Evaluating the impact of the Alzheimer Scotland Dementia Nurse Consultants/Specialists & Dementia Champions in bringing about improvements to dementia care in acute general hospitals

NHS Education for Scotland

Final Report

Sophie Ellison
Glenys Watt
Ian Christie

April 2014
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXECUTIVE SUMMARY</td>
<td>2</td>
</tr>
<tr>
<td>1 INTRODUCTION, AIMS AND METHODS</td>
<td>11</td>
</tr>
<tr>
<td>2 SETTING THE ROLES IN CONTEXT</td>
<td>17</td>
</tr>
<tr>
<td>3 FINDINGS: THE ROLES IN PRACTICE</td>
<td>26</td>
</tr>
<tr>
<td>4 ‘A NATIONAL FORCE FOR CHANGE’: FINDINGS ON ACTION AND IMPACT</td>
<td>45</td>
</tr>
<tr>
<td>5 BARRIERS AND ENABLERS TO CHANGE</td>
<td>64</td>
</tr>
<tr>
<td>6 CONCLUSIONS AND RECOMMENDATIONS</td>
<td>71</td>
</tr>
</tbody>
</table>

Appendices:

Appendix 1: References

## Acknowledgements

A note of thanks to all the Dementia Champions, Dementia Nurse Consultants/Specialists, colleagues of Dementia Champions and stakeholders locally and nationally who gave up their time to participate in interviews, focus groups, case studies and/or surveys for this evaluation. We’d also like to thank the evaluation sub-group (comprising representatives from NES, SSSC, Scottish Government and Alzheimer Scotland) for their advice and guidance throughout the evaluation, and Dr Stephen Smith who provided advice on aspects of methodological design. Thanks also to members of the SDWG, and NDCAN for advising on our research protocol and approaches to interviews with people with dementia and carers and for taking time to share their own experiences of dementia care with us, as well as to the group co-ordinators for organising.
Executive Summary

1 Introduction

This evaluation explores the achievements and impact of the Alzheimer Scotland Dementia Nurse Consultant/Specialist (ASN) and Dementia Champion (DC) roles to date and assesses how effectively the roles are working together to achieve improvements in dementia care in acute general hospitals. It offers key learning to inform future developments and sustainability.

2 Key contextual issues

Scotland’s population is ageing, and with older age comes a range of challenges including increased prevalence of dementia. There are approximately 88,000 people with dementia in Scotland; this is expected to double over the next 25 years. Scotland’s first Dementia Strategy was published in June 2010. The Strategy outlined a number of challenges and change actions, including a commitment to work to “improve the response to dementia in general hospital settings including alternatives to admission and better planning for discharge”.

Alzheimer Scotland launched the Dementia Nurse Consultant Programme in 2006, with posts created over a four year period in four territorial Health Boards. In 2010, Alzheimer Scotland launched a Dementia Nurse appeal, and as a result of this and matched funding from the Scottish Government, by the end of 2012, funding for a Dementia Nurse Consultant was available to each territorial health board in Scotland.

The Dementia Champions initiative is closely linked to the Alzheimer Scotland Nurse Consultant initiative and was established in 2011 with the aim of supporting 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 and at the interface between hospital and community settings. In combination, the roles are intended to provide a two-pronged improvement model with the ASN providing strategic leadership for change, supported by a body of operational change agents (the DCs).

The model was fairly embryonic at the start of the evaluation, with many ASNs new to post and only one cohort of 109 trained Dementia Champions. At the time of reporting there are 12 ASNs in post and four DC Cohorts (423 individuals) have completed training. Most Dementia Champions are nurses and allied health professionals. This evaluation focuses on the experiences and achievements of cohorts one to three; cohorts two onwards also included representation from Social Services.

Mid-way through the evaluation period, Scottish Government launched the 10 key improvement actions for acute settings to help focus improvement work around dementia and ensure resources such as the ASNs and DCs are used strategically and effectively. The national improvement programme that will support implementation of the key actions is currently in development.

---

1 Alzheimer Scotland website, 2014
3 Evaluation Aims and Objectives

Each cohort of the Dementia Champions training programme has been evaluated by co-delivers, the University of the West of Scotland (UWS). The programme has evaluated positively on each occasion. Engagement from participants has been high despite the intensity of the programme and the competing priorities of their day jobs. Key positive outcomes of the programme include: a significant shift towards more positive and person-centred approaches to dementia by participants over the programme period; participants’ perceptions about dementia being challenged and altered; and participants’ feeling confident at the end of the programme about their ability to influence change in the workplace.

This impact evaluation is concerned with the experiences and outcomes of Dementia Champions in practice after completion of the DC programme, as well as the experiences and outcomes of ASN in practice, and how the two roles are working together to achieve improvements in dementia care. The specific aims and objectives for this evaluation were to:

a. evaluate the impact of the introduction of Alzheimer Scotland Dementia Nurse Consultants/Specialists in bringing about improvements in the care of people with dementia in acute hospital care environments;

b. evaluate the impact of the introduction of Dementia Champions across health and social care organisations in bringing about improvements in the care of people with dementia in acute hospital settings;

c. explore the inter-relationship between Alzheimer Scotland Dementia Nurse Consultants/Specialists and the Dementia Champions in bringing about improvements;

d. explore how the introduction of Social Services Dementia Champions has impacted on the wider initiative; and

e. identify barriers/enablers to change in progressing the impact of these roles.

4 Methodology

A mixed-method evaluation approach was employed which involved: desk-based research; baseline and follow up qualitative interviews with each ASN; baseline and follow up qualitative interviews with key national stakeholders; consultation with and guidance from the evaluation steering group, and members of the Scottish Dementia Working Group (SDWG) and National Dementia Carers Action Network (NDCAN); in depth interviews with 30 Dementia Champions; baseline and follow up online surveys with DCs from cohorts one, two and three; consultation with a small number of people with dementia and carers of people with dementia; intensive case study research in four Health Board areas, involving qualitative consultation with the ASN, DCs, local strategic stakeholders and colleagues and line managers of DCs; analysis and reporting.
This evaluation employed a realistic rather than experimental approach; in doing so, while it cannot conclusively establish causal links between the two roles and particular outcomes, it is able to comment on the contribution (and potential contribution) of the two roles to dementia care improvements within acute settings and the key conditions that influence outcomes.

The methodology ensured all ASN and DCs (from cohorts one to three) were invited to contribute their views, thereby maximising involvement of the nationally available sample. The intensive case study research and qualitative interviews provided an in-depth understanding of the key issues affecting the roles and their ability to influence change. The approach was informed and shaped through consultation with and guidance from the Evaluation Steering Group, SDWG and NDCAN.

While the evaluation approach gathered a significant amount of rich, qualitative data to inform the key findings and recommendations, there were some limitations that should be noted:

- Challenges recruiting people with dementia and carers to take part in the evaluation resulted in limited exploration of outcomes and experiences for users and carers.
- Due to the relative immaturity and the evolution of the improvement model over the evaluation period, in some areas it is too early to assess impact.
- While 64% (205) of a possible 321 DCs responded to at least one survey, only 57 responded to both baseline and final surveys, limiting the possibility for measuring changes in impact or experiences over the evaluation period through the survey data.
- The disproportionately small number of Social Services Champions compared to NHS Champions and small number of Social Service respondents limits robust comparison between sectors from the survey data.

5 Key findings and messages from the evaluation

5.1 Impact of the roles to date

Improving experiences and outcomes for people with dementia care in acute general hospitals in acute general hospitals is recognised in Scotland’s Dementia Strategies as requiring significant cultural change and service development. Introduction of these two roles form part of wider initiatives being taken forward in Scotland. Despite the enormity of the task and the relative small scale and immaturity of the initiatives, a significant amount of change and improvement work has been initiated by the two roles, and would likely not have happened without them.

Both roles have been successful in raising the profile of dementia at a local level, both strategically and operationally, and to some extent nationally.
There have been significant achievements in some Board areas in terms of implementing education and training against the Promoting Excellence knowledge and skills framework and changing staff attitudes and practice towards people with dementia and their carers, although this is not yet widespread. The roles have supported progress in terms of improving: care environments; identification of dementia in acute settings; delivery of person-centred care; involvement of carers; and responses to stress and distress.

Overall, the experience has been highly positive and rewarding for DCs and ASNs, and has resulted in positive changes in DCs’ attitudes and practice.

In general the roles are viewed as key conduits and catalysts for change (within their sphere of influence) and a valued local source of dementia expertise. While it is too soon in terms of systematically evidencing improvements in the care of people with dementia, we can infer that their activities will support improved outcomes and experiences.

5.2 How are the two roles working together in practice to achieve change and how effective is the two-pronged model for change?

Local implementation of the ASN role and Memorandum of Agreement (MOA), which outlines ASN objectives, varies greatly across Health Board areas, relating to: AfC band and grade, seniority, involvement in recruitment of Dementia Champions, strategic positioning and physical location. These factors affect the ability of the ASN to influence change and affect the nature of the relationship between the ASNs and DCs.

While relationships between the two roles have developed positively in many areas over the evaluation period, there are significant local variations, and the model is still at the early stages of evolution in some areas. While the current MOA makes it clear that ASNs have a role to play in supporting implementation of the Dementia Champions initiative, it does not make explicit their role in supporting and co-ordinating the work of Champions in practice.

The model is working very successfully in some Board areas, with established mechanisms in place to ensure strategically co-ordinated joint working between the roles – this takes a variety of forms for example, local ASN-DC network meetings, site-based DC meetings supported and/or attended by an ASN, the ASN working with senior colleagues to ensure DCs are supported in their work. In these areas, much is being achieved by the two roles at both strategic and operational levels, despite the relatively small scale in terms of number of Champions compared to number of acute settings.

Where the model is working well there is a sense of shared direction and co-ordinated working between the roles; DCs feel more supported, informed and resilient; there is a collective sense of identifying as a ‘force for change’ and momentum for change and improvement is being built/sustained. Where collaboration between the roles is minimal, Champions can feel isolated and directionless and a lack of co-ordinated working may result in duplication.
In terms of the roles maintaining the sense of a ‘national force for change’, this is being sustained through national networking and support opportunities available to DCs and through the work of the Alzheimer Scotland National Nurse Consultants Group, which has developed positively over the evaluation period, with the group developing a shared identity, purpose and objectives. This shared national identity is a potentially fragile one due to DCs struggling to get time to access national events, and some ASN struggling to engage fully with the national Consultants’ group.

Social Services DCs tend to be located in services that are distanced from acute hospitals and have therefore, unsurprisingly, had limited influence in terms of directly influencing acute general hospital care for people with dementia. Integration of health and Social Services has not progressed at the pace anticipated when the DC initiative was introduced and therefore there are limited examples of Social Services DCs linking in with the work of the ASN or NHS Champions. Due to the complex landscape of the Social Services and the disproportionately low numbers of Social Service DCs compared to Health DCs, they are more likely to work in isolation, although in a small number of areas the Social Services Champions are linked into the local NHS DC network and ASN.

However, Social Services Dementia Champions have been effective and active in taking forward a wide range of changes and improvements within their own services and the wider Social Services, for example, implementing Promoting Excellence; influencing staff attitudes and practices towards people with dementia; improving the environment, delivery of person-centred care and involvement.

5.3 What have been the main barriers and enablers that have affected the ability of the initiatives to influence change?

The key barriers and enablers that have affected the ability of the ASN and DCs to influence change are highlighted in table 5.1 (overleaf), categorised into factors pertaining to individuals, organisations and the wider systems within which the roles operate. Often these are two sides of a coin, in that the absence of what is an enabler in some areas, is a barrier in others.
Table 5.1: Barriers and enablers to change

<table>
<thead>
<tr>
<th>Enablers</th>
<th>Barriers</th>
</tr>
</thead>
</table>
| **Individual** | • Commitment, passion and enthusiasm  
• Own knowledge, skills, contacts & experience  
• Seniority  
• Improved understanding of the lived experiences of people with dementia |
| • Lack of seniority  
• Lack of support to develop knowledge and skills  
• Lack of engagement and attitudes of others  
• Lack of support from other colleagues/professionals |
| **Organisational** | • Sufficient & dedicated time and resource  
• Strategic plans to maximise the impact of the roles  
• Local awareness of the two roles  
• Clarity about roles and expectations  
• ASN & DCS well-positioned to influence change  
• Strategic buy in & commitment  
• Geography and size of Board |
| • Lack of time and resource  
• Lack of support and development  
• ASN & DCS not positioned or supported to influence change  
• Lack of strategic buy in & commitment  
• Lack of clarity about roles and expectations  
• Geography and size of Board |
| **Systemic** | • Effective national policy, resources & support  
• Strong Statutory & Voluntary sector partnership working |
| • Scale of the task in hand  
• Systemic culture  
• Conflicting priorities & pressures |

### 5.4 Key issues affecting sustainability

Momentum is starting to build and a critical mass for change is developing; much has been achieved to date, considering the relative immaturity of the change model and the relatively small scale of the initiatives compared to the size of the acute workforce in Scotland and the enormity of the task they are contributing to.

ASNs and DCs have demonstrated significant dedication, enthusiasm and innovation in their roles, with many investing their own time and resources in progressing change. There are pockets of effective improvement activity evident in all Board areas as a result of the roles, with a number of Board areas demonstrating or developing strategic and co-ordinated approaches to the roles, thereby supporting more widespread and sustainable impact.

The good work achieved together with learning from the experiences of the roles to date needs to be shared and the initiatives nurtured and invested in to ensure sustainability and further development.

This evaluation has highlighted a number of issues which present a threat to the sustainability of the two roles and the improvement activity they have influenced to date. These are listed below.
Uncertainty about the future of the ASN role in many Board areas.

While in a number of Board areas ASNs are clearly strategically placed and supported, there are inconsistencies across Board areas.

ASNs are subject to many masters which means accountability, performance management and development and support of the role is varied and sometimes unclear and there are concerns that the ASN role may become diluted by local objectives as it is mainstreamed and may lose its national focus and influence.

While in a number of Board areas ASNs and Dementia Champions are working closely and collaboratively to take forward a co-ordinated approach to change, this is not consistent across all areas and where Champions are not being supported, and do not have a clear sense of leadership and direction, there is a significant risk their ability and motivation to continue to influence change will diminish.

While there is appetite, in most areas, for more Champions to be trained, they need to be strategically placed and well-supported to maximise their impact and the sustainability of their work. Larger NHS Boards, in particular, will need to plan for how they will ensure effective support for and development of a growing body of Champions as future cohorts graduate.

There is a role for both local and national stakeholders to play in mitigating these sustainability issues to ensure the roles can continue to evolve and flourish in future in pursuit of bringing about further and more widespread improvements in dementia care in acute settings. The following section highlights ‘key factors for success’ to support local and national stakeholders in developing and sustaining the roles.

5.5 ‘Key factors for success’ to inform future developments and sustainability

The evaluation confirms that the model is an appropriate and effective one for implementing change, but highlights that further development is required in a number of Board areas to maximise impact and ensure sustainability of the roles and all they have achieved to date.

The evaluation findings provide insight into the key factors that are present in areas where the model is better-established and working more effectively. Table 5.2 (overleaf) synthesises the elements which are required to maximise the future success and sustainability of the change model, acknowledging that in some areas some or all of these supporting factors are already in place.
Table 5.2: Key factors for success

<table>
<thead>
<tr>
<th>Key factors for success</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>At National Level</strong></td>
</tr>
<tr>
<td>• Continued commitment to the dementia improvement agenda with a continued focus on acute settings</td>
</tr>
<tr>
<td>• Delivery of person-centred care for people with dementia in acute general hospitals</td>
</tr>
<tr>
<td>• Continued national support for the National Consultants Network and active participation required of all ASNs</td>
</tr>
<tr>
<td>• Continued national support for the DCs to maintain and build their identity as a ‘national force for change’</td>
</tr>
<tr>
<td><strong>At local Level</strong></td>
</tr>
<tr>
<td>• There is ownership of the agenda at senior Board level and a clear strategic plan for how the two roles will support this and how their inputs link to the 10 key improvement actions.</td>
</tr>
<tr>
<td>• The role of ASN is clearly defined, including local and national objectives, and is at a sufficiently senior level to ensure strategic influence at Board level.</td>
</tr>
<tr>
<td>• There are clear expectations of the ASN role and there are appropriate management, accountability and development processes in place at Board level.</td>
</tr>
<tr>
<td>• Larger NHS Boards consider how Dementia Champions can be further developed to support the ASN role more strategically.</td>
</tr>
<tr>
<td>• The ASN is involved in strategically selecting candidates for the DC programme and ensuring line managers understand the role and are supportive.</td>
</tr>
<tr>
<td>• The ASN is proactive in developing an effective mechanism for ensuring Champions are supported and co-ordinated. This may be through providing support themselves, or identifying and co-ordinating alternative sources of support.</td>
</tr>
<tr>
<td>• Champions have a clear sense of direction, their learning and development is supported, their resilience is supported and good/innovative practice is shared. They have a sense of being part of a bigger force for improvement and not isolated.</td>
</tr>
<tr>
<td>• Champions have protected time to dedicate to the delivery of shared objectives.</td>
</tr>
<tr>
<td>• A clear plan for mainstreaming and sustaining the ASN role is established and thought is given to succession planning for the ASN role</td>
</tr>
</tbody>
</table>

6 Key Recommendations

*For NHS Scotland Boards*

1. Ensure there is a clear dementia strategy group and strategic plans in each Health Board that supports and focuses the ASN’s and DCs’ work in acute care. Positive examples exist in NHS Scotland and there is the opportunity to share and spread best practice in this respect.
2. Ensure clear reporting and accountability structures within the Health Board to manage, support and develop the role of ASN, ensuring national as well as local objectives are incorporated.

3. Ensure that the focus of the ASN role remains on bringing about improvements in acute general hospital care, as involvement of ASNs in multiple initiatives runs the risk of diluting the impact of the roles in this sector.

4. Consider the ‘key factors for success’ outlined in this report to inform developments locally in a way that maximises and effectively mobilises the contribution of the ASN and DC roles in supporting implementation of the ‘10 key change actions’.

5. Concurrently focus on up-skilling the whole acute care workforce in line with Promoting Excellence and ensuring an appropriate skills mix in all wards and units, in line with the Promoting Excellence priority set out in the ‘10 key change actions’.

For the Scottish Government and Alzheimer Scotland

6. Maintain the national leadership and focus for improvement on the acute sector, which is already signalled by the ‘10 Key Change Actions’ and should be further developed through the improvement programme for acute settings.

7. Support every Health Board to have an ASN post that is placed at strategic level, has a clear and consistent role and remit, and clear responsibilities for ensuring DCs are supported and co-ordinated. This will require a refresh of the original MOA for ASNs.

8. Undertake work to support Health Boards and ASNs to evidence the impact of improvement work in acute settings for people with dementia and their carers (this might form part of a wider monitoring and evaluation framework for the ‘10 Key Change Actions’).

For NHS Education for Scotland (NES) and Scottish Social Services Council (SSSC)

9. Monitor the role of the Social Services Champions and how they can best be supported to help contribute to improvements in care at the interface between the acute and community settings.

10. Provide ongoing support through shared learning and development sessions for the existing Dementia Champions.

For the Scottish Government and NES

11. Give further consideration as to how existing Champions continue to be developed through education and development pathways with a view to succession planning for future specialist and advanced roles in acute care.
1 Introduction, aims and methods

Chapter Summary

- The Alzheimer Scotland Dementia Nurse Consultant/Specialist and Dementia Champion roles are designed to offer a two-pronged (strategic leader supported by a body of operational change agents) approach to dementia care improvement.
- This report evaluates the experiences and impact of the roles in practice between October 2012 and January 2014.
- A realistic, mixed method evaluation approach was employed.

1.1 About this report

The Alzheimer Scotland Dementia Nurse Consultants/Specialists and the Dementia Champions are two distinct but inter-linked workforce development initiatives aimed at improving dementia care in acute general hospital settings and at the interface between hospital and community care. In combination, the programmes aim to bring about improvement through the model of a strategic leader for change supported by a body of operational ‘on the ground’ change agents, often collectively referred to as a ‘National Force for Change.’ They are intended to play a key role in supporting delivery of national priorities around dementia care, identified in the Scottish Government’s current (2013-2016) and previous (2010-2013) Dementia Strategies.

In August 2012, NHS Education for Scotland, on behalf of the Scottish Government, commissioned Blake Stevenson Ltd to evaluate the impact of the two roles in bringing about improvements in dementia care in acute general hospitals. This evaluation focuses on what the roles have achieved to date (individually and collectively) and the experiences of the roles in practice, with the expectation that key learning from this evaluation will help inform the future development and sustainability of the programmes.

The remainder of this chapter sets out the evaluation objectives, the key methods employed and clarifies use of key terms in the report.

1.2 Evaluation objectives

The aims and objectives for this evaluation as set out in the original brief were to:

...
a) evaluate the impact of the introduction of Alzheimer Scotland Dementia Nurse Consultants/Specialists in bringing about improvements in the care of people with dementia in acute hospital care environments;

b) evaluate the impact of the introduction of Dementia Champions across health and social care organisations in bringing about improvements in the care of people with dementia in acute hospital settings;

c) explore the inter-relationship between Alzheimer Scotland Dementia Nurse Consultants/Specialists and the Dementia Champions in bringing about improvements;

d) explore how the introduction of Social Services Dementia Champions has impacted on the wider initiative; and

e) identify barriers/enablers to change in progressing the impact of these roles.

Scoping interviews were undertaken with key national stakeholders in late 2012 to develop and refine the evaluation aims and objectives. Stakeholders identified a number of key improvement areas to focus on in terms of impact, highlighted in Fig 1.1 below.

**Fig 1.1: Impact areas for evaluation**

- Staff knowledge, understanding, and attitudes
- Screening for cognitive impairment and delirium
- Proactive and meaningful involvement of families/carers
- Appropriate discharge planning and discharge to community/home
- Dementia-friendly hospital environments
- Implementation of Promoting Excellence and the Dementia Standards
- Better outcomes and experiences for people with dementia and their carers

Furthermore, stakeholders expressed a desire for the evaluation to explore the following key questions in relation to how the roles are working in practice:
1.3 Overview of methods

Our evaluation methodology involved the following key elements:

- ongoing consultation with and advice from the Evaluation Steering Group, Scottish Dementia Working Group (SDWG) and National Dementia Carers Action Network (NDCAN);
- seeking ethical and Research and Development approval - the South East Scotland NHS Research Ethics Service (RES) advised us that formal ethical approval was not required;
- a desk-based review of the University of the West of Scotland’s evaluation reports for cohorts one, two and three of the Dementia Champion programme, the Alzheimer Scotland Dementia Nurse Consultant quarterly reports and Annual Review, abstracts submitted for Dementia Champion graduation events, and OPAC inspection reports produced within the evaluation period;
- attending days one and five of cohort three of the Dementia Champions programme and graduation events for cohorts two, three and four;
- baseline interviews with 12 key national and strategic stakeholders and follow up interviews with ten, representing Alzheimer Scotland, Scottish Government, NES, SSSC, Mental Welfare Commission and the Dementia Champion Programme Delivery Team;
- baseline interviews with the Dementia Nurse Consultant/Specialist in 13 Health Boards and follow up interviews with 11;
• online surveys and telephone interviews with Dementia Champions from cohorts one, two and three:
  - a baseline online survey undertaken seven months after each cohort completed the programme – this was completed by 154 Dementia Champions (a response rate of 48%) including 47 Champions from cohort one, 68 from cohort two and 39 from cohort three;
  - a final, follow up online survey completed by 108 Dementia Champions, representing a 34% response rate – this included 35 responses from cohort one Champions, 40 from cohort two, and 32 from cohort three; and
  - in-depth telephone interviews with 30 Dementia Champions (ten each from cohorts one, two and three, representing a range of Health Board areas, professional groups and including NHS and Social Services Champions);

• interviews with six people with dementia and two carers; and

• in-depth case study research in four Health Board areas, involving interviews and focus groups with 34 Dementia Champions, four Dementia Nurse Consultants/Specialists, 28 colleagues of Dementia Champions, including line-managers; and ten local strategic stakeholders.

1.3.1 Methodological benefits and limitations

This evaluation employed a realistic rather than experimental approach. In doing so, while it cannot conclusively establish causal links between the two roles and particular outcomes, it is able to comment on the contribution (and potential contribution) of the two roles to dementia care improvements within acute settings and the key conditions that influence outcomes.

The methodology ensured all ASNs and DCs (from cohorts one to three) were invited to contribute their views, thereby maximising involvement of the nationally available sample. The intensive case study research and qualitative interviews provided an in-depth understanding of the key issues affecting the roles and their ability to influence change. The approach was informed and shaped through consultation with and guidance from the Evaluation Steering Group, SDWG and NDCAN.

To protect the anonymity of research participants and minimise the risk of attribution, this report does not link respondents’ views or evaluation findings to Health Board and local authority areas. Findings and themes have been drawn out across the areas, making distinctions by key characteristics (board size, rurality, professional group, sector etc.) as appropriate.

There were a number of limitations to the methodology, listed below:

• Challenges recruiting people with dementia and carers to take part in the evaluation resulted in limited exploration of outcomes and experiences for users and carers.
The disproportionately small number of Social Services Champions compared to NHS Champions and small number of Social Service respondents limits robust comparison between sectors from the survey data. Any comparisons noted in the report were substantiated by qualitative data sources.

While 64% (205) of a possible 321 DCs responded to at least one survey, only 57 responded to both baseline and final surveys, limiting the possibility for measuring changes in impact or experiences over the evaluation period through the survey data. Comparing responses from the cohort of 57 Champions revealed few significant changes between the baseline and final survey therefore, unless otherwise stated, this report presents findings from the final survey as these represent the most current findings. We have presented some findings from the baseline surveys where these represent a significant or interesting change compared with the final survey.

It is important to note that during the first half of the evaluation, impact data was collected against outcome measures informed by stakeholder scoping interviews (see Fig 1.1, pg. 4); the action areas for improvement identified by cohort one Champions in UWS’ cohort 1 evaluation report; and the aims and objectives set out for both roles (see 2.4.1 and 2.5.1). Mid-way through the evaluation (May 2013) the Scottish Government launched the 10 key action areas for acute care which were intended to provide a driver for Boards to maximise use of resources such as the Dementia Champions and Dementia Nurse Consultants (see 2.3.2). At the suggestion of the Steering Group, from August 2013, impact data was collected and analysed against the 10 key action areas which encapsulate many of the original outcome areas.

1.4 A note on terminology

Unless it is pertinent to make the distinction between Nurse Consultants and Nurse Specialists, throughout this report we use the term Alzheimer Scotland Dementia Nurse Consultant, Dementia Nurse Consultant, or the abbreviation ‘ASN’ for ease and brevity.

Unless it is relevant to distinguish by profession or sector, we use the terms Dementia Champions, Champions and the abbreviation ‘DC’ to include NHS and Social Services Champions across the professions.

1.5 The layout of the report

The remainder of this report is set out as follows:

- chapter two sets out the national context within which the roles sit and describes the background to their development;
- chapters three and four present the main findings from the research in terms of the experiences, achievements and impact of the roles to date;
chapter five summarises key findings on the factors which have enabled and hindered the ability of the roles to influence improvements in dementia care; and

chapter six presents conclusions and recommendations to inform the future development of the roles.
2 Setting the roles in context

Chapter Summary

- The incidence of dementia is increasing and this has significant implications for care in acute general hospitals and at the interface between hospital and community care.

- Dementia is a national priority for Scotland, supported two dementia strategies. The first dementia strategy included a commitment to “improve the response to dementia in general hospital settings including alternatives to admission and better planning for discharge”.

- The ASN and DC roles were introduced to support delivery of national objectives around improvements in acute care. Combined, the roles are intended to provide a two-pronged improvement model with the ASN providing strategic leadership for change, supported by a body of operational change agents (the DCs).

- The model was embryonic at the start of the evaluation, with many ASNs new to post and only one cohort of 109 trained Dementia Champions. At the time of reporting there are 12 ASNs in post and four DC Cohorts (423 individuals) have completed training.

- Evaluation findings should be considered in light of the immaturity of the model and the relatively short period of time ASNs and DCs have been in post.

2.1 Introduction

This chapter outlines the key contextual issues which provide a backdrop to the evaluation. It sets out the wider national context within which the two roles were developed and operate, and briefly describes the two roles and the background to them. It is set out as follows:

- Dementia: prevalence and implications for acute general hospital settings;
- National dementia policy;
- Background to the Alzheimer Scotland Dementia Nurse Consultant initiative;
- Background to the Dementia Champion programme; and
- Chronology of programme implementation.
2.2 Dementia: prevalence and implications for acute general hospital settings

Scotland’s population is ageing, and with older age come a range of challenges including increased prevalence of dementia. There are approximately 88,000\(^2\) people with dementia in Scotland; this is expected to double over the next 25 years. While dementia is not restricted to older people, age is a significant risk factor and 96% of dementia suffers in Scotland are aged 65 or over. Research\(^3\) in 2009 by Alzheimer’s Society suggests a quarter of acute general hospital beds are occupied by people over the age of 65 with dementia – in 2014, this figure is likely to be an under-estimation. The research also found that 97% of nursing staff surveyed ‘always’ or ‘sometimes’ care for someone with dementia and that half the carers interviewed reported that admission to a hospital had had a negative impact on the person with dementia.

Often people with dementia present in acute general hospitals for treatment for other conditions and it is anticipated that multi-morbidity encompassing cognitive impairment will become the norm in Scotland. Acute hospital care staff will be expected to manage both physical and mental health problems (Cowdell, 2010; Marengoni et al, 2011; Keenan and Jenkins, 2011) and will need knowledge of interventions for communicating; managing agitation, nutrition, hygiene, and pain; and determining decision-making capacity (Weitzel, Robinson, et al.; 2011). People with dementia who have other health problems are more likely to be inappropriately admitted to hospital, are more likely to stay longer (often to the detriment of their wellbeing) and are more likely to be discharged directly to a care home.

Evidence suggests that the particular needs of people with dementia are often poorly understood by staff working in general medical settings such as hospital wards and emergency departments, and that work is required to ensure practitioners in these settings have the skills and knowledge to provide appropriate care for people with dementia. ‘Dementia: Decisions for Dignity’ (Mental Welfare Commission, 2010) reported on visits to 41 wards across nine Health Boards in Scotland. While many positive examples of the care and treatment of people with dementia were identified, the Commission also highlighted areas for improvement, including: the potential for avoiding admission through early intervention and support; involvement of families and carers; compliance with legal safeguards for people who lack capacity; awareness of human rights and incapacity legislation; improving the hospital environment to better support people with dementia; and reducing the number of people discharged to residential care.

2.3 National dementia policy

2.3.1 Scotland’s Dementia Strategies

Recognising the significance of these issues, dementia was made a national priority for Scotland with the publication of the **first Dementia Strategy in June 2010**. The Strategy outlined a

\(^2\) Alzheimer Scotland website, 2014

\(^3\) Alzheimer Society, 2009, Counting the cost: Caring for people with dementia on hospital wards
commitment to “improve the response to dementia in general hospital settings including alternatives to admission and better planning for discharge”. Actions set out in the Strategy included the development of ‘Standards of Care for Dementia in Scotland’ and ‘Promoting Excellence – a Framework for Health and Social Services Staff Working with People with Dementia, their Families and Carers’, both of which were launched in June 2011. The publication in June 2013 of Scotland’s second dementia strategy (2013-2016) confirmed the Scottish Government’s continued commitment to the agenda. The strategy acknowledges the significant achievements made over the past three years but continues to emphasise the need for improvements in acute general hospital settings.

The Strategies have seen the development of specific HEAT (health improvement, efficiency, access and treatment) targets relating to early diagnosis and post-diagnostic support; and are underpinned by the Charter of Rights for People with Dementia and their Carers in Scotland (Alzheimer Scotland, 2009) and informed by the lived experiences of people with dementia and their families and carers through the close involvement of the Scottish Dementia Working Group (SDWG) and, more latterly, the National Dementia Carers Action Network (NDCAN).

2.3.2 Introduction of a 10-point National Dementia Care Action Plan for Acute Care

Key to the second dementia strategy, was the announcement by the Cabinet Secretary for Health and Wellbeing in May 2013 (mid-way through this evaluation) of a 10-point National Dementia Care Action Plan for Acute Care to support the implementation of the Standards of Care for Dementia in acute settings and to support NHS Boards to make the required changes and to maximize workforce initiatives, including the Alzheimer Scotland Dementia Nurse Consultant Consultants and the Dementia Champions. The 10 point action plan is intended to provide a focus for the work of the Alzheimer Scotland Nurses and the Dementia Champions, and as of September 2013, the ASNs started reporting against these actions. In response to this policy development, data on impact was collected and analysed against these 10 key actions for the second half of this evaluation, from August 2013 onwards. A national improvement programme for acute care to support implementation of these 10 key actions is currently in development.

2.3.3 Broader improvement initiatives

Other national improvement initiatives have also supported national priorities around dementia and are a key part of the wider context within which the two roles sit. These include: the Healthcare Quality Strategy (with its ambition for universal provision of safe, effective and person-centred care); the integration of health and social care services; the person-centred care and patient experience programmes; ‘Reshaping Care for Older People’; Healthcare Improvement Scotland’s ‘Older People in Acute Care’ programme; the development of the Senior Charge Nurse (SCN) role and Clinical Quality Indicators (CQIs) through ‘Leading Better Care’; and the national Carers strategy and EPIC principles for working with carers.
2.4 Background to the Alzheimer Scotland Dementia Nurse Consultant initiative

Alzheimer Scotland launched the Dementia Nurse Consultant Programme in 2006, with posts created over a four year period in four territorial Health Boards. In 2010, Alzheimer Scotland launched a Dementia Nurse appeal. With matched contributions from the Scottish Government, by the end of 2012, funding for an ASN was available to each territorial health board in Scotland. Initial funding is for three years with the expectation Health Boards mainstream the post beyond this, with continued support of £10,000 per year from Alzheimer Scotland to maintain and develop the National Dementia Nurse Consultant Network and the role’s national focus.

2.4.1 Aims and objectives of the ASN role

The post is designed to fulfil a strategic leadership role with the aim of strengthening the knowledge, skills and professional leadership available to NHS Boards as well as contributing to the delivery of key national priorities and activities to improve dementia care. The posts were established by Alzheimer Scotland via a Memorandum of Agreement (MOA) with NHS Boards which set out the key objectives of the post. The employing NHS Health Board is responsible for:

- the management and professional development of the ASN;
- the appropriate organisational positioning of the post to ensure the ASN is enabled to contribute their dementia specific expertise across the organisation, both strategically and operationally; and
- making the existing organisational infrastructure, systems and processes available to support monitoring, auditing and measuring outcomes to demonstrate improvements in the quality of care received by people with dementia.

The posts are expected to contribute to the delivery of the following:

- A reduction in prescriptions of anti-psychotic medication or other sedatives as a means of controlling behaviour issues that present staff with a challenge
- An increase in satisfaction with care reported by patients with dementia or their carers
- A reduction in the number of people with dementia referred to residential care/ other hospital wards to wait for admission to residential care
- An increase in the number of people discharged home with flexible community support services put in place
ASNs report quarterly to Alzheimer Scotland and the Scottish Government. Up until September 2013, ASNs reported against the MOA; since September 2013 ASNs have reported progress against the 10 Key actions for acute care (see 2.3.2) as these are intended to provide the future focus for the role and encapsulate the original aims of the MOA.

2.4.2 Training and support for ASNs

Between February 2012 and January 2013, ASNs participated in a year-long bespoke, person-centred leadership development programme, ‘Promoting Excellence in Dementia Leadership’ as an introduction to the role. The leadership programme evaluated positively, although the evaluation report (Young & Douglas; 2013) reflects key external factors that impacted on its delivery and effectiveness:

- the ASN recruitment process took longer than expected meaning not all ASNs could participate and therefore the strong bond formed by those on the course was not present across the full ASN group;
- variations in the visions of Alzheimer Scotland and Health Boards for the role; and
- individual ASNs did not always have a clear direction, or a clear or shared understanding of their role, responsibilities, and priorities.

Since early 2013, the ASNs have received support from Alzheimer Scotland to develop their role and influence through the establishment of The National Network Group which meets bimonthly and includes AHP Dementia Consultants and other dementia specialist post holders. The group is intended to strengthen professional leadership in the area of dementia care and to develop a cohesive national group to lead on and contribute to the dementia improvement agenda.

2.5 Background to the Dementia Champion Programme

The Dementia Champion initiative is closely linked to the Alzheimer Scotland Nurse Consultant initiative. It was established in 2011 with the aim of supporting 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 and at the interface between hospital and community settings. The programme is delivered on behalf of NES/SSSC by the University of the West of Scotland in partnership with Alzheimer Scotland. The Dementia Champion role is intended to complement the ASN role to provide a two-pronged improvement model with the ASN providing strategic leadership for change, supported by a body of operational change agents (the DCs).

At the time of reporting, four cohorts of Dementia Champions (423 Champions in total) have graduated from the programme, with a fifth cohort underway (including Community Hospitals) and commitment from the Scottish Government to fund at least a sixth cohort. This evaluation
focuses on the work and experiences of the 321 DCs completing cohorts one-three. Most Dementia Champions are nurses and allied health professionals (AHPs). From cohort two onwards, the programme has also included representation from Social Services with the intention that those working in intermediate care teams might be able to influence improvements to acute setting discharge/admission pathways.

2.5.1 Learning outcomes for Dementia Champions

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

- 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.
- 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.
- 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.
- 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.
- 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.

2.5.2 Details of the training programme

The training programme comprises a blended learning course (over a six month period) with five contact days, a range of online learning in between contact days, and a half day placement in a community setting. Each participant is allocated a personal tutor to support their individual needs, and is required to complete three written assignments and undertake a change activity in their workplace. With each cohort, course content has been refined (particularly with regard to being inclusive of Champions working within Social Service settings); following cohort one, days one and
five of the programme have been delivered to the full cohort of Champions, rather than in regional groups, to strengthen the sense of the Champions as a national force for change.

2.5.3 Key findings from the University of the West of Scotland’s programme evaluations

End of programme evaluation reports produced by the University of the West of Scotland for each cohort of the Dementia Champion programme reveal that cohorts one to three evaluated positively on each occasion. Across the three cohorts, students engaged well with the programme and drop out was minimal, despite the intensity of the programme.

Supporting participants to be agents of change

Key positive outcomes of the programme evidenced in UWS’ evaluation reports include: a significant shift towards more positive and person-centred approaches to dementia by participants over the programme period; participants’ perceptions about dementia being challenged and altered; and participants’ feeling confident at the end of the programme about their ability to influence change in the workplace.

UWS’ evaluation demonstrates that the DC programme prompted the majority of participants to plan and begin to implement activities to improve the experiences of people living with dementia and their families. Key areas of action identified were around: the environment; education of staff; identification of people with dementia; facilitating communication with people with dementia; identifying and managing delirium; involving relatives and carers; and input from other professional groups. These areas of concern informed the design of the DC baseline survey for this evaluation and link with many of the 10 key actions that were latterly introduced to provide a focus for improvements in acute settings. In each cohort, over 90% of participants reported that they had or would change practice as a result of the Programme.

Key factors affecting the ability of DCs to influence change

UWS’ programme evaluations of cohorts one to three highlighted a number of issues of interest to this evaluation in terms of factors likely to influence the success and sustainability of the Dementia Champion role in practice, for example:

- the importance of recruiting the right people for the course and role (i.e., those who are motivated, able and willing);
- the importance of Champions having line management and organisational support both to undertake the programme and to lead and sustain change;
- the need for ongoing support – through contact with each other and the Dementia Nurse Consultants and Managed Knowledge Networks;
• difficulty managing the work associated with the Dementia Champions programme at the same time as their work role - while some participants were being supported to complete tasks within their workload, others were required to undertake tasks within their own time;

• the value to participants of spending time in a community setting seeing people living well with dementia and approaches to care that are more person-centred; and

• the value of the input from the Scottish Dementia Working Group in supporting improved understanding of the lived experiences of dementia.

2.5.4 National support for Dementia Champions

The Champions have been offered national support to help them maintain and develop resilience in their role and their presence as a ‘critical mass’ ‘national force for change’ through a number of national support mechanisms; these include regional network events facilitated by NES (which recently moved to a ‘Masterclass’ model, with one event held at the time of reporting); events facilitated through Scottish Social Services Council (SSSC) for Social Services Champions, and the Community of Practice held on the Managed Knowledge Network (MKN).

2.6 Chronology of implementation of the two roles

Tables 2.1 and 2.2 on the following page detail the timescales associated with the development and implementation of the two roles, highlighting the length of time in post for each ASN and the three cohorts of Dementia Champions at the conclusion of the evaluation. The tables demonstrate that the model was fairly embryonic at the start of the evaluation, with many ASNs new to post and only one cohort of 109 Dementia Champions having completed the programme. Findings reported in the following three chapters of this report should be considered in light of the relative immaturity of the roles and relatively short period of time they have been in post to achieve change and develop a model of working together, as well as the enormity of the challenges associated with influencing change in acute general hospital settings. At the time of reporting there are 12 ASNs in post and four DC Cohorts (423 individuals) have completed training.
Table 2.1  Dementia Champions: implementation timescales

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Course completion date</th>
<th>Length of time as Champions at time of evaluation conclusion</th>
<th>Number of Champions per cohort</th>
<th>Cumulative total number of Champions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>NHS</td>
<td>Social Services</td>
</tr>
<tr>
<td>Cohort 1</td>
<td>End February 2012</td>
<td>2 years</td>
<td>109</td>
<td>0</td>
</tr>
<tr>
<td>Cohort 2</td>
<td>Early September 2012</td>
<td>1 year 5 months</td>
<td>78</td>
<td>17</td>
</tr>
<tr>
<td>Cohort 3</td>
<td>Early February 2013</td>
<td>1 year</td>
<td>98</td>
<td>19</td>
</tr>
<tr>
<td>Cohort 4</td>
<td>End September 2013</td>
<td>5 months</td>
<td>84</td>
<td>18</td>
</tr>
</tbody>
</table>

Table 2.2  Alzheimer Scotland Dementia Nurse Consultants: implementation timescales

<table>
<thead>
<tr>
<th>Health Board</th>
<th>Start Date</th>
<th>Length of time as Dementia Nurse at time of evaluation conclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>October 2012</td>
<td>1 year 4 months</td>
</tr>
<tr>
<td>Borders</td>
<td>December 2008</td>
<td>Post ending as evaluation commenced</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>December 2012</td>
<td>1 year 2 months</td>
</tr>
<tr>
<td>Fife</td>
<td>April 2012</td>
<td>1 year 10 months</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>November 2012</td>
<td>1 year 3 months</td>
</tr>
<tr>
<td>Grampian</td>
<td>March 2012</td>
<td>1 year 11 months</td>
</tr>
<tr>
<td>Greater Glasgow &amp; Clyde</td>
<td>March 2012</td>
<td>1 year 11 months</td>
</tr>
<tr>
<td>Highland</td>
<td>August 2012</td>
<td>1 year 6 months</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>October 2011</td>
<td>2 years 4 months</td>
</tr>
<tr>
<td>Lothian</td>
<td>October 2009</td>
<td>4 years 4 months</td>
</tr>
<tr>
<td>Orkney</td>
<td>Recruiting to post</td>
<td></td>
</tr>
<tr>
<td>Shetland</td>
<td>March 2012</td>
<td>1 year 11 months</td>
</tr>
<tr>
<td>Tayside</td>
<td>December 2012</td>
<td>1 year 2 months</td>
</tr>
<tr>
<td>Western Isles</td>
<td>April 2012</td>
<td>1 year 10 months</td>
</tr>
</tbody>
</table>

The following chapter presents evaluation findings on the experiences of the roles in practice and how they are working together to influence improvements in dementia care.
3 Findings: the roles in practice

Chapter summary

- ASNs and DCs have demonstrated significant dedication and enthusiasm in their roles.
- Local implementation of the Dementia Nurse Consultant role has varied in terms of strategic positioning and focus and this has affected their ability to influence change.
- Relationships between Dementia Nurse Consultants and Champions have developed positively in most areas over the evaluation period and this appears to be an important factor contributing to the success of the two roles. This is better-established in some areas than others.
- Where the model is working well there is a sense of shared direction and co-ordinated working between the roles; DCs feel better supported, more informed and more resilient, and momentum for change and improvement is being built/sustained.
- Where collaboration between the roles is minimal, Champions can feel isolated, directionless and unsupported.
- Social Services DCs have been active in taking forward changes and improvements within their own services, however tend to be located in services that are distanced from acute hospitals and have therefore, unsurprisingly, had limited influence in terms of directly influencing acute general hospital care for people with dementia or admission/discharge pathways.

3.1 Introduction

This chapter presents evaluation findings on how the two roles are working in practice (individually and collectively) noting any developments over the evaluation period and highlighting where the model is working well and what is supporting this. The chapter explores evaluation objectives c, d, and e as well as the issues identified in early scoping interviews (1.2, Chapter 1). Evidence in this Chapter is drawn from interviews with national stakeholders, ASNs and Champions, the four case studies, and the two DC surveys.

3.2 The Alzheimer Scotland Dementia Nurse Consultant role in practice

3.2.1 Summary of current landscape

At the start of the evaluation there were ASNs in post in 13 of the territorial Health Boards, with a recruitment drive underway in the 14th Board area. At the time of reporting, there are 12 ASNs in post; one Board continues to experience challenges recruiting for the post and another Board discontinued the post when initial funding ended. In two other Board areas where the initial funding has ended, one Board has made the post a substantive permanent post, and the other has opted
to use the continued Alzheimer Scotland funding of £10K to support delivery of the national elements of the ASN role (linking in with the national network group and delivering joint objectives) part time, with the remainder of the post funded by the Board to deliver local objectives around dementia care and more broadly, care of older people. In two areas a team approach to the role was employed, with the role objectives split and built into two substantive and permanent posts. The other eight Boards are still in receipt of initial matched-funding, with end dates for the posts varying from one-two years’ time.

### 3.2.2 Summary of variations in local implementation of the post

The MOA (2.4.1) was designed to support consistency of the role and ensure ASNs work together at a national level towards shared objectives. While the MOA is a key reference point in most Board areas (along with specific local objectives in most instances), the post has been implemented differently at Board level to suit local need and circumstances, and reflects different approaches to sustainability planning. Fig 3.1 below summarises the key variations in how the role has been implemented in terms of strategic positioning and focus; these are discussed further below.

**Fig. 3.1: Local variations in ASN role**

### 3.2.3 Local variations in strategic positioning and sphere of influence

**Seniority of role**

The AfC band and grade Boards’ have attached to the role varies between Band 7 and Band 8b, with one post at Band 7. This presents a degree of inequity in terms of recompense for delivery of MOA objectives and creates a range in levels of seniority and organisational influence across the ASN group. The Band 7 example reflects an area has taken a team approach to the role, delegating some of the more (local) strategic elements of the post to the ASN’s line manager.
Seniority has impacted on the strategic influence of the ASN post, but factors such as the personalities of individuals and support from strategically-placed managers have mitigated this in some cases. In general, 8a was considered the minimum grade the post should be at to influence change at a strategic and Board-wide level. A lack of budgetary control at this level was highlighted (by a minority) as challenging and ASNs at this level were less likely to be involved in DC recruitment.

**Line-management**

Line-management of the role varies across Board areas. Four ASNs report directly to a Nurse Director; others are line-managed by Heads of Service, Service Managers or Lead Nurses for Mental Health and Learning Disabilities, primary care or Rehabilitation and Assessment. Where it was not the case, some ASNs reported they felt their role would be best positioned under the line-management of a Nurse Director due to the widespread and strategic focus of their work across multiple settings and the size of the nursing workforce; this perception was echoed in stakeholder interviews.

**Key partners and strategic groups**

ASNs work with many (and for the most part, similar) key partners in taking forward their work, indicating that they are attempting, to varying degrees of extent and success, to influence operationally, strategically and on a multi-disciplinary and multi-sectoral level. Common key partners are outlined in the diagram below:

The majority of ASNs sit on one or more strategic planning, implementation and/or delivery groups within their area, either at Board level or acute service level. This varies greatly from one ASN to another, as do group descriptors and remits. In some cases ASNs/someone from the ASN team chair these groups. Subject areas of key groups include: dementia, care of older people in
acute hospitals, Promoting Excellence, local Dementia Champion network/groups, vulnerable adults, person-centred care, Senior Nurse/other lead professional groups, integration, and quality improvement.

Close involvement with local strategic groups and key teams is important in enabling ASNs to promote and shape the dementia agenda locally among a wide range of senior and strategic staff. Some ASNs have found influencing at this strategic level more challenging than others as a result of a range of factors, including: their seniority and positioning; their previous experience of influencing strategically; the priority placed upon dementia in their area; and the role needing time to bed in. In the majority of areas this is improving over time as the clarity and purpose of the role develops and as the local and national profile of dementia rises.

**Physical location**

It is interesting to note the variations in where ASNs are located and how visible and physically accessible they are as a result. This varies, with some having their offices alongside Nurse Directors and other strategic staff with a Board-wide remit, including location within the Board Head Quarters; others are located within Practice Development, or at particular hospital sites. In one instance, being located within a single hospital site restricted the scope of the ASN to work beyond this site; a change of location to the Board Headquarters has strengthened recognition of the role as having a board-wide remit and function. Given the board-wide and national focus of the role and the awareness-raising remit, visibility and accessibility are important attributes which some ASNs feel could be improved by more thoughtful location.

**3.2.4 Local variations in the focus of the ASN role**

**Operational versus strategic focus**

The extent of operational and strategic focus at a local level varies across the ASN roles, in response to local need and objectives. Few ASNs have a clinical role, although most provide support and expertise to frontline staff with complex care cases and provide clinical supervision and support in ward areas. Some ASNs regularly work directly with groups of operational staff; others primarily do this through their network of Champions; and others work primarily at a strategic level, directing change at an operational level through Lead Nurses/Managers. ASNs are often inundated with requests for support and advice at all levels throughout their Board area, meaning the role is stretched in multiple and varied directions.

Variation in terms of operational/strategic focus of the role is greatest in the two areas that have taken a team approach to implementing the ASN role. In one area the operational and strategic elements of the MOA are split between two roles with the strategic role attending to national ASN work and local strategic work, and the operational role more focused on supporting the Champions and providing more “hands on” improvement support on the ground – both posts also have a clinical element through provision of a memory assessment service. This is a small, rural Board, and this was considered the most appropriate and sustainable way to implement the role.
rather than creating a new full time post at a Consultant level. In the other area the national and DC elements of the ASN role are carried out by one person (working 30 hours a week) in partnership with their line manager (an Associate Nurse Director) to achieve more strategic reach locally. Again, in this medium-sized Board, this approach was considered the most sustainable way to implement the role to secure its long-term continuation. In both these examples, the ASN was an existing post that has been shaped and extended to include the MOA objectives.

**Involvement in Dementia Champion recruitment**

During baseline interviews five (out of 13) ASNs had had some involvement in recruiting DCs and three (out of 13) planned to - many Dementia Nurse Consultants described themselves as “finding their feet” at this point. Follow up interviews reveal eight (of 11) have now been involved to some extent in recruiting to recent DC cohorts. Involvement in recruitment varies from actively identifying or influencing decisions about areas that would benefit from a DC, strategically nominating particular individuals, ensuring managers fully understand the nature and aims of the programme and sign up their support, asking managers for nominations, to limited or no involvement at all. There have been some issues that have hindered this process, for example ASNs not being included in the decision by senior managers; and DC cohorts being in place before the ASN was in post. Some ASNs continue to express frustration at not being in a position to influence local DC recruitment and selection. Stakeholders and many ASNs felt that to maximise effectiveness of the two roles, ASNs need to actively influence DC selection and placement.

**Involvement in Healthcare Improvement Scotland (HIS) Older People in Acute Care (OPAC) inspections**

Again involvement in HIS OPAC inspections varies across ASNs, with some integral to preparation and resultant action plans, and others on the periphery. Those involved more actively participate in a number of ways, summarised in the diagram below: 
OPAC inspections are seen as a “catalyst” for change and a lever for obtaining strategic buy in by many ASNs. However, disappointment was also expressed by some that they felt the inspections sometimes dominated their work, and often did not pick up on a lot of the good practice that is being undertaken and had generalised from poor practice that was highlighted. In a handful of areas, Champions are also strategically involved in Board responses to inspections, for example sitting on local OPAC groups, considering actions arising out of OPAC during local network meetings, and auditing each other’s wards through mock inspections (co-ordinated by the ASN).

3.2.5 Involvement nationally, including the National Dementia Nurse Consultant Group

The National Dementia Nurse Consultant Group was created during the evaluation period. ASNs reported that national network meetings are a valuable source of support. The ASN network meetings provide a forum for discussing shared issues such as how to support DCs, sharing experience and learning from other areas and developing a national group action plan. However, some ASNs struggle with attending meetings and suggested that the network meetings would be more effective if they took place at different locations across Scotland to allow ASNs from more remote areas to attend more easily. The general perception is that as this group develops further, it has the potential to become a cohesive and powerful voice in influencing improvements nationally, if active participation from the full ASN cohort can be secured.

A number of ASNs have developed a strong public and media presence, helping raise the profile of the group and Alzheimer Scotland; helping the public understand the role and purpose; and drawing attention to the work in their own Board areas. Some sit on other National groups such as the National Dementia Strategy Group and groups around frailty and delirium which enhances the group’s potential to influence at a national level. Some are involved in progressing shared research activities to further knowledge, understanding and practice in the field of dementia and many are engaged in work with universities as Honorary lecturers, sharing best practice to the next generation of health and social care staff.

3.3 How the Dementia Champion role is working in practice

3.3.1 Geographical distribution of Champions from cohorts one, two and three

Dementia Champions from cohorts one, two and three are located across 15 local authority areas and all territorial Health Boards, as well one Special Health Board (Golden Jubilee). As figure 3.2 below illustrates, the distribution of NHS Champions across the 14 territorial Health Board areas is roughly consistent with the relative population size of each area: the areas with the largest populations tend to have the largest proportions of Champions and vice versa. There is a disproportionately small number of Social Services DCs compared to NHS DCs and in five of the territorial health boards there were no Social Services Champions from cohorts two and three.

---

4 Based on data supplied by NES in relation to Champions graduating in cohorts one, two and three.
3.3.2 Job role\(^5\) of Champions from cohorts one, two and three

As figure 3.3 on the following page illustrates, Dementia Champions have a varied level of seniority. The professions most represented are Nursing and the Allied Health Professions. The two roles that account for the largest proportions of Champions are Staff Nurses and Charge Nurses.

---

\(^5\) Based on data supplied by NES in relation to Champions graduating in cohorts one, two and three.
3.3.3 Action plans for identifying change

Nearly all Champions (94%, 100) completed an individual action plan as part of the DC training programme, identifying key change areas they wished to progress in their own clinical areas. 68% (68) said they had achieved half or more of their action plan; 32% (32) have achieved less than half. The majority are satisfied with their overall level of progress with 77% (82) stating they were very or quite satisfied with their overall level of progress.

3.3.4 Involvement in improvement activities outside personal action plan

Nearly three quarters (74%, 79) of Dementia Champions reported being involved in implementing changes or activities outside of those listed in their own individual action plan. 19% (20) said they were not currently involved but planned to be in the future. Over four fifths (82%, 88) of Dementia Champions reported that they have some involvement in progressing work around strategic action plans in their Board area.

3.3.5 Influencing others

Dementia Champions have been able to influence the practices and attitudes of colleagues in a range of settings; most commonly their peers and those located closest to them. Figure 3.4 on the following page illustrates that Dementia Champions reported greatest success influencing and
raising awareness amongst colleagues in their own unit or ward, and within their own professional group. 99% of final survey respondents (106) felt they raised awareness among colleagues in their unit/team to at least some extent. 91% (97) of respondents to the final survey said they had raised awareness among colleagues in other units or teams at the same site to at least some extent. Influencing colleagues at other settings and health board or local authority staff involved in service management, policy and planning has been more challenging for Champions.

Fig. 3.4: To what extent have you been able to influence the following groups?

Key factors affecting Champions’ ability to influence and raise awareness with different staff groups include support from managers, proximity to colleagues, the strength of existing relationships, resistance to change by colleagues, seniority and time availability. While Champions with different levels of seniority generally feel able to influence colleagues to some extent, challenging inappropriate attitudes and behaviour, implementing and embedding change within their own or other ward settings, and with other professional groups tends to be easier the more senior their position for the reasons highlighted below:

- **Position of influence:** illustrated by the following quote which reflects other comments made, “It’s easier to address change with nurses if you’re their manager” [SCN Champion - interviewee]

- **Autonomy over own work priorities and time management:** illustrated by the following quote which reflects other comments made, “I manage my own time and have autonomy to do so... I choose my own priorities. I imagine it’s been so much harder for Band 5s to do this work” [Clinical Team Leader Champion - interviewee].
Influencing individuals outside their own professional group is most effective where DCs have a senior role in a multi-disciplinary team/department; where DCs are engaging with DCs from other professions through their local Dementia Champion network; where ASN have helped facilitate the relationship outside of the network meeting; or where, for example, Champions from different professions are co-located or closely located. Medical staff are considered the most challenging professional group to influence by Champions due to different cultural practices, hierarchy within the NHS, and an absence of Medicine-based Champions. However, this was not an issue for all Champions; some have achieved significant progress in influencing change in the practice of medical colleagues and wider professional groups, sometimes regardless of seniority.

The Dementia Champion Programme was cited as a key motivator when Champions felt they were struggling with influencing colleagues, as the following quote highlights: “the resistance [from colleagues] was starting to get my back up a bit, but the dementia champion course gives you a wee bite in your teeth that makes you keep going, and keep going, and keep going...”. Other key facilitators included support from other Champions and/or support from the ASN.

### 3.3.6 Engagement with national networking and support

Overall Champions perceive there to be a benefit in participating in the national and regional activities facilitated by NES and SSSC to help motivate them in their role, to share learning and experience, and to reinforce the sense they are a national group of change agents. The following quote from a DC illustrates feelings shared by others:

> “Sometimes I might think that I have no time or I am not achieving anything but attending a masterclass to talk with people in the same situation is essential. You came away with new ideas, new contacts and your enthusiasm recharged.”

As table 3.5 in the following page illustrates, the majority of those participating in the national networking opportunities provided have found them helpful or very helpful.

#### Table 3.5: nationally co-ordinated events

<table>
<thead>
<tr>
<th></th>
<th>Very helpful</th>
<th>Moderately helpful</th>
<th>Somewhat helpful</th>
<th>Not helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Masterclass (n=20)</td>
<td>7</td>
<td>10</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>SSSC Event (n=7)</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Regional learning network (n=73)</td>
<td>23</td>
<td>31</td>
<td>19</td>
<td>-</td>
</tr>
</tbody>
</table>

The main barriers to participation in national networking opportunities were not being released to attend, not having the time to attend, and for Boards more removed from the central belt, the

---

6 The data in Table 3.5 and 3.6 in relation to the Masterclass and the Managed Knowledge Network is based on responses to the final survey of Dementia Champions. Data related to the regional learning network is based on responses to the baseline survey. We did not ask about the regional network in the final survey because it had been superseded by the Masterclass approach.
cost and time associated with travelling to events. Less common barriers were lack of spaces at the event, and not knowing about the event.

Table 3.6: Use of Managed Knowledge Network (MKN)

<table>
<thead>
<tr>
<th></th>
<th>Very helpful</th>
<th>Moderately helpful</th>
<th>Somewhat helpful</th>
<th>Not helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managed Knowledge Network (n=68)</td>
<td>15</td>
<td>23</td>
<td>28</td>
<td>2</td>
</tr>
</tbody>
</table>

Around two-thirds of final survey respondents have used the MKN (64%, 68). Table 3.4 shows that nearly all said this was helpful to at least some extent. Champions commented that the MKN provided access to useful information which has helped to increase their knowledge, describing the MKN as a “good source of resources”, giving them “more knowledge and insight”; “a great forum for people sharing ideas and information sources”; and a “good way to contact other DCs.” One, remotely located Champion commented on how the MKN had helped overcome problems related to geographical location: “geographical location making things a little difficult...the Managed Knowledge Network has ensured I can still move forward.” A minority of Champions (in survey responses and qualitative research) highlighted issues with the MKN including “information overload”; it being complicated to use; under-use of the forum by other DCs limiting the value of the resource; and limited relevance to those who are not ward-based. Those who have not accessed the MKN explained this is primarily due to a lack of time.

3.4 The ASN-DC model in practice: how the roles are working together to achieve change

3.4.1 Initiating the relationship

The initiation of interaction between ASN and DCs varies – some ASNs contact their DCs before they start the DC training programme (often following involvement in their recruitment); some ASNs make contact during the programme to start getting DCs involved in the local network and objectives, in some cases facilitating buddying up with previous cohorts or providing support to complete the course; in some cases the DC initiates contact (either during or on completion of the course). Qualitative evidence from DCs and some stakeholders suggests that the expectation for initiating contact lies with the ASN and that in an ideal world ASNs would initiate contact with DCs at before they start the programme.

3.4.2 Developments in the ASN-DC model over the evaluation period

Over the evaluation period, relationships between ASNs and DCs in most Board areas have developed positively. A number of areas are now demonstrating well-established mechanisms for regular contact through local Dementia Champion groups or networks and/or site-based Champion groups, with shared objectives being agreed and progressed in a handful of areas. In
other areas, challenges remain and finding an effective way to facilitate this relationship is still a work in progress and an issue frequently discussed at ASN network meetings.

In the baseline interviews, many ASNs were at the early stages of assessing how best to bring together and use the Dementia Champions in their area to support improvements, with many recognising that DCs in their area were working in isolation and in some cases “struggling” or “floundering”. Over the evaluation period, the majority of ASNs have increasingly recognised the importance of their role in supporting and developing the Champions and have sought to establish a mechanism for this that suits the local circumstances. A number were at a more advanced stage during baseline interviews, and in most of these areas the relationship has developed well and consolidated over time, and as the number of Champions has increased.

As tables 3.7, 3.8 and 3.9 below demonstrate, most Champions responding to the final survey had had some contact with the ASN in their area. The 93 who had contact answered questions about frequency and usefulness. The majority found contact with their ASN helpful or very helpful in their role. The frequency of contact for most was on a less than monthly basis.

| Table 3.7: Contact with ASN (n=107) |
|----------------------------------|-----|-----|-----------------|
| Contact with ASN                 | Yes | No  | There isn’t one |
|                                  | 87% (93) | 9% (10) | 4% (4) |

<table>
<thead>
<tr>
<th>Table 3.8: Frequency of contact between DCs and ASNs (n=93)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of contact with ASN</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

| Table 3.9: Helpfulness of contact with ASNs (n=93) |
|---------------------------------|-----------------|-----------------|-----------------|
| Helpfulness of contact with ASN | Very helpful    | Moderately helpful | Somewhat helpful | Not helpful |
|                                  | 43% (40)        | 25% (23)         | 25% (23)        | 8% (7)      |

In many of the areas that have an established mechanism for meetings or joint working between the ASN and DCs, meeting frequency has reduced over the evaluation period due to difficulties getting DCs released; difficulties co-ordinating larger numbers as the local DC pool grows; and the increasing workload associated with the ASN role. Many areas that were meeting monthly have moved to six-weekly, or less often, with one area no longer meeting as a group but establishing other mechanisms for co-ordinating the work of the two roles (see text boxes overleaf). Where the local network meetings are effective at supporting and co-ordinating DCs, the frequency of contact is generally considered sufficient and is often complemented by contact between ASNs and DCs by email/phone and DCs meeting hyper-locally (e.g. in site-based groups, or collections of units or directorates). Although, in some areas where the ASN-DC relationship is more established, some Champions felt increased regularity of contact between DC and ASN, an increase in the number of Champions attending local meetings, and an increased focus on joint actions would further support them in their role.
In some areas ASNs have established a buddying approach, where DCs from earlier cohorts are matched to new DCs to support them when they complete the DC programme. DCs interviewed who had had a buddy found the experience very valuable.

The examples in the text boxes below outline how the ASN – DC model of working and support looks (and has evolved) in four case study areas, to illustrate the scope and variation in ASN-DC relationships and networks and potential approaches in variably sized and dispersed Board areas.

**Health Board A – Medium-sized Board, DCs mainly located across 2 acute sites**
The ASN and DCs meet every 2 months and have done since the start of the evaluation period. These meetings provide an opportunity for sharing learning, ideas and supporting the continued development of the DCs through education and organisational development sessions and use of appreciative enquiry. These meetings are used to agree areas to pilot change actions and review progress and the potential for roll out. Recently the Board approved 7 hours per month (to be used flexibly) of protected time for DCs to take forward change activities and it is anticipated this will significantly help DCs ability to progress change. The ASN and DCs have developed a joint workplan to direct their work, in addition to DCs having the freedom and support to take forward individual activities. The 10 key actions will be a key framework for developing this plan. In anticipation of challenges with DCs receiving the agreed protected time the ASN and line manager have agreed an escalation policy for negotiating with managers to ensure the time is given. A buddy system is in place where new Champions are paired up with Champions from previous cohorts.

**Health Board B – Large Board, high number of DCs spread across multiple sites**
The ASN used to meet monthly with DCs but this was challenging due to increasing number of DCs (dispersed across a large Board area) and the workforce and population size of the Board placing significant demands on the ASN. Email support and communication was used as an alternative method, but wasn’t effective at supporting DCs or building momentum as a group. The model is now that the ASN directs and supports DC activity through their respective directorates and Lead Nurses, although in one area a hyper-local DC network is facilitated through one DC who has been given protected time to spend on this. This offers a practical solution that allows for strategic co-ordination of a larger number of DCs in a large Board with widely dispersed Champions. However, more “diluted contact” presents challenges in terms of maintaining the resilience of the Champions, developing their sense of being part of a wider force for change and reducing duplication.

**Health Board C – Large Board with urban and rural areas and 3 main acute sites**
The ASN and the DCs previously met monthly on a Board-wide basis; meeting frequency was reduced to every six weeks due to the growing number of DCs, the growing time constraints placed on the ASN as a result of their strong national and strategic role. An Associate Director of Nursing also attends local network meetings when possible. In addition, some DCs meet locally at their own sites which the ASN attends when possible. This hyper-local meetings are often easier for DCs to attend and have been effective in providing a support network suitable to a growing number of DCs. The local meetings provide an opportunity for DCs to share good practice, for ASNs to provide updates on local and national policies and resources, and to co-ordinate the work of the DCs to support the 10 Key Improvement areas. The ASN also facilitates a buddy system, which creates a supportive relationship between DCs who are new or a struggling in their role and those who are more established.
Where an effective mechanism is not yet in place, the main challenges in establishing the ASN-DC relationship are most often: logistical issues associated with bringing Champions together (presented by geography, distance and number of DCs); competing commitments of the ASN role and local objectives; and lack of support from managers to facilitate time for DCs to engage. Most ASNs have begun to work through these issues, exploring alternative approaches to engage their DC network. These include: video conferencing, outreach to DC groups by ASN rather than all DCs coming together, pursuing protected time for DCs, facilitating regular contact in smaller groups but bringing the full group together for less regular, but more significant events throughout the year e.g., full day event with development sessions and inspirational/informative speakers.

3.4.3 The benefits of effective relationships between the roles

Qualitative evidence confirms that where the relationship between Champions and their ASN is effective, it can provide a range of support to enable DCs to develop and sustain their role as an agent of change as the diagram below illustrates:
Where relationships have developed well over the evaluation period, there is evidence that:

- ASN and DCs are **working more coherently and cohesively**, for example on joint objectives/plans (as well as Champions progressing individual projects and change actions).

- ASN and DCs are jointly **being built into strategic plans**, for example, relating to the 10 key improvement actions, and are actively contributing to preparation for and response to OPAC inspections.

- **DCs feel better supported and are more resilient** in their role, for example, they feel able to seek involvement from the ASN if they are experiencing difficulties getting colleagues on board, or support to access funding or advice to help take projects forward.

- **DCs feel better informed** about policy developments and resources that can assist them with making change (through ASNs keeping them regularly updated).

- **The relationship maintains a sense of momentum** which helps keep DCs motivated and resilient when progressing change is challenging.

During interviews and focus groups, Champions in areas where the ASN and DCs work more closely, described ASNs as “**motivational**, “**supportive”, “a role model””, “**brings clout to move things forward**”, “**our guru**” and made comments such as: “[ASN] always gives [their] honest opinion and won’t let you waste time on projects [they] don’t think will work, which is greatly appreciated”; and “it [local ASN dementia network] gets things done….they [ASNs] are a powerful force”. ASNs in many areas were also full of praise for the enthusiasm, commitment and achievements of the DCs and saw them as integral to their role and to their Board’s wider dementia improvement work.

On a number of occasions the absence of an ASN (due to leaving post/illness) was reported to have “**stalled**” or “**slowed down**” the level of activity and progress. As one Champion described it: “We need [ASN] at the helm to keep us right, to keep us going...we need our leader back... if we didn’t have [ASN] we wouldn’t be as far on, we wouldn’t have got to where we are”. In areas where the ASN had become less active or was no longer there, interviewees described a loss of momentum and a sense of isolation, for example, one Champion in this situation stated: “**things have fizzled out due to work pressures... it needs a person to keep it going**”. Other Champions responding to the survey supported the sentiment that a lack of leadership and support could lead to a lack of direction, as the following quotes illustrate: “[I] would like more direction and support to keep going”; and “It’s very subjective, you trot off on your own path but nobody tells you what you need to do”.

---

Impact evaluation of the Dementia Nurse Consultants/Specialists and the Dementia Champions
Responses across the research highlight that the need for and purpose of contact and close-working between ASNs and DCs is threefold as the following diagram demonstrates:

3.4.4 **DCs working together outside of local network meetings**

Nearly all Dementia Champions in the final survey (92%, 98) reported having some contact with other Dementia Champions in their area. 94% of NHS Champions (89) reported having contact with other Champions, compared with 73% of Social Services Champions (8). While this finding is not statistically significant and the number of Social Service respondents is small, our findings from qualitative interviews suggest NHS Champions are more likely to work together than Social Services Champions.

Survey responses show that contact between Dementia Champions takes a range of forms, with email contact as and when required (69%, 66) and Dementia Champion group meetings organised by the ASN (65%, 62) (see above) being the most common. Other forms of communication include:

- phone contact as and when required (53%, 51);
- contact with other DCs in their unit as part of their day-to-day job (33%, 32);
- group meetings arranged by a Dementia Champion (26%, 25); and
- one-to-one meetings with other DCs arranged by another Champion (20%, 19).

Figure 3.10 on the following page illustrates that nearly all DCs (98%, 94) who had contact with other Champions said this was helpful to at least some extent.
83\% of final survey respondents (79) agreed or strongly agreed with the statement: ‘working with other Dementia Champions has enabled me to achieve greater improvements to dementia care than working alone’. Qualitative evidence suggests that DCs who do not work alongside or have much contact with other DCs (or have much contact with the ASN) tend to feel quite isolated and directionless. We did not speak to any Champions who had “disengaged” from their role, but some ASNs suspected there may be Champions in their area who were struggling to achieve progress with their role as a change agent.

As 3.11 below illustrates, Champions reported more frequent contact with other Champions in the same ward or site as them, rather than Champions across their Health Board area.

Table 3.11: Frequency of contact between DCs

<table>
<thead>
<tr>
<th></th>
<th>Weekly</th>
<th>Monthly</th>
<th>Occasionally (less than monthly)</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>DCs in your ward/unit (n=88)</td>
<td>27% (24)</td>
<td>16% (14)</td>
<td>26% (23)</td>
<td>31% (27)</td>
</tr>
<tr>
<td>DCs in other wards/units at the same site as you (n=92)</td>
<td>13% (12)</td>
<td>33% (30)</td>
<td>46% (42)</td>
<td>9% (8)</td>
</tr>
<tr>
<td>DCs across your health board area (n=95)</td>
<td>4% (4)</td>
<td>19% (18)</td>
<td>54% (51)</td>
<td>23% (22)</td>
</tr>
</tbody>
</table>

Qualitative interviews with Champions confirm that in areas where the number of DCs is more concentrated, for example at one site/hospital, joint working and support for one another is more common and achievable. Examples of the purpose of these smaller group meetings ranged from a source of peer support and motivation, to learning and sharing from each other’s experiences, to auditing each other’s wards/unit, to working on change projects collaboratively.
There are examples where Champions in earlier cohorts, recognising the value of a critical mass and the size of the task in hand, are requesting additional Champions be trained in their area; there are also examples of Champions taking on local co-ordinating roles to bring Champions together more regularly outside of ASN meetings. There is a general sense that momentum is building as more Champions come on board and that with more Champions, their task becomes more manageable, as one Champion said: “It’s easier now that there are more DCs – there’s more fuel, more bodies that can help keep awareness raising and provide advice to staff on wards without a DC”.

3.5 The impact of the introduction of Social Services DCs on the wider initiatives

Social Services participants were introduced to the DC training programme from cohort two onwards. While the focus of the programme was always to remain on acute general hospitals and associated admission/discharge pathways, the national vision was that a range of intermediate care teams might be in place as a result of more integrated working between health and social care and that the introduction of Social Services Champions would help influence improvements to these pathways. However, integration has not progressed at the pace anticipated and the reality has been that Social Service Dementia Champions have more often ended up working in services that are quite disconnected or distanced from acute hospitals and the majority have not been in a position to influence care in acute settings or the pathways into/out of acute services. Furthermore, as Table 3.2 in this chapter illustrates, there is a disproportionately low number of Social Services DCs compared to Health DCs, and five Board areas do not yet have any Social Services Champions.

Unsurprisingly, given these contextual issues, the introduction of Social Services Champions has had a limited impact on the wider initiatives to date in terms of supporting improvements in acute care settings and overall, there is limited evidence from the evaluation of a collective approach to improvement being taken across health and social care. However, Social Services DCs have been active in taking forward and influencing a wide range of changes and improvements within their own services and the wider Social Services, for example, implementing Promoting Excellence; influencing staff attitudes and practices towards people with dementia; improving the environment, delivery of person-centred care and involvement.

Due to the complex landscape of the Social Services and the disproportionately low numbers of Social Service DCs compared to Health DCs, they are more likely to work in isolation and there is not much of a sense of a critical mass for change building yet, although there were examples of Social Services Champions starting to meet up if there were a number of them in an area, and some examples of them working alongside Dementia Ambassadors in their areas.

While there are few examples of Social Services DCs linking in with the work of the ASNs or NHS Champions, there have been developments in these relationships in a small number of Board areas over the evaluation period, despite the fact that there was no expectation set out in the
MOA that ASNs would have contact with Social Services Champions. Some areas are starting to demonstrate establish relationships and joint working and a number of ASNs now invite or plan to invite Social Services Champions along to their local Champions network. In a couple of areas, there are plans to use the Social Services Champions as a link into the Dementia Ambassadors to create a wider, joined up network of dementia specialists all working towards shared aims. In these areas, the involvement of Social Services Champions is valued by both Dementia Nurse Consultants and health-based Champions, and they see potential for involvement of the Social Services Champions to create links between services and to influence improvements in admission and discharge planning, as well helping reduce the numbers of people with dementia coming admitted to hospital. In larger Board areas, in particular, but other areas as well, ASN capacity, the growing number of NHS DCs and the distance of Social Services DCs from acute settings mean supporting and co-ordinating Social Services DCs is not feasible and future support for Social Services DCs in these areas will likely need to come from an alternative source.

Comments from both Champions and stakeholders suggest there has been value in the two sectors learning together through the DC programme as their different professional cultural backgrounds and norms have provided valuable debate as well as informing one another about their roles and how they can influence dementia care.

Chapter four explores the change actions and improvement work the ASNs and DCs have taken forward and influenced to date and evidence of the impact this has had.
4 ‘A National Force for Change’: findings on action and impact

Chapter Summary

- Despite the enormity of the task of achieving culture change within acute settings, the relative small scale and immaturity of the initiatives, a significant amount of improvement work has been initiated by the two roles that would likely not have happened without them.

- Both roles have been successful in raising the profile of dementia at a local level, both strategically and operationally, and to some extent nationally.

- There have been significant achievements in some Board areas in terms of implementing education and training against the Promoting Excellence framework and changing staff attitudes and practice towards people with dementia and their carers.

- The roles have supported progress in terms of improving: care environments; identification of dementia in acute settings; delivery of person-centred care; involvement of carers; and responses to stress and distress.

- Overall, the experience has been highly positive and rewarding for DCs and ASNs, and has resulted in positive changes in DCs’ attitudes and practice. Negative impacts include giving their own time which is often not recouped and the pressures of being an agent of change.

- In general the roles are viewed as key conduits and catalysts for change (within their sphere of influence) and a valued local source of dementia expertise.

- While it is too soon in terms of systematically evidencing improvements in the care of people with dementia, we can infer that their activities will support improved outcomes and experiences.

4.1 Introduction

This chapter presents findings on the key change actions and activities implemented and progressed by Dementia Nurse Consultants and Dementia Champions over the evaluation period, commenting on resulting outcomes and impact for staff, organisations and people with dementia and their carers, where evidence allows. Key findings are explored under the following headings:

- Raising awareness and influencing change (locally and nationally);

- Contributing to the 10 Key Improvement Actions (including impact on patient and carer experiences and outcomes); and

- Impact on Dementia Champions.
4.2 Raising awareness and influencing change (locally and nationally)

4.2.1 Influencing at a local level

There is a widespread perception across all stakeholder groups that the two roles have been instrumental in raising the profile of dementia at a local level and that the roles have, or are beginning to, positively influence improvements in dementia care, to varying degrees, both within acute settings and to a lesser degree at the interface between community and hospital care. The evaluation suggests dementia care improvement in acute settings is taking place at varying paces and with varying degrees of consistency and penetration across the different Board areas, and that there is a gradual sense of momentum for change building that the two roles have played a valuable part in this.

In general, the ASNs are perceived to have been effective at raising the profile of dementia within their Board areas, operationally and strategically. At a strategic level, ASNs have been instrumental in ensuring Chief Executives and Heads of Departments/Directorates understand the extent and long-term nature of the issue and the need for action – something stakeholders reported was not the case before the roles were established. In a minority of cases, progress in this respect has been slow and gaining Executive buy in and influence has been challenging. Many ASNs play a key role in raising awareness and driving improvement at an operational level as well, either individually raising awareness with multi-disciplinary teams, liaising with and working through department leads or other senior staff (e.g. lead nurses and SCNs) to disseminate good practice and influence improvements, or through their local Dementia Champion network.

While other national drivers have contributed to raised awareness, evaluation respondents view the ASNs as a key conduit and catalyst for change, and a valued local source of dementia expertise. Working at the ‘expert’ level of Promoting Excellence, ASNs are widely perceived as experts by their colleagues at all levels, providing a source of clinical advice and expertise to staff supporting and caring for people with dementia, providing advice at a strategic level to inform the planning, development and improvement of dementia services. For the most part, they are widely perceived to have been successful in supporting and influencing Board-wide actions to improve dementia care, with many making key contributions to local planning and action relating to OPAC inspections and the 10 Key improvement actions (see 4.4).

Complementing the ASN role, Dementia Champions are generally perceived to be effective at raising the profile dementia has at an operational level (with some influencing more strategically as well) and are viewed as key to progressing improvements in the experiences and outcomes of people with dementia and their carers/families, at their ward/unit level, and in some cases, beyond. They are viewed as advocates for good dementia care and for people with dementia and their carers, and are perceived by colleagues and stakeholders to have acted as a catalyst for developing the knowledge and practice of their teams.

Figure 4.1 below shows that nearly all Dementia Champions surveyed felt that the care of people with dementia in acute general hospitals (and to a lesser extent at the interface between acute
and community settings) has improved in their area to at least some extent since they completed the Dementia Champion Programme, with the majority feeling they have been able to influence this improvement to some extent. It is clear from survey responses and qualitative evidence that NHS Champions were more likely to feel that they had influenced improvements in acute hospitals, than Social Services Champions.

**Fig 4.1: Dementia Champions influencing change**

<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage Distribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has the care of patients with dementia in acute hospitals improved in your area? (n=106)</td>
<td>16% 47% 33% 4%</td>
</tr>
<tr>
<td>To what extent do you think you have influenced improvements in acute hospitals? (n=107)</td>
<td>8% 37% 39% 15%</td>
</tr>
<tr>
<td>Has the care of people with dementia at the interface between hospital and community settings improved in your area? (n=107)</td>
<td>4% 36% 56% 5%</td>
</tr>
<tr>
<td>To what extent do you think you have influenced improvements at the interface between hospital and community settings? (n=107)</td>
<td>1% 28% 48% 23%</td>
</tr>
</tbody>
</table>

### 4.3 Influencing change at a national level

Many ASNs play an active part in the National AHP and Nurse Dementia Consultants Group – in operation for just over a year at the time of writing, this group has evolved and become more established over the evaluation period, gaining a greater sense of purpose and direction. The group recently developed and published a vision statement and is currently working on an action plan to drive forward improvements nationally. While their work as a national group is somewhat in its infancy, a number of key activities have been taken forward at a national level through the group, including supporting the development and roll out of dementia friendly signage and the Getting to Know Me document (to replace ‘This is Me’ in all but one Board area) across Scotland.
4.4 Contributing to the ten key improvement actions for acute care

Since their launch in mid-2013 (midway through the evaluation) the 10 Key actions have provided a framework to guide the work of the ASNs and DCs; since September 2013, the Dementia Nurses’ quarterly reporting has been against these headings. The 10 actions reflect and formalise many of the key objectives the roles were already working towards and have therefore been used as key measures against which to analyse impact in this findings chapter, however it is important to note that evaluation data was only specifically collected against these 10 actions from August 2013 onwards. The ten key improvement actions are summarised in figure 4.1 below and explored in further detail in the remainder of section 4.4.

Fig 4.1: Ten key improvement actions

As stated in Chapter 2 (section 2.6) findings in terms of the impact of the two roles should be considered in light of the relative immaturity of the roles and the relatively short period of time they have been in post to achieve change at the time of reporting, as well as the enormity of the challenges associated with influencing change in acute general hospital settings.

Due to the variations in how ASNs and DCs work together across the Board areas and the variation in the activities they each take forward (independently and collectively) it is difficult to distinguish the direct contribution of each role and impossible to cover everything that has been undertaken to support each of the key actions in this report. Improvement activities reported through the evaluation ranged from activities undertaken by DCs in isolation, to small-scale pilots taken forward by individual DCs/small groups of DCs (both with and without ASN input), to co-ordinated and more wide-spread activity. The following section provides an overview of how the roles are

---

**10 Key Improvement Actions**

- Identify a leadership structure to drive and monitor improvements
- Develop the workforce against Promoting Excellence
- Plan and prepare for admission and discharge
- Develop and embed person-centred assessment and care planning
- Promote a rights-based and anti-discriminatory culture
- Develop a safe and therapeutic environment
- Use evidence-based screening and assessment tools for diagnosis
- Work as equal partners with families, friends and carers
- Minimise and respond appropriately to stress and distress
- Evidence the impact of changes against patient experience and outcomes

---
supporting progress towards each of the ten key actions, summarising common approaches and highlighting specific examples to give a flavour of the improvement work that has taken place.

While attribution is a challenge, respondents across the stakeholder groups were generally of the opinion that many of the examples of change highlighted below would likely not have happened, or certainly not have happened as quickly in the areas in question without the ASN and DC roles. As one NHS Champion said: “Change can take so long but this is happening quicker because of the two-pronged approach”.

### 4.4.1 Identifying a leadership structure to drive and monitor improvements

A strategic Board-wide Dementia steering group (names and representation vary greatly) is now in existence in many Board areas; where these exist they have been identified as the main leadership conduit for driving and monitoring improvements. In some areas the group pre-existed the ASN role, in other areas the ASN has been instrumental in establishing or supporting development of the group. The ten key actions are welcomed by ASNs and have provided a lever and focus for change in many areas and will underpin the work of the ASN and DCs going forward; there are examples in smaller Boards where the ASN is the nominated lead for the ten key actions.

Local Dementia Champion networks/groups, where they exist, sit below these strategic groups to support implementation of the ten key actions at an operational level (with some examples of Champions sitting on or linking in directly strategic groups around dementia or OPAC). In a small number of areas an Associate Director of Nursing (in addition to the ASN) attends Dementia Champion meetings, helping further develop the links between the operational and strategic leadership functions.

67% (69) of Dementia Champions felt they had supported the development of a leadership structure to drive and monitor improvements within their organisation to at least some extent.

### 4.4.2 Develop the workforce against the Promoting Excellence (PE) Framework

The development and delivery of training in line with the PE framework has been a major focus of the work of the ASNs and DCs; comments similar to “educating staff is the key to improvement” were regularly repeated throughout the evaluation research. There has been a significant amount of activity in this respect, with both ASNs and DCs involved, in different ways, in supporting staff at all levels to access dementia training at an appropriate level. Progress and success varies across Board areas, with some Boards at very early stages with this action and others more advanced. However, interviews and focus groups with ASNs, DCs, colleagues and stakeholders suggest significant numbers of people have been trained across the Boards as a result of the two roles.

ASNs, supported by various colleagues (including Champions in some instances) have been involved, to varying extents, in co-ordinating and carrying out a range of activities in relation to this key action, including:
undertaking training needs analyses;
mapping staff groups against the framework and developing guidance;
feedback into Board-wide/acute service workforce development strategies;
using PE resources to design and deliver tailored training;
providing clinical supervision to support implementation of PE in practice;
working with Higher Education Institutes to influence the design and delivery of undergraduate and postgraduate education;
making PE resources available as e-learning;
planning joint training for health and Social Services staff;
supporting the continued development needs of DCs in line with PE;
in one Board area, developing and delivering a three-tier Board-wide dementia training programme based on the Promoting Excellence Framework (3729 trained so far); and
local delivery of ‘Best Practice in Dementia Care’ training for clinical support workers from acute, primary care and mental health (one area has a training target of 400 staff).

82% (88) of Champions responding to the survey said they had helped develop the workforce against Promoting Excellence to at least some extent. This has primarily been at ward, site or department level. Activities most commonly undertaken are summarised in the diagram below.

- Undertaking ward/unit level training needs analyses
- Developing/distributing ward/unit-level resource packs based on PE materials
- Delivering ad hoc training and awareness raising sessions with colleagues within their unit
- Encouraging colleagues to undertake training e.g., complete Learnpro modules
- Developing information boards in ward areas using PE resources
- Role-modelling good practice in dementia care in their clinical setting, based on PE principles

Social Services DCs have helped scope the Enhanced dementia learning resource for social workers which is now available for newly qualified social workers.
In some areas there have been significant challenges in implementing PE. Common issues were: difficulties getting staff released for non-mandatory training; finding backfill for staff to be released even if funding is available; identifying suitable trainers locally; and staff resistance to training because they did not recognise a personal need for it.

During the case study research we consulted colleagues of dementia champions in each of the four areas. Many colleagues had attended formal training (e.g., Best Practice in Dementia Care for health care support workers), used PE resources (at informed or skilled level) or attended a dementia awareness-raising session as a result of the Champion and/or Dementia Nurse Consultant roles. In many cases, this was the first training/awareness raising the colleague had undertaken on dementia, including those working in Acute Care of the Elderly Wards.

Colleagues reported improved skills, knowledge and understanding as well as improved confidence in caring for people with dementia as a result of the training and working alongside a Champion. Colleagues also reported changes in their practice as a result of training, for example: spending more time with people with dementia on a one to one basis to provide more individualised care; more effective communication as a result of a better understanding of the needs of people with dementia; involving carers more proactively; understanding the importance of personal care plans and documentation; being more aware of the impact of the environment on people with dementia; being more proactive in providing additional assistance to people with dementia; being prepared to challenge bed moves involving people with dementia when there was no clinical need; increased awareness of signs of stress and distress and seeking to identify the cause rather than resort to use of sedatives. These practice changes were also observed and reported by Champions and their line managers who in addition noted improvements in the language, tone and approach of staff towards people with dementia. In general, respondents were confident practice changes in terms of improved attitudes and behaviours would be sustained by trained individuals, but felt more was required to ensure person-centred practice becomes universal practice.

While significant efforts have been made to roll out PE training, there remain large proportions of the workforce who still need training and evidence is required to establish if training is being implemented in practice and whether it is resulting in improved experiences and outcomes for people with dementia and their carers. Concerns were expressed by a minority that where ASN/DC working is less co-ordinated, there may be duplication of effort, or staff might be attending PE training at an inappropriate level. There is a role for both the ASN and DCs in addressing these issues.

**4.4.3 Plan and prepare for admission and discharge**

The ASN and DC programmes, to varying degrees, have supported several activities with the aim of improving admission and discharge. 78% (83) of Dementia Champions responding to the final survey felt they had influenced this action area to some extent.
The different change actions introduced by the two roles in relation to this action vary in nature and extent of implementation across and within Board areas and in some cases implementation is very small-scale or at the pilot or test of change phase. Examples of activities are listed below.

- Introducing symbols (such as ‘The Butterfly’ or ‘Forget Me Not’ symbol) to support improved identification of people with dementia from admission onwards.
- Anticipatory care planning (to reduce hospital admissions) is in progress or in place in a number of Board areas, with anticipation of wider roll out.
- Building ‘Getting to Know Me’ documentation into pre-assessment processes.
- Reviewing and developing new admission, transfer and discharge policies and protocols.
- Implementing AMT4 assessments as part of pre-assessment processes.
- Greater involvement of carers in discharge planning.
- One Board area is piloting an international project (REMODEM) to support people with dementia in remote and rural areas to continue living in their own homes.
- In one ward, as a result of the DC role, responsibility for discharge planning has been delegated to a band 5 nurse who works with carers and patients from the point of admission to plan for discharge and to make sure necessary supports are in place.
- One Board area is improving handover between acute and community care through closer working with Supported Discharge Teams, and linking in with Community-based mental health teams and other services to identify when someone with dementia is coming into hospital (to better plan for admission) and to give staff in acute settings the confidence to discharge patients promptly to reduce unnecessary discharge delays.
- Development of new services e.g. a Discharge Hub in one area to improve the patient pathway from hospital – this has reportedly demonstrated reductions in the length of stay and inappropriate transfers within acute settings.
- A number of ASN’s are involved in attending Multi-disciplinary Team meetings and liaising directly with people with dementia and carers around discharge planning with examples cited where care home admission had been avoided as a result with of people supported to return home with flexible packages of care.
- ASN in one area involved in undertaking follow up at home visits following discharge, or involved in escorting people on discharge to ease transition back into the community.
- ASN’s involved in reviewing complex cases and spreading learning across the Board.
As part of the MOA, by the end of the three year funding, ASN's are expected to have influenced a 25% reduction in the number of people with dementia referred to residential care or to other alternative hospital wards in order to wait for admission to residential care; and a 25% increase in the number of people discharged home with flexible community support services. A number of ASN's highlighted that that their Board’s figures around discharge to residential care settings were low or were indicating a decrease but this could not be solely attributed to their work or the work of the DCs. In other Board areas, data measurement has been challenging, for example, in one area they are reviewing this data but cannot differentiate between a planned-discharge to a care home, pre-admission; in another area, there are difficulties due to the reason recorded for discharge to a care home.

4.4.4 Develop and embed person-centred assessment and care planning

ASN's and DCs, are supporting more person-centred dementia care in a number of ways. In doing so they are helping to implement standards of care for dementia around respecting the wishes of people with dementia and ensuring they are regarded as a unique individual, as well as supporting the delivery of person-centred care more universally for all patients. This was one of the key actions Dementia Champions felt they had influenced most – the vast majority (92%, 98) of survey respondents feeling they had influenced improvements in this respect to at least some extent.

The primary actions undertaken in this respect have been the implementation of person-centred care planning through use of the ‘This is Me’ document initially, and subsequent development and implementation of ‘Getting to Know Me’. Many DCs have played a key role in implementing and trying to embed these documents through introducing it to their team and training staff in its application. ASN's have played a key role in getting the document rolled out more widely and the wide-spread implementation of GTKM has been a key achievement of the national group. Progress and speed of implementation varies greatly and Boards are each at very different stages with it and effort will be required to embed and sustain the approach. A number of OPAC inspection reports highlight the challenges in embedding this action, reporting that GTKM or personal plans are in place but use is patchy.

Use of GTKM allows staff to find out more about the patient and their preferences and is generally considered a useful tool in supporting improved person-centred care for people with dementia. Comments from Champions and their colleagues working in acute settings suggest that use of person-centred plans like this represents a departure from the norm for them in terms of the information they are used to collecting and the conversations they are used to having with patients. Examples were cited where staff have used GTKM more effectively minimise stress and distress, reporting how the information they gained about the patient through the assessment had supported them to recognise and respond more effectively to distressed behaviour. The widespread perception is that implementation of GTKM should make a significant difference to the experiences and outcomes of people with dementia.

Champions cited some examples of positive feedback from carers in relation to GTKM/TIM which suggested the process made them feel reassured about and more involved in the care of the
person they care for. There are examples of Social Services Champions using the documentation in community settings (which means some patients will already have a plan completed on admission to hospital), as well as acute areas using the documentation for all patients due to how useful they considered the information.

4.4.5 Promote a rights-based and anti-discriminatory culture

This action underpins the ethos and approach of the DC programme and the ASN vision statement. Both roles have had a significant impact in terms of improving understanding of and attitudes towards dementia in acute settings, within their individual spheres of influence. The majority of Champions who responded to our survey (94%, 101) felt they had helped promote a rights-based and anti-discriminatory culture to at least some extent.

Other key actions in this chapter have also influenced this action as rights-based and anti-discriminatory practice are underpinning principles of PE and person-centred care. The Dementia Standards have been a useful tool for ASNs and DCs in promoting a rights-based and anti-discriminatory culture, with examples where they have been used as a benchmark to measure appropriate dementia care in acute wards, or handed out to colleagues to support delivery of care that is firmly seated within a rights-based approach. The Charter of Rights has also been useful in this respect.

In interviews DCs frequently cited the role they have played in influencing the behaviour of colleagues, for example by challenging inappropriate use of language when speaking to or speaking about people with dementia. Line managers, colleagues and Champions in the case study areas commonly reported improvements in the language used by staff working alongside a Champion, as well as improvements overall in terms of staff attitudes towards people with dementia. For example, one Champion said: “They’re no longer saying ‘they [people with dementia] shouldn’t be here’ which was quite common before, but now looking at how best to support the person and trying to identify the reason for challenging behaviour or distress.”

For some DCs, becoming a DC has made them recognise that their own attitudes and behaviours towards dementia and people with dementia were previously inappropriate and stigmatising – the following quote reflects the sentiment expressed by quite a few DCs interviewees “in 20 years, I’d never had formal dementia training... I had negative attitudes, due to ignorance”. Some Champions reported that this had helped them understand the perspective of their colleagues which helped them in their change agent role, for example, one Champion said: “I am a role model now – I understand staff frustrations and how negative attitudes get formed and this makes it easier to challenge them.”

ASNs and DCs in some areas have identified completion of and compliance with AWI legislation as an area in need of improvement and this has been a common key focus of their work, as one acute-based Champion put it: “People [colleagues] didn’t understand AWI, or POA, they didn’t understand the powers family had or where potential risk of harm to the person [with dementia] could arise.” Some improvements in this respect were noted as a result of work by DCs and ASNs,
however in general, respondents feel there is further work to be done to properly embed improved compliance with AWI in practice. Champions from nursing working in acute general wards have found it particularly challenging to influence practice changes in the medical staff they work alongside with regard to adherence to paperwork and assessments relating to relevant legal frameworks. Examples of activity ASNs and DCs have undertaken to address this issue are summarised in the diagram below.

Discussion arose during the evaluation around whether use of the ‘Butterfly’ and ‘Forget Me Not’ symbols, as well as use of coloured crockery only for people with dementia or cognitive impairment (rather than for all patients) could be considered stigmatising actions. There is perhaps an opportunity for the ASN network to take forward further work and research into these issues, or to support DCs to do this so that they might take a view as a group to inform future implementation of these activities.

4.4.6 Develop a safe and therapeutic environment

The ASNs and DCs have implemented numerous changes to develop safe and therapeutic environments. As with all change actions, extent and nature of implementation varies across Board areas. Environmental adaptations designed to improve experiences and outcomes for people with dementia were a focus of the majority of the action plans of Champions consulted during this evaluation. 93% (99) of Champions felt they had influenced improvements with regards to developing a safe and therapeutic environment to at least some extent.

Champions commonly commented that the DC programme had made them very conscious about the impact of the environment on people’s experiences; something they had not previously considered, but which is integral to their practice now. As one Champion put it: “I’m looking at environmental factors more than I used to... numbers of people in an area, the noise levels... I look at these things a lot more and I think all the time now, what can I do, what can we change to make this better?”
Examples of the change actions implemented to make the care environment safer and more therapeutic for people with dementia are listed below.

- **Dementia friendly signage/ wayfinders** to assist with orientation and navigation (implemented initially in pockets by dementia champions, often laminating signs themselves, now being rolled out nationally by the National Dementia Nurse Network)
- **Quiet rooms**
- **Falls prevention training** for staff
- **Meal Time volunteers**
- **Use of Therapets**
- **Regular ‘comfort rounding’** (to ensure hydration and comfort needs are met)
- **Activity boxes** (to stimulate meaningful interaction and provide non-pharmacological alternatives to managing stress and distress)
- **Ready-prepared fresh fruit** pots (to improve nutrition)
- **Chairs in corridors** to provide a safe resting spot if patients wish to walk around the ward
- **Development of outdoor spaces/ sensory garden** for therapeutic purposes
- **Dementia-friendly clocks**
- **Contrast colours** to demarcate doors and windows
- **Crockery and water jugs/glasses that are easier to see** and therefore prompt hydration and feeding (some areas have opted to only provide contrast crockery to people with dementia, one area re-ordered more visible crockery for all patients so as not to discriminate)
- **Protected mealtimes** (to create a quieter, more relaxed environment and give staff more time to focus on providing support and assistance).

As the DC cohorts have progressed, there is some evidence that they are starting to address more challenging change actions with regard to the environment, for example reducing noise and unnecessary activity within ward settings. This can be challenging due to the pressures of the care environments and the need to constantly reinforce the importance of a calm and quiet environment with staff who are often over-stretched. However where Champions have managed to influence colleagues successfully, the result can be very positive, as the following DC quote illustrates:

“**Staff’s attitudes have changed hugely in A&E [as a result of DC’s awareness raising of how noise and activity can cause distress] – you used to see someone with dementia and there would be 2 or 3 nurses with the one patient, each doing something else and the poor patient... now you see them going in one person at a time, calmer more quietly.”**
A number of ASN have taken forward larger scale work to re-model the way hospitals provide care for older people, including people with dementia through establishment of Beacon Wards of good practice. This has involved the ASN providing close support to staff (including Champions) on the ground to improve dementia care and the environment in their ward. In the first area to introduce Beacon Wards, results of a baseline and follow up audit showed that improving the hospital environment and approaches to care could result in a range of positive outcomes: average length of hospital stay, prescriptions of psychotropic medication, falls, use of catheters and staff frustration levels all decreased, and carer satisfaction improved.

ASN have also been involved in consulting on environmental design for refurbishment or redesign projects to ensure new environments are dementia-friendly.

While a lot of activity has been undertaken by the two roles in respect of environmental improvements, these have been made within the context of existing buildings and structures that in many cases are fundamentally not dementia-friendly and this was frequently raised as a hindrance to impact in acute settings, as one Champion said: “If we could, we’d just bulldoze and start again!” Other challenges included finding funding to make environmental modifications and negotiating and liaising with procurement and estates departments to enable changes to happen. In some cases, ASN have provided support to mitigate these latter challenges.

4.4.7 Use evidence-based screening and assessment tools for diagnosis

In a number of areas, ASN, and DCs are supporting improvements with regard to screening and assessment for dementia and cognitive impairment, thereby supporting the implementation of the dementia standard around diagnosis (I have the right to a diagnosis). 78% (82) of Champions responding to the survey felt they had influenced improvements in the use evidence-based screening and assessment tools for diagnosis (48%, 51 to a moderate or large extent).

As with other change actions, introducing the tools has been simpler than rolling them out and embedding them, and this later stage is a work in progress in many areas. Some Boards have signed up to screening every person over 65 years old admitted to specified/any acute setting for cognitive impairment on admission, in medical admissions unit or at pre-assessment stages. Where this is the case, ASN have been involved in developing and piloting (sometimes with support from Champions) processes and pathways to support implementation and roll out of appropriate screening tools such as the 4-item Abbreviated Mental Test (AMT4) or Comprehensive Geriatric Assessment (CGA), and developing follow up pathways that lead to further assessment and diagnosis, where appropriate. Other activities undertaken to support this action area include use of the 4AT assessment tool (that enables staff to screen patients for delirium and cognitive impairment).

4.4.8 Work as equal partners with families, friends and carers

ASN and DCs have contributed to ensuring that carers of people with dementia are better supported, more involved in the delivery of and decisions about care, and in some cases, more
informed about dementia. In doing so, the roles are supporting implementation of the Standards of Care for dementia around carers (I have the right to have carers who are well supported and educated about dementia).

This was another key action area Champions felt most able to influence. 96% of Champions (103) felt they had influenced improvements around working with families, friends and carers as equal partners to at least some extent, and the majority (70%, 75) felt they had influenced this to a moderate or large extent. This was one of the areas most cited in qualitative research where Champions felt they had changed their practice and helped change the practice of their colleagues. A number of Dementia Champions that they are now much more aware of the important role of carers and are now more proactive in seeking carer involvement in practice, especially when supporting patients with dementia. DC colleagues also reported similar changes in staff practice as a result of training, support or awareness raising they had received through working alongside a DC. Colleagues’ comments suggest that carers find having a Champion in a ward/unit re-assuring as they feel more confident their loved one will be well-cared for. Colleagues and Champions commonly reported that working closely with families of people with dementia had often helped them recognise and respond more appropriately to signs of stress and distress in individuals.

Champions (in some case supported by the ASN) have initiated a number of projects or improvement actions within their areas to support this key action. Examples cited in the research include:

- introducing open or flexible visiting times, which has supported improved communication and relationships with relatives and improved person-centred care;
- enabling the carer to remain with the person they care for from admission onwards, supporting reduced stress for both patient and carer;
- an acute elderly care ward has introduced a Partners in Care project where personal care plans are developed, in partnership with the carer and person with dementia, to enable carers (where they want to be) to continue involvement in aspects of care they provide at home (e.g. feeding, drinking, personal hygiene) throughout the hospital stay.

Overall, ASNs appear to have had less direct impact on this action than Champions other than through the education and awareness raising they have delivered. GTKM, which is being rolled out nationally, is seen as key to supporting the involvement of carers in care planning and delivery and the workforce development work ASNs are involved in around Promoting Excellence is re-enforcing the need to involve carers as equal partners. Some ASNs are active with local carer groups and meetings and are involved in liaising directly with carers in complex case. In one area, the ASN works closely with the Carer Information Strategy worker on a range of activities including delivering training to staff on the importance of involving carers, and implementing the Equal Partners in Care (EPIC) core principles among staff.
4.4.9  Minimise and respond appropriately to stress and distress

In general, this was an action area respondents across the stakeholder groups felt the two roles had had a significant impact on. 95% of Champions (101) felt they had influenced improvements in terms of minimising and responding appropriately to stress and distress to at least some extent.

Interviewees noted that many of the actions already mentioned (e.g., involving carers and families, improving the environment, and educating the workforce) have helped minimise stress and distress for patients. ASN and DC roles, to varying extents, have placed a specific focus on supporting staff in acute (and less often, community) settings to be able to identify and respond to delirium to help drive improvement in terms of this action area. This has been through awareness raising, clinical supervision, and training (including promoting and delivering NES two day training course on psychological interventions for stress and distressed behaviour in dementia to acute and community colleagues).

The roles have also supported implementation, to varying degrees of: the 4AT tool in a number of areas to support early identification of delirium; guidelines on managing delirium; the Abbey Pain Scale and other pain assessment tools to improve staff’s ability to assess the pain levels of someone with cognitive impairment; testing for the new national delirium bundle; and in some areas policies have been developed around bed moves and inter-hospital transfer to ensure movement of people with dementia is for clinical need only and that any necessary moves are well-managed. These actions are all perceived to be supporting improvements in the management of stress and distress.

Some specific examples of activity and impact highlighted through interviews with ASNs and DCs include:

- In one area, a one week trial piloting screening for frailty and delirium on admission (coordinated by the ASN) saw the freeing up of seven acute care beds which was “unheard of” – funding has been secured to continue this work for a further 6 months.

- In another area, training a Violence and Aggression adviser as a DC means health and safety training across the Board area is now informed by an understanding of dementia and recognising signs of stress and distress which is reportedly enhancing staff’s ability to respond appropriately to patient’s whose distressed behaviour may be aggressive.

Respondents reported observing the following positive changes as a result of the work of the ASNs and DCs to minimise stress and distress:

- staff being better able to recognise when a person’s behaviour is abnormal for them;
- staff being better able to identify potential causes and triggers of stress and distress;
- staff being better able to manage pain for people with dementia; and
Impact evaluation of the Dementia Nurse Consultants/Specialists and the Dementia Champions

- staff demonstrating improved responses to people with dementia with seeking behaviours.

Another commonly occurring theme was the impact the work of the ASNs and DCs is having in terms of reducing bed moves and transfers for people with dementia, with examples of Champions and colleagues of Champions “putting their foot down” if they were asked to move a person with dementia to respond to bed pressures (however, in some cases the person was moved anyway). Some ASNs are looking to improve the monitoring of bed moves to enable them to measure this observation more robustly.

One of the objectives of the ASN role is to establish baseline measures of current practice in terms of medication prescribing practice as a means of managing patient behaviour, with the target of a 25% reduction in the number of people with dementia prescribed anti-psychotic medication or other sedatives as a means of controlling minor behaviour issues that present staff with a challenge. During baseline interviews some ASNs were struggling with how to measure the baseline data and others reported the current rate is low due to other interventions and initiatives. This challenge has continued throughout the evaluation period, although progress is being made in some areas through working with pharmacy colleagues and undertaking snapshot audits of practice.

4.4.10 Evidence the impact of changes against patient experience and outcomes

Overall, the roles have struggled in terms of collecting robust evidence of the impact they have had, however there is widespread belief that the work identified above is contributing to improvements in experiences and outcomes for patients and carers. As part of the MOA, ASNs are expected to achieve a 50% increase in satisfaction with care as reported by patients with dementia or their carers. While there is some anecdotal evidence and strong supposition that things have improved in this respect, none of the Board areas are currently robustly assessing and evidencing the impact of the two roles on patient experiences and outcomes. Robustly gathering patient experience data presents a challenging task for all Health Boards; doing so within the context of dementia care with a view to measuring the contribution of two initiatives that are inseparably linked to a raft of other improvement initiatives makes the task all the more complex. It is therefore not surprising that the roles, themselves, have struggled when this issue is far from resolved at a corporate level.

A few examples were cited during the evaluation where Dementia Champions are actively seeking feedback on a small-scale from carers, and in fewer cases, patients, about some of the changes they have implemented, with feedback (primarily through 1:1 discussions or satisfaction surveys) generally being positive and highlighting improved experiences and improved involvement in care. In the majority of cases, however, feedback is not often actively sought, and relies on the patient or carer taking the initiative.

95% (100) of Champions responding to the final survey felt they had improved patient experiences and outcomes to at least some extent. Champions and ASNs quite commonly cited reductions in
the number of complaints as an indicator of improved experiences for people with dementia and their carers, as well as for their wider patient group. There was a strong belief across stakeholder groups that where a Dementia Champion is present, or where a Dementia Nurse has been directly involved or had a significant influence amongst staff on the ground, the patient and carer journey is likely to be improved. However, given the nature of the evidence available, attributing outcomes to the work of the two roles remains challenging within a context of wider improvement initiatives and multiple influencing factors.

There was recognition across the respondent groups that more could be done to evidence the impact of improvement work for patients and carers. This is an action area ASNAs are keen to progress, with some citing developments in this respect (many at an early stage of implementation), for example:

- establishing dementia focus groups to discuss what went well/could be improved about care;
- working with the Patient Relations Department to get a quarterly report on any feedback received by the Board where dementia is a feature;
- training Champions to carry out their own research using a quality improvement model to build capacity to introduce and evaluate evidence-based improvements;
- looking at how to use patient experience tools to capture experiences of people with dementia in a comparable and measurable way;
- piloting the OPAC two-question person experience card; and
- patient and carer case studies.

In relation to this key action, general concern was expressed that any improvement in patient experiences and outcomes achieved as a result of the roles is most likely to be where a DC is present or the work of the ASN has had a direct impact on an area, and that the future challenge for Dementia Nurse Consultants and their partners (including the Champions) is to spread this more widely to ensure that care for people with dementia is good even when a Dementia Champion is not present.

Due to difficulties recruiting people with dementia and their carers to participate in the case study research, additional evidence was gathered (from interviews with a small number of people with dementia and carers of people with dementia, a review of acute setting stories involving people with dementia (in Scotland) from the Patient Opinion website and OPAC reports) to try and establish if there is a wider sense of improvement in the experiences and outcomes of people with dementia that the two roles and other national improvement activities may be contributing to. Findings from these evidence sources present a mixed picture in terms of the experiences and
outcomes of people with dementia in acute settings, although suggest improvements in terms of staff awareness and understanding of dementia.

4.5 Impact on Dementia Champions

Evaluation evidence suggests that the positive impact of being a Dementia Champion has been substantial for Champions themselves and is worth highlighting. Overall, despite the challenges and frustrations associated with implementing change, the experience seems to have been highly rewarding for Champions. A number said being a Champion had made them feel more positive about and enthused in their job, illustrated by one Champion’s survey response: “[Being a DC has] made me more motivated and given me a direction with my career”; and the following comment from an interviewee (Champion): “It’s given me a new lease of life in my job”. Those we spoke to who had been ‘nominated’ rather than elected to go on the course did not regret it.

Reflecting findings from UWS’ course evaluations, the majority of Champions participating in this impact evaluation reported changes in their own practice and the way they think about and work with people with dementia – this included individuals who had significant previous experience working with older people, people with dementia and in mental health settings. DCs reported that being a DC had given them a better understanding of dementia, the skills to enable them to deliver better care for patients with dementia, and the skills to support their colleagues to deliver better care as well. Other ways in which being a DC has impacted on Champions include:

- Improved IT skills
- Greater influence with Senior Managers
- Improved contacts and networks
- Better understanding of other services
- Prompting further study in dementia (e.g., Masters level)
- Able to provide advice to friends and family

The main negative impacts related to the limited amount of time Champions have to progress change; the fact that many put a lot of their own time in which the majority do not get back; and the emotional demands of being a Change Agent. Champions commonly reported challenges they had experienced in influencing the attitudes and practices of others, as well as challenges sustaining change once they had introduced it. References to the need to “keep chipping away” and “constantly challenge” were often made, with some feeling that their colleagues start to tire of their attempts to influence improvements, for example one Champion said: “it takes stamina as
“a Champion to keep going, keep chipping away... people stop talking to you after a while!” This concern was highlighted by stakeholders, and reflects the findings of the UWS course evaluations, that supporting resilience in Champions is crucial to ensure they are able to continue and cope in their role and to maximise their impact.

Informed by findings in relation to the implementation and impact of the roles, covered in the previous two chapters, the following chapter summarises the key barriers and enablers that have influenced the ability of the ASNs and DCs to bring about change to dementia care in acute settings and affect the sustainability of the roles.
5 Barriers and enablers to change

Chapter Summary

- Both roles are supported by national policy underpinned by strong (and unique) partnership working between the statutory sector and Alzheimer Scotland and are informed by the lived experiences of people with dementia and their carers. This has been key to the success of the initiatives.

- Ability of the roles to drive change has been affected by individual, organisational and systemic factors. Often barriers and enablers are two sides of the same coin, in that the absence of what is an enabler in some areas is a barrier in others.

- Key factors pertaining to individuals include levels of knowledge & experience, commitment and enthusiasm for the role; and attitudes of others.

- Key ‘Organisational’ factors, include seniority and positioning, local inter-relationships, tensions between local and national priorities, strategic implementation of the roles, and commitment to support and sustain the roles at Board level.

- Key ‘Systemic’ factors include national policy drivers, partnerships and support; the cultures and pressures within healthcare settings; and the enormity of the task involved in changing cultures and practices within acute settings.

5.1 Introduction

Having explored in the previous two chapters how the roles are working in practice, and what they are achieving, this chapter assesses and summarises the key factors that have enabled and/or hindered the Dementia Nurse Consultants and Dementia Champions in their challenging roles as leaders and agents of change. These factors influence the sustainability of the two roles and the work they have achieved. This chapter addresses objective ‘e’, and is informed by findings from all elements of the primary research undertaken as part of this evaluation.

The key barriers and enablers that have affected the ability of the ASNs and DCs to influence change, highlighted through the evaluation research, are summarised in table 5.1 on the following page, and explored in further detail in the remainder of this chapter. They are categorised into factors pertaining to individuals, organisations and the wider systems within which the two roles operate. As the table illustrates, often barriers and enablers are two sides of the same coin, in that the absence of what is an enabler in some areas, is a barrier in others.
5.2 Factors pertaining to individuals

**Personal commitment and enthusiasm** for improving care for people with dementia is an important success factor, demonstrated by the majority of Dementia Nurse Consultants and Dementia Champions. Adjectives such as “motivated”, “committed”, “passionate”, “enthusiastic” and “inspiring” were used on many occasions throughout the evaluation to describe individual Dementia Nurse Consultants and Dementia Champions – by colleagues, managers, by each other and by national stakeholders. References were also commonly made to the “can do attitude” of individuals and their propensity to persist or “keep chipping away” to influence improvements. The commitment of Dementia Champions is demonstrated by the examples we heard of Champions attending meetings on their days off and doing work related to their Champion role in their own time. While this is commendable, this is not sustainable and is something to be resolved at an organisational level. The fact that these roles do not suit everyone and the need for the “right people” to be recruited to the roles was commonly highlighted.

The **skills, knowledge and experience** of both ASN and Champions have similarly influenced the impact of their roles to date. For example, ASN who were already well-known within their Board and/or who already had significant experience of influencing at a strategic level found it easier to “hit the ground running” than others, for whom elements of the post have been “a steep learning curve”. The Dementia Nurse Consultant post is a challenging one and requires wide-ranging skills and experience, as well as time to settle into – as ASN have found their feet and become more
established in their post, momentum and improvement activity has started to build. It is likely a lot of the groundwork these initial posts have undertaken will pave a smoother path for subsequent recruitments to the post, but there is a need for Boards to consider their approaches to succession planning for the role given its multi-faceted requirements and the challenges recruiting to the role of ASN has presented in some areas. Similarly, the skills and knowledge of Champions has impacted on their ability to influence change. The DC training programme was commonly highlighted as a facilitator by Champions, for example, one Champion said as a result of the programme “I feel totally armed to tackle bad attitudes towards dementia. This has rubbed off on my team”. Many Dementia Champions reported that personal expertise, knowledge and/or experience in dementia care helps them to affect change. 42% of Champions identified their own level of knowledge as a facilitator in our baseline survey, and 44% in the final survey.

While the training and support the roles have received to date have supported their achievements, across evaluation participant groups, the importance of continued professional development and support for both roles was highlighted as a determinant of future influence and impact. With regards to the Champions, this was expressed in terms of a) supporting their resilience to continue to influence change and challenge poor dementia care when they see it, and b) supporting them to consolidate, develop and keep up to date their skills and knowledge in line with the Promoting Excellence Framework. With regards to the ASNs, stakeholders expressed the view that that supporting continued development of their professional skills in terms of media engagement, influencing strategically, and research to inform and develop best practice in dementia care would help them maximise the impact of their role, particularly as a national group.

Seniority of role has been a facilitator in affecting change for both roles as discussed in chapter two. This has been a more significant factor for Champions than ASNs (positioning of the ASN role in terms of line-management and strategic input has had a greater influence on their ability to influence change). In general, where Champions have had a supervisory, managerial or workforce development role and the autonomy to develop their own work plan and priorities, within or across teams, change has often been easier to implement. For example, some Champions in more senior positions said they could use their position to get non-Champion members of the team to lead on and embed change actions, giving the wider team a sense of ownership. Where Champions have held less senior roles, they have often found it more challenging to influence colleagues and change takes longer to implement and embed.

The prevailing negative attitudes of some colleagues have been a challenge for Dementia Champions, and to a lesser extent ASNs. For example, these attitudes have included: general reluctance to change and doing things differently, reluctance to training because there is no perceived need, perception that the Champion does not have sufficient authority to be introducing change, negative and stigmatising attitudes towards dementia that are well-embedded and negativity from colleagues towards the time Champions have been given to engage in training. In some cases, negative attitudes and resistance have resulted in the roles prioritising staff groups who will engage with them.
The lived experiences of people with dementia have underpinned the development of these two initiatives and the associated national policy and are a key component of the DC programme. Champions in particular commonly cited how these experiences had helped them understand the perspectives of people with dementia and their carers and consequently helped them to enhance their understanding of how to provide effective support and care. Champions have found this valuable in supporting change in their colleagues and felt that more experiential learning for practitioners would further support improvements in dementia care.

5.3 Organisational factors

As evidenced in chapter three, the varied implementation of the ASN role across different Health Boards has resulted in a lack of clarity and consistency in the role. This was highlighted during the Leadership Programme, and while progress has been made in this respect over the course of the evaluation, ASNs are still subject at times to tensions between local and national objectives and priorities which impacts on the focus and extent of their work. Some Dementia Nurse Consultants reported that it can be difficult to prioritise between local and national activities, feeling stretched in many different directions. Through the National Consultants Group a greater clarity of role does appear to be developing but the challenge will be maintaining and developing this once Boards mainstream the role. The evaluation has also highlighted variance in terms of expectations for the Dementia Champion role. Champions are utilised in various ways across Boards with some areas leaving Champions free to explore and pursue their own change actions and activities, and other areas taking a more co-ordinated approach where Champions are more strategically linked in and supported.

Evaluation evidence suggests that where the ASN is supportive Champions seem to have a greater sense of direction and common purpose; this is not as evident where Champions are working in isolation. Around a third of respondents saw the relationship with the ASN as a key facilitator to their work in both the baseline and final surveys. Where the relationship is effective the Dementia Nurse Consultant provides an important source of leadership, advice, support and guidance for Champions; and at the same time, the ASN is able to utilise the local DC network to progress local and national priorities on the ground. A lack of clarity of core roles may have influenced this - there is no formal requirement set out in the MOA for ASNs to support or work with DCs, or report on this, nor are there clear expectations of the role DCs should play in terms of supporting the ASN.

In addition to support from ASNs, support from managers and other Champions is also important in enabling Champions to influence change. Some Champions have been given dedicated time by their line manager to progress change actions, or they are allowed to claim back time they spend on their Champion role. Conversely, a lack of support from managers can be a significant barrier to Champions if, for example, they are not released from their clinical duties to work on their Champion role. Around a third of baseline and final survey respondents identified this as a facilitator. Nearly all respondents to our final survey of Champions (98%, 94) said this contact was helpful to at least some extent and 45% said it was helpful to a large extent. There
are several examples of Dementia Champions working together outside of local network meetings to jointly progress change actions, for example meeting on a site basis or as a collection of wards; where the ASN has been involved in feeding into this activity, this can be a useful alternative to the Board-wide meetings for maintaining direction and common goals amongst Champions that support the ASN’s work.

**Genuine buy in at a strategic level within Health Boards is another important factor** that supports Dementia Nurses Consultants’ and Dementia Champions’ ability to achieve change. As Chapter four discusses, the roles have significantly helped raise awareness at a strategic Board level of the issues and challenges posed by increased incidence of dementia within acute settings. Where Boards are embracing this and accepting that dementia is a long-term issue which cannot be ‘solved’ in a short period of time, both ASNs and DCs tend to feel more encouraged, and better supported; something which helps keeps them going when progress is slow and arduous. As chapter two reflects, the **appropriate positioning of ASNs** in terms of line management, prominent and accessible location, and involvement on strategic groups is both a sign of strategic buy in as well as a facilitator of influence at a strategic level. Similarly the **positioning of DCs** can impact on ability to influence change. In general, more may be achieved by a number of Champions working together in a concentrated area, rather than a number of Champions working in isolation across a large number of wards/units. Across stakeholder groups concern was expressed that Social Services, and NHS Champions reporting limited contact with their ASN and/or other Champions may be quite isolated. Some interviewees suggested there are areas where they feel Champions are spread too thinly to have a significant impact.

**Organisational commitment to the roles** is something which will impact on the sustainability of the roles and the ability of the roles to influence improvements in future. In terms of the ASN role, there are eight Board areas where the future of the role is undetermined (although the hope and expectation in the majority of these areas is that the post will be mainstreamed was initial funding ends). This lack of certainty around the future of the role impacts on: the ASN themselves and the long-term focus of the work they are able to progress locally and nationally, and on Champions’ and their perception of the Board’s commitment to the dementia agenda. Similarly, Boards have shown varying degrees of commitment to the Champion role – where commitment is demonstrably greatest, Boards have approved protected time (negotiated by the ASN) for Champions to dedicate to their change agent role, and /or made the roles integral at a strategic level to the Boards improvement work around the 10 key actions and OPAC. Building the roles into **strategic plans**, for example around the 10 key actions for acute care and in relation to OPAC, can maximise the impact and sustainability of the roles and ensure they are strategically used to drive forward improvement; this is happening in a small number of Board areas.

**A lack of time to implement change** is by far the biggest hindrance to Dementia Champions with two-thirds (66%, 66) identifying this as a barrier. They are constrained both by a lack of time to devote to Dementia Champion activities given the workload of their substantive post, and a lack of time among the staff they are trying to influence. Where areas have negotiated protected time for Champions it is anticipated there will be challenges ensuring this time stays protected amidst competing priorities, however areas pursuing this approach are also hopeful it will mitigate the
time-limitations that impact on DCs’ ability to influence change and will enable them to develop their role and secure time to participate in local DC networks or group projects.

**The geography and population size of Scotland’s Health Board areas varies dramatically.** It is important to note that each Health Board area has only one ASN, regardless of its size in terms of geography, population or workforce. These conditions affect what is feasible within a given area and the potential reach of both the ASN and DC roles. These factors also impact on the nature of contact and relationship that is feasible between the ASN and DC, and therefore it is not surprising that variations in this respect are great. Some ASNs and stakeholders reported that some Boards were too big for only one ASN and that additional support could be beneficial in some areas to maximise the impact of the two roles. This situation will become more challenging as future cohorts of DCs are trained and ASNs in larger Board areas are likely to require support to develop effective mechanisms for supporting and developing their DCs.

Levels of local **awareness of the ASN and DC roles** may affect the potential reach of the roles. For example, a minority of DCs involved in the evaluation did not know there was an ASN in post in their area, and many of the colleagues we consulted were unfamiliar with the ASN role. One OPAC inspection report highlighted that staff on the ground did not seem to be aware of the ASN role or how it could help them.

5.4 **Systemic factors**

**National dementia policy and drivers provide an important foundation for both roles.** There is widespread confidence in national dementia policy, and the Scottish Government’s continued commitment to the agenda has been a significant facilitator of change at both operational and strategic levels. The Dementia Standards and Promoting Excellence (and associated resources) have supported both Champions and Dementia Nurse Consultants in their roles. In general, the OPAC inspections and more latterly, the 10 Key Improvement actions are viewed as valuable levers for change that the roles have been able to use to their advantage. The dementia benchmarking measures are expected to provide a further useful tool once re-aligned to the new Strategy and made available to Boards. Throughout the evaluation, concerns were expressed across participant groups that if the national focus shifted, it would be difficult to retain the profile of dementia and continue to progress improvements in acute settings. Sustained commitment is required to achieve the cultural shift that is needed to ensure positive experiences and outcomes for people with dementia are universally achieved across both acute and community settings.

The fact national policy and the two programmes are underpinned by a strong (and somewhat unique) **partnership between the statutory sector and Alzheimer Scotland** and are **informed by the lived experiences of people with dementia and their carers** has added further impetus to the roles.
The roles have a **strong national and public presence**. There has been good press coverage of both roles, national stakeholders are regularly referencing the value of the roles, and effort has been put into the national showcasing of the roles. National support for the ASNs and DCs (through Alzheimer Scotland, NES and SSSC) is also valued. This activity creates a sense of momentum, and reinforces the roles as a ‘National Force for Change’.

A key challenge faced by Dementia Nurses and Champions is **the enormity of the task in hand**. More than once achieving culture change in acute settings was described as “like turning a tanker around, slow to achieve” and other similar sentiments were often echoed, including describing acute hospitals as “juggernauts”. Some interviewees also commented that it can be difficult to change attitudes and behaviours that have been embedded for a long time. Acute settings are traditionally task-orientated in nature and the person-centred delivery of care being promoted by the Champions and Dementia Nurses represents a significant departure from the norm. Furthermore, within acute settings a number of **conflicting pressures** were highlighted for example Accident and Emergency targets and bed pressures impacting on the ability of staff to resist bed moves for people with dementia; the built environment not being dementia friendly; and policies around issues such as healthcare acquired infections conflicting with delivery of person-centred care. Social Services Champions highlighted that similar systemic factors inhibit their ability to influence change – for example being commissioned to only spend short periods of time with clients which restricts the potential for care to be person-centred.

The following chapter presents conclusions and recommendations from the evaluation to inform the future development and sustainability of the ASN and DC initiatives.
6 Conclusions and recommendations

6.1 Introduction

This chapter provides conclusions from the evaluation and synthesises evaluation findings to highlight key factors to support the future success and sustainability of the two roles. It then leads into recommendations for consideration by different bodies: the Scottish Government and Alzheimer Scotland; NHS Education for Scotland and the Scottish Social Services Council; and Health Boards at local level.

6.2 Conclusions

The estimated doubling of the numbers of people with dementia in Scotland over the next 25 years poses significant challenges for health and social care services and in particular, acute general hospitals. To change and improve the ways in which people with dementia are cared for in hospital acute settings is an enormous task, requiring a widespread cultural shift in approaches to care. The role of the Alzheimer Scotland Dementia Nurse Consultants/Specialists and the Dementia Champions in bringing about improvements to dementia care in acute general hospitals is one element of a much bigger nationally-led improvement programme to ensure that these challenges are addressed and overcome. The second national dementia strategy (2013-2016) and the subsequent 10 Key Actions, introduced in mid-2013, provide the action plan going forward to guide the improvements required in acute care.

Within this context, this evaluation highlights that **momentum is starting to build and a critical mass for change is developing** through the roles of the ASNs and DCs; much activity has been achieved to date, considering the relative immaturity of the change model and the relatively small scale of the initiatives compared to the size of the acute workforce in Scotland and the enormity of the task they are contributing to.

As a result of the two programmes, there are now 14 strategic leaders of change and 430 operational change agents in place across Scotland; each an advocate for improvements in dementia care and each equipped with the skills and knowledge to role-model best practice in dementia care and to influence improvements within their own sphere. It is clear that **the two roles have raised the profile of dementia** at local level, both strategically and operationally, and to some extent nationally.

**ASNs and DCs have demonstrated significant dedication, enthusiasm and innovation** in their roles, with many investing their own time and resources in progressing change. There are pockets of effective improvement activity evident in all Board areas as a result of the roles, with a number of Board areas demonstrating or developing strategic and co-ordinated approaches to the roles, thereby supporting more widespread and sustainable impact.
Where the roles have been most effective there have been some notable improvements, particularly in terms of the skills and knowledge of staff; the care environment; involvement of carers; individualisation of care; and management of stress and distress. The roles have been able to challenge and address negative attitudes towards dementia and support improvements in the attitudes and practices of staff across a variety of professions and settings.

It has proved more difficult to measure and evidence the impact of these changes on patient and carer experiences and outcomes; this is a challenge at national and organisational level as well as for the roles themselves, and will require further work going forward. However it can be inferred from some of the improvement activities that these must have brought about benefits in terms of the outcomes and experiences of those with dementia and their carers in acute settings.

Local implementation of the ASN role and Memorandum of Agreement (MOA), which outlines ASN objectives, varies greatly across Health Board areas, relating to: AfC band and grade, seniority, involvement in recruitment of Dementia Champions, strategic positioning and physical location. These factors affect the ability of the ASN to influence change and affect the nature of the relationship between the ASNs and DCs. While relationships between the two roles have developed positively in many areas over the evaluation period, local variations are significant, and the model is still at the early stages of evolution in some areas. While the current MOA makes it clear ASNs have a role to support implementation of the Dementia Champions initiative, it does not make explicit their role in supporting and co-ordinating the work of Champions in practice.

The model is working very successfully in some Board areas, with established mechanisms in place to ensure strategically co-ordinated joint working between the roles – this takes a variety of forms for example, local ASN-DC network meetings, site-based DC meetings supported and/or attended by an ASN, the ASN working with senior colleagues to ensure DCs are supported in their work. In these areas, much is being achieved by the two roles, strategically and operationally, despite the relatively small scale in terms of number of Champions compared to number of acute settings. Where the model is working well there is a sense of shared direction and co-ordinated working between the roles; DCs feel more supported, informed and resilient; there is a collective sense of identifying as a ‘force for change’ and momentum for change and improvement is being built/sustained. Where collaboration between the roles is minimal, Champions can feel isolated and directionless and a lack of co-ordinated working may result in duplication.

The introduction of Social Services Dementia Champions has not had as great an impact on the wider initiatives and improvements in acute settings as initially hoped for as they have tended to be located in services that are more distanced from acute hospitals and have therefore had limited influence on the acute sector. However, they have been effective and active in taking forward a wide range of changes and improvements within their own services and the wider Social Services, for example, implementing Promoting Excellence; influencing staff attitudes and practices towards people with dementia; improving the environment, delivery of person-centred care and involvement. In some areas the relationship between the NHS and Social Services Champions has evolved positively. There is more that could be done to support Social Services Champions to contribute to the improvement agenda in particular linked to transitions between acute and community care.
The Dementia Nurse Consultants have developed their work as a group at national level over the evaluation period and this is potentially a highly useful group going forward, linking between national level and local implementation directly. The potential of the National Consultants group would be maximised by having an ASN at a strategic level in each Health Board, who is enabled to participate actively at national level.

6.1.1 Key issues affecting sustainability

The good work achieved together with learning from the experiences of the roles to date needs to be shared and the initiatives nurtured and invested in to ensure sustainability and further development. Continued commitment at national level is seen as essential.

This evaluation has highlighted a number of issues which present a threat to the sustainability of the two roles and the improvement activity they have influenced to date. These are listed below.

- Uncertainty about the future of the ASN role in many Board areas.
- While in a number of Board areas ASNs are clearly strategically placed and supported, there are inconsistencies across Board areas.
- ASNs are subject to many masters which means accountability, performance management and development and support of the role is varied and sometimes unclear and there are concerns that the ASN role may become diluted by local objectives as it is mainstreamed and may lose its national focus and influence.
- While in a number of Board areas ASNs and Dementia Champions are working closely and collaboratively to take forward a co-ordinated approach to change, this is not consistent across all areas and where Champions are not being supported, and do not have a clear sense of leadership and direction, there is a significant risk their ability and motivation to continue to influence change will diminish.
- While there is appetite, in most areas, for more Champions to be trained, they need to be strategically placed and well-supported to maximise their impact and the sustainability of their work. Larger NHS Boards, in particular, will need to plan for how they will ensure effective support for and development of a growing body of Champions as future cohorts graduate; it is not feasible to expect that one ASN can take on this task alone without appropriate support.

There is a role for both local and national stakeholders to play in mitigating these sustainability issues to ensure the roles can continue to evolve and flourish in future in pursuit of bringing about further and more widespread improvements in dementia care in acute settings. The following section highlights ‘key factors for success’ to support local and national stakeholders in developing and sustaining the roles.
6.3 ‘Key factors for success’ to inform future developments and sustainability

The evaluation confirms that where it is working well, the two-pronged ASN-DC model is an appropriate and effective one for implementing change, but highlights that further development is required in a number of Board areas to maximise impact and ensure sustainability of the roles and all they have achieved to date. The evaluation findings provide insight into the key factors that are present in areas where the model is better-established and working more effectively. Table 6.1 below synthesises the elements which are required at both national and local level to maximise the future success and sustainability of the change model, acknowledging that in some areas some or all of these supporting factors are already in place.

Fig. 6.1: ‘Key factors for success’ to inform future developments and sustainability

<table>
<thead>
<tr>
<th>Key factors for success</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>At National Level</strong></td>
</tr>
<tr>
<td>- Continued commitment to the dementia improvement agenda with a continued focus on acute settings</td>
</tr>
<tr>
<td>- Delivery of person-centred care for people with dementia in acute general hospitals</td>
</tr>
<tr>
<td>- Continued national support for the National Consultants Network and active participation required of all ASNs</td>
</tr>
<tr>
<td>- Continued national support for the DCs to maintain and build their identity as a ‘national force for change’</td>
</tr>
<tr>
<td><strong>At local Level</strong></td>
</tr>
<tr>
<td>- There is ownership of the agenda at senior Board level and a clear strategic plan for how the two roles will support this and how their inputs link to the 10 key improvement actions.</td>
</tr>
<tr>
<td>- The role of ASN is clearly defined, including local and national objectives, and is at a sufficiently senior level to ensure strategic influence at Board level.</td>
</tr>
<tr>
<td>- There are clear expectations of the ASN role and there are appropriate management, accountability and development processes in place at Board level.</td>
</tr>
<tr>
<td>- Larger NHS Boards consider how Dementia Champions can be further developed to support the ASN role more strategically.</td>
</tr>
<tr>
<td>- The ASN is involved in strategically selecting candidates for the DC programme and ensuring line managers understand the role and are supportive.</td>
</tr>
<tr>
<td>- The ASN is proactive in developing an effective mechanism for ensuring Champions are supported and co-ordinated. This may be through providing support themselves, or identifying and co-ordinating alternative sources of support.</td>
</tr>
<tr>
<td>- Champions have a clear sense of direction, their learning and development is supported, their resilience is supported and good/innovative practice is shared. They have a sense of being part of a bigger force for improvement and not isolated.</td>
</tr>
<tr>
<td>- Champions have protected time to dedicate to the delivery of shared objectives.</td>
</tr>
<tr>
<td>- A clear plan for mainstreaming and sustaining the ASN role is established and thought is given to succession planning for the ASN role</td>
</tr>
</tbody>
</table>
6.4 Key Recommendations

For NHS Scotland Boards

1. Ensure there is a clear dementia strategy group and strategic plans in each Health Board that supports and focuses the ASN's and DCs’ work in acute care. Positive examples exist in NHS Scotland and there is the opportunity to share and spread best practice in this respect.

2. Ensure clear reporting and accountability structures within the Health Board to manage, support and develop the role of ASN, ensuring national as well as local objectives are incorporated.

3. Ensure that the focus of the ASN role remains on bringing about improvements in acute general hospital care, as involvement of ASNs in multiple initiatives runs the risk of diluting the impact of the roles in this sector.

4. Consider the ‘key factors for success’ outlined in this report to inform developments locally in a way that maximises and effectively mobilises the contribution of the ASN and DC roles in supporting implementation of the ‘10 key change actions’.

5. Concurrently focus on up-skilling the whole acute care workforce in line with Promoting Excellence and ensuring an appropriate skills mix in all wards and units, in line with the Promoting Excellence priority set out in the ‘10 key change actions’.

For the Scottish Government and Alzheimer Scotland

6. Maintain the national leadership and focus for improvement on the acute sector, which is already signalled by the ‘10 Key Change Actions’ and should be further developed through the improvement programme for acute settings.

7. Support every Health Board to have an ASN post that is placed at strategic level, has a clear and consistent role and remit, and clear responsibilities for ensuring DCs are supported and co-ordinated. This will require a refresh of the original MOA for ASNs.

8. Undertake work to support Health Boards and ASNs to evidence the impact of improvement work in acute settings for people with dementia and their carers (this might form part of a wider monitoring and evaluation framework for the ‘10 Key Change Actions’).

For NHS Education for Scotland (NES) and Scottish Social Services Council (SSSC)

9. Monitor the role of the Social Services Champions and how they can best be supported to help contribute to improvements in care at the interface between the acute and community settings.
10. Provide ongoing support through shared learning and development sessions for the existing Dementia Champions.

_for the Scottish Government and NES_

11. Give further consideration as to how existing Champions continue to be developed through education and development pathways with a view to succession planning for future specialist and advanced roles in acute care.
Appendix 1

References

http://www.alzscot.org/campaigning/statistics
Douglas, T. & Young, K., (2013) Promoting Excellence in Dementia Leadership - a person centred leadership development programme for Dementia Nurse and AHP Consultants and Specialists from NHS Scotland Territorial Boards, evaluation report
NHS Education for Scotland and Scottish Social Services Council (2011) Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families, and carers.
University of the West of Scotland & Alzheimer Scotland (2012) Development, delivery and evaluation of a training programme to prepare NHS and Social Services Dementia Champions as change agents, Cohort 1 report
University of the West of Scotland & Alzheimer Scotland (2012) Development, delivery and evaluation of a training programme to prepare NHS and Social Services Dementia Champions as change agents, Cohort 2 report
University of the West of Scotland & Alzheimer Scotland (2013) Development, delivery and evaluation of a training programme to prepare NHS and Social Services Dementia Champions as change agents, Cohort 2 report