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Integrated Care Pathways for People with Dementia

Exploring the Potential for Ireland and the forthcoming National Dementia Strategy

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Table of Contents

Page Number

Introduction 2
Understanding Integrated Care Pathways 3
Practical Application of Integrated Care Pathways 4
Evidence of the Benefits of Integrated Care Pathways 4
Challenges 6
Profiling two Integrated Care Pathways Case Studies 7
Integrated Care Pathways and their relevance to the Irish context 15
Implications for Irish dementia policy 16
References 19
Introduction

Internationally, dementia strategies provide a clear guide to the content of high-quality health and social care services for people with dementia. In addition to specific strategy documents, many countries also have more detailed localised pathways intended to be a more comprehensive clinical guideline for health professionals.

This paper presents an analysis of integrated care pathways for people with dementia, defining what they are, how they operate in practice and the implications for dementia care policy in Ireland and in particular, for the forthcoming National Dementia Strategy.

There is an appetite for change in dementia care. Research suggests that the current level of care provision is uneven throughout the country with major deficiencies being identified in the standard of care of people with dementia in both acute hospital and long-stay facilities (Cahill, O'Shea and Pierce 2012). The development of a National Dementia Strategy for Ireland represents a unique and important opportunity for creativity in terms of providing a much clearer pathway, more positive outcomes and a smoother journey for the person with dementia and their families, along with better use of existing resources and cost savings for carers.

There are some significant differences between countries in terms of emphasis on stages of the care pathway. For example, there is a clear focus on risk reduction in the dementia services in Australia, along with primary care, access to counselling and community support (Brodaty and Cumming 2010). These aspects play a much less central role, for example, in dementia services in the UK where there is an emphasis on timely diagnosis and public and professional attitudes to dementia (Banerjee 2010). These key differences between emphases of service provision pose important questions about what priorities should be emphasised within the Irish health and social care system.

Dementia is often defined as a chronic condition characterised by symptoms such as disturbed memory, orientation problems, behavioural changes and comprehension. There are several different forms of dementia, of which Alzheimer's disease is the most common. These definitions stem from an illness-orientated understanding of dementia and can lead to excess disability (Drossel and Fisher 2006).

More recently, there has been a move to define dementia from the perspective of the person with dementia and as a disability (Gilliard, et al. 2005). Viewing dementia as a psychological and social disability allows for a more holistic understanding of the condition (Cahill, O'Shea and Pierce 2012). This shift in perspective, away from a medicalised model, is to be welcomed as it holds potential for emphasis to be placed on the quality of life of the person living with dementia. From this perspective, given the right enablement and supports there is more hope that a person may draw meaning and joy from life and continue to contribute to society and wider community despite their disability.
However, currently dementia is associated with an increase in the use of medical services and can pose a challenge with regard to care giving. Many hospitals are not designed to care for people with cognitive impairment and this may prove challenging in terms of caring for the individuals personhood in addition to the acute problem for which they were admitted (Moyle, et al. 2008). The needs of individuals with dementia are often complex and frequently require services from a number of organisations (Rees, et al. 2004).

**Understanding Integrated Care Pathways**

Integrated care pathways (ICPs) are instruments designed to map out the direction of clinical and administrative activities for all care professionals working with a diagnosis specific group.

Essentially, ICPs chronologically pinpoint the key steps to be taken throughout the person’s care journey (Rees, et al. 2004). Instead of reactive or crisis care, ICPs are designed to provide an improved service for both patients and carers through a more proactive care planning approach (Scottish Government 2010).

The establishment of ICPs is useful in that they aim to facilitate the introduction of clinical protocols, promote change in practice through the systematic collection of clinical data for audit, and improve communication with patients by providing them with a clear summary of their expected care plan (Campbell, et al. 1998).

There are two essential components that characterise care pathways: a service map, and a tool to audit the pathway (Saad, Smith and Rochfort 2008). The goals of ICPs are to enhance quality of care and quality of life, service user satisfaction, and system efficiency for individuals with complex needs (Kodner and Kyriacou 2000). ICPs are specific translations of broader national policy which enable the policy in the context of local circumstances (e.g. service availability, geography and population structure). Essentially, ICPs take agreed national policy and translate it into practice in a particular local context.

With Ireland’s ageing population on the rise, there will be a corresponding rise in the number of adults with long-term conditions such as dementia. The population of those aged 65 and over in Ireland currently represents 11% of our total population. This is expected to double from approximately 0.5 million today to over 1 million by 2031 (Cahill, O'Shea and Pierce 2012). A move towards more integrated working in terms of planning and service delivery could help achieve better outcomes for those with dementia and make the best use of current resources.

Integrated dementia pathways have been found to improve dementia services in terms of access to services and informing service users of the steps to be taken throughout their care journey (Saad 2004). In the UK, a NHS report regarding dementia services in the West Midlands outlined the core principles applicable to a good dementia pathway. These include respect for both patients and carers; adaptability and flexibility; a clear map and route finder; taking into account transitions and adjustments between pathway parts; links to other service providers.
for managing co-morbidities; and maximised personal control and empowerment (Saad, Smith and Rochfort 2008).

**Practical Application of Integrated Care Pathways**

Developing a dementia pathway is a complex undertaking for a number of reasons. Dementia is an umbrella term for many different diseases, all of which have similar symptoms, but different aetiologies (that is, causes), different management strategies and different licensed treatments.

The onset of dementia is generally gradual and there is no definitive biological marker of disease onset. Regardless of the specific type of dementia, each individual experiences it very differently with different presentations of problem features, physiological changes, psychological reactions, and family and community responses making definition of a proper response to dementia difficult.

More integrated working can also support people with long-term care needs through increased personalisation of care. Personalised care for people with dementia involves placing the individual at the centre of the care process and tailoring support to their individual needs. A person-centred approach to care can enhance service efficiency, avoid unnecessary hospital admissions (which in turn, reduces care costs), and has been found to reduce agitation in people with dementia living in residential care (Chenoweth, et al. 2009, Social Care Institute for Excellence 2008).

A personalised approach can be applied across all stages of the disease lifecycle including prevention, assessment, care planning, service provision and ongoing support (Social Care Institute for Excellence 2008). An effective integrated care pathway for dementia promotes personal control and empowers both patients and carers (Saad, Smith and Rochfort 2008).

ICPs can be used in the health service as a formalising mechanism for procedures that involve multi-agency working (Currie 1999). It has been suggested that a move from fragmented care in hospitals to anticipatory, integrated and continuous care in communities may help to promote health (Cook 2008). This is particularly true for dementia care where individuals tend to have multiple needs and may require skills belonging to multiple circles (Downs and Bowers 2008). More integrated health and community support can help to build relationships between different agencies to improve the health and wellbeing of patients and achieve efficiencies and can also help to reduce organisational barriers that may exist between these agencies (Social Care Institute for Excellence 2011).

**Evidence of the Benefits of Integrated Care Pathways**

The development of an effective ICP for dementia should incorporate a multidisciplinary specialist service team to guide the person with dementia and their caregivers as their condition progresses. An ICP is designed to be used as a guide and, where necessary, the professionals’ judgement may override the advice of the tool (Dementia ICP Development Group 2010, Hall 2001).
It is widely recognised that the implementation of ICPs is largely supported by both service users and staff as a result of increased service efficiency (Lowe 1998, Atwal and Caldwell 2002, Gunstone and Robinson 2006, Tucker 2010, Ham, Dixon and Chantler 2011, Hean, Nojeed and Warr 2011). The professional, organisational and patient-associated benefits of ICPs are numerous. In the UK, a qualitative study was conducted to investigate a multidisciplinary team’s experience of an ICP pilot in an in-patient dementia assessment service. The team identified benefits that included the pathway’s influence on care management, increased efficiency, improvements in team working and, most importantly, enhancement of the experience of patients and carers (Hall 2001).

Evidence also suggests that ICPs improve documentation of care (Main, et al. 2006) and deepen caregivers understanding of the sequence of medical practices for the patient (Kazui, et al. 2004). A systematic review conducted to examine the circumstances in which ICPs are most effective found that they are a useful tool in reducing variation in practice, improving physician agreement about treatment options and changing professional behaviours in the desired direction (Allen, Gillen and Rixson 2009).

Summary of Benefits
Individuals with dementia tend to have multiple needs and therefore often require multidisciplinary care. A move towards more integrated care can help to:
- bridge gaps that may exist between different agencies;
- place the focus on the individual needs of the person with dementia.

The current evidence base suggests that the development of an ICP for people with dementia is beneficial for both professionals and patients in terms of:
- increased efficiency;
- reduced variation in practice;
- improved inter-professional communication to help tailor support to individual patient needs.

For ICP implementation to be successful a focus on team development and education about integration is essential. The following diagram provides a good overview of essential features of an effective ICP.
Challenges

Although there is a strong evidence base for the benefits of ICPs, there are several challenges that must be addressed if an ICP is to be successful. There has been some concern that ICPs deliver ‘cookbook medicine’ as they are characterised by pre-determined stages of care (De Luc 2001). However, in some circumstances this can be viewed as a strength by helping to guide the novice practitioner (Gunstone and Robinson 2006) while more experienced practitioners can, where necessary, override the tool in favour of their clinical judgement (Hall 2001). Any deviations from the pathway are monitored and recorded through variance reporting in order that appropriate changes can be made to the ICP (Gunstone and Robinson 2006).

Other documented challenges include issues such as the lack of a defined common goal between members of a multidisciplinary team due to differing expectations; insufficient inter-professional communication; and diversity of practice at an organisational level, can contribute to poor outcomes in ICP implementation (Atwal and Caldwell 2002). Change management in terms of team development and education about integration can overcome these potential difficulties and foster effective inter-professional team working (Rees, et al. 2004). Generally there is a great deal of support for the principle of integrated care.
Profiling two Integrated Care Pathways Case Studies

A comprehensive literature search was conducted in order to get a sense of how the principles of integrated care are being applied internationally. As evidenced from a number of national dementia strategies, including Australia, Canada, the UK, France and the Netherlands, there is a large-scale move towards integrated systems of care.

In the UK, the NHS has rolled out integrated care pilots across a number of clinical areas, including dementia. What follows is an analysis of two of these pilot programmes in order to demonstrate the key features necessary for effective integrated care. These two cases were chosen as they offered the greatest level of detail and background information and provided us with information across a number of areas, which made them comparable.

Case Study 1: Newquay, England
The Newquay Dementia Integrated Care Pilot (Figure 2) was developed as part of a countrywide dementia programme in the UK and received two years funding from the Department of Health. In Newquay, 361 people live with dementia out of a population of 23,000. Within the next twenty years, this number of people with dementia is expected to double. Aware of this growing need and emerging pressures on specialist teams, the three GP practices in the Newquay Practice Based Commissioning Group began to explore new ways of caring for people with dementia in terms of an ICP approach.

The ICP approach piloted in Newquay was based on NICE Clinical Guidelines as well as recommendations from the National Dementia Strategy, the National Carers Strategy, and the National End of Life Strategy. This model of care emphasises close integrated working across health and social care systems, the delivery of GP led memory clinics in association with specialised support from community mental health teams, proactive case management as well as strengthening community networks and support.

Given the specific needs of people with dementia, the aim of the pilot was to separate dementia from the traditional structure of secondary care based “Older People’s Mental Health Services” and to place greater emphasis on treating dementia as a long-term condition, best managed through integrated and preventative case management anchored in primary care.

The Newquay ICP takes a person-centered approach, placing the individual with dementia and their family at the centre of service plans. Within this personalised framework, appropriately trained staff strive to meet specific personal needs in a timely and responsive manner.

The core objectives of the pilot included increasing the number of people receiving a diagnosis of dementia, improving health and life outcomes for people with dementia and their carers, and viewing dementia as a long term condition necessitating continuity of care from the point of diagnosis until the end of life.
The chosen approach involved GP centred case management; simple pathways and overlapping services; anticipatory care to prevent, defer and/or reduce the number of admissions to care homes and hospitals and to reduce length of stay; and shared expertise between and across ‘mainstream’ and ‘specialist’ services.

Implementing the pilot proved challenging for individuals and organisations with regard to behaviour, systems and processes. Overall, positive changes in care, staff and the experience of patients and carers has occurred in Newquay. However, it is difficult to pinpoint exactly what outcomes are directly attributable to the work of the pilot. Changing a model of service delivery across a whole system can prove challenging and therefore requires strong project management. Fully integrated care is not yet systemic in Newquay.
<table>
<thead>
<tr>
<th>Phase 1 Diagnosis</th>
<th>Case Management</th>
<th>Phase 2 Low Intensity</th>
<th>Case Management</th>
<th>Phase 3 Medium Intensity</th>
<th>Case Management</th>
<th>Phase 4 High Intensity</th>
<th>Case Management</th>
<th>Phase 5 Specialist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis via GP</td>
<td>GP</td>
<td>Specialist Memory Nurse</td>
<td>Community Matrons</td>
<td>Consultant (Psychiatrist)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>GP referral to memory clinic for diagnosis</td>
<td>Memory Advisor</td>
<td>Patient care delivered by CMHT</td>
<td>District Nurses</td>
<td>Consultant (Geriatrics)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Patient does not require CMHT input</td>
<td>Access to GP, Social Care and Community Health Services</td>
<td>GP</td>
<td>GP</td>
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<tr>
<td>Support to GP from CMHT Memory Nurse as required</td>
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<tr>
<td>Support from Memory Nurse as required</td>
<td>Support/input from CMHT</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Care Needs</th>
<th>Care Needs</th>
<th>Care Needs</th>
<th>Care Needs</th>
<th>Care Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia blood screens</td>
<td>Information</td>
<td>Information</td>
<td>Major physical health problems requiring intensive nursing support</td>
<td>Acute medical conditions</td>
</tr>
<tr>
<td>Physical checks</td>
<td>Advice</td>
<td>Advice</td>
<td>Acute difficult to manage behaviours with no physical cause</td>
<td></td>
</tr>
<tr>
<td>Patient profile</td>
<td>Monitoring</td>
<td>Weekly/Monthly Contact</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health promotion</td>
<td>Carer Support</td>
<td>Carer Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer/carer support</td>
<td>Access to Social Services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social care provision</td>
<td>Assessment of Risk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Crisis contact</td>
<td>Support with Activities of Daily Living (ADLs)</td>
<td></td>
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<tr>
<td>Services</td>
<td>Services</td>
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</tr>
<tr>
<td>Memory service</td>
<td>Health Promotion</td>
<td>Information and Advice</td>
<td>District Nursing</td>
<td>Regular consultant input</td>
</tr>
<tr>
<td>Interim care plan</td>
<td>Information and Advice</td>
<td>Needs/Risk Assessment</td>
<td>Community Matron Nursing</td>
<td>Hospital admission</td>
</tr>
<tr>
<td>Physical Health Check</td>
<td>Weekly/Monthly phone call</td>
<td>Local Hospital Admission</td>
<td>Consultant clinics</td>
<td></td>
</tr>
<tr>
<td>Cognitive Health Check</td>
<td>Weekly/Monthly home visit</td>
<td>Hospital at home</td>
<td>Home visits</td>
<td></td>
</tr>
<tr>
<td>Peer Support – Memory Café</td>
<td>Carer Support / Information</td>
<td>Falls clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Support / Information</td>
<td>Access to Respite</td>
<td>Physiotherapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive Stimulation Group</td>
<td></td>
<td>TIA clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication Review</td>
<td></td>
<td>Specialist Nurses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to Social Care</td>
<td></td>
<td>End of Life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual health check</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Peer Support – Memory Café</td>
<td></td>
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</tbody>
</table>

**Figure 2 - Newquay Dementia Integrated Care Pilot**
Case Study 2: Lanarkshire, Scotland

In October 2010, North Lanarkshire Community Health Partnership (CHP) was successful in a bid to become a demonstrator site for the Scottish Government’s Dementia Strategy. The focus of this pilot project is to investigate the impact of a whole system redesign in relation to the dementia pathway.

The pilot takes a strategic approach to the mapping out and analysing of the entire dementia pathway in order to identify the key areas in need of improvement. The Lanarkshire Dementia ICP (Dementia ICP Development Group 2010) (Figure 3) focuses particularly on improving rates of diagnosis and responding to challenging behaviour and aims to deliver clear pathway/s for people with dementia from onset to end of life care. It was put together by a local development group consisting of NHS staff, service users and carers, local authorities, voluntary organisations and the independent sector.

This stepped model of care adjusts care in stages according to the lack of effect of lower intensity interventions. This model promotes a person-centred approach and a move towards positive management of individual risk, maximising choice and access to evidence-based interventions. It has been designed for any person over 16 years of age who presents with dementia. The development of this ICP is ongoing in North Lanarkshire.
<table>
<thead>
<tr>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive Impairment – Assessment and Diagnosis</strong></td>
<td><strong>Complex Needs - Psychological and Behavioural Symptoms</strong></td>
<td><strong>Long-Term Care / End-of-Life Care</strong></td>
</tr>
<tr>
<td><strong>MDT Intervention</strong></td>
<td><strong>MDT Intervention</strong></td>
<td><strong>MDT Intervention</strong></td>
</tr>
<tr>
<td>Referral to memory service/outpatient clinic for assessment</td>
<td>Management of behavioural and psychological symptoms, including depression, psychosis, agitation and aggression</td>
<td>Advanced planning in relation to end of life care (reviewed at least annually)</td>
</tr>
<tr>
<td>History and examination – including carer, driving</td>
<td>Delivery of psychological therapies based on the principle of matched care (those referred to the service are matched to the appropriate level of treatment for the level of complexity of their difficulties)</td>
<td>Includes consideration of preferred place of treatment if condition worsens</td>
</tr>
<tr>
<td>Post-diagnostic support</td>
<td>All interventions are used by formal and informal carers working with people with dementia and for use by people with dementia</td>
<td>Gold Standards Framework – evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers</td>
</tr>
<tr>
<td>Advance planning</td>
<td>A checklist is used to aid the review of patients who develop BPSD – aims to provide structured review of the BPSD and precipitating factors (physical and environmental)</td>
<td>Lanarkshire Palliative Care Assessment Tool (LPCAT) – to assess and manage palliative care needs</td>
</tr>
<tr>
<td>Information and support for carers</td>
<td></td>
<td>Liverpool Care Pathway (LCP) – transfers the hospice model of care into other care settings</td>
</tr>
<tr>
<td>Services</td>
<td>Services</td>
<td>Services</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Dementia Cafes</td>
<td>Reminiscence therapy*</td>
<td>Care assessment</td>
</tr>
<tr>
<td>Post-diagnosis support groups</td>
<td>Validation therapy*</td>
<td>Community Care</td>
</tr>
<tr>
<td>1-1 support providing advice on planning for the future, living well with dementia, advanced statements on future treatment, anticipatory care planning and power of attorney</td>
<td>Non-pharmacological Interventions for Behaviour that challenges*</td>
<td>Hospital Care</td>
</tr>
<tr>
<td>Memory clinics – work closely with Alzheimer Scotland for post diagnostic support</td>
<td>Cognitive Stimulation Therapy*</td>
<td>Care homes</td>
</tr>
<tr>
<td>Dementia Awareness and Resource Pack – ensures dignity and respect and quality of care are met across all care settings</td>
<td>Cognitive Behaviour Therapy (for depression)*</td>
<td>Carer support</td>
</tr>
<tr>
<td></td>
<td>Caregiver interventions programmes*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Occupational Therapy Interventions*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Art Therapy*</td>
<td></td>
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</tbody>
</table>

**Figure 3 Lanarkshire Dementia Integrated Care Pathway**

* The availability of these interventions in Lanarkshire will be determined through the ongoing implementation of the Psychological Therapies Strategy*
Case Study Comparison: Newquay and North Lanarkshire

There are a number of similarities between the ICPs being rolled out in Newquay and North Lanarkshire. In both areas, a proactive care planning approach is taken to diagnosis and intervention. For instance, in Newquay, focus is placed on increasing the number of people receiving a diagnosis of dementia through improved access to assessment services. In North Lanarkshire, a proactive approach is also taken as the ICP aims to improve rates of diagnosis and tailor delivery of interventions across the key milestones of the journey through care.

In both ICPs, emphasis is placed on advanced planning with regard to end-of-life care. In both Newquay and Lanarkshire, dementia is viewed as a long term condition that requires continuous care from the point of diagnosis until the end of life.

There is a strong focus on psychological interventions across both ICPs, for example, cognitive stimulation therapy and access to memory cafes. Newquay and Lanarkshire both advocate a person-centred approach to care, where the individual with dementia and their carers are placed at the centre of service plans.

Improved partnership working with Community Mental Health Teams is also a key element of both ICPs. In North Lanarkshire, this is particularly evident with regard to palliative care as the Lanarkshire Palliative Care Assessment Tool (LPCAT) is mainly used by community nurses. In terms of multidisciplinary care and team development, Newquay and Lanarkshire employ a model of care that emphasises close integrated working across health and social care systems and shared expertise between professionals.

The ICPs will also be used to produce variance data about the care and interventions provided. This data is an essential component of the ICPs as it will allow comparisons to be made between the care being provided in each locality and the care planned by the ICP. The data collected will flag areas of the ICP that are in need of modification.

There are some differences between the two care pathways in terms of management and intervention. The model of care in Newquay centres largely on the GP and includes the delivery of GP-led memory clinics in association with proactive GP centred case management. In North Lanarkshire, the central role of the GP is not as evident. Lanarkshire does however appear to place more emphasis on developing the skills and knowledge of the non-specialist workforce, including those in A&E and GP practices through further training.

With regard to the development of services, both service users and carers were included in the local ICP development group in Lanarkshire. While this does not appear to be the case in Newquay, service users and their carers were invited to describe their experience of the Newquay ICP which may be useful in highlighting areas in need of further development.
Integrated Care Pathways and their relevance to the Irish context

The Irish dementia landscape is highly fragmented and inequitable in terms of access to services and supports. There are currently no defined care pathways for people with dementia in terms of home care support and day care and long-term care facilities. Services available to people with dementia are frequently inadequate, inconsistent and badly co-ordinated throughout the country (DSIDC 2012). Community support services for people with dementia and their carers are under-developed and often, people with dementia only come into contact with health and social services if a crisis occurs (O'Shea 2007).

A study examining family carers’ experience of their relative’s transition to a nursing home (Argyle, Downs and Tasker 2010) highlighted deficiencies in formal supports. It found that most respondents had problems with understanding and negotiating the system of formal support and, in some cases, inadequate or inaccessible domiciliary support influenced their decision to pursue nursing home care for their relative. Their confusion was exacerbated by fragmentation of services as well as cutbacks in formal support services. In terms of accessing support for the person with dementia at the pre-admission stage, the lack of availability of advice and guidance made a lasting impression on respondents with most feeling that improvements could be made in this area.

Dementia has not yet permeated into the minds of the public or policymakers when it comes to priority-setting and the allocation of scarce public resources (Cahill, O'Shea and Pierce 2012). This document highlights a number of key questions for consideration before integrated care for dementia can be successfully developed in Ireland.

Questions of system inefficiencies

It is clear that a large number of individuals and their families are marginalised by difficulties arising not just from the scarcity of services, but from the difficulties in negotiating the system, and inefficiencies or lack of joined up thinking between services. Inequalities in relation to access to services are considerable, with geographical location the strongest predictor of the level of service received. For instance, those in rural areas appear to be at a particular disadvantage due to high transport costs and the length of travel time to and from centres (O'Shea and O'Reilly 1999).

There are very limited supports currently in place to help the person with dementia and their carer negotiate the complex health and social care system. According to HIQA’s upcoming National Quality Standards for Safer Better Healthcare (2010) equity is a key aspect of a high quality and safe healthcare. It is these issues that ICPs are designed to address. A strong service-user voice in this respect, following the example of the Lanarkshire model would seem to be best practice in terms of addressing service-user voice.
Questions of economics
Given the evidence of fragmentation and inequality of service distribution around Ireland and the current economic climate, the need for efficient use of resources has never been greater. The evidence from this review shows some economic benefits of ICPs for dementia, however what they also show is the care needed towards matters of measurement. Such remodelling of services frequently results in changes to satisfaction but complexities in providing evidence of greater cost effectiveness. Any such changes in Ireland would be wise to involve the services of a health economist and pay close attention to the collection of robust baseline data for later comparison.

Questions of role clarity / competence
A clear message from this review is that case management is required if quality care is to be realised. This leads to the question – who will do this? While some steps in the pathway can be addressed by the reorganisation of existing services (and therefore, does not necessarily entail additional resources or budget) there is also a clear need for identified case workers in dementia care to facilitate the effective delivery of services. An Action Plan for Dementia (O'Shea and O'Reilly 1999) states that the most effective way of ensuring flexible and integrated care provision is through the introduction of a case management model to plan and co-ordinate services for people with dementia and their carers. The person with dementia should, where possible, play a major role in developing a personal care plan that fits their own particular preferences and circumstances.

With this in mind, a large body of very helpful work has been done (de Vries, Brooker and Porter 2010). They have suggested two key roles in dementia care which are competency-based rather than discipline specific. The first of these roles is the Primary Care Liaison Role to address the needs of people who present at GP practices with a range of memory loss, behaviour changes and changes in cognitive functioning symptoms. This role is intended to be commissioned by a practice based commissioning cluster of GPs, working with GP practices and lists and for working with these presenting clients to signpost them into the memory assessment process so that a differential diagnosis then follows.

The second role is the dementia care pathway coordinator, this role/service starts as soon as the diagnosis has taken place and this role/service then is the key to helping the person and their family to navigate their journey through the course of dementia and ensure they receive services to which they are entitled. ICPs offer local solutions to local problems.

Implications for Irish dementia policy
From a health policy context, dementia policy in Ireland has received relatively little attention and remained significantly under-resourced. People with dementia remain largely invisible in the ‘system’ despite the growing numbers. Within the Programme for Government there is a commitment to developing a National Dementia Strategy by 2013. Action is required to ensure that a National Dementia Strategy is implemented and that it delivers on the recognised needs of people with dementia.
and their carers and helps to improve their experience of living with dementia. The National Dementia Strategy will be the ideal platform for the launching of new ideas and ways of working. Developing ICPs will become an essential part of the future landscape of dementia care.

Given Irish demographics and the costs of dementia care of just over €1.69 billion each year (Cahill, O'Shea and Pierce 2012) Irish policy makers will have to find suitably sustainable and cost effective ways to not only support a good quality of life for the person with dementia but to also address the growing challenge it will present in the not-too-distant future. The population with dementia in Ireland is expected to increase from an estimated 41,447 in 2012 to 67,493 in 2021 and to 140,580 in 2041 (Cahill, O'Shea and Pierce 2012). One such exploration should be looking at ‘integrated’ care and how to effect change within an existing system that is disjointed, inequitable and highly fragmented.

Some tentative conclusions can be drawn from this review. Firstly, there is good practice in international experience that we can learn from where innovation and community action, coupled with service level commitment and attention to the voice of service users, have led to demonstrated improvements in the quality of life for people with dementia.

Secondly, it is clear that a one size fits all approach will not ‘retrofit’ into the landscape of dementia care in Ireland given the current unequal distribution of services nationally, which is further compounded by the impact of fragmented services historically. For this reason, it will be necessary to pilot an ICP in several test sites in Ireland to ensure that the model developed is sufficiently robust and transferable to be able to meet the needs of people with dementia across the country.

These test sites must develop a strong service user voice if they are to authentically represent people with dementia and their carers. Modern services should be developed in consultation with people with dementia, and where possible, they should play a major role in developing a care plan that reflects their own particular needs, preferences and circumstances. Notwithstanding this, one clear reason for incomplete assimilation of ICP’s is not paying enough attention to embedding the approach within local services. This should be a key objective of any pilot so that previous shortfalls in planning are not replicated. This embedding will require a significant sharing of expertise between the specialist services (currently in Community Mental Health Teams and Memory Clinics) and primary care services.

Thirdly, significant service reform can be achieved by integrating and planning care more effectively, getting people with dementia to use mainstream services where appropriate care is delivered in a more coherent manner. It is also the true to say that case management is required if integrated care is to become a reality with the potential to have a meaningful impact on the lives of those living with dementia.
The two competency-based roles described by de Vries, Brooker and Parker (2010), are the flexible responses required to address inequalities that exist in service provision. Clearly, this will require training and development as such roles do not already formally exist in Ireland. Careful placement of these roles within the system will be required with attention to embedding the ICP in wider care practice, and attention given to how best to join up fragmented services.

A recent research review on dementia care in Ireland states “... the best way to ensure that people get the services they need is to develop a system of case management for people with dementia... In this country, very few people with dementia have been allocated a case manager... a key contact person knowledgeable about a whole range of pertinent dementia related issues.” (Cahill, O'Shea and Pierce 2012)

Finally, there is a need to concentrate on issues of measurement and collect baseline data if pilot sites are to become more than mere islands of good practice. In order to present compelling evidence on cost effectiveness in such a complex change in practice data will have to convince policy makers of both the efficacy and cost effectiveness of such a system.

Argyle, E., Downs, M. and Tasker, J. 2010. Continuing to care for people with dementia: Irish family carers’ experience of their relative’s transition to a nursing home.


Dementia ICP Development Group 2010 *Dementia ICP Consultation Draft* [Online]. Available from:


