes aimed at enhancing dementia knowledge and awareness contribute to the overall level of staff preparedness. Therefore, sustainable dementia education programmes should be available for all service providers who are involved with people with dementia and such education should retain a strong person-centred focus.
- So as to maximise learning for current and future projects, there is a need to in-build parallel participatory evaluation of the processes involved in projects to develop integrated dementia care in addition to measuring outcomes. Evaluations should additionally plan to extend beyond the end-point of an individual project so as to evaluate for any ongoing impact over time.
- Consideration should be given to embedding dementia-specific key performance indicators and audit metrics into quality assurance systems to monitor ongoing organisational performance relating to dementia care integration.





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Appendices

Appendix 1: 4AT and PINCH ME Tools

4AT Assessment Tool		For guidance visit www.the4at.com
[1] Alertness: This includes patients who may be markedly drowsy (e.g. difficult to rouse and/or obviously sleepy during assessment) or agitated/hyperactive. Observe the patient. If asleep, attempt to wake with speech or gentle touch on shoulder. Ask the patient to state their name and address to assist rating.	Normal (fully alert, but not agitated throughout assessment)	0
	Mild sleepiness for <10 seconds after waking, then normal	0
	Clearly abnormal	4
[2] AMT 4: Age, date of birth, place (name of the hospital or building), current year.	No mistakes	0
	1 mistake	1
	2 or more mistakes/untestable	2
[3] Attention: Ask the patient: "Please tell me the months of the year in backwards order, starting at December." To assist initial understanding one prompt of "What is the month before December?" is permitted.	Achieves 7 months or more correctly	0
	Starts but scores <7 months/refuses to start	1
	Untestable (cannot start because unwell, drowsy, inattentive)	2
[4] Acute change or fluctuating course: Evidence of significant change or fluctuation in: alertness, cognition, other mental function (e.g. paranoia, hallucinations) arising over the last 2 weeks and still evident in the last 24 hours.	No	0
	Yes	4
4AT score - 4 or above: possible delirium +/- cognitive impairment; 1-3: possible cognitive impairment; 0: delirium or severe cognitive impairment unlikely (but delirium still possible if [4] information incomplete).		TOTAL

Figure 1A. The 4AT Tool³³



Figure 1B. PINCH ME Tool³⁴

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Appendix 2: DDCB Guidance Document³⁵



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 	<p>Creating Best Practice Operational Guidance Person-Centred Dementia Care</p>
<p>Consultation Group : Dementia Care Bundle Sub Group</p>	
<p>Guidance Statement:</p> <p>Person-Centred Dementia Care in itself is not a single intervention. Person-centred care provides a set of guiding principles for our actions in the field of dementia care that enable a strengths based, compassionate approach to dementia care in acute setting.</p> <p>Informed by a person-centred assessment, our philosophy of care involves the implementation of a small, straightforward set of evidence-based practices that, when performed collectively and reliably, have been proven to improve patient outcomes.</p>	
<p>Rationale:</p> <p>The purpose of a person-centred assessment is to ensure that we get to know the person rather than just the condition with which they live. This person-centred assessment will help to inform a person-centred approach to providing a safe and orientating environment; adequate nutrition and hydration; effective communication; knowing the person.</p>	
<p>Identified Process:</p> <p>The team on [ward name] ward will have an identified lead professional for PCC; this should be a senior member or nominated deputy. This lead professional will be responsible for:</p> <ul style="list-style-type: none"> • Ensuring that 100% of staff have read and understood the PCC Operational Guidance and have a signed copy placed in their personal files. • Directing a ward environment assessment with dementia-friendly design principles in mind and then adopting these principles where possible. • Identifying and reporting all staff training needs in relation to the delivery of PCDC. • Identifying individual staff members to become Dementia Champions. <p>It is the responsibility of every professional to ensure that they demonstrate a person-centred approach to the care and treatment of patients' with dementia.</p> <p>Knowing what matters to the person All patients' admitted to the hospital with a diagnosis/suspected diagnosis of dementia/delirium will have a 'Getting to know what matters to me' document completed within 48 hours of admission. Informed by the information contained in this assessment, ensure that the following action is taken for each individual patient:</p> <p>Safe & Orientating Environment</p> <ul style="list-style-type: none"> • Signage that includes pictures and text, toilet doors being painted a single distinctive colour and toilet seats and hand rails in a colour that contrasts with the walls and floor, pictures/objects or colours to help people find their way around (Brooke & Semlyen, 2017; Irish National Audit of Dementia Care in Acute Hospitals 2014). • The provision of personal items at the person's bedside also can help orientate and calm/relieve a person in distress in the ward environment. 	

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- Appropriate lighting and floor covering, adequate space and resources to support activities and stimulation (Royal College of Nursing, 2013)
- The use of day rooms/patient's lounges (eg. Rowan Lounge) where patients can sit out of the noisy, busy, acute environment could also be effective for people with dementia.
- Creating a homely environment in the day room with appropriate seating and access to meaningful activities would give people with dementia the opportunity to interact and socialise away from the acute environment (Irish National Audit of Dementia Care in Acute Hospitals, 2014).
- Accommodate people with dementia to prevent their functional deterioration while admitted and to promote a suitable and supportive environment- discuss in group re mobilisation.

Nutrition & Hydration

- Screening for malnutrition is recommended for every person with dementia with implementation of nursing care plan as per MUST score
- Close monitoring and documentation of body weight for every person with dementia i.e. weekly weight
- The provision of adequate food according to individual needs with respect to personal preferences is advised. This will be notified to catering staff via the whiteboard in the kitchen.
- Patients will be provided with appropriate assistance as required and prompts given to eat and drink if necessary.
- Food and drink is within the patient's reach.
- Patient is wearing dentures (if appropriate)

Communication

Each patient:

- Is responded to whenever they ask for attention or indicate a need.
- Who does not indicate a need within the past hour is approached to check how they are feeling. Any concerns will be relayed to senior staff.
- Is addressed by their preferred name
- Is physically comfortable
- Is wearing clean spectacles (if appropriate)
- Is wearing hearing aid, which is switched on and in working order (if appropriate);
- Is helped to orientate where appropriate and does not lead to distress
- Is offered emotional support and reassurance as required
- Is helped to the toilet
- Is pain and distress-free. Where appropriate the Abbey Pain Scale is used to assess for pain.

The team will ensure that all patients with a using the DCB and their family / carers' are provided with information and contact details for the Dementia Nurse Specialist

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Appendix 3: Prompt for Personal Profile Document in Nursing Care Plan³⁶

[illegible]

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Appendix 4: Invitation to Physiotherapy³⁷

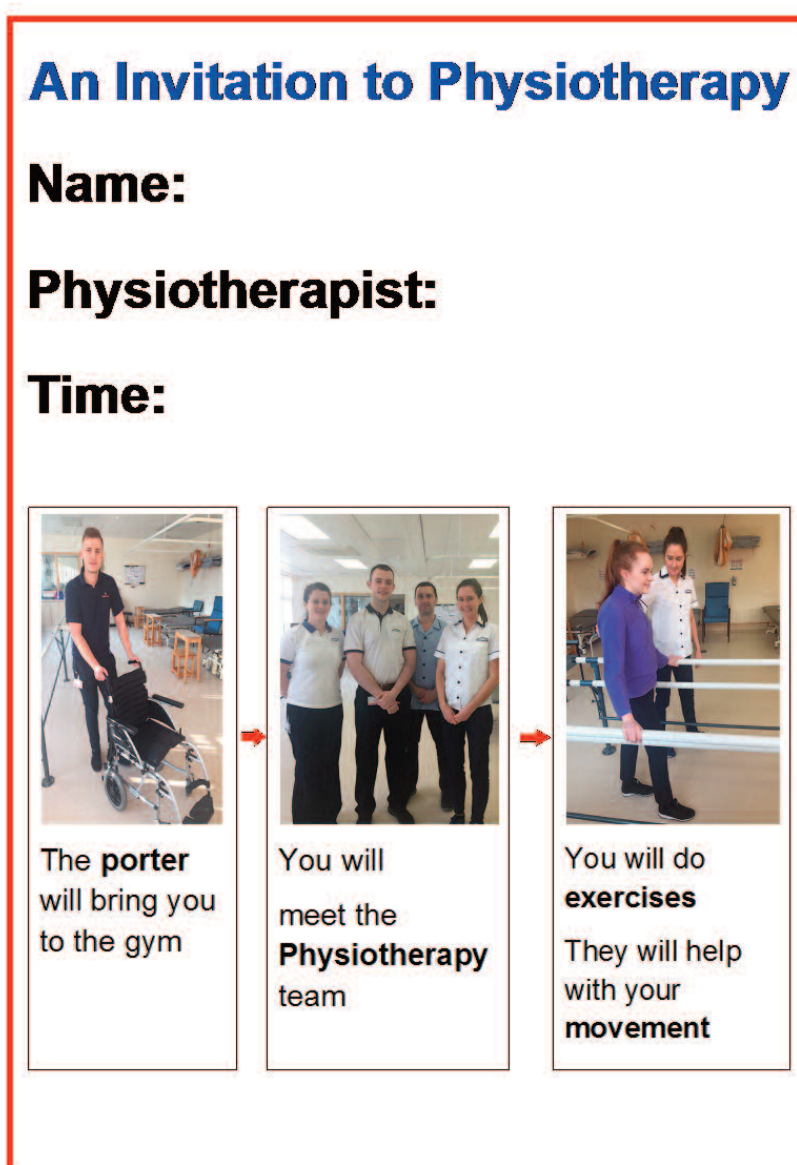


Figure 2A. Invitation to Physiotherapy



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Appendix 5: Chapter 6 Data Sources and Methodology

Details of every patient discharged from a public hospital in Ireland are recorded anonymously by the Hospital Inpatient Enquiry (HIPE) system. The source document for coding in Ireland for HIPE is the medical record or chart. The key medical information in a HIPE record includes the Diagnostic Related Group (DRG) that the patient has been assigned to. The HIPE system allows coding of one principal diagnosis and up to twenty nine additional diagnoses. The principal diagnosis is established by the coder to be chiefly responsible for occasioning the episode of admitted patient care. All additional diagnoses are then coded. An additional diagnosis is defined as a condition or complaint either coexisting with the principal diagnosis or arising during the episode of admitted patient care. The HIPE system allows coding of one principal procedure and up to nineteen additional procedures for each episode of care. The principal procedure is identified by the coder, and additional procedures are coded thereafter.

The other variables that are available from the HIPE records include: inter alia length of stay, source of admission, destination after discharge, gender, age and details about medical card holding and private insurance.

The Healthcare Pricing Office (HPO) publish a document called 'Ready Reckoner' which outlines the Casemix cost per case for each of the 698 inpatient DRGs in the classification system that they use. The document also indicates the range of days for what the HPO regard as a normal length of stay. The range can be quite wide. For example, in the DRG for dementia, B63Z, it varies from 23 to 57 days. Thus a patient with that DRG who is discharged after 25 days is assigned the same cost as a patient with the same DRG discharged after 50 days. Each patient in the same DRG whose length of stay falls within this range is assigned the same cost regardless of the actual number of days that s/he was an inpatient. If a patient has been an inpatient for a period longer than this normal range, we added a per diem cost based on data in the Ready Reckoner document. If a patient was an inpatient for a number of days less than the minimum of the normal range, we calculated cost based on a formula that takes into account the actual number of days in hospital. The following table contains a number of examples to illustrate this method for calculating costs. The cost data is from 2011, the most recent year for which that data is available.

DRG (dementia)	Length Of Stay	Casemix Cost per Case (€)	Minimum Number of Days for Normal Case	Maximum Number of Days for Normal Case	Cost for each Case
B63Z	1	12520	23	57	577
B63Z	9	12520	23	57	4920
B63Z	20	12520	23	57	10891
B63Z	36	12520	23	57	12520
B63Z	43	12520	23	57	12520
B63Z	137	12520	23	57	32200



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The variables of most interest such as length of stay and costs were not normally distributed and therefore the two-sample Wilcoxon rank-sum test was used with a 5% significance level to compare changes in various variables between 2014 and 2016. Chapter 6 reports z-statistics and p-values for the variables in question. A z statistic is the distance of a particular value from the mean, measured in units of the standard deviation, while a p-value is the probability of observing a sample value as extreme as, or more extreme than, the value observed, given that the null hypothesis is true.

There was an important change in the classification system between 2014 and 2017 which needs to be borne in mind when considering some of the results. Prior to 2017, all cases with a primary diagnosis of dementia were assigned the same DRG – B63Z. The ‘Z’ indicates that there is no distinction within that DRG between cases with severe complications and cases without. In 2017, a revised classification system was adopted. One of the changes was that the B63 DRG was split into two – B63A for cases with severe complications and B63B for cases without such complications. Of the 22 cases in 2017 with a primary diagnosis of dementia, 19 of them were classified as B63A while 3 were classified as B63B. The cost for a case within the normal range of B63A in 2017 was over €20,000, an increase of almost 60% on the cost of a case within the normal range of a B63Z case in 2014.









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