Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Evaluation of the Cork Integrated Dementia Care Across Settings (Cork-IDEAS) Project

HSE & GENIO DEMENTIA PROGRAMME

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

dementia
understand together

GENIO

EVALUATION OF THE CORK INTEGRATED DEMENTIA CARE ACROSS SETTINGS PROJECT

Submitted by:

Prof Anne-Marie Brady
Dr Louise Daly
Dr Brian Keogh
Mr Brendan Kennelly
Dr Aurelia Ciblis
Dr Amanda Drury
Dr Geralyn Hynes
Dr Mairéad Bracken-Scally
Ms Chiara Pittalis
Prof Mary McCarron

The School of Nursing and Midwifery
Trinity College Dublin
&
The Department of Economics
NUI, Galway

Date submitted: April 2018

Contact: Prof Anne-Marie Brady
Tel: 01-8963004/087-9088229
Email: abrady4@tcd.ie

Acknowledgements

The evaluation team would like to extend sincere thanks to the following organisations and individuals: those service users (people with dementia and their family carers) who gave their time to participate in the evaluation; Genio; the Health Service Executive; the Cork-IDEAS Project Lead, Dr Suzanne Timmons; the Dementia Nurse Specialist, Ms Mary Mannix; the Community Dementia Care Co-ordinator, Ms Siobhan Cahill; Ms Anne O’Hea, Occupational Therapist; the project consortium; and all of the service providers who participated in the evaluation.

Funding

This work was funded through grant #22074 by the Genio Trust with the support of The Atlantic Philanthropies and the Health Service Executive.

EVALUATION OF THE CORK INTEGRATED DEMENTIA CARE ACROSS SETTINGS PROJECT

Project Overview

Project Name: Cork Integrated Dementia care Across Settings (Cork-IDEAS): Mercy University Hospital and Cork Community Partnership to improve dementia care

Project Site: Mercy University Hospital Cork and Cork City Community

Project Lead: Dr Suzanne Timmons, Consultant Geriatrician, Mercy University Hospital; clinical co-lead of the Assessment and Treatment Centre in St. Finbarr's Hospital

Dementia Nurse Specialist: Ms Mary Mannix

Community Dementia Care Co-ordinator: Ms Siobhan Cahill

Dementia-friendly Environment: Ms Anne O'Hea, Occupational Therapist responsible for the environmental changes for dementia care

Consortium Name: Cork-IDEAS Consortium (Appendix 1)

Project Award Scheme and Value: A HSE and GENIO Dementia Programme 2013 grant to the value of €498,500 from the Integrated Care Pathway's grant stream of the innovation funding was awarded. A further €251,700 was committed by Mercy University Hospital through benefit-in-kind and additional supports.

Project Start and End: March 2014 – October 2017

Period of Grant: 3.5 years

Project Website: **http://www.muh.ie/index.php/for-patients/dementia-awareness**

EVALUATION OF THE CORK INTEGRATED DEMENTIA CARE ACROSS SETTINGS PROJECT

Table of Contents

Project Overview **3**
Glossary of Terms & List of Abbreviations **4**

Executive Summary **10**
Introduction 10
Evaluation Aims & Approach 10
Key Findings 11
Cork-IDEAS Project Impact and Outcome Findings 11
Cork-IDEAS Project Process Findings 12
Cork-IDEAS Hospital In-patient Activity Analysis 13
Recommendations for Enhancing Integrated Dementia Care 14

RE-AIM Framework **15**
1. Introduction **18**
1.1 Dementia Care in Acute Hospitals 18
1.2 HSE & Genio Dementia Programme 20

2. Cork-IDEAS Project – An Overview **21**
2.1 Introduction 21
2.2 Cork-IDEAS Setting 21
2.3 Aims of the Cork-IDEAS Project 22
2.4 Cork-IDEAS Organisation and Consortium 22
2.5 Cork-IDEAS Project Components 23
2.5.1 Integrated Care Pathway for People with Dementia 23
2.5.2 Dementia Nurse Specialist (DNS) 27
2.5.3 Community Dementia Care Co-ordinator (CDCC) 28
2.5.4 Environmental Changes and Occupational Therapist 29
2.5.5 Education and Awareness 32
2.5.6 Volunteers 32
2.5.7 Overview of Project Activities and Milestones 33
2.6 Summary 33

3. Methodology of Evaluation (Overview) **34**
3.1 Introduction 34
3.2 Aims 34
3.3 Objectives 34
3.4 Methodology Overview 35
3.5 Summary 38

4. Cork-IDEAS Project Impact and Outcome Findings **39**
4.1 Introduction 39
4.2 The Integration of Dementia Care 39
4.2.1 Integration of Dementia Care – ICP for Dementia 39
4.2.2 Integration of Dementia Care – DNS and CDCC roles 41
4.2.3 Integration of Dementia Care – Volunteers 48
4.2.4 Overall Integration of Dementia Care 49

4.3 The Physical Environment 57
4.4 Dementia Education and Awareness 60
    4.4.1 Awareness and Knowledge of Dementia 60
    4.4.2 Cork-IDEAS Education and Training Initiatives 65
4.5 Summary of Cork-IDEAS Project Impact and Outcome Findings 68

5. Cork-IDEAS Project Process Findings 69
5.1 Introduction 69
5.2 Function and Impact of the Cork-IDEAS Project Consortium 69
5.3 Factors Impacting on the Implementation of the Cork-IDEAS Project 70
    5.3.1 Factors Facilitating the Implementation of the Project 71
    5.3.2 Factors Challenging the Implementation of the Project 74
5.4 Summary of Cork-IDEAS Project Process Findings 77

6. Cork-IDEAS Hospital Inpatient Activity Analysis 78
6.1 Introduction 78
6.2 Discharges 79
6.3 Readmissions 80
6.4 Admission Source 80
6.5 Medical Card 81
6.6 Patient Death 81
6.7 Discharge Destination 81
6.8 Admission Source and Discharge Destination 82
6.9 Primary Diagnosis 83
6.10 Length of Stay 83
    6.10.1 Length of Stay: Primary and Secondary Diagnosis 83
    6.10.2 Length of Stay: Single and Multiple Discharges 84
    6.10.3 Length of Stay: Admission Source and Discharge Destination 84
    6.10.4 Length of Stay for People With, and Without, Dementia 87
6.11 Patient Cost 88
    6.11.1 Patient Cost: Primary and Non-Primary Diagnosis 89
    6.11.2 Patient Cost: Single and Multiple Discharges 90
    6.11.3 Patient cost: Admission source and discharge destination 90
6.12 Summary of Cork-IDEAS Hospital In-patient Activity Analysis Findings 92

7. Discussion 93
7.1 Introduction 93
7.2 Discussion 93
7.3 Sustainability of Project Gains 96
7.4 Considerations Relating to the Evaluation Findings 97
7.5 Conclusion and Recommendations for Enhancing Integrated Dementia Care 97

References 99
Appendix 1: Cork-IDEAS Consortium Members 103
Appendix 2: Cork-IDEAS Dementia Nursing Care Bundle 105
Appendix 3: Memory Intervention and Support Service (MISS) Referral Pathway 108
Appendix 4: Chapter 6 Data Sources and Methodology 109

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.

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.

Stakeholder

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

List of Abbreviations

CDCC:	Community Dementia Care Co-ordinator
CNM:	Clinical Nurse Manager
DCB:	Dementia Care Bundle
DNS:	Dementia Nurse Specialist
DRG:	Diagnosis Related Group
ED:	Emergency Department (A&E; Accident & Emergency)
FC:	Formal Carer
FG:	Focus Group
FU:	Follow-up
GP:	General Practitioner
HCA:	Health Care Assistant
HSE:	Health Service Executive
ICP:	Integrated Care Pathway
LTC:	Long Term Care
MISC:	Memory Intervention and Support Clinic
MISS:	Memory Intervention and Support Service
OT:	Occupational Therapist
PHN:	Public Health Nurse
PRN:	Pro Re Nata, as needed
SFH:	Saint Finbarr’s Community Hospital
SI:	Single Interview

Foreword

More than a quarter of in-patients 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 Cork-IDEAS project based in Mercy University Hospital, in partnership with local community services. The project, underpinned by a person-centred philosophy, aimed to develop an integrated care pathway (ICP) for people with dementia. Improving the experience of people with dementia and their families within the acute hospital was pivotal. Developing opportunities for appropriate supported hospital avoidance, supported discharge, and education and training for staff to facilitate person-centred care of people with dementia, were also focal points of the project.

The evaluation found that the Cork-IDEAS project functioned as a catalyst for change for dementia care integration and development within MUH and the community. The project, using a carefully planned process, successfully developed an ICP with two components: an Emergency Department (ED) ICP and an In-Patient ICP. The project consortium, its subgroups and designated project personnel, i.e. Dementia Nurse Specialist (DNS) and Community Dementia Care Co-ordinator (CDCC), facilitated the ICP development and implementation. The DNS, whose role was multi-faceted and evolving, made a substantial contribution to enhancing the care of people with dementia in the hospital. The CDCC, whose role also evolved to incorporate multiple components, succeeded in promoting person-centred care whilst establishing links and building relationships between the hospital, and statutory and voluntary bodies supporting people with dementia living in the community.

EVALUATION OF THE CORK INTEGRATED DEMENTIA CARE ACROSS SETTINGS PROJECT

To further enhance the experience of people with dementia in the hospital, environmental changes were made to the ED, a Care of the Older Person ward, and link corridors 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 Cork-IDEAS 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. The introduction of volunteer activities to support person-centred care and enhance well-being of people with dementia within the hospital was greatly valued and impacted positively.

I would like to thank the participants for sharing their experiences and insights with the research team. Their contribution it is hoped will feed directly into the future planning, development and integration of acute hospital and community services. I wish to acknowledge the excellent work of the research team from Trinity College Dublin and the National University of Ireland Galway, led by Dr Anne Marie Brady. We are grateful for the support of The Atlantic Philanthropies in funding this research. We continue to work closely with the HSE and National Dementia Office and hope that these findings will help inform National Clinical Programmes, support the implementation of the current National Dementia Strategy and inform any future iterations of it, and 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.

Dr. Maria Pierce,
Research Manager, Genio
April 2018

Executive Summary

Introduction

The Cork Integrated Dementia Care Across Settings project (Cork-IDEAS) project led by Dr Suzanne Timmons aimed to develop and deliver enhanced integrated care for people living with dementia. It ran for three and a half years from 2014 to 2017, and was situated within the Mercy University Hospital (MUH) Cork and linked community setting. The aims of the project were to:

i. Develop an integrated care pathway for people with dementia with a clear governance framework between acute hospital and community services, reflective of opportunities for appropriate supported acute hospital avoidance, supported discharge policies, education and training needs for staff, and a formal system for gathering information pertinent to caring for people with dementia,
ii. Provide alternatives to unnecessary hospital admission for the person with dementia,
iii. Improve the experience of the people with dementia and families/informal carers during hospital admission,
iv. Provide a clear template for other areas to replicate/adapt the process.

To achieve its aims, Cork-IDEAS incorporated a number of components, including:

- An Integrated Care Pathway (ICP) for Dementia Care,
- A range of dementia education and awareness raising activities,
- Environmental changes within MUH,
- A number of project-specific roles including: a Dementia Nurse Specialist (DNS) within MUH, a Community Dementia Care Co-ordinator (CDCC) and an Occupational Therapist (OT) to oversee environmental changes,
- A volunteer service overseen by a volunteer service co-ordinator.

Trinity College Dublin and the National University of Ireland, Galway were commissioned to evaluate this three year project (2014-2017).

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 alignment with implementation of the 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 Cork-IDEAS 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 Cork-IDEAS 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, Vogt and Boles, 1999; Gaglio, Shoup and Glasgow, 2013), which assessed project activity in terms of reach, effectiveness, adoption, implementation and maintenance. Recruiting people with dementia and their family carers to participate in study interviews can be challenging, and especially so when the recruitment is taking place within a hospital environment and around a time of acute illness. The evaluation set out to represent the perspective of all those intended to benefit from the Cork-IDEAS project (people with dementia, family carers and formal carers). However, the findings primarily represent the perspective of stakeholders within the hospital and community project setting as despite extensive efforts to recruit people with dementia, it was not possible to do so for the purposes of the evaluation.

Key Findings

Cork-IDEAS Project Impact and Outcome Findings

- Clear project governance with responsibility for project components designated to identifiable personnel were key factors in the project outcomes achieved.
- An ICP for Dementia Care was developed, piloted and implemented in the Emergency Department and three hospital wards in MUH.
- The activities which fed into the development of the ICP for Dementia Care ensured that it was attuned to both the person with dementia's journey and the organisational structures within MUH.
- The ICP piloting and its subsequent introduction in practice were centrally supported by the DNS and the enhanced level of dementia awareness achieved by other project activities.
- While evidence from multiple sources supported the use of the ICP, Dementia Care Bundle (DCB) and 'This is Me' document where introduced, the degree of implementation was variable.
- The role of the DNS evolved to be multifunctional encompassing: Cork-IDEAS project activities, provision of person-centred care, support of the ICP and DCB development and implementation, and education and consultancy.
- The cessation of the DNS role was perceived as having a significant negative impact on the potential for integration of dementia care within MUH and the sustenance of project gains into the future.
- The CDCC role was multifunctional encompassing: Cork-IDEAS project activities, a point of contact for dementia care support, advice or referral, provision of dementia care, a role in hospital avoidance and supporting hospital discharge, dementia care consultancy and representing the voice of dementia care on community committees.

- The community component of the Cork-IDEAS project, through the CDCC and consortium, was successful in building a network of relationships and service contacts relevant to dementia care; and a hub for peri- and post-diagnostic support, integrating and enhancing existing services in the community.
- Awareness of dementia and positive attitudes towards people with dementia among service providers, while high at baseline, improved post project implementation as measured by the Approaches to Dementia Questionnaire (Lintern and Woods, 1996). On average, there was a good level of dementia knowledge among respondents at both baseline and follow-up as measured by the Alzheimer's Disease Knowledge Scale (Carpenter *et al*., 2009).
- Dementia education and training was a key feature of the Cork-IDEAS project and a range of programmes were delivered that mostly drew from existing educational resources.
- The education programmes were positively evaluated and there was evidence of increased awareness of dementia particularly throughout the acute hospital.
- The project evaluation interviews and MUH 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.
- Environmental changes were highly visible and facilitated by expert input from a dementia experienced Occupational Therapist (OT). These changes appeared to enhance stakeholder buy-in and were widely recognised as resulting in greater understanding of the importance of how personalised and environmentally appropriate hospital settings can be used to enhance person-centred care.
- Evidence suggested that cross-fertilisation occurred between project components and that this resulted in a positive impact on the potential to enhance integrated dementia care within MUH.

Cork-IDEAS Project Process Findings

- Eight project facilitators were identified which supported the Cork-IDEAS project process and the achievement of its outcomes. These were:

    1. The ethos and culture of care within the project setting,
    2. Project lead(ership),
    3. Dedicated project personnel,
    4. Organisational support,
    5. Inter-disciplinary stakeholder and cross setting involvement,
    6. High visibility of early project impacts,
    7. The responsiveness of the project,
    8. Dovetailing with other clinical, educational or organisational developments.

- Project personnel demonstrated significant experiential learning, which was both incorporated into the project as it unfolded and articulated as learning for future projects.
- The project facilitators were active over the course of the project and were found to counterbalance the challenges. They were therefore likely to have strongly impacted on the project gains achieved.
- Three overarching challenges (with sub-components) were found to have impacted on the project over its time line. These were:
    - Project-related human resource considerations, including:
        - Project lead time involvement,
        - Developing and enacting project-specific posts,
        - Role-related temporal and resourcing factors,

  - The inherent complexity of the project (as with other projects of this nature) and competing initiatives, including:
    - Multiple components,
    - Multi-contextual settings,
    - Building inter-disciplinary and inter-departmental buy-in,
  - The acuity of care demands in the project setting.
- The project consortium was pivotal in building shared ownership and momentum for the integration of dementia care within the project setting.
- The hospital sub-consortium, and working groups, adopted a whole organisation orientation with multi-level stakeholder representation as and when relevant.
- The community sub-consortium provided a medium to build project awareness, bring interested stakeholders together and build strategic linkages between services that could support those living with dementia in the community.
- The hospital sub-consortium contributed to project awareness, its governance and component activities by facilitating the sharing of information and gathering of feedback, in addition to enhancing inter-disciplinary and inter-departmental understanding more broadly.

Cork-IDEAS Hospital In-patient Activity Analysis

- An analysis of the Hospital In-Patient Enquiry (HIPE) data showed that the total number of cases discharged from MUH with a diagnosis of dementia increased from 282 to 329 between 2014 and 2016.
- The proportion of cases admitted from Long Term Care (LTC) fell between 2014 and 2016 but there was little change in the proportion of cases discharged to LTC. The proportion of people who were admitted from home and discharged to LTC increased significantly.
- Overall, and in various sub-categories, there was little difference in the mean or median length of stay between 2014 and 2016. The length of stay of cases with a primary diagnosis of dementia fell considerably between 2014 and 2016 but the relatively small number of cases in 2014 meant that this decline was not statistically significant.
- The mean costs of all the cases with a diagnosis of dementia fell between 2014 and 2016 but the decline was not statistically significant.
- The costs of cases discharged to LTC increased between 2014 and 2016.
- The mean length of stay, and mean costs, were much higher for cases admitted from home and discharged to LTC than for cases discharged to home or admitted from LTC. Thus, the category of admittance/discharge which increased significantly between 2014 and 2016 is the one that has higher mean cost.

Recommendations for Enhancing Integrated Dementia Care

- 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 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 people with dementia's journeys, 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 and associated care bundles, 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.
- 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 assess 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.

RE-AIM Framework Applied to the Cork-IDEAS Evaluation

REACH

- The activities of the Cork-IDEAS project demonstrated success in terms of reach within Mercy University Hospital and the linked community area.
- The project successfully incorporated inter-disciplinary participation from key organisational, operational and clinical stakeholders within MUH and the community.
- An ICP, Dementia Care Bundle and 'This is me' document were developed and at the time of project end were implemented in ED and three of the MUH wards.
- The project personnel roles impacted directly on services users living with dementia, and in many cases their family carers, within the hospital and the community.
- Project personnel and their dementia care roles and expertise were widely known about by formal carers and these personnel were identified widely as the point of contact for dementia care and a source of support for complex dementia care when required.
- The education initiatives yielded considerable reach across the hospital and community sites with in excess of 1000 service providers receiving some level of dementia education.
- There was evidence of reach beyond the project context with examples of external sites consulting project personnel on aspects of dementia care innovation.

EFFECTIVENESS

- Advances in the integration of dementia care were achieved and there was evidence of enhanced understanding of the individualised needs of the person with dementia.
- The project lead, project consortium and project personnel were pivotal in the governance of project components and the implementation of activities to enhance integrated dementia care.
- The total number of cases discharged with a diagnosis of dementia increased from 282 to 329 between 2014 and 2016.
- Overall, and in various sub-categories, there was little difference in length of stay or costs between 2014 and 2016.
- The education initiatives were positively evaluated and there was evidence that they improved awareness of and responses to people with dementia.
- At project end, the care of the older person ward in MUH had been extensively re-developed using dementia-friendly design and a number of hospital wards had rooms with dementia-friendly colour schemes in place. While the link corridors' environmental changes had not been completed by project end, plans to do so were continuing.

ADOPTION

- Dementia-related in-reach and out-reach communication channels were enhanced between MUH and the community.
- There was evidence that the ICP, Dementia Care Bundle etc. were in use in those settings within MUH that they had been introduced to, although the degree of uptake was variable.
- The visibility of dementia and the uptake of innovations in integrated dementia care were heavily influenced by the presence of the project-specific personnel.
- Volunteer services in MUH were available to people with dementia and those not diagnosed with dementia on a needs based basis.

IMPLEMENTATION

- Effective leadership and the vision for integrated dementia care demonstrated by the project lead were central to the Cork-IDEAS project success.
- The project components and related activities demonstrated fidelity to the overall aim of the Cork-IDEAS project.
- In its implementation, the project demonstrated flexibility and responsiveness to the circumstances encountered as the project unfolded. This resulted in some redefinition/clarification of specific objectives and ongoing review and prioritisation of project activities over time.
- Project personnel were key drivers in the degree of project activity penetration achieved.
- Organisational support was a key factor in leveraging support for, and advancing activities relating to, the integration of dementia care.

RE-AIM Framework Applied to the Cork-IDEAS Evaluation

MAINTENANCE

- The issue of integrated dementia care sustainability, and indeed its growth, were considered in terms of the national landscape of health and dementia care policy and service planning.
- There was recognition of the challenges to the future sustainability of project gains although this was balanced with optimism for what had been achieved in the context of Cork-IDEAS.
- In consequence, the importance of developing action plans to support the maintenance of project gains was recognised.
- A decision to continue the project consortium with a potential name change and a re-visioning of dementia care focus, was confirmed.
- There were plans to continue the roll-out of the ICP and Dementia Care Bundle to the remaining wards in MUH.
- Business cases to support dementia specific roles within MUH and the community were submitted and progressed to agreement.
- Dementia specific awareness education was embedded within the MUH staff induction programme and a suite of dementia education programmes is now available to be delivered in response to demand.
- A commitment had been given to incorporate the principles of dementia-friendly design where possible in future hospital environmental works.
- There was a stated organisational commitment to support the integration of dementia care principles where possible in future development.

EVALUATION OF THE CORK INTEGRATED DEMENTIA CARE ACROSS SETTINGS PROJECT

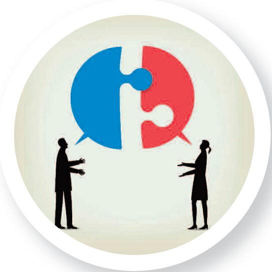
Advances in the **integration of dementia care** were achieved and there was evidence of **enhanced understanding** of the **individualised needs** of the person with dementia.

An **Integrated Care Plan for Dementia Care** was developed, piloted and implemented in the Emergency Department and on three hospital wards.

The **Dementia Nurse Specialist** and **Community Dementia Care Co-ordinator** roles **impacted** directly on **people living with dementia** and their **family carers**, within the hospital and the community.

Environmental changes overseen by the project Occupational Therapist resulted in greater understanding of how **dementia-friendly hospital settings** can support **person-centred care**.

The **staff education programmes** were positively evaluated and there was evidence of **increased awareness of dementia**.



Cross-fertilisation occurred between **project components**, resulting in a **positive impact** on **integrated dementia care**.

Organisational support and **inter-disciplinary participation** were key factors in advancing activities relating to the **integration of dementia care** within the hospital and the community.

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 those living 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 similar aged people without dementia, 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 number of gaps in dementia service provision, specifically: 94% of the hospitals surveyed did not have a dementia care pathway for people with dementia in place or planned, 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 multi-disciplinary 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*l., 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 and 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 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 & Genio, 2016).

In the hospital sector, funding was awarded in 2013 to projects in Mercy University Hospital (MUH) in Cork, St. James's Hospital, Dublin, and Connolly Hospital, Dublin, 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 & 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 Cork Integrated Care for DEmentia across Settings (Cork-IDEAS) project in MUH. Under this initiative, MUH and key stakeholders in the community have joined forces to establish more integrated and responsive services for people with dementia.

EVALUATION OF THE CORK INTEGRATED DEMENTIA CARE ACROSS SETTINGS PROJECT

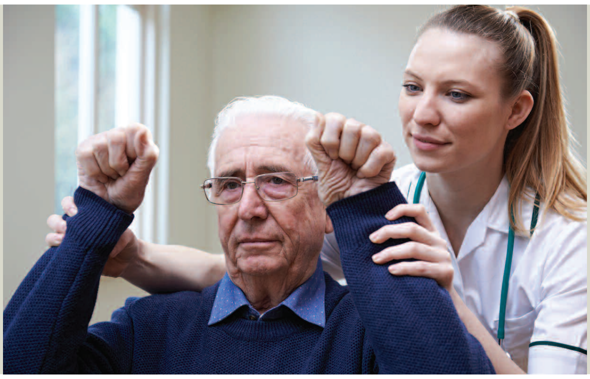
2.1 Introduction

The Cork-IDEAS project led by Dr Suzanne Timmons 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 and a half years, from March 2014 to October 2017. A further no cost extension was approved to December 2018 to cover the temporary recruitment of a Dementia Nurse Specialist (DNS) position as a bridge to a permanent appointment by MUH. This chapter provides an overview of the Cork-IDEAS project as it unfolded over the timeframe of the project.

2.2 Cork-IDEAS Setting

The Cork-IDEAS project was based in MUH in Cork. An estimated 5,425 people lived with dementia in Cork in 2011 (Pierce *et al*, 2014) and it is suggested that this number is likely to more than double over the next 15 years (Prince *et al*., 2015). Dementia is known to be underdiagnosed but approximately 27% of older people admitted to MUH have dementia (Timmons *et al*., 2015).

MUH is a voluntary hospital in the heart of Cork City and has approximately 350 beds and 1,200 staff. The main catchment area for the hospital is the north side of Cork city, which has a population of approximately 190,000, with 21 primary care teams, five day centres, and four community hospitals. The hospital also receives patients from the south side of Cork city as well as admissions for a range of specialist services from across Munster. The hospital treats about 19,000 inpatients and 22,000 Emergency Department (ED) patients annually. MUH provides a range of specialisms in inpatient, outpatient and day patient services for both public and private service users and is a teaching hospital with links to University College Cork and the National University of Ireland. It has a 15-bed dedicated ward for the care of older persons. MUH has strong links with St. Finbarr's Community Hospital (SFH) and St Francis Unit which is MUH's transitional care unit at St Mary's campus, Gurranabraher. SFH has a rotation system for geriatricians and provides a community-led Assessment and Treatment Centre with a rapid access clinic, multidisciplinary team input, a psychiatry of older-age service and specialised clinics including a memory clinic. The Cork Alzheimer's Café is also based in SFH. There are also links to the Kinsale K Cord project, a project funded under the HSE & Genio Dementia Programme, which aims to develop services to support people with dementia to remain at home and active in their communities.



2.3 Aims of the Cork-IDEAS Project

The Cork-IDEAS project aimed to develop and deliver enhanced integrated care for people living with dementia. A key feature of the project was that its elements were aligned with, or integral to, ongoing service developments intended to improve the care experience of people with dementia and their families/informal carers. The aims of the project, which was underpinned by a person-centred philosophy, were as follows [1]:

I. Develop an integrated care pathway for people with dementia with a clear governance framework between acute hospital and community services, reflective of opportunities for appropriate supported acute hospital avoidance, supported discharge policies, education and training needs for staff, and a formal system for gathering information pertinent to caring for people with dementia,
II. Provide alternatives to unnecessary hospital admission for the person with dementia,
III. Improve the experience of the person with dementia and families/informal carers during hospital admission,
IV. Provide a clear template for other areas to replicate/adapt the process.

2.4 Cork-IDEAS Organisation and Consortium

The Cork-IDEAS project was led by Dr Suzanne Timmons, Consultant Geriatrician, MUH, and clinical co-lead of the Assessment and Treatment Centre in SFH. The project brought together a number of stakeholders into a project consortium. This consortium consisted at any given time of approximately 40 members representing key services, statutory and voluntary, across the hospital and the community (see Appendix 1). A family carer was represented on the consortium. Its role was to lead out on project activities. 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 overall consortium was composed of an acute hospital consortium and a community consortium. Subgroups were established on a needs and activity-led basis to oversee project-specific components and the fulfilment of the Cork-IDEAS objectives. Within the hospital consortium, subgroups included: an ICP subgroup (which contained an ED working group), a subgroup for environmental changes and a subgroup for education. The project also employed three project-specific staff who sat on the consortium: a Dementia Nurse Specialist (DNS), a Community Dementia Care Co-ordinator (CDCC) and an Occupational Therapist (OT). Their project roles are outlined below.

---

[1] As stated in the HSE & Genio Dementia Programme 2013 application and the Genio Trust Terms and Conditions.

2.5 Cork-IDEAS Project Components

To meet the project aims, and enhance the nature and experience of dementia care, a number of inter-connecting project components were established. These are depicted in Figure 1 and an overview of each is provided in the following sub-sections.

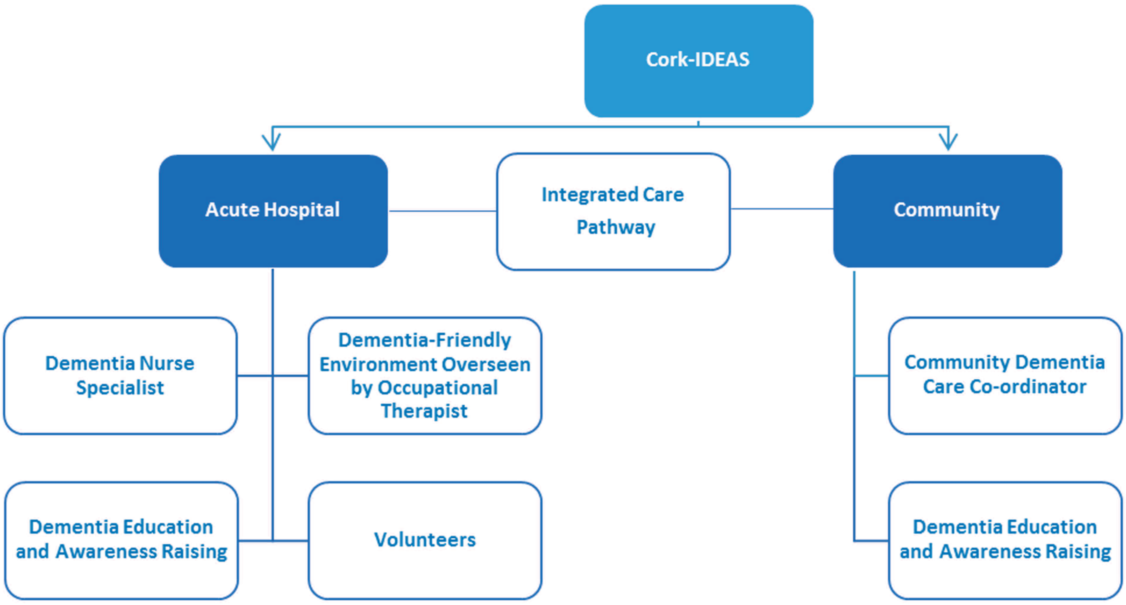


Figure 1. Overview of the Cork-IDEAS Project Components

2.5.1 Integrated Care Pathway for People with Dementia

The development of an ICP for people with dementia, with a governance structure between the acute hospital and community services, was a central component of the Cork-IDEAS project. The aim of the ICP was to improve the journey of a person with dementia transitioning from the community to and through the hospital, and during transition back to the community through the promotion of co-ordinated care, planned admissions where possible and the provision of personal information to facilitate person-centred care. It also aimed to assist and accelerate discharge into the community through enhanced discharge planning from hospital, and support for the person with dementia and families. The ICP produced contained two components: an ED and an in-patient component. While at the beginning of the project, it was envisaged that the overarching pathway would begin with a 'pathway in' component relating to a decision to admit a person with dementia from the community, due to the complexities involved, this was not formalised on the ICP document. However, the project intent to focus on and develop linkages into MUH and from there out to the community was developed via the activities of the DNS and CDCC described below (Sections 2.5.2 and 2.5.3). The education and awareness raising activities within the project (hospital and community components) also contributed to this (Section 2.5.5). Discharge to the community was incorporated within the in-patient component of the ICP and reference to the provision of discharge information to the GP was specified on the ED component of the ICP for those people with dementia discharged from the ED.

An overview of the ICP development process is presented in Figure 2. The process commenced with a review of all patients aged 70 years or older who presented to the hospital over one week which was repeated the following year. A case note review was performed, interviews on the ED experience conducted and a literature review relating to ICPs completed. The journeys of three people with dementia from the community to the hospital and back into the community were also used for process mapping which supported the ICP construction. To facilitate the ICP development, a subgroup consisting of 28 members was established in July 2015. It included an ED working group and was composed of key representatives from across the hospital.

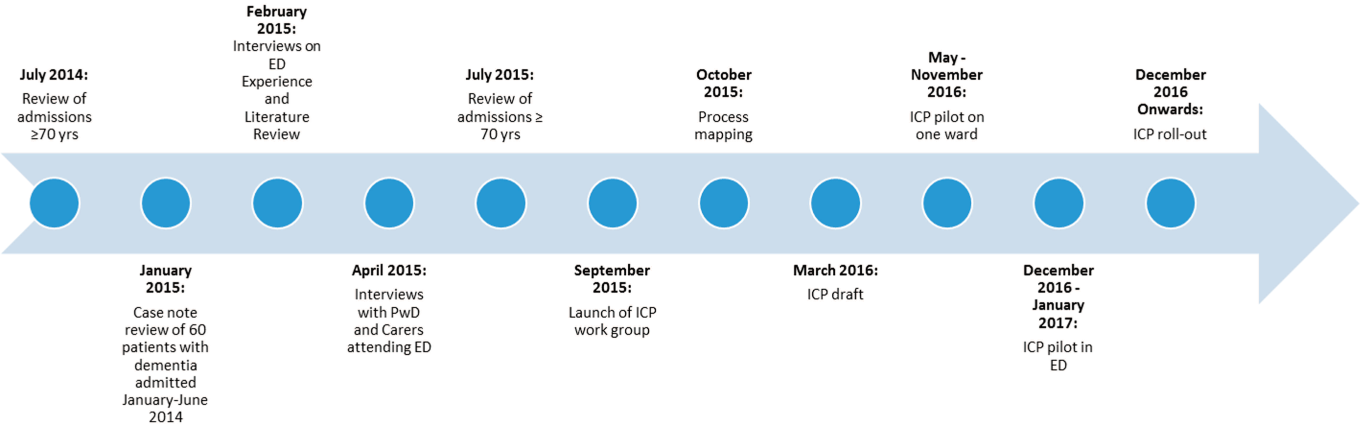
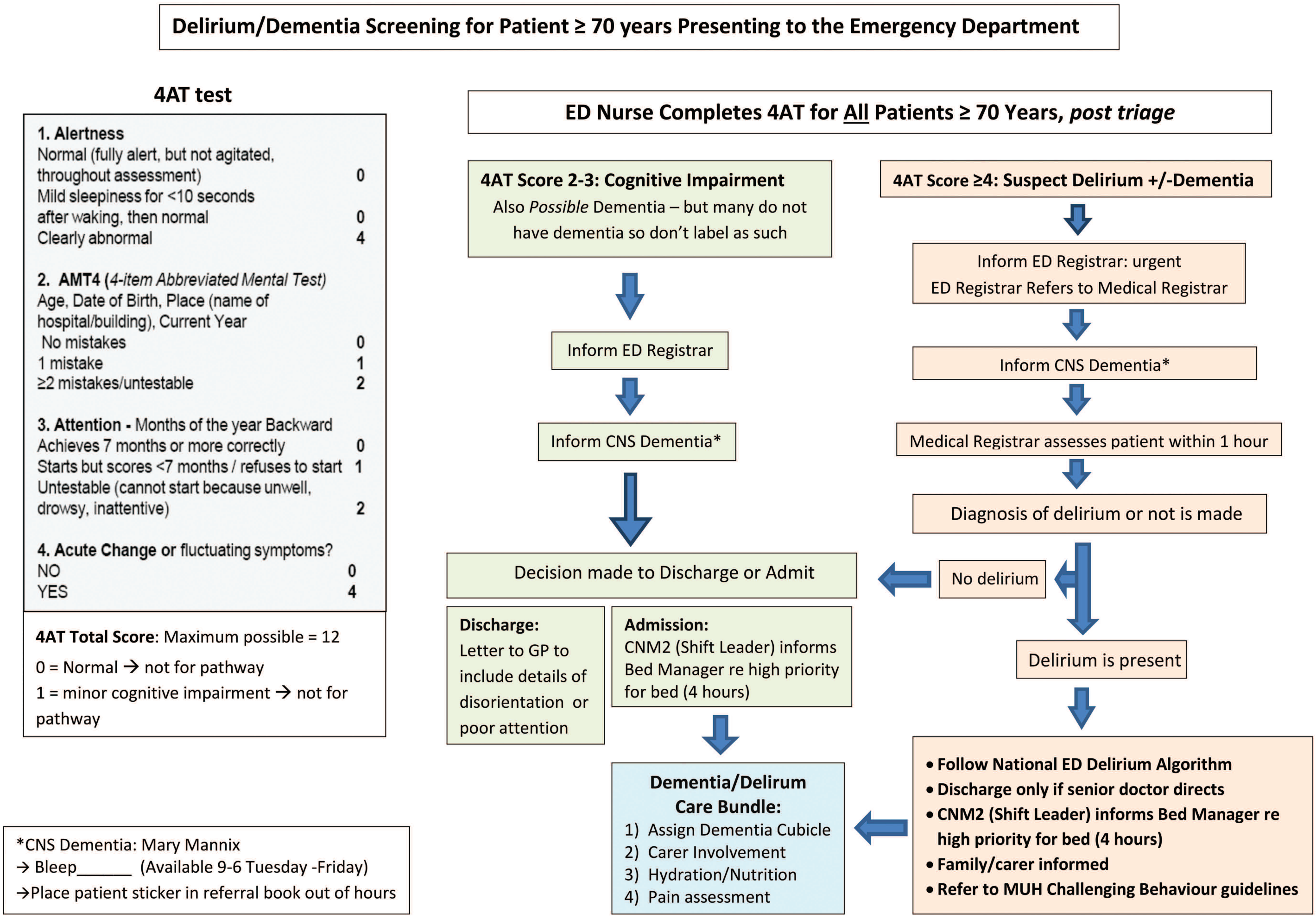


Figure 2. Overview of ICP Development

The two component ICPs, one for the ED and one for the in-patient wards, are illustrated in Figures 3 and 4.[2] Within the ICP, all those aged 70 years or over attending the ED are screened for cognitive vulnerability on admission. Use of the ICP enables the highlighting of person-centred needs for those with a diagnosis of dementia and their family carers and leads to the implementation of a dementia nursing care bundle. Those identified as having suspected dementia follow a pathway for dementia diagnosis investigation within the ICP with follow-up community support, while those with known dementia are referred back to specialist services if certain indicators exist (in all cases the GP and PHN are to receive updated information on dementia status such as revised prognosis, advance care planning, new care needs).

---

[2] Reproduced with the permission of Dr Suzanne Timmons, Cork-IDEAS Project Lead.



Delirium/Dementia Screening for Patient ≥ 70 years Presenting to the Emergency Department

4AT test

1. Alertness	
Normal (fully alert, but not agitated, throughout assessment)	**0**
Mild sleepiness for <10 seconds after waking, then normal	**0**
Clearly abnormal	**4**
2. AMT4 (*4-item Abbreviated Mental Test*) Age, Date of Birth, Place (name of hospital/building), Current Year	
No mistakes	**0**
1 mistake	**1**
≥2 mistakes/untestable	**2**
3. Attention - Months of the year Backward	
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 symptoms?	
NO	**0**
YES	**4**

4AT Total Score: Maximum possible = 12

0 = Normal → not for pathway

1 = minor cognitive impairment → not for pathway

ED Nurse Completes 4AT for <u>All</u> Patients ≥ 70 Years, *post triage*

4AT Score 2-3: Cognitive Impairment
Also *Possible* Dementia – but many do not have dementia so don't label as such

Inform ED Registrar

Inform CNS Dementia*

Decision made to Discharge or Admit

Discharge:
Letter to GP to include details of disorientation or poor attention

Admission:
CNM2 (Shift Leader) informs Bed Manager re high priority for bed (4 hours)

Dementia/Delirum Care Bundle:
1) Assign Dementia Cubicle
2) Carer Involvement
3) Hydration/Nutrition
4) Pain assessment

4AT Score ≥4: Suspect Delirium +/-Dementia

Inform ED Registrar: urgent
ED Registrar Refers to Medical Registrar

Inform CNS Dementia*

Medical Registrar assesses patient within 1 hour

Diagnosis of delirium or not is made

No delirium

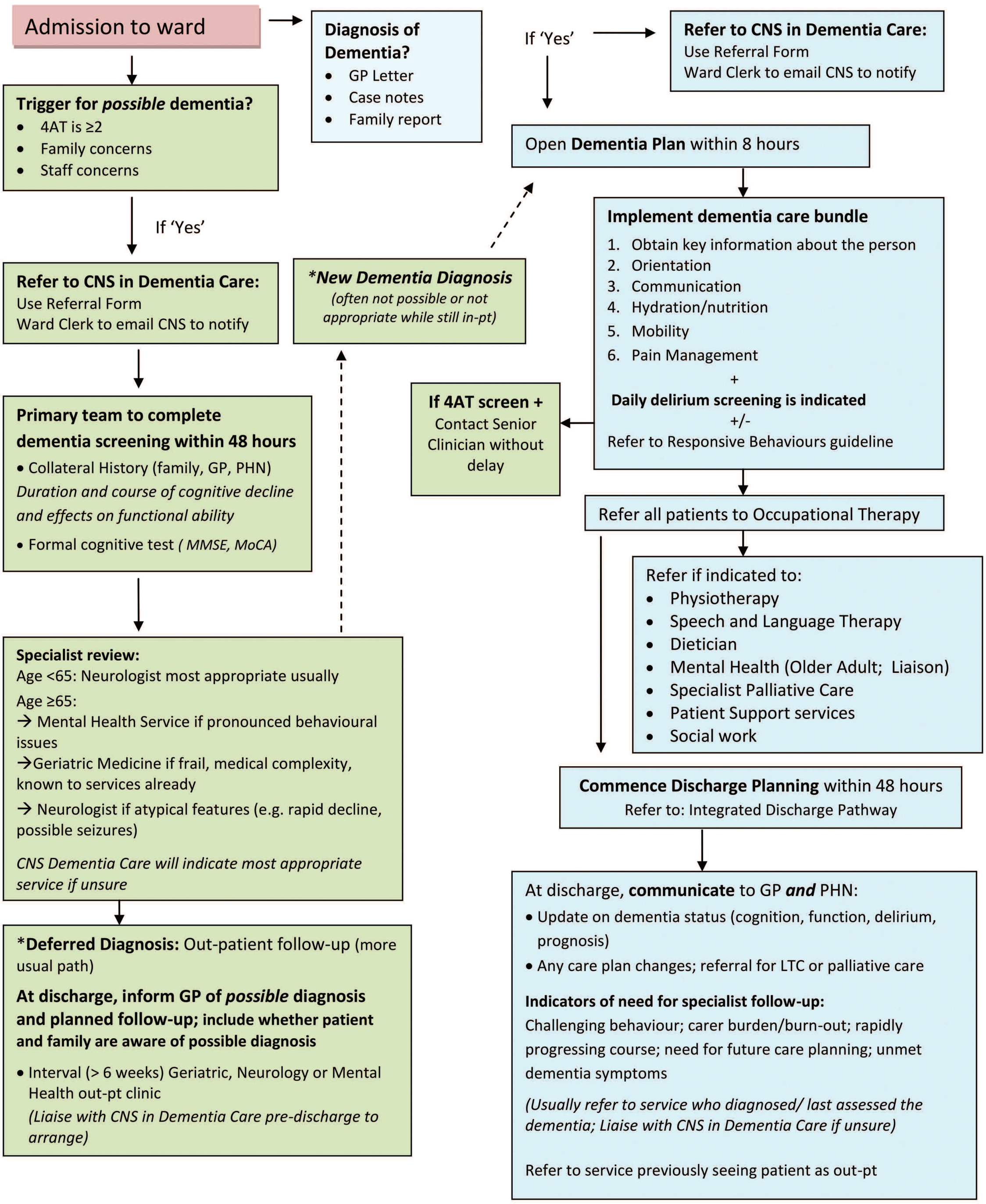
Delirium is present

- **Follow National ED Delirium Algorithm**
- **Discharge only if senior doctor directs**
- **CNM2 (Shift Leader) informs Bed Manager re high priority for bed (4 hours)**
- **Family/carer informed**
- **Refer to MUH Challenging Behaviour guidelines**

*CNS Dementia: Mary Mannix
→ Bleep______ (Available 9-6 Tuesday -Friday)
→Place patient sticker in referral book out of hours

Figure 3. Emergency Department ICP

Integrated Care Pathway for Dementia



Admission to ward

Diagnosis of Dementia?
- GP Letter
- Case notes
- Family report

If 'Yes'

Refer to CNS in Dementia Care:
Use Referral Form
Ward Clerk to email CNS to notify

Trigger for *possible* dementia?
- 4AT is ≥2
- Family concerns
- Staff concerns

If 'Yes'

Refer to CNS in Dementia Care:
Use Referral Form
Ward Clerk to email CNS to notify

Primary team to complete dementia screening within 48 hours
- Collateral History (family, GP, PHN)

Duration and course of cognitive decline and effects on functional ability

- Formal cognitive test *(MMSE, MoCA)*

Specialist review:
Age <65: Neurologist most appropriate usually
Age ≥65:
→ Mental Health Service if pronounced behavioural issues
→Geriatric Medicine if frail, medical complexity, known to services already
→ Neurologist if atypical features (e.g. rapid decline, possible seizures)

CNS Dementia Care will indicate most appropriate service if unsure

***New Dementia Diagnosis**
(often not possible or not appropriate while still in-pt)

*__Deferred Diagnosis:__ Out-patient follow-up (more usual path)

At discharge, inform GP of *possible* diagnosis and planned follow-up; include whether patient and family are aware of possible diagnosis
- Interval (> 6 weeks) Geriatric, Neurology or Mental Health out-pt clinic
  (Liaise with CNS in Dementia Care pre-discharge to arrange)

Open **Dementia Plan** within 8 hours

Implement dementia care bundle
1. Obtain key information about the person
2. Orientation
3. Communication
4. Hydration/nutrition
5. Mobility
6. Pain Management

+

Daily delirium screening is indicated

+/-

Refer to Responsive Behaviours guideline

If 4AT screen +
Contact Senior Clinician without delay

Refer all patients to Occupational Therapy

Refer if indicated to:
- Physiotherapy
- Speech and Language Therapy
- Dietician
- Mental Health (Older Adult; Liaison)
- Specialist Palliative Care
- Patient Support services
- Social work

Commence Discharge Planning within 48 hours
Refer to: Integrated Discharge Pathway

At discharge, **communicate** to GP ***and*** PHN:
- Update on dementia status (cognition, function, delirium, prognosis)
- Any care plan changes; referral for LTC or palliative care

Indicators of need for specialist follow-up:
Challenging behaviour; carer burden/burn-out; rapidly progressing course; need for future care planning; unmet dementia symptoms

(Usually refer to service who diagnosed/ last assessed the dementia; Liaise with CNS in Dementia Care if unsure)

Refer to service previously seeing patient as out-pt

Figure 4. In-patient ICP

Each of the ICPs was piloted, audited and then reviewed by the ICP subgroup. The pilot of the ICP in the ED took place from December 2016 to January 2017. No amendments were considered necessary following its piloting. The in-patient ward ICP pilot and follow-up audit occurred from May to November 2016 on one ward and some adjustments made following review of its pilot use. The ICP roll-out was then initiated in two further wards within the hospital where it was considered that people with dementia were most likely to be admitted.

The DNS trained staff in the areas where ICPs were introduced and ICP resource folders were provided to all clinical areas. To support the implementation of the ICP and personalised dementia care, the following were introduced over the course of the project:

- A six-item Dementia Nursing Care Bundle (DCB) was developed (Appendix 2). This involved a review of the Nursing Practice Guidelines linked to the DCB and their incorporation into the DCB to facilitate the effective utilisation and integration of existing resources.
- The 'This is Me' document, a person-centred background and social history document, was introduced to enhance the availability of person with dementia specific information to enable the personalisation of care.[3]

2.5.2 Dementia Nurse Specialist (DNS)

The DNS was employed by the project from May 2014 until March 2017. Similar to the other project appointments, the DNS was actively involved in the different Cork-IDEAS project components. The DNS project role was multifaceted involving: case management with people with dementia, family carers and staff to achieve and enhance person-centred care outcomes and developing awareness and understanding of person-centred dementia care within the project setting, for example, through education and training. The role components aimed to improve the hospital experience for people with dementia and to promote the principles of a dementia-friendly hospital within MUH. The majority of referrals to the DNS were received from members of the gerontology multidisciplinary team. Over the course of the appointment, the role evolved to incorporate multiple elements. These included (but were not limited to):

- Acting as a support resource and single point of contact for staff, people with dementia and family carers by offering dementia leadership, advice and expertise, and raising the visibility of dementia within the hospital,
- Conducting individual consultations and comprehensive assessments, including cognitive testing for persons with potential or diagnosed dementia in the ED or on the wards,
- Based on the outcomes of assessments, commenting on the abilities and person-centred care needs of a person with dementia, and where required, providing a collateral cognitive history as well as supportive information to staff,
- Dementia-specific support in the presence of complex care needs and/or responsive behaviours,
- Identification and introduction of dementia-specific assessment documentation, for example: cognitive assessments, the 'This is Me' document, a non-verbal pain indicator and a responsive behaviour monitoring log,
- Involvement in the pilot introduction of the Pool Activity Level (Pool, 1999),
- Liaison with the CDCC and prior to this appointment, provision of follow-up advice for the person with dementia post-discharge,
- Provision of complex discharge planning support, especially when discharge was delayed, as well as family support, advice and information,

---

[3] Of note, prior to the project three local nursing homes had patient passports in place (containing information somewhat similar to that contained within the 'This is me document'). The use of these passports for people with dementia who required transfer to MUH was to be explored by the Cork-IDEAS project during April 2016. As no such transfers/admissions to MUH happened in this timeframe, this activity could not occur.

- Arrangements for the provision of short-term home support for the person with dementia,
- Overseeing and active participation in activities relating to the development of the ICP (Section 2.5.1),
- Development of the accompanying six-item DCB,
- Supporting the pilot, audit, and subsequent roll-out of the ICP on wards and in the ED,
- Participation in the dementia education and awareness raising activities of the project (Section 2.5.5), including: education of nursing and other healthcare staff, hospital volunteers and Dementia Champions,
- Provision of education and training, including in-service training and opportunistic ED and ward-based education to nurses on the ICP and DCB,
- Contributing to the development of a patient information booklet on hospital admissions for people with dementia,
- Participating in the Cork-IDEAS project consortium,
- Participating in committees for other clinical pathways to maximise synergies,
- Consultation, for example, acting as a resource to other acute hospitals and consultation on the national template for the role for the Clinical Nurse Specialist (CNS) in dementia in acute care, and the National Dementia Office consultation on potential areas for development in the region.

2.5.3 Community Dementia Care Co-ordinator (CDCC)

The CDCC was initially appointed from April 2015 to October 2017 and based in the Assessment and Treatment Centre in SFH. This post was extended to December 2018 using joint Cork-IDEAS / Cork-Kerry Community Health Organisation (CHO) funding. The community area covered by the position was North/South Lee and included all services with links to MUH. The CDCC established links between the hospital, and statutory and voluntary community supports involved in supporting those living with dementia in the community. Referrals to the CDCC were mainly initiated by consultant geriatricians/psychiatry of old age, General Practitioners (GPs), the DNS and Public Health Nurses (PHNs). Over the course of the appointment the role evolved to incorporate multiple components. These included (but were not limited to):

- Consultation and collaboration with the DNS in MUH,
- Acting as a point of contact in the community for people with dementia, family carers and service providers in the community and on discharge from hospital,
- Liaison with, provision of support for and advice to PHNs, GPs and other service providers,
- Facilitation of hospital avoidance for people with dementia where appropriate, for example, through liaison with GPs to divert the person with dementia to the Assessment and Treatment Centre in SFH. The CDCC provided a support to GPs in facilitating alternative out-patient appointments to avoid ED presentations, where appropriate,
- Where ED attendance or hospital admission were required, the CDCC encouraged GPs to provide advance notification of the patient’s dementia condition to the hospital to expedite ED stay and/or hospital admission. The CDCC also advised GPs about the activity levels in ED to inform their decision-making about the timing of ED presentation, for example, where it was safe for the person with dementia to continue to be cared for at home overnight, the GP could advise the person to wait and present the following morning when the ED had quietened down,
- Provision of discharge support for people with dementia which involved liaison with the DNS to ensure connection with PHNs and other appropriate community services,

- Signposting the person with dementia and family carers to suitable services such as day care, respite care, voluntary services, support groups and carer training courses,
- Liaison with the Home Care Support Office co-ordinator to facilitate supports for people with dementia with high care needs,
- Facilitation of the transformation, comprehensive development and expansion of an existing monthly Memory Intervention & Support Clinic (MISC) in the Assessment and Treatment Centre in SFH, provided by an Advanced Nurse Practitioner, OT and Dementia Adviser from the Alzheimer Society of Ireland, since 2013. This was transformed into a responsive Monday-Friday Memory Intervention & Support Service (MISS), working closely with the existing providers and local consultants to re-define its purpose and referral pathways, and to develop the MISS into a hub for dementia post-diagnostic support in Cork city with a variety of existing spokes (Alzheimer’s Café, Art classes, mindfulness programmes) brought together to provide an integrated and responsive service (Appendix 3),
- Running a six-week memory gym group programme for persons with mild cognitive impairment and those newly diagnosed with dementia in collaboration with an OT,
- Collating a directory of community services relevant to people with dementia,
- Provision of community-based dementia education and awareness raising (Section 2.5.5) including: a baseline education/knowledge survey, a dementia training programme for PHNs developed in conjunction with Cathy Tobin (Centre for Nursing and Midwifery Education, HSE Dublin North East), a Dementia Care Education and Resource Guide detailing educational opportunities, contributing to the PREPARED programme (a web-based GP education programme led by Dr Tony Foley),
- Participating in the Cork-IDEAS project consortium,
- Participation in the development of the ICP.

2.5.4 Environmental Changes and Occupational Therapist

A project-specific OT with experience of working in a dementia-specific hospital ward in the United Kingdom was appointed part-time in January 2015 for nine months to develop and oversee the implementation of the environmental changes in collaboration with the DNS, hospital staff and the hospital development team. The role appointment was then extended, with the OT having four project designated hours per week until May 2017. Thereafter, the hospital committed to continue this role by providing 0.1 Full-time Equivalent protected time for dementia support for this OT. Changes to the hospital environment aimed to enhance MUH as a dementia-friendly environment. The changes consisted of three main components:

- Modifications to the care of the older person ward – completed,
- Modifications within the ED – completed,
- Modifications on link corridors between the two main hospital buildings – in progress at the time of report writing.

An overview of the environmental changes completed on the care of the older person ward and in the ED are presented in Table 1. In addition to these, a dementia-friendly bay was introduced on each of the four main hospital wards. Environmental changes to the two “link corridors”, which connect the separate parts of the hospital and provide a space to facilitate walking, seating and social connection, were designed and the planning process to implement the changes were in progress as the project reached its end. The planned changes included: enhanced way-finding to include dementia-friendly signage and orientations boards, and seating incorporating a water and forest theme in the seating area. As a consequence of the environmental design learning and experience gained, the OT created *'A Guide to Creating a Dementia Friendly Ward in the Acute Setting'.* This resource details key information and considerations when planning and implementing dementia-friendly environmental changes and it has been provided to the National Dementia Office. Moreover, consultation on dementia-friendly design principles was provided to the new transitional care unit, St. Francis Unit, and also on environmental changes in SFH.

Table 1. Overview of the Environmental Changes

Environmental Changes in the Care of the Older Person Ward:

- The flooring was replaced with a uniform, non-glossy and non-slip acoustic-absorbing surface to aid orientation and avoid falls.
- The ward was repainted with different colours to help way-finding and orientate people with dementia to their bedsides.
- Wallpaper containing flower motifs was placed on doors to help room recognition.
- Pictures were placed behind each bedside to aid way-finding and orientation.
- Dementia-friendly clocks and calendars were hung up on the ward.
- The ward was de-cluttered.
- Dispensers were installed to give the ward a tidier appearance.
- Fittings and fixtures were modified, for example, different coloured handrails were installed, and lighting and acoustics were made appropriate for people with dementia.
- Dementia-friendly signage for toilets, showers, etc., were introduced throughout the ward (and in the dementia-friendly rooms on the other main wards). These included increased contrast, text and images.
- A day room was modified for people with dementia to facilitate social interaction. The day room was designed to be comfortable and welcoming, and it allowed for time away from the busy ward. A fireplace and record player were donated and placed in the day room as were a sofa and a table with chairs.
- The Irish Examiner donated pictures for the ward which were hung up in the corridors and the day room to encourage mobility and to enable reminiscence.
- Flowers and plants were planted in an outdoor area visible from the ward. These covered a wall and aimed to enhance the view from inside the ward.
- A Cork Institute of Technology woodwork class donated two bird tables which were placed in the outdoor area, again to enhance the view.
- The DNS placed information regarding the purpose of and rationale for environmental changes within the ward nurses' office as a guide to existing and new members of ward staff.

Environmental Changes in the Emergency Department:

- One ED bay was rendered dementia-friendly with clearly identifiable wallpaper with a flower image for bed recognition, and orientation aids, such as a clock calendar. The bay, which is visible from the nurses' station, is a visual reminder for staff that the person occupying it may have dementia.
- Both bathrooms in the ED were provided with dementia-friendly signs, contrasting rails, as well as labels such as 'soap', 'hand towel', 'sink' etc.
- Dementia-friendly signage was erected to help the person with dementia find the bathrooms from the re-designed dementia-friendly bay.

2.5.5 Education and Awareness

The dementia education and awareness raising component of the Cork–IDEAS project ranged from raising awareness about dementia throughout the hospital and the community to specialised education for staff working in specific areas. There was an emphasis on the delivery of dementia education throughout the first year of the project as a foundation to enable and facilitate the implementation of the project and subsequent change throughout the hospital and community sites. This education was co-ordinated and delivered by a number of the project consortium members, including the Project Lead, Nurse Tutors from the Centre of Nurse Education in MUH, the DNS (Section 2.5.2), the CDCC (Section 2.5.3) and the OT (Section 2.5.4), amongst others. The educational component was informed by a needs analysis that was conducted at the beginning of the project in conjunction with the administration of awareness and knowledge of dementia surveys. A short general dementia awareness programme was offered to all staff across the community and hospital sites. In addition to this, community staff completed the two-day 'Enhancing and Enabling Well-being for the Person with Dementia' course which is part of the National Dementia Education Programme. They also attended a one-day training programme on responsive behaviours. Three nursing homes and one community hospital linked to the project received an Irish Hospice Foundation education programme relating to a palliative care approach and communication around end of life for people with dementia. Some staff in the acute hospital completed a four hour programme called 'Enhancing Well-being for the Person with Dementia in the Acute Hospital'. A number of individuals were identified and provided with support to undergo the national Dementia Champion training course as part of the project across the hospital and community. In addition, dementia and delirium awareness training and ICP information sessions were also offered to new and existing medical doctors and consultants. A number of awareness raising events (for example, a dementia awareness week) open to all staff throughout the lifetime of the project were held. MUH and University College Cork also hosted website information on the project and a project film was made entitled 'Innovation and Learning in Dementia Care - Cork-IDEAS project'. The main components of the educational initiative in the acute hospital and the community are presented in Table 2.

Table 2. Cork-IDEAS Main Education Programmes

Name of Programme	Duration	Acute Hospital	Community
General Dementia Awareness	45 minutes	√	√
Enhancing Well-Being for the Person with Dementia in the Acute Hospital	4 hours	√	
Enhancing & Enabling Well-Being for the Person with Dementia	2 days		√
Responsive Behaviours	1 day		√
Dementia Champion Training	150 hours	√	√
Growing Excellence in End of Life Care	2 days		√
Training for Medical Doctors	30 minutes	√	

2.5.6 Volunteers

Two forms of volunteering were introduced into MUH over the course of Cork-IDEAS: hospital volunteers and parallel to the project SAGE volunteers.

Firstly, the Cork-IDEAS project aimed to provide social support for people with dementia in the hospital, through the assistance of hospital volunteers. A dedicated Volunteer Services Officer was appointed in a voluntary capacity in the hospital to oversee this aspect of the project and to co-ordinate the activities provided by the trained volunteers. This volunteer service commenced in September 2015. All of the associated volunteers attended the four-hour 'Enhancing Well-being for the Person with Dementia in the Acute Hospital' training. The number of volunteers fluctuated as their time commitment depended on their availability. Over the course of the project there were approximately 20 volunteers trained, with up to 16 available in any one week at the time of the project evaluation ending. Applications to become a volunteer continue to be received and processed. Volunteers are identified by a green polo shirt and hospital issued identification badge. The nature of volunteer activities evolved over the course of the project. Of note, the volunteer service was not exclusively for a person with dementia, but the volunteers were trained to be able to provide this service for a people with dementia. Examples included:

- Providing company through sitting and conversing with a person with dementia,
- 'Buddy Walking' where a volunteer walked with a person with dementia. This began on two wards and was to be extended to other wards,
- Engagement in meaningful planned activities, for example, knitting, reading and discussing newspapers,
- Accompanying a person with dementia, for example, when transferring to the transitional care unit or radiotherapy/scanning in Cork University Hospital,
- Volunteer hairdressing.

A business case was submitted to the hospital in June 2017 to fund a 0.5 Full-time Equivalent Volunteer Coordinator post to support the sustainability of the volunteer service.

Secondly, parallel to the Cork-IDEAS project, the national advocacy and support programme, Support & Advocacy Services for Older People (SAGE; http://www.thirdageireland.ie/sage), was introduced in the hospital as a pilot. SAGE volunteers are trained and offer advocacy services for older people, including those with dementia. Four SAGE volunteers were active in the hospital for approximately one year and supported older people on the wards and in the ED. Close links were developed between the SAGE regional coordinator, who was a member of the project consortium, and the project lead to ensure volunteer roles were complementary and to understanding and ensure clarity with regards to the functions of the two volunteering forms. The hospital has a very active social work department and as time passed, it was felt by SAGE that the SAGE volunteers could be more useful elsewhere. At the time of project end, the input had been reduced to one SAGE volunteer who visited once a week for four hours.

2.5.7 Overview of Project Activities and Milestones

Figure 5 presents a timeline overview of the key Cork-IDEAS components, activities and milestones described in the previous sections.

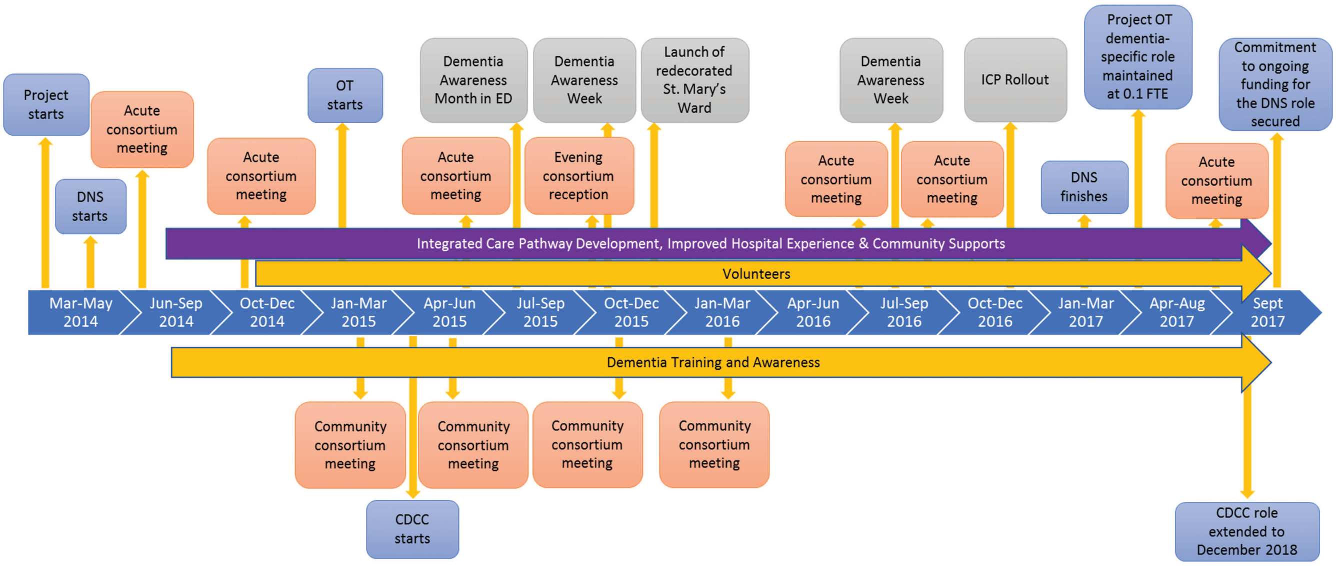


Figure 5. Overview of Cork-IDEAS Project Activity and Milestones

2.6 Summary

The Cork-IDEAS project aimed to develop and deliver enhanced integrated care for people with dementia underpinned by a person-centred philosophy. 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 Cork-IDEAS project.

3. Methodology of Evaluation (Overview)

3.1 Introduction

As outlined in Chapter 1, the authors of this report were commissioned to evaluate the Cork-IDEAS 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, Vogt and Boles, 1999; Gaglio, Shoup and Glasgow, 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 alignment with implementation of the National Dementia Strategy (Department of Health, 2014).

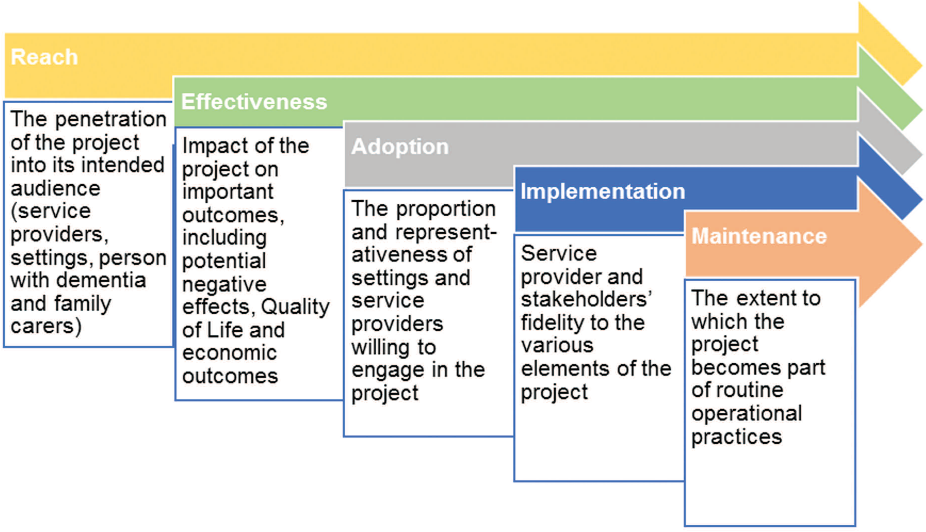
3.3 Objectives

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 Cork-IDEAS 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.

3.4 Methodology Overview

The evaluation is underpinned by an evaluation framework called RE-AIM (Glasgow et al., 1999; Gaglio et al., 2013), which is briefly presented in Figure 6. 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).



Reach: The penetration of the project into its intended audience (service providers, settings, person with dementia and family carers)

Effectiveness: Impact of the project on important outcomes, including potential negative effects, Quality of Life and economic outcomes

Adoption: The proportion and representativeness of settings and service providers willing to engage in the project

Implementation: Service provider and stakeholders' fidelity to the various elements of the project

Maintenance: The extent to which the project becomes part of routine operational practices

Figure 6. RE-AIM Framework Used in the Evaluation

There were four key aspects of the evaluation methodology as outlined in Figure 7.

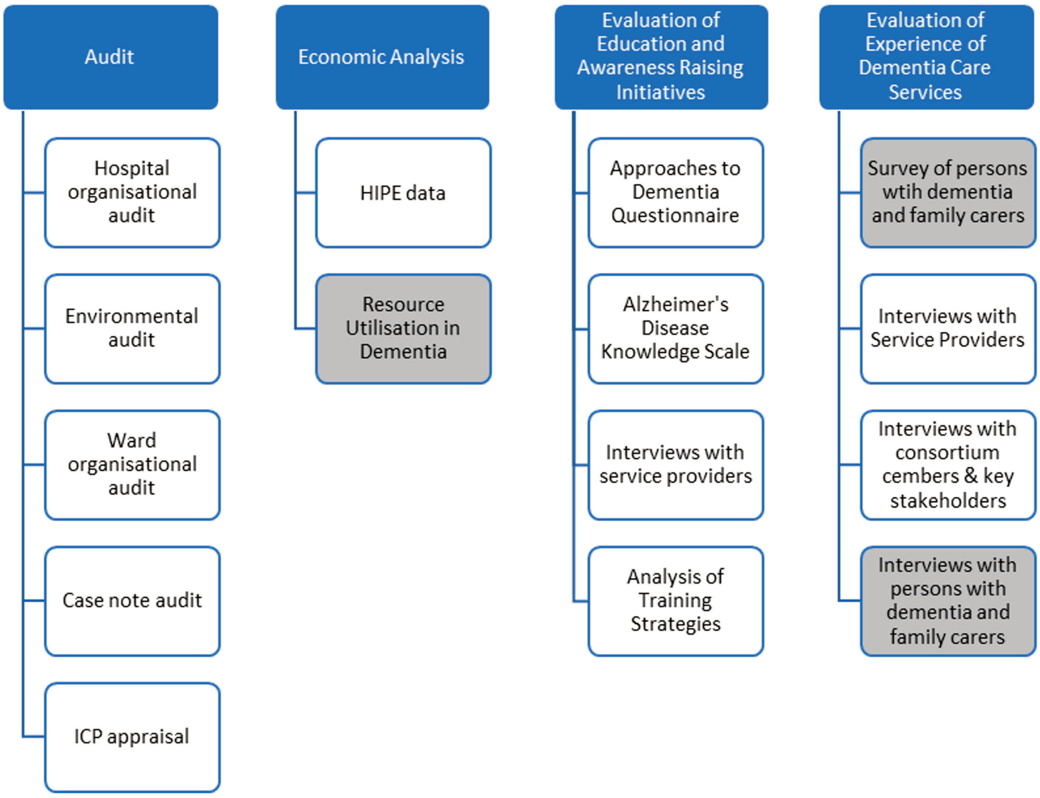


Figure 7. Overview of Evaluation Method [4,5]

Data collection for the evaluation occurred at two main time points, early on in the project timeline (Time 1 [T1]) and towards its end (Time 2 [T2]). Of note, T1 data collection commenced after the DNS was in post 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 Dublin's Faculty of Health Sciences Ethics Committee and the Clinical Research Ethics Committee of the Cork Teaching Hospitals. The total number of participants involved in each stage of data collection is provided in Table 3. 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. Therefore, from the outset, the experiences and perspectives of people with dementia and family carers were viewed as central to the evaluation. However, despite extensive efforts and the use

---

[4] 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).

[5] The Approaches to Dementia Questionnaire (Lintern and Woods, 1996) and Alzheimer's Disease Knowledge Scale (Carpenter *et al.*, 2009) were administered and the resultant data collected by the Cork-IDEAS project team.

of gatekeepers in the research site, nine family carers were recruited at T1, only four of whom participated in interview, and only one family carer was recruited at T2. It was not possible to interview people with dementia at T1 or T2. While limited, the data from the interviews with family carers at T1 was informative in terms of the experience of dementia in the hospital at the outset of the project. Factors that impacted on the difficulty encountered in recruiting people with dementia and family carers, included: the availability of potential participants fulfilling the evaluation study inclusion criteria[6] and the complexity of individual and care circumstances surrounding potential participants during hospital stays.

Table 3. Overview of Sample Sizes in Data Collection Stages

Participant Group/Source	Time 1	Time 2
Economic analysis	HIPE data for 2014 – 282 cases	HIPE data for 2016 – 329 cases
Awareness and knowledge survey*	499	347
Surveys of service users and family carers	9	1
Interviews with service users and family carers	4	0
Interviews with service providers (including consortium members & key stakeholders)	16	26

*Data collected by the Cork-IDEAS team

---

[6] 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 MUH and willing to participate in the evaluation study.

Figure 8 provides an overview of the timeline of data collection in relation to project activities.

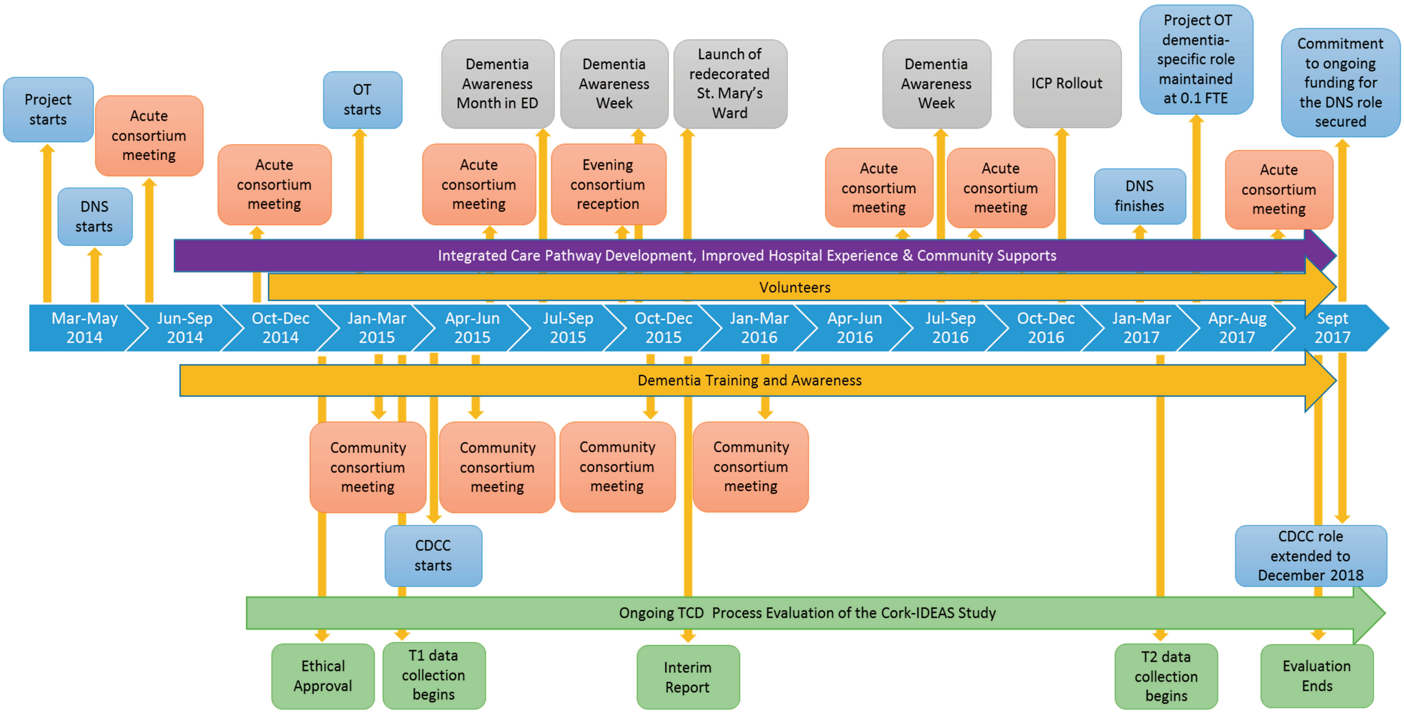


Figure 8.Overview of the Timeline of Project Evaluation Data Collection in Relation to Cork-IDEAS Project Activities

3.5 Summary

This chapter provided a brief overview of the methodology used to inform the conduct of the Cork-IDEAS evaluation. The findings of the evaluation are reported in the following three chapters:

- Chapter 4 – Cork-IDEAS Project Impact and Outcome Findings,
- Chapter 5 – Cork-IDEAS Project Process Findings,
- Chapter 6 – Cork-IDEAS Hospital In-patient Activity Analysis.

4. Cork-IDEAS Project Impact and Outcome Finding

4.1 Introduction

This chapter presents the findings that emerged from the evaluation of the Cork-IDEAS 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 The Integration of Dementia Care

As demonstrated in Chapter 2, the Cork-IDEAS project contained a number of elements that aimed to enhance the integration of dementia care on entry to, within and on discharge from MUH into the community. Evidence to inform the evaluation of the project in terms of these elements was obtained from multiple sources at T1, T2 and over the course of the project (Chapter 3). 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 – DNS and CDCC roles,
- Integration of dementia care – volunteers,
- Overall integration of dementia care.

4.2.1 Integration of Dementia Care – ICP for Dementia

As outlined in Chapter 2 (Section 2.5.1), the Cork-IDEAS project centred around the production of an ICP for dementia to improve the journey of a person with dementia from admission to discharge, via the promotion of co-ordinated care, planned admissions where possible, and provision of personal information to facilitate person-centred care, enhanced discharge planning and support for family carers. To this end, an ICP for dementia was devised, piloted, introduced and rolled out across parts of the hospital within the project timeline. The ICP consisted of two components: an ED component and a ward component (Chapter 2, Figures 3 and 4).

The evaluation identified a number of factors that supported the development and implementation of the ICP. The project structures (project consortium and associated ED and ward working groups, and designated project personnel) provided a clear ICP governance structure with designated responsibility for the component activities that fed into its development (Section 2.5.1). The literature review, process mapping of people with dementia's journeys and consultation with representatives of end-user groups through the consortium working groups assisted in building support and understanding of the needs of users, as well as providing multidisciplinary perspectives informing the development of the ICP content and format. Data from the evaluation interviews and the organisational audit (Section 4.2.4.1) suggested that the ICP was compatible with existing care pathways, for example, the frailty pathway. This suggests there was an awareness of the need to ensure complementarity to, and fit with, existing and planned organisational structures and processes to maximise the potential for ICP success.

The ICP was implemented in the clinical areas at a point when dementia awareness education/training was well advanced. The interviews with participants from these areas and key stakeholders within MUH suggested that the growing awareness and education provided a supportive context to the introduction of the ICP. There was a high level of willingness among staff to improve dementia care within MUH. This positive orientation toward change was attributed to having participated in one or more of the training types, as well as the visual impact and associated learning from the environmental changes that were occurring. The in-patient ward ICP was phased in on wards which were considered most likely to have patients with dementia admitted to them. The challenges of implementing the ICP may have been eased in these wards, as the potential benefit of the ICP was evident to those who were more frequently providing dementia care.

The DNS was identified by the majority of those interviewed as one of the most influential factors facilitating the introduction of the ICP, providing focused and ongoing education to support practitioners with responsibility for the implementation of the ICP. The flexibility of the manner in which this support was provided was a further facilitative feature, as it responded to the daily realities encountered by practitioners, for example, deferring plans to deliver on the ward education where clinical demands were acute on a particular day. This was spoken of by a number of participants as demonstrating the understanding and responsiveness of project personnel to the dynamic demands in the clinical area.

While there was generally widespread awareness of the ICP and its purpose, particularly among consortium members and participants from those wards where it had been introduced, there was an acknowledgement that uptake in using the ICP, and compliance with its components, sometimes was not occurring. Evidence of ICP usage and its impact on dementia care practice were therefore variable as reported in interview and in the checklist devised by the evaluation team and added to the patient case note audit at T2 (Section 4.2.4.3). Some of the reasons for this finding are included in the challenges to ICP uptake and impact reported later in this subsection. The additional checklist included in the patient case note audit was devised to establish the degree of permeation of specific ICP-related documentation and referral processes among twenty people with dementia. Most of the cases audited at T2 had a pre-existing diagnosis of dementia (72.2%). It is important to note that the patient case note audit included patients from five wards, only three of which had introduced the ICP. Twelve out of the 20 case notes audited (60%) were from these three wards. Of these, there was evidence that the ICP was activated in 66.7% of cases (for example, the patient was referred to the DNS and the dementia screening performed by the primary team within 48 hours). The 4AT (which is a validated screening tool for delirium, incorporated into the ICP) was recorded as used in the ED in only 25% of all 20 cases. The DCB was fully present in 21.1% of eligible cases (n=4), and a 'This is Me' document or patient passport was present in one-third of the patient case notes. More encouragingly, 65% of people with dementia were referred to the DNS, with almost all of these referrals reviewed by the DNS (92.3%). Furthermore, 90% of cases were referred to the OT, of whom all were reviewed. Finally, the discharge letter contained individualised dementia-related information in all cases where it was applicable, and reference to consultation with the CDCC was evident in 53.8% of those who had a discharge letter.

These findings were not surprising, however, as the roll-out following the pilot phase began within the last year of the project and time would be required for the associated changes to gain traction. This was referred to by one participant as a *"see saw effect, one day it will be great and then …" (FU SI FC 16)*.

When used, the ICP and DCB were reported to be user friendly and positively contributed to the integration of dementia care:

“We have the bundle in [name of ward]. It’s quicker when you kind of, when you know how to use it properly because all your care plans are integrated … so if you know how to use it properly it is quicker at the end of the day” (FU FG FC 04).

In terms of usability, participants described the visual and practical appeal of the ICP. The presentation of both components on a single page and use of colour-coding highlighted those with a possible or actual diagnosis of dementia. The inclusion of delirium assessment in the ED component was considered particularly beneficial. The conciseness of the ICP enhanced its clarity without compromising its cohesiveness. Furthermore, the integration of the ICP with existing systems, processes and guidelines enhanced the compatibility and usability of the ICP in clinical practice. An example of this was the involvement of the nursing practice development unit in assessing the compatibility of the DCB with existing nursing practice guidelines.

In terms of its impact on dementia care, participants with experience of using the ICP described enhanced co-ordination and timeliness of dementia care. This was in contrast to a perception of more fragmented care prior to the introduction of the ICP:

“We were doing the care [prior to Cork-IDEAS] but you are not getting to see it … It would be very fragmented whereas when you have it [DCB] as part of the structured care plan it’s there and it’s visible” (FU FG FC 05).

There were also experiential reports of an increase in appropriate timely referrals to allied health professions:

“So you know I suppose there was a clearer sense of a patient with dementia, there was more kind of highlighting earlier, I think. So we got the referrals earlier than we probably would have previously ..” (FU SI FC 08).

Participants suggested the ICP, DCB, ‘This is Me’ document and behaviour record charts contributed to more streamlined and greater personalisation of care, for example, via the identification of needs and dementia specific care planning. The accessibility of the ‘This is Me’ document was praised and it was highlighted that the document enhanced continuity of care and provided a level of person-centred information not previously available to some providers. Notable examples of this included staff involved in patient transfer or sitting with patients who were distressed:

“It is only since all this [Cork-IDEAS] came in, we are now more aware of, you know of how to relate to people and especially when [DNS] was here we found it great because what she brought in was that we now have thing, a chart (This is Me) at the end of their beds so we know what they like and dislike and their hobbies prior to coming in … So you know you are able to have a conversation with them now. And you are able to better relate to them” (FU SI FC 17).

There was also some indication that the ICP-associated documents had enabled some participants to enhance the care of patients with other conditions. For example, there was reference to the 'This is Me' document being used with patients who were non-verbal and who could not easily communicate their wishes and preferences.

Interview data suggested a number of challenges limited the uptake and potentially the sustainability of the ICP, including:

- The introduction of a new practice into an already busy and complex environment,
- Not all staff being aware of the ICP or its associated components,
- A lack of understanding of the actions required when using the ICP when staff had not received specific education in its use,
- Turnover of nursing staff creating a necessity for ongoing support of staff to ensure implementation the ICP,
- Inadvertent oversight of the potential to use the ICP,
- Competing demands upon healthcare professionals to sustain multiple clinical innovations in the ward environment, and
- Most significantly, the loss of the DNS support for the ICP implementation once the DNS role had ceased.

Participants were cognisant that efforts to embed changes associated with the ICP were at an early stage and were aware that it would take time for the pathway to be embedded and sustained. A number of participants identified the need for ongoing mechanisms to prompt and sustain implementation of the ICP and its associated components. Most evident here was a stated imperative to embed a DNS within MUH to encourage ICP traction and continue to build momentum:

> *"Now [the DNS] unfortunately is not, the position isn't available anymore. I suppose it's going to be a bit lost educating people about it (ICP) … Someone to push it, having someone on the ward designated to pushing it because, yeah if there was some there … then maybe. I think we need to be reminded about what we're doing wrong and what we're doing right" (FU FG FC 04).*

Indeed, plans to roll-out the ICP further across the hospital were deferred until such a time as a DNS was reinstated. This role was spoken about strongly in relation to the ICP by the majority of participants across the disciplines interviewed in two overarching ways:

1. As crucial to drive ongoing multi-disciplinary practitioner awareness of, and support for, the ICP,
2. To ensure ongoing ward-based ICP support, for example, via on the ground education in terms of how to use the pathway and its associated components.

These two mechanisms were recognised as a counterbalance to a number of the challenges to the maintenance of ICP uptake and hence to the ongoing integration of dementia care. It was also recognised that the presence of the OT with a designated role in dementia care, and the commitment of nursing and organisational management made important contributions to the maintenance of the ICP. A number of participants at ward management level reported their commitment to try to actively support the ICP until such time as a DNS role might be reinstated. However, it was acknowledged that this commitment would need to be ongoing and without a designated role would be situated amongst other clinical activities.

4.2.2 Integration of Dementia Care – DNS and CDCC roles

Two project-specific roles were introduced within the context of the Cork-IDEAS project to facilitate the integration of dementia care. The DNS role (Section 2.5.2) was primarily hospital-based and the CDCC (Section 2.5.3) was primarily community-based. In order to contribute to the achievement of the overall project aim, the DNS and CDCC roles were conceptualised and operationalised to incorporate both in-reach and out-reach components between the two settings.

4.2.2.1 The DNS role

The role of the DNS evolved over the course of the project but the evaluation identified a number of overarching and interacting components (Figure 9) within which the previously described role activities (Section 2.5.2) could be broadly situated.

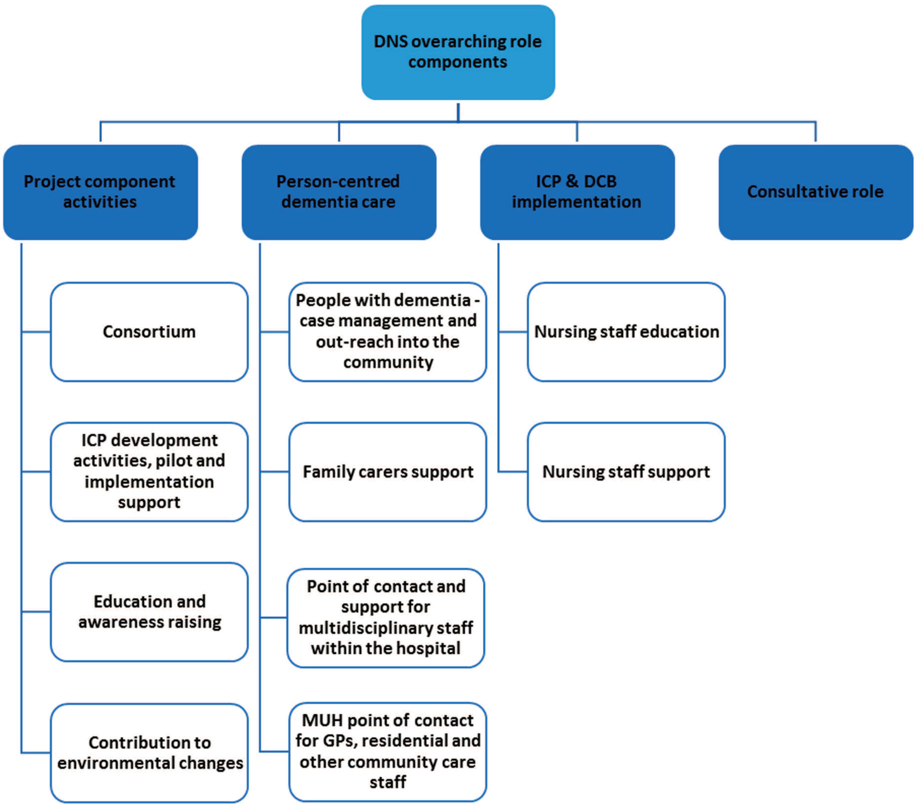


Figure 9. Summary of DNS Overarching Role Components

The impact of the DNS in terms of the development of the ICP and its introduction were outlined in the previous sub-section. However, the clinical contribution of the DNS role to dementia care enhancement was of equal importance to the project aims. The DNS's dementia expertise and clinical provenance were commended by participants; several made references to the DNS being the face of dementia care within MUH and the 'go to' person for complex case management advice. The data suggested the DNS role contributed to more personalised dementia care and streamlined assessments through the collection of more in-depth and accurate collateral histories, development of mechanisms to enhance the collection and recording of person-centred data, and her contribution to care planning for complex aspects of care for the person with dementia. As the DNS role evolved, and the awareness and understanding of the role developed, the frequency and appropriateness of referrals to the service increased. In addition, the DNS engaged in role modelling and activities to share her expertise that appeared to facilitate a degree of capacity-building in dementia care among staff:

> "It wasn't one of the…nurses on the ward who took this on as a project. It was an expert took it on. And I think that's where we had a huge advantage that [the DNS] was absolutely seen as having much more knowledge and someone to turn to" (FU SI FC 18).

The availability of the DNS to support and guide the person with dementia and family carers through the hospital journey was further highlighted:

> "I should point out that a number of people who would interact with the range of services that would require crisis hospital admission … the role of the CNS in the acute hospital would have made that transition, or the whole hospital experience, would have enhanced that and eased it for both the persons with dementia and the carers. So that [DNS] was a link person" (FU SI FC 14).
>
> "[The DNS] was a good link for the families especially that if there were any issues that there was a dementia CNS they could talk to. And then for, you know, going forward for going home, it just made the transition home easier" (FU FG FC 05).

There was also evidence to suggest that the DNS role had some success in terms of becoming identifiable to family carers and a model of good practice for other settings, with one particular example of a family member having contacted the role holder to ascertain if a similar contact was available in another hospital where a loved one was being admitted.

A number of factors assisted in facilitating the impacts associated with the DNS role. Many of these were associated with the way in which the role itself was implemented. For example, interview data suggested the DNS was successful in creating staff buy-in and building the momentum required to implement interventions to enhance dementia care within MUH. These outcomes were attributed to the communication skills and openness of the role holder and the maintenance of an active, ongoing, responsive and highly visible role presence.

Several important considerations were highlighted by participants in relation to the potential impact and outcomes of the DNS role. Firstly, the DNS role was a new position in MUH and the appointee herself was new to MUH. As a consequence, lead-in time was required to scope the function of the role, build inter-disciplinary relationships, and to raise awareness and understanding of the role. Secondly, the establishment of a DNS role in an acute hospital was a unique innovation at the time of project commencement. There was a consequent requirement to establish clear lines of reporting and responsibility as the project unfolded. As already illustrated, the evolution of the DNS role was dynamic. This responsiveness to evolving demands facilitated many of the role-associated outcomes achieved. However, the DNS role was complex, and frequently multiple components of the role were active at any one time. While this could be expected in a project like Cork-IDEAS, it was acknowledged that the role balance would become more clinically-focused once the project components (for example, the ICP) were more established and better embedded. However, the DNS role would need to continue to support the implementation of the ICP to overcome the challenges to sustainability outlined in section 4.2.1 as suggested here:

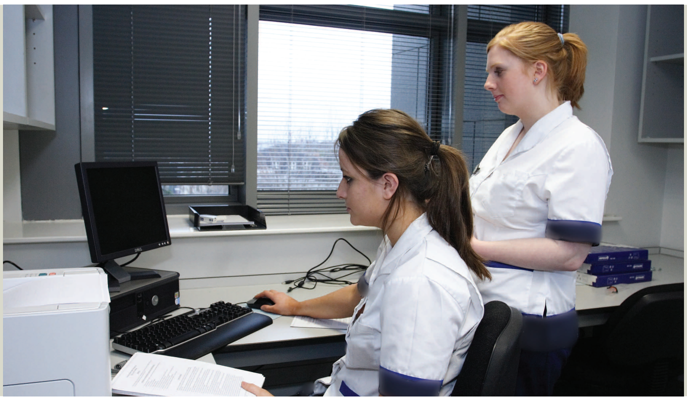
> *"The biggest gap of all is not having the presence of a CNS in the department to constantly remind staff of the importance of going through the pathway and it is a huge reminder for them, you know? To have a CNS is vital … It's a necessity really" (FU FG FC 06).*

Indirectly, reference to the impact of the DNS was equally manifest once the role had ceased:

> *"A huge loss, absolutely huge loss because you know you could just ring [DNS] and say, can I talk to you about this person, like I'd often bounce an idea off her and say, look is there something else I need to be doing different for this person. Or I'm not sure, I think there's something amiss here, can you review them to see is there something? … [DNS] was brilliant, a brilliant resource" (FU FG FC 04).*

Interview participants described several consequences arising from the cessation of the DNS role, including: a reduction in referrals to the CDCC, a decline in the use of the ICP, a lack of CNS support for staff, people with dementia and family carers with respect to dementia care, and a waning of support for the roll-out of the ICP and interruption of its roll-out across the remaining hospital wards. Finally, the absence of a point of contact within MUH for those outside of the hospital was considered a particular barrier to the integration of dementia care across settings.

The value of sustaining a DNS role was clearly recognised within MUH. At operational level, there were multiple references to the need to reinstate the role, while at project and hospital organisational levels, a business case was submitted to secure the role into the future and funding had been made available to employ a DNS in the short-term. At project end, the hospital had committed to the recruitment of a permanent DNS post.



4.2.2.2 The CDCC role

Similar to the DNS role, the CDCC role evolved over the course of the project and analysis of the role-related activities (Section 2.5.3) identified a number of overarching components (Figure 10). Again, similar to the DNS role, the CDCC role was complex and multifaceted, and while the responsibilities of the role were represented within components, it was evident that these components were inter-related.

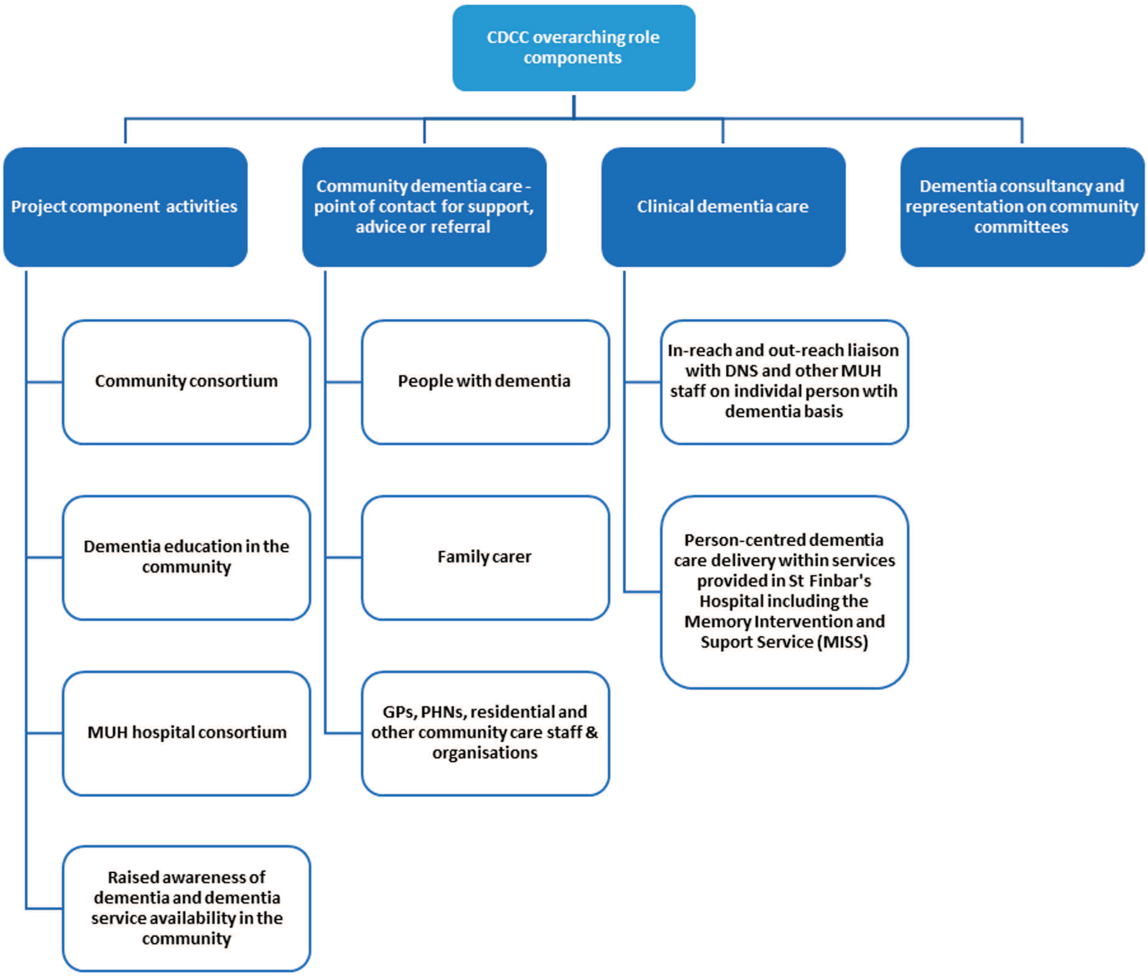


Figure 10. Summary of CDCC Overarching Role Components

The ICP produced in the Cork-IDEAS project included discharge planning and indicators for specialist service follow-up, and the CDCC had a role here, working closely with MUH staff and the DNS. However, evaluation of the community component of the project suggested the CDCC role facilitated enhanced integration of dementia care, and raised awareness of dementia and local dementia-related services and supports beyond just the hospital interface. It appeared that the enhanced integration of dementia care was related to the development of relationships and the sharing of information at community consortium meetings and between the community service network contacts established by the CDCC. These mechanisms facilitated knowledge of the Cork-IDEAS project and multi-way flow of dementia-specific information, suggesting the project had some success in penetrating the service and sectoral silos that are known to exist within the community care setting. In particular, the CDCC played a key role in expanding and enhancing the existing MISC into a MISS hub for dementia peri- and post-diagnostic support. The MISS is currently being evaluated by the service themselves and falls outside of this overall project evaluation.

As awareness and understanding of the CDCC role developed, the CDCC increasingly became a point of contact for dementia care in the community, and a recognised resource for people with dementia, family carers and the various healthcare and service providers in the community and MUH. Enhanced integration of dementia care was achieved through the facilitation of service navigation, hospital avoidance, expedited hospital admission when appropriate, and enhanced discharge into the community from the hospital setting. The integration of dementia care was further enhanced by the community service network contacts built up by the CDCC, as people with dementia and family carers were reconnected to pre-hospital supports, and new supports where feasible and required, upon returning home following discharge:

> *"Just for example, we just had somebody a couple of weeks and we were just having trouble getting the support in place and he was ready to go and his wife was ready, and so [CDCC] was able to step in there and actually help us to get him home." (FU SI FC 11).*

A number of factors facilitated the evolution of the CDCC role. Firstly, its development and impact were linked to the clinical credibility of the role holder. This was attributed to the CDCC appointee being an experienced Public Health Nurse with direct experience of how the structures and systems on the ground operated and it appeared that this may have expedited the CDCC's traction within the community. Secondly, the operationalisation of the CDCC role enhanced its development and reach. The role-holder was based in SFH alongside several community services that provided support for people with dementia and family carers, including the existing MISC. Although the role was newly established, the CDCC recognised the need to avoid transgressing the role boundaries of established community service providers. In doing so, the distinctness of the CDCC in terms of specialist dementia support became evident. Thirdly, the time allocated to surveying of dementia knowledge and awareness in the community ensured subsequent dementia education and mapping of dementia resources was responsive to community need. Finally, critical positive impacts of the CDCC role were her active support of service providers, positive role-modelling, enhancing the visibility of dementia in service delivery, and advocacy for people with dementia in the community through various committee memberships.

Challenges encountered in the development of the CDCC role included the delay in recruitment due to logistical difficulties of filling the role. As the CDCC appointee was not in position at the commencement of the project, this resulted in a delay to the community component of the Cork-IDEAS project. However, the progress that had already been made in MUH, including the established role of the DNS, meant that there was an established dementia care structure for the CDCC to connect with on role commencement. The two-way communication between the DNS and

CDCC made a significant contribution to the integration of dementia care between the hospital and community during the project. However, the cessation of the DNS role appeared to impact upon the degree of contact between the CDCC and the hospital, and the rate of discharge referrals from MUH to the CDCC. This may have been compounded due to the absence of reference to the CDCC in the discharge component of the hospital ICP (Section 2.5.1). Finally, similar to the DNS role in MUH, participants expressed concerns surrounding the potential consequences for person-centred dementia care in the community following cessation of the CDCC role at the end of the project:

> *"I suppose in the busyness of the clinics that there is cognitive testing, there's blood tests and everything, that you do need that somebody that is able to give that support. Otherwise it becomes very medicalised, and you do need somebody that is able to provide that [specialist dementia] support, and you do need somebody with the knowledge and skills… so without having somebody in the role of co-ordinator of dementia, I'd struggle to think how we could continue without a dedicated somebody." (FU SI FC 14).*

In recognition of this, a business case for the role was submitted to Cork-Kerry Community Healthcare Organisation (CHO) in Summer 2017, resulting in the position being extended until 31st December 2018, partly funded by Cork-Kerry CHO.

4.2.3 Integration of Dementia Care – Volunteers

The volunteer service component of the project was a new initiative within MUH, developed and overseen by a volunteer co-ordinator who sat on the project consortium. As in the DNS and CDCC project roles, both the nature and understanding of the volunteering role grew over time, resulting in more frequent requests for volunteer services, and diversification of activities provided by volunteers for people with dementia and other patients in the hospital (Section 2.5.6). The value of the volunteer service was spoken of by a variety of interview participants as having positive impacts for people with dementia, family carers and staff. Furthermore, the co-ordination and operationalisation of the volunteer service supported a person-centred approach to enhance the well-being of people with dementia. Participants identified measures to improve the continuity and person-centred nature of volunteer engagement with people with dementia, including centralised documentation of volunteer visits and activities with people with dementia and return visits to the person with dementia by the same volunteers. It was suggested these strategies could allow the volunteer to get to know the person, personalise the activities of the visit and respect the preferences of the person:

> *"I've had one or two patients that I've gone to every single week and like, and there was another patient now I used to paint her nails every week, she loved her nails … once I start painting her nails every week for her, she relaxes and starts chatting … so you do, you know develop a relationships with the patient and you like to see it through" (FU FG FC 01).*

A key impact of the volunteer service was that the role worked toward meeting the needs of people with dementia for social connection, comfort, accompaniment and engagement in enjoyable activity. Volunteers had the time to focus on and listen to the person with dementia and it was reported that the volunteer service freed up time for nurses and healthcare assistants (HCAs) to allocate to other care activities for all patients, including those living with dementia.

There was some inference that the need for volunteer support was difficult to anticipate in units such as the ED when compared with an in-patient ward setting, as people with dementia generally have a greater length of stay in ward settings, which permits greater planning for contact with volunteers. As such, there was a suggestion that in the less predictable ED setting, the use of volunteer services may not be as effective as potentially possible:

> *"I suppose we should be mindful of it (the volunteer service) and maybe phone sooner if we can. But sometimes they are just not available because most of these volunteers have set places to go at set times … whereas in A&E it's so random and uncontrolled that we don't know when we are going to meet them (people with dementia)" (FU FC FC 06).*

Overall, evaluation data supported the positive impact of the volunteer service and the desire to maintain the model into the future. Commitment to future growth of the volunteer model was demonstrated in the active recruitment of volunteers at external clinical sites linked to MUH and a business case was submitted to MUH management in Summer 2017 for the establishment of an ongoing volunteer co-ordinator post within MUH. A decision regarding this submission was awaited at the time of writing this report.

4.2.4 Overall Integration of Dementia Care

To evaluate the integration of dementia care practice within MUH, current practice was compared to international best practice using tools from the Irish National Audit of Dementia Care in Hospital (DeSiún *et al*., 2014).[7] The evaluation encompassed an audit of 20 patient case notes, an organisational audit, and ward organisational and environmental audits of three hospital wards[8] at T1 and T2. 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.

4.2.4.1 Hospital Organisation Audit

The hospital organisation audit examined structures, policies, processes and positions relevant to the care, treatment and support of people with dementia in a general hospital. Table 4 provides a summary of changes to the findings of the hospital organisational audit from T1 to T2. It is evident that there were many positive changes to organisational processes, as many of the responses had changed from either 'No' or 'N/A' at T1 to 'Yes' at T2. Many of these changes demonstrate the potential to enhance the integration of care for people with dementia as well as streamlining related administrative and clinical practices.

---

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

[8] One ward had 15 beds, the second 24 beds and the third 25 beds.

Table 4. Summary of Changes to Hospital Organisational Audit From T1 to T2

	Time 1	Time 2
Governance		
ICP for people with dementia in place	No	Yes
ICP adapted or fitted to acute, palliative and end of life care pathways	N/A	Yes
A senior clinician is responsible for the ICP	N/A	Yes (Consultant Geriatrician)
Designated office responsible for the protection of vulnerable adults	No	Yes
Champions for dementia at hospital level	No	Yes
Delivery of Care[9]		
Assessment of mood using a standardised instrument	No	Yes
Assessment of Dementia and Mental Health Needs[10]		
Policies or guidelines in place to ensure that people with dementia or cognitive impairment are assessed for the presence of delirium at presentation	No	Yes (ED ICP)
Policies or guidelines in place to ensure that people with dementia or cognitive impairment with behaviour changes suggesting delirium are clinically assessed by a trained and competent professional	Yes	Yes (Ward ICP)
Systems in place to ensure that suspected but not yet diagnosed dementia triggers a referral for assessment in the hospital or community	No	Yes (ED and Ward ICP)
Policy or guidelines stating patients over 70 admitted to the hospital are assessed for mental status[11]	No	Yes (ED ICP)
Protocol in place governing interventions for patients with challenging behaviour, aggression and extreme agitation suitable for use with patients with behavioural and psychological symptoms of dementia	Yes	Yes (guidelines referenced in ward ICP)
There is a section in the general hospital discharge summary for mental health diagnosis	No	No (but is included in the ward ICP)
Discharge		
Information about discharge and support is made available to patients and relatives	No	Yes
Information		
There is a formal system in place for gathering information pertinent to caring for a person with dementia	No	Yes ('This is Me'– referenced in ICP on 3 wards)
Recognition of dementia		
System in place to ensure all staff are aware of the person's dementia or condition and how it affects them (e.g. visual indicator, alert sheet or other)	No	No
Patient notes are organised in a way that it is easy to see the care plan	No	Yes
System in place to advise, support, involve family carers	No	Yes
System in place to ask the family carer about their wishes and ability to provide care and support of the person with dementia post-discharge	No	Yes

---

[9] All questions answered yes at T1 apart from those reported in this section.

[10] All questions answered yes at T1 apart from those reported in this section or where developments have involved the ICP for Dementia established in Cork-IDEAS.

[11] Note the INAD audit states age 65. The hospital policy states age 70 years.

Training, learning and development		
Training and knowledge framework or strategy identifying necessary skill development in working with and caring for people with dementia	No	Yes
Staff induction programmes include dementia awareness	No	Yes
Dementia awareness training provided to multidisciplinary and support staff in the last 12 months	No	Yes
Involvement of people with dementia and carers and their experiences included in ward staff training	No	Yes (use of video)
Specific resources supporting people with dementia		
Named lead in dementia care to provide guidance to staff	No	Yes
Person with overall responsibility for complex needs discharge has training in ongoing needs of people with dementia	No	Yes
Social worker or other designated person available to provide advice, support or referral to appropriate organisations to people with dementia and family carers	No	Yes
Access to advocacy service with experience and training in working with people with dementia	No	Yes
Liaison psychiatry		
Psychiatry liaison service in the hospital regularly provides routine mental healthcare to working age adults and to older people	Yes	No (to working age adults only)
Liaison psychiatry of old age		
Liaison psychiatry of old age provides emergency/urgent assessment	No	Yes
Liaison psychiatry of old age is provided by a specialist mental health team	No	Yes
Liaison psychiatry of old age based on site	No	Yes
Geriatric medicine		
No change in answers to this section from T1 to T2. At T1, Yes was answered to all relevant questions.		

4.2.4.2 Ward Organisational Audit

The ward organisational audit gathered information on staffing levels, support, service availability and provision of information to support the care of people with dementia on three wards[12]. All three wards had agreed minimum staffing levels, and systems were in place on a daily basis to review them. A system was in place to ensure ward staffing levels were sufficient to assist people with dementia at both time points. However, two of the wards were below minimum staffing levels by two full-time equivalent nursing posts and one full-time equivalent healthcare assistant post at T2. All wards had administrative support available from Monday to Friday.

Table 5 provides an overview of some of the key findings demonstrating where changes occurred between the two audit time points. The results suggested that a range of services which contributed to the care of the person with dementia were available at both time points. However, in some instances, there was an increasing trend of services

---

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

being available outside of the five-day week. In addition, the person responsible for co-ordination of care for the person with dementia was made known to family carers on all wards at T2. Furthermore, it was evident the components of the ICP and DCB including the 'This is Me' document and behaviour monitoring charts were used at T2 to enhance communication of the needs and preferences of the person with dementia. However, this was not uniform across all three wards. Protected mealtimes were stated to be in place on all three wards at T1, but by T2 this was only the case on one ward. However, all wards permitted carers to assist the person with dementia where required at T1 and T2 and were also able to provide food between mealtimes. Although opportunities for social interaction were available for people with dementia on all wards at T1, the removal of the day room facility on one ward meant this could only be facilitated on two wards at T2.

Table 5. Overview of Findings of the Ward Organisational Audit

	Time 1 (number of wards)	Time 2 (number of wards)
Staff support		
Provision for staff to attend dementia training	3	3
Guidance and support available from Dementia Champions (for any member of staff):	1	2
Nursing	1	2
Healthcare Assistants	1	1
Other	1	1
Staff caring for people with dementia have access to peer support:	2	1
Nursing	2	1
Healthcare Assistants	1	1
Other	1	1
System for staff development in place – appraisal and mentorship (any staff):	3	2
Nursing	3	2
Healthcare Assistants	1	1
Other	1	0
System for staff development in place – clinical supervision (any staff):	2	2
Nursing	2	2
Healthcare Assistants	2	2
Other	0	0
Services available to wards [13]		
Access to liaison psychiatry:		
Monday to Friday	2	1
24/7	1	2

---

[13] Services included in this section are those where there were changes from T1 to T2 on auditing. Other services were available but the audit revealed no change in service availability from T1 to T2.

	Time 1 (number of wards)	Time 2 (number of wards)
Staff support		
Access to psychiatry of older age:		
Monday to Friday	3	3
Access to geriatrician:		
Monday to Friday	2	0
Monday to Sunday	1	3
Access to occupational therapy:		
Monday to Friday	3	2
Monday to Sunday	0	1
Access to pharmacy:		
Monday to Friday	2	0
Monday to Saturday	1	3
Access to physiotherapy:		
Monday to Friday	1	2
Monday to Saturday	2	1
Protected mealtimes in operation	3	1
Opportunities for patients to socially interact	3	2
Information and communication		
The professional co-ordinating care is identified to relatives	1	3
System for communicating personal information to staff involved in caring for people with dementia	3	2[14]
Stated system to communicate the above:		
‘This is Me’ document’ and/or	2	2
Verbally during patient handover	1	1
System to communicate to ward staff specific behavioural or communication needs for people with dementia	3	3
Stated system to communicate the above:		
Behaviour analysis chart	1	2
Verbally during nursing handover	1	1
Documented in nursing notes	1	0
System to communicate behavioural or communication needs specific to the person with dementia to other staff outside of the ward	2	3

---

[14] When interpreting this finding, it should be noted that the ward which indicated that there was no ‘system for communicating personal information to staff involved in caring for people with dementia’ at T2, had been using care plans and nursing handover to communicate information at T1 and stated that the ‘This is me document’ was being introduced. The ward reported it continued to use nursing handover to communicate people with dementia’s needs at T2.

4.2.4.3 Patient Case Note Audit

The patient case note audit was conducted by two evaluation team members on the records of 20 unmatched people with dementia with a primary or secondary diagnosis of dementia who had stayed in the hospital for at least five days. Cases were identified by the Hospital In-Patient Enquiry (HIPE) data at T1 and T2. Records were selected by discharge date beginning in April 2014 and working back to January 2014 at T1 and January to March 2017 at T2. The audit gathered information on patient assessments, discharge planning and co-ordination, and referral of people with dementia to specialist services. The mean age of patients reviewed in the audit was similar at T1 (81.5; SD = 7.6) and T2 (80.3; SD = 8.4) and approximately half of patients were female (T1: 50%; T2: 45%). The mean length of stay in the hospital was 22.2 days at T1 (range = 6 74; SD = 16.98) and 16.5 days at T2 (range = 6 43; SD = 11.57) in the charts reviewed, however this difference was not statistically significant (t(38) = 1.24; p = 0.223). At both time points, the majority of cases were admitted from their own home. However, the number of participants admitted to MUH from residential care was higher at T1 (40%) than T2 (15%), while the number of those admitted from the home of their carer increased to 15% at T2, compared to none at T1. Furthermore, the number of participants discharged to their own home increased from 29% at T1 to 41% at T2. In relation to the use of antipsychotic medications, at T1, 25% of the people with dementia were prescribed such medications, all of whom had a pre-admission prescription. At T2, 65% were prescribed anti-psychotic medication, of whom 69% had a pre-admission prescription.

At T1, a number of strengths were identified including the comprehensive nature of multidisciplinary assessments. Taken together with the findings outlined in this chapter, the overall findings of the patient case notes audited suggested an improvement in dementia care within MUH following implementation of the Cork-IDEAS project. Table 6 presents a summary of some of the key findings of the patient case note audit at T1 and T2. As can be seen, there is an upward trend in many of the items with several increasing to 100% at T2.

Table 6. Overview of Findings from 20 Patient Case Note Audits

		Time 1		Time 2
Comprehensive Geriatric Assessment	**%**	**N**	**%**	**N**
Compliance with multidisciplinary assessments:				
Mobility	74%	14	100%	20
Nutritional status	70%	14	100%	20
Pressure sore risk	95%	19	100%	20
Presence of pain	90%	17	100%	20
Continence needs	94%	17	100%	20
Functioning	60%	12	70%	14
Problem list recorded	74%	14	100%	20
Medical history recorded:				
Mental health history	94%	17	100%	20
Co-morbid conditions	100%	19	100%	20
Collateral history recorded:				
Presence of cognitive decline	42%	8	100%	20
Duration of memory problems	17%	3	100%	20
Nature of dementia progression	37%	7	100%	20
Evidence for loss of function	55%	11	100%	20
Assessments recorded:				
Mental status test	50%	10	69%	11
Behavioural changes indicative of delirium	0%	0	70%	14
Recent changes in mood	10%	2	90%	18
Behavioural/psychological symptoms of dementia	5%	1	80%	18
Antipsychotic medication				
Number of people with dementia prescribed/ administered anti-psychotic medications during admission	25%	5	65%	13
% of whom had a prescription for antipsychotic medication prior to admission	100%	5	69%	9
% of whom had a prescription for PRN antipsychotic medication	40%	2	36%	5
% of those above who were administered PRN antipsychotic medication	100%	2	100%	5

	Time 1		Time 2	
Referral to services	**%**	**N**	**%**	**N**
Liaison psychiatry	10%	2	5%	1
Psychiatry of older age	0%	0	15%	3
Geriatric medicine [15]	25%	5	40%	8
People with dementia requiring social work assessment	35%	7	35%	7
% of whom received assessment	71%	5	86%	5
% of whom received formal care provision assessment	80%	4	100%	5
% of whom received a home safety/environment risk assessment	20%	1	80%	4
Palliative care				
Resuscitation status documented	50%	10	25%	5
Referred to palliative care	25%	5	15%	3
Family carers referred to bereavement support [15]	15%	3	0%	0
Discharge				
Number of cases with symptoms of delirium during admission	57%	8	69%	9
% of those whose delirium symptoms were summarised for discharge	75%	6	56%	5
Number of eligible cases where discharge plan was initiated within 24 hours [15]	43%	6	50%	6
Named discharge co-ordinator in discharge plan	100%	12	100%	13
Appropriate place of discharge and support needed discussed with[18]:				
Person with dementia	58%	7	92%	12
Family carer	69%	9	100%	13
Consultant	29%	4	100%	13
Multidisciplinary team members	36%	5	100%	13
Identified support needs documented	71%	10	100%	12
Cause of cognitive impairment summarised	50%	7	92%	12
Record keeping				
Organisation and ease of locating dementia-related documentation in patient record:				
Well organised	0%	0	35%	7
Adequately organised	70%	14	45%	9
Poorly organised	30%	6	20%	4

---

15 The majority of patients included in the case note audit spent the most time during the admission on a care of the older person ward and thus did not require referral to a geriatrician.

16 It was documented in three of the five cases referred to palliative care at T1 that the bereavement service was not required, refused or the patient had not family carer. None of the case notes at T2 contained such information.

17 Twelve (86%) of fourteen eligible case notes audited contained a discharge plan at T1 and thirteen (100%) of thirteen eligible case notes contained a discharge plan at T2.

18 Percentage of patients eligible for discharge (i.e. patient did not die, self-discharge, or was not transferred to another hospital/ward) (T1, n = 11; T2, n = 13).

4.3 The Physical Environment

An environmental audit was conducted in the same three wards of MUH as the Ward Organisational Audit to ascertain environmental modifications completed in the course of the Cork-IDEAS project between T1 and T2. It should be noted that the planned changes to the physical environment focused on one of these three wards as outlined in Section 2.5.4. 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) from the same three wards as the ward organisational audit. At T1, environmental factors hindering the delivery of effective and personalised dementia care, included: communal ward spaces accommodating clients with diverse needs, a lack of personalisation and privacy in the ward environment, a lack of access to an outdoor space, a lack of dedicated space for person-centred activity, the reallocation of communal spaces to other functions, the absence of effective orientation and way-finding cues, and design features which were a challenge to dementia-friendly care, for example, lighting and noise:

> *"But like we don't even have a day room now, do you know, that they (people with dementia) could go up and watch television" (FG FC 02).*
>
> *"… more input about the signage and the importance of it … like using different colours you know like contrasting colours … it's all very obvious when you know but if you don't know it's not obvious" (FG FC 04).*

A number of participants described a conflict between the need to promote the physical safety of the person with dementia, for example, with the use of electronic ward entry systems, and the need to uphold their right to independence and freedom of movement, while supporting the accessibility of the ward for family carers. Consequently, a number of those interviewed at T1 identified the need for environmental innovation to enhance the experience of dementia care within the hospital.

The majority of the environmental changes undertaken between T1 and T2 (Section 2.5.4; Table 1) took place on one ward as described in Chapter 2 (Section 2.5.4). Analysis of the audit data across all three wards at T1 indicated a range of dementia-positive aspects, including corridor space suitable for walking and spacious bathroom facilitates. However, none of the wards used dementia-friendly colour schemes to assist persons with dementia to orientate themselves or navigate the ward. By T2, all three wards showed evidence of using colour to provide orientation assistance to some degree, two wards implemented colour orientation assistance within particular areas of the wards, while one implemented changes throughout. There was a clear contrast between signage and background colours in all wards at T2. Further improvements were noted as people with dementia were able to view personal items, a clock and staff members from their bedside. Signage to toilet facilities was visible to some patients from the bedside and items such as soap dispensers, bins etc. were labelled with pictures and words on one ward. However, only one ward had a room available for people with dementia to take a break from the ward at T2.

In the course of the project, changes to the physical environment were consistent with design features that are internationally recognised as best practice and responded to many of the points raised by participants at T1. Furthermore, the ward where the majority of changes were implemented was described as representing the ideal of a dementia-friendly hospital setting. Examples of the changes that were made are shown in the images below.

Day Room in the Care of the Older Person Ward: Before and After Redesign [19]

Flooring in the Care of the Older Person Ward: Before and After Redesign [20]

---

[19] Images reproduced with the permission of Dr Suzanne Timmons, Cork-IDEAS Project Lead.
[20] Images reproduced with the permission of Dr Suzanne Timmons, Cork-IDEAS Project Lead.

In particular, participants discussed the benefit of the transition from a clinical to more personalised and homely design. Participants highlighted examples of how the redesigned spaces were being used to enhance person-centred care:

> "Then there is the day room there and the environment there and I have noticed that a lot more patients and their families are using that room now … because it's much more comfortable and it is homely" (FU SI FC 11).

T2 interview data demonstrated that environmental changes arising from the Cork-IDEAS project impacted upon the wider hospital environment and various health and social care professionals, functioning as an accessible and symbolic representation of the essence of the Cork-IDEAS project:

> "You put something in as strongly symbolic and as clearly seen as an environmental change, you know, and everybody knows about it, everyone appreciates it and it has really, really reinforced the positive, the appreciative aspect of the project" (FU SI FC 04).

Many participants, particularly those who attended dementia education described the environmental changes that had taken place, as well as the reasons they considered the changes to be dementia-friendly:

> *"I saw the flooring first and I thought why did they change it? It was a lovely bright floor … I realised then with the training and everything why. And the ways signs on the doors in [name of ward] and the photographs. And now I suppose it's on the ward as well so that you are aware that it is a dementia patient" (FU FG FC 01).*

The finding that those who had attended education indicated they better understood dementia-friendly environmental principles could suggest cross-fertilisation between the project elements and the benefits of a multicomponent project to enhance integrated dementia care. For example, on wards where only some dementia-specific bays existed, the use of colour to designate a dementia-friendly room was a reminder to staff that patients within those rooms may have dementia. There was some suggestion that being placed within such a space might enhance the experience of the physical environment and the person-centredness of care for the person with dementia. Some participants suggested awareness of the environmental changes that had taken place during the project highlighted how the impact of the hospital environment on dementia care and the person with dementia was scarcely questioned prior to implementation of the Cork-IDEAS project. However, this had changed for many of those at T2. Indeed the project had raised awareness of the wider impact of dementia-friendly design on patients' experiences of the clinical area and enhanced cognisance of the actions required to advance environmental developments in future environmental work.

> *"I think the flooring even for a start you know? It made so much sense when you say afterwards about you that the flooring is all one colour and there are no changes. And it made sense but none of us, I never recognised that when I was working there you know?" (FU SI FC 11).*
>
> *"… integrating the environmental piece into all of our project submissions to make sure that everything is dementia-friendly going forward … I think it's (dementia-friendly design has) got so much potential" (FU SI FC 09).*

The environmental impact of the Cork-IDEAS project extended beyond MUH, serving as an exemplar to other locations. Members of the project team provided consultancy on dementia-friendly design in MUH-linked organisations, including SFH and St. Francis Unit, and at least one other local initiative. Secondly, while the hospital funded much of the environmental change costs, the project team also partnered with the Mercy Foundation to fundraise for this project activity. This endeavour raised the public profile of the project and led to connections with the local community in Cork, and donations from the public which enhanced the environment (Section 2.5.4).

With reference to the learning from the process of environmental change, staff recognised the complexity involved in planning, implementing and embedding such change and the range of issues that needed to be considered. Specific challenges encountered in this regard included: making changes within an existing building, the costs associated with materials and change itself, and time required to plan and mobilise resources. Also, support is required from multiple stakeholders to implement the required works and there is a need to obtain permissions and meet regulatory requirements. Finally, the need to consider the logistical issues that arise when making environmental changes to a clinical environment, for example, the need to move patients and ensure 24-hour care delivery is not disrupted:

> *“I suppose the other learning was how difficult it is to make changes in a hospital. So because health and safety and fire regulations, a lot of things that you would like to do for best care of a person with dementia directly conflict with other agendas. So it is a lot of time and work” (FU SI FC 18).*

However, several factors facilitating environmental change were identified. Of central importance was the project OT who provided dementia-specific expertise and experience of environmental design. The OT drove the environmental change process to implementation and was considered the person to consult to ensure specific environmental changes would be dementia-appropriate. Indeed, the experiential learning of the OT led to the publication of *‘A Guide to Creating a Dementia Friendly Ward in the Acute Setting’* which is available for use in other hospitals to inform similar work. Other project personnel and consortium members, particularly the DNS, were also involved in environmental changes. There were suggestions that seeing the outcome of changes contributed to an onward momentum which eased successive environmental changes. The support of hospital management mobilised via the consortium also assisted in a number of ways, including financial support and commitment to embedding dementia-friendly design considerations in future hospital funding applications and developments.

4.4 Dementia Education and Awareness

4.4.1 Awareness and Knowledge of Dementia

The awareness and knowledge levels of staff in MUH were assessed by the Cork-IDEAS team, through a baseline survey conducted in the period August 2014 - January 2015 and a follow-up survey conducted from May - June 2016. Analysis at both time points was conducted by the evaluation team. The surveys were accompanied by an education needs assessment for hospital personnel and allied health care professionals at baseline and follow-up (all roles except nursing and healthcare assistants). The findings from this assessment demonstrated that there was quite a large number of ‘not sure’ responses, indicating a potential uncertainty around perceived knowledge needs. However, there was a high need identified in a number of areas, for example, knowledge to assess the capacity of people with dementia to be involved in decision making and respondents’ abilities to discuss difficulties and options with family carers.

The awareness and knowledge surveys were administered by the Cork-IDEAS project Research Support Officer, Dawn O'Sullivan, under the guidance of Dr Suzanne Timmons. A total of 499 staff completed 'The Approaches to Dementia' questionnaire (Lintern and Woods, 1996), which measures staff attitudes towards people with dementia, at baseline and 347 at follow-up. The 'Alzheimer's Disease Knowledge Scale' (ADKS) questionnaire (Carpenter *et al*., 2009) was also completed by staff who worked closely with people with dementia, 185 at baseline and 139 at follow-up. A profile of the overall surveys' respondents is presented in Tables 7 and 8. 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
Total no. of respondents	499
Breakdown of responses	315 - Approaches to Dementia questionnaire only 184 - Approaches to Dementia questionnaire & Alzheimer's Disease Knowledge Scale questionnaire
Gender	80% female
Mean age[21]	38 years (range 20-60 years)
Job roles	
Clinical Nurse Manager (CNM)	-
Healthcare Assistant (HCA)	30 (6%)
Staff nurse	154 (30.9%)
Allied health professionals	69 (13.8%)
Other ancillary and support staff	246 (49.3%)

Table 8. Sample Size and Demographics Follow up

	Follow-up
Total no. of respondents	347
Breakdown of responses	208 - Approaches to Dementia questionnaire only 139 - Approaches to Dementia questionnaire & Alzheimer's Disease Knowledge Scale questionnaire
Gender	76.4% female
Mean age[22]	39 years (range 21-61 years)
Job roles	
Clinical Nurse Manager (CNM)	30 (8.6%)
Healthcare Assistant (HCA)	26 (7.5%)
Staff nurse	83 (23.9%)
Allied health professionals	51 (14.7%)
Other ancillary and support staff	157 (45.3%)

---

[21] At baseline, age was only recorded for nurses and healthcare assistants.

[22] At baseline, age was only recorded for nurses and healthcare assistants.

Seventy percent (n = 349) of the 499 staff surveyed at baseline and 65% of the 347 (n = 226) surveyed at follow up, had worked in their current job for more than seven years. The cohort was therefore a very well experienced group. At baseline, the majority of these staff reported that they had a general understanding of what dementia was (69%) and that they felt comfortable working with a person with dementia (59%). These figures had risen at follow-up (80% and 71% respectively). Nurses, CNMs and HCAs were asked to self-rate their own knowledge of dementia on a scale of 1 to 10[23] and the majority at both baseline (85%, n = 157/184) and follow-up (83%, n = 115/139) perceived that they had some knowledge. While the percentage that perceived they had very good knowledge, increased from baseline (1.6%, n = 3/184) to follow up (5.8%, n = 8/139) these numbers were small and it should also be noted that the respondents were not matched.

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 where people with dementia are recognised as sentient beings. 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 (2001), 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 = 25.5; +12.5%) and the Personhood subscale (M = 47.4; +5.3%) indicating more hope and better recognition of personhood at follow up. However, one-third of the 499 respondents at baseline and over half of 347 respondents at follow-up believed that most older people have dementia. An overview of the summary scores is presented in Table 9. While there is an overall improvement in the scores at follow up, this should be interpreted with caution as the participants were not matched and there is no way of establishing if the participants attended the educational initiatives associated with the project.

Table 9. Approaches to Dementia Questionnaire Summary Scores

	Baseline		Follow-up		Change
	N	Mean (SD)	N	Mean (SD)	%
Hope sub-scale *(possible score 8-40)*	493	22.7 (5.2)	338	25.5 (5.1)	**+12.3%**
Personhood sub-scale *(possible score 11-55)*	494	45.0 (4.1)	338	47.4 (4.3)	**+5.3%**
Total Score *(possible score 19-95)*	490	67.6 (6.2)	333	72.9 (7.6)	**+7.8%**

---

[23] 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).

When looking at the mean scores of staff at close contact with people with dementia, 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 nursing staff. It is worth noting that there was little difference between the two groups mean scores at baseline.

Table 10. 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	186	66.6 (5.4)	199	76.0 (7.3)	+14.1%
Ancillary and support staff	307	68.2 (6.6)	134	70.8 (7.1)	+3.8%

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. The ADKS questionnaire was administered only to staff who had higher levels of contact with people with dementia. The baseline sample included 184 staff nurses and HCAs, while the follow-up sample was slightly smaller with 139 staff nurses, CNMs and HCAs. CNMs were not included in the baseline sample. Results are summarised in Table 11.

Table 11. Alzheimer's Disease Knowledge Scale Summary Scores

ADKS[26]	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 Follow-up	176 138	2.4 (0.7) 2.3 (0.7)	148 83	2.4 (0.7) 2.3 (0.7)	- 29	- 2.4 (0.6)	28 26	2.4 (3.4) 2.2 (0.8)
Risk Factors (possible score 0-6)	Baseline Follow-up	168 137	3.6 (1.2) 3.3 (1.2)	142 82	3.6 (1.1) 3.3 (1.1)	- 29	- 3.7 (1.2)	26 26	3.4 (1.3) 3.0 (1.4)
Symptoms (possible score 0-4)	Baseline Follow-up	178 138	3.2 (0.9) 3.2 (0.9)	148 83	3.2 (0.9) 3.2 (1.0)	- 29	- 3.2 (0.8)	30 26	3.0 (0.9) 3.3 (0.8)
Treatment & Management (possible score 0-4)	Baseline Follow-up	174 137	3.2 (0.8) 3.3 (0.8)	146 81	3.3 (0.8) 3.3 (0.8)	- 30	- 3.5 (0.7)	28 26	3.0 (0.9) 3.0 (0.8)
Caregiving (possible score 0-5)	Baseline Follow-up	175 136	3.9 (1.0) 4.0 (1.1)	146 80	3.9 (1.0) 4.1 (1.1)	- 30	- 4.1 (0.9)	29 26	3.8 (1.2) 3.9 (1.2)
Course (possible score 0-4)	Baseline Follow-up	167 137	2.9 (0.9) 2.7 (0.9)	139 83	2.9 (1.0) 2.6 (1.0)	- 29	- 2.7 (1.1)	28 25	3.0 (0.7) 3.9 (1.2)
Assessment & Diagnosis (possible score 0-4)	Baseline Follow-up	177 137	3.4 (0.7) 3.5 (0.7)	148 83	3.4 (0.7) 3.5 (0.6)	- 29	- 3.5 (0.8)	29 25	3.0 (1.0) 3.3 (0.7)
TOTAL (possible score 0-30)	Baseline Follow-up	147 130	22.4 (3.1) 22.3 (3.2)	123 78	22.6 (3.0) 22.4 (2.9)	- 27	- 23.0 (3.2)	24 25	21.4 (3.4) 21.5 (3.9)

As illustrated in the table, on average there was a good level of dementia knowledge among respondents at both baseline (M = 22.4) and follow-up (M = 22.3), 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: 11-28; follow-up: 14-30) is indicative of some degree of variability. The similarity between mean sores at both baseline and follow up is likely reflective of the fact that the sample was not matched and it is not known if they attended the educational programmes. 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 (except for the Course sub-scale, where there was a 30% improvement in the score of HCAs).

---

[24] Red indicates decrease in scores between T1 and T2.

4.4.2 Cork-IDEAS Education and Training Initiatives

Education and training initiatives were a central component of the Cork-IDEAS project and traversed the hospital and community sites. The central message of the education initiatives was that regardless of role or profession within the hospital or community, everyone had a part to play when it came to dementia and a united coherent approach was necessary. However, there were slight differences in the focus of these sessions depending on the context of care and the participants who attended. In the acute services, the emphasis was on helping staff get a sense of the hospital experience thorough the eyes of a person with dementia and some of the strategies that could be used to make their stay more comfortable while in the community, emphasis was placed on avoiding unnecessary hospitalisation and improving the overall quality of life for people with dementia. Nevertheless, the education sessions were underpinned by person centred approaches and stressed the importance of getting to know the person with dementia and using appropriate communication strategies to engage with the person. While the emphasis was on classroom based approaches that took place within the Centre of Nurse Education, these were supported by other less formal and opportunistic educational approaches that also took place as the project unfolded. As mentioned in section 2.5.5, a range of educational initiatives were used and the number of attendees are presented in Table 12. Some of the educational programmes were open to all staff but others were targeted at staff who had more contact with people with dementia as part of their roles (for example, staff nurses, HCAs and volunteers). The educational initiatives yielded considerable reach across both sites and were generally very well evaluated.

Table 12. Overview of Attendance at Educational Programmes

Name of Programme	Attendees
General dementia awareness	650
Education and training for medical doctors.	(approximately) 279
Enhancing Well-Being for the Person with Dementia in the Acute Hospital.	92
Enhancing & Enabling Well-Being for the Person with Dementia	43
Responsive behaviours	8
Growing Excellence in End of Life Care	12
Dementia Champion Training	22

Throughout the evaluation interviews and focus groups, there was a strong sense that the main impact of the education programme was that it increased the awareness and visibility of people with dementia throughout the hospital. This was described as a cultural shift in the way the participants considered people with dementia that resulted in a greater conversation around dementia generally. This was reflected in a change in the ways they interacted and worked with those affected, including their families. This is not to say that interactions were previously negative, but the education programme helped to drive home the need for positive interactions with people with dementia and the small but important approaches that can be implemented to enhance their experiences when they are hospitalised. This was supported by other initiatives within the acute sector, such as the availability of the DNS. The participants also talked about how they recognised that the approaches to care for the person with dementia needed to be different and this was reflected in more communication based and thoughtful interactions. For example, one of the participants talked about how staff took more time to explain things to the person with dementia and another participant talked about how attending the education programme allowed her to be more creative with caring interventions. There were also references to staff feeling empowered and more willing to engage with the person with dementia and this was not just from a frontline caregiver perspective. Some of the participants talked about being more aware and confident to talk to or help a person who looked like they were confused or lost. In the following quotation, the participant talks about how the education programme and other initiatives helped raise awareness and change practices among some of the support staff in the hospital:

> *"It's actually made people aware of dementia and the do's and don't' s. Prior to that we had no knowledge you know bringing a person into the lift, facing a mirror you know we never knew that that would affect somebody with dementia. Its only since all this came in we are now more aware of you know of how to relate to people and especially when [DNS] was here we found it great because what she brought in was that we now have a thing, a chart at the end of their beds so we know what they like and dislikes and their hobbies prior to coming in. And whether they were married. So you know you are able to have a conversation with them now. And you are able to relate better to them" (FU SI FC 17).*

There findings suggested that the initiatives throughout the hospital and the community had an impact on participants' engagement with people with dementia and that many participants were now equipped with some of the necessary skills to do so. For example, simple approaches such as holding a door open for someone or asking a person if they were okay were mentioned and highlight how small but important approaches could improve the overall experience for the person with dementia. In addition to the needs of the person with dementia, there were many references to the increased awareness of the family's experiences and needs as well. Finally, some of the participants provided anecdotal evidence of the success of the awareness programmes. For example, it was suggested that people with dementia and delirium were more likely to be recorded on discharge and that there appeared to be less one-to-one supervision of people with dementia.

Evaluations of the education and training programmes were generally positive and feedback consistently described them as excellent, important, insightful and useful. In addition, the facilitators of the programmes were praised in terms of the delivery and methods of teaching used. The video 'Barbara's story' (Guy's and St Thomas' NHS Foundation Trust 2014) was well referenced throughout the evaluation forms and the focus groups as having a major impact in terms of understanding the experiences of people with dementia particularly within the acute sector. From a facilitator point of view, the face-to-face programmes provided an opportunity to link the different initiatives that were happening throughout the hospital and community, and to present the project as a coherent whole. This was difficult during the early part of the project as the education programme began prior to the environmental changes or ICP development. A number of Dementia Champions were also trained as part of the project and while their education programme was in the main positively evaluated, their influence was less felt in terms of project impact than originally envisioned within the acute services. While a number of staff successfully completed the Dementia Champions course whilst working within the acute hospital, they did not remain as part of the workforce due to either leaving the service or being promoted to other positions. This meant that a critical mass of Dementia Champions was never achieved. There was also some reference to difficulties recruiting people to take up Dementia Champion training, particularly in the community, due to the commitment it entailed from a workload and time perspective. However, there were Dementia Champions trained and in place in the community and these were perceived as invaluable in terms of supporting the education initiatives and the primary healthcare services.

There were several issues that impacted on the delivery of the educational component. Firstly, early in the project, the educational lead retired and while she was replaced, it was generally felt that this was a loss of expertise in the area. However, there was still capacity to use experts from the clinical areas in the delivery of the programmes, including the DNS. Staffing issues were perceived as a particular challenge and releasing staff from the acute areas was especially difficult, despite attempts to encourage attendance at the programmes through reminders about them and by increasing the visibility of the project. The individuals who designed the educational initiatives were acutely aware that staff release and attendance were a potential concern and therefore designed programmes that were short with emphasis that participants could engage with longer, more comprehensive programmes if they wished. This posed an additional challenge as it was felt that a lot of content had to be covered within a relatively short timeframe and this was reflected in some of the evaluations. In addition, an embargo on staff replacement also had a negative effect on attendance at the education programmes. This was not an issue in the community where staff turnover was not as big a concern. Furthermore, there were also many references throughout the interviews to how the Cork-IDEAS project had to compete with other education and training that was happening around the hospital which sometimes took priority in terms of releasing staff to attend.

The Cork-IDEAS project team recognised that there was a need to sustain the educational initiatives beyond the life of the project and several strategies were put in place to achieve this. From the outset, programmes already being delivered were utilised and the project team were not only successful in terms of availing of these, but also alerting staff to their availability. This means that the education centre retains a suite of dementia education programmes that can be delivered in response to demand. The one hour awareness programme was also part of the national dementia programme although it was amended slightly for local use. This is now incorporated into the staff induction programme and all new staff will receive it going forward. The four-hour programme for staff working in the acute sector will also be retained and will be delivered post project, albeit not as frequently. Furthermore, dementia education will continue to feature strongly as the education team are committed to its promotion and delivery. Within the community, there are also plans to nominate one Public Health Nurse in each primary care team as a Dementia Champion.

There was also discussion during the stakeholder interviews about sustaining the impact of the educational initiatives. While there was a perceived need expressed in terms of someone to drive the education from a practice perspective, there was also a need for someone to help in the maintenance of their impact. Here the ICP was used as an example; while the ICP may be in place, staff may need to be made aware of it or reminded of its existence and Dementia Champions may have been ideally suited to assist here. The DNS was also ideally placed to ‘put a face’ on the education programme and both the Dementia Champions and the DNS were essential to its sustainability due to their immersion in clinical practice. In addition, the opportunistic educational opportunities which proved to be a successful strategy were unlikely to continue in the same way due to the lack of visible people engaged in these roles.

4.5 Summary of Cork-IDEAS Project Impact and Outcome Findings

- Clear project governance with responsibility for project components designated to identifiable personnel were key factors in the project outcomes achieved.
- An ICP for dementia care was developed, piloted and implemented in the ED and three hospital wards in MUH.
- The activities which fed into the development of the ICP ensured that it was attuned to both the person with dementia's journey and the organisational structures within MUH.
- The ICP piloting and its subsequent introduction in practice were centrally supported by the DNS and the enhanced level of dementia awareness achieved by other project activities.
- While evidence from multiple sources supported the use of the ICP, DCB and 'This is Me' document where introduced, the degree of implementation was variable.
- The role of the DNS evolved to be multicomponent encompassing: Cork-IDEAS project activities, provision of person-centred care, support of the ICP and DCB development and implementation, and consultancy.
- The cessation of the DNS role was perceived as having a significant negative impact on the potential for integration of dementia care within MUH and the sustenance of project gains into the future.
- The CDCC role was multicomponent encompassing: Cork-IDEAS project activities, a point of contact for dementia care support, advice or referral, provision of dementia care and, dementia care consultancy and representing the voice of dementia care on community committees.
- The community component of the Cork-IDEAS project, through the CDCC and consortium, was successful in building a network of relationships and service contacts relevant to dementia care; and a hub for peri- and post-diagnostic support, integrating and enhancing existing services in the community.
- Awareness of dementia and positive attitudes towards people with dementia among service providers, while high at baseline, improved post project implementation as measured by the Approaches to Dementia Questionnaire (Lintern and Woods, 1996). On average, there was a good level of dementia knowledge among respondents at both baseline and follow-up as measured by the Alzheimer's Disease Knowledge Scale (Carpenter *et al*., 2009).
- Dementia education and training was a key feature of the Cork-IDEAS project and a range of programmes were delivered that mostly drew from existing resources.
- The education programmes were positively evaluated and there was evidence of increased awareness of dementia particularly throughout the acute hospital.
- The project evaluation interviews and MUH 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.
- Environmental changes were highly visible and facilitated by expert input from a dementia experienced OT. These changes appeared to enhance stakeholder buy-in and were widely recognised as resulting in greater understanding of the importance of how personalised and environmentally appropriate hospital settings can be used to enhance person-centred care.
- Evidence suggested that cross-fertilisation occurred between project components and that this resulted in a positive impact on the potential to enhance integrated dementia care within MUH.

5. Cork-IDEAS 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 Cork-IDEAS project. These findings are presented with reference to the:

- Function and impact of the Cork-IDEAS project consortium,
- Factors impacting on the implementation of the Cork-IDEAS project:
  - Factors facilitating the implementation of the project,
  - Factors challenging the implementation of the project.

5.2 Function and Impact of the Cork-IDEAS Project Consortium

The findings of the evaluation provided clear support for the contribution of the Cork-IDEAS project consortium to the project outcomes achieved. Pivotal to this success was the strategically chosen membership of both sub-consortia, including key organisational personnel from various management, departmental and discipline levels within the hospital consortium, and representatives from key disciplines and services in the community consortium. As the project developed, the role of the community consortium appeared to evolve, serving as a medium of communication and network-building rather than a driver for project components. Thus, while it did not function as might have been envisaged at the outset, it did appear to serve a valuable function in:

1. Bringing together interested parties,
2. Raising awareness of both dementia and the Cork-IDEAS project developments,
3. Providing a new forum to identify and build strategic linkages between services that could support those living with dementia in the community.

The role of the hospital consortium was more streamlined to focus on the project-related activities located within the hospital and raising the profile of dementia throughout the MUH organisation. A whole-organisation multi-level perspective was adopted in the set-up and operationalisation of the hospital consortium to bring key stakeholders together. It was further evident that members' roles were dynamic throughout the life of the project consortium and particular roles may be more active and involved at different points of the implementation of Cork-IDEAS. Although some consortium members believed they didn't have an active project role per se, they found the consortium process interesting and engagement with the consortium process facilitated their awareness of progress within various components of the project. This enhanced communication of project-related information to colleagues and facilitated project-related feedback to the consortium from organisational, departmental and disciplinary perspectives. Importantly, the consortium also functioned as a forum where emerging challenges could be brought, solutions identified and stakeholders mobilised to action them. The consortium was spoken of as a means of supporting the project to gain traction and enhanced understanding of service and disciplinary roles and functions. Indeed, some members described new learning and enhanced appreciation of other roles and disciplines, as a consequence of their participation in the consortium.

A number of factors were identified as influencing the overall positive experience of consortium membership. The frequency and timing of consortium meetings were not considered overly onerous on its members and several highlighted the efficiency of communication during meetings. In addition, some consortium members were also on the working groups that were established to advance particular project components (Chapter 2, Section 2.5) and this dual membership was advantageous to the achievement of project aims. However, several members suggested that a longer lead-in time would have been advantageous to project implementation, and a number felt consortium meetings could have been scheduled more regularly. Overall though, there was a sense that the way in which the consortium functioned was linked to the sustenance of participants' commitment to, and interest in, dementia care and the Cork-IDEAS project:

> *"I suppose the huge benefits and learning for me, was working with a wider multidisciplinary team. I think you have to leave your own specific care discipline … when you go into those kind of meetings, you know? Because it's about everybody looking to see what is the service that we want to offer our patients … and making sure everybody in on the same page … even those who may not be clinically focused, they have other expertise that the can bring to it (the project)… I found those, the consortium meetings you know very invigorating, or very informing … which you can't say about every meeting that you go to" (FU SI FC 01).*

Taken together, the findings in relation to the Cork-IDEAS project consortium demonstrate its success in enhancing partnership and building shared ownership and momentum for the integration of dementia care in MUH. There was also some suggestion of the potential for organisational benefits beyond the life of the project. Indeed, towards the end of the project, a decision to continue the consortium had been confirmed, albeit with plans to potentially change the name and re-vision its precise purpose in terms of integrating dementia care.

5.3 Factors Impacting on the Implementation of the Cork-IDEAS Project

The previous chapter discussed factors that were found to impact on the individual components of the Cork-IDEAS project. However, the project evaluation findings identified a number of overarching project facilitators and challenges that were particularly influential in terms of how the project developed and the outcomes which were achieved. Analysis demonstrated that facilitators frequently counterbalanced the challenges encountered and that this was likely to have made a strong contribution to the project gains (Figure 11). Although the project facilitators appeared to be continuously active over the course of the project, some of the challenging factors were particularly active at certain times only. It was also evident that the project-specific personnel engaged in 'learning in action', incorporating their ongoing experiential learning into the project as it unfolded. At T2, they further demonstrated evidence of having reflected on project activities and processes, so as to articulate and share their learning for future projects.

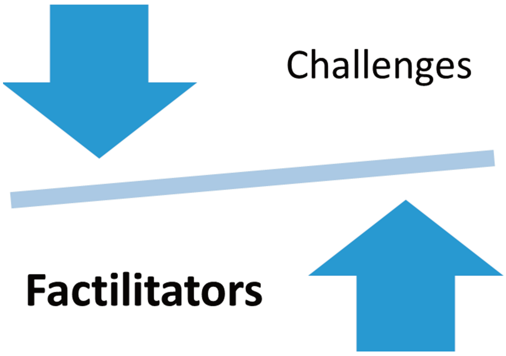


Figure 11. Project Facilitators Acting as a Counterbalance to Project Challenges

5.3.1 Factors Facilitating the Implementation of the Project

Eight project facilitators were identified which taken together represented the factors that were active in supporting the onward movement of Cork-IDEAS over its timeline (Figure 12).

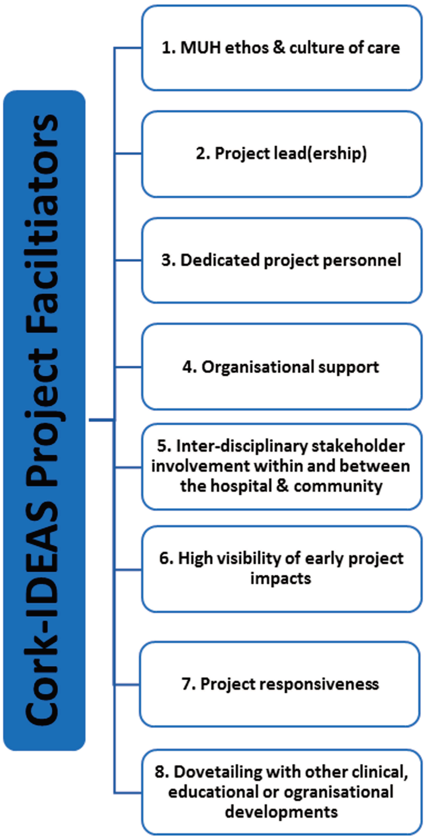


Figure 12.
Overview of Project Facilitators

1. The **ethos and culture of care within MUH** was repeatedly identified as an enabler of the outcomes achieved over the course of the project. At T1, for example, many participants spoke of the hospital's existence within the heart of the local community and the ethos of caring and personalisation of care as being particularly attuned to meeting the needs of people living with dementia. However, there were also references to the acute setting as busy and fast paced, with an emphasis on throughput and discharge, as shown here:

> *"And like in the acute hospital everything moves so fast here now you know? It has changed so much really in the last few years even, you know the focus is, you it's a quick treatment and treating whatever issue they came in with and out the door" (SI FC 02).*

At T2, comments about the unsuitability of the acute hospital to meeting the needs of the person with dementia were much less common. Indeed, comments about the environment became more focused upon the growing awareness of the means by which the hospital environment and stakeholders could support the needs of the person with dementia. This positive growth was in part linked to a "really fantastic, 'yes we can' attitude" (FU SI FC 04) that was related to the overarching ethos and culture of care within MUH. Linked to this, the smaller size of the hospital and its value system appeared to support interdisciplinary and interdepartmental working to facilitate the project aims:

> *"There's always the opportunity to bring the values of your organisation into everything you do … But I think the fact that we are a close knit team you know, definitely helps" (FU SI FC 01).*
>
> *"The [name of hospital] is really good for people working together … Openness to improving and to working together with different people… constantly improving" (FU FG FC 02).*

2. The **Project Lead** was highly identifiable from early on in the evaluation as a key driver in providing leadership for dementia care improvement and initiating, driving and sustaining dementia care integration within the project settings. In terms of the project gains, many participants referred to the crucial role that strong leadership played within the context of Cork-IDEAS, with one stating *"It's all about leadership really" (FU SI FC 13).* The open and facilitative style of leadership displayed was remarked upon as bringing about clarity in the project purpose and inspiring a will to succeed among the evaluation participants. There was also reference to the importance of the leadership role being linked to a person who would still be there following the project conclusion. This was identified as an important support for the maintenance of dementia care as an ongoing priority in the hospital and linked community settings.

3. As described in Chapters 2 and 4, a number of **dedicated project personnel** were incorporated into Cork-IDEAS who each had responsibility for particular project components and/or aspects of clinical dementia care. The evaluation highlighted the importance of the strategic choices made in relation to the type of roles developed to advance the project aim of enhancing the integration of dementia care. The project personnel were central to the outcomes achieved, with participants describing them as:

- Being the face of the overall project on the ground,
- The points of contact for, and drivers of, specific role-linked project components,
- An important source of support for staff to enhance dementia care delivery and meet the specific dementia care needs of people with dementia and their family carers.

It is evident from the results of the evaluation and the intention to work towards embedding the project roles on an ongoing basis that these roles were perceived to be important to the implementation and sustenance of positive gains from projects such as Cork-IDEAS beyond their conclusion.

4. The **support of the organisation** was evident at multiple levels throughout the hospital, and further enabled the project. The project consortium members included organisational stakeholders who were strategically identified as being able to provide corporate sponsorship, and in some instances, support and leverage resources required to advance project activities. It was suggested that this support functioned as a conduit to unlocking potential blockages along the trajectory of the project:

> *"… used me as leverage . my role … has been sort of as a sponsorship role … from an organisational perspective…so I'd say if they ran into a little bit of trouble they could just escalate to me and we could move it on" (FU SI FC 09).*
> *"… in giving the project a voice at the executive table" (FU SI FC 01).*

In addition, there were indications that organisational level knowledge of the enhancements to dementia care achieved, and their impacts in practice and on the wider system, had led to a commitment to embed dementia-friendly principles into future organisational developments where possible.

5. While organisational support was a pivotal project enabler, so too was **interdisciplinary stakeholder involvement** within, and between, the hospital and community contexts. Key stakeholder involvement functioned to enable network building and two-way flow of information into the project to inform the development of realistic project components responsive to the realities of practice, and out of the project to build momentum and advance dementia care buy-in among inter-disciplinary, inter-departmental, and to some degree, inter-sectoral stakeholders.

6. The communication and buy-in outlined above, along with the environmental changes, enhanced the **visibility of the early project impacts** and were an unanticipated but extremely important means of raising dementia awareness early on.

7. Analysis of the intended Cork-IDEAS project components and eventual outcomes, demonstrated that the project was **responsive** to emerging considerations, in that project aims and activities were adapted over the timeline of the project:

> *"We had a lot of goals in our project … we thought we were going to do too much. I'm very reconciled to the fact that we ran with the things we were winning on … I think there comes a time where you think listen this was a great idea but actually it's just not for now, not for here" (FU SI FC 19).*

In so doing, it moved to focus on aspects that:

- Had the best chance of achieving completion in the required time-frame,
- Were realistically scaled (for example, large-scale environmental changes focusing on one ward, one ED bay and the link corridors), or
- Best met the needs and expectations encountered on the ground (for example, end-of-life care educational input for residential settings).

This is not to say, however, that aspects of the project were overlooked or unaddressed. Instead, plans were adjusted and the related activities and consequent outcomes in those instances may have created a more solid foundation to build on and enhance person-centred dementia care into the future.

8. The final project enabler identified suggested that where developments to support the integration of dementia care **dovetailed with other clinical, educational or organisational activities**, there was the potential for synergistic benefits. Particular examples of this included the incorporation of national developments in the early identification of delirium in older adults with the development of the ED dementia care ICP (Chapter 2, Figure 3) and the incorporation of dementia awareness into new staff induction moving forward.

5.3.2 Factors Challenging the Implementation of the Project

Three overarching challenges were identified that impacted on the implementation of Cork-IDEAS over the project timeline (Figure 13). Some of these contained levels of complexity that taken together had the potential to exert a negative effect on the likelihood of achieving the intended project aims. However, as outlined above, the project facilitators frequently served to mediate and/or counter the challenges outlined below.

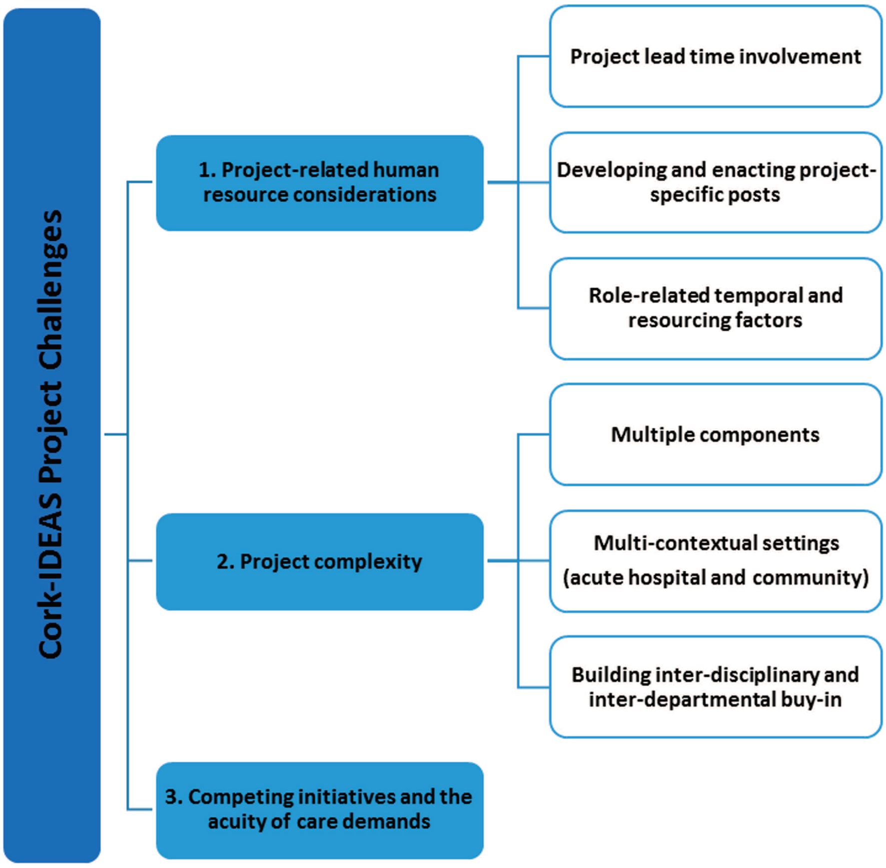


Figure 13. Overview of Project Challenges

1. Although the previous section ascribed project successes in a large part to project roles, it was evident that there were some **project-related human resource considerations** that were considered challenging at various times.

Firstly, due to the complexity of the project, there was a considerable **time commitment required from the project lead.** Project-related activities carried out by the project lead were taken on in addition to the roles and responsibilities of the person's overall role within MUH. Indeed, the time needed to fulfil the role as project lead was somewhat beyond expectations of the role at the project's inception. This underestimation came about for several reasons, including the scope of the project and the intention for activities undertaken by the project lead to be shared rather than carried out by a single person. This finding led to consideration of whether projects such as Cork-IDEAS might benefit from a designated project manager role in addition to the project lead. However, the degree of involvement of the project lead, her familiarity with and to staff in the clinical setting, and her knowledge of and commitment to the project were important facilitators of the project (Section 5.3.1).

Secondly, the project-specific roles introduced were new, and were **developed and enacted** over a tight timeline, parallel to the onward movement of project components. This meant considerable work was required of project-specific role-holders to: acclimatise to the clinical contexts where they were new to the setting, develop clinical roles, identify responsibilities, build new communication and reporting relationships, and lead out on project components.

Thirdly, the commencement and end dates for the project roles differed and this led to **role-related temporal & resourcing challenges.** In one instance, this was due to delays in the recruitment process and the CDCC role commenced later than anticipated as a result. This inevitably altered the timeline for the community component of the project. The DNS role also ended prior to the overall project and this had consequences for the support of the ICP roll-out and related education (Section 4.2.2).

Finally, while decisions had been made regarding the continuation of project personnel roles (Section 7.3) at the time of writing this report, there was some inference to concerns about long-term resourcing during the project implementation. During interviews, staff highlighted the positive impacts on dementia care practice that they had experienced from having the DNS and CDCC roles in place. However, some expressed concerns about the uncertainty that existed at the time with regard to the future resourcing of these roles. There was concern about the potential loss of these roles and it was suggested by one participant that a commitment at the outset of a project to sustain a new role, should it prove beneficial, would help to alleviate such concerns.

2. As with other projects of this nature, Cork-IDEAS was acknowledged to have a high degree of inherent **project complexity.** Firstly, as demonstrated in Chapters 2 and 4, the project was **multi-component** in nature and these components were ongoing simultaneously. While this was pivotal to the achievement of its aims, there was a necessity to maintain a consistent balance across the project components, each of which had multiple associated activities. This was required to ensure push-through to deliver on the stated project purpose and was an ongoing challenge.

Secondly, the project was **multi-contextual** in that it involved hospital and community settings. These settings are heterogeneous in nature with differing systems of service provision, organisation and delivery. Although the ultimate aim to enhance quality of care and service-user well-being and quality of life were the same, it was evident that project activities differed in some ways, despite some cross-over. The complexity here was further added to by the intent to enhance and embed dementia-related communication links between hospital and community.

Thirdly, to achieve its ends, the project required **interdisciplinary and inter-departmental buy-in** from across the hospital. Reference to the positive involvement of such stakeholders within the project consortium and the facilitating role of interdisciplinary stakeholders on the ground have been addressed previously (Sections 5.2 and 5.3.1). However, before these positive contributions could be leveraged to work towards enhancing and integrating dementia care, there was a need to firstly create buy-in and commitment from stakeholders:

> *"At the start when it (Cork-IDEAS) came you know that we were getting this project and there was a bit of fear … And actually if you go back [now] and ask people sure you know it wasn't like that … it's just that we have a better place for people" (FU SI FC 11).*
>
> *"Staff on the wards are so busy and they have such, you know everybody has a big patient load so it can be hard … for people to be engaged with all their patients all day and then taking on new projects, it's a balancing act" (FU FG FC 05).*

This required a focused effort and entailed a lead-in time to build momentum. It is also likely to be an ongoing requirement into the future to maintain the profile of dementia care and to build on project gains.

3. The nature of healthcare is acknowledged to be fast paced, demanding and dynamic with organisational and clinical improvements constantly introduced and evaluated. **Cross-competing initiatives and the acuity of care demands** are to some extent unavoidable when engaging in projects such as the one reported herein. It was therefore not surprising that there were some references to participants' cognisance of the realities within the hospital and community care systems into which Cork-IDEAS was introduced, with descriptions of the clinical setting being "already over-burdened" and the *"sheer competitiveness of demands on the [hospital] wards" (FU SI FC 04).*

The data demonstrated that such considerations did have an impact on the project, for example, in terms of challenging the potential for project components to gain traction. This in turn resulted in high reliance on project personnel to devote significant and ongoing effort to promote staff engagement with project initiatives in practice. It also necessitated readiness to quickly adapt and change plans to meet the clinical realities on the ground, for example, on a given day where clinical demands were extremely high. There was also a suggestion that even though various healthcare projects were intended to be in patients' interests, and therefore to be welcomed, they were all different, even if some commonalities existed. This had led to fatigue in some cases, and created a potential perception of projects being in competition:

> *"I underestimated how in any time you promote one thing something else loses out … nothing is neutral" (FU SI FC 18).*

5.4 Summary of Cork-IDEAS Project Process Findings

- Eight project facilitators were identified which supported the Cork-IDEAS project process and the achievement of its outcomes. These were:
    - The ethos and culture of care within the project setting,
    - Project lead(ership),
    - Dedicated project personnel,
    - Organisational support,
    - Inter-disciplinary stakeholder and cross setting involvement,
    - High visibility of early project impacts,
    - The responsiveness of the project,
    - Dovetailing with other clinical, educational or organisational developments.
- Project personnel demonstrated significant experiential learning, which was both incorporated into the project as it unfolded and articulated as learning for future projects.
- The project facilitators were active over the course of the project and were found to counterbalance the challenges. They were therefore likely to have strongly impacted on the project gains achieved.
- Three overarching challenges (with sub-components) were found to have impacted on the project over its time line. These were:
    - Project-related human resource considerations, including:
        - Project lead time involvement,
        - Developing and enacting project-specific posts,
        - Role-related temporal and resourcing factors,
    - The inherent complexity of the project (as with other projects of this nature) and competing initiatives, including:
        - Multiple components,
        - Multi-contextual settings,
        - Building inter-disciplinary and inter-departmental buy-in,
    - The acuity of care demands in the project setting.
- The project consortium was pivotal in building shared ownership and momentum for the integration of dementia care within the project setting.
- The hospital sub-consortium, and working groups, adopted a whole organisation orientation with multi-level stakeholder representation as and when relevant.
- The community sub-consortium provided a medium to build project awareness, bring interested stakeholders together and build strategic linkages between services that could support those living with dementia in the community.
- The hospital sub-consortium contributed to project awareness, its governance and component activities by facilitating the sharing of information and gathering of feedback, in addition to enhancing inter-disciplinary and inter-departmental understanding more broadly.

6. Cork-IDEAS Hospital Inpatient Activity Analysis

6.1 Introduction

This section of the evaluation focuses on data concerning inpatient cases discharged from MUH in 2014 and 2016. Data on all patients who were discharged from MUH with either a primary or a secondary diagnosis of dementia in 2014 and 2016 was obtained from the HIPE office at MUH. 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 4. 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 Cork-IDEAS 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 after October 2017 that would have meant waiting until data from 2018 was available. That data will probably be available around April 2019. 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 2016 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 2016. 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 could 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 various variables between 2014 and 2016. 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.

6.2 Discharges

Table 13 presents a breakdown of the number of cases and patients in 2014 and 2016. In 2014, MUH discharged a total of 221 patients and 282 cases with a diagnosis of dementia. Some 176 patients had a single discharge, while 45 patients had between two and four discharges. Single discharges accounted for 62.4% of cases, while the 45 patients with multiple discharges accounted for 37.6% of the cases. In 2016, MUH discharged a total of 259 patients and 329 cases with a diagnosis of dementia. Two hundred and five patients had a single discharge, while 54 patients had between two and five discharges. The proportion of cases accounted by single and multiple discharges (repeat admissions) was almost identical in 2016 as 2014.

The increase in the number of cases from 282 to 329 (an increase of almost 17%) is part of a longer trend in MUH of increasing number of cases with dementia. While this trend had been evident before the project began, data from 2015 (there were 308 cases with dementia discharged from MUH that year) and 2016 is consistent with the objective that the programme would lead to more attention paid to the possibility of dementia being a relevant diagnosis following the initiation of the Cork-IDEAS project. Other factors may also have played a role. The increase between 2014 and 2016 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 MUH.

Table 13. Cases and Patients Discharged with Dementia

Number of discharges (repeat admissions)	Number of patients	Number of cases	Percent of cases (%)	Cumulative percent of cases (%)
2014				
1	176	176	62.4	62.4
2	35	70	24.8	87.2
3	4	12	4.3	91.5
4	6	24	8.5	100
Total multiple	45	106	37.6	100
Total	221	282	100	
2016				
1	205	205	62.3	62.3
2	45	90	27.4	89.7
3	7	21	6.4	94.8
4	2	8	2.4	98.5
5	1	5	1.5	100
Total multiple	55	124	37.7	100
Total	260	329	100	

6.3 Readmissions

There were 61 discharges in 2014 where the patient had previously been discharged in 2014. In 31 of these cases (50.8%), a patient was readmitted to MUH within 30 days of their previous discharge. There were 69 discharges in 2016 where the patient had previously been discharged in 2016. In 32 of these cases (46.4%), a patient was readmitted within 30 days of their previous discharge. The decrease in the proportion of cases in which a patient was readmitted within 30 day was not statistically significant at the 5% level of significance ($z = 0.51$; $p = 0.61$).

6.4 Admission Source

Most people diagnosed with dementia were admitted from home. In 2014, patients were admitted from home in 208 cases (73.8%), while patients were admitted from long-term care (LTC) (including nursing homes, convalescent homes or other long stay accommodation) in 60 cases (21.3%). In 2016, patients were admitted from home in 281 cases (85.4%), while patients were admitted from LTC in 36 cases (10.9%). The proportion of cases where patients were admitted from home increased by 11.6% between 2014 and 2016 ($z = -3.59$; $p = 0.0003$) while the proportion of cases admitted from LTC fell by 10.4% ($z = 3.5$; $p = 0.0005$). It isn't clear whether these changes are once-off changes or whether they can be attributed to specific elements of the Cork-IDEAS project.

Table 14. Admission Source

Admission source	Number of cases	Percent of cases (%)	Cumulative percent of cases (%)
2014			
Home	208	73.8	73.8
LTC	60	21.3	95
Other	14	4.9	100
Total	282		
2016			
Home	281	85.4	85.4
LTC	36	10.9	96.4
Other	12	3.7	100
Total	329		

6.5 Medical Card

Most cases in both years involved people with medical cards. In 2014, 87.2% of cases involved patients with medical cards, while in 2016, 84.2% of cases involved patients with a medical card.

6.6 Patient Death

In 2014, 14.9% of cases with a diagnosis of dementia resulted in death which occurred during their stay in the hospital, while in 2016, 10.3% cases resulted in death, a decrease of 4.6%. The decrease was not statistically significant at the 5% level of significance (z = 1.7; p = 0.089) although it was significant at the 10% level.

6.7 Discharge Destination

In 2014, patients were discharged to home in 123 cases (43.6%) and to LTC in 82 cases (29.1%). Combined, these two destinations accounted for 72.7% of discharge destinations in 2014. In 2016, patients were discharged to home in 160 cases (48.6%) and to LTC in 106 cases (32.2%). These two destinations accounted for 80.9% of discharge destinations in 2016, an increase of 8.1% compared to 2014.

Table 15. Discharge Destinations

Discharge destination	Number of cases	Percent of cases (%)	Cumulative percent of cases (%)
2014			
Home	123	43.6	43.6
LTC	82	29.1	72.7
Death	42	14.9	87.6
Other	35	12.4	100
Total	282	100	100
2016			
Home	160	48.6	48.6
LTC	106	32.2	80.9
Death	34	10.3	91.2
Other	29	8.8	100
Total	329	100	100

6.8 Admission Source and Discharge Destination

Table 16 shows the breakdown of cases by admission source and discharge destination for three specific categories – cases admitted from home and discharged to home, cases admitted from home and discharged to LTC, and cases admitted from LTC and discharged to LTC. The cases that resulted in death have been excluded from Table 16.

In 2014, 50% of these cases were admitted from, and discharged to, home. This proportion increased to 52.9% in 2016 (z = -0.66; p = 0.51). In 2014, 14.6% of cases had home as the admission source and LTC as the discharge destination. The comparable figure in 2016 was 23.7% of cases. The increase in this category was statistically significant (z = -2.65; p = 0.008).

In 2014, 18.8% of cases were admitted from, and discharged to, LTC whereas only 10.5% of cases in 2016 were admitted from and discharged to LTC. Once again, this change was significant (z = 2.72; p = 0.007). The changes in the second and third categories are important and large changes over a very short time period and it will be important to track whether these changes persist over the next few years. The increase in the home-LTC combination is particularly important for the hospital because, as will be discussed later, mean length of stay and costs are considerably higher in this combination than either of the other two combinations. Two further features of the home-LTC combination are worth noting. The first is that cases in this category are more likely to have a primary diagnosis of dementia and the second is that almost half of the cases in this category were admitted with a primary diagnosis with a disease of the respiratory system or a disease of the kidney and urinary tract.

Table 16. Admission Source and Discharge Destination

Admission source	Discharge destination	Number of cases	Percent of cases	Cumulative percent cases
2014				
Home	Home	120	50	50
Home	LTC	35	14.6	64.6
LTC	LTC	45	18.8	83.3
Other		40	16.7	100
Total		240	100	100
2016				
Home	Home	156	52.9	52.9
Home	LTC	70	23.7	76.6
LTC	LTC	31	10.5	87.1
Other		38	12.9	100
Total		295	100	100

6.9 Primary Diagnosis

Twenty cases (7.1%) had a primary diagnosis of dementia in 2014, while 40 cases (12.2%) had a primary diagnosis of dementia in 2016. The increase of 5.1% in the proportion of cases for which dementia was the primary diagnosis was statistically significant at the 5% level of significance (z = -2.1, p = 0.036). As outlined elsewhere in this evaluation, a key objective of the Cork-IDEAS project was raising awareness of the possibility of a diagnosis of dementia in MUH. The significant increase in the number of cases with a primary diagnosis of dementia and the increase in the number of cases with a primary or secondary diagnosis of dementia suggest that the project could be meeting this objective.

6.10 Length of Stay

Length of stay ranged from one day to 236 days in 2014. The mean length of stay was 16.5 days, while the median was 9 days. In 2016, the length of stay ranged from one day to 149 days. The mean length of stay was 18.2 days, while the median was 9 days. The difference between the mean and median length of stay reflects a small number of cases with a very long length of stay as well as the relatively large number of cases where the length of stay was 1 day. For example, in 2014 there were 5 cases whose length of stay was over 100 days while in 2016 there were 7 such cases. There was no statistical difference in length of stay between 2014 and 2016 (z = -1.44; p = 0.25).

6.10.1 Length of Stay: Primary and Secondary Diagnosis

In both years, the mean and median lengths of stay were higher for cases where the primary diagnosis was dementia. The mean and median lengths of stay for cases with a secondary diagnosis of dementia were very similar in 2014 and 2016 (Table 17). The mean and median lengths of stay for cases with a primary diagnosis of dementia decreased considerably between 2014 and 2016 although this decrease was not statistically significant (z = 0.52; p = 0.6).

Table 17. Length of Stay by Diagnosis of Dementia

Diagnosis	Number of cases	Mean length of stay	Median length of stay
2014			
Primary	20	47.5	31.5
Non-primary	262	14.2	8
Total	282		
2016			
Primary	40	33.9	18.5
Non-primary	289	16	8
Total	329		

6.10.2 Length of Stay: Single and Multiple Discharges

As mentioned earlier, a multiple discharge case involved a patient who had at least two discharges in a given year. As Table 18 shows, the mean and median lengths of stay were higher for single cases than multiple cases in both years. The mean length of stay for single cases were almost the same in 2014 and 2016. The median length of stay was the same in 2014 and 2016. The mean and median lengths of stay for multiple cases were somewhat higher in 2016 than 2014.

There was no statistical difference in length of stay for cases involving patients who had a single discharge (z = -0.27; p = 0.79) or for cases involving patients who had multiple discharges (z = - 1.34; p = 0.18) between 2014 and 2016.

Table 18. Length of Stay by Number of Discharges

Discharges	Number of cases	Mean length of stay (Days)	Median length of stay (Days)
2014			
Single	176	19.6	10
Multiple	106	11.5	6
Total	282		
2016			
Single	205	19.2	10
Multiple	124	16.4	8
Total	329		

6.10.3 Length of Stay: Admission Source and Discharge Destination

Cases with home as the admission source had higher mean and median lengths of stay than cases with LTC as admission source in both years. There was a small decrease in the mean and median length of stay from 2014 to 2016 for cases with LTC as the admission source. There was a small decrease in mean length of stay and a small increase in the median length of stay from 2014 to 2016 for cases with home as the admission source (Table 19). Neither change was statistically significant.

Table 19. Length of Stay by Admission Source

Admission source	Number of cases	Mean length of stay (Days)	Median length of stay (Days)
2014			
Home	208	19.2	9
LTC	60	7.9	6
2016			
Home	281	18.8	10
LTC	36	7.8	4

The mean length of stay for cases with LTC as the discharge destination was more than twice as high as for cases with home as the discharge destination in both 2014 and 2016. The median length of stay for cases with LTC as the discharge destination was also higher than for cases with home as the discharge destination in both 2014 and 2016 (Table 20).

The mean and median lengths of stay increased from 2014 to 2016 for cases with either home or LTC as the discharge destination but these changes were not statistically significant (z = -1.58, p = 0.11 for cases discharged to home; z = -0.52, p = 0.6 for cases discharged to LTC).

Table 20. Length of Stay by Discharge Destinations

Discharge destination	Number of cases	Mean length of stay (Days)	Median length of stay (Days)
2014			
Home	123	10.7	7
LTC	82	23.4	9.5
2016			
Home	160	12	8.5
LTC	106	27.8	12

The mean and median length of stay for particular combinations of admission source and discharge destination were also examined, as shown in Table 21. In 2014, cases in which patients were admitted from, and discharged to, LTC had a mean length of stay of 7.8 days and a median length of stay of 6 days. Cases in which patients were admitted from, and discharged to, home had higher mean and median lengths of stay of 10.8 and 7 days respectively. Cases in which patients were admitted from home and discharged to LTC had a mean length of stay of 44.2 days and a median length of stay of 29 days. This is more than four times higher than either of the other two types of case. There was a similar pattern in 2016 although the relative difference between length of stay of cases where admission source was home and discharge destination was LTC and the other two types of cases was more like threefold than fourfold. While there is no way of knowing for certain why these cases had higher longer lengths of stay on average, it is possible that cases admitted from home and discharged to LTC include a higher proportion of patients with higher levels of dependency, more complex multi-morbidity and greater care needs than cases admitted from home and discharged to home. There is also a possibility that a longer stay in hospital can lead to de-skilling and increased disability of people with dementia (Malone 2014), which might be a factor contributing to their discharge to LTC rather than home. Another possible contributory factor could be that patients who are going to be discharged to LTC may have to wait in hospital while a suitable place is found and/or until an application for funding under the Fair Deal Scheme is processed. It is not clear, however, if the decision to discharge a person with dementia to LTC is driving the length of stay or conversely if a longer length of stay in hospital is influencing decisions to transfer a person to LTC or even an indication of difficulties in putting community-based supports in place to support a discharge home. Furthermore, it should be noted that the LTC category in the HIPE data includes convalescent homes as well as nursing home and long stay accommodation. A discharge to a convalescent home may be a short-term measure while the person is rehabilitating from whatever illness led to the hospital admission. Similarly, some people with dementia might be discharged to a nursing home for respite before discharge home. Unfortunately, there is no way of cross checking how long a person stays in LTC in cases where people are discharged to LTC following a hospital episode or if the eventual destination is home.

There was no statistically significant difference in length of stay for cases admitted from, and discharged to, home between 2014 and 2016 ($z = -1.38$; $p = 0.17$) or in length of stay for cases admitted from home and discharged to LTC ($z = 1.09$; $p = 0.28$) or in length of stay for cases admitted from, and discharged to, LTC ($z = 1.2$; $p = 0.23$).

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				
Home	Home	120	10.8	7
Home	LTC	35	44.2	29
LTC	LTC	45	7.8	6
2016				
Home	Home	156	11.8	8
Home	LTC	70	36.6	22.5
LTC	LTC	31	7.5	4

This breakdown is particularly interesting because it shows that of the possible destination-discharge combination, the Home to LTC category is the one where the mean length of stay is much higher than either of the other two possible combinations. As mentioned above, there are a number of possible reasons why that particular category would have longer length of stay. The data did not allow the identification of whether some of the people with dementia in that combination are examples of ‘delayed discharge’. It is certainly possible that administrative and logistical delays in finding suitable LTC could be a contributing factor in the longer mean length of stay for people coming from home who were discharged to LTC. It should also be noted that the mean average length of stay in the Home to LTC category decreased between 2014 and 2016.

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

The length of stay for people with dementia to people without dementia for cases discharged with a Diagnostic Related Group (DRG) of Respiratory Infection or Urinary Tract Infection was compared. The DRGs in question were those with the most cases for the dementia cohort in 2014 and 2016. The comparison group was people aged 65 or older who were discharged with one of these DRGs but without a diagnosis of dementia.

While length of stay was generally higher in the group with dementia, the only DRG where the difference was statistically significant was for the Urinary Tract Infection DRG in 2016 ($z = -2.11$; $p = 0.035$). Previous research in Ireland on the impact of a diagnosis of dementia on length of stay found mixed results. Connolly and O’Shea (2015) suggested that people with dementia had considerably longer hospital stays than people without, controlling for the primary procedure. Their analysis is based on national HIPE data and not on individual level data as is available for this particular evaluation. Briggs et al. (2017) found that the presence of dementia did not have an effect on length of stay for a group of patients with dementia compared to a group without dementia when other relevant factors were accounted for. An earlier study by Briggs et al. (2016), which looked at individual level data from Tallaght Hospital, found that length of stay for patients with dementia with 5 different primary diagnoses was always longer than for older patients with the same primary diagnoses who did not have dementia. The papers by Briggs et al. (2016, 2017) used broader categories of diagnoses than are used in this evaluation. As more data comes available on length of stay for these particular DRGs in the next few years, this will be an important issue to analyse.

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	15	16.3	11
E62B	Respiratory infection	16	8.3	5.5
L63A	UTI	21	17.3	11
Not diagnosed with dementia				
E62A	Respiratory infection	75	17.1	10
E62B	Respiratory infection	111	7.6	6
L63A	UTI	82	12.5	7

Table 23. Length of Stay of Cases With, and Without, a Diagnosis of Dementia, 2016

DRG	DRG description	Cases	Mean length of stay (Days)	Median length of stay (Days)
Diagnosed with dementia				
E62A	Respiratory infection	28	20.1	15
E62B	Respiratory infection	18	14.9	7.5
L63A	UTI	21	22.8	13
Not diagnosed with dementia				
E62A	Respiratory infection	90	15.9	10
E62B	Respiratory infection	61	8	6
L63A	UTI	94	9.8	7

6.11 Patient Cost

The HPO calculates a casemix cost for every DRG in the classification system that they use. That cost is 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 4 which contains a number of examples. The inpatient costs of every case in 2014 and 2016 were assigned using this method.

As discussed in Appendix 4, the calculation of an individual cost number for every case is an estimate of the actual cost incurred by MUH for each of the cases in this dataset. Nevertheless, the estimates presented below represent a considerable advance on previous work in this area which had to assume that the cost of a stay in an acute hospital was exactly the same regardless of the diagnosis that a person received. For example, Connolly and O’Shea (2015) used a unit cost of €809 as the average cost of an inpatient day. The figures used in this evaluation differ in two important respects from the Connolly and O’Shea (2015) analysis. In the first case, the cost of each case varies by the DRG that s/he is assigned. Secondly, the per diem costs available from the HPO that are used in the estimates of the cost of patients who remain in hospital longer than the maximum number of days allowed for their specific DRG is considerably lower than the €809 figure used in Connolly and O’Shea (2015).

In 2014, patient costs ranged from €577 to €106,948. The mean cost per case was €9,287, while the median was €6,035. In 2016, patient costs ranged from €577 to €56,946. The mean cost was €8,649, while the median was €6,187. The large difference between the mean and median costs in each year indicates that there were a small number of patients with very high costs. The median patient costs in 2014 and 2016 were very similar, with the 2016 median being €152 higher than that of 2014. The mean patient cost was €638 lower in 2016 than it was in 2014 but the difference was not statistically significant (z = -0.89, p = 0.38).

The main factor determining patient cost was length of stay. There was a strong correlation (r = 0.72 for 2014, r = 0.81 for 2016) between length of stay and patient cost. The other factor in determining cost was the DRG that a patient was assigned to. The skewness of the cost data is reflected by the fact that the 10 most expensive cases accounted for 14% of the total cost in 2016. This group of 10 included 6 of the 7 cases where length of stay was over 100 days. In 2014, the 10 most expensive cases accounted for 20% of the total cost.

6.11.1 Patient Cost: Primary and Non-Primary Diagnosis

Patient costs were higher for cases with a primary diagnosis of dementia compared to cases where dementia was a secondary diagnosis. The mean cost for cases with a secondary diagnosis decreased by €414 between 2014 and 2016, while the median remained the same. The mean and median cost for cases with a primary diagnosis of dementia decreased by €5,407 and €2,444 respectively between 2014 and 2016.

There was no statistically significant difference in the costs of cases with a primary diagnosis of dementia between 2014 and 2016 (z = 0.61; p = 0.54) or in the costs of cases with a secondary diagnosis between 2014 and 2016 (z = -0.61; p = 0.54).

Table 24. Patient Cost by Diagnosis of Dementia in 2014 and 2016

Diagnosis	Number of cases	Mean patient cost (€)	Median patient cost (€)
2014			
Primary	20	16,314	12,520
Non-primary	262	8,751	6,035
Total	282		
2016			
Primary	40	10,907	10,076
Non-primary	289	8,337	6,035
Total	329		

While the difference between 2014 and 2016 in the costs of cases with a primary diagnosis of dementia may not have been statistically significant, the difference is striking and reflects the much shorter mean length of stay for such patients. As noted already, the number of cases with a primary diagnosis increased from 20 to 40. It's not clear therefore whether the fall in costs in this category was due to a change in the type of cases with a primary diagnosis or is it due to the Cork-IDEAS project itself. This is clearly an indicator that needs to be monitored closely over the next few years.

6.11.2 Patient Cost: Single and Multiple Discharges

Mean patient costs were higher for single cases than multiple cases in 2014 while the opposite was true in 2016. The mean cost for single cases decreased by €1,737 between 2014 and 2016, while the median cost increased by €61. The mean and median costs for multiple cases increased by €1,186 and €804 respectively between 2014 and 2016. There was no statistical difference in costs for cases with patients who had a single discharge (z = 0.16; p = 0.87) or for cases with multiple discharges between 2014 and 2016 (z = -1.6; p = 0.11).

Table 25. Patient Cost by Number of Discharges

Discharges	Number of cases	Mean patient cost (€)	Median patient cost (€)
2014			
Single	176	10,488	6,237
Multiple	106	7,294	5,231
Total	282		
2016			
Single	205	8,751	6,298
Multiple	124	8,480	6,035
Total	329		

6.11.3 Patient cost: Admission source and discharge destination

Cases with home as the admission source had higher mean and median costs than cases with LTC as admission source in both years. Mean and median costs increased by €707 and €360 respectively between 2014 and 2016 for cases with LTC as the admission source. Mean costs decreased by €1,398 for cases with home as the admission source while median costs did not change between 2014 and 2016. In neither case, were the costs significantly different in 2016 compared to 2014 (z = -0.27, p = 0.79 for cases admitted from home and z = -0.73, p = 0.46 for cases admitted from LTC).

Table 26. Patient Cost by Admission Source

Admission source	Number of cases	Mean patient cost (€)	Median patient cost (€)
2014			
Home	208	10,026	6,035
LTC	60	6,437	5,272
Total	268		
2016			
Home	281	8,698	6,035
LTC	36	7,077	5,632
Total	317		

The mean cost of cases discharged to home decreased by €574 while the median cost increased slightly between 2014 and 2016. These differences were not statistically significant (z = -0.59; p = 0.56). The mean and median costs of cases discharged to LTC increased by €987 and €909 respectively between 2014 and 2016. These differences were significant at the 10% level (z = -1.69; p = 0.09).

In both years, patient costs were significantly higher for cases discharged to LTC than cases discharged to home (z = -2.9, p = 0.003 in 2014 and z = -5.2 p< 0.0001 in 2016.)

Table 27. Patient Cost by Discharge Destinations

Discharge destination	Number of cases	Mean patient cost (€)	Median patient cost (€)
2014			
Home	123	6,962	5,153
LTC	82	10,358	6,035
Total	205		
2016			
Home	160	6,388	5,231
LTC	106	11,345	6,944
Total	266		

The difference in the costs of cases discharged to home and LTC is due mainly to the costs of cases admitted from home and discharged to LTC. In 2014, the cost of cases admitted from home and discharged to LTC was significantly higher than either the costs of cases admitted from and discharged to home (z = -4.7; p< 0.0001) or the costs of cases admitted from and discharged to LTC (z = 4.2; p< 0.0001). The same was true in 2016. The costs in each of these categories were explored to see if there were any differences of note between 2014 and 2016 but none of the differences were significant (p-values ranged from 0.51 to 0.70).

Table 28. Patient Cost by Admission Source and Discharge Destination

Admission source	Discharge destination	Number of cases	Mean patient cost (€)	Median patient cost (€)
2014				
Home	Home	120	6,939	5, 132
Home	LTC	35	15,640	10, 671
LTC	LTC	45	6,127	5, 313
Total		200		
2016				
Home	Home	156	6,268	5,171
Home	LTC	70	13,279	8,989
LTC	LTC	31	6,986	5,231
Total		257		

6.12 Summary of Cork-IDEAS Hospital In-patient Activity Analysis Findings

- An analysis of the Hospital In-Patient Enquiry (HIPE) data showed that the total number of cases discharged from MUH with a diagnosis of dementia increased from 282 to 329 between 2014 and 2016.
- The proportion of cases admitted from LTC fell between 2014 and 2016 but there was little change in the proportion of cases discharged to LTC. The proportion of people who were admitted from home and discharged to LTC increased significantly.
- Overall, and in various sub-categories, there was little difference in the mean or median length of stay between 2014 and 2016. The length of stay of cases with a primary diagnosis of dementia fell considerably between 2014 and 2016 but the relatively small number of cases in 2014 meant that this decline was not statistically significant.
- The mean costs of all the cases with a diagnosis of dementia fell between 2014 and 2016 but the decline was not statistically significant.
- The costs of cases discharged to LTC increased between 2014 and 2016.
- The mean length of stay, and mean costs, were much higher for cases admitted from home and discharged to LTC than for cases discharged to home or admitted from LTC. Thus, the category of admittance/discharge which increased significantly between 2014 and 2016 is the one that has higher mean cost.

7. Discussion

7.1 Introduction

This chapter considers the findings of the evaluation of the Cork-IDEAS project and the considerations pertaining to sustaining project gains. This chapter will be presented with reference to the following subsections:

- Discussion,
- Sustainability of project gains,
- Considerations relating to the evaluation project findings,
- Recommendations for enhancing integrated dementia care.

7.2 Discussion

The Cork-IDEAS project aimed to develop and deliver enhanced person-centred integrated care for people with dementia within, and between, MUH and the community. To achieve this aim, the project incorporated a number of components including: the development of the ICP for Dementia Care, the appointment of a number of project specific personnel within the hospital and the community, the provision of dementia awareness raising and education activities, the introduction of a volunteer service and the development of the hospital environment to be more dementia-friendly. Evaluation of the overall project indicated that it aligned with a number of the priority areas outlined in the National Clinical and Integrated Care programmes for Older People operated within the Health Service Executive, and the Irish National Dementia Strategy (Department of Health, 2014). Indeed, the learning from the evaluation could inform such programmes and the implementation of the Irish National Dementia Strategy (Department of Health, 2014), and potentially contribute to the development of future iterations of it. For example, the strategy highlights an imperative to advance integration and multi-disciplinary collaboration across care settings and the need to ensure acute care settings are dementia friendly in terms of clinical and environmental components. It also identifies that people with dementia who enter an acute care setting should transition through and back in to the community in as short a timeframe as appropriate to their needs. As demonstrated in both the project description (Chapter 2) and the evaluation findings (Chapters 4-6), the activities within Cork-IDEAS centralised all of these elements and sought to introduce innovations to achieve lasting and meaningful developments in terms of dementia care integration.

The Cork-IDEAS project was therefore particularly timely in that it occurred within a national landscape of review and reform of older persons' services, and a growing political and policy focus on dementia care. Both the Integrated Care Programme for Older Persons (Health Service Executive, 2017b) and the National Clinical Programme for Older People (Health Service Executive, 2013) aim to advance the cohesion of services for older adults particularly in the context of primary and secondary care settings. Fundamental to this aim is the development of service and pathway integration for those with complex health and social care requirements, such as those living with dementia. Within the Irish National Dementia Strategy (Department of Health, 2014 p.25), the necessity for dementia specific ICP's are identified as a priority action that facilitate *"the right care and support, in the right place and at the right time".* Such care pathways are recognised as essential to achieving effective person-centred care via centralisation of the person with dementia and fitting supports to identified individual needs (Irving and McGarrigle, 2012). However, while the development of ICPs for dementia care are currently advocated internationally, there is very limited evidence in terms of the experiences of and actual contribution and impacts of ICPs to dementia care. This is complicated by the multiple uses to which the term is applied and that ICPs can be used to refer to the continuum of dementia care or a part thereof (Samsi and Manthorpe, 2014). The Cork-IDEAS study is one of the first in the Republic of Ireland to develop and introduce an ICP for dementia care along with two other HSE & GENIO funded projects (Chapter 1, Section 1.2). As such, it is innovative and the related learning in terms of the project process and outcomes findings previously outlined have much to offer to the scant evidence base that currently exists and other settings intending to implement similar developments.

The evaluation of the project demonstrated that it was successful in developing an ICP (with ED and acute hospital in-patient ward applicability) and by project end had achieved some success in its introduction into MUH. Consideration of the Cork-IDEAS ICP and its usage and impact within the project site (Chapter 4, Section 4.2.1), demonstrates that it compares well with the purpose of ICPs described in Chapter 1 (Section 1.1). It further demonstrates compatibility with many of the items included on the Great Ormond Street Hospital for Children's adaptation of the West Midlands NHS 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, the document content and its development. There was also evidence to demonstrate its use in practice, however, this was variable and there were likely to be challenges in maintaining its uptake and indeed roll-out to the whole hospital without ongoing support and a readily available point of care contact for its use, and indeed complex dementia care more broadly in practice. Both interview and audit data provided evidence that a degree of streamlining of dementia care had also occurred within the hospital and that raised awareness of dementia and the person-centred needs of those living with dementia admitted to the hospital was in evidence. Within the community, there was appreciable progress in terms of: building strong linkages between the community based network of services available to those with dementia, communication linkages between the hospital and services in the community (for example, GPs, PHNs etc.), and raising knowledge and awareness of dementia within the community. Through these, and the activities of the DNS and CDCC, there was evidence of enhanced person-centred communication within the community as well as in-reach and out-reach between the community and MUH. Efforts were made to support hospital avoidance through advice to GPs or alternatively through MISS and supporting ED presentation when necessary. There was some indication of enhanced discharge planning and post discharge support for people with dementia. It is also likely that the project-related developments within the community could serve as a foundation for the development of a community focused ICP into the future.

The project evaluation demonstrated that the complexity of dementia care is not the domain of a single profession or setting. It similarly found that to achieve integration of dementia care, multi-component interventions adjusted to the particular characteristics of a defined setting are likely to be required. In addition, dementia care innovations need to be fitted to existing systems and structures, while also sometimes requiring system adaptations so as to maximise both their fit and uptake. The Cork-IDEAS project showed cognisance of these considerations. It was both conceptualised and operationalised in terms of a number of project components, each of which added value in terms of the outcomes achieved. Indeed, the synergistic impacts of for example, visible environmental changes, dementia awareness raising and education interventions were shown to create a supportive context within which to introduce the ICP. Similarly, the project roles (Project Lead, DNS, CDCC, OT) were widely identified as the face and points of care contacts for dementia care within the project setting as well as key drivers of the overall project and its components.

In summary, the evaluation demonstrated that Cork-IDEAS functioned as a catalyst for change in terms of dementia care integration and development within MUH and the community. The findings of the project evaluation supported the complex and iterative nature of ICP and dementia service, education and environmental developments. They also clearly demonstrated that for such development to truly occur, the organisation in terms of its levels and the dynamics between these levels need to be considered. As such, the requirement for multi-level organisational and key stakeholder input required to affect whole organisation and inter-sectoral dementia care change was shown. Linked to this was the finding that the amount of time involved in achieving dementia care integration outcomes that are effective, efficient and context appropriate, cannot be underestimated and the process if intended to cross care settings becomes even more complex and time intensive. It was further shown that key in achieving outcomes such as those incorporated in the Cork-IDEAS project are:

- Strong project leadership with a project lead possessing dementia care and policy expertise, and workload allowance to devote to the project,
- A sufficient lead in and planning phase,
- Stakeholder buy-in achieved through, for example, the consortium approach,
- Collaborative working to set timelines,
- Visible project personnel on the ground with dementia care expertise who champion project innovations,
- A supportive organisational culture,
- Ongoing support for project components during implementation.

Many of these factors are consistent with aspects of the steps of effective implementation science outlined by Meyers *et a*l. (2012). These writers further highlight the importance of evaluating and learning from innovations such as Cork-IDEAS as a critical step in the implementation process. As the findings reported herein demonstrate, doing so enables the identification of learning from the project process as it unfolds over time as well as its outcomes. However, as the evaluation of Cork-IDEAS finished with the project, it is not possible to evaluate any changes beyond the timeframe of the project and indeed if the gains achieved are maintained, which would offer additional learning. One element that could be relatively easy to address this in the short term, is to implement and embed a process that would examine key indicators in an ongoing manner, such as dementia care auditing metrics, or length of stay and costs for the next few years, as data becomes available. It is unrealistic, for example, to expect significant change in length of stay or patient costs in the first or second year of a major hospital-wide intervention such as Cork-IDEAS and as such it is desirable that evidence continues to be analysed.

This discussion has outlined key considerations in terms of the Cork-IDEAS 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.

7.3 Sustainability of Project Gains

The evaluation of Cork-IDEAS demonstrated stakeholders' concern with issues relating to the sustainability of project-related achievements. Importantly, the evaluation showed that a consideration of sustainability was implicitly and explicitly in-built into the Cork-IDEAS project. In almost all instances, for those interviewed, there was a recognition of the dynamic and ongoing nature of enhancing integrated care for those living with dementia. In addition, despite the Cork-IDEAS project having an end date, there was no sense that the need to continue dementia care development was ending as plans to support sustainability were being pursued. Many of these have already been referred to in the findings chapters, however, in summary:

- A decision to continue the project consortium had been confirmed at project end. The consortium were considering a potential name change and a re-visioning of their focus with regard to integrated dementia care,
- Business cases to support the appointment of a DNS, CDCC and Volunteer Co-ordinator were submitted, with the funding of a permanent DNS role agreed by MUH, the OT dementia-specific role continued at 0.1 FTE, the CDCC post funded till December 2018, and the Volunteer Co-ordinator part-time post still under consideration,
- The intent to roll-out the ICP across the hospital was in place, although there were indications that this would require the support of the permanent DNS role,
- Sustainability plans were in place relating to dementia care education and awareness raising,
- Environmental changes were ongoing at project end (for example, the link corridors),
- There was a clear organisational commitment to support the integration of dementia-friendly principles in future organisational developments where possible.

In terms of the project setting, the need to embed positive changes to ensure they become part of the ongoing fabric of the physical and operational structures within MUH and the linked community setting was clear. To attain this goal, the project consortium and designated project roles were clearly identified as key mechanisms both to maintaining project gains and also to build on what had been achieved by the project's end. However, there were very real concerns about the active challenges to sustainability that threatened to lead to the reduction or potential loss of the dementia care integration gains without measures to counteract them. These included:

- Competing local and national initiatives that could push dementia care integration down the hierarchy of concern,
- The risk of the effect of passing time on the visibility of dementia care within the project settings,
- An acute care system orientation that will by its nature continue to emphasise fast throughput and patient flow alongside the aim of greater person-centeredness,
- The need for designated personnel to provide complex dementia care, subject specialist knowledge and clinical dementia care support on an organisational and individual basis for people with dementia,
- The need for the designated personnel to have the skillset to also drive the dementia care agenda nationally, inter-organisationally, and with staff at the point of care,
- The reality of staff mobility and turnover lessening the potential presence of front-facing staff who benefitted from the Cork-IDEAS components to champion dementia care within the project site.

Recognising these challenges, the project evaluation identified a number of local factors that could support efforts to maximise the sustainability of project gains moving forward. These included: the need to capitalise on the current momentum for integration of dementia care, the potential to in-build audit of dementia care practice within standardised auditing metrics, and the need to nurture those who come forward with innovative suggestions as to how to improve dementia care practice within MUH. Finally, the potential to widen and publicise the reach of the Cork-IDEAS project components to benefit those without dementia exists, as it was recognised that the principles of good dementia care have the potential to enhance quality of care and well-being for service users more broadly. In addition, for a number of those interviewed, a wider lens was adopted, situating the project more broadly in terms of the national context. In such instances, sustainability was considered in terms of the existing dementia services and structures and the policy landscape of dementia care nationally. Linked to this, were references to the need for health and social care service funders to support integrated dementia care innovations, such as Cork-IDEAS, that have demonstrated positive impact.

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 the light of the following considerations:

- The evaluation set out to represent the perspective of all those intended to benefit from the Cork-IDEAS project purpose (formal carers, people with dementia and family carers). However, the evaluation findings primarily represent the perspective of stakeholders within the hospital and community project setting as despite significant effort to recruit people with dementia and family carers, there was very limited success in doing so (Chapter 3, Section 3.4) and this was mainly at the early time point (T1) of data collection.
- The evaluation ended at the point of the agreed end date of the Cork-IDEAS project and as such it is not possible to comment on ongoing impacts of the project on dementia care locally into the future. The Cork-IDEAS project timeline has however been extended with a no cost extension to December 2018 to support the development of DNS and CDCC posts.

7.5 Conclusion and Recommendations for Enhancing Integrated Dementia Care

This report presented the findings of the evaluation of the Cork-IDEAS project, which had as its purpose to develop and deliver enhanced integrated care for people living with dementia within the project setting. Effective care in dementia requires the seamless delivery of service across the continuum of care delivery. On the basis of the findings of the project evaluation, the following recommendations are proposed for enhancing integrated dementia care.

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 people with dementia's journeys, 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 and associated care bundles, 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.
- 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.

References

Allen, D., Gillen, E. and Rixson, L. (2009) Systematic review of the effectiveness of integrated care pathways: what works, for whom, in which circumstances? *International Journal of Evidence–Based Healthcare,* 7 (2): 61-74.

Bloomer, M., Digby, R., Tan, H., Crawford, K. and Williams, A. (2016) The experience of family carers of people with dementia who are hospitalised. *Dementia*, 15 (5): 1234-1245.

Borbasi, S., Jones, J., Lockwood, C. and Emden, C. (2006) Health professionals' perspectives of providing care to people with dementia in the acute setting: Toward better practice. *Geriatric Nursing*, 27 (5): 300-308.

Briggs, R., Coary, R., Collins, R., Coughlan, T., O'Neill, D. and Kennelly, S.P. (2016) Acute hospital care: how much activity is attributable to caring for patients with dementia? *QJM: An International Journal of Medicine*, 109 (1): 41 – 44.

Briggs R., Dyer, A., Nabeel, S., Collins, R., Doherty, J., Coughlan, T., O'Neill, D. and Kennelly, S.P. (2017) Dementia in the acute hospital: the prevalence and clinical outcomes of acutely unwell patients with dementia. *QJM: An International Journal of Medicine, 1*10 (1): 33-37.

Bryman, A. (2012) *Social Research Methods*. Oxford, UK: Oxford University Press.

Cahill, S., O'Shea, E. and Pierce, M. (2012) C*reating excellence in dementia care: A research review for Ireland's national dementia strategy.* Dublin and Galway: Living with Dementia Research Programme, Trinity College Dublin and Irish Centre for Social Gerontology, National University of Ireland Galway.

Campbell, H., Hotchkiss, R., Bradshaw, N. and Porteous, M. (1998) Integrated care pathways. *BMJ: British Medical Journal*, 316 (7125): 133.

Carpenter, B.D., Balsis, S., Otilingam, P.G., Hanson, P.K. and Gatz, M. (2009) The Alzheimer's disease knowledge scale: Development and psychometric properties. *The Gerontologist*, 49 (2): 236-247.

Connolly S. and O'Shea E. (2015) The impact of dementia on length of stay in acute hospitals. *Dementia*,14 (5): 650-658.

Daly, L., McCarron, M., Higgins, A. and McCallion, P. (2013) 'Sustaining Place'–a grounded theory of how informal carers of people with dementia manage alterations to relationships within their social worlds. *Journal of Clinical Nursing,* 22 (3-4): 501-512.

Davis, N. (2005) *Integrated Care Pathways: A guide to good practice.* Wales:National Leadership and Innovation Agency for Healthcare.

De Siún, A., O Shea, E., Timmons, S., Mc Ardle, D., Gibbons, P., O' Neill, D., Kennelly, S. and Gallagher, P. (2014) *Irish National Audit of Dementia Care in Acute Hospitals.* Cork: National Audit of Dementia Care.

Department of Health (2014) *The Irish National Dementia Strategy*. Dublin: Department of Health.

Doyle, L., Brady, A.M. and Byrne, G. (2009) An overview of mixed methods research. J*ournal of Research in Nursing*, 14 (2): 175-185.

Doyle, L., Brady, A.M. and Byrne, G. (2016) An overview of mixed methods research – revisited. *Journal of Research in Nursing,* 21 (8): 623–635.

Gaglio, B., Shoup, J.A. and Glasgow, R.E. (2013) The RE-AIM framework: a systematic review of use over time. *American Journal of Public Health,* 103 (6): e38-e46.

Glasgow, R.E., Vogt, T.M. and Boles, S.M. (1999) Evaluating the public health impact of health promotion interventions: The RE-AIM framework. *American Journal of Public Health*, 89 (9): 1322-1327.

Great Ormond Street Hospital for Children NHS Foundation Trust (2010) *How to produce and evaluate an integrated care pathway (ICP): information for staff:* NHS Foundation Trust. Retrieved from: http://www.gosh.nhs.uk/health-professionals/integrated-care-pathways on 30 October 2017.

Guy's and St Thomas' NHS Foundation Trust (2014) *'Barbara's Story'.* London: Guys and St Thomas NHS Foundation Trust. Available: https://www.guysandstthomas.nhs.uk/education-and-training/staff-training/barbaras-story.aspx Retrieved from:on 12th April 2018.

Health Service Executive (2013) *National Clinical Programme for Older People (NCPOP)*. Dublin: Health Service Executive.

Health Service Executive (2016a) *Dementia Statistics: Facts and Figures* (online). Retrieved from: http://www.hse.ie/eng/services/list/4/olderpeople/dementia/about-dementia/dementia-stats/ on 01 February 2017.

Health Service Executive (2016b) *2016 Year in Review* (online). Retrieved from: http://www.hse.ie/eng/about/Who/clinical/Newsletter-CSPD-Winter-2016-December-v13-FINAL-End-of-year-update.pdf on 22 June 2017.

Health Service Executive (2017a) *Integrated Care News and Events* (online). Retrieved from: http://www.hse.ie/eng/about/Who/clinical/integratedcare/news/on 22 June 2017.

Health Service Executive (2017b) *Integrated Care Programme for Older Persons* (online). Retrieved from: https://www.hse.ie/eng/about/Who/cspd/icp/older-persons/ on 2nd November.

Health Services Executive and Genio (2016) *HSE & Genio Dementia Programme 2012-2018.* Westmeath: Genio.

Hung, L., Phinney, A., Chaudhury, H., Rodney, P., Tabamo, J. and Bohl, D. (2017) "Little things matter!" Exploring the perspectives of patients with dementia about the hospital environment. *International Journal of Older People Nursing,* 0 (0): 1-11.

Irving, K. and McGarrigle, L. (2012) *Integrated Care Pathways for People with Dementia: Exploring the Potential for Ireland and the forthcoming National Dementia Strategy.* Dublin: Alzheimer Society of Ireland.

Keogh, F., Howard, E., McGuire, M. and De Siun, A. (2016) *Dementia Consortia: Integrated networks to deliver individualised supports for people with dementia and their family carers.* (online). Genio. Retrieved from: https://www.genio.ie/our-impact/research-evidence/dementia-consortia on 03 June 2017.

Lieber, E. and Weisner, T.S. (2010) Meeting the practical challenges of mixed methods research. In: Tashakkori, A. and Teddlie, C. (eds) *SAGE handbook of mixed methods in social and behavioral research.* Thousand Oaks, CA: SAGE.

Lintern, T. and Woods, R.T. (1996) The Dementia Care Practitioner Assessment (DCPA). *Journal of the British Association for Service to the Elderly,* 63: 12-18.

Lintern, T.C. (2001) *Quality in dementia care: Evaluating staff attitudes and behaviour.* Doctoral Dissertation. Wales: University of Bangor.

Loughlin, D. and Brown, M. (2015) Improving surgical outcomes for people with dementia. *Nursing Standard,* 29 (38): 50-58.

Malone,M.L. (2014) Acute care of people with dementia in the general hospital. *In Excellence in Dementia Care Research Into Practice 2nd edn*. (Downs, M. and Bowers B.eds) Maidenhead: Open University Press, McGraw-Hill Education.

Meyers, D.C., Durlak, J.A. and Wandersman, A. (2012) The quality implementation framework: A synthesis of critical steps in the implementation process. *American Journal of Community Psychology,* 50 (3-4): 462-480.

Middleton, S., Barnett, J. and Reeves, D.S. (2001) What is an integrated care pathway? *Evidence Based Medicine,* 3 (3): 1-8.

Moyle, W., Borbasi, S., Wallis, M., Olorenshaw, R. and Garcia, N. (2011) Acute care management of older people with dementia: a qualitative perspective. *Journal of Clinical Nursing,* 20 (3-4): 420-428.

Mukadam, N. and Sampson, E.L. (2011) A systematic review of the prevalence, associations and outcomes of dementia in older general hospital inpatients. *International Psychogeriatrics,* 23 (3): 344-355.

Nolan, L. (2007) Caring for people with dementia in the acute setting: a study of nurses' views. *British Journal of Nursing*, 16 (7): 419-422.

Nolan, L., McCarron, M., McCallion, P. and Murphy-Lawless, J. (2006) *Perceptions of stigma in dementia: An exploratory study.* Dublin: School of Nursing and Midwifery, Trinity College Dublin.

O'Sullivan, D., Mannix, M. and Timmons, S. (2017) Integrated care pathways and care bundles for dementia in acute care: concept versus evidence. *American Journal of Alzheimer's Disease & Other Dementias,* 32 (4): 189-193.

Palinkas, L.A., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N. and Hoagwood, K. (2015) Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health*, 42 (5): 533–544

Pierce, M., Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland 2011-2046.* Mullingar: Genio.

Pierce, M. and Pierse, T. (2017) Prevalence of dementia in Ireland. *In Developing and Implementing Dementia Policy in Ireland* (O'Shea, A., Cahill, S. and Pierce M. eds) Galway: Centre for Economic and Social Research on Dementia, National University of Ireland, Galway.

Pool, J. (1999) *The Pool Activity Level (PAL) Instrument: A practical resource for carers of people with dementia.* London: Jessica Kingsley Publishers.

Prince, M., Wimo, A., Guerchet, M., Ali, G.C., Wu, Y.T. and Prina, M. (2015) *The Global Impact of Dementia. An Analysis of Prevalence Incidence Costs and Trends.* London: Alzheimer Disease International.

Rees, G., Huby, G., McDade, L. and McKechnie, L. (2004) Joint working in community mental health teams: implementation of an integrated care pathway. *Health & Social Care in the Community,* 12 (6): 527-536.

Rotter, T., Kinsman, L., James, E., Machotta, A., Gothe, H., Willis, J., Snow, P. and Kugler, J. (2010) Clinical pathways: Effects on professional practice, patient outcomes, length of stay and hospital costs. *Cochrane Database Systematic Review,* 3 (3). Retrieved from: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD006632.pub2/pdf/ on 03 June 2017.

Samsi, K. and Manthorpe, J. (2014) Care pathways for dementia: current perspectives. *Clinical Interventions in Aging*, Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4259257/ on 12 June 2017.

Scerri, A., Innes, A. and Scerri, C. (2015) Discovering what works well: exploring quality dementia care in hospital wards using an appreciative inquiry approach. *Journal of Clinical Nursing*, 24: 1916-1925.

Smyth, W., Fielding, E., Beattie, E., Gardner, A., Moyle, W., Franklin, S., Hines, S. and MacAndrew, M. (2013). A survey-based study of knowledge of Alzheimer's disease among health care staff. *BMC Geriatrics*, 13 (1): 2.

Suarez, P. and Farrington-Douglas, J. (2010) *Acute Awareness: Improving hospital care for people with dementia.* London: The NHS Confederation.

Timmons, S., Manning, E., Barrett, A., Brady, N.M., Browne, V., O'Shea, E., Molloy, D.W., O'Regan, N.A., Trawley, S., Cahill, S., O'Sullivan, K., Woods, N., Meagher, D., Ni Chorcorain, A.M. and Linehan, J.G. (2015) Dementia in older people admitted to hospital: A regional multi-hospital observational study of prevalence, associations and case recognition. *Age Ageing*, 44: 993-999.

Wimo, A., Wetterholm, A.L., Mastey, V. & Winblad, B. (1998) Evaluation of the resourse utilization and caregiver time in antidementia drug trials: A quantitative battery. In: Wimo, A., Karlsson, G., Jönsson, L. & Winblad, B. (eds) *The Health Economics of Dementia*. London, England: Wiley.

Wolfs, C.A.G., Dirksen, C.D., Severens, J.L. et al. (2011) The costs and benefits of an integrated approach to dementia. *Tijdschr Psychiatr,* 53 (9): 657-665.

Woolrych, R. and Sixsmith, J. (2013) Integrated services for dementia: The formal carer experience. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 9 (4): 528.

Appendix 1: Cork-IDEAS Consortium Members

Cork-IDEAS is committed to maintaining constructive relationships with all of its consortium members and to work collaboratively, with other organisations that are aligned with its mission.

Acute Hospital Consortium, Mercy University Hospital

Consultant Geriatrician (lead)	Dr. Suzanne Timmons
Chief Executive Officer	Ms. Sandra Daly
Director of Nursing	Ms. Margaret McKiernan
Assistant Director of Nursing	Ms. Maria Connolly
Clinical Directors	Prof. David Kerins (until 2017); Dr. Kieran O' Connor
Nurse Educators	Ms. Doreen Lynch (until 2015); Ms. Elizabeth Myers
Dementia Nurse Specialist	Ms. Mary Mannix (2014-2017)
Older Persons Nurse Specialist	Ms. Mary Hayes
Advanced Nurse Practitioner in ED	Ms Sile O'Grady
Psychiatry of Old Age Service	Dr. Elaine Dunne (from 2015)
Consultant Geriatrician	Dr. Catherine O'Sullivan
Emergency Dept. consultant	Dr. Adrian Murphy (from 2016)
Discharge coordinator	Ms. Eileen Looney
Occupational Therapy Manager	Ms. Anne Quirke
Occupational Therapist (Dementia)	Ms. Anne O'Hea
Senior Physiotherapist	Dr. Ruth McCullagh
CEO, Mercy University Foundation	Mr. Micheál Sheridan
Clinical Nurse Manager	Ms. Sharon Maher
Patient Liaison Officer	Ms. Josephine Griffin
National Advocacy Unit	Ms. Anne Harris (2014)
Volunteer coordinator (unpaid position)	Ms. Mary Barry-Murphy (from 2015)
Therapy representative	Ms. Emer O'Regan
Representative from Cork University Hospital	Dr. Paul Gallagher

Community Consortium

Psychiatry of Old Age Service	Dr Aoife Ni Chorcorain (2013-2015)
Head of Social Care, Cork-Kerry CHO	Ms. Gabrielle O'Keeffe,
Director of Nursing, North Lee	Ms. Cora Williams
Advanced Nurse Practitioner, St. Finbarr's Hospital	Ms. Mary J Foley
Alzheimer Society Ireland, Cork branch	Ms. Vanessa Bradbury
Primary Care Community Worker	Mr. Aidan Warner
Carer	Mr. Patrick O'Keeffe
St. Luke's Nursing Home	Mr. Bruce Pierce/Ms Oonagh O'Driscoll
Montenotte Care Choice Nursing Home	Ms. Joanne Williams
Home Instead Care Providers	Ms. Noeleen Cronin
General Practitioner, North Lee	Dr. Eoin Monahan
General Practitioner, South Lee	Dr. Jim Harty
Community mental health nurse	Ms. Esther Kennelly
Home Help Coordinators, North/South Lee	Mr. Garett Cody and Mr. Ken Anthony
Medical Officer, Marymount University Hospice & Hospital	Dr. Catherine Sweeney
PREPARED project representative (GP)	Dr. Tony Foley
Family Carers Ireland	Mr. Peter Cox

The Cork-IDEAS project also wishes to acknowledge University College Cork researchers, Ms. Dawn O'Sullivan and Ms Lorna Kenny, who provided administrative support to the consortium meetings, and the geriatric registrars, especially Dr. Megan Alcock and Dr. Mary Buckley, for their support.

Appendix 2: Cork-IDEAS Dementia Nursing Care Bundle [25]

Dementia Nursing Care Bundle

Patient ID sticker

Care Bundle to be opened within 8 hours of Admission
Core practices identified and delivered to each patient with dementia
Family/ Carer involvement is integral and encouraged in the provision of care

1) Staff know key information about the patient within 24 hours of admission
2) A continued level of orientation is encouraged and optimised
3) Personalised communication takes place with the patient frequently, skilfully and compassionately,
4) Nutrition and hydration are adequate for the individual patient, are in line with patient preference, and are provided in a way that is geared to patient capability
5) Mobility is encouraged while in hospital, a safe walking environment is maintained and all patients are assessed for risk of falling
6) Pain management is timely and adequate

1) Staff know key information about the patient within 24 hours of admission		tick
This is me' or similar document to be provided/filled out by family/carer on admission, and kept with end of bed notes	Made available to all staff providing care and to accompany patient to all departments	
	Recontact family to obtain document	
	Document obtained	
	Copy given to provider	
	Nursing Practice Guidelines	**opened**
2) **Orientation** a continued level of orientation is encouraged and optimised. Use cues: signage, clocks, calendars and 'This is me' document.	Confusion	
	Psychological care	
3) **Communication** Personalised communication takes place with the patient/family/carer frequently, skilfully and compassionately	Communication deficit	
	Knowledge deficit	
4) **Nutrition and hydration** are adequate for the individual patient, are in line with patient preference and are provided in a way that is geared to patient compatibility	Reduced food intake	
	Weight loss	
	Altered bowel habits	
	Altered urinary pattern	
Family are encouraged to assist with meals, if assistance is required	→	
Patient is weighed on admission and record on NEWS chart	→	
Food and fluid intake recorded for three days on admission	→	
Bowel monitoring chart is maintained	→	
5) **Mobility** is encouraged while in hospital, a safe walking environment is maintained and all patients are assessed for risk of falling	Reduced mobility	
	Identified risk of falls	
	Unsteady gait	
6) **Pain Management** is timely and adequate People with dementia may be unable to identify and report pain accurately; therefore pain assessment which is appropriate to the individual is vital	Pain	

Please record variances in section 7 Completed By: __________ (print) signed: __________ Date: __________ Time __________

---

[25] Reproduced with the permission of Dr Suzanne Timmons, Cork-IDEAS Project Lead.

Section 7 Variance to Dementia nursing care bundle/Nursing practice guideline:

If unable to open any section of care bundle, document the reason for this:

Date	Time	Variance	Action taken	Outcome	Signature

Dementia Nursing Care Bundle (as per MUHNPG)

Mercy University Hospital

Patient label

Consultant:

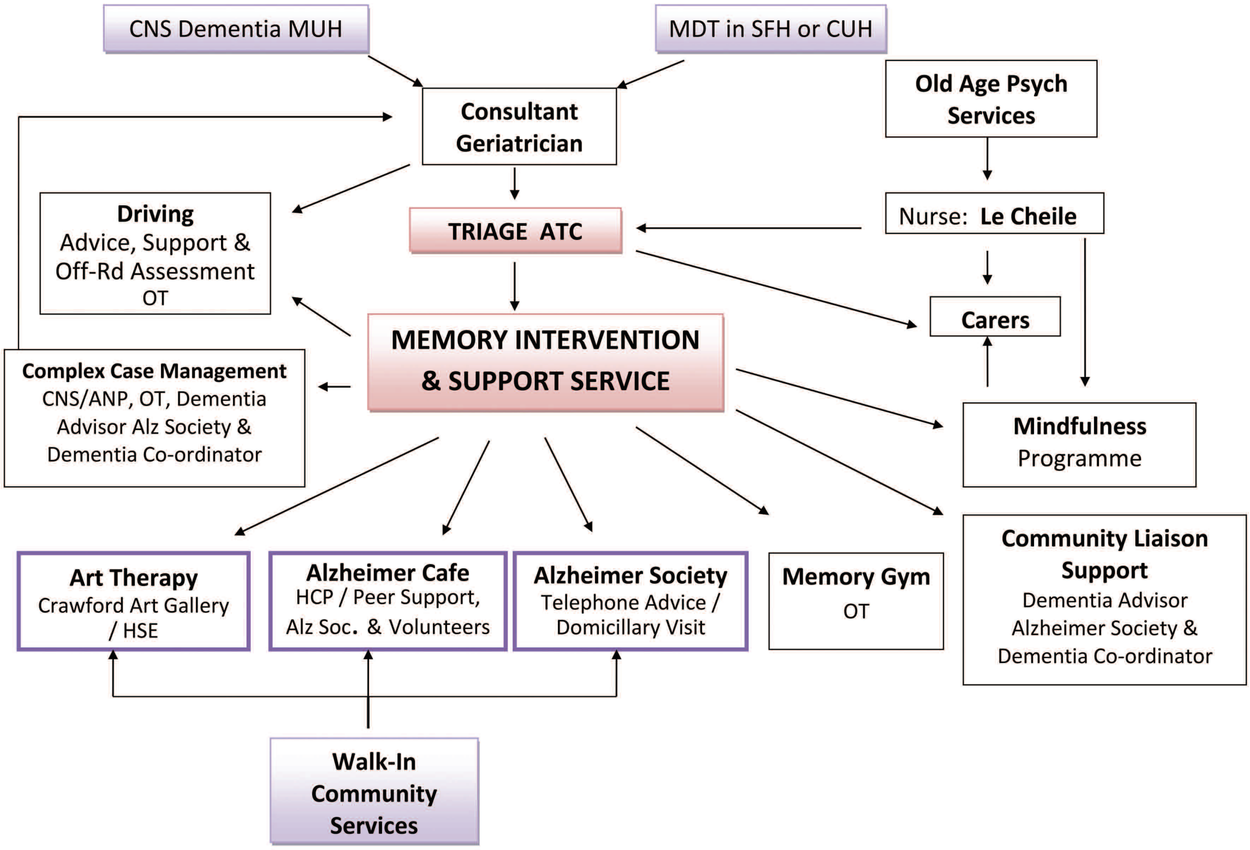
RID

Date	Time	Diagnosis No.	Nursing Diagnosis	Expected Outcome	Signature	Date/Time Discontinued	Signature
		D	Confusion	That Patient will reorientated as required while maintaining safety at all times			
		D	Psychological care	That patient is psychologically supported and anxieties and fears are relieved with clear communication			
		D	Communication deficit	That patient will be communicated with through verbal and non verbal cues and staff anticipate observing for same			
		D	Knowledge deficit	That patient will be made fully aware of all procedures and results			
		D	Potential for complication R/T Reduced food intake	That diet will be provided and monitored to ensure optimum uptake to ensure wellbeing			
		D	Weight loss	That same will be monitored and interventions put in place to ensure patients intake improves to prevent any further weight loss			

Name: RID: DOB:

Date	**Time**	**Diagnosis No.**	**Nursing Diagnosis**	**Expected Outcome**	**Signature**	**Date/Time Discontinued**	**Signature**
		D	Altered bowel habit	That patients bowels will be observed ensuring normal bowel habits are maintained			
		D	Altered urinary output	That urine output is monitored and deviations re reviewed to prevent			
		D	Unsteady gait	That patient's safety will be maintained and physio will be involved to assess same			
		D	Reduced mobility	That patient will be assisted as required to maintain safety. That physio will be involved.			
		D	Potential for complication R/T Identified risk of falls	That same will be prevented through education			
		D	Pain	That patients will be pain free			
		D					
		D					

Appendix 3: Memory Intervention and Support Service (MISS) Referral Pathway [26]



---

[26] Reproduced with the permission of Dr Suzanne Timmons, Cork-IDEAS Project Lead

Appendix 4: 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	12,520	23	57	577
B63Z	9	12,520	23	57	4,920
B63Z	20	12,520	23	57	10,891
B63Z	36	12,520	23	57	12,520
B63Z	43	12,520	23	57	12,520
B63Z	137	12,520	23	57	32,200

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.

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Trinity Centre for Practice and Healthcare Innovation
School of Nursing & Midwifery
Trinity College Dublin
24 DOlier Street
Dublin 2
Ireland

+353-1-896-2692

nursing.midwifery@tcd.ie

nursing-midwifery.tcd.ie