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SECTION 1: Background

1.1 In line with other European countries Scotland’s population is ageing, with the number of people of pensionable age projected to increase from 1.04 million in 2010 to 1.32 million by 2035\(^1\), a 26% increase (GROS, 2012). While increased life expectancy is to be welcomed, older age encompasses a range of challenges including increased prevalence of long term conditions, one of which is dementia.

Current figures suggest that just over 84,000 people in Scotland have dementia of whom 96% are aged 65 or over (Alzheimer’s Scotland, 2012). Dementia is an umbrella term covering a wide range of syndromes characterised by progressive loss of cognitive abilities, including Alzheimer’s, vascular, Lewy Body, and frontal lobe dementia, as well as conditions associated with chronic abuse of drugs and alcohol such as Wernicke and Korsakoff type dementias. While age is one of the main risk factors for dementia, it also affects other age groups; there is a higher incidence of rarer cases of dementia in younger people, and the rise in dementia associated with the increased longevity of people with Down’s syndrome is a challenge for health and social care providers. Projections suggest that the number of people with dementia will double in the next four decades (Mashta, 2007).

There is agreement that early identification and treatment for people with dementia is beneficial (NICE/SCIE, 2006; Mental Health Foundation, 2010; Milne, 2010; Scottish Government, 2010b). Evidence suggests that both pharmacological and non-pharmacological treatments are likely to have maximum effect during the early phase of dementia (National Audit Office, 2007). Acetylcholinesterase inhibitors are now recommended for mild to moderate dementia, and early diagnosis enables those affected and their families to plan for the future (NICE/SCIE, 2011). However, receiving a diagnosis can take time, with those affected initially consulting their general practitioner (GP) prior to being referred to one of a range of specialists who may carry out further tests over a number of weeks or months. Lack of awareness of the symptoms of dementia, fear of stigma, and/or lack of insight may deter people from seeking support, and levels of diagnosis and treatment in the UK have been found to be low in comparison with other European countries including France, Sweden, Ireland and Spain (Department of Health, 2009). Thus it is possible that a significant proportion of older people admitted to hospital may have dementia, but not have received a diagnosis. In Scotland up to 30% of all people admitted to medical wards are described as having significant memory problems, however, only 30% have a diagnosis of dementia (Mental Welfare Commission for Scotland 2010).

A recent review reported that multi-morbidity affects more than half of all older people and is associated with increasing age, gender and socioeconomic status (Marengoni et al, 2011). Mental health problems have been found to be common in older people admitted to general hospitals (Keenan and Jenkins, 2011). It is anticipated that multi-morbidity will become the norm in Scotland, often encompassing cognitive impairment, thus nurses will be expected to manage both physical and mental health problems (Cowdell, 2010; Marengoni et al, 2011; Keenan and Jenkins, 2011). Indeed Weitzel, Robinson, et al. (2011) suggest that nurses caring for patients with dementia will need knowledge of interventions for communicating; managing agitation, nutrition, hygiene, and pain; providing spiritual care; and determining decision-making capacity.

The Government is committed to reducing the proportion of people aged 65 and over admitted as emergency inpatients two or more times in a year, increasing the number of people aged 65+ with

\(^1\) Takes into account changes in state pension age.
high level care needs at home, and improving the quality of healthcare experience (Scottish Government, 2010a). Despite this, figures derived from the Social Work Inspection Agency indicate that the number of unplanned admissions to hospital for older people has increased (MacIntyre and Stewart, 2011). People with dementia who have co-morbid conditions are more likely to be inappropriately admitted to hospital and, once there, to stay longer than people without dementia. They are also more likely to be admitted to a care home on discharge (Scottish Government, 2010b), which has implications for both the patient and their carers who have been found to experience feelings of guilt (De Silva and Curzio, 2009).

Recognition of the importance of dementia as the population ages has resulted in a spate of policy documents across the UK including A Charter of Rights for People with Dementia and their Carers in Scotland, (Alzheimer Scotland, 2009); Living Well with Dementia: A National Dementia Strategy, (Department of Health, 2009); Scotland’s National Dementia Strategy, (Scottish Government, 2010b). Over the same period consultations were held in Wales and Northern Ireland with a view to developing their own Dementia Action Plans.

Further reports and guidelines published over the following two years focusing on the process of achieving improved care for people with dementia included Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy (DoH, 2010a), Nothing ventured, nothing gained: risk guidance for people with dementia (DoH, 2010b), and Standards of Care for Dementia in Scotland: Action to support the change programme, Scotland's National Dementia Strategy (Scottish Government, 2011a).

In Scotland dementia is a national priority with specific HEAT (health improvement, efficiency, access and treatment) targets relating to early diagnosis and the management and support of those affected. Despite this, there is recognition that support for people with dementia and their carers could be improved (Scottish Government, 2010b). A report prepared by Alzheimer Scotland (2009) indicated that half the carers interviewed reported that admission to a hospital had had a negative impact on the person with dementia. The report also revealed that more than one third of people with dementia admitted to hospital from their own homes were subsequently discharged to a care home. These findings prompted the Mental Welfare Commission for Scotland to visit people with dementia in general hospitals.

The Commission reviewed the care of 194 people in 41 wards across nine NHS Boards, focusing specifically on admission, the care journey, consent and lawful medical treatment, safety and restrictions, the care environment, staff training and specialist mental health support, and discharge from hospital (Mental Welfare Commission for Scotland, 2010). While many of the findings were positive, attention was drawn to the potential for avoiding admission through early intervention and support e.g. falls prevention, lack of involvement of relatives and carers, poor adherence to legal safeguards for people who lack capacity, lack of awareness of human rights and incapacity legislation, the potential for improving the hospital environment for people with dementia, and the excessive number of people discharged to care homes.

A recent audit of dementia care carried out in England by the Royal College of Psychiatrists’ Centre for Quality Improvement (2011) showed that, while the majority of hospitals had policies in place relating to the admission, assessment, and care of people with dementia, there was a lack of evidence that policies were being carried out in practice. Access to liaison psychiatry was often not available at weekends or evenings, impacting on emergency or urgent referrals. Collation and communication of information relating to the individual preferences was patchy. Not all hospitals had a system in place to inform staff that a person had dementia and how it affected them as an individual, staff training was fragmented, and discharge was often found to be poorly managed with families not being involved. There was a lack of evidence demonstrating leadership at Trust/Health Board or hospital level in terms of identifying Champions or leads.

Findings from the published literature painted a similar picture with a number of authors drawing attention to shortcomings in the care of people with dementia in acute settings (e.g. Borbasi and
which may impact on both patients and their carers (Douglas-Dunbar and Gardiner, 2007). Potential difficulties including communication, assessment, the physical environment, organizational systems, influence of key players, and accepted practice in dementia care are acknowledged in a number of studies (e.g. Borbasi and Jones, 2006; Miller, 2008; Cowdell, 2010; Jootun and McGhee, 2011).

1.2 Education for health and social care professionals working with people with dementia

The role of nurses is seen as central to future care of people with dementia (Hoe and Thompson, 2010; Bridges and Wilkinson, 2011). However, findings of a survey of higher education provision relating to Higher Education Institutions (HEIs) in England and Wales revealed that coverage of dementia within nursing, allied health professions, and social work pre-registration courses was often limited (Pulsford, Hope and Thompson, 2007). While there was greater input within mental health nursing courses than adult nursing or other professions, coverage was found to be variable, and often dependant on the interest of individual lecturers. The survey also found that both pre-registration courses and continuing professional development (CPD) failed to address physical healthcare, issues of culture and identity, or young onset dementia. A similar picture is evident in other countries, e.g. America schools of nursing have only recently started teaching geriatric care, thus most nurses have had little or no training (Allen and Close, 2010).

1.3 Evidence based practice

There has been a significant increase in the quantity of research focusing on dementia within the UK and internationally, however there can be considerable delay between the findings of research and change in practice. Henderson, Winch, et al. (2006), conducted a study which used educational strategies to raise awareness of dementia care research evidence, and inclination to use this knowledge in future practice. Participants’ attitudes toward research and the likelihood of using research findings, was measured before and after the intervention using the Edmonton Research Orientation Survey (EROS). Results indicated that there were no significant changes between the before and after measures. The authors concluded that implementing evidence based changes did not necessarily result in staff becoming more aware, or more likely to use research based knowledge to solve problems in the future.

Other studies have also shown that changing practice takes more than ‘knowing’ what should be done. Cowdell (2010) claimed that nurses endeavour to provide optimal care, but find this difficult. Cowdell asserted that traditional knowledge based education is unlikely succeed and suggested that education needs to target health professionals at a cognitive and emotional level, allowing them to ‘see’ people with dementia differently. Borbasi, Jones, et al. (2006) also reported challenges to health professionals implementing best practice in Australia. This study found that environmental, socio-cultural, and economic issues served to maintain the ‘status quo’.

The importance of translating research into practice was highlighted in a paper by Draper et al (2009) working in Australia. The authors drew attention to the considerable quantity of research focusing on dementia and the challenges involved in communicating the findings to the mix of individuals required to facilitate change, e.g. policy makers, service providers, educators, and members of the public. Draper et al emphasised the importance of interpersonal contact in the transfer of knowledge and implementation of change including:

- Opinion leaders: source of advice
- Facilitators: formal role in implementing change
- Champions: advocates of ideas or projects with enthusiasm and strong connections
- Linking agents: problem solvers
- Change agents: work with people to change behaviour
Other interventions have also stressed the benefits of key individuals championing change. McCrae and Banerjee (2011) described the evaluation of a redevelopment programme within a mental health service for older adults. The evaluation adopted a realist model collecting qualitative and quantitative data over time. The authors reported that the programme was generally well accepted. However, adoption of the new model was not uniform across all teams, with progress in one team being hampered by lack of staff and resistance to change. The authors reported that the study demonstrated that ‘whole system’ change could be achieved if sufficient effort was targeted at the needs of staff involved. Cherry, Hahn, et al. (2009) reported the findings of a study in which primary care physicians received education relating to the identification, diagnosis and management of people with dementia. The study used evidence-based practice guidelines to establish quality benchmarks supported by training and other interventions. Findings indicated that it was possible to improve quality of dementia care through physician education, but the authors suggested that education needs to be embedded in a system of care management and that practitioners required to be linked to other individuals and agencies. Ploeg, et al (2010) used mixed methods to explore ways in which ‘nursing best practice champions’ influence the use of best practice guideline recommendations through:

1. Dissemination of information via education and mentoring
2. Being practice leaders at interdisciplinary committees
3. Tailoring guidelines and implementation strategies to their own organisation

However, Ploeg et al questioned the title ‘champion’, and suggested that there was disparity between different roles using this title. Based on the study Ploeg concluded that ‘champions’ were change agents that take on multi-dimensional roles, such as educator, facilitator, mentor, leader, policy developer, and evaluator. Thompson, Estabrook, and Degner (2006) also identified inconsistency in the use of various terms based on their reviews and meta-analysis. They concluded that, irrespective of the terminology, the concept appeared to be based on the premise that interpersonal contact increased the probability of behavioural change in health care.

Beer et al, (2010) reporting on an Australian study provided details of an evaluation of an educational intervention for general practitioners and staff caring for people with dementia in residential facilities. The development of the educational intervention was based on the findings of a literature review and identification of available resources. An expert reference group, comprising national and local experts in dementia education, input to the development of the programme, which took a learner centred approach, using best available evidence, and active learning strategies. The reference group also contributed towards the concept of Dementia Champions to support the sustainability of the education within the residential care facilities, by liaising with the education programme staff, and facilitation of the programme. The programme covered six main topics, 1) communication with residents and family members, 2) personal care activities, 3) positive values, 4) behaviours of concern, 5) pain management, and 6) dementia, depression, and delirium. The Dementia Champions undertook the role of facilitator which included:

♦ Attending education sessions
♦ Encouraging staff attendance
♦ Providing short education sessions
♦ Maintaining and lending education programme resources
♦ Providing brief orientation to new staff
♦ Cultivating enthusiasm amongst staff caring for residents with dementia

The evaluation of the programme involved recording attendance, participant feedback, and feedback relating to change in practice. The authors concluded that the Dementia Champions model of local empowerment was acceptable and feasible, providing local reinforcement and sustainability, although reported attendance was poor. Unfortunately, no information was available relating participants’ knowledge of dementia, or any impact on care received by residents – further evaluation is planned.
A similar programme was introduced in Scotland in 2007 (Waugh, 2011). The aim of the programme which was developed in partnership between NHS Dumfries & Galloway, the University of the West of Scotland, Alzheimer Scotland, and User and Carer Involvement (UCI), was to improve the care of people with dementia type illnesses within general hospital environments by developing Dementia Champions’ skills, knowledge, and attitudes in order for them to then disseminate this to their clinical teams. The course comprised thirteen training days over a period of 18 months, with theoretical input provided by members of the training team or invited specialist speakers, and action learning. The programme also involved input from carers who shared their personal experiences. In addition to the thirteen training days champions spent a full day in a day setting where the emphasis is on social interaction and mental stimulation rather than physical care.

Evaluation indicated that the Dementia Champions believed that the carers’ personal experiences, role modelling by the training teams, and the experience acquired during day opportunities had directly enhanced care.

1.4 Political responses

Recognition that the knowledge and understanding of dementia amongst health and social care staff, including non-specialist staff in general hospital settings and/or Accident and Emergency impacts on the experiences of people with dementia and their carers has attracted increasing attention (e.g. Scottish Government, 2011b). The Scottish Dementia Strategy (2010) states that:

Staff working with people with dementia need to have the right skills and knowledge to deliver services in a way which treats people with respect and dignity and which improves their quality of life and wellbeing.

Two recently published documents are of particular relevance, Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families, and carers (NHS Education for Scotland and Scottish Social Services Council, (NES/SSSC) 2011), and Common Core Principles for Supporting People with Dementia: A training guide for the social care and health workforce (The Department of Health, 2011).

The Department of Health Guide, which includes eight core principles, aims to build the confidence of health and social care staff, as well as people who come into contact with people with dementia in another setting. It does not distinguish between the levels of expertise required by members of staff associated with their role.

The NES/SSSC Framework details the knowledge and skills all health and social services staff should aspire to when working with people with dementia, their families and carers. The document, which is designed to be used in a number of ways e.g. personal, service provider, and organisation, presents information relating to skills and behaviour relating to dementia care at four levels depending on level of contact the reader/user has with people with dementia and their families:

1. Dementia informed practice: baseline knowledge and skills for all staff
2. Dementia skilled practice: staff with direct and/or substantial contact
3. Enhanced dementia practice: regular and intense contact, providing specific interventions, and/or direct/manage services
4. Expertise in dementia practice: expert specialist role

Staff are encouraged to use the Framework individually to enhance their own knowledge as well as in supervision/review to identify training needs. It can also be used at an organisational level to support staff development, or when working with people with dementia and their families to ensure that they are aware of services available and their rights.
SECTION 2: The Dementia Champions Programme 2011/2012

Section 1, above, provided information relating to the factors that prompted the Scottish Government and NHS Education for Scotland to commission work focusing on dementia, which in turn led to the Dementia Champions Programme 2011/2012. This sections presents information relating to the aims of the programme, the development and delivery team, the programme itself, and participants.

2.1 Aim of programme

To develop, deliver, and evaluate a training programme to prepare NHS and Social Service Dementia Champions as Change Agents for practice.

Specific objectives:

People who have completed the Dementia Champions training programme will, in line with their role and responsibilities, be able to:

1) Understand, recognise and respond to the impact of the physical, emotional, social, cultural and spiritual environment on the maintenance of rights, choice, identity, dignity and equity for the person with dementia, in an acute hospital setting.

2) Understand, identify and respond with evidence based best practice, to the physical and mental health issues that may affect the individual course of a person’s journey through care in the acute hospital environment.

3) Understand and identify the complexities associated with dementia in the acute hospital setting that may have legal and ethical implications and act to safeguard the best interests of people with dementia, families and carers.

4) Understand, apply and evaluate a range of interventions to reduce stress and distress and promote functional capacity and quality of life for the person with dementia, in the acute hospital setting, paying particular attention to demonstrating kindness, caring and compassion.

5) Understand and implement leadership and change agent skills and knowledge to enhance and improve the care of the person with dementia in every area of their influence, utilising existing and developing quality improvement systems, sharing good practice forums and knowledge networks.

2.2 The project team

Building on earlier work carried out in NHS Dumfries and Galloway (Waugh et al, 2011), individuals with an interest in the care of people with dementia from the University of the West of Scotland and staff from Alzheimer Scotland developed and submitted a successful bid to Development, Delivery and Evaluation of a Training Programme to Prepare NHS and Social Services Dementia Champions as Change Agents. The work has been funded by the Scottish Government through NHS Education for Scotland.
Members of the team responsible for delivery of the face to face sessions included Anna Waugh (UWS) and Barbara Sharp (AS), Margaret Brown (UWS) and Jenny Henderson (AS), Jo Oliver (UWS) and Julie Miller (AS), and Angela Kydd (UWS) with support from another team member. The aim was to have the same individuals on each site wherever possible. When this did not prove possible, team members either moved to other venues to provide cover or additional staff including Raymond Duffy (UWS) and Kevin McKay (AS) provided cover. Brian Johnson (UWS) undertook the role of Moderator for all written work, and Pauline Banks (UWS) took responsibility for the evaluation with support from other members of the team. Administrative support was provided by Jacqui Hunter (UWS, Dumfries), Helen Kane (UWS, Hamilton), and Patricia McQuarrie (AS, Glasgow). Kirsty Wilson (AS) provided additional support with the organisation of the Graduation event.

2.3 The Programme

The Dementia Champions training programme was offered as a blended learning programme, comprising five study days with the training team and a half day spent in a community setting in order to provide an insight into the ways in which dementia impacts on those affected at different stages in their journey and in different settings. The five study days were facilitated by members of the training team at four sites, Edinburgh, Glasgow, Hamilton, and Perth. Participants are asked to access and read, watch e-learning resources before each study day; these activities were designed to underpin the face to face sessions. An online forum using UWS virtual learning environment (Blackboard) was established to enable participants to access materials, communicate with each other, and access support from members of the education/evaluation team. Champions who had difficulty accessing or using the VLE were provided with support.

In order to promote engagement, participants were asked to enter into a learning contract covering course attendance, engagement with e-learning materials, completion of an activity within their work environment, and three written tasks.

Study days were divided into two main sessions, one in the morning and one in the afternoon, group activities, and visits from a number of invited speakers and guests including carers (Study day 2), Alzheimer Scotland (Study Day 3), the RNIB (Study Day 3), Teresa Douglas, Programme Lead Dementia, NHS Education Scotland, and Hugh Masters, Nursing Officer, Scottish Government (various visits).

Table 1: Timetable

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<td><strong>Day 1:</strong> Introduction to the course and its aims</td>
<td>Person Centred Care</td>
<td>♦ Access and complete 'Recognising and assessing care needs' in the Acute Care Dementia Learning Resource. ♦ View the 'Coping with Dementia' DVD</td>
</tr>
<tr>
<td><strong>Day 2:</strong> Person centred screening and assessment</td>
<td>Vulnerability Issues Working with Carers</td>
<td>♦ Access and complete 'Recognising and assessing care needs' in the Acute Care Dementia Learning Resource. ♦ View the 'Coping with Dementia' DVD</td>
</tr>
<tr>
<td>Morning</td>
<td>Afternoon</td>
<td>Preparatory work</td>
</tr>
<tr>
<td>---------</td>
<td>-----------</td>
<td>------------------</td>
</tr>
</tbody>
</table>
| **Day 3:** The Hospital Environment and Fundamentals of Care | Legislative Frameworks | ✦ Access and complete 'Meeting the needs of the person who is distressed' in the Acute Care Dementia Learning Resource.  
✦ View the 'Spirituality' DVD.  
✦ Read 'Coping with Dementia: a practical handbook for carers'  
✦ Legislative frameworks exercise |

| Day 4: Communication, stress and distress | End of Life Care | ✦ Access and complete 'Leaving the ward' in the Acute Care Dementia Learning Resource  
✦ Access Spiritual Care Matters |

| Day 5: Planning for Discharge | Ending the Programme and moving forward | |

In addition to the Study Days and accessing pre-course materials, participants were asked to complete and report on three activities over the course of the Programme. Further details of this aspect of the programme are included in the section relating to evaluation, Table 3, page 12. Completion of the Programme, enabling participants to become Dementia Champions, required submission of all three written assignments completed to a satisfactory standard and attendance at 80% of the Study Days.

### 2.4 Recruitment

NHS Boards were provided with information about the programme and asked to identify appropriate staff to undertake the programme; the importance of line managers providing support for participants throughout the duration of the programme was emphasised. NHS Education for Scotland (NES) allocated places. Figure 1 shows the stages involved in recruitment, examples of the documents used are included in the appendix, page 55.
Figure 1: Flow Chart: stages involved in recruitment and selection of participants

FLOW CHART TO GUIDE THE NOMINATION AND APPLICATION PROCESS

PARTICIPANT IDENTIFIED BY SENIOR SPONSOR
Please refer to Attachment 2 Information & Guidance for Senior Sponsors

PARTICIPANT ISSUED ATTACHMENTS 3 & 4
Information & Guidance for Participants Application Form

PARTICIPANT COMPLETES APPLICATION FORM PART A AND RETURNS TO SENIOR SPONSOR

SENIOR SPONSOR COMPLETES APPLICATION FORM PART B AND RETURNS TO PARTICIPANT

PARTICIPANT RETURNS APPLICATION FORM TO NES BY 1ST SEPTEMBER 2011

NES CONFIRMS PARTICIPANTS WITH NHS BOARD BY 15TH SEPTEMBER 2011

PRE-COURSE INFORMATION SENT TO PARTICIPANTS BY 29TH SEPTEMBER 2011
2.4.1 Participants

One hundred and thirteen health professionals from 14 NHS Boards were initially registered, see Table 2. Seventy-eight (73.6%) were nurses, 20 (18.9%) allied health professions, seven reported being responsible for education, e.g. practice development, three were managers, and one was a Consultant Physician.

Table 2: Participants: NHS Board, initial registrations, and completions

<table>
<thead>
<tr>
<th>NHS Board</th>
<th>No initially registered</th>
<th>No graduated March 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Ayrshire and Arran</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>NHS Borders</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>NHS Dumfries and Galloway</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>NHS Fife</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>NHS Forth Valley</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>NHS Grampian</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>NHS Greater Glasgow &amp; Clyde</td>
<td>19</td>
<td>13</td>
</tr>
<tr>
<td>NHS Lanarkshire</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>NHS Lothian</td>
<td>16</td>
<td>12</td>
</tr>
<tr>
<td>NHS Orkney</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>NHS Shetland</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>NHS Tayside</td>
<td>21</td>
<td>18</td>
</tr>
<tr>
<td>NHS Western Isles</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>NHS National Waiting Times Centre</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>113</td>
<td>93</td>
</tr>
</tbody>
</table>

Nine participants withdrew during the course of the programme. Reasons for withdrawal included long term illness (n=4), family bereavement and work commitments (n=1), and lack of IT skills (n=1). Ninety-three Dementia Champions graduated at a ceremony attended by Nicola Sturgeon, Deputy First Minister and Cabinet Secretary of Health and Wellbeing, held at Dynamic Earth in Edinburgh on 14th March. Ten participants, who were unable to reach the requirements of graduation, are continuing to work towards completion.

2.5 Delivery

The Dementia Champions Programme was delivered across Scotland between October 2011 and February 2012. Twenty-two Study Days were delivered, the five scheduled study days in four locations, and two extra days. The first extra day was scheduled because the first Study Days fell within the October school holidays. Due to severe weather on the 8th of December 2011 participants at both Edinburgh and Hamilton were sent home half way through the day, others were unable to attend due to difficulty with transport. Thus an extra day was organised in Hamilton on 12th of January for those that were unable to attend. The following table provides further details:

Table 3: Location of study days and number of participants

<table>
<thead>
<tr>
<th>Location</th>
<th>October</th>
<th>November</th>
<th>December</th>
<th>January</th>
<th>February</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edinburgh</td>
<td>32</td>
<td>30</td>
<td>21</td>
<td>26</td>
<td>27</td>
</tr>
<tr>
<td>Glasgow</td>
<td>20</td>
<td>23</td>
<td>24</td>
<td>21</td>
<td>22</td>
</tr>
<tr>
<td>Hamilton</td>
<td>21</td>
<td>22</td>
<td>20</td>
<td>22</td>
<td>26</td>
</tr>
<tr>
<td>Perth</td>
<td>27</td>
<td>27</td>
<td>21</td>
<td>29</td>
<td>25</td>
</tr>
<tr>
<td>Hamilton</td>
<td>12</td>
<td>-</td>
<td>-</td>
<td>11</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>113</td>
<td>102</td>
<td>86</td>
<td>109</td>
<td>101</td>
</tr>
</tbody>
</table>
2.6 Evaluation of Dementia Champions Programme

Because of the short timescale of the project, it was not possible to evaluate the impact on service delivery using objective measures; however, it was possible to measure satisfaction with the training programme, and 'distance travelled' in terms of participants’ achievement of learning outcomes. In order to do this, participants were asked to:

a) Complete a questionnaire/evaluation survey at the end of each of the study days
b) Complete the Approaches to Dementia Questionnaire (ADQ) (Lintern and Woods, 1996) prior to commencing the programme and again at the end
c) Complete a questionnaire/evaluation survey at the end of the programme
d) Carry out and submit reports relating to three work based tasks, see table 4.

Table 4: Work-based tasks/assignments completed as part of the Dementia Champions Programme

<table>
<thead>
<tr>
<th>Assignment</th>
<th>Activity</th>
<th>Written work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community reflection</td>
<td>Arrange and attend a community placement</td>
<td>A reflective account of experience (1,000 words)</td>
</tr>
<tr>
<td>Clinical Evaluation &amp; Action Planning</td>
<td>Carry out an evaluation of own clinical area, using the 'Supporting Change' tool.</td>
<td>Report of activities. (2,000 words max)</td>
</tr>
<tr>
<td></td>
<td>Identify and prioritise key areas of need, focusing upon Indicators 1-4</td>
<td></td>
</tr>
<tr>
<td>Change Assignment</td>
<td>Plan, with own team changes/ actions to take place</td>
<td>Report of activities. (2,000 words max)</td>
</tr>
<tr>
<td></td>
<td>Carry out the changes/ actions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Evaluate 'work done so far' against the elements of good practice</td>
<td></td>
</tr>
</tbody>
</table>

Participants were asked to consent to their written work contributing to the evaluation of the programme. An application for ethical approval for the programme evaluation was submitted to the University of the West of Scotland Research Ethics Committee, and approval granted on 7th October 2011.

The remainder of the report is divided into three sections:

1. Participant evaluation of undertaking the programme
2. Distance travelled
3. Discussion and recommendations
SECTION 3: Participant evaluation of undertaking the programme

A questionnaire evaluation survey was developed for completion following each of the study days focusing on the specific content and stage in the programme. Participants were asked to complete the questionnaires before they left in order to maximise responses. However, a number of participants failed to complete evaluation forms for a variety of reasons and thus the number of responses does not always correspond to the number of people who attended on each day. The following table sets out the topics that were covered in each of the evaluations, and the number of responses received:

Table 5: Topics included in evaluations questionnaires by Study Day

<table>
<thead>
<tr>
<th>Topic</th>
<th>Day 1 (n=109)</th>
<th>Day 2 (n=95)</th>
<th>Day 3 (n=86)</th>
<th>Day 4 (n=68)</th>
<th>Day 5 (n=98)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approaches to Dementia Questionnaire</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Satisfaction with course pack</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction with pre-Study Day activities and materials</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Study Day content and materials</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Venue and catering</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Virtual learning environment (VLE)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Tutor support</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Recruitment to the course</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delivery of the Dementia Champions Programme</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Value of work-based tasks/assignments</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Best and least favorite aspects of the Programme</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Self efficacy relating to role of Dementia Champion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

3.1 Joining the programme

It can be seen from the flow chart, Figure 1, page 10, above that ‘Dementia Champions’ packs including learning materials and information about the programme were sent out to participants’ workplaces in advance of the course commencing. Participants were asked how they had felt when they received their pack through the post, and if the information provided had been sufficient and useful. Eighty-one participants (74.3%) indicated that the information provided had been sufficient and useful; four indicated that it was not sufficient/useful, and ten were unsure.
Overall thirty-four participants reported that they had felt positive about receiving their packs, expressing feelings of anticipation:

- Excited, felt it was a worthwhile aspect to be involved in
- Grateful, information looked interesting and good quality

A small number of participants (18) expressed mixed feelings:

- Excited, but also with trepidation

Others (34) reported feeling anxious or overwhelmed:

- A bit overwhelmed as I didn't really know what to expect about the course
- Initially anxious

Fourteen participants drew attention to the amount of work involved:

- I got an inkling that this was going to be more work than I had been led to believe
- Implies a lot of work ahead

Unfortunately, it transpired that although study packs had been sent out two weeks before the first Study Day, a number of participants had not received them, or had only recently received them:

- Hurried, as only received night before first training
- Only got yesterday, felt unprepared

Packs were sent to participants’ workplaces and in some instances sat in mail rooms or with managers rather than being passed on immediately on receipt. Thus, a number of participants indicated that they had joined the course at very short notice and, in some cases did not think that they, or their line managers, understood the amount of work that would be involved in undertaking the programme:

- Wasn't given much choice about doing the course didn't really feel it was a good time for me. However, I do feel it is beneficial for me and hopefully the ward and our patients
- Don't think S.C.N has proper insight to importance of course and amount of study required

### 3.2 Virtual Learning Environment (VLE) and Pre-Reading

Prior to each Study Day participants were asked to access and read or view material available on the VLE site. These materials underpinned the activities carried out on the Study Days. Participants were asked to indicate on a five point scale from Very useful to Not at all useful, how useful they found each activity – the higher the score the more useful each activity was perceived to be. The following table indicates that the majority of materials were rated positively with only Legislative Frameworks having a mean rating of less than 4.0. Further information relating to the evaluation of pre-course materials is included below.
Table 6: Evaluation of pre-course materials, number of participants who accessed materials and mean rating: the higher the score the more useful materials were perceived to be

<table>
<thead>
<tr>
<th>Day</th>
<th>Materials</th>
<th>Freq.</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The ‘Facing Dementia’ book and DVD</td>
<td>80</td>
<td>4.19</td>
</tr>
<tr>
<td>1</td>
<td>Charter of Rights for People with Dementia &amp; their Carers in Scotland</td>
<td>88</td>
<td>4.38</td>
</tr>
<tr>
<td>1</td>
<td>Coming into the ward</td>
<td>89</td>
<td>4.37</td>
</tr>
<tr>
<td>2</td>
<td>Recognising and Assessing Care Needs</td>
<td>92</td>
<td>4.23</td>
</tr>
<tr>
<td>2</td>
<td>Coping with Dementia</td>
<td>80</td>
<td>4.14</td>
</tr>
<tr>
<td>3</td>
<td>The Care experience</td>
<td>85</td>
<td>4.27</td>
</tr>
<tr>
<td>3</td>
<td>Legislative frameworks</td>
<td>78</td>
<td>3.95</td>
</tr>
<tr>
<td>4</td>
<td>Meeting the needs of the person who is distressed</td>
<td>59</td>
<td>4.33</td>
</tr>
<tr>
<td>4</td>
<td>Spirituality DVD</td>
<td>38</td>
<td>4.82</td>
</tr>
<tr>
<td>4</td>
<td>Coping with Dementia: a practical handbook for carers</td>
<td>66</td>
<td>4.27</td>
</tr>
<tr>
<td>5</td>
<td>Leaving the ward</td>
<td>92</td>
<td>4.09</td>
</tr>
</tbody>
</table>

As part of the evaluation of each Study Day, participants were asked about the amount of work involved in undertaking the pre Study Day reading/activities. It can be seen from Table 7, below, that the number of participants who evaluated the pre Study Day reading/activities varied between Study Days. In some cases this was because participants had been unable to access the materials for a variety of reasons, including not having had access to the Dementia Champions pack that had been sent out prior to Day 1. The number of evaluations completed in January was low due to disruption caused by severe weather which had an impact on the time available.

Table 7: Amount of work involved in accessing and completing pre-study day reading/activities: frequency and percentage of participants attending each day

<table>
<thead>
<tr>
<th>Study day</th>
<th>No problem</th>
<th>Quite a bit, but manageable</th>
<th>Too much, difficult to manage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Oct (n=65)</td>
<td>21 19.3%</td>
<td>39 35.8%</td>
<td>5 4.6%</td>
</tr>
<tr>
<td>2 Nov (n=82)</td>
<td>31 32.6%</td>
<td>61 64.2%</td>
<td>0 -</td>
</tr>
<tr>
<td>3 Dec (n=85)</td>
<td>8 9.3%</td>
<td>54 62.8%</td>
<td>23 26.7%</td>
</tr>
<tr>
<td>4 Jan (n=66)</td>
<td>23 33.8%</td>
<td>38 55.9%</td>
<td>5 7.4%</td>
</tr>
<tr>
<td>5 Feb (n=92)</td>
<td>61 62.2%</td>
<td>31 31.6%</td>
<td>0 -</td>
</tr>
</tbody>
</table>

Overall a majority of participants indicated that the work involved in completed activities between Study Days was manageable. However, it can be seen that more than a quarter of those who completed an evaluation in December indicated that the amount of work had been too much, difficult to manage. Participants were invited to comment on the pre-Study Day reading/activities. A number of themes emerged across the Programme including, a) Access to on-line resources, b) Level of work involved, and c) Value of the materials.

a) Access to online resources

The Dementia Champions programme was supported by Blackboard, the UWS virtual learning environment. For some participants who were not familiar, or comfortable, with IT this created challenges. However, help was available at any time and almost all participants were soon adept at using the system. The evaluation following Study Day 3 included questions relating the use of Blackboard. Forty-four participants 51.2% reported that they found it easy or very easy, 39 (45.3%) indicated that they had had a few problems initially but that they had been resolved, and three (4.5%) said that they were not managing to use it. Given that support was available for anyone who was experiencing difficulty it was disappointing that even a small number of participants continued to experience difficulty throughout the programme. Nevertheless, a number
of participants reported having difficulty accessing materials either from the VLE or using YouTube, particularly if trying to do so within their workplace:

Unable to run the DVD’s on computers in workplace due to data protection

Not able to access YouTube on hospital computer

Fortunately, a majority of participants did not experience any difficulty with access:

I find the online material very easily accessible

b) Level of work involved

Some participants reported that they experienced difficulty managing the work associated with the Dementia Champions Programme at the same time as their work role, participants who missed the first Study Day found catching up particularly difficult. It was suggested that it would have been useful to have known about all the pre-course materials at the beginning of the programme:

Would have been helpful on Day 1 to give us five day programme i.e. pre-day activities

And that further guidance relating to the time required for different aspects of the pre-Study Day activities would enable better planning. It can be seen from Table 7, above, that a higher proportion of participants reported difficulty in December – participants indicated that a busy period in the workplace as well as family commitments at this time of year was compounded by deadlines for assignments, making the programme particularly challenging:

Homework request was far too much considering two assignments have to be handed in within a week of each other.

Very time consuming on top of what we have to do already and full time working and other life pressures.

c) Value of the materials

Not all comments were negative; some participants reported that they found the activities and materials useful preparation for the Study Days, highlighting gaps in their knowledge:

Good to do before attending Study Day

The more I read, the more I realise I don't know

Pre-course work is useful to help set the scene for the day

There were a number of specific glitches, for example, following Study Day 4 a number of participants indicated that they had been confused about the requirements:

Accessed document on spirituality as per Blackboard but wasn’t aware of Meeting the Needs of the Person who is Distressed, or Spirituality DVD

Several participants reported that they had found the legislative material particularly difficult to manage:

The legal material was heavy going
Would be easier to read the legislation if it was more ‘user friendly’

Was upset by the difficulty of the pre-course material.

Other comments were mixed, with some participants reporting that pre-course materials did not relate to the content of the study days, and others thinking they did:

The pre-reading has not been utilised within any of the days. It would have been better if they’d explained that they’re separate.

3.3 Study Days

As mentioned earlier each Study Day involved two main sessions; for the evaluation participants were asked to rate each session on a five point scale from Very useful to Not at all useful, the higher the score the more useful the sessions were perceived to be, see Table 8.

Table 8: Evaluation of Study Day sessions, number of participants who completed evaluations and mean rating: the higher the score the more useful sessions were perceived to be

<table>
<thead>
<tr>
<th>Day</th>
<th>Study Day Sessions</th>
<th>Freq.</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction to Programme</td>
<td>83</td>
<td>4.31</td>
</tr>
<tr>
<td></td>
<td>Person-centred care</td>
<td>83</td>
<td>4.37</td>
</tr>
<tr>
<td>2</td>
<td>Person-centred screening and assessment</td>
<td>91</td>
<td>4.26</td>
</tr>
<tr>
<td></td>
<td>Vulnerability and carers</td>
<td>90</td>
<td>4.47</td>
</tr>
<tr>
<td>3</td>
<td>Hospital Environment &amp; Fundamentals of Care</td>
<td>79</td>
<td>4.47</td>
</tr>
<tr>
<td></td>
<td>Legislative frameworks</td>
<td>56</td>
<td>4.34</td>
</tr>
<tr>
<td>4</td>
<td>Communication, stress and distress</td>
<td>65</td>
<td>4.28</td>
</tr>
<tr>
<td></td>
<td>End of Life Care</td>
<td>65</td>
<td>4.31</td>
</tr>
<tr>
<td>5</td>
<td>Discharge from Hospital</td>
<td>95</td>
<td>4.00</td>
</tr>
<tr>
<td></td>
<td>Leadership and change</td>
<td>78</td>
<td>3.91</td>
</tr>
</tbody>
</table>

Participants were also asked whether they thought that each Study Day had been useful overall, and if they had met their objectives/expectations. Table 8, above, indicates that all the sessions were rated positively; the following table indicated that the Study Days were thought to have been useful, overall, and met the majority of participants’ objectives/expectations.

Table 9: Evaluation of Study Day, overall usefulness and whether they met objectives/expectations: percentage of participants

<table>
<thead>
<tr>
<th>Study Day</th>
<th>Usefulness of Study Day</th>
<th>Meeting objectives/expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Useful</td>
<td>Not useful</td>
</tr>
<tr>
<td>1</td>
<td>90.4</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>96.8</td>
<td>2.1</td>
</tr>
<tr>
<td>3</td>
<td>90.7</td>
<td>4.7</td>
</tr>
<tr>
<td>4</td>
<td>91.2</td>
<td>4.4</td>
</tr>
<tr>
<td>5</td>
<td>87.8</td>
<td>4.1</td>
</tr>
</tbody>
</table>
While the above figures are of interest, giving an overview of participants’ views relating to the programme, they lack the depth that can be gained from participants’ comments. The following section, which presents information derived from the open ended questions relating to each of the Study Days, provides further insight:

**Study day 1:** Introduction to Programme (a.m.); (p.m.) Person-centred care (p.m.)

A number of participants indicated that they thought that the first Study Day had not been pitched at the right level:

_Bit too basic_

_I feel this cohort appeared already realistically aware of issues discussed. I felt we could have [been] challenged more_

Other comments concerns related to the link to work roles, the way in which the content related to other sessions and the wider environment, and the level and delivery of materials:

_Bit unsure how I will take this forward within my current role._

_I would have appreciated contextual information re how course/training workshops fit together to meet outcome of Champion training_

_I thought I was coming to standardise procedure through NHS Scotland for dementia patients so that I could go back to my area with pathway which could be used to meet standards_

A number of participants indicated that they had not known what to expect, others had not expected to be required to carry out so much work, or did not link the content to the care of people with dementia:

_Don’t know what expectation I had_

_I was expecting to be given information and advice etc about helping people with dementia in hospital. I hope this happens later_

A small number of participants felt that the programme was overly geared towards nursing:

_Had a nursing bias at times_

Approximately nine out of ten participants rated their facilitators (88.1%), reading materials/handouts (91.7%), discussion (90.8%), and activities/workshops (90.8%) as good or very good. Sixty-five participants (59.6%) indicated that their practice would change as a result of the first Study Day.

**Study Day 2:** Person-centred screening and assessment (a.m.); Vulnerability and carers (p.m.)

The second day included a film made with carers for the Programme, and a visit from local carers. A number of participants reported that they had found Study Day 2 more useful than Study Day 1:

_This session, I felt, was far more enjoyable, relevant and thought provoking. Food for thought…_

_Appeared to get much more information this time in a manner that I enjoyed._
Exceeded my expectations, very enlightening

Participants indicated that they had particularly enjoyed the visits from carers:

- Very informative to meet carers to get realistic view
- Enjoyed listening to the carers’ stories and concerns
- Carers sharing experiences was illuminating and aided understanding

However, some participants found it quite difficult to listen to carers’ experiences:

- I feel a bit sad after today as we have focussed on the bad practice going on.
- Does come across very negative at times towards nursing staff and I do find this quite demoralising

One participant admitted feeling defensive, while others focused on the potential for change:

- Think it is going to be a challenge to change practice
- [I] understand some patients and carers have had bad experiences, but I suppose we can only strive forward to ensure care improves
- Feel inspired and motivated to move forward and lead change, maybe in small ways to begin with, but significant ways

Attention was drawn to the benefits of discussion and networking:

- Group work was good, listening to experiences and ideas from different health boards, starting to network.
- Enjoyed the discussion aspect of the day

**Study Day 3:** Hospital Environment & Fundamentals of Care (a.m.); Legislative frameworks (p.m.)

The third study day involved input from two visiting speakers, the first from Alzheimer Scotland covered legislation, and the second from the RNIB gave an overview of some of the issues relating to vision for people with dementia. Due to adverse weather, several participants were unable to attend the sessions in Edinburgh and Hamilton, which both had to be shortened. An extra session was organised in January to enable participants to cover materials that they had missed.

The pre Study Day reading relating to the legislative framework caused several participants difficulty. However, input from Jim Pearson, Alzheimer Scotland engendered lively discussion and a greater appreciation of the importance of this topic:

- The lecture we were given on the day was excellent and really directly informative about the legislation - it was direct and to the point
- Legislative framework is important - quite complicated if you don't deal with it regularly - thus you would/should seek advice always if/when required
- I am more aware of where to access support if struggling around area of capacity
**Study Day 4:** Communication, stress and distress (a.m.); End of Life Care (p.m.)

Comments relating to day 4 suggest that participants had weathered the difficulties experienced in December, with a majority of comments being positive:

- *This has probably been my favourite session - so valid and applicable - very touching with regard to palliative care*
- *This was probably the best of the four days, excellent,*

Others referred to the case studies presented:

- *Case studies are a good way to promote learning and discussion. I do not feel I have learned anything new today, but reinforces current knowledge.*
- *A.m. session could have been expanded on, more scenarios etc*

**Study Day 5:** Discharge from Hospital (a.m.); Leadership and change (p.m.)

The final day differed from others as it was more interactive. While some participants welcomed the less structured nature of the final day:

- *Felt the interactive session with the ICP was much more useful and enjoyable than a power point presentation*
- *Liked the group communication*

However, it did not suit everyone:

- *Too much discussion - would have liked clearer guidance to discharge planning something for us to measure our practice on …*

It was apparent that some participants had developed a shared identity over the five months of the programme:

- *Very motivating and encouraging to hear how this course has impacted on all the participants, and hear how we are all going to initiate change…*
- *I found it an excellent session today - we were much more relaxed with each other - More vocal and openly sharing our fears, hopes and aspirations*

However, others remained uncertain about whether or not they could instigate change:

- *I think we already know what needs to be done to improve dementia but in the real world we don't have the authority or financial budget to make the changes*
- *I think that the expectations of what it means to be a Dementia Champion have still not been fully explained*

### 3.3.1 Delivery of the Programme

Participants were invited to share their views on the balance between facilitator input, group activities/workshops, and discussion. Ninety-two participants (93.9%) indicated that they thought the balance had been *good or very good*, two thought it had been *poor*, and four did not answer
this question. Participants were invited to include comments. Thirty-nine participants chose to include some comment. Seven comments suggested that there had been too much group work and that groups had not always worked very well:

- Group activities tend to be dominated by stronger members thus not always able to participate
- Group size could be smaller
- Sometimes a little too long on the group work.

Nine participants thought that the group work had been particularly useful and would have liked more:

- More group activities/workshops - I enjoy the challenge

Several participants thought it would have been useful if groups had had an opportunity to move around more and share ideas:

- Mix/rotate the groups more
- More group-work early on in the programme to encourage groups to mix

Participants reported having particularly valued input from people with dementia and family members as well as other external speakers including Alzheimer Scotland, and the RNIB.

- Balance is very good - would like more input from service users and families
- All facilitators good but particularly found input from Alzheimer Scotland and RNIB helpful
- Enjoyed external visitors - perhaps a visit from a care provider so we get a new perspective

A number of participants indicated that they would have liked more input relating to physiology and diagnosis of dementia:

- I would like to have learned more about the pathology and management of dementia

### 3.3.2 Work based tasks and written assignments

Participants were asked to indicate, on a scale from ‘1’ Very useful to ‘5’ Not at all useful, how useful they had found the three assignments: 1) Community reflection, 2) Clinical Evaluation & Action Planning, and 3) Change Assignment. Analysis revealed that all assignments were rated as having been useful, with the half day spent in the community being rated as very useful by a higher proportion of participants than the other two, see Table 10.

**Table 10:** Perceived usefulness of Assignments: mean and standard deviation

<table>
<thead>
<tr>
<th>Assignment</th>
<th>Mean</th>
<th>STD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assignment 1: Community reflection (n=98)</td>
<td>4.28</td>
<td>.871</td>
</tr>
<tr>
<td>Assignment 2: Clinical Evaluation &amp; Action Planning (n=97)</td>
<td>4.10</td>
<td>.895</td>
</tr>
<tr>
<td>Assignment 3: Change Assignment (n=89)</td>
<td>4.02</td>
<td>.929</td>
</tr>
</tbody>
</table>
Forty-nine participants included comments relating to the Assignments. There was a mixture of positive and negative views:

*Have enjoyed all of the assignments and hope I can carry on pushing for the change I have proposed.*

*I did not find the assessment useful at all. I think it was far too much expected especially considering the very short duration of the course.*

Some participants felt that there was a lack of clarity about what was required:

*Felt that remit and expectations of assignments has changed/evolved during direction of course which may have been helpful to know at the beginning …*

*I think that these could have been discussed more in the programme - the start anyway.*

Several participants indicated that there was not enough time allocated to complete Assignments:

*Found it difficult to get time to do Assignments. Work commitments - did not get study time*

*I think I would have benefitted from further study time from my healthcare trust to complete Assignments, as I have used a lot of my own time*

And that the deadlines for submission of assignments were too close together:

*Not enough time between 1-2 assignments*

*Two and three too similar and too little time apart…. Would have preferred them amalgamated*

*They were very close together for submission. Found this difficult along with workload*

Amongst the positive comments, several participants drew attention to the *Supporting Change* workbook which was found to be useful:

*Completing these had been very helpful in focusing our thoughts through use of the [workbook] and helped us come up with a work plan. I feel it would have been beneficial to use the document as a focus for some of the study days*

*The clinical evaluation document is a really powerful tool … I feel this needs more emphasis.*

Participants valued the support provided by tutors:

*Reassurance and ability to discuss with course leaders was vital.*

*Good support from tutors.*

Other comments referred to specific Assignments:

*1st assignment was insightful and enjoyed meeting client group in different environment; was more relaxed than acute setting.*

*Found them useful to stimulate thoughts, challenges, team involvement, although [I] wasn’t aware of this expectation before course.*
An interesting way to reflect upon care whilst implementing change

A number of comments indicated that participants would have liked the Programme to be accredited:

Very challenging to complete within given time frame and existing work load. Lot of work for non-accreditation

It would have made the assignments more meaningful if the work was accredited

Given the amount of time being put into this course it is a shame it’s not being accredited

3.4 Support to undertake the Dementia Champions Programme

3.4.1 Personal Tutors

All participants were allocated a personal tutor who was available and in contact with them between study days. Fifty-three participants (61.7%) reported that they had been in contact with their tutor by email, seven (8.1%) by telephone, and one using text. Thirty-three participants, 55.9% of those who had had contact with their tutor reported that the support that they had received had been very good, 25 (42.4%) that it had been good, and one that if had been very poor.

I am always emailed promptly [by tutor] and feel reassured by correspondence

Really impressed by the speed with which [tutor] responds to email communications

Fifty-five participants (64.0%) reported that they had had contact with their tutors between study days, 30 (34.9%) had not had any contact.

Not needed to contact so far but I know if I can if I need to

Haven't needed to contact tutor as yet

It appeared that the majority of participants used the tutor system to suit their needs, catching tutors on course days, and making contact with another tutor if their tutor is not available.

3.4.2 Support in the workplace

Participants were asked how satisfied they were with the support that they were receiving in their workplace, for example to undertake pre-course activities, the community placement, and assignments. Twenty-four participants (41.9%) were either satisfied or very satisfied, 37 (43.0%) reported that they were neither satisfied or dissatisfied, and eleven (13.6%) were dissatisfied. This section prompted the largest number of comments, with almost all participants adding something to their evaluation form.

Some participants reported that they had difficulty managing the workload, those who were ‘sent’ on the course rather than volunteering, reported that they were not given adequate information relating to the course prior to beginning. While some participants were being supported to complete tasks within their workload, others were required to undertake their community experience within their own time; and a majority were undertaking pre-Study Day activities at home due to time pressure and inability to access course materials on NHS computers. While we recognise that there are pressures within the NHS, NHS Boards were asked to identify participants and to support them while they undertook the Programme.
3.5 Most and least useful aspects of Dementia Champions Programme

Finally, participants were asked to think of all the learning materials that they had accessed online, the five Study Days, and the three assignments and to indicate what had been the most useful and least useful parts of the programme for them, and why. Eighty-eight participants responded to the question relating to positive aspects of the Programme:

Table 11: Positive aspects of the Dementia Champions programme

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Freq.</th>
<th>Aspect</th>
<th>Freq.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online learning resources</td>
<td>15</td>
<td>Legal aspects</td>
<td>6</td>
</tr>
<tr>
<td>Community placement and reflection</td>
<td>14</td>
<td>Multiple tools discussed</td>
<td>5</td>
</tr>
<tr>
<td>Meeting other people facing similar challenges</td>
<td>13</td>
<td>Managing stress and distress</td>
<td>4</td>
</tr>
<tr>
<td>Supporting Change workbook</td>
<td>9</td>
<td>ICP</td>
<td>3</td>
</tr>
<tr>
<td>Carers’ visit and case studies</td>
<td>8</td>
<td>Access to Domus room</td>
<td>2</td>
</tr>
<tr>
<td>Everything</td>
<td>8</td>
<td>Study day 3</td>
<td>3</td>
</tr>
<tr>
<td>Assignments</td>
<td>7</td>
<td>Study day 4</td>
<td>1</td>
</tr>
<tr>
<td>Group discussions</td>
<td>6</td>
<td>Study day 5</td>
<td>2</td>
</tr>
</tbody>
</table>

Sixty-four participants included comments relating to aspects of the Programme that they perceived to be least useful or caused them difficulty:

Table 12: Negative aspects of the Dementia Champions programme

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Freq.</th>
<th>Aspect</th>
<th>Freq.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Internet/VLE</td>
<td>8</td>
<td>Lack of time</td>
<td>2</td>
</tr>
<tr>
<td>Assignments</td>
<td>6</td>
<td>‘The way forward’: lack of clarity</td>
<td>2</td>
</tr>
<tr>
<td>Legal aspects</td>
<td>4</td>
<td>Carers’ visit and case studies</td>
<td>1</td>
</tr>
<tr>
<td>Lack of relevance to specific role</td>
<td>4</td>
<td>Study day 1: level of input and lack of clarity</td>
<td>8</td>
</tr>
<tr>
<td>Community placement and reflection</td>
<td>2</td>
<td>Study day 5: (no specific reason given)</td>
<td>3</td>
</tr>
</tbody>
</table>

3.6 Summary

The evaluation of the Dementia Champions programme was predominantly positive, with participants rating the Study Day sessions, pre-course materials, work-based tasks/written assignments, and delivery positively. However, there were issues relating to participants’ initial understanding of the programme, and the level of work involved which many of them had not anticipated. We will return to these issues in Section 5.
SECTION 4: Impact of the Dementia Champions Programme: ‘distance travelled’

As discussed earlier we were keen to carry out a robust evaluation of the Dementia Champions Programme. We were conscious that we were not in a position to evaluate the impact on practice due to the short nature of the programme which was delivered over five months. In order to address this limitation, participants were asked to complete a number of tasks and submit written reports. The aim of the written work was to gauge ‘distance travelled’ whilst undertaking the programme. The following section presents the findings in two sections, the first focusing on the impact on participants themselves, followed by the potential for change following the programme. Both sections include analysis of qualitative and quantitative data.

4.1 Impact on Participants

Information relating to the impact on participants was derived primarily from scores derived from the Approaches to Dementia Questionnaire completed at the beginning of the programme and again at the end, and reflections included within the written work submitted following the half day spent in a community setting for people with dementia.

4.1.1 Approaches to Dementia Questionnaire

Participants were asked to complete the Approaches to Dementia Questionnaire (ADQ) (Lintern and Woods, 1996) prior to attending the first study day and on final day (see appendix, page 70). This 19 item scale, which was based on factor analysis of scores derived from 200 care staff in the UK, provides a Total score (range 19-95), and two sub-scores, Hope and Person Centred. It has been found to be reliable, Cronbach’s alpha Total Score 0.83; Hope 0.76; Person-Centred 0.69. Test retest reliability is reported at 0.76 for Total Score, Hope 0.70, and Person-Centred 0.69. The scores derived from ADQ relate to scores derived from the Dementia Styles Questionnaire, responses to video vignettes and observed staff behaviour indicating that the scale is valid. Lintern and Woods report that the sub-scale, Hope, predicts staff behaviour in terms of social interaction with people with dementia, involvement in activities and stimulation and the quality of care interactions.

Unfortunately not all participants had completed the ADQ prior to attending the first study day. Some participants completed it on the first day or emailed their responses. However, because this was a ‘before’ measure, responses that were not received immediately could not be included. Overall 83 completed questionnaires were received at Time 1, and 89 at Time 2, the final study day. Table 13 below presents the mean and standard deviations at Times 1 and 2.

Table 13: ADQ scores at Times 1 and 2: mean and standard deviation

<table>
<thead>
<tr>
<th></th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>Total</td>
<td>80.66</td>
<td>6.06</td>
</tr>
<tr>
<td>Hope</td>
<td>31.0</td>
<td>3.74</td>
</tr>
<tr>
<td>Person-centred</td>
<td>49.73</td>
<td>3.96</td>
</tr>
</tbody>
</table>

As mentioned above, not all participants had completed the questionnaire prior to attending on the first day, and not all participants attended/completed the questionnaire on Study Day 5. Scores derived from only 60 participants could be matched to allow repeated measure analysis, thus analysis was carried out using both paired sample and independent sample t-tests in order to avoid excluding any data, see Table 14.
### Table 14: Analysis of ADQ scores derived from participants at Times 1 & 2

<table>
<thead>
<tr>
<th></th>
<th>Paired sample</th>
<th>Independent sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>$t_{(59)} = -2.743$, $p = .008$</td>
<td>$t_{(169)} = -2.743$, $p = .014$</td>
</tr>
<tr>
<td>Hope</td>
<td>$t_{(59)} = -1.808$, $p = .076$</td>
<td>$t_{(169)} = -1.808$, $p = .146$</td>
</tr>
<tr>
<td>Person-centred</td>
<td>$t_{(59)} = 2.166$, $p = .034$</td>
<td>$t_{(170)} = 2.166$, $p = .040$</td>
</tr>
</tbody>
</table>

It can be seen from Table 14 above, that there was a significant shift towards a more positive approach to dementia between Time 1 and Time 2, with the bulk of this being accounted for by the items associated with Person-centred approaches. Although it is customary to accept 95% cut off as evidence of significance in a study of this nature, it is of interest to notice that the shift in Hope identified in the paired sample analysis was significant at the 92% level, which given the relatively small number of participants included in this analysis ($n=60$) is promising.

While a statistically ‘significant’ finding can be rewarding in itself, the ADQ scores only relate to two points in time. The addition of qualitative data derived from participants’ written work had the advantage of providing information relating to the process of change.

#### 4.1.2 Dementia Champions Community placements

The first work-based activity involved participants spending a half day in a community setting involving people with dementia, the aim being for professionals working in an acute environment to gain an understanding of what life is like for people with dementia when they are not affected by another condition resulting in their admission to hospital. Participants were asked to organise their own placements, with the understanding that identifying a potential venue would increase their knowledge of resources for people with dementia in their own locality.

Participants reported having visited a range of venues organised by Alzheimer Scotland, the NHS, local authorities, and third sector organisations including:

- Day centres ($n=61$)
- Dementia cafes ($n=8$)
- Shadowed a dementia nurse specialist/care worker ($n=7$)
- Alzheimer Scotland initiatives including music café, Forget-me-not initiative which involves volunteers visiting people with dementia who are in care ($n=7$)
- Specialist assessment units ($n=4$)
- Acute settings including a secure unit ($n=3$)
- Care homes ($n=3$)
- Sheltered housing complex ($n=2$)
- An evening session in a community setting ($n=1$)
- A memory clinic ($n=1$)
- The younger persons’ support service ($n=1$)

Following the community placement participants were asked to submit a reflective account of their experiences. Overall 100 reflective accounts were submitted, and the following section presents a qualitative analysis of these reflective accounts. Quotations are included to illustrate specific issues and are not representative of the views or experiences of dementia participants as a whole.

In general participants spoke positively of their community placement, highlighting the work of their community colleagues, volunteers and informal carers, and acknowledging the benefits of knowing more about support in the community:

*I did not know that these services existed and I now feel that I can support people and carers with dementia more effectively …*
4.1.2.1 Expectations

Several participants (n=31) reported that they had felt apprehensive about organizing and attending their placement:

- I felt very apprehensive prior to my visit.
- I was hesitant to arrange my placement there. I was aware that I was apprehensive about spending time with people with dementia…

In some cases apprehension was linked to stereotypical images of either the venue or the people who would be there:

- I imagined a regimented, clinical environment which was managed by a strict schedule.
- Before visiting the day care centre I possibly had a fairly tunnel vision of what day care was all about, perhaps seeing it as a kind of babysitting service.
- I was trying to imagine caring for so many people with dementia all the one unit, and how depressing, and stressful this was going to be.
- I had visualised a group of people wandering about, confusion and the inability of individuals being able to hold a conversation.

Other participants reported being unsure what to expect:

- I felt anxious, nervous, and apprehensive and did not know what to expect.
- As someone who has never had to deal with dementia from a personal perspective I found it daunting.

4.1.2.2 A different environment

Participants spoke of being out of their comfort zone:

- I was initially very apprehensive at attending [the dementia café] as I had never heard of a dementia café before and as such I had no preconceptions of what to expect or what happens at one and as such I was completely out of my comfort zone.
- I did still feel nervous and I feel this was due to the fact of coming out of my comfort zone of my clinical area…

They also expressed concern that they might be perceived to be ‘intruding’ and would be unwelcome:

- I was worried that the group may view me as an outsider or a nuisance or even be suspicious as to why I was there.
- I was apprehensive about attending the Dementia Cafe, as I did not want to be seen as invading a place that people with dementia and carers considered safe.

While some participants reported having had mixed feelings about their community placement, others predominantly saw it as an opportunity (n=10):
Prior to my visit I felt some trepidation as I felt that it would highlight huge deficits in the care that we deliver in an acute setting. I was also intrigued to view how people were managed in this setting and the interactions that take place.

I was looking forward with interest to the experience and keen to see what I could learn from the experience that may be of benefit for individuals with dementia and their families within the acute hospital setting …

Participants drew attention to their usual work environments and the difference between the acute and community settings:

I have only really been exposed to the care of the patient with dementia in busy and acute medical settings.

4.1.2.3 Previous experience of working with people with dementia

Perceptions of the probability of people having dementia on individual wards varied, for example referring to a care of the elderly ward:

There is often a large percentage of patients who suffer from Alzheimer’s disease or dementia in addition to their acute medical condition.

Compared to a vascular surgery/amputee rehabilitation ward:

On occasion, we have persons with dementia on our ward.

Those who worked in an acute setting with limited contact with people with dementia had ‘further to travel’ in terms of understanding dementia than their colleagues whose roles encompassed dementia:

I have had limited exposure to people with dementia, having worked mainly within the acute sector.

As a general trained nurse, my knowledge and understanding of mental illness is very limited.

My current role is to support the implementation of the Scottish Dementia Strategy

Team leader in Dementia Liaison Team OT

Only one person reported that the venue they visited was not a model to be emulated:

Negative – felt that place was not good…

4.1.2.4 Benefits of the community placement

For many participants seeing people with dementia, and their families, in a more relaxed environment had been valuable (n=41):

I found it useful to witness people in a ‘Dementia Friendly’ environment as it allowed me to appreciate, a bit more, how unsettling, upsetting and probably scary admission to a general ward may be.
Participants reported that their perceptions had been challenged and altered, resulting in an enhanced understanding of the impact of dementia on individuals and their families:

I can now see my view of people with dementia was extremely narrow, and without realising it I had pigeon-holed them into a group of people who are distressed and upset most of the time.

Prior to my time spent in a day care facility … I do not think I fully appreciated the impact a diagnosis of Dementia has, not only on the individual, but also on the family and carers.

This reflection has reinforced the fact that there is a great deal that I don’t understand about dementia… how it can change the whole dynamics of a couple, or family.

My vision of a person with dementia has changed, instead I see an individual with a life story which gives me insight into the needs of that individual.

Participants reflected on the amount that they had learned from a half day in a different setting:

I must admit that my views have been very much changed for the better after this visit.

I have learned much from my placements and the course

and expressed their surprise at the positive attitudes that they experienced in the community and how much they had enjoyed an activity that they had initially felt ambivalent about:

The most surprising thing for me was the amount of genuine laughter I observed throughout this day.

The atmosphere was fun and spontaneous, (I hadn’t expect to enjoy my time there so much).

I enjoyed my experiences in the community and feel I now have a different perspective on things than when working in the ward.

Attention was drawn to the need to question accepted practice in acute settings, and the potential for implementing some of the approaches that they had seen in the community into their own workplace:

There are activities and resources that are used within community settings that could be easily used within a clinical environment.

[The visit] has opened my mind in such a positive way, much more than I would have expected.

The home visit and this reflection have reinforced in me the need for patience and understanding, rather than control and compliance…

4.1.2.5 Less positive impact of community placement

A number of participants (n=6) indicated that their community placement had made them feel uncomfortable and question their own practice:

Before visiting the day care centre had I been asked how I dealt with patients with dementia I would have said, ‘I do it well’… on reflection, although I feel I do strive to deliver best care, I do sometimes let this group of patients down
In the acute care setting we aim to deliver person-centred care but in reality, after observing this support visit, I do not think we really are.

I personally feel inadequate as a nurse caring for these patients. I feel that these patients are let down by the acute sector of the health service

I feel that within the acute setting we tend to examine patients from the outside-in rather than the inside-out.

Suddenly I am aware of my shortcomings. I now know why I feel uncomfortable.

One participant reflected on her loss of role in the community environment:

In my professional role, I am always used to being in control, and I did not feel in control at all [in community placement], I would go as far to say I felt lost in what I perceived to be an alien environment to me.

### 4.1.2.6 Motivation

Despite some participants reporting a loss of confidence following their community placement, a significant proportion of the participants (30) reported that they had felt motivated to make changes:

As the programme progresses, I am becoming more motivated and passionate about driving change to facilitate better care for these patients in the future.

My time in the community has given me positive motivation to make some changes in my work area.

A Senior Charge Nurse indicated that she felt her community placement had been so beneficial that she wanted other staff to benefit from similar opportunities:

I found attending the dementia cafe a very positive and beneficial experience, especially in regards to the patients sharing their experiences … as a result of the visit, I am recommending to my nurses that they attend one of the dementia cafes.

A number of participants highlighted the importance of staff attitudes:

The senior staff member who showed me around was very enthusiastic and had a very positive attitude. She just exuded pride in their work which I found very refreshing in the modern NHS, and if I’m honest I felt a bit envious of her enthusiasm.

The day centre staff’s enthusiasm filled me with hope, and I now look forward to instilling some of that in my colleagues.

One participant acknowledged that she might have to begin with her own attitude:

I realised that the area that needed developed in my ward was staff attitudes and motivation… as Charge Nurse in the ward I need to start with my own attitude and not be so negative towards the possibility of change and the need to change.
4.1.2.7 Families and informal carers

Participants drew attention to their enhanced understanding of the importance of involving family members and other informal carers in the care of people with dementia in all settings:

The experience [community placement] has also highlighted the importance of involving carers when planning care for people with dementia. This is something I feel we fall down on in the hospital, often viewing their input as interfering and unrealistic within the acute environment.

I feel it is essential that family members and carers are involved as much as possible in the care of an individual with Dementia.

Participants acknowledged that policies and procedures designed to protect patients can have a detrimental impact if imposed without reference to individual circumstances:

[Family involvement] is something that I feel is not always well accommodated within my own ward environment due to policies such as ‘Protected mealtimes’ being taken to an extreme level.

Lack of understanding dementia is evident as we ask family, friends or carers to leave while we take the patient through the admission process. Not only is the person with dementia in an unfamiliar environment, but we also isolate them from the people who truly know them.

Reference was also made to the potential unintended impact of safety procedures:

We need to carefully carry out risk assessments to ensure we strike a balance between risk taking and attaining a degree of independence.

A number of participants drew attention to the input of volunteers, a source of support not currently used within their wards, which was perceived to be beneficial for both the patients with dementia and the volunteers:

I found it a very useful hearing about the ‘Forget-me-not’ project and learning more about how volunteers can improve the lives of people in care settings.

I now feel that volunteers can bring another dimension to the care of the patient. The support and fulfilment that the volunteers gain was something that I admit to underestimating.

4.1.2.8 Maintaining momentum

The above quotations demonstrate that the community placements had a significant impact on the participants and that many gained ideas that could be taken back to their own wards. However, one participant drew attention to the scale of change needed:

I left the community setting with an initial feeling of elation from witnessing such good practice; this however, was quickly replaced by the enormity of the task ahead.

Participants stressed the difference between acute and community settings, and the difficulties of trying to get everything right:

The ‘Forget me Not’ campaign challenges stereotypical ideas about old age and dementia, originating in an Audit Commission Report (2000) *Forget Me Not: Mental Health Services for Older People*. 
The ward environment is very busy. People from all disciplines asking questions, carrying out examinations, performing procedures, all the coming and going of other patients and relatives and not forgetting the unfamiliar sounds and smells.

I often found that nursing patients with dementia seemed somewhat demanding, and at times stressful because their needs were often unpredictable, time consuming and frequently unmet. This often left me feeling inadequate and overwhelmingly frustrated …

One participant suggested that future input should take cognizance of the very real difficulties that exist for staff in acute settings as well as focusing on shortcomings:

In future courses it might be beneficial to focus on the pressure and challenges experienced by ward staff caring with people with dementia in an acute setting whilst they are in an acute delirium state due to illness. Highlighting some areas of good practice as well as bad; therefore encouraging improvement of practice in a more positive way.

Despite acknowledging potential difficulties, participants reported that they were already developing plans for change:

Acute settings are very different to those in the community, but I think that I can implement some changes to hopefully improve things.

Clarifying my thoughts will, I feel, better equip me in completing an evaluation of an area within my remit, participate, and support staff members to reflect on this process, and allow the team to move forward in the change process.

4.1.3 Summary: impact of dementia champions programme on participants

The above section presented an analysis of data derived from the ADQ which revealed a shift towards a more person centred approach. Following this the findings of an analysis of the reflections submitted by dementia participants after their community placement, which was undertaken between study days two and three, were presented.

One of the benefits of reflection is that, by definition, it encourages those involved to take time to consider a particular phenomenon – in today’s busy world too often individuals react and move on. It is apparent from the champions’ reflections that they had taken time to consider the differences between practice in the community and their own acute areas. They had also put these differences in context, considering what could be adapted for use in an acute area. The data gave some understanding of the journeys that some of the participants had undertaken during the programme.

Participants acknowledged their apprehension, and in some cases resistance, to arranging and undertaking a community placement which would involve stepping outside their normal work environment and ‘comfort zone’. For some participants, current practice in their day to day working lives compared unfavourably with the person-centred approaches to supporting people with dementia in the community that they encountered. These differences resulted in some participants feeling uncomfortable, and questioning the values within their own workplace. For others the differences between practice in their community placement and current workplace immediately engendered a commitment to instigate change, adapting practice seen in the community to their own areas. Ultimately all participants were able to explore the potential for reappraising the way in which people with dementia are cared for in acute settings, identifying and building on good practice. However, it was apparent that some of the ‘confidence’ evident on Study Day 1 had been dented. The honesty involved in some of the reflections was considerable and we are very grateful to the participants for sharing their thoughts and experiences with us.
4.2 Potential for the future

This section begins with the reflections and reports relating to assessment of participants’ workplaces and plans for the future undertaken included in the second work-based task and written assignment, *Clinical Evaluation and Action Planning*, undertaken using the *Supporting Change* workbook. This is followed by data derived from the third work-based activity and written work, *Change Assignment*. Finally data relating to participants’ self reported self-efficacy and stated intentions to instigate change provided further understanding of the impact of the programme on the future Dementia Champions.

In order to augment the interesting findings reported above we now turn to the qualitative data derived from the second and third assignments. The second activity involved participants carrying out an evaluation of their own work environment facilitated by the *Supporting Change* workbook; the third activity involved the development of an action plan. Data included in the following section was taken from a sub-sample of assignments completed by participants attending each site, Edinburgh, Glasgow, Hamilton and Perth.

4.2.1 Clinical Evaluation & Action Planning

Participants were asked to carry out an evaluation of their own clinical area, using the ‘Supporting Change’ workbook, and identity and prioritise key areas of need, focusing upon Indicators 1-4. A number of participants asked if they could conduct a group evaluation of their workplace and submit a joint assignment. Because we had not anticipated this, different groups were given conflicting advice. While some of the work carried out was of high standard, it was difficult to disentangle who had been responsible for which aspects. It was subsequently decided that while individuals could work together, future assignments must be individually prepared and submitted.

Overall ninety-nine participants submitted satisfactory assignments; in a number of instances first submissions did not achieve the required standard, for example participants had not consulted with other staff, or their evaluation lacked rigour. However, with support from tutors a majority were able to address areas of concern.

Participants reported that they used the Supporting Change Document as requested:

> I used the NES Dementia Champions Supporting Change document to assist in this process.

One participant indicated that it had been difficult to use the Supporting Change workbook as it was thought to be heavily weighted to the nursing staff working on wards within the acute hospital setting.

Another participant reported having developed their own template:

> We put together an audit template to look at patient documentation including if there was an appropriate Adults with Incapacity form in place, we looked at the patient bed space, the ward environment, how the patient looked and what they understood about their admission and if there were relatives with the patient and how they felt about their relatives stay in hospital.

A majority of participants consulted with colleagues:

> In order to carry out the evaluation, I spent time discussing the issues with my colleagues both in small groups and as individuals.
Set up a group to discuss firstly the reason the Dementia Champion programme was introduced and explain the indicators and the supporting change document; there was a fantastic response to my request and each area invited was represented.

Unfortunately consultation was not always easy:

Arranging this meeting was complicated due to annual leave plans and our imminent move to other hospital accommodation. It was further complicated when [representative from one discipline] declined to be involved, [representatives from another discipline] were unable to attend the meeting, despite agreeing that it would be appropriate, and the [representative from a third discipline] fractured her wrist.

The number of individuals consulted varied according to participants’ role and ease of access:

A Dementia Working Group has been set up which I chair along with membership from key stakeholders from primary and community services, Social Care as well as acute care services.

I have a group of 4 colleagues to assist…

In some instances families had been included in the consultations:

I have also asked some families to write me a short statement about how well we do and where they think we can improve.

Participants reported areas of concern, and plans for addressing these, within their own workplaces. In some cases plans had been developed and implemented, while in other locations assessment was ongoing. Areas of concern fell into eight main categories:

a) Environment
b) Education
c) Identification of people with dementia
d) Facilitating communication with people with dementia
e) Identifying and managing delirium
f) Involving relatives and carers
g) Input from other professional groups
h) Challenges

a) Environment

Several participants reported that they had identified shortcomings within the hospital environment:

We have carried out an assessment of the environment in … an acute assessment and rehabilitation ward for older people using the Dementia design tool principles. This was carried out by the Alzheimer Specialist Nurse and the Senior Charge Nurse (SCN). From this assessment recommendations have been made … The SCN has been working with estates and facilities to work out a plan for implementation including securing the funding.

A resource pack is being planned with such items as appropriate signage, items such as appropriate clocks, activities such as games and reminiscing materials for use as required for patients with dementia. This pack will be readily available for all staff members to utilise as necessary.
The environment is also an area that I feel will continue aim to progress and change for the better of patients, to reduce their anxieties, increase their confidence and to maintain some sense of self and life skills whilst in hospital.

**Having signs up within the ward area for recognition of place**

**Having a clock that patients can read**

**Having a quiet area/room away from all the noise and activity of the busy ward**

**Developing a memory board.**

### b) Education

The need for education and training was raised in many assignments. Proposed education/training was both formal and informal:

*It is hoped to design and implement informal on-ward sessions to facilitate discussions on our care of the patient with dementia*

*Training has been scheduled for the end of January/beginning of February 2012*

*Staff will also benefit from education in the area of the laws relating to people with dementia*

### c) Identification of people with dementia

Several participants reported that they were going to introduce the *Butterfly Scheme* in order to ensure that people with dementia could be identified in order to receive appropriate support:

*Develop a system for identifying patients with dementia*

*Introducing the Butterfly Scheme will enable staff to identify someone with dementia who may require extra support by displaying the small butterfly on the board*

### d) Facilitating communication with people with dementia

The introduction of the *This is Me* document was proposed by a considerable number of participants:

*It was agreed that the ‘This is Me’ document will be used in future*

Attention was drawn to the importance of all staff understanding the importance of the scheme and how it worked:

*Ensuring the ‘This is Me’ document is used with all dementia and suspected dementia patients and getting the nursing staff to fully embrace this valuable and simple tool.*

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3 The Butterfly Scheme allows hospital staff to identify patients who have dementia using a discreet symbol. Staff should receive training and ensure that informal carers are happy for it to be used.
And relatives and carers being involved in the development of the document:

Ensure all patients’ relatives/caregivers with dementia are given the ‘This is Me’ document

The importance of taking the time to talk with patients was highlighted, and the potential for involving volunteers where possible:

Try to make time to chat with patients with dementia, we are currently looking into volunteers coming to the ward to talk or play dominoes with the patients.

e) Identifying and managing delirium

Identify and coping with patients with delirium was an issue raised in many assignments:

Raise the staff understanding of delirium to then be able to distinguish it from dementia

Another area of concern for the team is the management of delirium even although we have protocols in place… a snap shot audit of all admissions to the acute receiving unit will be carried out measuring against the working protocol. The feedback from this will be discussed at the Dementia working group and recommendations made as to the way forward.

During the discussion on indicator three [in the Supporting Change workbook] the team have highlighted the need to assess the application of the delirium protocol as well as the use and prescribing of psychoactive medication.

f) Involving relatives and carers

Several participants drew attention to issues relating to the involvement of relatives and carers, both in terms of ensuring their wellbeing:

Ensure their families receive the right level of support.

Looking pan [NHS Board] on guidance related to adherence to visiting times and protected mealtimes, need a uniformity of approach that has flexibility at its core. We also need to realise that carer breaks and refreshments are part of the process.

Good communication with family members (review of visiting hours)

And because of the benefits of their presence for the person with dementia:

Ensure there is a provision for carer’s to stay with the patient as much as possible

g) Input from other professional groups

Participants highlighted the importance of liaising with other professionals:

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4 ‘This is me’ is a booklet that someone with dementia going into hospital can give to staff to help them understand the condition. It provides information about the person including needs, preferences, likes, dislikes and interests etc.
It is anticipated that the assistance of the mental health liaison team will be sought when designing the educational sessions.

Staff would also benefit from training to recognise when to involve the psychiatric liaison team.

Establish Dementia working group with Dementia Champions, internal colleagues currently involved in projects such as the training of healthcare support workers …

Invite representative from Alzheimer’s Scotland or other interested parties/stakeholders.

h) Challenges
Some participants acknowledged that change might take time:

Although the enthusiasm and interest is there, due to the numerous other commitments I have within my role, I have limited time to make the above changes and am only able to chip away slowly to make these changes.

4.2.2 Change Assignment

The third work-based task and written assignment that participants were asked to undertake involved them working with their own team to identify the changes/actions to be instigated, carry out the changes/actions, and evaluate ‘work done so far’ against the elements of good practice, and write and submit a report. Because the time between the evaluation and action planning was short, participants were advised that the report should focus on what you had been done so far and what they planned to continue doing.

Ninety-five assignments were submitted and, as with previous written work not all assignments initially achieved the required level and additional support was offered by tutors. Because of the very tight timescale and overlap between the second and third assignments, only a small number of examples are included below, focusing specifically on work that has taken place and participants’ perceptions of impact, rather than work which is planned.

4.2.2.1 Involving families

A number of participants reported changing the way in which staff interacted with relatives and carers, taking a more flexible approach:

The first change we made was to stop separating the patient with dementia from the relative during the admission process. So far the results of this change have been very obvious… I think the relatives feel more valued as a carer and the importance of their role in looking after their relative with dementia is recognised. The patients are also much more relaxed to have familiar faces around so the admission process has become much smoother for everyone including the staff.

4.2.2.2 Knowing the person

Several participants reported having instigated the use of the This is Me document, which was generally well accepted by staff:

The ‘This is Me’ document is currently stored within the nursing documentation, ideally right at the front for ease of access for all clinical staff… So far, the document is working well within the ward and is proving to be an invaluable asset in improving the care of patients with dementia.
The staff have found the [This is me] document to be of great benefit when caring for dementia patients.

One participant reported that use of the This is Me document had reduced the levels of medication prescribed and in turn the number of falls:

*By having this document we have reduced the amount of medication the patient receives in hospital. Staff are much more likely to look into why the patient is behaving this way rather than get them prescribed medication. This in turn has reduced the number of falls during the day, therefore reducing the number of fractures and increased stays in hospital.*

While the above appeared to be anecdotal evidence, another participant reported that the use of the 'This is me' was currently being audited in their area, although details of what this audit would involve were not included.

### 4.2.2.3 Education

Again a number of participants reported that educational initiatives had been introduced in their clinical environment, in some instances running concurrently with the Dementia Champions programme:

*Following each tuition day, I have taken the knowledge back and shared it with my colleagues immediately and have tried to ensure that I keep them informed and up to date with the plans for changes within the ward… These sessions have been linked closely with the psychiatry in old age team… are on-going … time is allocated on a regular basis to allow these to take place.*

In some areas participants undertaking the Dementia Champions programme worked together to instigate change. For example, within one NHS Board, the NES e-learning materials have been converted into SCORM compliant package hosted on LearnPro which will ensure that dementia awareness will reach a wider audience across the Board. The same NHS Board has developed a training programme with both mandatory and recommended topics/materials. There are plans for 33 members of staff to complete it in the first instance; the impact will be fully evaluated.

Another positive initiative involves the inclusion of dementia awareness within induction sessions:

*There has been agreement to include dementia awareness sessions into corporate induction… From March 2012 a dementia awareness session will be included on day one of induction as this session is appropriate to both [trained and untrained] groups of staff.*

### 4.2.2.4 Environment

While many participants were aware of environmental changes that would be beneficial, there appeared to be significant challenges to overcome in some areas. Lack of resources and inflexible plans dampened some of the enthusiasm; however, there were reports of some changes being implemented, and in other cases a commitment to discuss potential changes with relevant gatekeepers in the near future:

*We have put up signs on the doors of the toilets with a picture and words to make it clearer to the patients. All the signs have also been lowered to eye level to make them more obvious.*

*I have myself (with my daughter’s help) printed Toilet and Shower signs and have these put on each appropriate door at wheelchair level and feel that already these are beginning to show a difference.*
A meeting and walk round has been arranged with the site manager from our hospital in order to ascertain what [environmental changes are] feasible and can be funded.

Our line manager and present Senior Charge Nurse have agreed that we can all be involved in discussions with the estates department about the clinical area should be refurbished to provide a safer and friendlier area for dementia patients.

4.2.2.5 Building a critical mass

Participants reported that they recognised the benefits of working with others and had sought partners to take work forward:

I have already made many links with fellow dementia champions, the dementia nurse and AHP dementia consultant within my area. We have now scheduled our first formal meeting - the purpose of this will be the beginning of setting up a Managed Clinical Network to help each other take forward changes.

I have also gained an extensive support network of professionals which has been invaluable.

‘Support of individuals with dementia’ has been made a standing item on the agenda for our hospital based AHP meetings …this has enabled us to focus on supporting one another in gaining confidence in providing a person centred [approach] when working with people with dementia.

Some participants recounted instances of sharing their knowledge with other professional groups in order to bring about change:

I am meeting with the consultants on my ward to ask them to inform the junior doctors they must have a nurse present when breaking bad news, which includes giving a diagnosis or suspected diagnosis of dementia.

We have requested a slot at the March Clinical Governance Group to discuss with the Geriatricians and Clinical Nurse Managers how we could streamline our patients directly from A&E to our ward.

The above examples of small and larger scale initiatives and projects were commendable given the short timescales, demonstrating real commitment to improving the experiences of people with dementia and their carers. However, it would be unwise to paint and entirely rosy picture, a number of participants reported that they had not found implementing change easy:

Although [introducing This is Me] has been a relatively small change and initially perceived as relatively straight forward, I have found this enormously challenging.

I have tried to take back to the ward with me topics that I have learned and shared with other members of staff. This has been an eye opener as some staff are not keen to accept change and question everything that I have tried to do and don't seem to see the need for change.

4.2.3 Change Agents

The above information relating to the impact of the Dementia Champions Programme sought to explore the potential for change as the participants adopt their new role as Dementia Champions. Information derived from the written assignments demonstrate that participants had identified ways in which the care of people with dementia could become more person centred, that they had
identified specific aspects of their working practice and/or environment that they would like to change, and that they had developed plans for taking this work forward. We were interested in participants’ perceptions of their ability to achieve the changes, i.e. did they believe that they could become Change Agents? In the questionnaire distributed at the end of Study Day 5, participants were asked if they had/would change practice as a result of the Dementia Champions Programme. They were also asked to indicate, on a scale from ‘0’, Cannot do at all, to ‘100’, Highly certain can do, how confident they were that they could demonstrate the learning outcomes associated with the Dementia Champions Programme. These questions were based on the concept of Self-efficacy (Self-efficacy is defined as ‘the conviction that one can successfully execute the behavior required to produce the outcomes’ (Bandura, 1977; 2006).

Ninety-two participants (93.9%) reported that they had or would change practice as a result of the Programme, three indicated that they would not make changes, and three were unsure. The following chart shows that participants’ mean levels of confidence ranged from just over 70% confidence in dealing with legal and ethical issues, to almost 77% confidence relating to their ability to recognise and respond to the impact of the physical, emotional, social, cultural and spiritual environment on the maintenance of rights, choice, identity, dignity and equity for the person with dementia, in an acute hospital setting.

**Figure 2:** Reported confidence in ability to fulfil learning outcomes

<table>
<thead>
<tr>
<th>Learning Outcome</th>
<th>Confidence Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implement leadership and change agent skills and knowledge to enhance and improve the care of the person with dementia in every area of your influence, sharing good practice with others.</td>
<td>73</td>
</tr>
<tr>
<td>Apply and evaluate a range of interventions to reduce stress and distress and promote functional capacity and quality of life for the person with dementia, in the acute hospital setting.</td>
<td>72</td>
</tr>
<tr>
<td>Recognise and deal with the complexities associated with dementia in the acute hospital setting that may have legal and ethical implications and act to safeguard the best interests of people with dementia, families and carers.</td>
<td>71</td>
</tr>
<tr>
<td>Respond with evidence based best practice, to the physical and mental health issues that may affect the individual course of a person’s journey through care in the acute hospital environment.</td>
<td>73</td>
</tr>
<tr>
<td>Recognise and respond to the impact of the physical, emotional, social, cultural and spiritual environment on the maintenance of rights, choice, identity, dignity and equity for the person with dementia, in an acute hospital setting.</td>
<td>76</td>
</tr>
</tbody>
</table>

While Figure 2, above, gives a clear visual picture of participants’ self-reported confidence, it does not convey the considerable variation between participants. Table 15, below, presents the mean, range, and standard deviation for each of the five learning outcomes. It can be seen that the range...
and standard deviations were sizeable, indicating that levels of confidence varied considerably across the group.

**Table 15:** Reported confidence in ability to fulfil learning outcomes: mean, standard deviation, and range

<table>
<thead>
<tr>
<th>Learning outcome</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognise and respond to the impact of the physical, emotional, social, cultural</td>
<td>30</td>
<td>100</td>
<td>76.74</td>
<td>17.163</td>
</tr>
<tr>
<td>and spiritual environment on the maintenance of rights, choice, identity, dignity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>and equity for the person with dementia, in an acute hospital setting.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respond with evidence based best practice, to the physical and mental health</td>
<td>30</td>
<td>100</td>
<td>72.81</td>
<td>15.941</td>
</tr>
<tr>
<td>issues that may affect the individual course of a person's journey through care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>in the acute hospital environment.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recognise and deal with the complexities associated with dementia in the acute</td>
<td>30</td>
<td>100</td>
<td>70.94</td>
<td>17.356</td>
</tr>
<tr>
<td>hospital setting that may have legal and ethical implications and act to</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>safeguard the best interests of people with dementia, families and carers.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apply and evaluate a range of interventions to reduce stress and distress</td>
<td>0</td>
<td>100</td>
<td>72.29</td>
<td>18.381</td>
</tr>
<tr>
<td>and promote functional capacity and quality of life for the person with</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>dementia, in the acute hospital setting.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Implement leadership and change agent skills and knowledge to enhance</td>
<td>30</td>
<td>100</td>
<td>74.79</td>
<td>15.893</td>
</tr>
<tr>
<td>and improve the care of the person with dementia in every area of your</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>influence, sharing good practice with others.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Unfortunately we did not ask questions relating to Self-efficacy at Time 1, and thus do not have a baseline. However, the analysis demonstrates that participants were able to gauge and report their own levels of confidence and that some Dementia Champions are well placed to forge ahead instigating their planned changes, while others will require additional support. Some of the, unsolicited, comments from participants suggest that the impact of the programme will **not** be short-lived:

*Taking part in this programme has been a privilege and an eye opening experience. I am excited for the future and I am thrilled to be a part of the front line staff who are changing the care of patients with dementia for the better.*

*I feel invigorated with the ideas this Dementia programme has given me and feel empowered and motivated in order to lead and change Dementia Care within our Hospital.*

*I feel since I started the Dementia champion course that I have learnt so much, but realise there is still so much to learn. I get frustrated at the time it takes to get things implemented but this is part of the challenge.*

One participant who undertook assessment and change planning as part of a team believed that this had helped clarify the role of Dementia Champion:

*I've found being involved in the action planning with this team has helped me to be much clearer in what my role will be as a Dementia Champion and what that will this look like, as I*
can see how this is already affecting change and look forward to undertaking the evaluation of the other five indicators in the change document with this team.

*Dementia is a subject that is very close to my heart and I have enjoyed every aspect of this course. I will be proud to call myself a Dementia Champion and will try my best to pass on all that I have learned to my colleagues at work.*
SECTION 5: Discussion

The Dementia Champions programme was delivered over five months from October 2011 to February 2012, a typically busy period within the NHS, and for most families. Despite this, 93 participants completed on time, and a further ten are continuing to work towards completion. The submission date for the final assignment was at the end of February with Graduation in the middle of March, thus there was little room for manoeuvre. We are confident that most of those who are still working towards completion will achieve this, given that there is potential for them to catch up on any sessions that they have missed with the next cohort. Additional support will also be available from the project team. While the final comments including above are extremely positive, the data relating to self efficacy indicates that there is no room for complacency. The following discussion will focus initially on recruitment of participants across the NHS Boards, followed by issues raised by participants relating to the delivery of the programme. Because evaluation of the programme was ongoing over the five months of delivery, with feedback from participants following each Study Day, a number of changes or modifications were implemented as soon as the difficulty or potential for improvement was identified. In addition, during this period, the project team successfully developed and submitted a bid to deliver the Dementia Champions programme to a further 200 health and social services staff. Development of this bid provided an opportunity for the team to assess the current programme and consider aspects which could be improved. Thus a number of changes are already in place for the next 200 participants who will undertake the programme in two cohorts of 100 beginning in May and October 2012.

5.1 Recruitment: Identification of participants and pre-programme materials

The stages involved in identification and recruitment of participants is included in Figure 1, page 10; documents are in the appendix, page 55. Information relating to the programme was sent by NES to each NHS Board in Scotland indicating that a Senior Sponsor should identify potential participants and that:

> It is essential that the people who undertake the Dementia Champions training are willing, able and will receive organisational support to lead and sustain change in their own area and contribute to your Board's strategic plans to implement the Standards of Care for Dementia in Scotland.

The information also indicated that participants should have:

An interest in, and motivation, to drive continual improvements in the quality of care and support for people with dementia in the acute general hospital settings [and] receive organisational support to:

- Attend 5 days face to face training
- Undertake study and learning activities, in addition to face to face training.
- Undertake assessment to ensure their competence as a Dementia Champion

Potential participants were then expected to complete part A of the application form and return it to the Senior Sponsor so that they could complete part B. Despite this a number of participants indicated that neither they, nor their managers understood the amount of work that would be involved in undertaking the programme.

Because recruitment to the programme was undertaken by NES, the programme team from UWS and Alzheimer Scotland was provided with a list of addresses for delivery of pre-programme materials. Much of the material from NES and the programme team was sent to NHS Managers, rather than staff who subsequently enrolled on the programme, with the result that a number of
participants only received the information immediately before they attended the first Study Day, or did not receive it at all.

In order to address this, the project team hopes to identify participants for the second cohort earlier, enrol them onto the VLE and seek their preferred address, postal or email, for communication. However, we recognise that this may be difficult for a number of reasons, and understand that NES will also stress the importance of information about the programme being communicated to potential participants in advance.

The information sent to NHS Boards cited above raises two additional issues, 1) that participants should receive organisational support to undertake the programme, and 2) receive organisational support to lead and sustain change.

1) While many participants did receive considerable support to undertake the programme, there were reports of participants not only undertaking pre-study day reading and assignments in their own time, but also taking days off to attend the Study Days and the community placement. Where there was a lack of support it placed an additional burden on participants who were trying to complete the programme, it was particularly difficult if participants were unable to attend a Study Day as completion required 80% attendance.

In order to address this, NHS Boards have been asked to provide participants in subsequent cohorts with an additional two days study time in addition to the five Study Days and half day for the community placement.

2) Information derived from the written assignments indicated that some participants were experiencing a number of challenges implementing, even minor, changes. While planning and implementing change may be particularly challenging due to the current climate of austerity, there are many changes that can be made that require imagination rather than financial commitment. It is vital that Dementia Champions receive support within their own Boards to support these changes.

5.2 The programme

Level of input: A number of participants indicated that they thought that the first Study Day was not ‘at the correct level’ for them. Interestingly almost six out of ten participants who attended (59.6%) the first Study Day indicated that their practice would change as a result of the input. This suggests that participants who felt that the material was not at the correct level may have been unclear about the aims of the programme, i.e. that it was not just about increasing their knowledge, but that it was about enabling them to communicate what they currently knew, plus what they learned on the programme, to others in order to improve care for people with dementia more widely. Some of this misunderstanding may have been due to participants not receiving the pre-programme information in time, and the fact that participants attending the four sites received information from different tutors, and thus inevitably there was some inconsistency.

Consistency of information: There were also a number of comments about lack of, or inconsistent information being given to participants. In order to ensure that all participants receive the same messages, participants in Cohort 2 will attend a ‘common’ first day which will be delivered in a conference style and be based in Hamilton. While we recognise that there may be logistical issues for participants travelling to Hamilton we believe that the benefits of the shared experience will outweigh any drawbacks. Advantages include:

♦ Uniformity of information received
Participants meeting each other and understanding the scale of the Dementia Champions programme

Ability to receive input from invited speakers who would be unable to attend repeated sessions

Face to face meeting with tutors

Demonstration of the VLE

Access to the Domus room

Access to VLE and on-line materials: One of the nominee characteristics listed in the information sent to NHS Boards indicated that participants should have:

IT literacy skills and knowledge in computer awareness, e-mail and internet use and PC and Internet access (broadband access)

Access to a computer was vital in order to access the pre-study day materials and submit written work. Fortunately only a small number of participants reported that they were unable to access IT, either in their workplace or elsewhere. However, even for those who did have access to IT some problems did arise, email communication between NHS Boards and other institutions is intermittently problematic, some staff did not have access to their own email account, and many NHS Boards block the use of YouTube, where a number of useful materials are available. In order to overcome some of the communication issues participants were asked to provide an alternative email address, and wherever possible alternative addresses were provided for reference materials.

In addition to the changes listed above designed to ensure that participants receive consistent messages, one member of the programme team has taken the main responsibility for the VLE, ensuring consistency for participants throughout the programme. Support will be available for any participants who are experiencing difficulty.

Group size: A small number of participants attended a Study Day at a different location from the one they had been assigned to for a variety of reasons. Meeting participants from other sites appeared to be beneficial and one participant suggested that more movement, or mixing of groups would be beneficial. The conference-style delivery on Study Days 1 and 5 will address this, enabling participants from a larger number of different NHS Boards to mix and share ideas and experiences.

Tutors/facilitators found the groups large to manage and believe that smaller groups would be advantageous. Thus future delivery will involve delivery on five sites, with each group comprising approximately twenty participants.

Timescale: Several participants reported that they struggled with the workload, particularly prior to Christmas when a busy period at work and family commitments coincided with the submission dates for assignments. The programme is demanding for people who are working full-time and have family commitments. In order to ameliorate this, delivery for the second and third cohorts will be spread over a longer period, giving more time to manage pre Study Day materials and complete work-based tasks and written work.

Status of the Dementia Champions programme: A number of participants indicated that they thought that the programme should be accredited. While there is potential for the programme to be accredited in the future, there are issues that would require to be explored. The programme
delivered to the first 100 participants, was designed for participants working within an acute setting, while participants were expected to be in a position which would enable them to instigate change, there were no requirements for previous academic achievement. Participants were asked to complete three work-based tasks and prepare and submit written reports relating to this work. However, assessment reflected the applied nature of the work, at the Enhanced Dementia Practice level. Not all participants achieved the required standard with their first submission. Participants’ ratings of the usefulness of all three assignments were positive, with the community placement having the highest mean rating. Despite these positive ratings, some participants really struggled with the deadlines and requirements of the programme in its current form. Future participants would need to think carefully about whether the additional work required to attain ‘academic rigour’ would enhance the ‘usefulness’ in this instance.

5.3 Final comments

Information derived from participants’ written work and evaluation of the programme indicated that, as an outcome of their experience of attending the programme, the students had engaged with the extensive programme materials and quality drivers. In addition to the very personal journeys that some participants shared in their reflections, a majority had planned and begun to implement a wealth of activities to improve the experiences of people living with dementia and their families. A study carried out by Rodrigues and Marquett (2010) focusing on continuing education in gerontology and geriatric care involved health professionals attending education and training to develop Action Plans in order to implement changes based on their new knowledge. A three month follow up indicated that 61% had successfully implemented their action plans. The authors concluded that developing and writing action plans was a useful tool for monitoring behaviour over time. It would be hoped that there are plans in place to follow progress relation to the Action Plans developed by the first cohort of Dementia Champions.

Despite confidence engendered by the findings of Rodrigues and Marquett, it should be borne in mind that the Dementia Champions programme only lasted for five months. Data derived from the self-reported self efficacy scales indicated that some participants were not confident that they could successfully execute the behavior required to produce the outcomes. Some participants reported difficulty introducing quite minor changes. Acknowledging potential fallibility or difficulty overcoming hurdles should not be seen as a weakness, but rather an accurate perception of the potential challenges ahead. Evidence from the published literature indicates that initiatives may encounter a range of factors that hinder progress, for example difficulties with communication, assessment, the physical environment, organizational systems, influence of key players, and accepted practice in dementia care (Borbasi and Jones, 2006; Miller, 2008; Cowdell, 2010; Jootun and McGhee, 2011).

A number of participants spoke of gathering other Dementia Champions or individuals with an interest in dementia together, providing support to each other and deriving strength from their numbers. It is vital that the Dementia Champions continue to build on these contacts and receive ongoing support. Again evidence from the literature reinforces the benefits communication and personal contact (McCrae and Banerjee, 2011; Cherry, Hahn, et al., 2009; Beer et al, 2010; Ploeg, et al, 2010).

We are aware that NES has plans for ongoing support, facilitated by Theresa Douglas, Project Lead for Dementia. A number of sessions are already planned for the newly graduated Dementia Champions, bringing them together as a group. Support will also be available from the Dementia Nurse Consultants, soon to be located in all NHS Boards. In addition, support can be accessed via the Dementia Champions area of the NHS Scotland Dementia Managed Knowledge Network (MKN)3, which offers information, resources and opportunities for discussion to anyone with an interest in the health and social care of people with dementia. The MKN network is being

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developed in partnership with NES Knowledge Services Group, the Dementia Services Development Centre, and the Institute for Research in Social Services (IRISS); the Community of Practice for Dementia Champions provides a safe and secure place for the Champions to discuss the challenges and problems that are part of the reality of working in a complex system supporting and caring for often vulnerable people.

Because changes which were instigated during the delivery of the Dementia Champions Programme to the first cohort, and modifications that will be incorporated into future delivery, have been detailed above, this report contains few specific recommendations. However, we do recognise the importance of the delivery team being responsive to the current environment within health and social care as well as the needs of participants, and being flexible should a need for modification be identified. We also recommend that the progress made by the new Dementia Champions is monitored in order to ascertain what factors enable them to have the greatest impact.
References


Appendix
Dear

Acute General Hospital Care - National Dementia Champions Development Programme - CALL FOR NOMINATIONS

I am writing as a follow up to the Advanced Notification letter sent by Hugh Masters, Nursing Officer (Mental Health and Learning Disabilities) Scottish Government on 11th July 2011.

We have had considerable demand for the course. I note that you have requested 10 places and I am pleased to inform you that 7 places have been allocated to NHS Forth Valley. Should additional places become available we will contact you again in early September 2011.

To obtain maximum benefit from the development programme and assist you in the identification of appropriate nominees please refer to the attached: The information for Senior Sponsors and Participants includes detailed information about the programme including delivery dates and venues.

- Attachment 1 - Flow chart to guide the nomination and application process
- Attachment 2- Information and Guidance for Senior Sponsors
- Attachment 3 – Information and Guidance for Participants
- Attachment 4 - Application Form

I would be grateful to receive your nominations by the 1st September 2011 at the latest and thereafter we will confirm the participants and the programme providers will issue pre course information.

If you require any further information or clarification please do not hesitate to contact myself or Patricia Howie, Educational Projects Manager at patricia.howie@nes.scot.nhs.uk or 0131 220 8094.

Yours sincerely

Susanne Forrest
Programme Director

cenc

1. BACKGROUND AND CONTEXT

Scotland’s National Dementia Strategy was launched in June 2010 and outlines key actions to improve the knowledge and skills of staff working in health and social care to enable them to work with people with dementia and their families and carers.

To support the educational actions arising from the strategy the Scottish Government (SG) commissioned NHS Education for Scotland (NES) and Scottish Social Services Council (SSSC) to produce Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers which was launched alongside the Standards of Care for Dementia in Scotland in June 2011.

The SG has given a commitment to improve the care of older people in acute general hospitals, including implementation of the Dementia Standards, being led and overseen by the Chief Nursing Officer for Scotland. The Dementia Champions programme will support NHS Boards in meeting the standards, and taking forward the broader Scottish Government strategic objectives for dementia care in general hospitals.

The Dementia Champions Programme forms part of wider initiatives to support improvements in the care and treatment of people with dementia in general hospital settings including the establishment of Alzheimer Scotland Nurse Consultants/Specialists in NHSScotland Boards.

2. ABOUT THE PROGRAMME

2.1 General information

The aim of the programme is to support the development of champions as change agents in improving the experience, care, treatment and outcomes for people with dementia, their families and carers in general hospitals. It is a model which has been disseminated widely and positively evaluated in Western Australia and the UK, as well as a small number of programmes delivered in NHS Scotland.

The programme will be provided on behalf of NES by the University of the West of Scotland in partnership with Alzheimer Scotland. These organisations have successfully delivered a Dementia Champions programme in NHS Dumfries and Galloway over the past 5 years.

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6 Senior Sponsor refers to a named person in the organisation responsible for nominating the participant and providing organisational support as part of the Board’s strategic approach to dementia care e.g. Unit Manager or Associate Nurse Director

7 CEL to be issued by SG imminently

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2.2 Programme Structure and Requirements

The programme will be delivered via blended learning, comprising:

2.21 Attendance at 5 face to face training days delivered separately between October 2011 and February 2012 and attendance for a half day in a community setting that supports people with dementia.

The study days will take place in Edinburgh.

The study day dates are listed below:

Day 1 18th October 2011
Day 2 15th November 2011
Day 3 8th December 2011
Day 4 17th January 2012
Day 5 7th February 2012

Participants will be required to attend all study days:

2.22 Participation in online learning activities prior to and during the programme.

2.23 Participation in work based learning activities in between face to face training days focussed on bringing about positive change in their area of practice.

2.24 Assessment activities including completion of a portfolio of practice and reflective accounts. Please note robust assessment is a requirement of the programme to ensure participants exit the programme with the knowledge and skills to undertake the Dementia Champion role. Assessments have been designed to minimise the workload for participants and focus activity on action planning and undertaking change in the workplace in a way that will support your Board’s implementation of the Standards of Care for Dementia in Scotland.

2.3 Participant Support

Participants will receive detailed programme information prior to the programme, and face to face, online and telephone support from the programme team throughout the programme.

NES will continue to support participants via regional learning networks after completion of the programme. Please also see section 4 for expectations for organisational support.

3. NOMINEE SELECTION GUIDANCE

The target audience for the programme are acute general hospital staff, including nurses, allied health professionals, medical staff and where appropriate social workers.

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8 Please note it is not a requirement of your Board to organise this.
It is essential that the people who undertake the Dementia Champions training are willing, able and will receive organisational support to lead and sustain change in their own area and contribute to your Board’s strategic plans to implement the Standards of Care for Dementia in Scotland.

The following criteria should be considered by the NHS Board, the Senior Sponsor.

3.1 Nominee Characteristics and Organisational Support

Please consider the following criteria when selecting nominees:

- Staff members with an interest in, and motivation, to drive continual improvements in the quality of care and support for people with dementia in the acute general hospital settings who are prepared to and will receive organisational support to:
  - attend 5 days face to face training
  - undertake study and learning activities, in addition to face to face training.
  - undertake assessment to ensure their competence as a Dementia Champion.
  - participate in ongoing learning and development, following initial preparation, including ongoing engagement in regional learning networks.

- Staff members with IT literacy skills and knowledge in computer awareness, e-mail and internet use and PC and Internet access (broadband access)
- Staff members with the potential to be developed so they can act as change agents and positional leaders who will influence change in their area of practice (and when appropriate more widely) including cascading information and education about dementia to other staff, as well as contributing to educating and developing others to become dementia champions.
- Staff members, who will receive support within their practice area to develop, implement and evaluate a locally agreed change action plan during the programme.
- Staff members with the capacity to undertake the training in their current role, with further local, organisational and NES support and supervision to enable them to apply the learning into practice as well as lead and sustain change in their area.

3.2 Organisational Positioning

3.21 Relationship with the Champions and Alzheimer Scotland Nurse Consultants/Specialists

The Dementia Champions Programme forms part of wider initiatives to support an infrastructure for change and improvements in the care and treatment of people with dementia in general hospital settings including the establishment of Alzheimer Scotland Nurse Consultants/Specialists in NHS Scotland Boards.

When selecting nominees we invite you to consider when selecting nominees the relationship between the champions and existing or planned Alzheimer Nurses roles in your Board.
3.22 Maximising Impact

The Champions Programme is a starting point in building up a developmental infra structure in general hospitals.

Further training opportunities will be made available in 2012/13 and the Champions, and where applicable the Alzheimer Scotland nurses in your Board, will be in a position to further cascade the Champions programme to others.

We would recommend that when considering nominees in this instance you may wish to consider a focused approach, for example:

- Targeting staff to undertake the programme in particular hospitals/units and wards in your Board. Previous learning has suggested that when more than one champion is situated in a particular ward or unit the impact on practice and change can be maximised.
- With reference to the above point considering the potential for a multi disciplinary/agency team approach to nominations

We would also suggest that priority be given to selecting nominees working in the following areas:

- General Medical Units/Wards
- General Surgical wards (including Orthopaedic Sugary Units/Wards
- Accident and Emergency Departments
- Intermediate Care Teams

3.22 Maximising the Developmental Opportunities for Nominees

Participation in the programme has the potential to bring significant development opportunities for nominees and this should be considered in your selection process.

Previous learning suggests that in addition to the acquisition of enhanced knowledge and skills in dementia care, participants will also develop skills and attributes in leadership and change agency.

The programme is not academically credited however; the programme has been designed against the Enhanced Dementia Level set out in the NES/SSSC Promoting Excellence Framework which is mapped against the NHS Knowledge and Skills Framework (KSF). Participants will be able to use the learning gained as part of their KSF JDR and PDP processes.

All participants on successful completion of the programme will receive a 'Certificate of Completion' and be recognised by Alzheimer’s Scotland as a Dementia Champion.

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9 If this is of interest to participants there is the potential for academic credit for completing the programme being sought via UWS.
It is also the intent that completion of the training programme will be celebrated at a Scottish Government/NES sponsored national event in March 2012.

4. NEXT STEPS

Please refer to the Flow Chart (Attachment 1).

If you require any further explanation or detail please contact:

Susanne Forrest  
susanne.forrest@nes.scot.nhs.uk  
0131 220 8080

Patricia Howie  
patricia.howie@nes.scot.nhs.uk  
0131 220 8094

PLEASE NOTE THAT APPLICATION FORMS SHOULD BE SUBMITTED NO LATER THAN THE 1st SEPTEMBER 2011
INTRODUCTION

Congratulations you have been nominated by your NHS Board to undertake a Dementia Champions training programme. This is an important programme that is being rolled out across Scotland in 2011/12.

The person who nominated you should have already discussed this with you. This information and guidance document is designed to give you some more information and answer any specific questions you might have.

You should read this information before completing Part A of the application form that should also have been sent to you.

ABOUT THE PROGRAMME AND WHAT THIS MEANS FOR YOU

Why have I been nominated?

We asked your organisation to nominate people who:

- Have the potential to be developed as change agents in improving the experience, care, treatment and outcomes for people with dementia, their families and carers in general hospitals.
- Have an interest in, and motivation, to drive continual improvements in the quality of care and support for people with dementia in the acute general hospital settings
- Would benefit in several ways by undertaking the programme
- Had the organisational commitment to support you in undertaking the programme

What does the programme involve and what is my commitment?

The aim of the programme is to support the development of champions as change agents in improving the experience, care, treatment and outcomes for people with dementia, their families and carers in general hospitals.

The programme will be delivered via ‘blended learning’ as described below and you would need to commit to:
Attending 5 face to face training days delivered separately between October 2011 and February 2012 and when possible attendance for a half day in a community setting that supports people with dementia. The study days will take place in Edinburgh.

The study day dates are listed below:

Day 1  18th October 2011
Day 2  15th November 2011
Day 3  8th December 2011
Day 4  17th January 2012
Day 5  7th February 2012

You will be required to attend all study days:

- Participation in online learning activities prior to and during the programme.
- Participation in work based learning activities in between face to face training days focussed on bringing about positive change in their area of practice.
- Participation in Assessment activities including completion of a portfolio of practice and reflective accounts. Please note robust assessment is a requirement of the programme to ensure participants exit the programme with the knowledge and skills to undertake the Dementia Champion role. Assessments have been designed to minimise the workload for participants and focus activity on action planning and undertaking change in the workplace in a way that will support your Board’s implementation of the Standards of Care for Dementia in Scotland.
- To do some of the above it is important that you have IT literacy skills and knowledge in computer awareness, e-mail and internet use and PC and Internet access (broadband access)

What support will I receive to complete the programme?

Participants will receive detailed programme information prior to the programme, and face to face, online and telephone support from the programme team throughout the programme.

In nominating you your organisation has committed to ensure that you:

- Will be released to attend the training days and be supported to find time to undertake additional work based activities
- Have further local, organisational and NES support and supervision to enable you to apply the learning into practice as well as lead and sustain change in your area.

NES will continue to support participants via regional learning networks after completion of the programme.

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10 Please note it is not a requirement of your Board to organise this
**What will I gain from completing the programme?**

Participation in the programme has the potential to bring significant development opportunities for you and the service you deliver for people with dementia and their families and carers.

Previous learning suggests that in addition to the acquisition of enhanced knowledge and skills in dementia care, participants also develop skills and attributes in leadership and change agency.

The programme is not academically credited however; the programme has been designed against the Enhanced Dementia Level set out in the NES/SSSC Promoting Excellence Framework which is mapped against the NHS Knowledge and Skills Framework (KSF). You will be able to use the learning gained as part of your KSF JDR and PDP processes.

All participants on successful completion of the programme will receive a ‘Certificate of Completion’ and be recognised by Alzheimer’s Scotland as a Dementia Champion.

It is also the intent that your completion of the training programme will be celebrated at a Scottish Government/NES sponsored national event in March 2012.

**WHAT YOU SHOULD DO NEXT?**

If you want to go forward with your application please fill out section A on the Application Form you have been sent and return to the person who has nominated you to complete section B. You should then return the application form to NES no later than the 1st September 2011. The return address is detailed on the form. If you require any further explanation or detail please contact the person who nominated you.

On receipt of your application we will be in touch with further information soon.

Thank you for your interest in this opportunity.

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11 If this is of interest to participants there is the potential for academic credit for completing the programme being sought via UWS.
APPLICATION FORM – PART A

TO BE COMPLETED BY APPLICANT

Name: 

Job Title: 

Department: 

Health Board: 

Address: 

Email: 

Telephone: 

1. Please describe your current clinical role and how you and your practice area will benefit from you being a Dementia Champion?
2. Please detail your previous experience of working with people with dementia and their families and carers and previous education and training you have undertaken in this area.

3. Please describe a change project / initiative (however small) you have successfully undertaken in your practice area and something that you would like to have the opportunity to change.
NOMINEE

Signature: ...........................................................................................................
Name: ......................................................................................................................
Job Title: ..................................................................................................................
Dept: ..........................................................................................................................

After you Senior Sponsor has completed section B please return this form to
Wayne Duffy, Project Administrator at NHS Education for Scotland, Hanover Buildings,
66 Rose Street, Edinburgh EH2 2NN or mentalhealth@nes.scot.nhs.uk
by the 1st September 2011
## NOMINATION FORM – PART B

**TO BE COMPLETED BY SENIOR SPONSOR**

<table>
<thead>
<tr>
<th><strong>4.</strong> Please confirm that time will be available to the above named nominee to undertake this training programme</th>
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<tr>
<th><strong>5.</strong> Please outline how you will provide local and organisational support for the nominee to enable them in implementing changes in practice and environment to improve the experience for people with dementia their families and carers.</th>
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</table>
SENIOR SPONSOR

Signature: 
Name: 
Job Title: 
Dept: 

Please return this form to the Nominee for submission to NES.
# Approaches to Dementia Questionnaire (ADQ) Lintern and Woods, 1996

Please indicate to what extent you agree or disagree with each of the following statements:

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<tr>
<th>Please tick:</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<tbody>
<tr>
<td>1. It is important to have a very strict routine when working with dementia sufferers</td>
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<td>2. People with dementia are very much like children</td>
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<td>3. There is no hope for people with dementia</td>
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<td>4. People with dementia are unable to make decisions for themselves</td>
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<td>5. It is important for people with dementia to have stimulating and enjoyable activities to occupy their time</td>
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<td>6. Dementia sufferers are sick and need to be looked after</td>
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<td>7. It is important for people with dementia to be given as much choice as possible in their daily lives</td>
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<td>8. Nothing can be done for people with dementia, except for keeping them clean and comfortable</td>
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<td>9. People with dementia are more likely to be contented when treated with understanding and reassurance.</td>
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<td>10. Once dementia develops in a person, it is inevitable that they will go down hill</td>
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<td>11. People with dementia need to feel respected, just like anybody else</td>
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<td>12. Good dementia care involves caring for a person’s psychological needs as well as their physical needs</td>
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<td>13. It is important not to become too attached to residents</td>
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<td>14. It doesn’t matter what you say to people with dementia because they forget it anyway</td>
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<td>15. People with dementia often have good reasons for behaving as they do</td>
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<td>16. Spending time with people with dementia can be very enjoyable</td>
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<td>17. It is important to respond to people with dementia with empathy and understanding</td>
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<td>18. There are a lot of things that people with dementia can do</td>
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<td>19. People with dementia are just ordinary people who need special understanding to fulfil their needs</td>
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