



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



## Evaluation of the St. James's Hospital DemPath Integrated Care Pathway Project

**HSE & GENIO DEMENTIA PROGRAMME**





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### Submitted by:

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

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

Date submitted: May 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 DemPath Project Lead, Prof Brian Lawlor; the Project Manager, Dr Natalie Cole; the DemPath nurse, Ms Louise Murphy; the project consortium and work package teams; 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.

© School of Nursing and Midwifery, Trinity College Dublin, The University of Dublin (May 2018). All rights reserved.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### Glossary of Terms & List of Abbreviations

#### Glossary of Terms

##### Cognitive Impairment

A noticeable and measurable decline in cognitive abilities including memory and thinking which extends beyond the expected decline of normal ageing.

##### 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.

##### DemPath Advocate

Any individual who expressed an interest in caring/supporting the individual with dementia by implementing new changes in their area and who preferred not to teach or become a DemPath Facilitator.

##### DemPath Facilitator

An individual trained by the project to deliver the level 1 programme within their own areas using pre-prepared documentation and who may also have developed or become involved in dementia-related projects within their area of work.

##### 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.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 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.

### Special

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

### Stakeholder

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



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### List of Abbreviations

AHP:	Allied Health Professional
CNM:	Clinical Nurse Manager
DRG:	Diagnosis Related Group
ED:	Emergency Department (A&E; Accident & Emergency)
FG:	Focus Group
FU:	Follow-up
GP:	General Practitioner
HCA:	Health Care Assistant
HSE:	Health Service Executive
ICP:	Integrated Care Pathway
JI:	Joint Interview
LTC:	Long Term Care
MedEl:	Medicine for the Elderly
OT:	Occupational Therapy/Therapist
PHN:	Public Health Nurse
PRN:	Pro Re Nata, as needed
SI:	Single Interview
SLT:	Speech and Language Therapy/Therapist
SJH:	St. James's Hospital
UTI:	Urinary Tract Infection





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### Project Overview

**Project Title:** Development of an Integrated Care Pathway (ICP) for people with a cognitive impairment led by St. James's Hospital; 'DemPath'

**Project Site:** St. James's Hospital (SJH), Dublin 8

**Project Lead:** Prof Brian Lawlor, Consultant of Old Age Psychiatry, SJH Dublin

**Project Manager:** Dr Natalie Cole

**DemPath Nurse:** Ms Louise Murphy

**Expert Advisory Group (EAG):** Dr David Anderson (Psychiatry- UK); Dr Carmen Carroll (Geriatrics, UK); Ms Mary Bruce (Dementia Training- UK)

**SJH Steering Group:** Prof Davis Coakley, Consultant Geriatrician, SJH; Ms Josephine Donlon, Assistant Director of Nursing, Medicine for the Elderly (MedEl), SJH

#### Work Package (WP) Teams:

**Awareness and Education WP (In House):** Ms Cecilia Craig, Dementia Services Information and Development Centre (DSIDC); Ms Mary Bell, Centre for Learning and Development (CLD); Dr Kevin McCarroll, Mercer's Institute for Successful Ageing (MISA); Ms Carol Mullen, Nursing Practice Development Unit

**Awareness and Education WP (Community):** Ms Cecilia Craig, DSIDC; Mr Matthew Gibb, Director of DSIDC; Dr Kieran Harkin, Family Carers Ireland; Dr Rosaleen Lannon, Mercer's Institute for Research on Ageing; Mr Neil Dunne, Director of Public Health Nursing, HSE Dublin South; Mr Ros O'Byrne, Director of Nursing, Harvey Healthcare; Ms Geraldine Walsh/Joan Kennelly, Bellvilla Nursing Home

**Infrastructure and Environmental Design WP:** Mr Matthew Gibb, Director of DSIDC; Mr Denis Roche, National College of Art and Design (consultancy basis); Ms Mary Lovegrove, Irish Hospice Foundation; Ms Helena Bates, Clinical Nurse Specialist, Psychiatry for the Elderly

**ICP WP:** Dr Siobhan Hutchinson, Neurology; Dr Geraldine McMahon, Clinical Effectiveness Lead, Emergency Medicine; Dr David Robinson, Geriatrics, MedEl; Dr Conal Cunningham, Geriatrics, MedEl; Dr Elaine Greene, Psychiatry; Ms Josephine Donlon; Ms Siobhan Nunn, SCOPE (Health & Social Care Professions (Speech & Language, Social Work, Clinical Nutrition/Dietetics, Occupational Therapy & Physiotherapy)); Ms Aoife O'Gorman, Occupational Therapist (OT); Mr Sean Farrell, Clinical Nurse Manager (CNM) III, ED; Dr Clodagh O'Dwyer, Acute Medical Assessment Unit (AMAU); Dr Jeanette Golden, Psychiatry; Ms Kate Bentley, IMS (provides Information and Communication Technology (ICT) applications, technical support and management information)



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

**User and Expert Consultation WP:** Ms Deirdre Horan, Family Carers Ireland; Ms Avril Easton, Alzheimer Society of Ireland; Mr Seamus Greene, service user

**Community 'In-reach'/'Out-reach' links:** Dr Kieran Harkin, Family Carers Ireland; Ms Deirdre Horan, Family Carers Ireland; Six family carers for people with dementia (accessed through Family Carers Ireland); Nursing homes (private and public in area); Ms Anne Kearney, HSE Manager of local health office; Mr Neil Dunne, Director of Public Health Nursing, HSE Dublin South

**Consortium Members:** Consisting of the project lead, project manager, DemPath nurse, work package teams, and expert advisory committee as outlined above

**Project Award Scheme and Value:** A HSE and GENIO Dementia Programme 2013 grant to the value of €500,000 from the Integrated Care Pathway's grant stream of the innovation funding was awarded. Additionally the HSE has provided €443,000 (benefit in kind) funding through the consortium.

**Project Start and End:** April 2014 – October 2017

**Period of Grant:** 3 years (with 6 month extension)



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### Table of Contents

Glossary of Terms & List of Abbreviations	3
Project Overview	6
<b>Executive Summary</b>	<b>12</b>
Introduction	12
Evaluation Aims & Approach	13
Key Findings	14
DemPath Project Impact and Outcome Findings	14
DemPath Project Process Findings	15
DemPath Hospital Inpatient Activity Analysis Findings	15
Recommendations for Enhancing Integrated Dementia Care	16
<b>RE-AIM Framework Applied to the DemPath Evaluation</b>	<b>18</b>
1. Introduction	21
1.1 Dementia Care in Acute Hospitals	21
1.2 HSE & Genio Dementia Programme	23
<b>2. DemPath Project – An Overview</b>	<b>24</b>
2.1 Introduction	24
2.2 DemPath Setting	24
2.3 Expected Outcomes and Aims of the DemPath Project	25
2.4 DemPath Organisation, Consortium and Project Roles	26
2.4.1 Project-Specific Roles	27
2.5 DemPath Project Components	28
2.5.1 Integrated Care Pathway	28
2.5.2 Environmental Adjustment	37
2.5.3 Education and Training	41
2.5.4 Overview of Project Activities and Milestones	43
2.6 Summary	43
<b>3. Methodology of Evaluation (Overview)</b>	<b>44</b>
3.1 Introduction	44
3.2 Aims	44
3.3 Objectives	44
3.4 Methodology Overview	45
3.5 Summary	47
<b>4. DemPath Project Impact and Outcome Findings</b>	<b>48</b>
4.1 Introduction	48
4.2 Integration of Dementia Care	48
4.2.1 ICP for Dementia	48
4.2.2 Project Roles	55
4.2.3 Overall Integration of Dementia Care	57





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

4.3	The Physical Environment	66
4.4	Dementia Awareness and Education	71
4.4.1	Awareness of Dementia	71
4.4.2	DemPath Education and Training Initiatives	73
4.5	Summary of DemPath Project Impact and Outcome Findings	77
<b>5.</b>	<b>DemPath Project Process Findings</b>	<b>78</b>
5.1	Introduction	78
5.2	Function and Impact of the DemPath Project Governance and Organising Structure	78
5.3	Factors Impacting the Implementation of the DemPath Project	79
5.3.1	Factors Facilitating the Implementation of the Project	79
5.3.2	Factors Challenging the Implementation of the Project	85
5.4	Summary of DemPath Project Process Findings	91
<b>6.</b>	<b>DemPath Hospital Inpatient Activity Analysis</b>	<b>92</b>
6.1	Introduction	92
6.2	Discharges	93
6.3	Readmissions	94
6.4	Admission Source	94
6.5	Medical Card	95
6.6	Patient Death	95
6.7	Discharge Destination	95
6.8	Admission Source and Discharge Destination	96
6.9	Primary Diagnosis	96
6.10	Length of Stay	96
6.10.1	Length of Stay: Primary and Secondary Diagnosis	98
6.10.2	Length of Stay: Single and Multiple Discharges	99
6.10.3	Length of Stay: Admission Source and Discharge Destination	99
6.10.4	Length of Stay for People With, and Without, Dementia	100
6.11	Patient Cost	102
6.11.1	Patient Cost: Primary and Non-Primary Diagnosis	103
6.11.2	Patient Cost: Single and Multiple Discharges	104
6.11.3	Patient Cost: Admission Source and Discharge Destination	104
6.12	Specials Services	105
6.13	Summary of DemPath Hospital Inpatient Activity Analysis Findings	106
<b>7.</b>	<b>Discussion</b>	<b>107</b>
7.1	Introduction	107
7.2	Discussion	107
7.3	Sustainability of Project Gains	110
7.4	Considerations Relating to the Evaluation Findings	112
7.5	Conclusion and Recommendations for Enhancing Integrated Dementia Care	113
	<b>References</b>	<b>115</b>
	<b>Appendices</b>	<b>119</b>
	<b>Appendix 1: Chapter 6 Data Sources and Methodology</b>	<b>119</b>



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### Foreword

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

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

This report describes the evaluation of one of these three acute hospitals, the DemPath project based in St. James's Hospital, in partnership with local community services. The project, underpinned by a person-centred philosophy, aimed to develop an ICP for people with a cognitive impairment. Improving the experience of people with a cognitive impairment and their families within the acute hospital was pivotal. Developing opportunities for appropriate supported hospital avoidance, timely discharge, and education and training for staff to facilitate person-centred care of people with a cognitive impairment, were also focal points in the creation of the ICP.

The evaluation found that the DemPath project made gains in terms of dementia care integration and development within the hospital and the community. The project, using a carefully planned process, successfully developed an ICP for people with a cognitive impairment admitted to the hospital. The project consortium, its subgroups and designated project personnel, i.e. Project Manager and DemPath nurse, facilitated the ICP development and implementation. The project management approach adopted by the project was successful in counterbalancing pressure on resources across the hospital by funding these project-specific roles.

To further enhance the experience of people with dementia in the hospital, environmental changes were made to the ED, the Mercer's Institute for Successful Ageing (MISA) building, Hollybrook Lodge and an acute gerontology admission ward. 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 DemPath 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.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

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 also wish to acknowledge the excellent work of the research team from Trinity College Dublin and the National University of Ireland Galway, led by Prof Anne-Marie Brady. We are grateful for the support of the Atlantic Philanthropies in funding this research. We continue to work closely with the HSE and National Dementia Office and hope that these findings will help inform the ongoing implementation of the National Dementia Strategy and will contribute to making the provision of care and support to people with dementia and their families, across both acute hospital and community settings, more responsive and personalised.

**Elaine Howard,**  
Programme Manager - Dementia, Genio  
May 2018







## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

### Executive Summary

#### Introduction

The DemPath project led by Prof Brian Lawlor was funded through a grant by the Genio Trust with the support of The Atlantic Philanthropies and the HSE. The aim of the project was to create an effective 'dementia-friendly' Integrated Care Pathway (ICP) for all people with dementia, irrespective of age, who were admitted to and discharged from St. James's Hospital (SJH) by improving the care environment, and by increasing awareness of dementia and associated care needs through education and training. The project ran for three and a half years, from April 2014 to October 2017. The initial expected outcomes of the project were as follows:

- I. There will be a fully functioning ICP for people with dementia of all age groups within SJH and its catchment area,
- II. There will be an increased level of awareness and recognition of dementia and its management in community and hospital settings,
- III. There will be significant improvements in the quality of care environment in the acute hospital for people with dementia and their caregivers,
- IV. The ICP will have demonstrated efficiencies, cost savings and sustainability with fewer acute hospitalisations and a shorter length of stay for people with dementia,
- V. The care model will have demonstrated transferability, initially within the SJH group and later, nationally,
- VI. Caregivers and service users will have a greater knowledge, involvement and sense of ownership of the care process,
- VII. The quality of the care experience for the person with dementia and their caregiver will be significantly and measurably improved,
- VIII. Staff will have received dementia-specific training.

As the project unfolded, its scope evolved to meet perceived demand and fit with hospital staff and key stakeholders' priorities for change. While the overarching aim of DemPath remained the same, the focus changed from being solely on people with dementia to include all those with a cognitive impairment aged over 65 years. The specific aims of the project were revised as follows<sup>2</sup>:

- I. Develop an ICP for people with a cognitive impairment admitted to the hospital, by establishing a clearly defined pathway into and out of the acute sector, facilitating admission avoidance where appropriate, standardising assessment, early intervention, timely discharge and improving 'in-reach'/'out-reach' linkages.
- II. Facilitate 'dementia-friendly' environmental adjustment to key areas within the hospital; the Emergency Department (ED), general wards in the new Mercer's Institute for Successful Aging (MISA) building, and the Hollybrook Lodge (community based) Long Term Care (LTC) facility.
- III. Provide education and training in dementia to all face-fronting staff throughout the hospital, as well as targeted training to specific staff groups, to improve awareness and knowledge among staff in contact with people with dementia.

1 A cognitive impairment is a noticeable and measurable decline in cognitive abilities including memory and thinking which extends beyond the expected decline of normal ageing.

2 As stated in the Genio Dementia Programme 2013 application and the Genio Trust Terms and Conditions.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

To achieve its aims, the DemPath project incorporated a number of components including:

- An ICP for dementia care,
- A range of dementia education and awareness raising activities,
- Environmental changes within SJH and Hollybrook Lodge.

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 ICPs 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 DemPath 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 ICPs nationally.

An exploratory mixed methods study involving both quantitative and qualitative approaches was used to provide a comprehensive evaluation of the DemPath 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.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

### Key Findings

#### DemPath Project Impact and Outcome Findings

- The project achieved gains primarily in relation to process mapping, the implementation of the 4AT for the assessment of cognitive impairment in the ED, design of a Hospital Passport and the inclusion of a standardised section on cognitive impairment in the hospital discharge letter.
- There was mixed success in other areas of the ICP development and roll-out, as per interview data, for example, standardised transfer of 4AT information from the ED to ward level; although progress was underway to include this in the Electronic Patient Record (EPR) to address this.
- The project roles were successful in implementing change to enhance care for people with dementia and cognitive impairment.
- Designated roles to implement and maintain change were highlighted as necessary, especially given the complexity and size of SJH and the pressure on resources.
- The hospital organisational audit of dementia care in SJH demonstrated that there had been positive changes between T1 and T2, for example, there was an increase in the availability of relevant training. There was also evidence of the move towards enhanced integration of care for people with dementia, for example, the hospital began using standardised instruments to assess mental state and mood of people with dementia, developed guidelines regarding the prescription and administration of antipsychotic drugs, and implemented systems to enhance dementia recognition and awareness among healthcare professionals in the ward environment.
- The ward organisational audit confirmed the presence of staffing shortages and difficulties in releasing staff from duties to attend dementia training. This was addressed however, at least in part, by the availability of on-the-job guidance and support offered by DemPath facilitators and advocates.
- The case note audit demonstrated mixed results relating to assessment of discharge planning and coordination for people with dementia.
- There was positive practice in relation to multidisciplinary and mental health assessment as per the audit findings.
- There were challenges in the organisation of the patient record.
- There were positive environmental changes implemented in the ED and Hollybrook Lodge, and improved wayfinding/signage in the MISA building, with indications of plans to support continuance of changes.
- Challenges in the physical environment of the hospital arose in audit and service user data, however. Many of these challenges were outside the project brief.
- A suite of education and training programmes were provided and these were streamlined to meet perceived needs. Overall, these programmes were positively evaluated and a number of impacts on practice were reported.
- DemPath facilitators were also trained and these made a significant contribution to the project by engaging in formal and informal education with staff as well undertaking smaller dementia related projects.
- DemPath facilitators were highlighted as a significant stakeholder in the potential for sustainability of project gains.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### DemPath Project Process Findings

- The success of the DemPath project was contingent upon not only the project roles but also upon the cooperation and work of a consortium structure and a number of key individuals and staff groupings including DemPath facilitators.
- Importantly, visible clinical leadership in an area or strand of the project was more likely to result in positive outcomes.
- Six project facilitators were identified which supported the DemPath project process and the achievement of its outcomes. There were:
  1. Organisational support and developments,
  2. Support from project funder,
  3. Linking in and embedding within existing structures,
  4. Excellence in practice,
  5. Person on the ground,
  6. Dynamic and responsive consortium.
- A number of challenges were found to have impacted on the project. Notably, the majority of these were highlighted at both T1 and T2 data collection:
  1. Impediments to patient flow,
  2. Lack of stimulation and activity for people with dementia,
  3. Absence of standardisation,
  4. Deficits in communication (inter-staff communication, as well as poor linkage and communication between the hospital and community),
  5. Pressure on resources,
  6. Insufficiently experienced or trained staff,
  7. Primary function to manage physical health needs.

### DemPath Hospital Inpatient Activity Analysis Findings

- The total number of cases discharged with a diagnosis of dementia increased from 426 to 496 between 2014 and 2016. Around 10% of cases in each year had received a primary diagnosis of dementia.
- Overall, and in various sub-categories, mean or median length of stay declined significantly between 2014 and 2016 (for example, mean length of stay for all cases was 52.0 days in 2014 and 33.7 days in 2016).
- Length of stay was generally higher for people with dementia than for people without dementia who had received the same primary diagnosis (for example, in 2016, mean length of stay for those with a primary diagnosis of syncope and collapse was 25.2 days for people diagnosed with dementia and 10.2 days for people not diagnosed with dementia).
- The mean costs of all the cases with a diagnosis of dementia fell significantly between 2014 and 2016 (for example, there was a decrease in mean and median costs of €7,276 and €1,266 for cases with home as the admission source between 2014 and 2016).
- The cost of specials services (an observation service provided to a patient or patients within the hospital to ensure their safety) was an important additional cost incurred within SJH. The proportion of cases diagnosed with dementia that received specials services increased from 18% to 30% between 2014 and 2016. The mean and median cost of specials services declined between 2014 and 2016 (for example, the mean cost of specials was €20,415 in 2014 and €13,411 in 2016).



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### Recommendations for Enhancing Integrated Dementia Care

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

#### Project-Specific Recommendations

- Process mapping emerged as a critical first step in developing an ICP and corporate support for this is recommended for the development of ICPs moving forward.
- Indirectly the study uncovered some unanticipated areas for further investigation in relation to the effect of hospital environmental design on people with dementia including, for example, the use of single rooms in dementia care.
- Ongoing monitoring and further development of project-specific changes will be of benefit to ensure maintenance of project gains.
- Embedding project-specific changes into existing organisational structures and resources is important to ensure sustainability of changes.
- Key to the success of implementing integrated care within the acute environment is that every category of staff has to be informed about, and participate in project activities and person-centred responses.
- Reinforcement of the positive impact of meaningful engagement and social interaction for people with dementia would be beneficial for all categories of service providers.
- It is recommended that the activity analysis be repeated in 2018 to analyse the full impact of the intervention.

#### Broader Evaluation Recommendations

- The person with dementia and their individualised needs should at all times be central to innovations to enhance integrated dementia care.
- To achieve meaningful impact, a dementia-friendly orientation needs to be embedded in the strategic objectives and operational planning of an organisation.
- A whole organisation approach to the integration of dementia care is advocated with involvement of key multi-level and inter-departmental stakeholders with the power to leverage support and facilitate required actions.
- Innovation in integrated dementia care requires clear governance and visionary leadership, and such leaders require dedicated resources to support dementia care development.
- A consortium approach is recommended for projects designed to design, test and implement innovations to develop integrated dementia care.
- Inter-sectoral involvement is required where innovations in dementia care are designed to cross the continuum of care. Such involvement should focus on developing collaborative networks and the setting up of effective in-reach out-reach communication systems between those involved.
- Innovations in dementia care (for example, ICP development) and dementia-friendly environmental design are time intensive and require extensive planning inputs to include process mapping of the journeys of people with dementia, evidence review and stakeholder consultation.
- Associated projects need to factor in sufficient lead-in time to devising related interventions and the planning activities involved should be viewed as sub-components of the overall intervention.
- Innovations in dementia care, such as ICPs, require ongoing point of care support through dedicated dementia-specific roles which are highly visible and whose role-holders have expertise in complex dementia care.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

- Where dementia-specific roles are shown to have a positive impact, there needs to be commitment and resources to continue them if gains in dementia care integration are to be maximised and built upon.
- When introducing innovations such as ICPs, both opportunistic and dedicated education programmes aimed at enhancing dementia knowledge and awareness contribute to the overall level of staff preparedness. Therefore, sustainable dementia education programmes should be available for all service providers who are involved with people with dementia and such education should retain a strong person-centred focus.
- So as to maximise learning for current and future projects, there is a need to in-build parallel participatory evaluation of the processes involved in projects to develop integrated dementia care in addition to measuring outcomes. Evaluations should additionally plan to extend beyond the end-point of an individual project so as to evaluate for any ongoing impact over time.
- Consideration should be given to embedding dementia-specific key performance indicators and audit metrics into quality assurance systems to monitor ongoing organisational performance relating to dementia care integration.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

### RE-AIM Framework Applied to the DemPath Evaluation

#### REACH

- There was a high level of awareness about the DemPath project and activities throughout the hospital, associated facilities and community care services.
- The primary reach of the ICP was focused within the Emergency Department (ED) and focused on standardised assessment and identification of cognitive impairment in the ED, Acute Medical Assessment Unit (AMAU) and in the pre-assessment clinic for elective surgery.
- In terms of the reach of the educational initiatives, an estimated total of 1500 SJH staff attended project education events.
- Basing some of the DemPath education days within the community greatly increased the reach of these initiatives to community based service providers through increased accessibility.
- The planned reach of environmental changes to the ED undertaken by the project was surpassed as the project also influenced environmental change within SJH MISA Building through the Wayfinding project, and within Hollybrook Lodge through creation of a more 'homely' environment.
- The adjusted ED bays and improved wayfinding in the MISA building are likely to positively influence the journey of care for all service users, not just those with cognitive impairment.

#### EFFECTIVENESS

- There was evidence of an enhanced understanding of the individualised needs of the person with dementia as indicated, for example, in interviews with hospital staff and progress was achieved in the integration and personalisation of dementia care within the hospital.
- A further benefit from the education and training carried out by the DemPath consortium has been an improvement in staff attitudes towards people with dementia and an openness to engage.
- Organisational support and parallel developments, support from the project funder and embedding changes within existing structures were recognised as contributing to overall project effectiveness.
- The project successfully mapped the journey of the person with dementia from the ED, through inpatient stay and to discharge.
- A Hospital Passport (which incorporated patient information such as demographic details, hobbies and interests, and preferred routine) for use with people with cognitive impairment was drafted by the consortium, successfully trialled in one ward and positively reviewed.
- The total number of cases discharged with a diagnosis of dementia in SJH increased from 426 to 496 between 2014 and 2016 which may be a result of the projects focus on identification of cognitive impairment.
- The nature of the project meant that conventional costs benefit analysis could not be employed. The approach used involved outlining the changes in critical variables, such as length of stay and patient cost, using Hospital In-Patient Enquiry (HIPE) and other data. Overall, and in various sub-categories, mean or median length of stay declined significantly between 2014 (M = 43.5) and 2016 (M = 30.3) though length of stay was generally higher for people with dementia than for people without dementia who had received the same primary diagnosis.
- Educational initiatives were evaluated positively and were seen to be effective in raising awareness of dementia and the opportunities for service providers to provide person-centred care, as well as being effective in informing staff of project developments and their significance as they occurred.
- Environmental changes in the ED were evaluated positively by service users and hospital staff alike.
- There was positive progress made in terms of in-reach/out-reach and relationship strengthening between SJH and local providers of community care (GPs, Public Health Nurses etc).



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### ADOPTION

- The DemPath consortium and work package teams included representation and engagement from a high proportion and range of service providers within SJH and from community settings. It was noted that a number of those involved committed a large amount of time and resources to project activities in spite of the ongoing pressure on resources.
- Improved linkages between SJH and the community were developed as a result of the project through education events, and most notably through the introduction of a standardised section on cognitive impairment on the SJH discharge letter.
- Greater traction was made in terms of developing and implementing the ICP within the ED than in other areas of the hospital. This may be because this area was the initial focus of the project and was positively influenced by the presence of project leaders, education and environmental adjustment, which consequently resulted in staff being more receptive to implementing project changes.
- DemPath facilitators were recruited from SJH as well as from local community sites demonstrating good representativeness of settings and service providers willing to engage in the project, to conduct dementia education training and to undertake mini projects.

### IMPLEMENTATION

- Initial plans by the consortium evolved significantly over the course of the project as the consortium responded to time constraints, unfolding service and resource challenges and learning from the project. However, the project components and related activities still demonstrated fidelity to the overall aim of the DemPath project.
- Audits undertaken by the consortium during the course of the project demonstrated that compliance levels with standardised assessment for cognitive impairment varied. Interviewees outlined that compliance levels were higher when a full complement of staff was available and when project leaders were on the ground.
- Designated project roles (namely the project manager and DemPath nurse) as well as the consortium, DemPath facilitators and other key project leaders were critical for the successful implementation of the project.
- The plan for environmental adjustment was adapted significantly over the course of the project but this was positive in terms of affecting the greatest level of change, for example, greater than planned changes were implemented in the Mercer's Institute for Successful Ageing where a high proportion of those living with cognitive impairment are likely to attend.

### MAINTENANCE

- The formation of a revised DemPath consortium, led by the project lead, supports the likelihood of sustaining a focus on dementia care within SJH.
- The DemPath Coordinator role (commenced December 2017) is likely to have a positive influence on the maintenance of project gains in terms of the ICP. This role will be positioned to further develop and implement the ICP as well as auditing and monitoring changes which have been introduced to date.
- Notwithstanding the project achievement, given the size and complexity of SJH and associated facilities, additional and dedicated personnel will be needed to bring about the complete implementation of an ICP for dementia across the hospital. A conservative figure of three nursing staff/specialists in dementia care was proposed by the project team.
- As SJH has a strong Centre for Learning and Development, and is the base of the national Dementia Services Information and Development Centre (DSIDC), this increases the likelihood of maintenance of project education activities.
- The inclusion of dementia awareness training on the staff induction programme is an important milestone for maintenance of education gains. A series of online e-learning modules are in development as well as further education and awareness days for staff in SJH and community partners to continue to improve skills and knowledge relating to dementia and dementia care.
- The strong relationship built between the consortium and key stakeholders in the hospital such as Facilities Management means that it is likely that dementia-friendly design principles will be used in any future environmental changes within the hospital.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### DemPath Key Achievements



There was a move towards **enhanced integration of care** for people with dementia.

The project was successful in **mapping the care pathway**, implementing **assessment of cognitive impairment**, design of a **hospital passport**, and inclusion of a standardised section on cognitive impairment in the hospital **discharge letter**.



The **project roles** were successful in implementing change to enhance care for patients with dementia and cognitive impairment.

A suite of **education and training programmes** were provided and **DemPath facilitators** were trained, and both had a number of impacts on practice.



Project success was contingent upon the project roles, the cooperation and hard work of a **consortium** structure and a number of **key individuals and staff groupings**.

**Organisational support** and **linking with existing structures** were key factors in advancing activities relating to the **integration of dementia care** within the hospital and the community.







## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 1. Introduction

#### 1.1. Dementia Care in Acute Hospitals

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

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

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

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

It is suggested that up to 29% of people in acute Irish hospitals may have dementia (Department of Health, 2014; Timmons *et al.*, 2015) and the cost of additional days of hospital admission due to dementia has been estimated to be in excess of €199 million per annum (Connolly and O'Shea, 2015). The acute hospital setting is often perceived as a disorientating and stressful place by and for people with dementia, and international research has indicated that negative hospitalisation experiences can lead to cognition and functional ability declines (Suarez and Farrington-Douglas, 2010; Hung *et al.*, 2017). The reasons for this are multifactorial. For example, the acute hospital is fast-paced, with a predominant task and illness orientation which can be challenging for people with dementia, as their needs are frequently complex (Borbasi *et al.*, 2006; Moyle *et al.*, 2011). Research has further identified the inadequacy of the hospital as a dementia care environment (Nolan *et al.*, 2006; Nolan, 2007), with poor understanding of the needs of people with dementia, insufficiencies in communication and disconnects between the acute hospital and other health and social care settings (Daly *et al.*, 2013), each impacting negatively on people with dementia. For a multiplicity of reasons, it is not surprising that people with dementia in the acute setting are reported to have poorer care outcomes, a longer duration of stay compared to people without dementia of a similar age, higher mortality and a greater risk of admission to residential care (Mukadam and Sampson, 2011; Department of Health, 2014). The Irish National Audit of Dementia Care in Acute Hospitals (De Siún *et al.*, 2014) revealed a number of gaps in dementia service provision, specifically: 94% of the hospitals surveyed did not have a dementia care pathway for people with dementia, only 36% of people with dementia were subject to an assessment of function and only 43% had a standardised assessment of cognition status recorded in their clinical records.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

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

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

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



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 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 St. James's Hospital, Dublin (SJH), Mercy University Hospital in Cork, 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 DemPath project in SJH. Under this initiative, SJH and key stakeholders in the community joined forces to establish more integrated and responsive services for people with dementia.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### 2. DemPath Project – An Overview

#### 2.1 Introduction

The DemPath project led by Prof Brian Lawlor was funded through a grant by the Genio Trust with the support of The Atlantic Philanthropies and the HSE. The project was intended to create an effective 'dementia-friendly' ICP for all people with dementia, irrespective of age, who were admitted to and discharged from SJH by improving the care environment, and by increasing awareness of dementia and associated care needs through education and training. The project ran for three and a half years, from April 2014 to October 2017. This chapter provides an overview of the DemPath project as it unfolded over the timeframe of the project.

#### 2.2 DemPath Setting

The DemPath project was based in SJH, Dublin 8, and the surrounding community catchment area of Dublin South inner city. SJH is the largest teaching hospital in Ireland with approximately 1,000 beds, and provides many of the core clinical services for people with dementia living in the area. The Memory Clinic, Hospital 4, Old Age Psychiatry and Medicine for the Elderly (MedEl) provide assessment, acute admission facilities, rehabilitation and respite care for such patients, and liaise closely with primary care, health and social services, and voluntary agencies such as the Alzheimer Society of Ireland and Family Carers Ireland. Hollybrook Lodge serves as a community-based LTC facility and operates under the governance of SJH. Community services in the area include home help services (Bride Street, Liberties and Rialto), meals on wheels (Guild of the Little Flower, Rialto Parish Centre), day care (Bellvilla Community unit and Rialto Day Centre), and the HSE Dublin South City Mental Health Service. Long stay units in the area include Bellvilla and the Meath Community Unit.

There are approximately 16,339 people over the age of 65 in the Dublin South City area, and approximately 1,416 of these individuals are estimated to have dementia (Pierce and Pierse, 2017). The average cost per week of a bed in SJH is €5,600 (i.e. €800 per day) bringing the estimated cost of inpatient days for those with a primary and secondary discharge diagnosis of dementia to approximately €17 million in 2012 (based on Hospital In-Patient Enquiry (HIPE) data). As the project application explained, even a modest saving of 10% on average length of stay could result in approximately €1.7 million saving to the hospital.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

### 2.3 Expected Outcomes and Aims of the DemPath Project

The initial target population of the DemPath project was people with dementia of all ages, with the following expected outcomes:

- I. There will be a fully functioning ICP for people with dementia of all age groups within SJH and its catchment area,
- II. There will be an increased level of awareness and recognition of dementia and its management in community and hospital settings,
- III. There will be significant improvements in the quality of care environment in the acute hospital for people with dementia and their caregivers,
- IV. The ICP will have demonstrated efficiencies, cost savings and sustainability with fewer acute hospitalisations and a shorter length of stay for people with dementia,
- V. The care model will have demonstrated transferability, initially within the SJH group and later, nationally,
- VI. Caregivers and service users will have a greater knowledge, involvement and sense of ownership of the care process,
- VII. The quality of the care experience for the person with dementia and their caregiver will be significantly and measurably improved,
- VIII. Staff will have received dementia-specific training.

As the project unfolded, its scope evolved to meet perceived demand and fit with service provider and key stakeholders priorities for change (further discussed in Chapter 5, Section 5.3.1). While the overarching aim of DemPath remained the same, the focus changed from being solely on people with dementia to include all those with a cognitive impairment<sup>3</sup> aged over 65 years. The specific aims of the project were revised as follows<sup>4</sup>:

- I. Develop an ICP for people with a cognitive impairment admitted to the hospital, by establishing a clearly defined pathway into and out of the acute sector, facilitating admission avoidance where appropriate, standardising assessment, early intervention, timely discharge and improving 'in-reach'/'out-reach' linkages.
- II. Facilitate 'dementia-friendly' environmental adjustment to key areas within the hospital; the Emergency Department (ED), general wards in the new Mercer's Institute for Successful Aging (MISA) building, and the Hollybrook Lodge LTC facility.
- III. Provide education and training in dementia to all face-fronting staff throughout the hospital, as well as targeted training to specific staff groups, to improve awareness and knowledge among staff in contact with people with dementia.

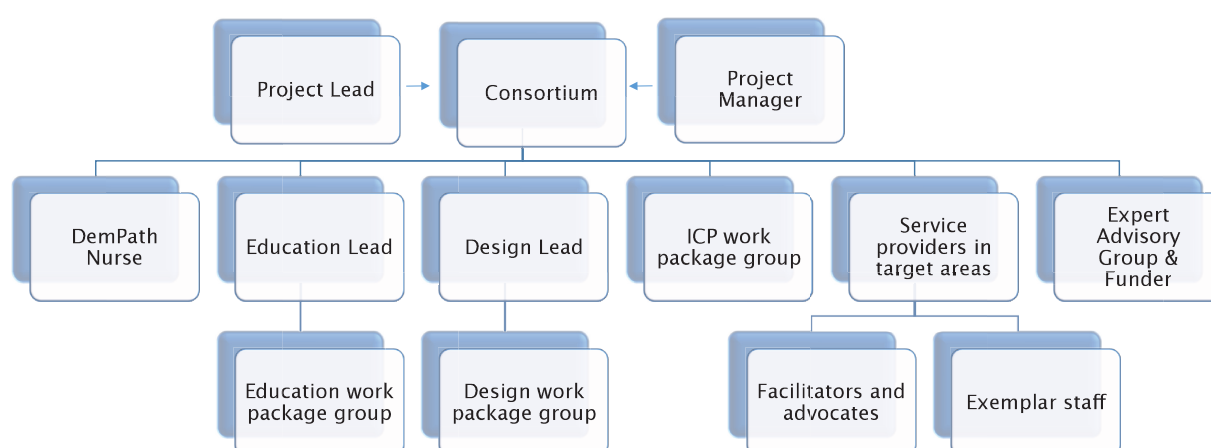
<sup>3</sup> A cognitive impairment is a noticeable and measurable decline in cognitive abilities including memory and thinking which extends beyond the expected decline of normal ageing.

<sup>4</sup> As stated in the Genio Dementia Programme 2013 application and the Genio Trust Terms and Conditions.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

### 2.4 DemPath Organisation, Consortium and Project Roles

The DemPath consortium was led by the project lead, Prof Brian Lawlor, and a project manager specifically employed by DemPath. The consortium brought together a number of stakeholders and those with the knowledge and experience to contribute to the development and implementation of an ICP for people with a cognitive impairment in SJH. The consortium met on a monthly basis. 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. 'Work package' teams were established on a needs and activity-led basis to oversee project-specific components and the fulfilment of the DemPath objectives. The project also employed two project-specific staff who sat on the consortium: a project manager and a DemPath nurse with expertise in dementia care. The success of the DemPath project was contingent upon not only the project roles, but also upon the cooperation and work of the consortium structure and a number of key individuals and staff groupings (see Figure 1). There was quite diversified "driving" of the project in SJH (as illustrated in Figure 1 and the project's various work packages) compared to projects in the other two hospital sites, namely Mercy University Hospital, Cork, and Connolly Hospital, Dublin.



**Figure 1. Overview of Diversified Driving of the Project**



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### 2.4.1 Project-Specific Roles

The project manager and DemPath nurse roles were two full-time roles funded by the project and are described below.

#### 2.4.1.1 DemPath Project Manager

The DemPath project manager, under the guidance of the project lead, held a primary role in developing, coordinating and implementing the project. The project manager role was in place from project commencement and was a key driver for the project and was actively involved in the different strands of the project. This multifaceted role included:

- Membership of consortium and work package groups,
- Being on the ground as the face of the project,
- Overseeing and active participation in activities relating to the development of the ICP (section 2.5.1),
- Providing overall direction, support and management functions to each of the work package leads and their teams, and meeting regularly with them,
- Responsibility for the project budget,
- Liaising with key stakeholders and service providers in SJH and the community,
- Developing relevant documentation and paperwork, for example, stakeholder analysis, work plans, Standard Operating Procedure (SOP),
- Supporting the development, pilot, auditing and subsequent roll-out of the ICP components,
- Organising consortium, work package, and other relevant meetings,
- Organising DemPath education days,
- Maintaining a record of progress and activities,
- Point of contact for project funders and completing monitoring forms for the funder on a regular basis,
- Dissemination of project activities locally and more widely,
- Reviewing the relevant literature.

#### 2.4.1.2 DemPath Nurse

The DemPath nurse role commenced in April 2016, approximately two years after the project had started, and ended in March 2017. The DemPath nurse played a key role in the ICP and education strands of the project. Her activities included:

- Acting as a support resource and single point of contact for staff by offering dementia leadership, advice and expertise and raising the visibility of dementia within the hospital,
- Overseeing of, and active participation in, activities relating to the development of the ICP (section 2.5.1),
- Identifying and introducing dementia-specific documentation including the Hospital Passport,
- Auditing completion and implementation of project tools and activities (for example, completion rates of the 4AT by ED staff),
- Overseeing the completion of the 4AT in the ED and the transfer of information on cognitive impairment to ward level,



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

- Repeating project-specific education with service provider groups, as needed, to maintain momentum for the project,
- Participating in the DemPath consortium,
- Organising DemPath education days,
- Coordinating DemPath facilitator support group meetings and providing a supportive role to facilitators.

### 2.5 DemPath Project Components

There were three primary strands of the project: ICP; environmental adjustment; and education and training. Development of community linkages was incorporated within the project strands. An overview of each of the project strands is provided in the following sub-sections.

#### 2.5.1 Integrated Care Pathway

An ICP is a methodology for the mutual decision-making and organisation of care for a well-defined group of patients, in this case people with a cognitive impairment, during a well-defined period. The aim of an ICP is to enhance the quality of care by improving patient outcomes, promoting patient safety, increasing patient satisfaction, and optimising the use of resources. The sub-sections below outline progress made by the DemPath project in the development of an ICP for people with a cognitive impairment as well as highlighting a number of tasks related to the ICP initiated and/or identified by the project to be brought forward in the future.

##### 2.5.1.1 Planning and Mapping

The target population for the ICP encompassed people with a cognitive impairment, aged 65 and over. This included people with a known diagnosis of dementia admitted to SJH, or people without a previous diagnosis of dementia who showed signs of delirium or cognitive impairment at assessment within the ED. The ICP intended to standardise care for people with a cognitive impairment by improving key components of care such as awareness of staff, supporting timely and appropriate assessment, thereby enabling early intervention and facilitating timely discharge or hospital admission avoidance where appropriate, and by improving 'in-reach'/'out-reach' linkages with community services.

Project set-up and coordination involved the development of a consortium, a number of work package groups as well as an Expert Advisory Group (EAG). There was extensive consultation with key stakeholders and service providers within SJH at this initial planning stage. This approach continued throughout the project to garner their views and input on proposed project developments and to adapt these as needed based on feedback. Communication with the EAG was ongoing throughout the project and was primarily in the form of teleconferencing. A communication plan was created to raise awareness and maintain momentum for the project within, and outside of, SJH. This involved development of the DemPath logo, posting of regular updates on the SJH intranet, and distribution of posters, leaflets and emails (including stands in the foyer and outside the canteen in SJH).





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

The consortium endeavoured to involve people with dementia and family carers as a reference to their work. They initiated and maintained contact with people with dementia and family carers for people with dementia, primarily through focus groups conducted by the project manager, to facilitate service user feedback. A 'mystery shopper' experience of service users, undertaken by the DemPath consortium, was used to establish the problems occurring in the wayfinding experience in SJH to inform the environmental design element of the project. This involved the attendance of people with dementia and family carers (recruited by the project manager through initial contacts made through Family Carers Ireland) whereby they were requested to test the wayfinding experience in the hospital by trying to find a number of locations by following hospital signage. A baseline observational study involving a small number of people with dementia (n = 3) in the ED conducted by a student of the National College of Art and Design on behalf of the DemPath team, identified the experience of people with dementia in the ED, and the environmental facilitators and barriers they encountered in the department. The following issues facing people with dementia in the ED at SJH were identified as a result of this study:

- Long waits in bays or corridors,
- Accompanying family members had inadequate space,
- Bays often shared,
- Loud noises, announcements, bleeps from machines,
- Long waiting times to admission.

An overview of the ICP development process is presented in Figure 2. Multiple stakeholders engaged in process mapping meetings where 'as is mapping', gap analysis and 'to be' process mapping was undertaken by consortium members and key hospital staff in consultation with Mr Paul Rafferty (Quality Improvement Facilitator, HSE National Clinical Programmes). This was a substantial milestone of the project and visually captured the baseline or 'as is' state of the hospital process, culture and capabilities in addition to providing a gap analysis to document gaps and difficulties in the system. It also sought to process map the 'to-be' as to how the hospital process, culture and capabilities should appear in the future to provide optimum care for people with a cognitive impairment. The review of the patient journey uncovered a number of issues, including, for example, absence of standardised screening or assessment for dementia/delirium, variance in the use of cognitive assessment instruments, considerable duplication in the collection of information across sectors (for example, medical history), multiple referrals for second opinion, and a generalised discharge letter that provided insufficient information on dementia. This part of the overall process was informed by a scoping review of best practice dementia care, and a report was generated and reviewed by the ICP team. DemPath Facilitators, recruited from within the hospital and community to deliver training to their peers within their respective work environments (see Section 2.5.3), provided assistance in developing and progressing the ICP, where relevant. This work was also supported by DemPath 'advocates', individuals who had not completed DemPath facilitator training but acted as 'drivers' for the project, for example, a consultant in the ED facilitating access to service providers and documentation.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

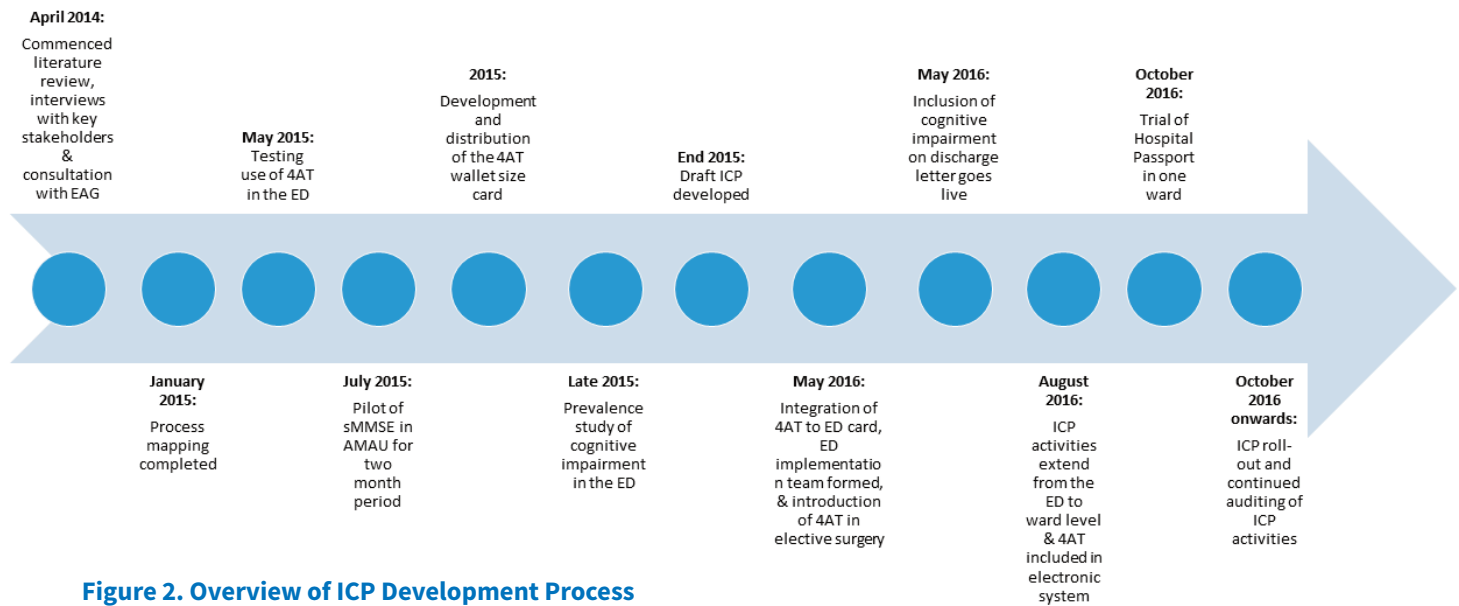


Figure 2. Overview of ICP Development Process

### 2.5.1.2 Testing and Implementing Draft ICP Within the ED

Based on the outcomes of process mapping, a proposed ICP was developed (see Figures 3, 4 and 5).

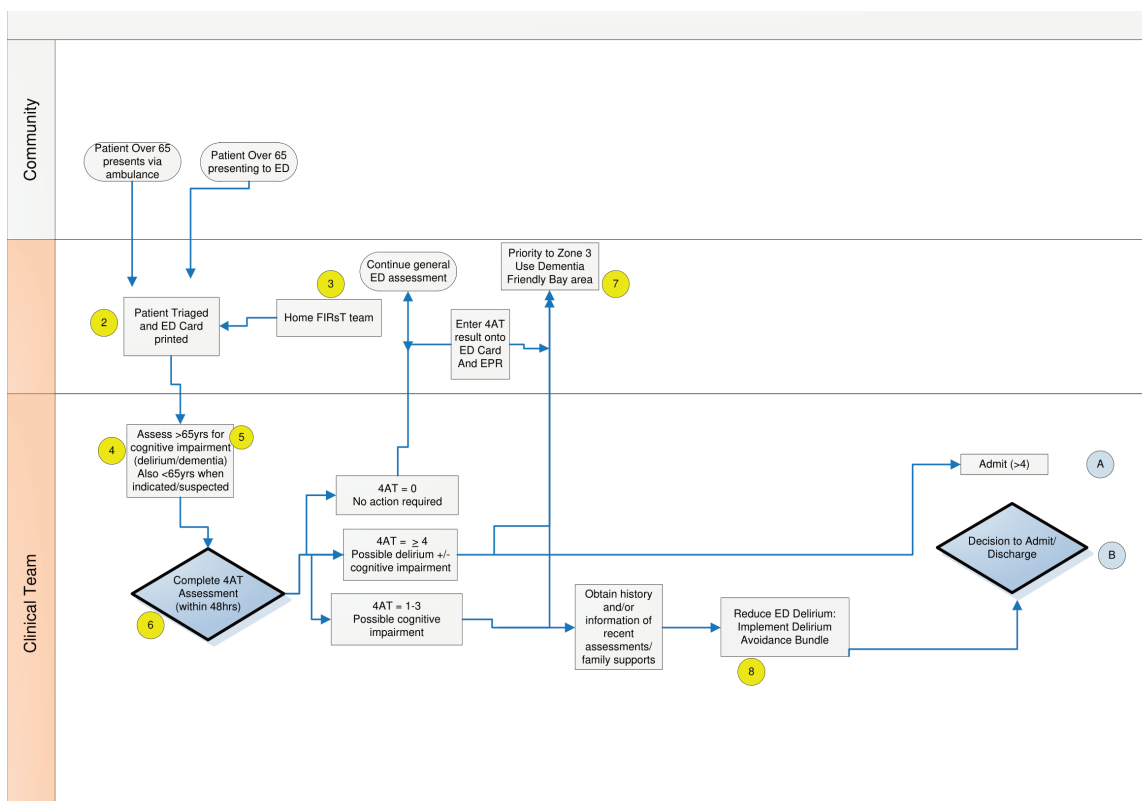


Figure 3. DemPath ICP Part 1- ED Based

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

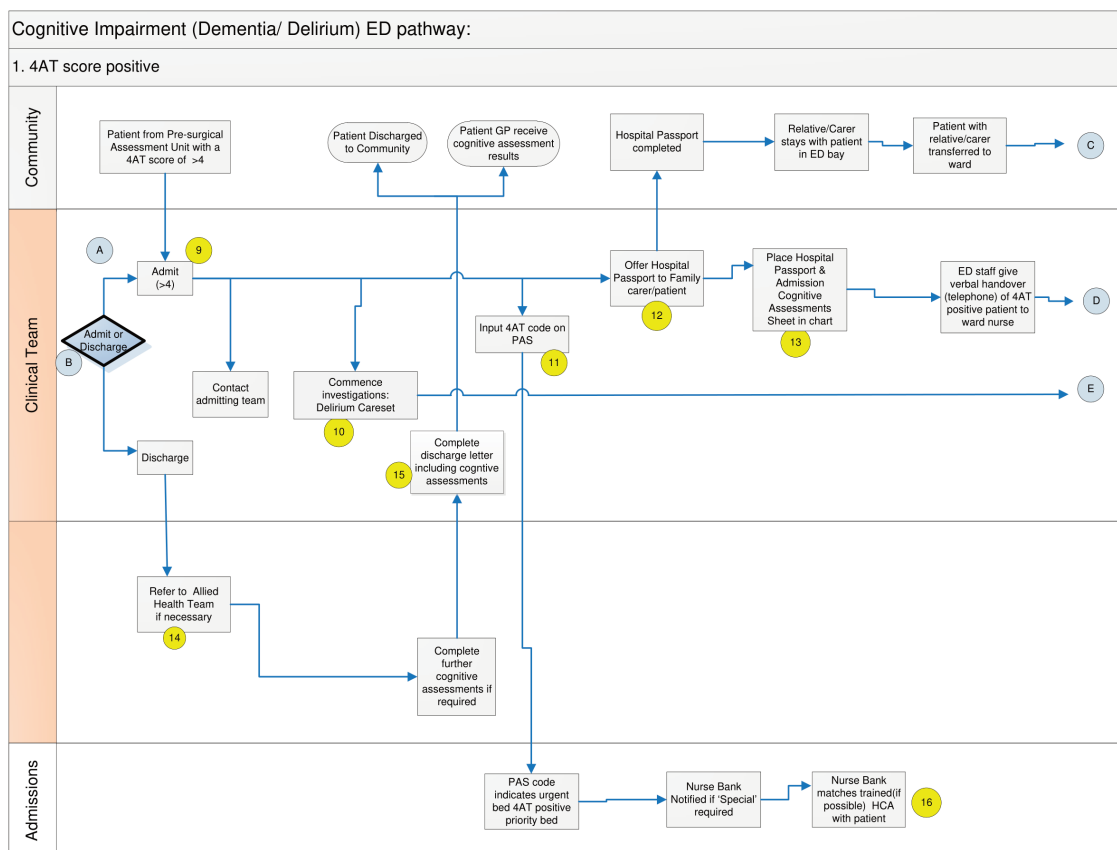


Figure 4. DemPath ICP Part 2- Ward Based

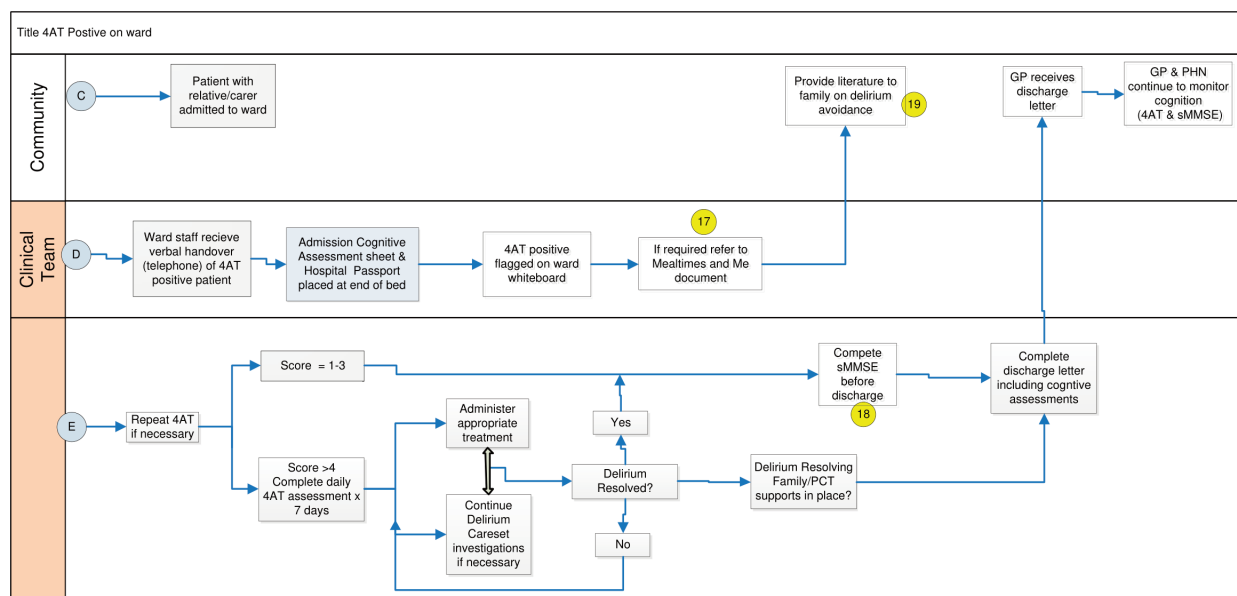


Figure 5. DemPath ICP Part 3- Ward Based




## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

As a starting point to the ICP the 4AT, a validated screening tool for delirium, was proposed to facilitate standardised assessment for delirium and cognitive impairment and disorder of all persons over 65 years on presentation to the ED. Associated testing and piloting took place thereafter (see Figure 2) whereby use of the 4AT in the ED was tested. The sMMSE (standardised mini mental state examination (Molloy and Standish, 1997)) was introduced as part of the ICP following a pilot in the AMAU. A point prevalence study using the 4AT was conducted in preparation for the ICP to anticipate the workload implications for ED staff and to inform resource allocation for the next steps in the ICP. A wallet sized version of the 4AT was developed which was sized to fit in the staff ID holder. This was distributed to all ED staff to ensure that the tool was easily accessible. The consortium were successful in incorporating the 4AT onto the ED patient record card (standardised paperwork).

An ED implementation team was formed to act as a driving force for the initial stage ICP in the ED and conducted process mapping of a care bundle (a structured way of organising care comprising of a small number of evidence-based practices) in the ED (see Figures 6, 7, 8 and 9). This was intended to improve the assessment and management of delirium and cognitive impairment within the hospital.

**Emergency Department**  
**Dementia/ Cognitive Impairment/ Delirium Pathway**



Patients Name \_\_\_\_\_ DOB \_\_\_\_\_ MRN \_\_\_\_\_  
 Date \_\_\_\_\_ Time \_\_\_\_\_  
 Signature \_\_\_\_\_  
 4AT Score \_\_\_\_\_  
 Emergency Registrar notified of 4AT Score [ ]

**Complete 4AT for all patients over 65**

<p><b>1. Alertness</b></p> <p>Normal (fully alert, but not agitated, throughout assessment) 0          Mild sleepiness for &lt;10 seconds after waking, then normal 0          Clearly abnormal 4</p> <p><b>1. AMT4</b></p> <p>Age, date of birth, place (name of the hospital or building), current year.</p> <p>No mistakes 0          1 mistake 1          2 or more mistakes/untestable 2</p> <p><b>2. Attention</b></p> <p>Ask the patient: "Please tell me the months of the year in backwards order, starting at December." To assist initial understanding one prompt of "what is the month before December?" is permitted.</p> <p>7 months or more correctly 0          Starts but scores &lt; 7 months / refuses to start 1          Untestable (cannot start because unwell, drowsy, inattentive) 2</p> <p><b>3. Acute Change</b></p> <p>Evidence of significant change or fluctuation in: alertness, cognition, other mental function(eg. paranoia, hallucinations) arising over the last 2 weeks and still evident in last 24hrs</p> <p>No 0          Yes 4</p> <p><b>Total Score</b> _____</p>	<p><b>4AT Score &gt; 4= Suspected Delirium</b></p> <p>Use Dementia Care Bundle above but</p> <ul style="list-style-type: none"> <li>Complete Delirium Careset</li> <li>ED registrar screens for reversible causes</li> <li>ED register contacts Medical Registrar</li> </ul> <p>Signed _____</p> <p>Medical Registrar assesses patient</p> <p>Signed _____</p> <p>Full details recorded in medical notes</p>
--	--

<p><b>4AT Score 1-3= Suspect Dementia or known dementia</b>  <b>Implement Dementia Care Bundle while in ED</b></p> <p>1. Assign to dementia Cubicle [ ] Time _____</p> <p>2. Encourage carer/ family member to remain with patient</p> <p>3. Hospital Passport offered to patient/carer and included in clinical notes on admission [ ]</p> <p>4. Complete Pain assessment: provide analgesia as indicated Time _____</p>	<p><b>If decision to admit:</b></p> <p>Input on PAS 4AT positive Urgent Bed [ ]</p> <p>Ensure Yellow Cognitive Assessment sheets are included clinical notes [ ]</p> <p>Hospital Passport included in clinical notes [ ]</p> <p><b>If decision not to admit</b></p> <p>Referral to OT/Fraility Team in ED [ ]</p> <p>GP letter includes assessment by OT/FrailityTeam [ ]</p> <p>Family member/ carer informed of 4AT error [ ]</p>
---	---

**Figure 6.**  
**4AT and ED Care**  
**Bundle Part 1**



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 4 AT ASSESSMENT on Admission

Patient's name: \_\_\_\_\_ Date: \_\_\_\_\_

MRN: \_\_\_\_\_ DOB: \_\_\_\_\_ Gender : Female [ ] Male [ ]

Examiner: \_\_\_\_\_

	Score	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
<b>1. ALERTNESS</b>								
Normal (fully alert but not agitated)	0							
Mild sleepiness <10 secs after waking, then normal	0							
Clearly abnormal	4							
<b>2. AMT4</b>								
Age, date of birth, place(name of building), current year								
No mistakes	0							
1 mistake	1							
2 or more mistakes/untestable	2							
<b>3. ATTENTION</b>								
Ask patient "Please tell me the months of the year in backwards order, starting at December"								
7 months or more correct	0							
Starts but scores <7months/refuses to start	1							
Untestable (cannot start because unwell, drowsy, inattentive)	2							
<b>4. ACUTE CHANGE OR FLUCTUATING COURSE</b>								
Significant change or fluctuation in: alertness, cognition, other mental function (e.g. paranoia, hallucinations) arising over the last 2 weeks and still evident in the last 24hrs.								
No	0							
Yes	4							
<b>Total Score (Max 14)</b>	<b>14</b>							

Figure 7. 4AT and ED Care Bundle Part 2



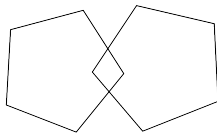
## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

### sMMSE

Patient's name: \_\_\_\_\_ Date: \_\_\_\_\_

MRN: \_\_\_\_\_ DOB: \_\_\_\_\_ Gender : Female [ ] Male [ ]

Examiner: \_\_\_\_\_

	Max Score	Patient Score
<b>Orientation</b>		
• What is the year? Season? Date? Day? Month?	5	_____
• Where are we? Country? County? Town? Building? Floor?	5	_____
<b>Registration</b>		
• Name 3 objects (ball, car, man)(take 1 second to say each). Then ask the patient to name all 3 after you have said them. (Give 1 point for each correct answer. ) Repeat them until the patient learns all 3. Number of trials: _____	3	_____
<b>Attention and Calculation</b>		
• Spell the word WORLD backwards please (Give 1 point for each correctly positioned letter)	5	_____
<b>Recall</b>		
• Ask for the names of the 3 previously mentioned object (Give 1 point for each correct answer)	3	_____
<b>Language</b>		
• Point to a pencil and a watch. Ask the patient to name them	2	_____
• Have the patient repeat the following phrase: "No ifs, ands, or buts" Ask the patient to follow this command: "Take a paper in your right hand, fold it in half and put it on your lap"	3	_____
• Ask the patient to write a sentence below:	1	_____
• Have the patient copy this design:	1	_____
		
• Ask the patient to read and obey the following:  "CLOSE YOUR EYES"	1	_____
<b>Total</b>	<b>30</b>	_____

Patient's sentence: \_\_\_\_\_

Figure 8. 4AT and ED Care Bundle Part 3



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

4AT $\geq 4$ Possible delirium is a medical emergency .....
4AT 1-3 Possible cognitive impairment
<b>Possible delirium</b>  Flag patient for admission and inform admitting team of delirium Search for causes and order delirium dataset – FBC, U/E, LFT's bone, CRP, Glucose, TFT's urine dipstick, CXR Consider CT Brain (eg. If suspected head injury, stroke, encephalitis)  Check for: Sepsis Hypoxia Electrolyte abnormalities Pain Urinary retention New Medications or drug withdrawal e.g. opioids/benzodiazepines Alcohol withdrawal
Avoid: <ul style="list-style-type: none"><li>• Sedatives unless patient is a threat to themselves or others or is very distressed</li><li>• Physical restraints</li><li>• Catheters where possible</li><li>• Constipation</li></ul> Do: <ul style="list-style-type: none"><li>• Orientate in a quiet environment (eg dementia friendly ED bay)</li><li>• Manage pain (consider dementia pain score eg Abbey)</li><li>• Ensure adequate hydration and nutrition</li><li>• Review all medications</li><li>• Early and regular mobilisation</li><li>• Encourage independence with ADLs</li></ul> Agitation: <ul style="list-style-type: none"><li>• Situate the patient in a quiet area (dementia friendly ED bay) and consider one-to-one care</li><li>• If agitation is severe and there is a potentially risk to self or others, use oral medication in small doses and increase gradually if necessary. Initially, use haloperidol but if not tolerated use lorazepam</li><li>• Avoid haloperidol or olanzapine in those with Lewy Body Dementia or Parkinson disease</li><li>• If oral therapy fails, consider IM or IV – discuss with senior colleague and monitor closely</li></ul>

Figure 9. 4AT and ED Care Bundle Part 4





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

The care bundle for people with a '4AT positive' score (scoring 1-3 on 4AT indicating suspect or known dementia) (see Figure 6) included, for example, assigning to dementia-friendly cubicle (see Section 2.5.2 for a description), and hospital passport (see Section 2.5.1.3) being offered to the patient/carer and included in clinical notes on admission. It was also proposed that where the 4AT score was greater than 4 (i.e. in cases of suspected delirium) (see Figure 6), that the delirium care set is completed, and an ED registrar screens for reversible causes and contacts a medical registrar. There were further proposed components to the care bundle, depending on whether or not the individual was admitted to SJH or not. Where a decision was made to admit the patient, a number of tasks (see Figure 6) were proposed, including, for example, input on the Patient Administration System that the patient is 4AT positive and requires a bed urgently. Where a decision was made not to admit the individual, other tasks were proposed (see Figure 6), including, for example, referral to OT/Frailty team in the ED.

During the course of the project, the digital screen/electronic whiteboard in the ED was introduced as an update to the whiteboard communication system for recording active patients/cases and a marker for 4AT positive (indicating delirium or cognitive impairment, as determined by the DemPath team) was included on this as part of the care bundle. Significant progress was achieved in developing the ED care bundle over the course of the project, and its implementation was still ongoing at the time of reporting and will need evaluation in the future.

### 2.5.1.3 Testing and Implementing Draft ICP at Ward Level

The use of the 4AT as part of standardised assessment for initial cognitive impairment was introduced for inpatients within a new pre-assessment clinic for elective surgery which commenced during the lifetime of the project. As a consequence, nursing staff in the pre-anaesthetic clinic began linking in with the DemPath nurse when a patient had a 4AT positive score. A recording sheet was designed to be included in the patient chart to facilitate ongoing recording of 4AT scores following inpatient admission to SJH and was awaiting wider implementation at the time of reporting. The 4AT score was included in the Patient Administration System to identify those who are 4AT positive in order to potentially provide nursing staff with more time to manage the patient as they would be aware of cognitive impairment and/or delirium earlier and to highlight that a bed was required urgently.

A Hospital Passport (which incorporated patient information such as demographic details, hobbies and interests, and preferred routine) was drafted by the consortium. In the long term, it was planned to initiate completion of this in the ED and then continue at ward level. The Hospital Passport, at the time of reporting, had been successfully trialled in Mary Mercer's ward and a wider hospital roll-out was planned to be implemented.

The DemPath team developed a standardised template entry for cognitive impairment to be included on the reverse of the discharge letter serving as a prompt for doctors, and this is now part of routine discharge documentation with the hospital. Significant progress was made in establishing improved links between SJH and the community through education events (outlined below) as well as involvement of community representatives on the consortium. The project manager liaised regularly with the HSE Manager of the local health office and attended community healthcare meetings.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

### 2.5.1.4 ICP Related Activities Identified for Future Implementation

Below is a list of tasks identified by the DemPath project through the development of the ICP for implementation in the future. Notably, some of these were initiated but not fully completed in the project lifetime:

- Full implementation of an ED care bundle for patients with a 4AT positive score,
- Verbal handover of patients with 4AT positive score from ED to ward level,
- Use of whiteboards at ward level for identification of patients with 4AT positive score,
- Routine inclusion of cognitive assessment sheet and Hospital Passport in patient folder at end of bed at ward level,
- Implementation of Hospital Passport across all wards for patients with a 4AT positive score,
- Matching of trained Health Care Assistants (HCAs) with patients by the nurse bank (central facility used to provide nursing, HCA and other healthcare staff to the hospital; including both agency staff and staff employed by the hospital),
- Standardised use of the sMMSE as part of the ICP,
- Tele-mentoring as a monthly liaison with nursing homes to discuss complex cases,
- Continued monitoring of cognition (4AT and sMMSE) in the community post-discharge from the hospital,
- Responsive behaviour and appropriate use of antipsychotic medication policies for people with dementia in the hospital to be finalised.

### 2.5.2 Environmental Adjustment

The original DemPath plan for environmental adjustment was to focus on the ED bay areas and 1-2 wards within MedEl. However the scope of environmental adjustment evolved over the course of the project and was extended to include the MISA build<sup>5</sup> and Hollybrook Lodge. The DemPath project activity coincided with the MISA build, and provided a unique opportunity to influence environmental design within this purpose-built facility on the SJH site. In consultation with the MISA architectural team, the DemPath project part-funded and influenced the design of wayfinding orientation cues for the MISA building that were specifically designed to make navigation of the building more dementia-friendly. Key features of the new signage designed included (see Image 1): jumbo sized floor directions; colour coding of individual floors in the building; use of written word and associated picture in signage throughout the building; utilisation of walls and pillars for signage at key decision-making points; and tilted floor directories to provide additional cueing at lifts (as reported by project lead, December 2016). This was informed by the 'mystery shopper' experience (see Section 2.5.1.1). The DemPath team liaised with Facilities Management in SJH on a number of occasions to inform them of progress in the development and to secure implementation of environmental adjustments. This served to keep them abreast of project developments and provide education and raised awareness around dementia-friendly design principles.

<sup>5</sup> During the project timeline, a new building was constructed on the grounds of SJH which houses Mercer's Institute for Successful Ageing (MISA) and is commonly referred to as the MISA building.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATH INTEGRATED CARE PATHWAY PROJECT



**Image 1. MISA Wayfinding<sup>6</sup>**

A substantial achievement in this project was the design and customisation of two dementia-friendly bays for people with dementia in the ED. The DemPath consortium were guided by a small observational study of people with dementia in the ED undertaken by a student from the National College of Art and Design (see Section 2.5.1.1) and the outcomes of research on bed bay design in the UK, specifically at Croydon NHS Trust in London and Whiston Hospital in Merseyside. The DemPath team consulted with experienced service providers in the area of dementia-friendly environmental change, in order to develop a proposed list of changes for the ED bay areas. Significant changes were implemented when bays were completed in August 2016. The key alterations included (see Image 2):

- General decluttering,
- Small storage unit by the window,
- Gloves dispensers above the sink,
- Two fixed folding chairs installed,
- Curtain replaced with a hard folding screen,
- Changed colour scheme of walls and panels,
- Time display to indicate morning/afternoon/evening/night installed above the entrance and on the back wall,
- LED RGB ceiling mounted light panels with a small wall-mounted control panel to adjust levels and colour of light were installed in both ED cubicles .

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT



**Image 2. ED Bays Before and After Alterations<sup>7</sup>**

While the alterations did not compromise the ability of the bay to hold two trolleys as the chairs installed could be folded up compactly, it was hoped that, where possible, the bay would be used for one trolley only in the case of a patient with dementia or other cognitive impairment.

During the course of the DemPath project an opportunity presented to contribute to upgrading of the day room in Mary Mercer's ward, an acute gerontology admission ward in SJH. This was not part of the original DemPath plan for environmental adjustment but was seen as an important need as the project evolved due to the high proportion of people with cognitive impairment in this ward. Prior to refurbishment, the day room was used for storage of a large amount of equipment, and was viewed as being a somewhat inhospitable environment. Changes implemented included: painting of walls; wainscoting on lower section of walls; new purple blinds; introduction of a sectioning wall to divide storage and seating areas; floor to ceiling shelving placed on the sectioning wall; window seating area introduced; and television hung on the wall (see Images 3 and 4<sup>8</sup>). The sectioning of the room for storage and seating areas served to improvement the functionality of the day room, though some items and equipment remain stored in the seating area.

<sup>7</sup> Image provided by DemPath consortium.

<sup>8</sup> Photos taken by evaluation team with permission of the CNM in Mary Mercer's ward.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT



**Image 3. Sectioning Wall with Shelving and Window Seating**



**Image 4. Sectioning Wall Introduced to Divide Storage and Seating Areas**

Following an approach by the Assistant Director of Nursing, a report on the Hollybrook Lodge environment, including recommendations for further development, was compiled by the environmental design lead. As a consequence, the DemPath team liaised with Hollybrook Lodge in planning environmental adjustment. The DemPath project made a small amount of funding available to Hollybrook Lodge and assisted them in sourcing fire place surrounds and other items from a local architectural salvage warehouse. The overall aim of the renovation was to make the environment more 'homely' and less clinical for residents, and one of the key changes implemented was to change the focus of the dining room as the focus was previously the television.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 2.5.3 Education and Training

A large component of the DemPath project comprised of education and training initiatives which were described as Level 1 and Level 2 training. An overview of the programmes can be found in Table 1.

**Table 1. Overview of Education and Training Programmes**

<b>Level 1 Training</b> (targeting all staff in SJH including community area)	<b>Duration</b>	<b>Number of staff</b>
Dementia awareness (existing staff)	1 hour	392
Dementia awareness (as part of the corporate induction programme)	1 hour	671
<b>Level 2 Training</b>		
Facilitators Training	2 days	63
Dementia awareness (2 hour programme provided to nursing home staff)	2 hours	300
Dementia awareness (2 hour programme provided to multidisciplinary team members in the community)	2 hours	30
Introduction to Cognitive Stimulation Therapy (delivered to CNMs)	4 hours	6
Communication (completed by DemPath Facilitators and then disseminated to their peers)	2 hours	223*
Dementia Life Stories/Activities programme (Nursing and HCAs)	2 days	8
Dementia awareness for security staff	3 hours	33
General Practitioner Training (Dementia/Delirium/Communication/ Responsive behaviours)	1 hour	32
In service training on the implementation of the 4AT assessment tool in the Emergency department)	30 mins	60
In service training on the implementation of the 4AT assessment tool and 'getting to know me' document for Hollybrook nurse managers)	1 hour	6
In service ICP training for interns	1 hour	33
Training on dementia design	3 hours	35
<b>Study Days and Awareness Events</b>		
Brain awareness day	1 day	400+
Public lecture on responsive behaviours in dementia delivered by Prof Helen Kales, University of Michigan.	2 hours	100
Exercise and ageing delivered by Dr Stefan Schneider, University of Cologne	2 hours	40
DemPath presentation at CNMs' study day	2 hours	60
National College of Art and Design dementia design presentation	2 hours	79
Dementia Education Day 1	1 day	166
Dementia Education Day 2	1 day	132
Dementia Education Day 3	1 day	110
Dementia Education Day 4	1.5 days	143
Dementia Education Day 5	1 day	121
*223 hospital based, numbers not recorded in the community		



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

Programmes were divided into level 1 and level 2 programmes which reflected their length and depth. Level 2 programmes consisted of a short one-hour general dementia awareness programme which was open to all staff throughout the hospital and community sites. From July 2014, this was also included, with slight changes, in the corporate induction programme for all newly appointed staff. Level 2 programmes varied in length and were delivered to what were described as 'front facing staff' who had more contact with people with dementia as part of their roles. Most level 2 programmes were longer in duration and were developed in response to the needs of different groups of staff throughout the hospital and community sites. The level 2 programmes, while they had overarching principles, were tailored to meet the needs of service providers who worked in diverse areas.

The project also adopted an innovative 'train the trainers' approach and to this end, at the time of reporting, approximately 50 'DemPath Facilitators' were prepared. Facilitators were recruited either because they came forward or showed an interest in the area of dementia care and were asked if they wished to be involved. Notably, many of the DemPath facilitators attended training outside of working hours due to difficulties in being released from duty to attend training. The role of the facilitators was to deliver the level 1 programme within their own areas and if they requested they would be taught to teach some level 2 programmes. While they were mostly health professionals, this was not the intention and efforts were made to recruit facilitators from support staff as well. A significant number of facilitators were from community based roles (for example, PHNs, or nurses based in LTC). The facilitators were prepared for their role by attending the two day facilitators course. It was recognised that some of the staff had prior knowledge and experience of dementia and therefore only had to attend the second day. Once prepared, the facilitators were encouraged to deliver the awareness programme using pre-prepared documentation that was accessible on the DemPath shared drive. As they became more experienced, the facilitators were encouraged to deliver level 2 programmes although this required additional preparation. In addition, the facilitators began to develop or become involved in dementia-related projects within their respective areas. Facilitators who came to realise that teaching was not for them, chose to engage in other activities such as involvement in dementia-related projects. The facilitators were supported by members of the education work package group including the DemPath nurse. There was also a monthly facilitators' support group meeting (three-monthly post-project completion) which they were encouraged to attend. This was valued by the facilitators not just as a medium to provide and receive support but also to receive updates on the DemPath project and dementia.

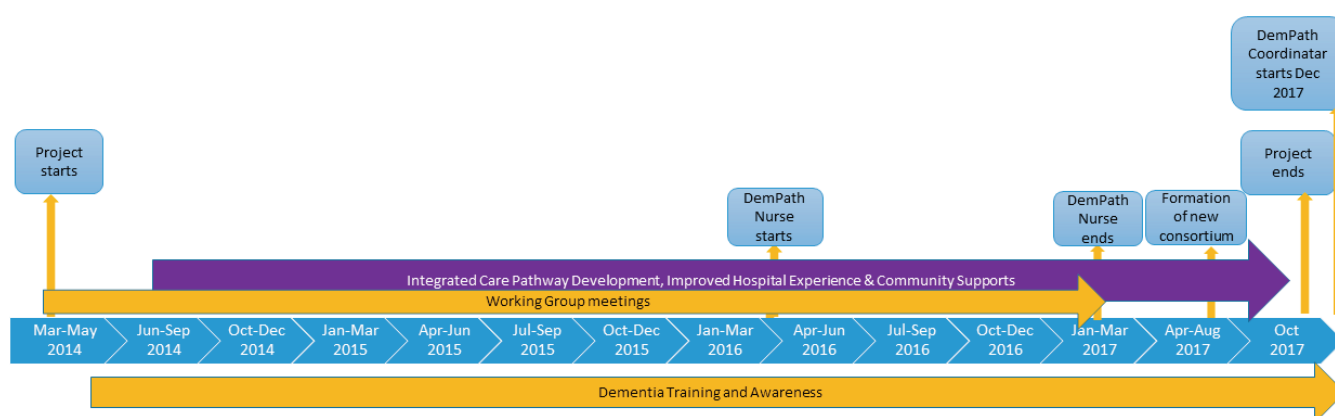
The project also raised awareness of the two day training that was being run as part of the National Dementia Education Programme, facilitated by the Centre for Learning and Development in SJH. In addition, there were also a number of public engagement and staff awareness events which were organised throughout the life of the project. A dementia handbook was designed for all frontline staff as a reference to help them "understand the person with dementia" and as an adjunct to the formal education programmes. The handbook had undergone a number of iterations as part of the review process and was awaiting final production at the time of report writing. While the level 1 and 2 programmes formed the core of the DemPath education and training initiatives, other activities (such as the development of the dementia handbook) emerged in response to need as the project progressed. The project also developed an e-learning programme based on the level 1 and level 2 educational programmes and the ICP which will be hosted on the hospital's LearnPath, SJH's online education system.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### 2.5.4 Overview of Project Activities and Milestones

Figure 10 presents a timeline overview of the key DemPath project components and activities described in the previous sections.



**Figure 10. Overview of DemPath Project Activity**

### 2.6 Summary

The DemPath project aimed to develop and deliver enhanced integrated care for people with cognitive impairment. 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 DemPath project.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 3. Methodology of Evaluation (Overview)

#### 3.1 Introduction

As outlined in Chapter 1, the authors of this report were commissioned to evaluate the DemPath project as part of a larger evaluation of the HSE & Genio Dementia Programme. The complexities concerning dementia care provision, alongside the capacity of the health system to respond, present significant challenges for any project seeking to improve care and support for the person with dementia. An evaluation of such projects requires attention to the set-up, implementation process, impact and sustainability of the initiatives. To this end, the evaluation methodology adopted for the project reported here, was informed by action research with emphasis on context, relationship, process and outcomes, and is underpinned by the well-established RE-AIM evaluation framework (Glasgow *et al.*, 1999; Gaglio *et al.*, 2013).

#### 3.2 Aims

The aims of the evaluation were to:

1. Understand how ICPs can change and improve service delivery and outcomes for people with dementia and their families,
2. Explore the roll-out of ICPs 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 DemPath 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 ICPs nationally.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

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

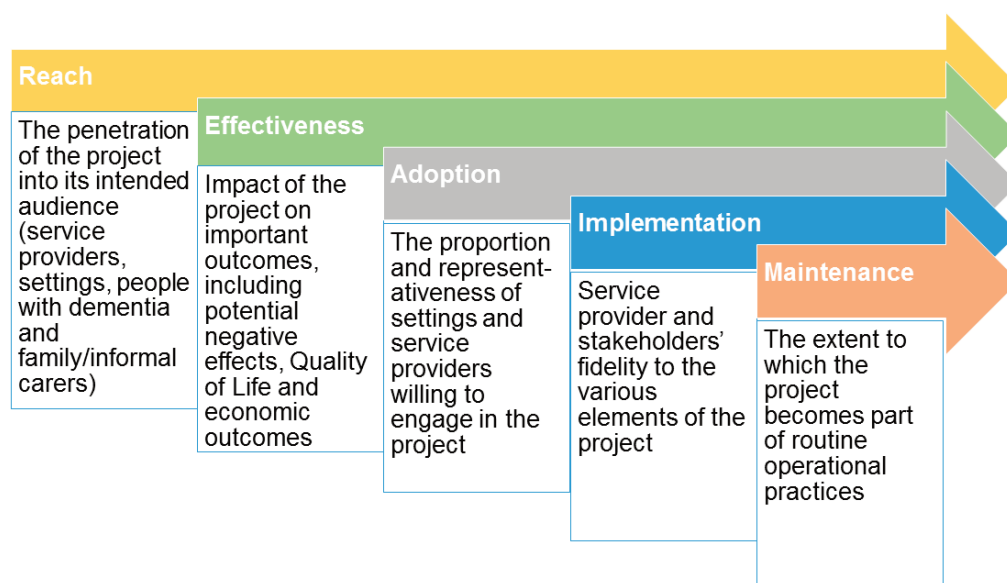
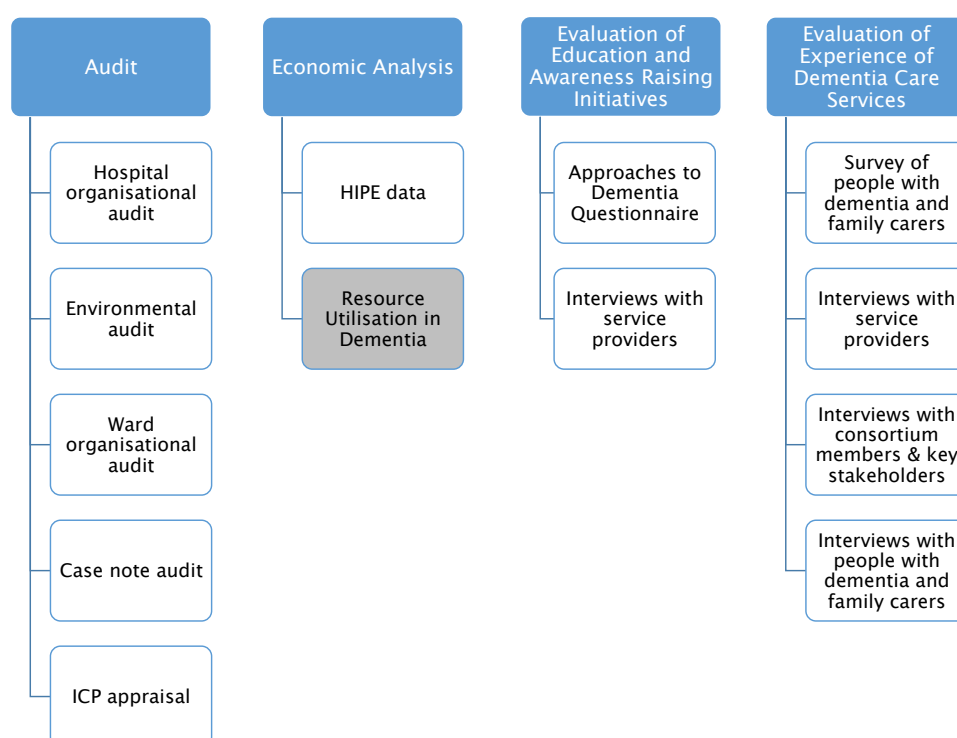


Figure 11. RE-AIM Framework Used in the Evaluation

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

There were four key aspects of the evaluation methodology, as outlined in Figure 12.



**Figure 12. Overview of Evaluation Method** <sup>9,10, 11</sup>

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 occurred a number of months after the project had started and as such, T1 data reflects the 'early in-project status' as opposed to pre-project status. In order to capture the process related details of the project as they unfolded, additional data were collected on an ongoing basis. A purposeful sampling strategy was adopted to identify participants (Palinkas *et al.*, 2015), with ethical approval granted by Trinity College's Faculty of Health Sciences Ethics Committee, the Joint Research Ethics Committee for SJH, and from the HSE South Eastern Area Research Ethics Committee. The total number of participants involved in each stage of data collection is provided in Table 2.

<sup>9</sup> It was not possible to include data sources shaded in grey (Wimo *et al.*, 1998) in the evaluation due to very limited amount of such data that it was possible to collect.

<sup>10</sup> The Approaches to Dementia Questionnaire (Lintern and Woods, 1996) was administered and the resultant data collected by the DemPath project team.

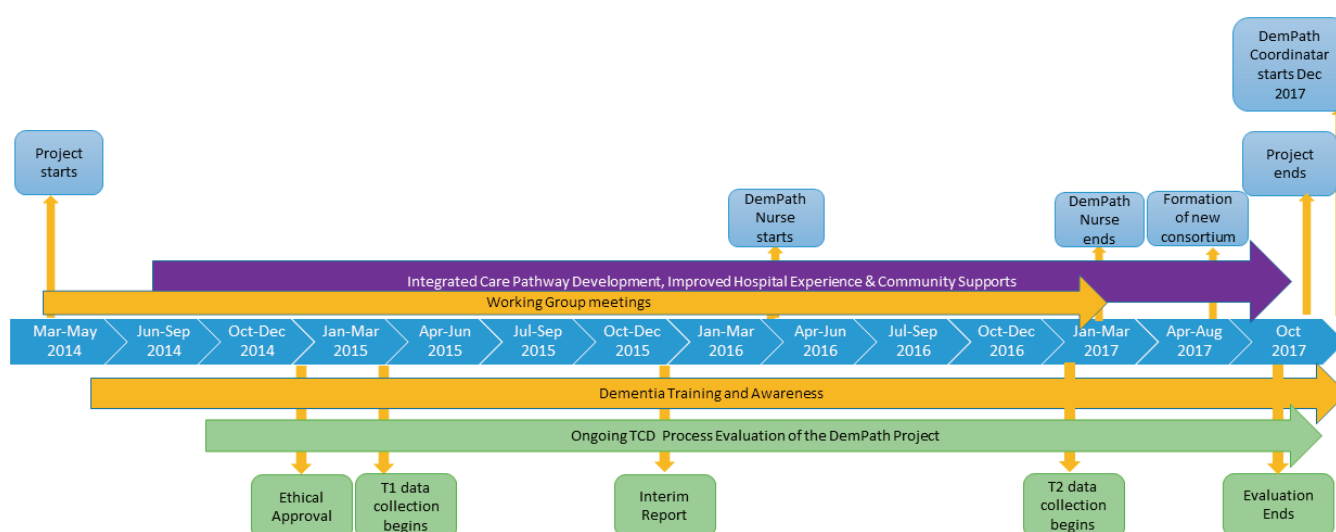
<sup>11</sup> The same wards were not audited at T1 and T2, except the ED as the project team requested that different wards which were more greatly impacted by project activities be audited at T2.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

**Table 2. Overview of Sample Sizes in Data Collection Stages**

Participant Group/Source	Time 1	Time 2
Economic analysis	HIPE data for 2014 – 426 cases	HIPE data for 2016 – 496 cases
Awareness and knowledge survey	1182	919
Surveys of service users and family carers	26	20
Interviews with service users and family carers	8	17 (including 10 ED-specific)
Interviews with service providers (including consortium members & key stakeholders)	43	47

Additionally, ED data for presentations of all those aged 65 and over during 1-30 November 2015 was accessed through the support of the consortium and analysed by the evaluation team. Figure 13 provides an overview of the timeline of data collection in relation to project activities.



**Figure 13. Overview of the Timeline of Project Evaluation Data Collection in Relation to DemPath Project Activities**

### 3.5 Summary

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

- Chapter 4 – DemPath Project Impact and Outcome Findings,
- Chapter 5 – DemPath Project Process Findings,
- Chapter 6 – DemPath Hospital Inpatient Activity Analysis.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### 4. DemPath Project Impact and Outcome Findings

#### 4.1 Introduction

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

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

#### 4.2 Integration of Dementia Care

As demonstrated in Chapter 2, the DemPath project contained a number of elements that aimed to enhance the integration of dementia care on entry to and within the hospital and on discharge from SJH 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:

- ICP for dementia,
- Project roles,
- Overall integration of dementia care.

##### 4.2.1 ICP for Dementia

The development of the ICP will be considered in the following sub-sections:

- Process mapping,
- 4AT and the ED,
- Personalisation of care,
- In-reach/out-reach,
- Sustainability of ICP related changes.

##### 4.2.1.1 ICP for Dementia – Process Mapping

One of the first steps in the development of the ICP was the baseline process mapping of the journey from admission to discharge for the person with dementia and this turned out to be one of the major successes of the consortium. Given the unique complexity of SJH this was a significant undertaking and a challenging process. However, the investment in this stage of ICP development proved worthwhile as the process mapping was valuable to project learning and as a mechanism to understand patient flow. Corporate support was a key enabler for success of this process mapping. The evaluation team worked with the consortium to contribute to developing





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

understanding of the patient journey through the hospital. As part of this, the evaluation team conducted a small sub-study looking at presentation to the ED by over 65s (An overview of this is provided in the box below).

### Sub-Study: Audit of Admission to Emergency Department (ED) - Over 65s

Early findings from the evaluation of 2014 SJH HIPE data revealed that 99% of all admissions with a dementia diagnosis came from home. As this was a surprising result to the consortium, the evaluation team undertook an analysis of source of presentation to the ED of all those aged 65 and over during November 2015. Key findings included:

- Of the 858 presentations, 46% were male (n = 396) and 54% were female (n = 462), with an average age of 77.55 years (Min = 65.07, Max = 100.16, SD = 7.61).
- The majority (78.9%, n = 677) of the 858 presentations occurred Monday to Friday. Of these, 67.2% (455/677) occurred between the hours of 9am and 5pm. Therefore, a total of 53% (455/858) of all presentations of over 65s in the month occurred between 9am and 5pm on a week day. There was no significant difference between home presentations and LTC presentations in relation to whether the presentation occurred within or outside of these hours.
- The majority (94.8%, 813/858) of all presentations came from home. The remainder were either from LTC (4.2%, 36/858) or were from Our Lady's Respite & Hospice (3/858), St Patrick's Mental Health (3/858), Hollybrook Lodge (2/858), or convalescence in Mount Carmel (1/858).
- The majority (59.2%, 500/845, 13 missing) of presentations were admitted. The remainder were either discharged (40.2%, 340/845) or died (0.6%, 5/845). There was no significant difference between groups (home, LTC, other) in this outcome (admitted, discharged or died).

### 4.2.1.2 ICP for Dementia – 4AT and the ED

Due to the finite resources of the project and the size of SJH, a decision was made by the consortium to focus on particular aspects of the ICP development to maximise the impact of a selected number of changes rather than implementing a complex series of changes throughout the hospital and community with minimal impact. It was decided to develop the ICP to encompass assessment for delirium and for other cognitive impairments as well as dementia. Standardisation of assessment through the use of the 4AT for identification of cognitive impairment/dementia/delirium in the ED was a key focus of ICP development. This was identified as the first point of contact for patients and a key stage in the patient journey. Therefore, the consortium used the 4AT in the identification of cognitive impairment as an opportunity to standardise assessment. Partial progress had been achieved with the implementation of the 4AT in the ED and pre-assessment elective surgery clinic at project end as it was in use but not consistently. At the time of reporting, this approach to standardise assessment of cognitive impairment was not yet uniform practice within the ED. This was possibly related to significant pressures during the project period and the high turnover of staff, in particular trainee doctors, within the ED. The bureaucracy of the hospital structure was highlighted in interviews with hospital staff as having an impact on the project timeline and efforts to improve or standardise dementia care whereby there were significant delays involved in having documents and changes approved and implemented. For example, the inclusion of the 4AT on the ED card took a long time to achieve as documentation changes had to be reviewed and approved at a number of levels including the requirement to go through documentation committees.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

The ward organisational audit (detailed further in Section 4.2.3.2) implied the implementation of the 4AT was not yet standardised in the ED; only two charts (10%) at T2 contained evidence of its implementation. T2 audit data also suggested that the 4AT was operational but implementation as yet inconsistent on the wards. It was noted in T2 interviews with hospital staff that compliance was greater when the DemPath nurse was present and was influenced by the presence of the DemPath nurse to drive assessment due to early stage of adoption by personnel across both nursing and medicine. Whilst awareness and implementation of the 4AT was reported by a proportion of hospital staff to be limited, others reported positively on their experience of the 4AT. Positive reports included the 4AT as being user friendly, quick and easy to use, and lessening the demand on specialist resources:

*"We'd find a lot of the times we get many referrals to assess cognition so if we're, like if somebody presents with delirium and things like that and a lot of our assessments aren't sensitive to delirium and we found since the 4AT was introduced that it's kind of lessened the reliance on MMSEs and lessened the reliance on us completing formal cognitive assessments, that they rely quite heavily on the 4AT to assess for any cognitive difficulty and we've definitely found that a benefit in our prioritisation of our referrals...So it's the 4AT basically is lessening the demands." (FU FG AHP 2)*

It was also reported by hospital staff that it was difficult to implement the 4AT in the ED due to pressure on resources and the nature of ED interactions. A number of ED staff highlighted that some patients in the ED were finding it difficult to answer the attention-related question and could become distressed. The staff believed that the unfamiliar surroundings and the stress of being in hospital and needing medical attention could be contributing to the difficulty that people were having in answering this question:

*"I think it's good. It can be quite difficult to do in areas like triage or when the place is really, really busy, because I find personally sometimes it can get the patient a bit distressed. Especially if they are coming out of their own environment and then you're asking them to count backwards and the month and if they can't do it - they normally could do it - and I find it actually can distress people, that's my experience with the 4AT." (FU FG ED Nurses)*

The importance of education and sustaining motivation for its use amongst staff through active involvement of project personnel was emphasised in maintaining compliance with completion of the 4AT. One interviewee outlined that being formally instructed in how to implement the 4AT was highly beneficial and it was interventions such as this which served to increase the awareness and use of the 4AT among service providers. Hospital staff emphasised the importance of ongoing education for staff, both in terms of the 4AT and dementia awareness and management.

Interview data pointed towards difficulty in the movement from ED to ward level within the project ICP, in terms of both the transfer of 4AT and Hospital Passport information. This was also raised in the comment section in the audit data. This manifested primarily in poor transfer of 4AT assessment information to ward level. For example:

*"People coming up from A&E if you are screening their notes I've never seen that (4AT information)...  
No and I cover A&E on my team and I've not come across that. Because I'm in trauma and we cover it" (FU FG AHP 1)*



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

A 4AT positive score was linked to a flag on the ED whiteboard as part of the project ICP, however, this was not mentioned by hospital staff in interviews, only by consortium members, suggesting that this awareness is not yet commonplace among hospital staff which may be due to its introduction close to the final stage of the project. It was outlined that the 4AT is being incorporated by the Frailty Intervention Team within the ED, and is being included on the electronic patient record (EPR), so should therefore become part of routine practice. It was also outlined that because the 4AT is now a national tool, this should increase the likelihood that its use will continue in SJH and that awareness and implementation will be extended in time.

### 4.2.1.3 ICP for Dementia – Personalisation of Care

In order to develop more personalised dementia care within the ED, another aspect of the care bundle for those with cognitive impairment identified by the 4AT was provision of the Hospital Passport (including “Mealtimes and Me”) by ED staff and completion of this by the patient’s family or carer. It emerged that full compliance with completion of this was not yet achieved during the project timelines. Findings from the evidence of ICP usage and 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 4.2.3.3). The case note audit revealed some evidence that people with dementia were placed in the new dementia-friendly bays while in the ED. Interestingly, there was some suggestion that emphasis might be better placed on patient flow through the hospital rather than on the care within ED. However staff in the ED did report that the project activity focused attention on the wait times for people with dementia and reported using their influence to minimise delays and to ensure access to the support of family carers:

*“Normally, like nurses on the floor, we highlight to the sister in charge on the floor and then they kind of liaise with the admissions or who is like prior...prior to them, and then it’s the...kind of they prioritise them and try and get them as early up to the beds, like.” (FU FG ED Nurses)*

Hospital staff reported that patient information such as likes and preferences were not commonly available, indicating that the Hospital Passport was not yet routinely completed. The importance of having patient information such as likes and preferences available was highlighted by both service users and service providers throughout interviews:

*“Patients with dementia need constant reassuring and familiarity. Even using a family member’s name helps to calm and things they like should be put on their chart. It is as important as the medication they get.” (Service user questionnaire, Family Carer 7)*

Security staff, in particular, highlighted that they were provided with very little information when called to assist with a patient on a ward, for example, whether the patient has cognitive impairment or is likely to be reactive to a high-visibility security jacket. Hospital staff described a number of cases where having patient information and using this to engage with the patient had been a very positive experience:

*“We’ve another patient that had an interest in horses, so you’d make up something about a horse and this patient was able to converse about horses for three or four hours. It breaks up that first three hours, you’ve got the patient then nice and calm, your day goes an awful lot smoother.” (FU SI Security 2, describing experience of ‘specialing’)*



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

It was felt by some interviewees that there was often poor handover of this type of patient information demonstrating the potential benefit of a wider roll-out of the Hospital Passport:

*"I know the staff that we have, they find it difficult to interact with these people. Now whereas if they could have some information to say look you have to spend X amount of time throughout the day to try and get this patient to talk, or to try to get them up and moving. Because we could, as security officers we could do an awful lot more than just sit there and stare at the four walls, waiting for this patient to do something. Whereas if we went into the room and maybe read a paragraph of a newspaper or if they were into sports read the sports section of the newspaper. They mightn't be able to read, may be short-sighted or not understand what words are written in front of them. But if, you know, the staff can do something for these patients it makes the transition an awful lot easier for them." (FU SI Security 2)*

The significance of interaction with people with dementia was highlighted in terms of preventing boredom and responsive behaviours. Despite recognition of the importance of patient information and interaction, limited usage of the Hospital Passport was reported in interviews. Many hospital staff reported that patient information is only available for those being 'specialised'<sup>12</sup> or was only available in a small number of wards. Questionnaire data demonstrated that only 5/16 family carers at T2 were asked for details that would help staff care for their relative such as their usual routine and preferences (similar to 6/26 reporting this at T1). Only 8/16 were asked about food preferences or dietary requirements for their relative at T2, though this had increased from 7/19 at T1. Furthermore, just 8/13 service users at T2 (compared to 11/16 at T1) reported that staff asked what the person with dementia preferred to be called. In interviews, hospital staff highlighted that it is often difficult to collect patient information from family members due to time pressures.

Flexibility around visiting times was reported by family carers and importantly, this differed to T1 where family carers reported inflexibility around visiting times. Difficulties in communication with hospital staff were identified by family carers at both T1 and T2. This related to not being informed of what to expect following the dementia diagnosis as well as having difficulties in accessing information about the person with dementia and communicating with staff (see Case Study 1). Data from the service user questionnaire did demonstrate some small improvement in this across the course of the project (see Table 3).

**Table 3. Service User Questionnaire Data Relating to Information and Communication**

	Time	Yes – N (%)		No – N (%)
Was there a named nurse or other contact who you could talk to about the care of your relative introduced to you on this ward	T1	10 (38)		16 (62)
	T2	8 (50)		8 (50)
		Yes, always – N (%)	Yes, sometimes – N (%)	No – N (%)
Were you able to speak with a senior member of the nursing staff when you wanted to	T1	3 (12)	16 (67)	5 (21)
	T2	7 (44)	7 (44)	2 (12)
Were you kept informed about the care and progress of your relative during their admission	T1	4 (15)	14 (54)	8 (31)
	T2	6 (37)	7 (44)	3 (19)

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



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### Case Study 1<sup>13</sup> : A Son's Perspective on His Mother's Stay in SJH

Mary, aged 93, spent a week in St. James's Hospital in 2017 and is now back in her own home. Mary has a diagnosis of Alzheimer's disease. She receives three hours home help per week and attends a day centre four days a week. All other care (including staying overnight with Mary each night) is shared among her adult children. Mary has a moderate to high level of independence, though has a relatively poor quality of life (as measured by a number of psychometric tools designed to measure independence and quality of life). Mary's son John, aged 50, was extremely positive about the clinical management and care received by his mother in the hospital. He found the acute hospital environment a challenging space. In particular he identified the busyness of the environment, the very limited time that staff had available to provide care, and challenges in communication. For example, he had difficulty in gaining updates from staff on his mother's condition and he did not know if there was a named nurse assigned to his mother's care that he could speak to. Consequently, John suggested that a handout or flyer be given to family members when their relative is admitted to the hospital giving information on how to obtain updates.

*"It was incredibly frustrating you know, not just for us but for others, it seemed that the people at the desk never had the information so it would have stopped us going to them every day if they just told us that's where 'the nurse' is. So that's one thing, its basic, basic communication... It all comes back to the updates and a feeling of an attitude of unhelpfulness from some people. That's really my main take-away. But we are still happy you know with the care she got."*

John also reported experiencing challenges with the physical hospital environment both in terms of the space available to move around and access due to locked doors on the ward and the need to buzz through. At discharge, John was given a discharge summary document which he viewed very positively and stated that this was very useful when interacting with the PHN following discharge.

Throughout the interviews, other examples of personalisation of care by hospital staff were mentioned. These included:

- Adjusting times for lights on/off,
- Providing an evening snack,
- Playing music for people with dementia,
- Allowing families to bring in food for the person with dementia,
- A 'special' engaging in group activities with patients,
- Bringing patients to the shop.

The implementation, in 2016, of the use of 'patient support'<sup>14</sup> staff rather than HCAs acting as specials was highlighted as a barrier to the provision of personalised care as it was perceived that patient support staff do not engage in the same level of interaction with people with dementia as HCAs. It was noted that further training and education is required for patient support staff in order to engage with the person with dementia. Hospital staff outlined that security staff were sometimes asked to 'special' when HCAs encountered difficulties in specialising. This highlighted gaps in training for HCAs but the fact that security staff may not have sufficient training either was also pointed out by some hospital staff.

<sup>13</sup> Pseudonyms are used to protect the identity of respondents.

<sup>14</sup> Patient support staff do not provide assistance with feeding, toileting, bathing etc. when specialising, in comparison to a HCA who would also provide assistance with these activities when specialising.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Existing systems in place within the hospital system, at times, impacted on the provision of personalised dementia care. These systems included infection control guidelines on storage of food, restrictive visiting times, and catering staff shift patterns, which limited the times at which meals could be prepared and delivered. Another challenge to the provision of optimum dementia care identified by hospital staff interviewed was insufficient availability of staff to support people during meal times which can result, for example, in meal trays being out of reach of patients. There was a reluctance on the part of catering staff to actively assist or leave trays in reach of those with dementia for fear of falls, incidents and liability:

*“Our staff have found it’s happened to us before that if our staff, if they move a patient and if they break a patient’s bone or anything you know... so they are not allowed to go near a patient.” (FU FG Catering)*

There were also difficulties identified in relation to crossing areas and systems within the hospital when advancing ICP formation and introduction. This related to staff categories, hospital areas and buildings, as well as electronic systems. The project did however make progress in terms of identifying gaps in the transition of patient information between the various IT systems which were active within the hospital, identifying duplicative data collected, and advancing the process of streamlining patient information. Because the project spanned a number of directorates and governance structures within, and outside of, the hospital the rate of change was variable and in some instances was much slower than others.

### 4.2.1.4 ICP for Dementia – In-Reach/Out-Reach

One of the overall goals of the project was to improve in-reach/out-reach links between the hospital and the community. A notable and important project gain was the success in introducing a standardised section on cognitive impairment into the discharge letter where details of 4AT assessment and outcomes could be reported. This served a number of important purposes, as outlined by interviewees (for example, keeping community care providers informed of cognitive impairment, improving the transition between hospital and community, prevention of duplication of assessment), but with the primary aim of preventing repeat presentations to the ED. The case note audit revealed that six charts (35%) audited at T2 contained individualised dementia-related information in the discharge letter. However, it appeared that the discharge letters relating to people with dementia who were admitted for reasons other than dementia were less likely to contain this information.

### 4.2.1.5 Sustainability of ICP Related Changes

While under consideration by the consortium, the sustainability of the changes implemented as part of the ICP were, as yet, somewhat unclear. Importantly, at the time of reporting, the development and roll-out of the ICP was still at an early stage. There was evidence of organisational knowledge acquired and commitment to move this forward within the consortium. This knowledge and commitment is an important building block in the further development and refinement of the ICP. As suggested by one interviewee: *“they touched everything, which is amazing, you know, because then everybody has a little bit of it but as regards the sustainability, does it get lost then because you only have a touch of it rather than it becoming the culture.” (FU FG AHP 2).*





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

It was stressed by the consortium that implementing such substantial organisation change and educating a large number of staff as proposed is a slow process that needs continuous and careful facilitation. Therefore it was acknowledged that three years was not sufficient time to implement, embed and ensure sustainability of all the proposed changes. The process of change was more complex than originally foreseen and therefore the pace of change was more protracted, though in such a large and multi-component organisation this might not be unexpected. As part of the project, the Hospital Passport was used in one ward with a plan to implement this hospital-wide once trialled. This seemed less likely to come to fruition however as the consortium had experienced difficulties in the standardised implementation of this in the selected ward. There was concern over who would print documentation developed as part of the project, such as the Hospital Passport, once the project had ceased however at the time of reporting there were plans to upload the Hospital Passport and other documentation onto the SJH Intranet (central location) so that staff can retrieve this documentation on all of the wards and print as required. Further success was achieved in incorporating the 4AT in the EPR and communication to community health professionals with the discharge documentation.

### 4.2.2 Project Roles

The project adopted a project management<sup>15</sup> rather than a clinical lead approach, and for the most part, injected project resources into these activities. It was acknowledged that the overall management of the project and its various components consumed more time than was originally envisaged. For this reason, interviewees reported positively on having a budget for project staffing. It was a key strength of the project that there were dedicated project personnel to counterbalance pressure on resources across the hospital. The project manager, and the broad variety of work driven by this role, was viewed very positively. Whilst not having a clinical background, the post holder endeavoured to, and was successful in, forming relationships and positive interactions with a variety of service providers within and outside of the hospital as well as being active on the ground in several areas within the hospital:

*"What [Project Manager] had to do was to come into the hospital and learn everyone's names, learn who are the key people in all those. I never got to know half of stuff, I think [Project Manager] did really well. And at the same time [Project Manager] was always there you know, I don't know how [Project Manager] did it, I couldn't do what [Project Manager] did." (FU JI Consortium 2)*

*"[Project Manager] has a lovely way with bringing people on board and a way of, of telling people about it, and saying to people 'I don't understand, you know, bring me back to basics' instead of pretending to understand and that really is helpful." (FU SI Key Stakeholder 1)*

This relationship building was a primary impact of the role and had a consequential positive impact on the project purpose. It was noted that the project manager was resourceful in managing the various work packages of the project, although the size and breadth of SJH and the scope of the project meant it was challenging for one person to manage. This points towards an overly ambitious project goal at the outset in developing a comprehensive ICP spanning the hospital and community in-reach/out-reach, given the timeframe for the project. This provides evidence of the unfolding need and appropriate response of the consortium to refine and reduce the scope of the project in order to implement more effective changes for people with dementia. It was acknowledged that it would be difficult to maintain momentum for the project when the project manager role ceased, highlighting the potential downside of the use of an independent project management based role as it was not integrated into the overall hospital system.

15 A project management approach involves planning, initiating and executing tasks to achieve specific goals and criteria within a specified timeframe.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

The project lead role was also viewed positively with particular mention of the lead's vast expertise and knowledge in the area of dementia and cognitive impairment as well as the lead's skills to engage with and influence key stakeholders to gain their support. The ability of both the project lead and project manager to connect with and bring key stakeholders and categories of service providers on board was an important strength of the DemPath project and had a positive impact on the achievement of project aims.

The project focus of resources on the project manager role was complemented by the use of a project-specific nurse role, the DemPath nurse, for a period of time during the project. Some interviewees felt that the delayed involvement of a nurse role negatively impacted project gains which resulted in an exponential amount of work for other project drivers at the project start-up stage. This meant that it was more difficult to maintain a record of project progress (for example, development of smaller projects which were carried out by DemPath facilitators but not under the project remit). Another interviewee felt it was timely that this role was implemented when the project was more established and the initial groundwork was completed. It was suggested that the delayed implementation of this role was in order to try to achieve a shared ownership for the ICP and improvements in dementia care:

*"I think probably it was a good decision at the beginning not to necessarily put clinical posts within the project, you know, because there was the sense that if they, if [project lead] did do that it would be how many were required, at what grade were they required, but also then are they there, is there an expectation then that they're there forever, is there an expectation that all the work goes to them and nobody else takes the ownership, and what [project lead] was trying to do was I suppose cultural change and everybody to take a piece of responsibility here and to embed it in their own thing. I think it became clearer and we talked about it and [project lead] said there was a need for, to touch the patient really and to have that clinical piece." (FU SI Key Stakeholder 1)*

The DemPath nurse's clinical knowledge and previous experience in the acute setting, and indeed within the SJH setting itself, was of crucial benefit to the role. She was viewed as having a large amount of leverage with hospital staff because of her familiarity with their roles and activities. Indeed, the benefits of the nurse role in being seen as an 'insider' was highlighted, though it was reported that at times it was still difficult to get staff to engage in project activities. Numerous hospital staff, during interviews, mentioned the DemPath nurse by name when discussing dementia care, highlighting her infiltration to areas and groups across the hospital. As with the project manager role, the DemPath nurse role was seen by some key stakeholders to be significantly more onerous than initially envisaged. Challenges inherent in the operationalisation of the role included the lack of administrative support for the role, the ongoing workload of auditing the various project elements, and the consumption of a large proportion of time through the education strand of the project. By consequence, the DemPath nurse was unable to take on a patient caseload, despite a desire to do so. It was suggested by some interviewees that given the complexity and size of SJH, a number of nursing roles would be required to adequately address the needs of people with dementia and successfully implement an ICP for this patient group:

*"Really I suppose James's hospital needs a team of three dementia nurses, one in the AMAU (Acute Medical Assessment Unit), one in ED, and one in MedEl. That's the way I would envision it, to really influence the hospital, you know...it's just a huge role. You would quickly find yourself...burnt out" (FU SI Consortium 3)*



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

At the time of reporting, a DemPath coordinator had commenced. This one-year role was designed to coordinate and implement the DemPath programme. Further information on this role is included in Chapter 7.

In summary, the project roles and the project management approach employed as part of the DemPath project had a positive impact on the outcomes of the project. As discussed further in Sections 5.2 and 5.3.1, these roles, together with other DemPath project governance structures acted in a dynamic and responsive way to operationalise resources and enact positive change to improve the care journey for those with dementia and other cognitive impairments.

### 4.2.3 Overall Integration of Dementia Care

Increased awareness of the overall integration of dementia care practice within SJH was evidenced in hospital staff:

*“The last year or so, there's been a lot more focus on the dementia patient themselves, what we can do to make their stay more comfortable, not what we can do to get them out as quick as possible. Obviously that's still at the forefront but it's more to make sure that they're stay is more comfortable, lessen the anxiety they're feeling because that'll have a knock-on effect on their discharge, it would mean they've a quicker and a safer discharge home.*

*And then discharge planning is more long term rather than just get out. Does that make sense, how can the person, the focus is back on how can the person be happy at home and what is the risk for them to be readmitted.” (FU FG AHP 2)*

The evaluation also probed for evidence of changing practice in relation to dementia through the audit data. Current practice was compared to international best practice by the evaluation team using tools from the Irish National Audit of Dementia Care in Hospital (De Siún *et al.* 2014)<sup>16</sup>. The evaluation encompassed an audit of 20 patient case notes, an organisational audit and audits of three hospital wards and the ED at T1 and T2. The same wards were not audited at T1 and T2, except the ED<sup>17</sup> as the project team requested that different wards which were more greatly impacted by project activities be audited at T2. The audit tools included 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 (addressed in Section 4.3). Collectively, the tools provided an indication of dementia care at the point of admission to hospital, during admission and at the point of discharge.

<sup>16</sup> The evaluation team received full permission to use the INAD (DeSiun *et al.* 2014) tools.

<sup>17</sup> T1: One ward had 30 beds, the second 31 beds and the third 25 beds. T2: Two wards had 31 beds each and the third had 28 beds. The ED had 31 beds at both time points.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 4.2.3.1 Hospital Organisational Audit

The hospital organisational audit examined structures, policies, processes and positions relevant to the care, treatment and support of people with dementia in a general hospital. At T1, the hospital had a number of structures, policies and practices in place to support people with dementia and their family carers during admission. These included:

- Availability of Dementia Champions,
- Psychiatry of Old Age and geriatric medicine services,
- Existence of policies and guidelines governing the use of interventions for the person with dementia presenting with behavioural and psychological symptoms of dementia,
- Use of social and environmental assessments which consider formal and informal care provision, financial support needs and home care assessment,
- Training and knowledge framework for dementia-related care.

Although dementia awareness training was made available to all staff groups at T1, it was evident that a number of specific skills and knowledge training courses for service providers were sporadically implemented, particularly for doctors, as the courses had not been provided to members of the organisation for over 12 months. By T2, all of the additional training courses had been made available to all staff, including communication skills, management of responsive behaviour, assessing risk and support for people with dementia with hearing or visual impairments, and assessing capacity of the person with dementia.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Table 4 provides a summary of changes to the findings of the hospital organisational audit from T1 to T2, which demonstrates that substantial progress has been made and points towards the potential to enhance the integration of care for people with dementia. For example, systems to enhance dementia recognition and awareness among healthcare professionals in the ward environment were implemented between T1 and T2.

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

	Time 1	Time 2
<b>Governance</b>		
A care pathway for patients with dementia is 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 implementation and/ or review of the care pathway	No	Yes
A named senior clinician is responsible for implementation of the care pathway	N/A	Yes
There is a named officer with designated responsibility for the protection of vulnerable adults	No	No
There is a process in place to regularly review hospital discharge policy and procedures, as they relate to people with dementia	No	Yes
<b>Delivery of Care</b>		
The multidisciplinary assessment includes:		
■ An assessment of mental state using a standardised instrument	No <sup>18</sup>	Yes
■ An assessment of mood using a standardised instrument	No	Yes
■ An assessment of collateral history from a carer/relative of onset and pattern of cognitive dysfunction or presence of behavioural and psychological symptoms of dementia	No	Yes
As part of initial assessment, the patient's Body Mass Index (BMI) or weight is recorded, wherever possible	N/A	Yes
Protected mealtimes are established in all wards that admit adults with known or suspected dementia	No	Yes
Wards' adherence to protected mealtimes is reviewed and monitored	N/A	Yes
<b>Assessment of Dementia and Mental Health Needs</b>		
There are policies or guidelines in place to ensure that patients with dementia or cognitive impairment are assessed for the presence of delirium at presentation	No	Yes <sup>19</sup>
There are policies or guidelines in place to ensure that patients with dementia or cognitive impairment with behaviour changes suggesting the presence of delirium, are clinically assessed by a healthcare professional who is trained and competent in the diagnosis of delirium	No	Yes <sup>20</sup>

<sup>18</sup> A tool is used to assess mental state; however it is not standardised.

<sup>19</sup> Assessment for delirium had been implemented in SJH and the Standard of Practice had been approved by the Medical Board, however, the policy documents were still under development by the Nursing Practice Development Unit at the time of the T2 evaluation.

<sup>20</sup> See previous footnote.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

There are systems in place to ensure that where dementia is suspected but not yet diagnosed, this triggers a referral for assessment and differential diagnosis either in the hospital or in the community	No	Yes
There is a policy or guideline stating that an assessment of mental state is carried out on all patients over the age of 65 admitted to hospital	No	Yes
There is a protocol in place governing the prescription and administration of antipsychotic drugs for patients displaying violent or challenging behaviour, aggression and extreme agitation, which is suitable for use in patients who present with behavioural and psychological symptoms of dementia	N/A	Yes
There is a section or prompt in the general hospital discharge summary for mental health diagnosis and management	No	Yes
<b>Discharge</b>		
The transfer policy states that relatives and carers should be kept informed of any moves within the hospital	No	Yes
<b>Information</b>		
There is a formal system (pro-forma or template) in place for gathering information pertinent to caring for a person with dementia	No	Yes
<b>Recognition of Dementia</b>		
There is a system in place across the hospital that ensures that all staff in the ward or care area are aware of the person's dementia or condition and how it affects them	No	Yes
There is a system in place across the hospital that ensures that staff from other areas are aware of the person's dementia or condition whenever the person accesses other treatment areas	No	Yes
There is a system in place to ensure that carers are advised about the care support available	Yes	Yes
There are clear guidelines regarding involvement of carers and information sharing, this includes:		
■ Making sure the carer knows what information will be shared with them	No	No
■ Asking the carer about the extent they prefer to be involved with the care and support of the person with dementia whilst in hospital	No	Yes
■ Asking the carer about their wishes and ability to provide care and support the person with dementia post-discharge	No	Yes



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Training, Learning and Development		
There is a training and knowledge framework or strategy that identifies necessary skill development in working with and caring for people with dementia	Yes	Yes
Staff induction programmes include dementia awareness training	Yes	Yes
Training provided to staff in the last 12 months:		
■ How to support people with hearing/visual impairments	No	Yes
■ How to assess the capacity of the person with dementia	No	Yes
■ Communication skills specific to people with dementia	No	Yes
■ Approaches to behaviour that challenges, including management of aggression and extreme agitation for doctors	No	Yes
■ Assessing risk whenever the use of restraint or sedation is considered	No	Yes
The experiences of people with dementia and their carers is included in the training for ward staff	Yes	Yes
Specific Resources Supporting People with Dementia		
There is a named lead in dementia care in the hospital, to provide guidance advice and consultation to staff	No	Yes
There is a named person who takes overall responsibility for complex needs discharge and this includes people with dementia	No <sup>21</sup>	Yes
There is a social worker or other designated person responsible for working with people with dementia and their carers, and providing advice and support, or directing to appropriate organisations or agencies	No	Yes
There is access to advocacy services with experience and training in working with people with dementia	No	Yes

### 4.2.3.2 Ward Organisational Audit

The ward organisational audit<sup>22</sup> gathered information on staffing levels, support, service availability and provision of information to support the care of people with dementia in three wards and the ED at each time point. Both T1 and T2 audits confirmed the presence of staffing shortages. All wards had agreed minimum staffing levels, and systems were in place on all but one ward at T1 to review these levels. Although all wards and the ED reported nursing and HCA vacancies at both time points, only one ward indicated minimum staffing levels were not achieved at T2, compared to all wards and the ED reporting this issue at T1. Nursing and HCA vacancies were usually filled through the hospital internal pool or agency staff, however multiple wards reported these resources do not always cover existing shortages, therefore existing staff must do considerable overtime. Occasionally some vacancies cannot be covered at all. All wards and the ED had administrative support on weekdays at T1 and T2.

Table 5 provides an overview of key findings from the ward organisational audits, identifying key changes between the audit time points. Both T1 and T2 audits showed that release from duties to attend dementia training was a persistent issue. At T1, neither the ED nor the three wards audited had staff cover arrangements in place to facilitate dementia training, by T2, two of the three wards had a system in place to facilitate training, though this was still not in place in the ED. Nevertheless, by T2 the audit revealed that staff members could avail of on-the-job guidance and

<sup>21</sup> Bed managers take overall responsibility for complex needs discharge, including people with dementia

<sup>22</sup> The ward and environmental audits were completed by a CNM with two researchers from the evaluation team.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

support offered by DemPath facilitators and advocates in both the ED and wards. This was the case, for example, in the AMAU wards where two DemPath facilitators (one CNM and one HCA) provided access to information, peer support and reflective practice groups to all staff caring for people with dementia. In one of the wards audited at T2, there were no DemPath facilitators, but one of the nurses with master-level qualifications in dementia acted as main contact point for staff in all dementia related queries. Notably, the T1 audit did not reveal the presence of such supports at the start of the project.

**Table 5. Overview of Findings of the Ward Organisational Audit.**

	Time 1 (number of wards)	Time 2 (number of wards)
<b>Staff Support</b>		
Provision for staff to attend dementia training	0	2
System for staff development in place:		
Appraisal and mentorship	3	0
Clinical supervision	4	0
Guidance from Dementia Champion	0	3
Peer support	0	2
Reflective practice	0	2
Faith specific support	3	3
<b>Services available to wards<sup>23</sup></b>		
Protected mealtimes in operation	1	3
Systems in place to ensure staffing levels are adequate at meal times to assist people with dementia	1	2
Staff encouraged to report missing uneaten meals	3	4
Ward is able to provide food between mealtimes	1	3
Opportunities for patients to socially interact	2	0 <sup>24</sup>
<b>Information and communication</b>		
Verbal/Written/Pictorial information available about:		
Ward routines	3	4
Hospital complaints procedure	4	4
Patient advocacy	2	4
Patient information disclosure policy	4	4
The professional co-ordinating care is identified to relatives	4	2
System for communicating personal information to staff caring for people with dementia	3	4
DemPath Facilitator	0	2
Hospital Passport	0	2
DemPath whiteboard	0	1
System to communicate to specific behavioural or communication needs for people with dementia	4	4
4AT	0	4
DemPath whiteboard	0	2

23 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.

24 As this was based on wards in AMAU at T2, there would be limited opportunities for patients to interact in comparison to other less acute wards.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

Overall access to allied healthcare and other specialised services (for example, palliative care) was good in all wards (mostly daytime service Monday to Friday). At T2, liaison psychiatry was available Monday to Friday (daytime) in all of the audited wards and in the ED. Psychiatry of Old Age was available during the day from Monday to Friday on the three wards audited at T2 but not in the ED while geriatric services were available seven days per week (daytime) in these three wards and Monday to Friday (daytime) in the ED. All wards and the ED reported access to OT, social work, pharmacy, physiotherapy, dietetics, Speech and Language Therapy (SLT), and specialist palliative care at both time points.

Although the majority of wards (T1: 1/3; T2: 3/3) operated a protected mealtime system and all wards had arrangements in place to signal the need for help with eating, only half of the wards had a system to ensure sufficient staffing levels to help people with dementia to eat and choose food if required (T1: 1/3; T2: 2/3). However, all wards allowed family carers to visit and assist during mealtimes. Opportunities for patients to socially interact over mealtimes (i.e. eat together) were present only in two of the wards at T1 and none of the wards at T2.

### 4.2.3.3 Patient Case Note Audit

The patient case note audit<sup>25</sup> 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 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 had discharge dates from 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. There were no differences in the average age of the sample between T1 and T2, approximately half of the sample were male (T1: 40%; T2: 50%). The average length of stay in the hospital increased significantly from 22.6 days at T1 (range = 5-72; SD = 21.5) to 44 days at T2 (range = 6-120; SD = 39.9;  $t(29.2) = 2.12$ ;  $p = 0.043$ ) (length of stay explored further using HIPE data in Chapter 6). However, this average increase may be attributed to five people with dementia who were admitted to the hospital for more than 90 days at T2, of whom four were discharged to LTC, and one who died in the hospital. The majority of participants were admitted from their own home at T1 (70%) and T2 (75%), however, of those who were admitted from their own homes, less than two-thirds returned home directly upon discharge at T1 (64%) and T2 (40%). Overall, at T2 a greater proportion were discharged to LTC (T1: 35%; T2: 59%). No people with dementia were discharged to the home of their family carer at T1 or T2. It is notable that there was an increasing trend in the use of antipsychotic medication at T2 (see Table 6), however, these findings should be interpreted in the light of the audit being completed on a sample of 20 patient case note audits only.

Table 6 provides a summary of key findings arising from the case note audit. The audit revealed mixed results relating to assessment, discharge planning and coordination. The T1 audit revealed positive practice in relation to multidisciplinary and mental health assessment for people with dementia, which were largely sustained at T2. However, assessment of collateral cognitive and behavioural history was evident at T1, with only marginal improvements in the assessment of collateral cognitive decline and delirium-related behavioural changes.

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



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

**Table 6. Overview of Findings of the Case Note Audit**

	Time 1 (N = 20)		Time 2 (N = 20)	
<b>Comprehensive Geriatric Assessment</b>	%	n	%	n
Compliance with multidisciplinary assessments:				
Mobility	90%	18	90%	18
Nutritional status	80%	16	95%	19
Pressure sore risk	95%	19	100%	20
Presence of pain	100%	20	95%	18
Continence needs	95%	19	100%	19
Functioning	60%	12	5%	1 <sup>26</sup>
Problem list recorded	95%	19	95%	19
Medical history recorded:				
Mental health history	95%	18	95%	19
Co-morbid conditions	100%	20	95%	18
Collateral history recorded:				
Presence of cognitive decline	55%	11	65%	13
Duration of memory problems	45%	9	25%	5
Nature of dementia progression	45%	9	15%	2
Evidence for loss of function	50%	10	25%	5
Assessments recorded:				
Mental status test	45%	9	50%	9
Behavioural changes indicative of delirium	10%	2	30%	6
Recent changes in mood <sup>27</sup>	15%	3	15%	3
Behavioural/psychological symptoms of dementia <sup>28</sup>	10%	2	15%	3
<b>Antipsychotic medication</b>				
Number of people with dementia prescribed/administered antipsychotic medications during admission	20%	4	40%	8
% of whom had a prescription for antipsychotic medication prior to admission	75%	3/4	75%	6/8
% of whom had a prescription for PRN antipsychotic medication	25%	1/4	50%	4/8

<sup>26</sup> A Barthel ADL assessment was considered a formal assessment of functioning. Notably, the admission sheet included selected questions on activities of daily living, but there was not sufficient information for a formal assessment.

<sup>27</sup> This assessment was not required for all patients.

<sup>28</sup> This assessment was not required for all patients.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Referral to services				
Liaison psychiatry	5%	1	0%	0
Psychiatry of older age	20%	4	25%	5
Geriatric medicine <sup>29</sup>	20%	4	30%	6
People with dementia requiring social work assessment	63%	12	60%	12
% of whom received assessment	92%	11/12	92%	11/12
% of whom received formal care provision assessment	92%	11/12	83%	10/12
% of whom received a home safety/environment risk assessment	33%	4/12	70%	7/12
Palliative care <sup>30</sup>				
Resuscitation status documented	40%	8	45%	9
Referred to palliative care	15%	3	15%	3
Discharge				
Number of cases with symptoms of delirium during admission	69%	9	35%	6
% of those whose delirium symptoms were summarised for discharge	33%	3/9	33%	2/9
Cause of cognitive impairment summarised	15%	2	41%	7
Number of eligible cases where discharge plan was initiated within 24 hours <sup>31</sup>	8%	1	12%	2
Named discharge co-ordinator in discharge plan	75%	9	94%	16
Appropriate place of discharge and support needed discussed with <sup>32</sup> :				
People with dementia <sup>33</sup>	25%	3	67%	8
Family carer	62%	8	77%	13
Consultant	8%	1	71%	12
Multidisciplinary team members	46%	6	65%	11
Identified support needs documented	42%	5	25%	4
Record keeping				
Information about dementia found in a specific section of the patient record	4	20%	0	0%
Information about dementia care and support needs found in a specific section of the patient record	12	60%	1	5%
Organisation and ease of locating dementia-related documentation in patient record:				
Well organised	20%	4	0	0
Adequately organised	45%	9	65%	13
Poorly organised	35%	7	35%	7

29 Of those referred to geriatric medicine, four (40%) were admitted to a care of the older person ward, and the remainder (n = 6, 60%) were admitted to surgical, orthopaedic and acute or general medical wards. People with dementia admitted to care of the elderly wards were more likely to be referred to geriatric medicine ( $\chi^2(1) = 6.54, p = 0.01; OR = 9.33$ ).

30 Not relevant for all patients.

31 One (8%) of thirteen eligible case notes audited contained a discharge plan at T1 and two (12%) of seventeen eligible case notes contained a discharge plan at T2.

32 Percentage of patients eligible for discharge (i.e. patient did not die, self-discharge, or was not transferred to another hospital/ward) (T1, n = 13; T2, n = 17).

33 At T1 and T2 it was documented that a number of people with dementia refused or were unable to engage in discussion of the appropriate place of discharge (T1: n = 1, 5%; T2: n = 5, 25%). Therefore the eligible sample for this item varied (T1: n = 12; T2: n = 12).



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Organisation of the patient record was a consistent problem between T1 and T2. At T2, more than one-third of case notes were poorly organised. Although the patient records were structured, filing patterns did not always adhere to this structure, with items misplaced or filed in a non-sequential manner. Partial digitisation of patient records contributed to inadequate organisation of the patient record, for example, nutrition and social work assessments were only available on the EPR system, separate to the hardcopy patient record which contained patient-related communication, as well as medical and nursing notes and results of clinical examinations.

Although discharge planning for people with dementia remained challenging between T1 and T2, a greater number of people with dementia had a single named discharge coordinator, and discussions about place of discharge with the person with dementia, carers, consultants and multidisciplinary team members improved at T2.

### 4.3 The Physical Environment

The ED was where the majority of environmental changes were implemented by the project. As outlined in Chapter Three, there was additional data collected specific to the ED and the environmental changes which took place in this area. The following are the key findings in the ED environmental sub-study:

- Most family carers found the colour scheme and adjustable lighting to have a soothing effect on patients as well as being pleasant for relatives, though a lack of information or labels identifying the system and instructions on how to use it was highlighted.
- In general family carers confirmed that they found the screen better than the curtains. Some mentioned it was helpful during medical examinations, when the patient was in need of toileting assistance, and for sleeping. However, half preferred to keep the screen open to avoid affecting the work of nurses and medical staff or simply to be able to see the outside area: *"In actual fact to see the coming and goings and the people were so busy and that, it passed the time to be honest about it, you know."* (SI ED01)
- There was unanimous agreement among family carers that the seats were an invaluable addition to the cubicles. They allowed family members to stay with their relatives and gave patients more options for comfort. In contrast, family carers who had experienced the unaltered bays reported being unable to find seating at busy times and one interviewee said she had to stand for nine hours.
- Many family carers provided positive feedback on the time display. They believed this to be a particularly useful feature for people with dementia, who often have memory difficulties and can be easily disoriented. One carer noted that the display did not show the correct information during her visit to the ED and highlighted this could be a potential source of further confusion for people with dementia.
- The decluttering of bays was noticed by three family carers who mentioned the 'clean feeling' of the bays.
- Because of the location of the altered bays close to the nurses' station, interviewees outlined that this meant there was some noise coming into the cubicles, but the majority did not find it overly bothersome. On the contrary, one family carer thought that keeping people with dementia close to the nurses' station was *"a lovely idea"* (SI ED02) and another was glad to have access to the water stand near the desk.
- Family carers appreciated the privacy provided by the altered cubicle, which contributed to making their relatives at ease and more relaxed.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

- Overall ED nurses didn't seem to have particularly strong views on the individual features of the design alterations. From their perspective the most useful change was the availability of a designated space for people with dementia. They felt that such space created more privacy for people as the bays were generally only used for one trolley, allowed family carers to stay with their relatives, and facilitated easier and faster assessment by doctors.
- Additionally, ED nurses felt that the experience from the project and being involved (directly or indirectly) in the design changes contributed to raising awareness about the potential challenges faced by people with dementia in the ED environment and the need to adopt a particular approach to their care.

A number of learning points emerged from the interviews with hospital staff. The scarcity of best practice guidance for dementia-friendly environments and environmental audit tools specific to the ED was noted. As a result, the methodological approach to the design alterations made reference to a variety of sources which were then adapted to the particular needs of the hospital site. Difficulties in sourcing some items for use in the altered bays were also outlined which resulted in delays in completing the bays (for example, foldable chairs with arm rests which could be secured to the wall took an extended period of time to obtain). The consortium were advised by some service providers that the proposed changes were not 'clinical' enough. This provided an opportunity for education and discussion with staff locally around dementia and dementia-friendly environmental changes. The high-stress environment of the ED, dominated by the urgency to attend to the immediate needs of a high number of patients, quickly and efficiently as possible, was a challenge. Careful balance was required to implement changes without affecting the ability of ED staff to perform their job or compromising the safety of patients. The need to comply with other needs of the ED (for example, consideration of an unfixed chair as a safety risk) also had to be considered. A number of items mentioned by hospital staff at T1, continued to be a concern at T2. These included:

- The lack of a bedside table or similar facility to help people with dementia during mealtimes; a fixed or pull-out solution was suggested,
- Persistent issues with the availability of beakers/liquid containers for patients,
- The unsuitability of the ED environment for people with dementia and the lack of a suitable alternative (for example, specialised assessment unit).

The consortium endeavoured to be flexible and responsive in how they approached the implementation of project changes. When hospital staff felt they were gaining something from the project, they were more likely to engage and subsequently when they saw the benefits of the environmental changes implemented, they were more amenable to assisting with other aspects of the project.

*"Initially there was resistance, like 'oh how are we going to manage?' Because it's two spaces that are taken up, because we have a space issue here in ED, but just..."*

*Well I think, I think it was down to the nurses actually realising the need and it goes to show that the patients are the priority in...in every nurse here in ED. Because, yes, space was gone and it did cause us...you know, there was issues, but I think when we seen it work, you know, and you know that the patient with dementia has a room to go to, I think that overweighed everything really." (FU FG ED Nurses)*



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

The other area in which the project focused their efforts for environmental change was the MISA building. This was primarily in relation to improving signage and wayfinding within the building. The project received the 'European Foundations' Initiative on Dementia (EFID): Valuing the expertise of people living with dementia' award in 2018 for this work. While difficulty in accessing and influencing key stakeholders was highlighted, through determination and consistent efforts by the consortium, complemented by the ability of the project to provide funding for the design of proposed new wayfinding measures, significant progress was made. It was highlighted that once the stakeholders were aware of the suggestions being made, they were fully supportive. Close collaboration and exchange of ideas with architects and other contractors served as facilitators in achieving a more effective design. The technical advice of these professionals helped the team assess the practical feasibility of some of the proposed design features to facilitate orientation and wayfinding. The consortium linked with Facilities Management and this was important in both implementing change, as well as increasing awareness for the significance of dementia-friendly design among this stakeholder group. As reported by the consortium, Facilities Management were very receptive to the proposed changes and formed a positive relationship with the project manager which facilitated progress. The plans for wayfinding and signage originally developed through DemPath funding were scaled back to be more feasible, but were still seen as impacting change by hospital staff in creating a more dementia-friendly environment and more user-friendly signage.

Interestingly, the stark contrast between the MISA building and the main hospital was highlighted whereby the MISA environment was viewed as being much more suitable for people with dementia. One cohort of patients was temporarily moved to the MISA building during a re-organisation of wards and interviewees outlined that the patients were then reluctant to return to the main hospital. Furthermore the physical environment of the MISA building was viewed very positively in terms of space, layout and colour. For example, the white nurses' station against a purple background used within the MISA building was highlighted in interviews as being dementia-friendly.

The use of single rooms in MISA, while beneficial and often the preference of many patients, was suggested as sometimes being problematic as they may lead to isolation and patients can then often be unwilling to move into a shared ward. Furthermore, patients may feel like they are *"in a prison, being locked up in a room all the time"* (FU FG HCA), particularly when a special is *"sitting at the door like a security man"* (FU FG HCA):

*"When they are in the single side rooms on their own it probably doesn't sound nice but them walls get in on you. Them rooms do funny things to you and if you're in there morning, noon and night, that's it."* (FU FG Catering)

The environmental changes recommended for and implemented within Hollybrook Lodge were not part of the original project plan but evolved organically through liaison between the design lead and the Assistant Director of Nursing in Hollybrook Lodge (see Chapter 2, Section 2.5.2). Here, the DemPath consortium were involved in the implementation of positive environmental change beyond the original project scope through the provision of advice, information, and a small amount of funding. There was a lot of positivity around the changes in Hollybrook Lodge from a variety of stakeholders, including members of the local community whereby some materials purchased from suppliers were provided at a greatly discounted rate.

Similar to T1, the nature of the physical environment in acute care was highlighted at T2 as a potential barrier to provision of optimum dementia care:

*"I can only view it as being a major challenge for staff on a day-to-day basis because it's difficult enough for a patient full stop to be, to find a location for them that's appropriate and safe for their care, to then have a further need for that patient to be cognisant of their dementia or their own cognitive state, adds to that."* (FU SI Key Stakeholder 2)



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Section 5.3.2 provides further discussion around the acute environment as a potential barrier to the optimisation of the physical environment for people with dementia. Promisingly, there were some minor improvements in the physical environment evident through analysis of service user questionnaires (see Table 7). For example, a greater proportion of service users reported that the ward had a calm atmosphere at T2.

**Table 7. Service User Questionnaire Data Relating to Physical Environment**

	Time	Yes – N (%)		No – N (%)
Was the ward clearly signposted (i.e. areas in the ward, for example, the toilets)	T1	20 (87)		3 (13)
	T2	15 (100)		-
	Time	Yes, always – N (%)	Yes, sometimes – N (%)	No – N (%)
Did the ward have a calm atmosphere	T1	7 (30)	11 (48)	5 (22)
	T2	6 (43)	6 (43)	2 (14)

It was felt by hospital staff that it was difficult to both implement and assess the impact of changes within the acute environment given the pace and nature of service. The following environmental challenges highlighted by hospital staff in interviews at T1 were still in evidence at T2:

- Difficulties in wayfinding within SJH outside of MISA where wayfinding changes were implemented,
- The location of MISA down a number of corridors,
- The busy, over stimulating and noisy nature of the acute environment,
- The lack of access to outdoor space, including 'locked doors' to outdoor spaces,
- Poor signage for important facilities, including toilets, throughout the hospital,
- Clocks not being in patient view,
- Lack of space for patients to move about.

Within the hospital, difficulty in accessing equipment (for example, soap dispenser covers, different coloured toilet seats) that aren't the norm was highlighted as a difficulty in implementing dementia-friendly environmental change as part of the project.

The environmental audit was conducted in conjunction with the ward organisational audit at T1 and T2 to ascertain environmental modifications undertaken in the course of the DemPath project to support people with dementia, including orientation, accessibility and promotion of independence. While the project did not carry out any ward based changes except changes to one of the wards day rooms, the audit is useful here in examining whether there were any changes implemented during the course of the project as possible ripple effects of the project or cultural change. The project gains in terms of dementia-friendly care environment were limited to specific areas of the hospital and was naturally constrained by project timelines and resources. As might be anticipated, the audit revealed persistent shortfalls in regard to the suitability of the hospital environment in the main hospital (i.e. outside of the MISA building) for people with dementia at T1 & T2. The key findings of this audit are presented below. Notably, the environmental audit included one ward which had environmental adjustment as part of the project.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### Key Findings of the Environmental Audit

- The audit revealed a number of gaps in the suitability of the ward environment for people with dementia. In particular, there were mixed results in relation to orientation and wayfinding cues in the ward environments, with an absence of distinct colour schemes and signage in the majority of wards.
- Clocks were visible from the bed to some patients in only two of the wards and a calendar was not visible to patients on any of the wards.
- In regards to personal space, messages from relatives and personal objects, including self-care items, were visible to most people with dementia in the wards where this was possible<sup>34</sup>.
- In the ward environments, all wards at T2 allocated people with dementia beds which were visible to staff (T1: 1/3; T2: 3/3).
- None of the wards audited at T1 or T2 had floor level changes and in most cases the floors were plain and not 'busy', with subtle polishing and non-slip surfaces.
- Toilets were visible from the bedspace in the majority of wards at T2 (T1: 0/3; T2: 2/3), the doors carried signs in two of the wards at T1 and T2, and the toilet doors were a different colour to the walls in all of the wards, which is believed to be useful for older people with sight difficulties, especially if affected by dementia (Pollock 2003, Cunningham 2006). Toilets and bathrooms were big enough for assisted toileting in all the wards, except the ED. Single sex toilet and washing facilities were available in most cases (T1: 3/3; T2: 2/3). Hand rails and large handles to support patients were provided in 4 out of 6 wards but many did not have a raised toilet seat (T1: 1/3; T2: 1/3). Call or alarm buttons were visible and in reach in the toilet or bathroom in the majority of wards (T1: 2/3; T2: 3/3).
- Measures to promote independence of patients and social interaction continue to be limited. The environmental audit showed that space for active people with dementia to walk up and down while visible to staff and staff visible to them was available in all wards. However in most cases this space is simply the ward corridor.
- Although equipment to support mobility could be readily provided, most of the wards were not adapted to assist people with mobility difficulties (T1: 0/3; T2: 1/3).

In terms of the sustainability of the physical environment changes implemented by the project, numerous interviewees felt that the wayfinding implemented by the project in the MISA building would serve as a legacy for the project, with the possibility to extend this across the hospital at a later stage, particularly given the enthusiasm shown by Facilities Management for this change. The altered ED bays were seen as an exemplar of a dementia-friendly ED environment and it was suggested that a more limited version of these changes could be implemented within the remaining ED bays in the future.

The environmental design strand of the project was an evolving process, where plans were adapted and refined as the project advanced. This approach to the design affected the original timeline as decision-making required more time than expected, but the flexibility allowed the design team to address constraints and take advantage of opportunities as they arose. The final product was a more focused and essential design compared to the original plan.

<sup>34</sup> The ED and the two AMAU wards are designed to accommodate only very short-stays



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 4.4 Dementia Awareness and Education

#### 4.4.1 Awareness of Dementia

The dementia awareness levels of staff in SJH were assessed using a survey by the DemPath team at two time points; first, between November 2014 and January 2015 and for a second time between March and May 2017. Analysis of data from both time points was conducted by the evaluation team. A total of 1,182 staff completed the survey at baseline and 919 at follow-up. A profile of the overall surveys' respondents is presented in Table 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. Notably, 59% (n = 542/919) of respondents at follow-up reported that they had also completed the baseline survey.

**Table 8. Sample Size and Characteristics**

	Baseline	Follow-up
<b>Total no. of respondents</b>	1182	919
<b>Gender</b>	85% female	84% female
<b>Age</b>	34% 18-34 years	34% 18-34 years
	56% 35-54 years	53% 35-54 years
	10% 55-74 years	13% 55-74 years
<b>Job roles</b>		
Nursing <sup>1</sup>	527 (44.6%)	436 (47.4%)
Administrative	198 (16.8%)	109 (11.9%)
Allied health professionals <sup>2</sup>	91 (7.7%)	59 (6.4%)
Medical Scientist	76 (6.4%)	50 (5.4%)
Doctor	69 (5.8%)	111 (12.1%)
Hospital catering	40 (3.4%)	32 (3.5%)
Healthcare Assistant	35 (3.0%)	31 (3.4%)
Pharmacist	15 (1.3%)	12 (1.3%)
Security	15 (1.3%)	14 (1.5%)
Hospital housekeeping	12 (1.0%)	12 (1.3%)
Other staff <sup>3</sup>	104 (8.8%)	49 (5.3%)

1 Including staff nurse, student nurse, CNM, and Clinical Nurse Specialist.

2 Including social workers, clinical nutritionists, SLTs, OTs, and physiotherapists.

3 Other roles included those within IT, research etc.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Fifty nine percent (n = 687) of those surveyed at baseline and 46% of those surveyed at follow-up (n = 417) had worked in their current job for more than seven years. The cohort was therefore quite an experienced group. Respondents were asked to self-rate their own knowledge of dementia on a scale of 1 to 10<sup>35</sup> and the majority at both baseline (59%, n = 689/1182) and follow-up (52%, n = 475/919) perceived they had some knowledge. The percentage that perceived they had very good knowledge increased substantially from baseline (7.0%, n = 82/1182) to follow-up (39.6%, n = 364/919). However, it should be noted that the respondents were not matched.

'The Approaches to Dementia' questionnaire (Lintern & Woods 1996) measures staff attitudes towards people with dementia. The questionnaire comprises two scales, the first of which explores respondents' hope for people with dementia and their life and the second measures respondents' recognition of personhood. Higher scores indicate a more positive attitude to dementia or a higher level of awareness.

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

- 'Hope' sub-scale; based on 8 items with a maximum score of 40,
- 'Recognition of Personhood' sub-scale; 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 sub-scale (M = 33.5; +30.9%) and the Personhood sub-scale (M = 51.1; +10.8%) indicating more hope and better recognition of personhood at follow-up. 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 respondents were not matched and therefore it is not possible to establish with certainty if they 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)	1,182	25.6 (5.2)	918	33.5 (6.7)	+30.9%
Personhood sub-scale (possible score 11-55)	1,182	46.1 (5.6)	919	51.1 (5.3)	+10.8%
Total Score (possible score 19-95)	1,182	71.7 (9.2)	918	84.6 (11.1)	+18.0%

<sup>35</sup> 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).

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Comparing the mean scores of staff in close contact with people with dementia, namely doctors, nurses and HCAs, with those of staff with lesser exposure to people with dementia<sup>36</sup>, there was a positive change in approaches to dementia scores for both groups between baseline and follow-up (Table 10). It is worth noting that there was little difference between the two groups mean scores at baseline i.e. both groups demonstrated positive attitudes towards people with dementia.

**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)	
Doctors, nursing staff and HCAs	610	70.8 (9.9)	581	88.2 (9.9)	+24.6%
All other staff	572	72.5 (8.3)	337	78.4 (10.4)	+8.1%

### 4.4.2 DemPath Education and Training Initiatives

A large component of the DemPath project was devoted to education and considerable resources were used to implement a range of programmes and activities over the life of the project. Conceptualisation, planning and implementation of the programmes was overseen by an education work package group who met monthly to plan and coordinate activities. The educational activities were enhanced by the contribution of individuals already involved in delivering dementia education programmes and by using programmes that already existed from the National Dementia Education Programme. From the outset, the initiative planned to be responsive, delivering programmes that were based on the needs of medical, nursing and Allied Health Professionals (AHPs) and support staff. Prior to implementation and planning of the programmes, several focus groups were held with key stakeholders to make sure that the programmes were applicable to the needs of the professionals and to ascertain the appetite for their delivery. Overall, the educational programmes designed for the project were well attended and positively evaluated. Of the 919 staff who completed the awareness of dementia survey at follow-up, 62% (n = 573/919) had attended a DemPath one hour awareness session. Positive feedback on the education and training from hospital staff interviews included:

*“It was nice to find out about statistics, how many people suffer, how many families are involved in Ireland and why we should pay attention to this problem and so on. And some tips how to deal with the people. And also dementia term was explained as well, which was good.” (FU SI Security 1)*

36 This included, for example, AHPs, security, housekeeping, catering, administrative, medical scientists, pharmacists and laboratory staff



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

Of those who provided feedback on the DemPath education (n = 502) as part of the awareness of dementia survey, just 3% reported that they had not found this useful in their job though for more than half of these individuals (n = 9/16), they reported that this was because they do not have direct contact with people with dementia in their role. Positive feedback from the survey data included:

*"I must admit that before the training I was not comfortable communicating with people with dementia and now I am much more confident." (FU Survey ID 381)*

The overall aims of the programmes were to increase the awareness and visibility of people with dementia throughout the hospital and community sites and to make their experience when in hospital a little more positive. The educational vision is summarised in the following quotation:

*"My vision is that everyone in the hospital would have some more, an increased awareness about people with dementia. So that they can, at the minimum, say hello to them. That, you know, anybody with dementia coming into the hospital no matter who they meet, whether it's them walking in towards a ward and some staff member from the cleaning services passes by, that they would be able to say hello to them and feel confident about it. And that I suppose the experience of people with dementia would be more positive than it was." (FU FG Facilitators)*

In addition to the formal education programmes, the project also included a number of themed DemPath study days that were organised throughout the hospital and community and highlighted specific topics or areas that were of interest in the area of dementia. These contributed to raising awareness of the DemPath project and were generally well attended. Hospital staff reported positively on being able to pop in and out of sessions depending on their availability and interest in particular sessions throughout the course of the day. The multidisciplinary nature of these study days was also viewed positively and this was important in light of interviewees reporting poor dementia education levels among some service provider groups. These study days, together with the other DemPath training and education initiatives, provided valuable in-reach/out-reach between the hospital and community. A high rate of attendance of PHNs in particular at project education days was reported and particularly strong links built with one local primary care practice was noted by hospital staff as a result of this.

A number of interviewees alluded to the impact on practice of the educational initiatives. This included:

- More timely referrals of people with dementia to the geriatrician,
- Inclusion of people with dementia in Common Summary Assessment Report (CSAR<sup>37</sup>) assessment by social workers,
- Increase in the number of on the ground 'champions'/advocates for dementia,
- Personalised care provided more frequently,
- The ability to frame things in the context of dementia, for example, the understanding that a person with dementia may not be eating because of their dementia,
- Development of 'mini projects' (outlined further below),
- Increased discussion of dementia among service providers,
- Attempting to fast track people with dementia through the ED,
- Increased understanding and recording of hypoactive and hyperactive delirium.

37 A care needs assessment often completed as part of applications for the Nursing Home Support Scheme



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

Because the hospital and community sites served by DemPath were many and the staff numbers so large, the consortium and education work package group had to be dynamic and responsive and considerable thought was given to how the educational initiatives could be facilitated effectively and with maximum impact. The length of education programmes was kept to a minimum to try to overcome the difficulties in realising staff from duty to attend education and training:

*“When we did it at the beginning there was nothing out there that was that short, snappy one hour that would allow the person to be able to get released from the ward for that hour and then back.” (FU SI Consortium 5)*

Furthermore, sessions were run in a flexible way to ensure maximum attendance. For example, one hour sessions were sometimes split into 20 minute sections to facilitate attendance in areas where staff shortages or difficulties releasing staff were a concern. While this was labour intensive and time consuming, the benefit outweighed the cost in terms of accessing staff who were working in areas that were extremely busy. In addition, the sessions were conducted in convenient locations throughout the hospital which also allowed for ease of access for the participants. A staged approach was used to provide DemPath facilitator training such that hospital staff would not need to be released from duties for lengthy periods of time, as well as avoiding information overload:

*“We needed to do it step wise, so that everybody was comfortable at the level they were at, and then progress. So it gave them enough information that they could teach the level below them basically. And then kept adding to that information to them. So they can then get a bit more information and give the level 2 so they were always very comfortable with the material that they had.” (FU SI Consortium 5)*

The consortium invited community care providers (GPs and PHNs) to attend various education sessions following their interest in use of the 4AT assessment tool in the community.

While the level 1 programme was relatively short, it was designed to deliver key information and messages about dementia within a relaxed and informal setting. For example, staff were reminded that people with dementia are not a homogenous group and that each person is different. In addition, some communication strategies were introduced so the staff attending would have more confidence when interacting with a person with dementia. The video ‘Barbara’s story’ (Guy’s and St Thomas’ NHS Foundation Trust 2014) was also used to help staff to understand the experience of a person with dementia within the acute services.

As mentioned earlier, a number of focus groups were held with nurses, AHPs and HCAs to inform the development of the level 2 programmes by the education work package group. From these focus groups, a thematic analysis was conducted by the subgroup and a number of areas as knowledge deficits emerged among the staff. Some of these subjects were already covered by the Centre for Learning and Development (CLD) and didn’t require additional action apart from letting staff know of their existence (for example, responsive behaviours emerged as an important learning need, but this was already delivered as part of the National Dementia Education Programme). For those that were not already in existence, a bespoke programme was designed and delivered. Programmes that were designed were communication, dementia and design, life story and activities, with a programme on nutrition and a programme on ethics under development. In addition to these level 2 programmes, some staff were targeted and specific education delivered to them. An example of this is the education that the security staff received covering dementia awareness, communication and design. Support staff such as the security staff were perceived as important in the education programme as they were often involved in looking after people with dementia although





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

not necessarily targeted in initiatives such as this. This was perceived as a worthwhile exercise and one that was valued by the security staff as evidenced by their feedback.

The SJH Campus posed significant challenges in terms of its size and staff numbers. From the outset, this was recognised as a potential barrier to the reach of the education programme. To address this, the idea of training DemPath facilitators emerged early in the design of the educational initiatives. This served two purposes, firstly, to assist in the delivery of the educational programmes and, secondly, to help achieve a level of sustainability when the project was finished. The facilitators got involved in or started what were described as 'mini projects'. This was an unexpected outcome as the facilitators were generally only expected to deliver the level 1 or level 2 programmes. While some of these mini projects were small they demonstrated the facilitators' commitments to changing practices to improve the experiences of people with dementia. Other projects initiated by the facilitators were more ambitious. Examples of these are the blue crockery project<sup>38</sup> and the nutrition and dementia guide (Irish Nutrition and Dietetic Institute 2016) published by the Irish Nutrition and Dietetic Institute in conjunction with the DemPath project. In terms of their work delivering the education programme and recognising dementia care development needs within their areas, the facilitators described themselves as one of the project's biggest resources.

There were a number of challenges to implementing the education component of the DemPath project. The size of the hospital and the number of staff to be educated were challenges that have already been mentioned. While the education leads had a general understanding that the area served by the project was significant, it was not until the education started did they realise the extent of the task that they had embarked on:

*"I suppose for me although we knew in our head how big this hospital is and we knew by the figures, the employees, and I keep saying this, but I didn't, none of us quite realised how big it was until we went out there and tried to change something or tried to do something." (FU JI Consortium 2)*

When the DemPath project was conceptualised and implemented, a number of other large and substantial changes were happening simultaneously. For example, some large-scale building work was initiated which created staff movement and re-organisation removing focus from the educational initiatives. In addition, the educational component had to also compete with other education that was sometimes perceived as having a greater priority (for example, basic life support and manual lifting and handling).

It was suggested in interviews that more detailed, practical, action-focused education is needed in the future for doctors as it was felt that the current training is too basic in the area of dementia. The need to ensure HCAs and security staff providing specialising have received adequate dementia education was emphasised by hospital staff including HCAs providing this specialising service.

38 Trialling of blue plates on one ward to establish whether their use would increase food intake by patients.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

### 4.5 Summary of DemPath Project Impact and Outcome Findings

- The project achieved gains primarily in relation to process mapping, the implementation of the 4AT for the assessment of cognitive impairment in the ED, design of a Hospital Passport, and the inclusion of a standardised section on cognitive impairment in the hospital discharge letter.
- There was mixed success in other areas of the ICP development and roll-out, as per interview data, for example, standardised transfer of 4AT information from the ED to ward level; although progress was underway to include this in the EPR to address this.
- The project roles were successful in implementing change to enhance care for people with dementia and cognitive impairment.
- Designated roles to implement and maintain change were highlighted as necessary, especially given the complexity and size of SJH and the pressure on resources.
- The hospital organisational audit of dementia care in SJH demonstrated that there had been positive changes between T1 and T2, for example, there was an increase in the availability of relevant training. There was also evidence of the move towards enhanced integration of care for people with dementia, for example, the hospital began using standardised instruments to assess mental state and mood of people with dementia, developed guidelines regarding the prescription and administration of antipsychotic drugs, and implemented systems to enhance dementia recognition and awareness among healthcare professionals in the ward environment.
- The ward organisational audit confirmed the presence of staffing shortages and difficulties in releasing staff from duties to attend dementia training. This was addressed however, at least in part, by the availability of on-the-job guidance and support offered by DemPath facilitators and advocates.
- The case note audit demonstrated mixed results relating to assessment of discharge planning and coordination for people with dementia.
- There was positive practice in relation to multidisciplinary and mental health assessment as per the audit findings.
- There were challenges in the organisation of the patient record.
- There were positive environmental changes implemented in the ED and Hollybrook Lodge, and improved wayfinding/signage in the MISA building, with indications of plans to support continuance of changes.
- Challenges in the physical environment of the hospital arose in audit and service user data, however. Many of these challenges were outside the project brief.
- A suite of education and training programmes were provided and these were streamlined to meet perceived needs. Overall, these programmes were positively evaluated and a number of impacts on practice were reported.
- DemPath facilitators were also trained and these made a significant contribution to the project by engaging in formal and informal education with staff as well undertaking smaller dementia related projects.
- DemPath facilitators were highlighted as a significant stakeholder in the potential for sustainability of project gains.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### 5. DemPath 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 DemPath project. These findings are presented with reference to the:

- Function and impact of the DemPath project governance and organising structure,
- Factors impacting on the implementation of the DemPath project:
  - Factors facilitating the implementation of the project,
  - Factors challenging the implementation of the project.

#### 5.2 Function and Impact of the DemPath Project Governance and Organising Structure

As outlined in Section 2.4, there was quite diversified “driving” of the project in SJH compared to projects in the other two hospital sites, namely Mercy University Hospital, Cork, and Connolly Hospital, Dublin. DemPath divided the project into various strands and associated work package groups. This approach was praised and seen to be an important facilitator for project gains. Participants attributed the effectiveness of the consortium to a shared ownership of the overall project aims and objectives with all members contributing their knowledge and experience. This shared ownership, combined with the working groups in order to distribute workload to optimise progress, was seen as particularly effective. Importantly, visible clinical leadership in an area or strand of the project was more likely to result in positive outcomes. Such leadership crossed sectors and clinical directorates in the project. There was some complexity to the education and design lead roles as the staff involved were not SJH staff, so project funding was provided for these positions. While these roles were very successful in progressing these work packages of the project, the roles are not sustainable in this format when the project funding expires which raised concerns for the sustainability of these activities. Importantly however, the Dementia Services Information and Development Centre (DSIDC) played an active role in the education and training of SJH staff before the DemPath project and will continue to do so after the project finishes.

Consultant physicians in some of the key areas of project activity within SJH were identified by interviewees as important leaders for the project within the ED. Their support included, for example, visibility in supporting the project, having a role in the project consortium, and contributing to the process mapping of the project. Their contribution to a number of aspects of the project was quite significant and played an important part in gaining traction in the forward movement of the ICP within the ED. During interviews, a particular consultant within AMAU was also highlighted as being an important figure in rolling out the ICP. These are examples of how individual staff in target areas for the project were critical to the project process. The project ‘facilitators’ and ‘advocates’ were identified as critical in the development, roll-out and sustainability of the project as they were recruited from and embedded in a number of areas and positions within SJH, as well as in the community (See Section 4.4 for more information).

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Consortium members involved in project development and roll-out were open to sourcing particular expertise to inform aspects of the project where it was felt that the expertise was not already within the consortium, for example, in utilising a professional design team for the MISA wayfinding initiative. This demonstrated the consortium's ongoing analysis of the strengths, skills and knowledge possessed and when and where to source additional expertise when required. They were also able to draw upon the expertise of the EAG, as well as the project funder (see Section 5.3.1) which provided additional knowledge and expertise, and an 'outsider' perspective.

### 5.3 Factors Impacting the Implementation of the DemPath Project

The 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. The consortium regularly incorporated their ongoing experiential learning into the project as it unfolded.

#### 5.3.1 Factors Facilitating the Implementation of the Project

A range of factors that facilitated the implementation of the project were identified. An overview is provided in Figure 14.

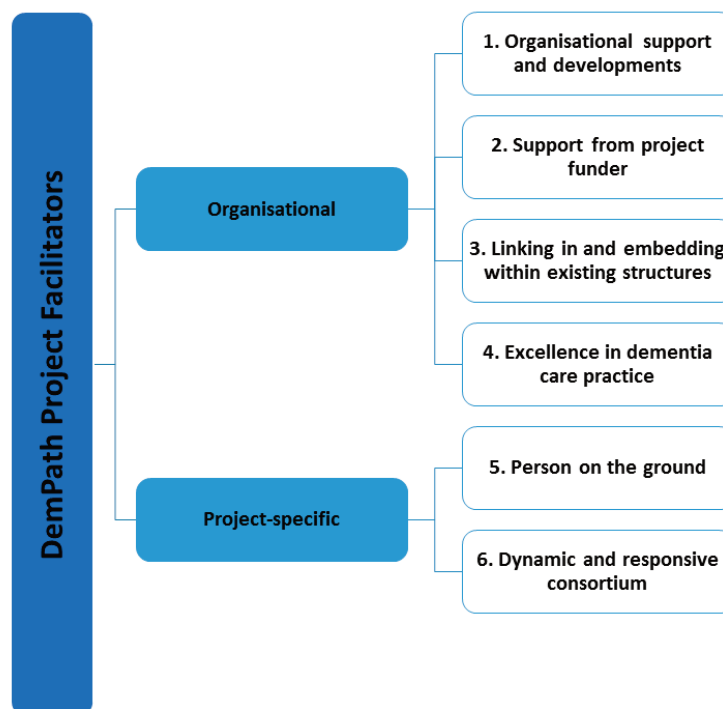


Figure 14. Overview of Project Facilitators



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

**1. Organisational support**, from top level management to frontline staff, emerged as a key facilitator for the project. The recent development of the MISA building and identification of successful ageing as a strategic objective of the hospital, with SJH demonstrating leadership in the area of successful ageing proved to be an important project facilitator. Senior management support was evident and also acted as an important facilitator for the project. While there was a change of CEO during the course of the project, it was acknowledged that both were supportive of the project. Another important development in terms of management support which took place under the auspices of the project was a meeting of senior management personnel and key stakeholders to discuss and plan implementation of various aspects of the project. This was seen as a key milestone in bringing stakeholders on board and gaining support from the top down.

Consortium members felt that the majority of service providers were consistently supportive of the project, providing a lot of time in this regard. Accordingly, it was felt that this was an indicator of the potential for longer term support for the project and sustainability of project gains:

*"The positive side of that then I suppose is that if you feel that people are doing this above and beyond their job that it will be sustained because they see benefit of it and they understand why it wants to be done." (FU SI Consortium 5)*

One difficulty however highlighted here was the compartmentalisation of SJH and the consequent compartmentalisation of support and leadership for the project. This alluded to difficulty in expanding support for the project from a small group to whole organisation level.

A range of **other parallel organisational developments** in the hospital acted as facilitators to the implementation of the project. These included:

- Use of OT and physiotherapist assessment of patients in the ED to accelerate discharge (for all patients, and not just those with dementia),
- Development of the MISA building and the movement of patient cohorts to this setting during the project timeline,
- Protected mealtimes initiative.

These developments fit well with the project ethos and because there was organisational support for these developments, they contributed positively to the project development and roll-out.

**2.** The organisational support received by the project was complemented by **support from the project funder**. As well as providing financial support, the Dementia Programme Manager in Genio provided consultation, advisory support, and specialist knowledge to the project. The Dementia Programme Manager provided support on an ongoing basis as well as at regular formal monitoring meetings. The funder provided opportunities for the consortium to attend relevant training and information events, and meet with the consortia from other hospital sites in order to discuss challenges and learn from each other. Importantly, the funder was supportive of, and enabled the project to develop and evolve as needed throughout. All of the above advanced the development and roll-out of the project and served as an important facilitator to the implementation of the project.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

**3. Linking in and embedding within existing structures**, where possible, was something which the project endeavoured to do in order to maximise the use of existing resources. This worked well in terms of progressing the project and also achieving sustainability of a number of project aspects as the resources will continue to be in place following the project end date. This included, for example, representing the perspective of dementia on the falls management project. Here, the interaction and cooperation of inter-related projects, programmes and structures facilitated synergy and a greater impact than the sum of their separate parts.

**4. The impact of positive ‘role models’ who demonstrated excellence in dementia care practice emerged from interviews.** Some hospital staff referred to specific examples of positive interaction by staff with people with dementia. For example:

*“I find the catering staff on the ward are brilliant. They are really, really good. Even in terms of, you know, because you’ll see the menus like flung down for half an hour just out of pure, like they go out on the trays but you’ll see them going in and engaging. Now I don’t know whether that’s part of the DemPath but it’s just a really personal touch that they’ll go up and be like what do you want today?” (FU FG AHP 1)*

Indeed, the significance of catering as a service provider group engaging and interacting with people with dementia was emphasised. During interviews, they demonstrated considerable knowledge and experience with people with dementia and outlined ways in which they personalise care provided, for example, buying food items for patients unavailable through the hospital or providing patients with adaptations of the menu items (*“I’ve another man and he’s two year with me and he loves the puréed porridge, puréed coddle, but he has to have four boxes a night.” (FU FG Catering)*) There appeared to be disconnect, however, between what is possible and what staff are aware of, given, for example, reports that only a small proportion of catering staff offer the full range of menu options available to people with dementia. To this end, there was variable leadership in regard to empowering hospital staff (catering and others) to provide personalised care to people with dementia.

Another example discussed in hospital staff interviews of excellence in dementia care practice was a consultant facilitating overnight leave for a patient to return home temporarily. Seeing excellence in dementia care practice impacting positively on the patient journey reinforced the importance of person-centred care for service providers. Case Study 2 provides an example of the provision of meaningful engagement by one HCA.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### Case Study 2<sup>29</sup> : Provision of Meaningful Engagement and Personalised Care

Arthur has been working as a Healthcare Assistant in St. James's Hospital for less than five years. He described a process of getting to know a patient when they are moved to the ward; getting to know their interests and hobbies in order to build rapport and develop a meaningful connection. Sometimes this process is facilitated through the provision of patient information in the form of the Hospital Passport. Arthur endeavours to speak to the HCAs going off shift when he starts work each day to get an update on patients. This supplements patient information provided at staff handover by nursing staff. He will further supplement this with information garnered through interaction with the patient and members of their family.

Meaningful interaction with the patient might involve speaking to the person about GAA, music, films, their family etc. Something which Arthur regularly does, is to play music for patients in the ward; in each case this will be music that the patient has expressed an interest in. *"Now I've often done it on my lunch break, I'd go into a certain person and I'd say, do you like Dean Martin, because I love Dean Martin and I'd stick it on for them and just let it play for about twenty minutes and they do be delighted."*

Arthur includes meaningful engagement in his interaction with patients when physical care needs have been met and *"they're settling down."* It is easier to make time for this kind of interaction when 'specialing'. He often uses his break time to play music for and converse with patients as he finds it can be hard to always have time for meaningful engagement during working hours due to pressure on resources. He was very enthusiastic about the benefits of this engagement and interaction for patients, in terms of keeping them both calm and happy; *"they love it"*. It was also evident that Arthur himself enjoys this engagement and interaction. He highlighted, however, that there are sometimes challenges engaging in one-to-one interaction with people with dementia in single rooms. For example, in the past he was accused of stealing by a patient who misplaced a personal item. There are sometimes difficulties for other HCAs engaging in one-to-one interaction with patients who are perceived by other staff members as being idle, though Arthur outlined that the CNM on his ward is cognisant of the benefits of meaningful engagement and facilitates this. Finally, Arthur highlighted the need for further training in dementia for all HCAs.

Some hospital staff felt they are perceived as skiving when they are talking to, or partaking in meaningful engagement with, a person with dementia, particularly if they are in a single room. This then discourages them from this kind of positive activity:

*"You get some nurses that come after you, they really do think you're hiding and especially if the nurse, if she does come up and say to you, where were you, I'd say hold on a minute, just relax for a minute, I'm after being talking to that man or woman, and they go off the deep end."* (FU FG HCA)





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

This highlighted a need for service providers, at all levels, to be more aware of the complexities of care for people with dementia and the need for meaningful engagement and social interaction.

There was evidence of other efforts made by some hospital staff to provide excellence in dementia care. This included:

- A nurse buying monopoly money to give to a person with dementia who “*loved to go to work and he’d come in and he’d be really worried about his wages in the office.*” (FU FG AHP 1),
- Engaging in meaningful engagement with people with dementia on their breaks,
- A person providing one-to-one special observation who walks outdoors with a patient who was a runner,
- A CNM who facilitated a person with dementia to sit at the nurses’ station.

5. The presence of a **person on the ground** (in particular the DemPath nurse) was a significant strength of the project in facilitating change. The importance of having a ‘face’ to the project and having someone on the ground renewing the project message was emphasised in terms of maintaining project visibility and compliance with project activities (for example, completing the 4AT). This was of particular importance given the high number of staff in SJH and the high changeover rates of doctors/interns. It was highlighted that compliance dropped significantly at times when the DemPath nurse or other key project leaders were not active on the ground ‘policing’ project activities.

*“With any other initiative in the hospital there is a face to the name, do you know. It just needs to be plugged, it just needs to be keep being plugged and like awareness.” (FU FG AHP 2)*

*“I think very much the learning has been that as processes are being put in place they have to be minded and they have to be watched and constantly people on them because the moment you take yourself off it, it immediately starts to fall.” (FU SI Key Stakeholder 1)*

6. An important strength of the consortium and a facilitator for the project was the ability of consortium members to be **dynamic and responsive** in relation to overcoming challenges encountered. Importantly, the overall scope of the project was adjusted in response to project learning whereby the proposed impact was narrowed in order to maximise change and to try to achieve sustainability of changes made as part of the project.

*“In terms of the depth of that process map, mapping, I think we really had to cut our cloths to suit our measures, I think we had to really focus on the basics here, you know, and the basics aren’t, haven’t been done in the hospital at all in terms of detection...I think there’s a lot of knowledge and there’s a lot of understanding but in terms of actually people doing assessments, you know, getting the doctor or nurse to do the 4AT on a consistent basis just like taking the blood pressure and pulse, that’s, until we get that, you know, as part of the culture, you know. And that’s gonna take more time. So I mean then all the other things I think in time will follow.” (FU SI Consortium 1)*

While the project began with the objective of developing an ICP for dementia, it evolved to become somewhat different and encompass other cognitive impairments and delirium. The reasoning behind this was twofold, as reported in interviews with consortium members. Firstly, in the initial stages of the project, it emerged that undiagnosed and unidentified dementia and cognitive impairment was as relevant as diagnosed dementia.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Secondly, this was an effort to improve completion of the 4AT amongst service providers. By highlighting the relevance of responding to cognitive impairment in the acute environment, and by increasing the number of patients to whom the proposed changes/ICP would be relevant, the project was seen as having a greater potential for impact:

*"I did find that the delirium with regards the clinical staff was the way to shoehorn in all the rest of the pathway...It was perceived as being 'this is a community issue, the care of the person with dementia, this is not really acute'...I would actively say keep the delirium and that would be your door in. Because it's something that clinical staff feel that they can act on...The other side of it is why we didn't just stick with the dementia was because of the numbers and the massive amount of change that we are asking for the ED and AMAU to do, we wouldn't have got that change if we didn't have the numbers of people...Unless you were addressing something that is the major issue things won't change." (FU SI Consortium 5)*

Other examples of the consortium's responsiveness to challenges and dynamic nature included:

- Linking in with IT and catering and bringing them on board when issues arose,
- Evolution of environmental design plans to maximise impact,
- Dealing with staff in more 'subtle' ways,

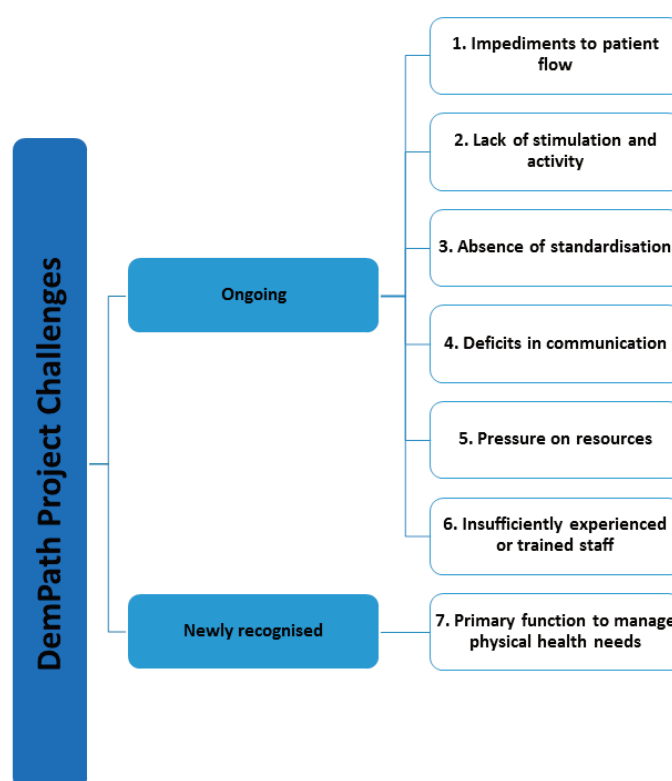
*"What we've noticed is that like for instance we would advocate always that a person with dementia, they shouldn't be in a cubicle with another person right beside them. That is not the best environment for them. Initially when you went down to ED they would be like 'my God that's impossible, we have got overcrowding', so I said 'right that's fine, we'll design the cubicles that it will take two trolleys no problem'. But we have never had two trolleys in that cubicle at all. So by not going in gung-ho sometimes and saying 'well this is best policy and you need not to put', it was a more subtle way." (FU SI Consortium 5)*

- Holding education events in the community to encourage community attendance,
- Using the wayfinding initiative and reporting of same as a means of highlighting environmental difficulties and highlighting the project with key stakeholders,
- Use of a student from the National College of Art and Design to track three patients' ED journey.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 5.3.2 Factors Challenging the Implementation of the Project

A number of ongoing issues identified at T1 as factors challenging the implementation of the project continued to be issues at T2. One new challenge was also identified at T2. Figure 15 provides an overview.



**Figure 15. Overview of Challenges to Project Implementation Highlighted**

**1. Impediments to patient flow**, while senior management felt it had improved somewhat, was highlighted as a major challenge. This was associated with a number of factors including: difficulties in finding suitable and/or dementia-specific LTC; significant number of 'ward of court' cases; delays in applications for the Nursing Home Support Scheme; families being unhappy with LTC positions offered; limited power of Discharge Coordinator; delayed diagnosis; and delays in assessment of capacity. At both T1 and T2 of the hospital organisational audit, it was reported that the management team regularly reviews information in relation to delayed discharges in which people with dementia can be identified, which is a positive activity in attempting to improve dementia care. Reluctance by doctors in the hospital to diagnose dementia was highlighted by hospital staff as a potential barrier to patient flow as it was likely to result in delayed access to relevant services and supports. Hospital staff felt that some doctors were reluctant to make a decision on and/or document capacity. It was found that procedures around



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

assessing and documenting capacity were not standardised across the hospital. Here, diagnosing the person with dementia and disclosure of this diagnosis was seen by some hospital staff as positive as it enables access to relevant support and healthcare services for people with dementia and their family:

*"They don't have a label (diagnosis)...And I'm meeting with this woman who's looking after this man, who's struggling, who's got a burn and has no idea he has dementia...And when you say the word, their face drops and you nearly feel like it's not your job as a social worker to do it. But I have to promote that man being labelled so that he can have a pathway that goes somewhere. Whereas if not, the people are living with it every day but by doctors not telling them or by saying 'oh, you have a cognitive impairment' or 'you have a low MMSE', they're using labels, they're using medical jargon but families just want to know do they have Alzheimer's or dementia." (FU FG AHP 1)*

Again, similar to T1, the variation across medical teams in readiness to and timelines around establishing capacity of people with dementia were highlighted as contributing to potential delays and in particular the challenge at reaching such a substantial and life altering decision in assessing a person with dementia at a single time point and indeed during an acute hospital admission. The delays in assessment for capacity were relevant primarily in cases where there was a proposed transition to LTC. The Assisted Decision-Making (Capacity) Act (Government of Ireland, 2015) which recognises and maximises a person's right to make their own decisions and outlines four levels will be fully commenced in the near future, and will raise questions around delays in assessment for capacity which will have implications for the findings here.

**2. The lack of stimulation and activities** was reported by hospital staff as associated with people with dementia sleeping more during the day and being awake for a large part of the night. The benefits of interaction with hospital staff, as well as other patients (for example, engaging in group activities in a day room) were highlighted:

*"There's a lot of focus on their mealtimes but there is people with dementia who aren't eating or drinking, or eating and drinking minimally, and what else can we do to support them and help them enjoy their days. I think it probably, even a small bit of focus on activities and boredom, you know, would make a big difference." (FU FG AHP 2)*

It was suggested that providing training to those providing specialising services on meaningful engagement with the person with dementia could address, at least in part, this shortcoming. Suggested activities included, for example, listening to music, reading a newspaper or book, singing, reminiscence, doing puzzles or colouring. It was also felt that specials or HCAs assisting people with dementia and other patients in getting dressed (i.e. out of pyjamas/nightdress), doing their hair and/or applying makeup would be beneficial for patient well-being. The activities coordinator in Hollybrook was reported positively on by AHPs.

**3. Difference in policy and practices across the hospital and the absence of standardisation** was highlighted as a major factor challenging the implementation of the project. Examples of this reported by hospital staff in interviews included:

- Life story interventions to gather personalised patient information used in MISA only,
- Dementia flagged on whiteboard in burns ward and ED only,
- Limitations on visiting hours vary across hospital,
- Inconsistent availability of food items such as eggs, toast and snacks across wards,
- Picture menu in MISA only,
- 'Creative life' activities<sup>40</sup> being implemented in MISA only,
- Variability in staff skillset in managing people with dementia between and within wards.

40 Innovations introduced by the creative life appointee including a variety of art and creative activities.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Furthermore, some project changes (for example, implementation of the Hospital Passport at ward level) were introduced in some parts of the hospital and not rolled out as yet to others, which added to this absence of standardisation.

**4. Deficits in communication** were highlighted in terms of poor inter-staff communication, as well as poor linkage and communication between the hospital and community. Gaps in inter-staff communication identified by hospital staff included a limited interface for exchange where there is no case conference structure or multidisciplinary team support and poor quality of handover. Importantly, deficits in inter-staff communication were also identified by service users. One service user interviewed, for example, reported experiences of hospital staff not appearing to be aware of the person with dementia's diagnosis and that she would most likely forget their interaction shortly thereafter. There were also experiences reported, however, where the hospital staff appeared aware of the dementia diagnosis and interacted with the person with dementia in tandem with the family carer and just 2/11 of those who completed questionnaires at T2 reported that staff did not appear to understand the needs of the person with dementia related to their dementia (compared to 3/21 at T1). The poor communication links between the hospital and community, as at T1, were emphasised. A lack of support and the risk of shortfalls upon discharge in community support to prevent repeat admissions and repeat presentations to the ED was highlighted at T2:

*"Cognitive assessments have been done, cognitive impairments have been highlighted, vulnerable adult has been highlighted, but no matter what you do they're still discharged to be readmitted two or three days later. But it comes back to probably supports in the community and that as well and links between the hospital and the community to support a person like that to go home, you know, like to turn them around and to send them home, like who's accepting them home, do they want to go home, do they understand their capabilities, do they have supports of people coming in and there just isn't the supports really, sure there isn't?" (FU FG AHP 2)*

At T1, the hospital organisational audit showed that the management team did not regularly review information in relation to readmissions to identify people with dementia. However, this was in place at T2 pointing to an increased focus on the integration of dementia care. Regular review of readmissions would positively impact the patient journey and increase service provider awareness of this issue.

**5. Pressure on resources**, including staff shortages, resulted in a compromised service being provided to patients. Specific examples of the impact of the pressure on resources highlighted by hospital staff included:

- Reduction in the amount of interaction between hospital staff and patients,
- Rapid admissions from the ED department to AMAU unavailable at times due to bed shortage,
- No designated SLT role for dementia so limited time to dedicate to this,
- Challenges in provision of adequate nutrition and hydration (including not enough HCAs to support patients to eat and drink, HCAs' shift finishing at 4.30 and teas served at 4.45, patients not being prepared for meal times and meals arriving and going cold, and limited food choices being available for SLT to recommend for patients),
- HCAs called to another ward as short staffed but this leaves the original ward under staffed,
- Inadequate number of specials released to cover patient need,
- Lack of funding available for any extra resources, for example, art materials or games for patients,
- Reduction in the number of respite beds available,
- Poor availability of staff to cover sick leave, maternity leave, etc.,
- Delays in moving patients from the ED because of patient flow considerations, for example, inpatient bed capacity.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

The service user questionnaire provided some relevant data here in relation to assistance in personal care from staff (Table 11<sup>41</sup>). Though the numbers are small, it is promising that despite the huge pressure on resources highlighted by hospital staff, the proportion of times which people with dementia were always assisted with personal care by staff had improved somewhat across time points.

**Table 11. Service User Questionnaire Data Relating to Assistance from Staff**

Did staff provide help with	Time	Yes, always – N (%)	Yes, sometimes – N (%)	No – N (%)
Using the toilet or any continence aids	T1	10 (45)	11 (50)	-
	T2	8 (67)	3 (25)	1 (8)
Having a bath	T1	10 (59)	4 (23)	3 (18)
	T2	7 (64)	2 (18)	2 (18)
Eating meals	T1	6 (43)	5 (36)	3 (21)
	T2	5 (45)	4 (36)	2 (18)
Getting dressed and maintaining your personal appearance	T1	7 (30)	13 (57)	3 (13)
	T2	6 (46)	5 (38)	2 (15)

A volunteer programme was suggested here in order to relieve pressure on staff resources. It was highlighted that this pressure on resources was a major factor challenging the implementation of the project given that hospital staff were very much stretched prior to taking on any additional project activities. The consortium outlined difficulty in this regard:

*“The big challenge was that everything was done on a voluntary basis. So in another kind of project management experience you'd have staff and they would be accountable to achieving x, y, z. Whereas this was on the goodwill of individuals who were already stretched in their own position. So it took a lot longer in that respect to achieve what we wanted to achieve. We had lots of goodwill but not the time to actually be able to invest into it. So I think that is the challenge.” (FU SI Consortium 5)*

It was recognised by hospital staff that engaging in project activities placed an extra demand on resources. Accordingly, when there was a greater number of staff on the ground, compliance in completing project activities was much greater according to the project manager, demonstrating a clear link between progressing the project and the human resources available. The difficulty in resourcing project activities into the future to ensure sustainability was highlighted by the project lead who outlined that although there was strong senior manager support for the project, there was difficulty in securing funding.

<sup>41</sup> Data is only included here for those who reported that help was needed in these areas i.e. data excluded for those who reported that they did not need help. Data is also excluded for “I don't know” responses.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

6. The issue of **insufficiently experienced or trained staff** was highlighted at both T1 and T2. One family carer, for example, felt that hospital staff were insufficiently experienced in dealing with and caring for people with dementia:

*"This isn't a suitable place for her anyway. She needs to be in a place where people have experience of dealing with people with dementia and those types of problems." (FU SI Family Carer 4)*

Another family carer outlined that the level of competency of hospital staff in dealing with people with dementia seemed to vary greatly across the hospital. One other family carer felt that hospital staff needed to be more empathetic towards people with dementia and described coming to visit the person with dementia on a particular day when she was very distressed and screaming but was not being attended to by staff.

The consortium highlighted some difficulties in bringing service providers on board at times whereby service providers felt that dementia/cognitive impairment was not relevant to their area of work. This suggests a need to raise further awareness of the prevalence of people with dementia and cognitive impairment in SJH.

7. The nature of the hospital as having the **primary function to manage physical health needs** emerged as an important factor challenging the implementation of the project:

*"Whilst we often try to, either formally or informally, say 'this is your home', the reality is it's not your home, it's a hospital. We can try and make it as comfortable and familiar as possible but ultimately we are a hospital and we have to function as a hospital and the reason someone is here is because they have some level of acuity (acute illness) that requires them to be in hospital or else they shouldn't be here and we're trying to find another alternative venue for them that is appropriate for their needs." (FU SI Key Stakeholder 2)*

One of the barriers to implementing changes in the physical environment of the hospital was the recurring observation by hospital staff that the primary function of the hospital is to deal with medical needs. There were efforts made to implement environmental changes in the day room of one of the hospital wards but there was poor satisfaction with changes made:

*"There are some difficulties in [ward name] and the patient group who use it. There'll always be a problem in relation to where they store certain items. While people are staying there and whether they have these very big chairs like buxton chairs and basically, when you've got very frail, or people with mobility problems, these chairs are the only real option to keep them comfortable and you know, they're not just in bed. So they can get them out and move them to different parts of the ward. So they are always going to be there and there's very few places to actually store those. So they may well end up being in the day room." (FU SI Consortium 4)*

The ability to adjust the physical environment in the ED was also constrained by the necessity to maintain the bays' primary function of meeting urgent medical need:

*"People are in there saving lives at times. You know, it's not comfortable, you can't have a nice piece of chintzy furniture. Or a nice, you know, velvet drapes; you know that's not going to work. You can't make ED homely; it's not designed to be homely. You know, it really is, it's the hard edge of medicine in there." (FU SI Consortium 4)*



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

While this related primarily to environmental changes, it was a multi-faceted issue. This related to catering issues such as the important health and safety reasons behind why patients cannot store food in hospital fridges, have to sign a declaration if they want to consume food not supplied by the hospital or may have to use a plastic beaker for drinking hot liquids. Movement between wards was highlighted as a regular occurrence; at T2, 12/16 family carers reported that their relative had been moved between wards while in the hospital (similar to T1 where 19/26 reported their relative was moved between wards). In line with this, the hospital organisational audit at both T1 and T2 reported that the transfer policy does not state whether people with dementia should only be moved for reasons pertaining to their care and treatment. One family carer suggested that their relative was moved frequently due to a high level of responsive behaviours which were problematic for staff. The sometimes high level of patient moves between wards was highlighted by hospital staff, however, in terms of the necessity to house patients in wards relevant to their acute medical condition and the need to re-designate patients based on demand for beds within particular specialist areas:

*“They come in through ED, from ED they might to AMAU, then they're identified resp (respiratory), oncology, whatever, from there they go to respiratory ward into a bay ward, then they've been diagnosed with some sort of infection, so then they're popped into a side room. Next thing their infection goes away and somebody new with an infection comes in, they're popped out of the side room, no free bed in the bay and they have to go off to the other ward that the patient with the new infection has come in. And you can't help it...It's basically making room, it's slotting cubes around the place so that they can make room for the patients coming in.” (FU FG AHP 2)*

Again, this related to the primary function of the acute hospital as caring for patients' physical health needs. It emerged from interviews that in acute care, dementia is often seen as secondary. By consequence, it was suggested that there may be less emphasis on physiotherapy and other rehabilitation for people with dementia as they sometimes struggle with following instructions so they sometimes receive less intensive care.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### 5.4 Summary of DemPath Project Process Findings

- The success of the DemPath project was contingent upon not only the project roles but also upon the cooperation and work of a consortium structure and a number of key individuals and staff groupings including DemPath facilitators.
- Importantly, visible clinical leadership in an area or strand of the project was more likely to result in positive outcomes.
- Six project facilitators were identified which supported the DemPath project process and the achievement of its outcomes. There were:
  1. Organisational support and developments,
  2. Support from project funder,
  3. Linking in and embedding within existing structures,
  4. Excellence in practice,
  5. Person on the ground,
  6. Dynamic and responsive consortium.
- A number of challenges were found to have impacted on the project. Notably, the majority of these were highlighted at both T1 and T2 data collection:
  1. Impediments to patient flow,
  2. Lack of stimulation and activity for people with dementia,
  3. Absence of standardisation,
  4. Deficits in communication (inter-staff communication, as well as poor linkage and communication between the hospital and community),
  5. Pressure on resources,
  6. Insufficiently experienced or trained staff,
  7. Primary function to manage physical health needs.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### 6. DemPath Hospital Inpatient Activity Analysis

#### 6.1 Introduction

The nature of the DemPath project meant that conventional cost benefit analysis could not be employed in the evaluation. The effects of the project ranged so broadly across the hospital that it was not possible to capture all of them. Additionally, for many of the benefits identified in the previous chapters, it was impossible to assign a monetary valuation to these effects. These difficulties are particularly germane to the question of putting a monetary valuation on the effects of the project on the patient experience in SJH. The approach in this evaluation therefore has followed a methodology whereby the changes in critical variables such as length of stay, patient cost, and cost of specials are outlined. The changes identified in the sections which follow can be considered alongside the changes discussed in the previous two chapters. Taking all of these changes into account, a decision maker or funder will be in a good position to judge whether the additional resources spent on the project represent good value for money.

This section of the evaluation focuses on activity data comparing inpatient cases discharged from SJH in 2014 and 2016 with either a primary or a secondary diagnosis of dementia. Data was obtained from the HIPE office at SJH and 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 1. The analysis covers three broad issues: source of admission and destination of discharge, length of stay, and inpatient costs. A substantial minority of the patients received 'special observation services' while they were in hospital. The HIPE coding system that is currently used in Ireland does not allow such services to be included in the HIPE records for each patient. Data on the quantity and cost of the specials was obtained from the Finance Office at SJH and this data is analysed in Section 6.12.

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 DemPath 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 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.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

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 12 presents a breakdown of the number of cases and patients in 2014 and 2016. In 2014, SJH discharged a total of 370 patients and 426 cases with a diagnosis of dementia. Three hundred and twenty seven patients had a single discharge, while 43 patients had between two and five discharges. Single discharges accounted for 76.8% of cases while the 43 patients with multiple discharges accounted for 23.2% of the cases. In 2016, SJH discharged a total of 414 patients and 496 cases with a diagnosis of dementia. Three hundred and forty eight patients had a single discharge, while 66 patients had between two and four discharges. Single discharges accounted for 70.2% of cases in 2016 so there was an increase of 6.6% in the proportion of cases accounted for by multiple discharges in 2016.

The increase in the number of cases from 426 to 496 (an increase of 16.4%) is part of a longer trend in SJH of increasing number of cases with dementia. While this trend had been evident before the project began, data from 2015 (there were 467 cases with dementia discharged from SJH 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 DemPath 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 SJH.

**Table 12. Cases and Patients Discharged with Dementia**

Number of discharges	Number of patients		Number of cases		Percent of cases (%)		Cumulative percent of cases (%)	
	2014	2016	2014	2016	2014	2016	2014	2016
1	327	348	327	348	76.8	70.2	76.8	70.2
2	34	54	68	108	16	21.8	92.7	91.9
3	6	8	18	24	4.2	4.8	97	96.8
4	2	4	8	16	1.9	3.2	98.9	100
5	1	-	5	-	1.2	-	100	-
Total	370	414	426	496	100	100	100	100



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 6.3 Readmissions

There were 56 discharges in 2014 where the patient had previously been discharged in 2014. In 17 of these cases (30.4%), a patient was readmitted to SJH within 30 days of their previous discharge. There were 82 discharges in 2016 where the patient had previously been discharged in 2016. In 27 of these cases (32.9%), a patient was readmitted within 30 days of their previous discharge. The increase in the proportion of cases in which a patient was readmitted within 30 day was not statistically significant ( $z = -0.32$ ;  $p = 0.75$ ).

### 6.4 Admission Source

It is clear from the data in Table 13 that the vast majority of people diagnosed with dementia were admitted from home. In 2014, patients were admitted from home in 420 cases (98.6%), while patients were admitted from LTC (including nursing homes, convalescent homes or other long stay accommodation) in three cases (0.7%). In 2016, patients were admitted from home in 477 cases (96.2%), while patients were admitted from LTC in 13 cases (2.6%). The proportion of cases where patients were admitted from home decreased by 2.4% between 2014 and 2016 ( $z = -2.26$ ;  $p = 0.02$ ) while the proportion of cases admitted from LTC increased by 1.9% ( $z = -2.2$ ;  $p = 0.03$ ). The extremely low number of cases admitted from LTC is puzzling. It seems to reflect a practice in SJH whereby the contact address on admission is generally given as a private home residence even if the patient is admitted from long term residential care. A number of cases were identified in the dataset where a patient was discharged to LTC and subsequently readmitted to SJH and in every such case the person's admission source was listed as a private residence instead of LTC.

**Table 13. Admission Source**

Admission source	Number of cases		Percent of cases		Cumulative percent of cases	
	2014	2016	2014	2016	2014	2016
Home	420	477	98.6	96.2	98.6	96.2
LTC	3	13	0.7	2.6	99.3	98.8
Acute hospital	3	3	0.7	0.6	100	99.4
Psychiatric hospital/unit	-	3	-	0.6	-	100
Total	426	496	100	100	100	100

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 6.5 Medical Card

A majority of cases in both years involved people with medical cards. In 2014, 76.5% of cases involved patients with medical cards, while in 2016, 83.9% of cases involved patients with a medical card. The increase in the proportion of cases where the patients had a medical card was statistically significant ( $z = -2.97$ ;  $p = 0.003$ ).

### 6.6 Patient Death

In 2014, 16.2% of cases ( $n = 69$ ) with a diagnosis of dementia died in hospital while in 2016, 12.1% ( $n = 60$ ) cases resulted in death, a decrease of 4.1%. The decrease was not statistically significant at the 5% level of significance ( $z = 1.79$ ;  $p = 0.07$ ) although it was significant at the 10% level.

### 6.7 Discharge Destination

Table 14 contains information on the destinations that patients with dementia were discharged to in both years. In 2014, patients were discharged to home in 177 cases (41.6%) and to LTC in 123 cases (29.1%). In 2016, patients were discharged to home in 186 cases (37.5%) and to LTC in 234 cases (47.2%). These two destinations accounted for 80.9% of discharge destinations in 2016, an increase of 14.3% compared to 2014 ( $z = -5.2$ ;  $p < 0.001$ ). The increase in the proportion of cases discharged to LTC is particularly striking. Most, but not all of that increase, is accounted for by declines in the proportion of discharges going to non-emergency hospitals and to various other destinations. The 'other' category in Table 14 includes transfers to a non-acute private hospital, transfers to a psychiatric unit, and transfers to a private external rehabilitation facility.

**Table 14. Discharge Destinations**

Discharge destination	Number of cases		Percent of cases		Cumulative percent of cases	
	2014	2016	2014	2016	2014	2016
Home	177	186	41.6	37.5	41.6	37.5
LTC	123	234	28.9	47.2	70.4	84.7
Death	69	60	16.2	12.1	86.6	96.8
Hospital (non-emergency)	34	12	8.0	2.4	94.6	99.2
Other	23	4	5.4	0.8	100	100
Total	426	496	100	100	100	100



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 6.8 Admission Source and Discharge Destination

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

In 2014, 49.6% of these cases were admitted from, and discharged to, home. This proportion decreased to 42.2% in 2016 ( $z = 2.1$ ;  $p = 0.04$ ). In 2014, 34.2% of cases had home as the admission source and LTC as the discharge destination. The comparable figure in 2016 was 50.5% of cases. The increase in this category was statistically significant ( $z = -4.6$ ;  $p < 0.00$ ). It isn't clear what conclusions can be drawn about these changes given the possibility that the admission source category is not recorded accurately in SJH.

**Table 15. Admission Source and Discharge Destination**

Admission source	Discharge destination	Number of cases		Percent of cases		Cumulative percent of cases	
		2014	2016	2014	2016	2014	2016
Home	Home	177	184	49.6	42.2	49.6	42.2
Home	LTC	122	220	34.2	50.5	83.8	92.7
Other		58	32	16.2	7.3	100	100
Total		357	436	100	100	100	100

### 6.9 Primary Diagnosis

Thirty nine cases (9.2%) had a primary diagnosis of dementia in 2014, while 54 cases (10.9%) had a primary diagnosis of dementia in 2016. While the increase of 1.7% was not statistically significant ( $z = -0.87$ ,  $p = 0.38$ ) it is consistent with DemPath's objective of improving the diagnosis of dementia in SJH.

### 6.10 Length of Stay

The HIPE data records the length of stay for each case. A striking feature of the SJH data was that there were a number of discharges in both years whose length of stay was very long. For example, there were two patients discharged in 2014 whose length of stay exceeded three years and four other patients whose length of stay was over 300 days. In 2016, one patient was discharged after being in hospital for almost two years while three other patients were discharged after a stay of over 300 days. Including a small number of cases with extremely long length of stay has the potential to distort the overall picture that is of interest. Therefore, any analysis where the results are significantly affected by the inclusion of outliers (defined arbitrarily as patients with a length of stay over 300 days) is noted in the following sub-sections.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

The overall data on length of stay is summarised in Tables 16, 17 and 18. Length of stay ranged from one day to 1,223 days in 2014. The mean length of stay was 52 days, while the median was 18 days. In 2016, length of stay ranged from one day to 643 days. The average was 33.7 days, while the median was 14 days. The impact of including the outliers is particularly noteworthy in 2014 where the mean length of stay falls by 8.5 days when six outliers are excluded. There was a statistically significant decline in length of stay between 2014 and 2016 ( $z = 3.3$ ;  $p < 0.001$ ) whether or not the 10 outliers were included. Reducing length of stay was a major objective of DemPath and, while more evidence is needed, the fall in length of stay indicates that DemPath was having its intended effect on this important indicator, though it is acknowledged that there are many other systems reasons which may have contributed to this.

**Table 16. Mean and Median Length of Stay, 2014 and 2016, All Cases**

Year	Number of cases	Mean length of stay (days)	Median length of stay (days)
2014	426	52.0	18
2016	496	33.7	14

**Table 17. Mean and Median Length of Stay 2014 and 2016, Without Outliers**

Year	Number of cases	Mean length of stay (days)	Median length of stay (days)
2014	420	43.5	18
2016	492	30.3	14

**Table 18. Mean and Median Length of Stay 2014 and 2016, Outliers**

Year	Number of cases	Mean length of stay (days)	Median length of stay (days)
2014	6	648	448.0
2016	4	455	435.5

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 6.10.1 Length of Stay: Primary and Secondary Diagnosis

Tables 19 and 20 illustrate the length of stay for patients with, and without, a primary diagnosis of dementia. In both years, the mean and median lengths of stay were significantly longer for cases where the primary diagnosis was dementia ( $z = -2.5$  and  $p = 0.014$  in 2014 and  $z = -6.0$  and  $p < 0.00$  in 2016.) Previous work on this topic in Ireland (Briggs *et al.* 2016) did not differentiate between cases with a primary diagnosis of dementia and cases with a secondary diagnosis. The SJH data illustrated that this is an important distinction.

There was a large increase in the length of stay for cases with a primary diagnosis between 2014 and 2016 although this increase was not statistically significant. The increase in the mean length of stay for cases with a primary diagnosis was due to the impact of the ten outliers. When the outliers were excluded mean length of stay was slightly lower in 2016 than 2014. The decline in length of stay for cases with a secondary diagnosis of dementia between 2014 and 2016 was statistically significant.

**Table 19. Length of Stay by Diagnosis of Dementia, All Cases**

Diagnosis	Number of cases		Mean length of stay (days)		Median length of stay (days)	
	2014	2016	2014	2016	2014	2016
Primary	39	54	66.4	85.7	36	45.5
Non-primary	387	442	50.5	27.4	17	13.0
Total	426	496				

**Table 20. Length of Stay by Diagnosis of Dementia, Without Outliers**

Diagnosis	Number of cases		Mean length of stay (days)		Median length of stay (days)	
	2014	2016	2014	2016	2014	2016
Primary	39	51	66.4	63.7	36	43
Non-primary	381	441	41.1	26.4	17	13
Total	420	492				

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

### 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. The mean and median lengths of stay were higher for single cases than multiple cases in both years. Length of stay for both type of cases fell between 2014 and 2016, significantly so for single cases ( $z = 2.7$ ;  $p = 0.007$ ). The decline in length of stay for multiple cases was not significant ( $z = 1.4$ ;  $p = 0.17$ ).

### 6.10.3 Length of Stay: Admission Source and Discharge Destination

Since most cases were admitted from home it follows from the previous analysis that the fall in length of stay for cases admitted from home between 2014 and 2016 was significant ( $z = 3.4$ ;  $p < 0.001$ ). Length of stay was much longer when the destination was LTC rather than home (See Table 21). The difference was statistically significant in both years ( $z = -9.4$ ,  $p < 0.001$  in 2014 and  $z = -10.5$ ,  $p < 0.001$  in 2016). Length of stay was also longer for discharges to LTC compared to discharges to non-emergency hospital or other destinations. The decline in length of stay between 2014 and 2016 was statistically significant regardless of the destination. For example, the median length of stay with LTC as a destination declined by 29.5 days ( $z = 4.3$ ;  $p < 0.001$ ).

**Table 21. Length of Stay by Discharge Destinations**

Discharge Destination	Number of cases		Mean length of stay (days)		Median length of stay (days)	
	2014	2016	2014	2016	2014	2016
Home	177	186	27.1	12.1	9	7.0
LTC	123	234	85.3	51.6	63	33.5
Hospital (non-emergency)	34	12	46.6	17.7	33	12.0
Other	23	4	78.1	23.0	19	12.5
Total	357	436				

Length of stay for different combinations of both admission source and discharge destination is shown in Table 22 below. In 2014, cases in which patients were admitted from and discharged to home had mean and median lengths of stay of 27.1 and 9 days respectively. Cases in which patients were admitted from home and discharged to LTC had mean and median lengths of stay that were 58.8 and 54.5 days longer than cases with home as the admission source and discharge destination ( $z = -9.4$ ;  $p < 0.001$ ).

In 2016, cases in which patients were admitted from, and discharged to, home had mean and median lengths of stay of 12 and 7 days respectively. Cases in which patients were admitted from home and discharged to LTC had mean and median lengths of stay that were 37.8 and 27 days higher than cases with home as the admission source and discharge destination ( $z = -10.4$ ;  $p < 0.001$ ).

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

The mean and median lengths of stay of cases with home as the admission source decreased by 15.1 and 2 days between 2014 and 2016 ( $z = 2.4$ ;  $p = 0.01$ ). The average and median lengths of stay of cases with home as the admission source and LTC as the discharge destination decreased by 36.1 and 29.5 days between 2014 and 2016 ( $z = 4.4$ ;  $p < 0.001$ ).

**Table 22. 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	2016	2014	2016	2014	2016
Home	Home	177	184	27.1	12.0	9.0	7
Home	LTC	122	220	85.9	49.8	63.5	34

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

The final issue examined is to compare the length of stay for people with dementia to people without dementia for a number of DRGs. The five DRGs that were most common as primary diagnoses for people with dementia were E62A and E62B (Respiratory Infection), F73A (Syncope & Collapse), and L63A and L63B (Urinary Tract Infection, UTI). The comparison group was people aged 65 or older who were discharged with one of these DRGs but without a diagnosis of dementia. Mean and median length of stay for these DRGs is contained in Tables 23 and 24.

For each of the five DRGs selected, mean and median lengths of stay were longer for people with dementia than for people without dementia in both years. In 2014, the difference in length of stay between the respective groups was statistically significant for the syncope and collapse DRG and for both of the UTI DRGs. In 2016, the difference in length of stay was statistically significant for one of the respiratory infection DRGs (E62B) and one of the UTI DRGs (L63B).

Previous research in Ireland on the impact of a diagnosis of dementia on length of stay found mixed results. Connolly and O'Shea (2015) concluded that people with dementia had considerably longer hospital stays than people without dementia. Their analysis was 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 dementia patients with five 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.* 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.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

**Table 23. 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)
<b>Diagnosed with dementia</b>				
E62A	Respiratory infection	22	56.6	19.5
E62B	Respiratory infection	13	35.5	13
F73A	Syncope & collapse	26	46	34.5
L63A	UTI	24	57.3	28
L63B	UTI	18	44.1	12
<b>Not diagnosed with dementia</b>				
E62A	Respiratory infection	127	34.5	15
E62B	Respiratory infection	99	17.2	10
F73A	Syncope & collapse	126	20.6	8
L63A	UTI	168	30.2	13
L63B	UTI	136	21.4	6

**Table 24. 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)
<b>Diagnosed with dementia</b>				
E62A	Respiratory infection	22	16.9	11.5
E62B	Respiratory infection	15	44.5	11
F73A	Syncope & collapse	14	25.2	12.5
L63A	UTI	48	35.6	15.5
L63B	UTI	14	29.4	28.5
<b>Not diagnosed with dementia</b>				
E62A	Respiratory infection	213	16.8	10
E62B	Respiratory infection	66	15.6	6
F73A	Syncope & collapse	132	10.2	6
L63A	UTI	229	24.7	12
L63B	UTI	79	9.5	5

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 6.11 Patient Cost

The HPO calculates a casemix cost for every DRG in the classification system that they use. That cost was assigned to any patient who has been in hospital within a range that the HPO has classified as normal for that DRG. The HPO has also designed algorithms to calculate costs for outliers – patients who are discharged either before the minimum, or after the maximum number of days allowed for in any given DRG. Further details are available in Appendix 1 which contains a number of examples. The inpatient costs of every case in 2014 and 2016 were assigned using this method. In this sub-section the cost of any special services received by patients is not included.

As discussed in Appendix 1, the calculation of an individual cost number for every case is an estimate of the actual cost incurred by SJH 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 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.

The basic data on costs is contained in Tables 25 and 26 below. In 2014, patient costs ranged from €516 to €428,010. The mean cost was €20,061, while the median was €9,268. In 2016, patient costs ranged from €712 to €194,385. The mean cost was €13,388, while the median patient cost was €8,116. The mean and median costs in 2016 were €6,673 and €1,152 lower than in 2014 ( $z = 2.2$ ,  $p = 0.03$ ). The difference between the average and median costs in each year indicates that there were a small number of patients with very high costs. The influence of the 10 outliers on mean cost is a large one – mean costs in 2014 were over €3,000 lower when the six cases with length of stay of over 300 days were excluded.

The main factor determining patient cost was length of stay. There was a very strong correlation ( $r = 0.94$  for 2014,  $r = 0.92$  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 16% of the total cost in 2016 and 23% in 2014 where the influence of two of the outliers was particularly strong.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

**Table 25. Mean and Median Patient Costs, All Cases**

Year	Number of cases	Mean patient cost (€)	Median patient cost (€)
2014	426	20,061	9,268
2016	496	13,388	8,116

**Table 26. Mean and Median Patient Costs, Without Outliers**

Year	Number of cases	Mean patient cost (€)	Median patient cost (€)
2014	420	16,944	9,235
2016	492	12,421	8,017

### 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 with a secondary diagnosis of dementia in 2016 (see Table 27). There was a significant decline in costs for cases with a secondary diagnosis between 2014 and 2016 ( $z = 2.4$ ,  $p = 0.02$ ). The mean costs of cases with a primary diagnosis increased between 2014 and 2016 ( $z = -0.61$ ,  $p = 0.54$ ). The increase in mean costs for cases with a primary diagnosis was reversed when the 10 outliers were excluded.

**Table 27. Patient Cost by Diagnosis of Dementia in 2014 and 2016**

Diagnosis	Number of cases		Mean patient cost (€)		Median patient cost (€)	
	2014	2016	2014	2016	2014	2016
Primary	39	54	17,396	22,270	12,520	12,520
Non-primary	387	442	20,329	12,303	8,889	6,958
Total	426	496				



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 6.11.2 Patient Cost: Single and Multiple Discharges

Mean and median patient costs were significantly higher in both years for single discharge cases than for multiple discharge cases ( $z = 3.6$ ,  $p = 0.0003$  in 2014 and  $z = 2.7$ ;  $p = 0.008$  in 2016). There was a decline in costs for single discharges between 2014 and 2016 ( $z = 2.4$ ;  $p = 0.02$ ) and a decline in mean but an increase in median costs for cases involving multiple discharges.

**Table 28. Patient Cost by Number of Discharges**

Discharges	Number of cases		Mean patient cost (€)		Median patient cost (€)	
	2014	2016	2014	2016	2014	2016
Single	327	348	22,441	14,808	9,811	8,987
Multiple	99	148	12,200	10,050	6,035	6,477
Total	426	496				

### 6.11.3 Patient Cost: Admission Source and Discharge Destination

There was a decrease in mean and median costs of €7,276 and €1,266 for cases with home as the admission source between 2014 and 2016 ( $z = 2.4$  and  $p = 0.02$ ).

Table 29 contains details of how costs varied with discharge destination. Costs were significantly higher in both years for cases discharged to LTC compared to cases discharged to home ( $z = -9.2$ ,  $p < 0.001$  in 2014 and  $z = -9.4$ ,  $p < 0.001$  in 2016). Mean costs fell for all four possible destinations between 2014 and 2016 although there was no change in the median costs of cases with home as the destination. The decline in the cost of cases discharge to LTC was statistically significant ( $z = -9.2$ ,  $p < 0.001$ ).

**Table 29. Patient Cost by Discharge Destinations**

Discharge destination	Number of cases		Mean patient cost (€)		Median patient cost (€)	
	2014	2016	2014	2016	2014	2016
Home	177	186	11,280	7,368	5,770	5,770
LTC	123	234	29,416	18,391	17,445	11,355
Hospital (non-emergency)	34	12	19,906	10,384	10,076	8,577
Other	23	4	28,350	9,869	9,302	5,577
Total	357	436				

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Length of stay for different combinations of both admission source and discharge destination is shown in Table 30. Cases admitted from home and discharged to LTC incurred significantly higher costs than cases admitted from and discharged to home in both years ( $z = -9.3$ ,  $p < 0.001$  in 2014 and  $z = -9.2$ ,  $p < 0.001$  in 2016). The mean and median costs for cases admitted from home and discharged to LTC decreased by €12,119 and €6,793 between 2014 and 2016 ( $z = 4.4$ ;  $p < 0.001$ ).

**Table 30. Patient Cost by Admission Source and Discharge Destination**

Admission source	Discharge destination	Number of cases		Mean patient cost (€)		Median patient cost (€)	
		2014	2016	2014	2016	2014	2016
Home	Home	177	184	11,280	7,354	5,770	5,770
Home	LTC	119	220	29,636	17,517	18,015	11,222
Total		296	401	-	-	-	-

### 6.12 Specials Services

Hospitals often assign a 'special observation service' to people with dementia to ensure their safety. These services are not included in HIPE data because technically they are not considered as a medical procedure. Therefore receiving a specials service doesn't have any impact on the level of DRG that the HIPE coders assign a patient to nor is the cost of specials services factored into the unit cost of each DRG. The total cost of specials services can be very large and it is important to consider these costs if the data is available. Fortunately, the finance department at SJH were able to supply data on specials services provided to people discharged with dementia and this data is analysed in this sub-section.

Of the 426 cases discharged in 2014, 80 (18.8%) cases were assigned a special. Of the 496 cases discharged in 2016, 150 (30.2%) cases were assigned a special. The increase in the proportion of cases assigned a special was statistically significant ( $z = -4$ ;  $p < 0.001$ ). Overall, the cost of specials services is a significant addition to the total cost of care for both cohorts. The cost of specials services was 16% of the total cost of care for all patients diagnosed with dementia (total cost including both the HIPE based cost and the cost of specials services) in 2014 while in 2016 the proportion of total costs accounted for by specials was 23%.

The mean cost of specials in 2014 was €20,415, while the median cost was €7,232. The mean cost was €13,411 in 2016, while the median patient cost was €3,935 (see Table 31 below). The large fall in mean and median cost between 2014 and 2016 was statistically significant at the 10% level ( $z = 1.9$ ;  $p = 0.061$ ).

Cases with a primary diagnosis of dementia were more likely to be allocated specials services. For example, in 2016, over half of the cases with a primary diagnosis of dementia were assigned a specials service while only 27% of the cases with a secondary diagnosis were assigned one. The cost of specials services were higher for people with a primary diagnosis although the difference was not statistically significant in either year.

## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

**Table 31. Cost of Specials Assigned to Cases by Diagnosis of Dementia**

Diagnosis	Number of cases		Mean specials cost (€)		Median specials cost (€)	
	2014	2016	2014	2016	2014	2016
Primary	15	29	22,092	25,440	10,368	4,095
Non-primary	65	121	20,028	10,528	6,494	3,932
Total	80	150				

There has been very little research done on the cost of specials services in Ireland and the data analysed here represents a significant development as regards research on inpatient costs for people with dementia in Ireland.

### 6.13 Summary of DemPath Hospital Inpatient Activity Analysis Findings

- The total number of cases discharged with a diagnosis of dementia increased from 426 to 496 between 2014 and 2016. Around 10% of cases in each year had received a primary diagnosis of dementia.
- Overall, and in various sub-categories, mean or median length of stay declined significantly between 2014 and 2016 (for example, mean length of stay for all cases was 52.0 days in 2014 and 33.7 days in 2016).
- Length of stay was generally higher for people with dementia than for people without dementia who had received the same primary diagnosis (for example, in 2016, mean length of stay for those with a primary diagnosis of syncope and collapse was 25.2 days for people diagnosed with dementia and 10.2 days for people not diagnosed with dementia).
- The mean costs of all the cases with a diagnosis of dementia fell significantly between 2014 and 2016 (for example, there was a decrease in mean and median costs of €7,276 and €1,266 for cases with home as the admission source between 2014 and 2016).
- The cost of specials services (an observation service provided to a patient or patients within the hospital to ensure their safety) was an important additional cost incurred within SJH. The proportion of cases diagnosed with dementia that received specials services increased from 18% to 30% between 2014 and 2016. The mean and median cost of specials services declined between 2014 and 2016 (for example, the mean cost of specials was €20,415 in 2014 and €13,411 in 2016).



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

### 7. Discussion

#### 7.1 Introduction

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

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

#### 7.2 Discussion

The DemPath project, following revision of the project scope (as outlined in Chapter 2) aimed to create an effective 'dementia-friendly' ICP for all people with dementia admitted to and discharged from SJH by improving the care environment, and by increasing awareness of dementia and associated care needs through education and training. To achieve this, the project design incorporated a number of components including: the development of an ICP for dementia (adjusted to cognitive impairment during the project), the provision of dementia awareness raising and education activities, and the development of the hospital environment to be more dementia-friendly. A consortium approach was employed whereby a group of individuals, agencies and organisations came together with the agreed goal (Keogh and Pierce, 2017) of supporting the development of an ICP for dementia. The project objectives were aligned with national priorities, as outlined in the National Clinical and Integrated Care Programmes for Older People operated within the HSE and the Irish National Dementia Strategy (Department of Health, 2014). For example, the strategy highlights the need to ensure all those dealing with people with dementia be appropriately trained and DemPath's strategy to include all face fronting staff was responsive to this priority area. Further priorities identified are dementia-friendly acute care environments, clarity in care pathways for all concerned, timely diagnosis, care at lowest point of acuity and seamless transitions in care. As demonstrated in both the project description (Chapter 2) and the evaluation findings (Chapters 4-6), the activities within the DemPath project reflected many of these elements and sought, from within finite resources, to introduce innovations to achieve lasting and meaningful developments in terms of dementia care integration.

There is a national landscape of review and reform of older persons' services, and a growing political and policy focus on dementia care and concern for the appropriate usage of acute hospital beds. This means that the DemPath project was timely. The objective of both the Integrated Care Programme for Older Persons (Health Service Executive, 2017b) and the National Clinical Programme for Older People (Health Service Executive, 2013) is to further develop interconnections between services for older adults. The development of integrated services and pathways for those with complex care requirements, including people with dementia, matches this objective. Within the Irish National Dementia Strategy (Department of Health, 2014, p. 25), the necessity for dementia-specific ICPs are identified as a priority action that facilitate *"the right care and support, in the right place and at the right time"*. Such ICPs are critical in the provision of effective person-centred care for the person with dementia, as well as matching supports to identified needs (Irving and McGarrigle, 2012). Despite international advocacy for the



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

development of ICPs for dementia care, the potential contribution and impact of ICPs on dementia care and the experiences of service users and service providers in their use are not well documented. The DemPath project is one of the first in the Republic of Ireland to develop and introduce an ICP for dementia care along with two other HSE & GENIO funded projects (Chapter 1, Section 1.2). Therefore, the learning from the process and outcomes of the project have the potential to contribute hugely to the evidence base, as well as influence the development of ICPs for dementia in other settings.

The evaluation of the DemPath project demonstrated that it was successful in influencing care and in planning an ICP but implementation was still ongoing by project end. Consideration of the DemPath ICP and its impact and usage within the project site demonstrates compatibility with many of the defining criteria as outlined in the Integrated Care Pathways Appraisal Tool (West Midlands NHS, 2006; Great Ormond Street Hospital for Children NHS Foundation Trust, 2010), particularly in relation to process elements in developing an ICP. However, the interviews with hospital staff highlighted that the ICP (as outlined in Chapter 2) was not yet fully implemented in the hospital by project end and that additional resources would be needed to realise the projects goals given the unique complexity and size of SJH. The project took place in the context of a range of external factors such as the pre-existing and pre-defined community care structures, variability in home care packages, inconsistency in out-of-hours services and Nursing Home Support Scheme processes and availability of LTC beds that influence the journey of care, which are beyond the immediate control of the project but impacted on it. These factors have a bearing on achieving timely transition in, and out of, the acute hospital as they lead to difficulties in reducing the length of hospital stay and increasing rates of discharge to the community. Both interview and audit data provided evidence that a degree of streamlining of dementia care had 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. The findings of the awareness of dementia survey further demonstrated a high level of dementia awareness amongst service providers. There was some 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), and raising awareness of dementia within the community.

The success in process mapping the existing care delivery around dementia does provide a very useful mechanism to understand the patient flow and will provide a sound basis to enable dialogue between relevant sectors and professions within SJH. Indeed, this process mapping is an important milestone of the consortium and an important step in the development of an ICP within SJH, as well as a key marker of adoption of the initiative. The DemPath project work to date confirms the interdisciplinary and inter-departmental coordination that shapes the standard of dementia care in this acute care context. A notable outcome of learning to date from the evaluation team is the shared ownership of dementia care across professional groups and sectors within the hospital and the need for a cooperative approach to embed enhanced systems of working and communication in dementia care. Considerable investment of human resource time is evident in the work to date and further adoption and implementation of the proposed ICP will require strategic championing at all levels within the organisation. Importantly, any innovations developed need to be fitted to existing systems and structures, with consideration of any system adaptations required to maximise their fit and uptake. As evidenced in interview data, the DemPath consortium was aware of the significance of this. It is clear that considerable organisational knowledge and influence is needed to effect such substantial change within an organisation such as this and future project design should give consideration the leadership value across all sectors in the organisation and professional influence needed to achieve significant cultural change.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPETH INTEGRATED CARE PATHWAY PROJECT

A number of actual and potential challenges to the advancement of the DemPath project were evident in the findings. The reach of an ambitious project of this nature is influenced by the organisational systems and politics, and processes of communication that are inherent in a large and complex hospital of this size. Innovations such as this can be challenging in the ongoing context of competing priorities and therefore maintaining momentum with limited resources could be a challenge. Successful implementation is contingent on support from a multitude of professional groups and departments that influence the integration of dementia care. The creation of a clinical lead for dementia from within professional groups may assist in establishing or embedding the strategic organisational influence needed to shape the processes of care. The creation of a named nursing lead had been discussed by the DemPath consortium with the senior nursing management team as a means to realise the successful implementation of ICP and, in particular, care bundles around dementia care.

The evaluation demonstrated that the DemPath project made gains in terms of dementia care integration and development within SJH and the community. The findings supported the complexities of ICPs and dementia services, education and environmental developments. The significance of buy-in from multiple levels of stakeholders and all categories of service providers has been emphasised. Also highlighted was the complexity in developing an ICP which crossed multiple areas, services and systems and the time intensive nature of this was emphasised. Some facilitators shown to contribute towards achieving outcomes such as those incorporated in the DemPath project included:

- A planning and process mapping phase with corporate support,
- Visible project personnel on the ground with dementia care expertise complemented by project leaders driving change in key areas throughout the organisation,
- A supportive organisational culture, and
- 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 al.* (2012). Ideally, the implementation process should operate in tandem with the evaluation process in order to facilitate process learning. This evaluation does not wholly evaluate changes that occurred beyond the timeframe of the project or if the gains achieved were maintained, as the evaluation of DemPath finished with the project. One relatively easy approach to address this in the short-term, would be to implement and embed an ongoing process examining key indicators, such as dementia care auditing metrics, or length of stay and costs over 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 the DemPath project and as such it is desirable that evidence continues to be analysed over time.

This discussion has outlined key considerations in terms of the DemPath 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.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 7.3 Sustainability of Project Gains

It was highlighted in interviews with hospital staff that the timeframe of the project was not sufficient for a project of this scale in such a complex and multi-faceted site. Therefore, it was difficult to implement a plethora of changes as part of project, meaning that the project focused on a smaller number of changes to be implemented and maintained. The sustainability of the ICP, developed as part of the project, depends upon the maintenance of a number of procedures by service providers in SJH as well as in the community. As the 4AT is now printed on the ED card, this ensures that the tool is accessible and visible but ongoing monitoring will be required to ensure completion and compliance rates are maintained. Education of new staff in completion of the 4AT will also be required on an ongoing basis. At the interview stage of the evaluation, it was planned that the 4AT would be integrated by the Frailty Intervention Team (FIT) in the ED and that project paperwork would be integrated into e-documentation within SJH. Embedding project activities into existing teams, operations and structures is critical for the sustainability of project activities. As outlined in chapter 4, there were low levels of completion of the Hospital Passport as part of the project, as well as poor transfer of ICP activities from ED to ward level. Therefore, there will need to be a concerted effort to boost awareness and fidelity to these activities in order to ensure the success of the ICP.

The environmental adjustments undertaken will act as a legacy for the project. It is likely that when renovation is needed in other areas of the hospital, that the particular techniques, strategies and equipment types utilised by the project will be replicated. The consortium built a strong relationship with Facilities Management who took on board the recommendations made by the project. It is therefore likely that dementia-friendly design principles will be considered in future environmental changes in the hospital. Some of the changes implemented (for example, bay changes in the ED), have the ability to adapt to be more cost effective if rolled out on a larger scale which is a key strength and is promising in terms of sustainability.

The education work package group, along with the consortium, recognised the importance of incorporating strategies to sustain the educational initiatives after the DemPath project finished. The difficulty in moving from service provider awareness to a culture of being dementia-friendly was highlighted by hospital staff and this is a potential challenge to sustainability. The projects gains in the education strand appear positive in terms of sustainability though as it was highlighted that there was a huge amount of work involved in the education strand, it was felt that there would need to be a dedicated full-time role to wholly maintain the education strand of the project into the future. Sustainability of the initiatives was supported by the strong educational infrastructure that pre-existed within SJH. This includes the CLD (the SJH educational centre) and the DSIDC (which has a nationwide remit specifically in dementia) which are both based in SJH. Both are committed to delivering specialist dementia education and are supportive of sustaining education initiatives implemented by the project. As DSIDC is a national centre for excellence in dementia, this is extremely valuable. Importantly, at the time of reporting, one of the consortium was Acting Director of DSIDC. At the time of T2 data collection, there were plans for CLD to continue to roll-out dementia education days similar to those conducted as part of the project. The corporate orientation programme was recognised as an excellent platform and the education work package group negotiated with hospital management to secure inclusion of the dementia awareness session as part of the induction programme for all staff (including doctors). While this took some time, they were eventually successful and this was seen as a major accomplishment in terms of sustainability. The consortium applied for Continuous Professional Development (CPD) points for a number of the education programmes and this helps ensure their sustainability as it improves their credibility for service providers.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

Another strategy to achieve sustainability were the DemPath facilitators and from an early stage they were seen as drivers of dementia education and awareness within the clinical areas, which continued after the formal DemPath project period came to an end. Their maintenance is supported by commitment from the DSIDC and the establishment of the three-monthly support group. Finally, the development of an e-learning programme based on the level 1 and level 2 educational programmes including education on the ICP will be hosted on the hospital intranet site (local launch anticipated June 2018 and national launch anticipated September 2018). A number of modules were developed and included on LearnPath, SJH's online education system. These can continue to be used on an ongoing basis. Other efforts to sustain DemPath education gains included plans to continue to include information on DemPath in ongoing weekly GP training in SJH.

Given the emphasis on having a person on the ground, the sustainability of some strands of the project are in question when dedicated project roles (including the design and education leads) are no longer funded and the drive to implement change is ceased. However, the project funder had implemented a one year DemPath Coordinator role in SJH following project completion. The DemPath coordinator who has a clinical background had recently commenced the role at the time of reporting. This role, which will be in place for a one-year period initially, is designed to lead out on the further development of the ICP in SJH as well as oversee the sustainability of the programme. A brief overview of the role is provided below. This role, which commenced in late December 2017 will be highly beneficial given that the importance of renewing changes was highlighted by hospital staff. The impact and influence of this role remains to be seen but is intended to influence a permanent position. As highlighted in Chapter 4, it was suggested that three ongoing nurse roles would be needed in order to affect and maintain change within SJH. At the time of reporting, the consortium were developing plans to recruit a dementia lead through a new Global Brain Health Institute (GBHI) position and a plan to put forward a business case for a Clinical Nurse Specialist/ANP lead.

### DemPath Coordinator Role Overview

The coordinator role encompasses a number of key elements including patient/client advocacy, education and training, audit and research, and consultancy. A sample of the key duties and responsibilities in each of these areas<sup>42</sup> is given below.

- Establish, maintain and improve procedures for collaboration and cooperation between acute services, primary care and voluntary and other support organisations,
- Contribute with the support of CLD and DSIDC to the design, development and implementation of dementia related resources for patients, families and/or carers,
- With DSIDC and CLD, help coordinate education programmes for nursing, multidisciplinary team colleagues and key stakeholders in hospital and community settings as appropriate,
- Identify, initiate and conduct nursing and medical team audit and research projects relevant to the area of dementia,
- Identify, critically analyse, disseminate and integrate best evidence relating to care of the person with dementia,
- Develop person-centred care pathways to promote the integrated model of care delivery for the person with dementia,
- Develop and maintain relationships with specialist services in voluntary organisations which support patients in the community.

<sup>42</sup> Extracted from the role overview provided by the DemPath Coordinator.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTM INTEGRATED CARE PATHWAY PROJECT

DemPath facilitators were empowered to implement changes and develop relevant projects and were vital to the success of the project, as discussed in Chapter 5. At the time of T2 data collection, there were plans for further facilitator training and meetings/support groups to continue and DSIDC was interested in maintaining both these functions. In addition, the consortium had liaised with Quality and Safety Improvement Directorate (QSID) in SJH in relation to integrating this group into the overall hospital governance. Many of the other individual leaders identified (see Chapter 5, Section 5.2) were not funded by the project so are likely to continue to promote project activities and optimum dementia care following completion of the project. Moreover, the individual who filled DemPath nurse position remains within SJH and is motivated to improve dementia care.

There were efforts to develop a sustainability plan during the course of the project. For example, key stakeholders from the HSE were invited to the HSE and Genio dementia briefing event held in December 2016 to bring them on board to work towards the sustainability of changes. The consortium have since gone on to develop a business plan, and all stakeholders were involved in this process. Shared responsibility means that sustainability is more likely. Following the cessation of consortium meetings, consortium meetings and work package groups were streamlined into a new consortium of key stakeholders including representation from education, design, and ICP. This is chaired by the Project Lead and is designed to act as a forum for review, and discuss opportunities which arise and respond to these.

### 7.4 Considerations Relating to the Evaluation Findings

While it was originally intended to complete interviews with both the person with dementia and their family carer, the reality of this stage of data collection meant that it was not possible and/or suitable to include the person with dementia in the interview. In some cases the person with dementia was an inpatient in the hospital or a resident of LTC, and in other cases the person was deemed to be too cognitively impaired by the family carer to participate.

A limitation of the ward organisational and environment audits is the small sample size and the comparison of different wards at the two time points. The ward environmental and organisational audits were conducted on just three wards and the ED at each time point, with the support of a single member of staff, therefore it is not possible to ascribe changes in ward environments and organisation solely to the introduction of the project. Notably, different wards were audited at T1 and T2. The ED is naturally limited in terms of environment due to its purpose and associated layout (more acute, short-stay, shared environment), therefore some aspects could not be substantially altered via the project goals. Most notably, two of the units audited formed the AMAU, which shared staff, policies, protocols, and practices in relation to patient care. The acute and short-stay nature of this unit contributed to care practices which may not be optimal for people with dementia, including the lack of visibility of personal items, and absence of space for people with dementia to socially interact at mealtimes and appropriate space to mobilise under supervision from staff were a product of this environment. It is possible that audit of different ward environments would have provided different results.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 7.5 Conclusion and Recommendations for Enhancing Integrated Dementia Care

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

#### Project-Specific Recommendations

- Process mapping emerged as a critical first step in developing an ICP and corporate support for this is recommended for the development of ICPs moving forward.
- Indirectly the study uncovered some unanticipated areas for further investigation in relation to the effect of hospital environmental design on people with dementia including, for example, the use of single rooms in dementia care.
- Ongoing monitoring and further development of project-specific changes will be of benefit to ensure maintenance of project gains.
- Embedding project-specific changes into existing organisational structures and resources is important to ensure sustainability of changes.
- Key to the success of implementing integrated care within the acute environment is that every category of staff has to be informed about, and participate in project activities and person-centred responses.
- Reinforcement of the positive impact of meaningful engagement and social interaction for people with dementia would be beneficial for all categories of service providers.
- It is recommended that the activity analysis be repeated in 2018 to analyse the full impact of the intervention.

#### Broader Evaluation Recommendations

- The person with dementia and their individualised needs should at all times be central to innovations to enhance integrated dementia care.
- To achieve meaningful impact, a dementia-friendly orientation needs to be embedded in the strategic objectives and operational planning of an organisation.
- A whole organisation approach to the integration of dementia care is advocated with involvement of key multi-level and inter-departmental stakeholders with the power to leverage support and facilitate required actions.
- Innovation in integrated dementia care requires clear governance and visionary leadership, and such leaders require dedicated resources to support dementia care development.
- A consortium approach is recommended for projects designed to design, test and implement innovations to develop integrated dementia care.
- Inter-sectoral involvement is required where innovations in dementia care are designed to cross the continuum of care. Such involvement should focus on developing collaborative networks and the setting up of effective in-reach out-reach communication systems between those involved.
- Innovations in dementia care (for example, ICP development) and dementia-friendly environmental design are time intensive and require extensive planning inputs to include process mapping of the journeys of people with dementia, evidence review and stakeholder consultation.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

- Associated projects need to factor in sufficient lead-in time to devising related interventions and the planning activities involved should be viewed as sub-components of the overall intervention.
- Innovations in dementia care, such as ICPs, require ongoing point of care support through dedicated dementia-specific roles which are highly visible and whose role-holders have expertise in complex dementia care.
- Where dementia-specific roles are shown to have a positive impact, there needs to be commitment and resources to continue them if gains in dementia care integration are to be maximised and built upon.
- When introducing innovations such as ICPs, both opportunistic and dedicated education programmes aimed at enhancing dementia knowledge and awareness contribute to the overall level of staff preparedness. Therefore, sustainable dementia education programmes should be available for all service providers who are involved with people with dementia and such education should retain a strong person-centred focus.
- So as to maximise learning for current and future projects, there is a need to in-build parallel participatory evaluation of the processes involved in projects to develop integrated dementia care in addition to measuring outcomes. Evaluations should additionally plan to extend beyond the end-point of an individual project so as to evaluate for any ongoing impact over time.
- Consideration should be given to embedding dementia-specific key performance indicators and audit metrics into quality assurance systems to monitor ongoing organisational performance relating to dementia care integration.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### 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*, 110 (1): 33-37.
- Bryman, A. (2012) *Social Research Methods*. Oxford, UK: Oxford University Press.
- Cahill, S., O'Shea, E. and Pierce, M. (2012) *Creating 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.
- CSO (2012) *Census 2011 Profile 2 Older and Younger*. Dublin: The Stationery Office.
- Cunningham, C. (2006) Understanding challenging behaviour in patients with dementia. *Nursing Standard*, 20: 42-45.
- 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.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

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. *Journal 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. Retrieved from: <https://www.guysandstthomas.nhs.uk/education-and-training/staff-training/barbaras-story.aspx> on 12 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 1 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 2 November 2017.

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*, 12 (3): e12153.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

Irish Nutrition and Dietetic Institute (2016) *Nutrition and Dementia: A practical guide when caring for a person with dementia*. Dublin: Irish Nutrition and Dietetic Institute.

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. and Pierce, M. (2017) Personalised care for people with dementia in Ireland. In: O'Shea, E., Cahill, S. and Pierce, M. (eds) *Developing and Implementing Dementia Policy in Ireland*. Galway: Centre for Economic and Social Research on Dementia.

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.

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.

Molloy, D.W., and Standish, T.I. (1997). A guide to the standardized Mini-Mental State Examination. *International Psychogeriatrics*, 9 (S1): 87-94.

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.





## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

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*. Westmeath: Genio.

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

Pollock, R. (2003) *Designing Interiors for People with Dementia*. Stirling: Dementia Services Development Centre, Stirling.

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 3 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.

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 Chorcair, 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.

West Midlands NHS (2006) *Integrated Care Pathways Appraisal Tool (ICPAT)*. West Midlands, UK: West Midlands NHS.

Wimo, A., Wetterholm, A.L., Mastey, V. and Winblad, B. (1998) Evaluation of the resource 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.



## EVALUATION OF THE ST JAMES'S HOSPITAL DEMPATHTH INTEGRATED CARE PATHWAY PROJECT

### Appendices

#### Appendix 1: Chapter 6 Data Sources and Methodology

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

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

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

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

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.







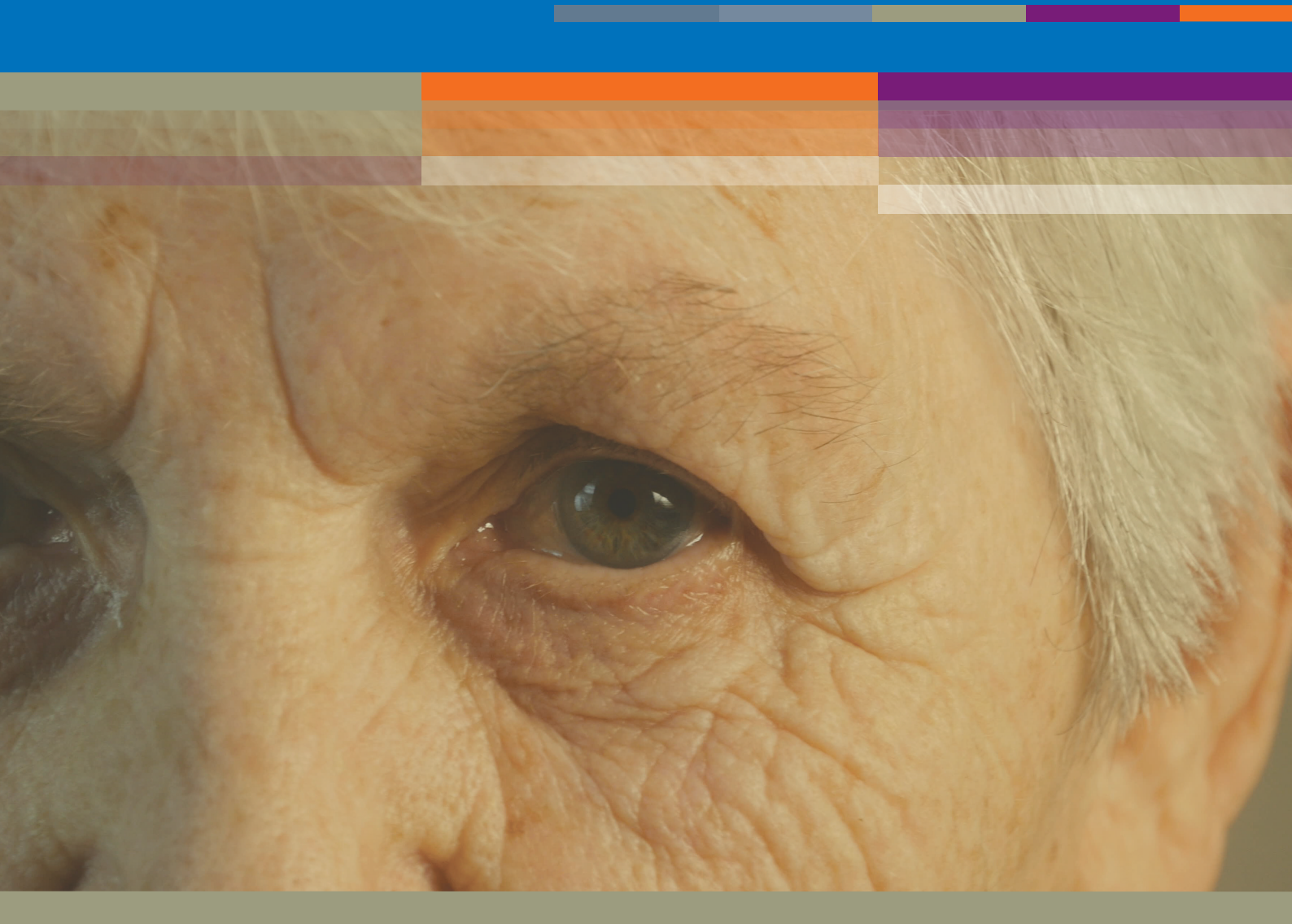




**Trinity College Dublin**

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](mailto:nursing.midwifery@tcd.ie)



[nursing-midwifery.tcd.ie](http://nursing-midwifery.tcd.ie)

© School of Nursing and Midwifery, Trinity College Dublin,  
The University of Dublin, (May 2018). All rights reserved.