An Early Intervention and Integrated Model of Approach to providing care, support and education for older adults and their carers living with dementia in the community.

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**PROJECT TITLE:** An Early Intervention and Integrated Model of Approach to providing care, support and education for older adults and their carers living with dementia in the community.

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SUMMARY

Background: Dementia is a complex condition that impacts on the lives of approximately 90,000 people in Scotland (Alzheimer Scotland 2015) and 2464 over 65's within North Ayrshire (QOF 2014). Greater demands are being made on community nursing due to the policy shift from acute to community care, an ageing population and the focus now on supporting people with long term conditions (Scottish Government 2009). The Modernising Nursing in the Community 2020 (NHS Education for Scotland 2015) vision is for everyone to live longer healthier lives at home with an integrated health and care system that focuses on anticipating needs and supporting people to manage their long-term conditions.

Aim: To increase post diagnosis referrals to a community nursing team, shifting the focus from a reactive nursing task intervention to a more proactive approach, enabling patients and their carers’ the opportunity to access a coordinated and integrated pathway of care and support from health, social and third sector care providers. This would include provision of education for staff to encourage a person-centred approach to care for the individual living with dementia.

Method: Data was collated from the General Medical Practice register for a number of patients with a diagnosis of dementia recorded on the dementia register and that were known to the district nursing service and recorded on the caseload database between July 2015 (start of project) and Dec 2015 (end of project). Data was extracted from an excel workload tool used to plan district nursing visits, and would provide information on district nursing planned face-to-face and non-face-to-face time with patients and carers living with dementia pre project, and also during the six month duration of the project. The team; which consisted of four district nurses, recorded the amount of time spent with each individual directly or indirectly each day. The number of hours identified on the workforce tool related to care for patients or carers living with dementia. Community nursing staff were asked to rate their level of knowledge relating to dementia on a scale of 1-10 at the onset of the project and then repeated again following the delivery of training and experiential learning during the period of the project. An electronic audit tool was employed to record if the Standards of Care for Dementia Scotland (Scottish Government 2011) were adhered to within the assessment, care planning and review process.

Results: Analysis of the data shows a significant increase in the numbers of patients from the General Medical Practice dementia register recorded on the district nursing caseload following completion of this project.

There was a significant improvement in the level of district nursing knowledge pre and post project with the district nursing team recording that their level of knowledge had increased following involvement with this project and through engaging with e-learning and attending study days.

Audit of district nursing documentation demonstrated that 80 percent of patient records referred to the ‘I’ statements from the Standards of Care for Dementia Scotland (Scottish Government 2011).
BACKGROUND

Dementia is a complex condition that impacts on the lives of approximately 90,000 people in Scotland (Alzheimer’s Scotland 2015) and 2464 over 65’s within North Ayrshire (QOF 2014). Estimates suggest that the number of people living with dementia is set to rise to 127,000 within the next 20 years and this predicted increase in dementia prevalence will have significant health and socioeconomic challenges (Martin-Khan 2014) and also considerable health and cost impact on carers in comparison with non-carers (RCN 2013).

This project enabled community nurses to play a focal role as co-ordinators of care for this growing number of adults with dementia and their carers in Ayrshire. Greater demands are being placed on community nursing due to the policy shift from acute to community care, an ageing population and the focus now on supporting people with long-term conditions (Scottish Government 2009). Modernising Nursing in the Community 2020 (NHS Education for Scotland 2015) vision is for everyone to live, longer healthier lives at home with an integrated health and care system that focuses on anticipating needs and supporting people to manage long-term conditions. The model of approach for this QNIS ‘Catalyst for Change’ project aspired to help maintain physical, psychological and social health and well-being, anticipating any decline before it became acute, ensuring individuals’ living with dementia were not admitted to hospital unnecessarily and stayed connected to the community. The growing complexity of the community nursing caseload requires maximising the potential for the workforce to meet the needs of clients with increasingly complex co-morbidities and dependencies. Analysis of caseload activity and community nursing intervention for individuals living with dementia and carers within North Ayrshire appears to be intermittent, ad-hoc and reactive to crisis. Information from a workforce and SBAR reporting tool developed by the project lead and currently used by the community nursing team within North Ayrshire demonstrated that a high proportion of visits related to tasks such as continence, urinary catheter care and medication administration.

Referral of individuals living with dementia to the community nursing team appeared to be limited to whenever there was a functional need or crisis management. There were no proactive pathways utilized by the district nursing service for review and support of these patients. This conflicts with the key outcomes of the National Dementia Strategy (Scottish Government 2013) highlighting a need to ensure that care is flexible, reliable, accessible and that more people with dementia, their families and their carers are being involved as equal partners in managing their care throughout the journey of their illness. Improving the quality of care received is an essential component for addressing disadvantage, discrimination and stigma (Vernooij-Dassen et al 2005). Older adults (over 65 years) and carers living in North Ayrshire face widespread discrimination and inequality as a consequence of social and economic factors (Audit Scotland 2012). The prevalence of dementia increases with age, and most people living with dementia are over the age of 65 (Heese 2015) It has been found that older people with dementia are exposed not only to the stigma associated with mental illness but also to age discrimination (Benbow and Jolley 2015). Dementia is not a normal ageing progression and expectations that it is, leads individuals to assume that it is not responsive to intervention (Wortmann 2013). Attitudes such as these undermine the autonomy and decision-making capacity of people with dementia (Milne 2010) meaning that people living with dementia are also at risk of discrimination and infringements of their human rights.
because they do not have the capacity to challenge such abuses and face a poorer quality of life than the general population (Alzheimer Scotland 2014). There are also significant health inequalities in sections of the community, due to wider determinants like poverty (NHS Education for Scotland 2014). Studies have highlighted that from 5% of the most deprived data zones in Scotland, 3.7% were found to be within North Ayrshire, with deprivation levels continuing to rise (Scottish Index of Multiple Deprivation 2012). The scale and challenge of supporting individuals with dementia is increasing and NHS Ayrshire and Arran has higher than both the Scottish and UK average percentage of patients with a diagnosis of dementia registered by GP practices (QOF 2014). General Practitioners often struggle to deal with many of the issues faced by patients living with dementia due to appointment time constraints (Leach and Shepherd 2014). Under diagnosis of dementia in primary care may not be attributed to lack of diagnostic skills, but rather to the interaction of case-complexity and pressure on time (Lliffe et al 2009).

Community nurses are therefore in an ideal position within primary care to support patients and their families as they work at the interface between patient and environment, and are recognized as being leaders in designing services that meet the needs of the local population whilst tackling inequalities (Leach and Shepherd 2013).

The community nursing team has the advantage of accessibility, timely response, and the knowledge and experience of liaising with other professionals and agencies. Community mental health nurses (CMHN) have a key role in responding effectively to the newly identified needs of people with early dementia, district nurses however are often one of the first professionals to notice changes in a person’s behaviours and cognitive state (Manthorpe and Lliffe 2007). The strategic plan (Scottish Government 2013) to support timely diagnosis and enhance patient care outcomes would suggest that all community nurses should be able to recognize the possibility of dementia and support those undergoing referral or assessment and throughout all stages of their illness. Training in dementia recognition and continuity of support cannot be restricted to CMHNs (Manthorpe, Lliffe and Eden 2003) and the role of community health nurses must grow along with the increasingly ageing population and the resulting increase in people living with dementia, identifying needs, and providing subsequent management and coordinating services (Huang et al 2013).

General Practitioners in NHS Ayrshire and Arran play an important role in the detection and management of dementia and are generally the first point of contact for individuals with suspected cognitive impairment or dementia. Timely diagnosis enables people to plan ahead while they still have capacity to do so and means they can get early and effective access to drug and other interventions, which can sustain their cognition, mental wellbeing and quality of life (Scotland Government 2013). Referral to mental health services for a formal diagnosis is the gateway to one-year post diagnostic support within NHS Ayrshire and Arran.

Information and treatment and clear referral and support pathways are in place within North Ayrshire, however ongoing support throughout all stages of the condition to end of life appears to be fragmented with no clear care management structure in place.
AIMS AND OBJECTIVES

The project had three primary drivers; pathway for post diagnostic support is clear and understood, provision of education for staff, and integration of health, social care and third sector approaches to assessment, care planning with an outcome focused approach to care. The potential objective being to increase post diagnosis referrals to a community nursing team shifting the focus from a reactive nursing task intervention approach to a more proactive approach, enabling patients and their carers’ opportunity to access a coordinated integrated pathway of care and support. This project sought to provide a continuing pathway (Appendix 1) involving a small pilot aligned to a North Ayrshire General Medical practice with a practice population of 6150.

New legislation has set out the framework for integration in Scotland (Scottish Government 2015) providing an opportunity for a joint approach to co-ordinate the interventions required to support people living with dementia. Improving the ability of people with dementia to live well with support in the community may require a series of connections spanning both health and social care. Where integrated care models have been successful there is evidence to show that close collaboration between local authorities, service providers, third sector and frontline staff have been instrumental to that success (RCN 2013). This QNIS ‘Catalyst for Change’ project provided an opportunity for an integrated approach building on an existing model of collaborative health and social care support for older people within North Ayrshire. The project aimed to provide a pathway of referral and support for individuals living with dementia and their carers. Co-ordination by the community nursing team incorporated the key components of the 8 Pillar Model of Support (Alzheimer Scotland 2015) following on and complementing the 5 Pillar model of Support coordinated by the community mental health team. The Pillar models of support promote a committed practitioner to ensure all needs are coordinated. This project aimed to provide individuals and their carers equitable access to community support post diagnosis, throughout all stages of the illness; early, moderate, severe and end of life and therefore parallel to the support offered to individuals diagnosed with cancer. Studies suggest that palliative care for individuals living with dementia is not currently tailored to the unpredictable trajectory of this condition (Treolar, Crugel and Adams 2009). Compared with cancer and other long-term conditions, people with dementia may have different end of life needs, including communication and cognitive difficulties (Candy et al 2015). Studies have shown that carers and individuals may find health and social care systems difficult to navigate (Peel and Harding 2010), and that successful care management involves supporting individuals to ‘navigate the system”, with effective communication between professionals being a key factor in achieving a positive outcome (Khanasov, Vedel, and Pluye 2014).

Integration of health, social care and third sector approaches to assessment and care planning and an outcome-focused approach to care was a key element of the project plan. Post diagnosis the individual would be referred by the General Practitioner to the district nursing team who would co-ordinate the provision of an integrated health and social care approach. Implementation would facilitate a ‘team around the person’ approach as highlighted and advocated by the Dementia Carers Voices Survey (2015), with an identified named health or social care professional ensuring co-ordination and access to a hub of support and expertise across health, social care and third sector services.
The lead professional responsible for care management would be identified on the hub meeting agenda. The Community Mental Health Nursing team would continue to lead the care for the assigned diagnostic and post diagnostic period. Continuing care management would be the most appropriate health or social care professional identified.

Care management involves a pro-active approach to care and involves establishing a key practitioner to co-ordinate care and this approach is relevant at all stages of dementia. The national health and wellbeing outcomes framework (Scottish Government 2015b) shapes the planning and delivery of health and social care services to ensure engagement of individuals and carers at assessment and review. A personal outcomes approach is adopted to ensure that care and support are appropriate and effective. This project would aim to facilitate outcomes for individuals meeting the Standards of Care for Dementia in Scotland (Scottish Government 2011). The team approach would draw on greater capacity and resources collectively through partnership working. The hub meeting and close collaboration provided opportunity to share interprofessional knowledge and skills and provide a unified and cohesive approach as advocated within health and social care policy. An outcome-focused approach changes the focus away from service-led approaches to focusing more on engaging and enabling individuals and their carers.

The project created an opportunity to work closely with third sector organisations. The Alzheimer’s Scotland North Ayrshire advisor was a crucial member of the team and was actively involved with one-to-one and group education to support formal and informal carers from the onset. This third sector involvement would increase the team’s awareness of other avenues for the provision of advice, support and education. Provision of education for staff was a key component of the project. Training needs analysis of community nurses within the project pilot area identified that although staff had experiential practice based learning, nurses expressed concern that they had never received formal education on dementia. NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) developed Promoting Excellence: A Skills and Knowledge framework (Scottish Government 2011) detailing the knowledge and skills all health and social services staff should aim to achieve in relation to the role they play in supporting people with a diagnosis of dementia, and their families and carers. The aim was to enable community nursing staff within the project team to access NHS Education for Scotland (NES) comprehensive learning resource ‘Dementia Skilled- Improving practice ‘modules and attend a training day delivered by a trainer from North Ayrshire Health and Social Care Partnership. QNIS ‘catalyst for change’ funding would facilitate the release of staff to engage with training and attend training dates.

There is evidence to suggest that the current workforce have insufficient training and skills to work with people with dementia (Gandesha et al 2012, National Clinical Audit 2013).

It is estimated that individuals with dementia occupy 25% of general hospital beds in the NHS with this rising to 40% in certain groups such as elderly care wards, with only half having a prior diagnosis of dementia (Commissioning for Quality and Innovation 2014). Initiatives such as the Dementia Champions Programme in Scotland were derived to prepare health and social care staff in acute settings as change agents to drive the provision of education and increase the awareness of acute staff caring for individuals with dementia (Banks et al 2013). An
important component for an education programme for nurses carrying out a holistic assessment is enabling the nurse to understand the impact that cognitive changes have on the individual’s functional, social and psychological areas of their life. (While et al 2010). The development of educational intervention for primary care staff promotes person-centred responses to dementia and studies have shown that post-training, there are statistically significant improvements in understanding of person-centred care for people with dementia; attitudes to early diagnosis and awareness of non-cognitive dementia symptoms (Edwards, Voss and Iliffe 2015). Person-centred approach to dementia education allows for an exploration of the issues from the perspective of the person with dementia and it also allows for a consideration of their rights (Loveday and Downs 2012).

Educational interventions developed to improve dementia diagnosis and management have shown to be successful in increasing the number of dementia diagnoses and in changing attitudes and knowledge of health care staff (Perry et al 2008). Dementia education intervention for the project team aimed to foster person-centred attitudes involving all members of a primary care team, and integrated care team including receptionists and administrative support staff.

**METHODS AND APPROACHES**

In April 2004, the Quality Outcome Framework (QOF) was introduced as a voluntary reward incentive as part of the General Medical Services (GMS) contract to encourage GP practices to improve the care of patients with long-term conditions. Surgeries were responsible for maintaining a QOF dementia register to record patients with a formal diagnosis of dementia. The first phase of the project was to review the primary care dementia register within the pilot practice and determine which patients on the register were known to the district nursing team and recorded on the district nursing caseload database.

Clear referral and support pathways for one-year post dementia diagnosis are in place within North Ayrshire. This is one of the key HEAT performance measures (Scottish Government 2015). It was important to meet with the community mental health team to review the dementia register and share information regarding these patients and identify those who were receiving follow up care from the CMHNs.

The community mental health nurses have an important role with regards to information, advice and support during the diagnostic and post diagnostic period and the district nursing team wished to complement and enhance the care and support without duplication or encroachment of duties. Implementation of the pathway in the initial stages involved reviewing electronic health and social care records to ascertain whether the individual or their carer had a care manager. The Data Protection Act (1998) and the Human Rights Act (1998) provide the legal and ethical parameters within which we can share information across agencies and develop information-sharing protocols. A consent to share information document was obtained during the assessment process and this facilitated patient related discussions with the relevant parties at the multi-agency hub meeting. A community nurse identified patients from the register who did not have a lead practitioner involved in their care and offered a domiciliary visit. The purpose of engaging with the individual was to offer a supportive and accessible contact. This approach required significant time investment to
‘catch up’ with existing patients on the register and concurrently visit newly referred patients from the practice. This process involved assessment, care planning and review, setting a standard to ensure that all individuals would have an outcome focused approach to their care and therefore adhering to the Standards of Care for Dementia (Scottish Government 2011). Dementia assessment and support can be depicted as both specialist and generic roles and the CMHNs recognised that patients who they were offering support to would benefit from an assessment relating to their physical health problems. Many older adults with dementia present with co-morbidities and physical health problems (Manthorpe, Liliffe and Eden 2003) and these physical co-morbidities are often treatable or reversible and include issues such as incontinence, malnutrition, sleep disorders and poor mobility (Bunn et al 2014). An excel worksheet utilised within the project team to plan and record nature and complexity of visits, including time allocation was employed to retrieve data specifically relating to visits for individuals with dementia. This was detailed as either face-to-face time or non-face-to-face time. Baseline information was retrieved for the month prior to commencement of the project. Non-face-to-face time included periods spent liaising with General Practitioners and other health, social and third sector agencies. Non face-to-face time also included gathering information from previous consultations and electronic records in preparation for the first visit.

Ensuring preparation prior to a first encounter is very important as competence and professional credibility is considered necessary for district nurses when establishing a trusting relationship with patients (Nygren-Zotterman et al 2014). Multidisciplinary team (MDT) meetings were hosted within ‘Anamcara’, the dementia respite unit located within North Ayrshire. Core team members attended each meeting (appendix 1) and peripheral agencies were invited as generated by the needs of the individual.

This was an opportunity to discuss individuals referred to the hub and support facilitation of their outcomes. The agenda was distributed to attending members in advance to provide opportunity to collate information and the following information was detailed: Why a MDT referral was made? And who made the referral? The minutes of the meeting detailed the MDT recommendation and professionals responsible for implementation. The second phase involved facilitating learning and confidence with this new practice whereby district nurses were supporting individuals with dementia using a holistic, proactive approach. The MDT meetings contributed to brief educational opportunity for all members of the team who benefited from shared professional learning and expertise. For evaluation purposes the community nursing staff were asked to rate their level of knowledge relating to dementia on a scale of 1-10 at the onset of the project (appendix 2) and then repeat following delivery of training and experiential learning gained during the period of the project.

FINDINGS

Quantitative findings- Patients recorded with a dementia diagnosis on the primary care database increased from twenty three patients to thirty patients within the six-month period. This database was adjusted to add new patients and remove patients who were deceased or had left the practice. The number of patients on the register known to the district nurse team dramatically increased from only one patient to twenty seven patients (fig 1). An excel workload tool employed to plan district nursing visits would provide information on district
nursing planned face to face and non face to face time with patients and carers living with dementia pre project and during the six month duration of project. The team of four district nurses recorded the amount of time spent with each individual directly or indirectly each day (fig 2). The district nursing team were asked to rate their level of knowledge relating to dementia at the beginning of the project and at the end of the project. The staff rated their knowledge on a scale of 1-10 (1 being lowest level of knowledge). All staff members showed an increase in knowledge as a result of being involved with the project.

An electronic audit questionnaire of documentation was carried out to evaluate whether the ‘I’ statements from the Standards of Care for Dementia in Scotland were achieved (fig 4).

![Figure 1 Number of patients recorded on dementia register and on district nursing caseload July 2015 (start of project) and Dec 2015 (end of project).](image)
Figure 2 Number of hours identified on workforce tool related to care for patients/carers living with dementia.

Figure 3 District Nursing team were asked to rate their knowledge of dementia on a scale of 1-10 (1 being lowest level of knowledge) pre and post project.
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**Content of patient held record**

![Content of patient held record](image)

*Figure 4. An audit of documentation and adherence with standards of care for dementia*
DISCUSSION

The project aimed to develop an integrated health and social care pathway to provide support for older adults and their carers living with dementia in the community co-ordinated by a district nurse. The nurse would ensure equitable access to support, information and care from diagnosis throughout all stages of their illness to end of life.

It is evident from the analysis of data from the dementia register and corresponding district nursing caseload numbers that prior to the project, co-ordinated care management from community nurses was minimal. Figure 1 indicates the district nursing team knew only one individual identified from the dementia register. Caseload management is a vital component of the district nurse role and as this pathway of care evolved it demonstrated that nurses needed to be proactive in their approach to effectively manage caseloads. Examining and comparing the profile of district nursing caseloads with practice lists at a practice level is necessary to ensure that the health and social needs of individuals and carers are met (Bain and Baguley 2012). Approaches to improving care focused on interprofessional collaboration with General Practice and referral to the district nurse and pathway of support for patients diagnosed with dementia. The supportive role that district nurses play needed to be clearly articulated and recognised as caring for people with dementia in primary care demands the same systematic approach as the management of other long-term conditions. Follow-up of both individuals with dementia and their carers should be incorporated into the district nursing caseload and allow integrated case management and person centred approach to care, including opportunity for anticipatory care planning.

Eleven patients on the register were newly diagnosed and were receiving post diagnostic support and follow up from the CMHNs, however, following discussion with the post diagnostic team it was recognised that eight of the patients within the first year post diagnostic period would benefit from introduction and support from the district nursing team. One-year post-diagnostic support from the community mental health team provides newly diagnosed individuals and their carers with support in adapting emotionally and physically to their condition. The CMHNs facilitate access to low levels of support and signposting. Timely recognition and diagnosis is a prerequisite for improving dementia care, however diagnosis often occurs late in the disease process (Vernooij-Dassen et al 2005) and the prevalence of comorbidity in individuals with dementia is high (Bunn et al 2014). Patients presenting in primary care with dementia often have a high level of medical comorbidity (Schubert et al 2006) and the eight patients deemed as appropriate for district nursing support were presenting with cognitive and physical decline. A co-ordinated approach to supporting individuals with dementia out-with the post-diagnostic period of support appeared to be limited within the pilot area and there was no joint practice intervention for when patients started to decline.

Delivering Integrated dementia care: The 8 pillars model of community support (2012) discusses the fact that individuals living with dementia have a range of symptoms and benefit from a co-ordinated team approach of practitioners from health, social care and third sector who all have differing skill sets to offer. The hub meeting and pathway of support facilitated this co-ordinated team approach, and offered an opportunity for the community mental health team to refer patients for discussion who required an increased level of support and also increased the district nursing teams’ awareness of patients within the practice who had been diagnosed with
dementia. The district nurse can be a key factor in identifying patients with dementia (Waldorff et al 2001) and during the span of the project four of the patients encountered by the district nursing team for other clinical reasons were recognised as having symptoms of dementia and referred for diagnostic evaluation. Two other patients identified as having cognitive impairment impacting on their mental and functional ability declined referral for diagnostic evaluation. These patients continued to receive support from the district nursing team and ongoing monitoring of their condition, ensuring that they would receive equitable access to support despite not having a formal diagnosis of dementia. Studies suggest that barriers to diagnosis for individuals and carers include misinterpretation or denial of symptoms and fear of stigma (Dungen et al 2011).

Educating and increasing the community nursing teams’ insight and recognition of these barriers to diagnosis was an important aspect of the project. Facilitating a person-centred approach to discussing dementia is necessary as Vernooij-Dassen et al (2005) suggests there is a strong association between fear of diagnosis and social isolation. Educational support for community health nurses should be focused on instilling confidence to help them recognise and respond to people with dementia (Huang et al 2013).

Figure 2 indicates that the level of district nursing intervention increased substantially from twelve hours face-face time and two hours non face-face time to at its peak forty five hours face-to-face time and twelve hours non face-face time during the month of October. The increase in hours delivering support and care to patients with dementia suggests that there may have been a pre-existing unmet need for this client group. The community nursing team pre project had a varied range of contact with individuals with dementia and their carers. Episodes of care included wound care, catheter and continence care and palliative care. Their professional responsibility to provide holistic support through co-ordination and care management for individuals with dementia and their carers was not apparent and this is supported in the findings whereby only one person from the dementia register was actually identified on the district nursing caseload.

Face-to-face time and non-face-to-face time patient encounters pre project did not have the diagnosis of dementia recorded within nursing documentation and this was only identified through retrospective audit and recognition of patients following review of the General Practice dementia register.

The goal of caseload management is co-ordination of care, assessment, planning, monitoring and evaluation to improve patient outcomes (Ervin 2008). It is important to review caseloads and workloads to ensure that resources are utilised effectively and are directed towards individuals with the greatest need (Bain and Baguley 2012). This increase in face-to-face time for individuals with dementia and their carers did require a high proportion of time allocated for case management during the period of the project, as this was a large cohort of patients previously unknown to the team. The number of hours would be expected to reduce after this initial ‘catch up’ period and allocated time would then be limited to reviewing existing patients and assessing new patients. The number of new patients to the caseload averaged at three per month. This proactive and holistic approach to dementia care may have the potential to reduce time spent on reactive task interventions and crisis management and this has been demonstrated in the care of other long term conditions, involved coordinating input from other
In Figure 3, a benchmark of the district nursing teams’ knowledge regarding dementia prior to the project was recorded to gauge whether or not this increased following the education delivered and experience gained throughout the project. Time was allocated for “A Skills and Knowledge framework’ e-learning module supported by educational training sessions delivered locally at ‘Anamcara’ dementia respite unit. All staff were provided with an opportunity to try an ageing suit, which simulates visual and hearing impairment and involves weights and straps to restrict movement. The ageing suit is designed to provide staff with an insight as to how elderly patients, with or without dementia, may feel performing everyday tasks. This opportunity was described positively with all staff reporting to have increased empathy for the challenges faced when physical disability may be compounded with cognitive difficulty. The opportunity to liaise with other health, social care and third sector partners was reported to be an important dimension to learning and the opportunity to spend time within the dementia respite unit facilitated by the unit manager, a key member of the project team, was very valuable. Alzheimer’s Scotland North Ayrshire advisor readily provided information to staff on a wide range of topics. This included advice on the different types of dementia, capacity and legal issues, caring for someone with dementia, welfare benefits and other resources available for carers.

Dementia awareness sessions were provided to the wider district nursing team and also the staff within the pilot General Medical Practice were given the opportunity to become ‘dementia friends’. This is an Alzheimer Scotland initiative to change the way people think, act and talk about dementia. Improving the quality of care for people with dementia and the treatment and care they receive is an essential component of the National Dementia Strategy (Scottish Government 2010) and community health nurses that possess a high level of confidence in dementia care are considered to positively influence the way individuals living with dementia and their carers are approached (Huang et al 2013). Education has been shown to improve knowledge, attitudes, and confidence in health professionals providing care for patients with dementia (Nayton et al 2014, While et al 2010, Bryans et al 2003).

At the end of the project all the community nurses reported a significant increase in their knowledge relating to dementia. A regulatory standard has been set that pre-registration nurses receive dementia training (NMC 2010) therefore similarly if supporting individuals with dementia is a significant role of the district nurse as part of the integrated support model of care then community provision of education requires to be a key element of community nursing professional development. Figure 4 demonstrates results of an electronic audit tool. An electronic audit questionnaire of documentation was carried out to evaluate whether the ‘I’ statements from the Standards of Care for Dementia in Scotland were achieved. Five sets of documentation from patients with dementia on the district nursing caseload were selected randomly.

The objective of the audit was to measure if the assessment and care planning process recorded information relating to the ‘I’ statements from the Standards of Care for dementia in the patient record. The standards of care inform health and social care staff what is expected of them in order to improve the quality of care they provide, each standard is measurable and all staff have equal responsibility for meeting these standards. Audit of patient documentation was the
chosen method for this project. It has not been within the scope of this study to report on all data relating to the ‘I’ statements from the Standards of Care.

‘I have a right to a diagnosis’

Four of the patient records had recorded a diagnosis of dementia and type of dementia was recorded. One did not have a diagnosis recorded and this may have been because a referral to diagnostic mental health services had been declined or the patient had been referred to diagnostic mental health services and had not formally received a diagnosis at time of audit and had therefore not been coded on the EMIS general practice dementia register. Facilitating timely diagnosis is important in order to enable the individual and carer to benefit from information, support and possible treatment. The community nurses recorded if the patient was currently receiving post diagnostic support by the CMHN.

It was important that there was clarity regarding the CMHN as named nurse during the post diagnostic support period in order to prevent patient and carer misperception of roles. The community nurses had opportunity to accompany the CMHN on visits to observe the diagnostic assessment process. This provided the district nurses with an insight into the approach and was therefore an additional learning opportunity.

‘I have the right to have carers supported and educated about dementia’

Five of the patients had been provided with information about the condition and advice on managing symptoms and treatment from the CMHNs. It was recorded in two of the audited records that there was no longer input from the CMHNs and the individuals and carers welcomed future visits from the district nursing team for advice and support and stated that they were reassured that there was a locally accessible service. Information and support is very important for carers when they take on an ‘active’ caring role (Berry 2013) and it is recommended that carers should be offered access to a range of person centred interventions including individual or group education (Dow and Robinson 2014).

Family carers for four individuals accepted an offer to attend a group information session or a one-to-one session provided by Alzheimer Scotland North Ayrshire advisor. The group session was arranged at a local venue to encourage attendance. Provision of education and support delivered in different formats; telephone, internet, peer groups etc, tailored to the needs of the individual and or carer is important. Support and advice is recognised as helping to enhance coping skills, boosting confidence, increasing knowledge, and preparing the individual and carer for the future (Milne, Guss and Russ 2013). One of the patients included in the audit had three hospital admissions recorded in the two-month period prior to the project. It was detailed within the patient notes that he was discharged from hospital following a second episode of delirium attributed to a urinary tract infection on both occasions. Delirium is a separate condition in itself; however, dementia is known to be an important independent risk factor increasing delirium risk by between two to five times (Fong et al 2015). The assessment documentation detailed that this male patient had been catheterised during a hospital admission following a fall. The catheter had remained in situ following discharge and reason for insertion was not reviewed. Urinary tract infection attributed to the use of an indwelling urinary catheter, is one of the most common infections acquired by patients and the most important
intervention to prevent infection is the removal of the catheter (Nicolle 2014). The catheter had been inserted as the gentleman had reduced mobility at the time of his first admission; however on review there was no long-term requirement and the community nurse subsequently removed the catheter. There were no further hospital admissions recorded during the span of this project and the gentleman’s main carer; his wife has been supported to manage his continence.

The ‘right to have carers educated and supported’ is multifaceted and may involve many dimensions of support; teaching carers to cope with behavioural, psychological and physical symptoms. Incontinence has been identified as a significant burden for carers (Drennan et al 2012). Supporting this gentleman’s carer by providing the individual with a comprehensive assessment of continence, which addressed the environment, cognitive and functional ability of the individual, was very important.

‘I have the right to be treated as a unique individual’

All of the documentation had recorded whether ‘The getting to know me’ dementia resource funded by Alzheimer Scotland and Scottish Government had been provided. This document provides the opportunity for individuals to record specific needs or preferences they want family, formal and informal carers to know. ‘The getting to know me’ document had been completed by one individual in the audit group and shared with day care respite services.

The content of the district nursing profile promotes a person centred approach to assessment and care planning. Involvement of the individual and addressing their needs in relation to activities of daily living was evident in the five patient records included in the audit. Detailed information was recorded for three patient records and included important information relating to health and social care needs, including hobbies and family relationships. Provision of adequate time to provide a holistic assessment is essential. Being listened to and acknowledged as an equal by health professionals has been shown to have a significant influence on patients’ self-perception and sense of dignity (Tranvag, Petersen and Naden 2014).

‘Right to be independent as possible and included in community’

Two thirds of people with dementia live in the community, and the mainstay of support for those living in the community is provided by around half a million family carers (Alzheimer’s Society 2007). The policy drive is to enable individuals living with dementia to stay in the community (Scottish Government 2010) and provide information and support to equip carers to continue the caring role. Three of the patients had main carers identified and two patients lived independently. All patients had been referred to dementia community support services, North Ayrshire Health and Social Care Partnership and four continued to receive this support. The dementia support service provides advice, information and specialist support, which address the unique needs of people living with dementia and their carers.

The support is provided within the home or the local community with the aim of assisting the individual to continue to live at home for as long as possible.

The dementia support service is led by a key member of the project team and supports the
team to work with the individual to develop a care plan focused on outcomes identified to maintain and improve quality of life for the individual and their carer. This service offered opportunity for patients to stay connected to the community and a number of memory cafes run by the support workers in Ayrshire provide a welcoming setting for patients and carers to meet and talk to people in a similar situation.

The audit identified from the patient records that two of the patients had been introduced to local support groups, and one patient had been provided with the opportunity to experience day care and visit the local dementia respite unit. This had been a vital opportunity and reassuring to one of the patient’s elderly spouse who was finding the caring aspect increasing difficulty as his partner was declining cognitively and physically. Findings suggest that adult day services can assist carers to organise their care provision time more productively and to the advantage of the individual with dementia and carer (Gaugler et al 2003).

Assistive technology promotes independence and quality of life and can be categorised as supportive with regards to safety, communication and leisure (Newton and Robinson 2013). Assistive technology is an umbrella team that includes assistive and adaptive devices for people with differing levels of disabilities including cognitive and functional impairment. The documentation identified that one individual had assistive technology falling into the ‘safety’ category. Door sensors had been installed to inform relatives if the individual left the house during the night and a sensor floor mat to detect and alert relatives in the event of this individual falling out of bed. Telecare engagement sessions had been provided to health and social care staff to increase their awareness regarding assistive technology devices available.

Electronic tablets may be used as a memory prompter to alert individuals to medication times and therefore can promote independence and reduce unnecessary reliance on homecare services. Signposting to technology may be an important aspect of a person-centred approach to care and meeting the standards of care for dementia with regard to promoting independence and connecting to the community. Cudd and Mountain (2014) suggest that advancing technology and the impact it may have on facilitating individuals with dementia to stay at home is very substantial.

‘I have the right to end of life care that respects my wishes’

No patient records from the five included in the audit had evidence that end of life care and wishes had been discussed. Community nurses encourage anticipatory care planning with patients with long-term conditions and patients diagnosed with palliative cancer diagnoses. The importance of having end of life conversations with individuals living with dementia and their carers is paramount, as involving them in decisions when they have cognitive capacity will help ensure these wishes are respected.

Individuals often share their end of life preferences with family members through informal discussion (Black et al 2009), however people may often be inhibited to talk about death, and the unknown trajectory of this condition means discussions may never take place (Alzheimer’s Society 2014). Opportunity for community nurses to be involved with individuals with dementia and their carers from the outset when diagnosed may enable the nurse to acquire that information as the nurse-patient/carer relationship develops. A person-centred approach to
caring for an individual with dementia involves early communication and involvement in decision-making. This can improve end of life care that respects their preferences and more importantly allows the opportunity for them to articulate their preferences (Denning, Jones and Sampson 2012).

CONCLUSION

There are many influences on the direction of community nursing and there are often pressures placed on this generalist health professional towards meeting the increasing demands of long-term conditions which previously have predominately been under the scope of other professional groups. The escalating prevalence of dementia globally (World Health Organisation 2015) will mean that strategies and policies will be required to find innovative ways to respond to and design services to meet the demand. This project aimed to provide an integrated early intervention pathway of support that could attempt to respond to this increased challenge of meeting the needs of individuals living with dementia and their carers, in the knowledge that in this financial climate, resources would be static at best. A district nurse offered individuals with dementia and their carers’ access to advice from a hub of multidisciplinary professionals.

The implication from this project is that providing a streamlined integrated health, social care and third sector team approach may improve the availability of care and support. The government’s 2020 vision (Scottish Government 2011b) advocates that ensuring person centred approaches to care requires collaboration between community nurses and multi agencies. Person-centred co-ordinated care transversing mental and physical health across health and social care can help meet the differing care needs of individuals (Scottish Government 2015). The number of patients on the General Practice Medical Register known to the district nursing service increased as a direct result of this project and there was a shift of district nursing resources directed towards this client group. This therefore increased the number of patients accessing advice, education and support from diagnosis throughout the trajectory of their illness. This strengthens the need for district nurses to be a key professional in maximising the potential for this client group to access support before crisis intervention is required. It was out with the confines of this project to measure the quality of this increased quantity of care and is therefore a recommendation for further study.

The nature of referrals to district nursing services prior to this study had been limited to task intervention and this was identified on workload planning tools. The results from this project suggests that by applying a proactive caseload management approach to meeting the needs of individuals with dementia this may counter unscheduled visits and provide opportunity for planned holistic care. This ‘Catalyst for Change’ project implies that improving collaboration between professional groups in responding to the needs of individuals and sharing expertise and advice with each other is a step towards achieving the integrated care model advocated within North Ayrshire Health and Social Care Partnership framework and the strategic plan of the Scottish Government (2011b). Integrated approaches to dementia care are shown to increase the quality of care provision (Perry et al 2008). Current models of caseload management need to be challenged to take into account changing demographics and consider models of support that include not only community nursing skills and capability, but draw on support from partners, such as social services, voluntary and independent sector. Multi agency understanding regarding the importance of identifying patients with dementia early, and
supporting the individual and their carers is key to improving quality of care and support (Waldorff et al 2001), and recognising that although community mental health nurses have a key role in effectively meeting the newly identified needs of people diagnosed with dementia, other nurses working in the community are also encountering individuals in the early stages of dementia. In the context of a policy objective to identify people with dementia earlier, all community nurses should be able to recognize the possibility of dementia diagnosis and support those undergoing referral or assessment. Their confidence in doing so should be enhanced by continued professional development and training.

The next steps will be to evaluate this model and embed this service design as mainstream practice within North Ayrshire Health and Social Care partnership placing individuals with dementia and their carers at the heart of the care coordination relationship. If the model is evaluated successfully, this will hopefully secure longer-term health and social care integration funding for the community nursing workforce to have the capacity to formalise referral and integrated assessment processes in order to deliver high quality personalised care. This will involve continuing to working closely and to help achieve person centred outcomes with third sector partners and increase number of dementia champions within health and social care teams.
REFERENCES


## FINANCIAL REPORT

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EARLY INTERVENTION INTEGRATED APPROACH TO SUPPORTING INDIVIDUALS/CARERS LIVING WITH DEMENTIA

- Home care manager
- Dementia support co-ordinator
- CPN Post Diagnostic team
- Alzeimers UK
- AHP
- Social worker, older people services
- District Nursing team
- Respite Services manager
- Pharmacy Advisor
- Palliative Specialist Nurse
- Telehealth & Telecare Adaptors/ Aids
- Dietician
- Housing

Memory assessment services

PRE +POST DIAGNOSIS REFERRAL

GP

Patient/carer

Post Diagnostic Team

EARLY INTERVENTION INTEGRATED APPROACH TO SUPPORTING INDIVIDUALS/CARERS LIVING WITH DEMENTIA

Early intervention  intermediate  end of life  pathway

1. Patient/carer
2. Memory assessment services
3. PRE +POST DIAGNOSIS REFERRAL
4. GP
5. Post Diagnostic Team

- Early intervention
  - Memory assessment services
  - PRE +POST DIAGNOSIS REFERRAL
  - GP
  - Post Diagnostic Team

- Intermediate
  - Home care manager
  - Dementia support co-ordinator
  - CPN Post Diagnostic team
  - Alzeimers UK
  - AHP
  - Social worker, older people services
  - District Nursing team
  - Respite Services manager
  - Pharmacy Advisor
  - Palliative Specialist Nurse
  - Telehealth & Telecare Adaptors/ Aids
  - Dietician
  - Housing

- End of life

- Pathway