



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



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

Key Findings

HSE & GENIO DEMENTIA PROGRAMME





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Introduction

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

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

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

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

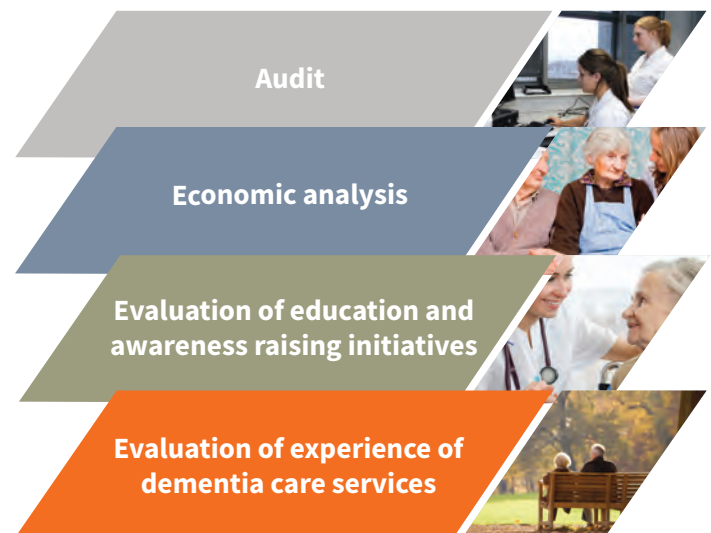
Trinity College Dublin and the National University of Ireland, Galway were commissioned to evaluate this three year project (2014-2017).

Evaluation Aims & Approach

The aims of the evaluation were to:

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

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





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An exploratory mixed methods approach involving both quantitative and qualitative approaches was used to provide a comprehensive evaluation of the Cork-IDEAS project. An evaluation of such projects requires attention to the set-up, implementation, process, impact and sustainability of initiatives.

Therefore, the evaluation was informed by an action research approach and underpinned by a framework called RE-AIM (Glasgow, Vogt and Boles, 1999; Gaglio, Shoup and Glasgow, 2013), which assessed project activity in terms of reach, effectiveness, adoption, implementation and maintenance. The evaluation set out to represent the perspective of all those intended to benefit from the Cork-IDEAS project (people with dementia, family carers and formal carers). However, the findings primarily represent the perspective of stakeholders within the hospital and community project setting as despite extensive efforts to recruit people with dementia, it was not possible to do so for the purposes of the evaluation.

Key Findings

Cork-IDEAS Project Impact and Outcome Findings

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





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



Cork-IDEAS Project Process Findings

- Eight project facilitators were identified which supported the Cork-IDEAS project process and the achievement of its outcomes. These were:
 1. The ethos and culture of care within the project setting,
 2. Project lead(ership),
 3. Dedicated project personnel,
 4. Organisational support,
 5. Inter-disciplinary stakeholder and cross setting involvement,
 6. High visibility of early project impacts,
 7. The responsiveness of the project,
 8. Dovetailing with other clinical, educational or organisational developments.
- Project personnel demonstrated significant experiential learning, which was both incorporated into the project as it unfolded and articulated as learning for future projects.



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- Three overarching challenges (with sub-components) were found to have impacted on the project over its time line. These were:
 - Project-related human resource considerations, including:
 - Project lead time involvement,
 - Developing and enacting project-specific posts,
 - Role-related temporal and resourcing factors,
 - The inherent complexity of the project and competing initiatives, including:
 - Multiple components,
 - Multi-contextual settings,
 - Building inter-disciplinary and inter-departmental buy-in,
 - The acuity of care demands in the project setting.
- The project consortium was pivotal in building shared ownership and momentum for the integration of dementia care.
- The hospital sub-consortium, and working groups, adopted a whole organisation orientation with multi-level stakeholder representation.

- The community sub-consortium provided a medium to build project awareness, bring interested stakeholders together and build strategic linkages between services in the community.
- The hospital sub-consortium contributed to project awareness, governance and activities by facilitating information sharing and feedback, and enhancing inter-disciplinary and inter-departmental understanding.

Cork-IDEAS Hospital In-patient Activity Analysis

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



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Recommendations for Enhancing Integrated Dementia Care

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



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



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

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



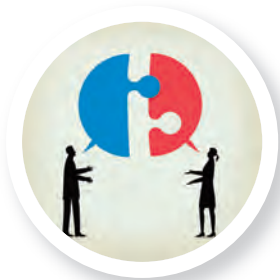
Environmental changes overseen by the project Occupational Therapist resulted in greater understanding of how **dementia-friendly hospital settings** can support **person-centred care**.



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



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



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





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