The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority

Review of the Implementation of NICE Clinical Guideline 42: Dementia

Overview Report

June 2014

Assurance, Challenge and Improvement in Health and Social Care

www.rqia.org.uk

The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland. RQIA's reviews aim to identify best practice, to highlight gaps or shortfalls in services requiring improvement and to protect the public interest. Our reviews are carried out by teams of independent assessors, who are either experienced practitioners or experts by experience. Our reports are submitted to the Minister for Health, Social Services and Public Safety, and are available on the RQIA's website at www.rqia.org.uk.

Membership of the Review Team

Ms Lesley Edgar	NICE Implementation Facilitator, Northern Ireland
Mr Hall Graham	Head of Primary Care, RQIA
Mr Jim McIlroy	Project Manager, RQIA
Ms Patricia Corrigan	Project Administrator, RQIA

People who assisted with the fieldwork for the review

Mrs Angela Belshaw	Project Manager, RQIA
Mrs Helen Hamilton	Project Manager, RQIA

RQIA wishes to thank Ms Theresa Clarke, Mrs Jennifer Stewart, Mr John McErlane and Mr Wayne Goddard (Head of Strategy and Delivery (Vulnerable People), NHS Doncaster Clinical Commissioning Group) for their contribution to the stakeholder event, and the Alzheimer's Society for its assistance with engaging people living with dementia and their carers.

Table of Contents

Executive Summary

The Regulation and Quality Improvement Authority (RQIA) has a responsibility to provide assurance in relation to the implementation of clinical guidelines produced by the National Institute for Health and Care Excellence (NICE).

In 2011, NICE published updated clinical guidelines for dementia, that offer best-practice advice on the care of people living with dementia and support for their carers. These guidelines make recommendations for specific types of dementia as well as recommendations that apply to all types of dementia.

This review examined the progress of the implementation of NICE clinical guideline 42: Dementia in each of the Health and Social Care trusts. The review did not specifically examine the quality of the dementia care services being provided by the trusts.

At the time of release, all trusts received clinical guideline 42 and circulated it at a senior level within their organisations; however, the onward circulation to staff was limited. Trusts now have organisational policies and formal mechanisms in place for the dissemination, implementation, monitoring and assurance of NICE clinical standards and guidelines.

In most cases, full implementation of NICE guidelines is not anticipated to happen quickly and may take several years. The review found that implementation of clinical guideline 42 was limited, and a contributing factor was considered to be the release of the dementia strategy in November 2011. It was found that trusts tended to prioritise work on the implementation of the dementia strategy over the implementation of the guideline.

The dementia strategy provides the direction for service development and is underpinned by clinical guideline 42, which can provide the tools to support implementing change.

In November 2013, as part of the review methodology, RQIA hosted a stakeholder event which was themed 'Sharing Experiences, Improving Care'. It provided an opportunity for a range of HSC staff working in dementia care to: discuss the initial findings from the review; identify learning that may improve the implementation of clinical guidelines; and share areas of good practice linked to clinical guideline 42.

As part of the event, various people were invited to provide a presentation. These included people living with dementia, the NICE Implementation Facilitator for Northern Ireland, the Head of Strategy and Delivery (Vulnerable People), NHS Doncaster Clinical Commissioning Group and RQIA. Trusts also presented an area of good practice linked to clinical guideline 42.

The views of people living with dementia and their carers was an important aspect of the review. Through focus groups set up by the trusts and Alzheimer's Society, the review team met with people living with dementia and

their carers, who shared both positive and negative experiences of using dementia care services.

The review identified significant developments currently being undertaken within the dementia care services, which will complement the current good practice. However, these developments are mostly linked to the implementation of the dementia strategy, rather than clinical guideline 42.

Trusts acknowledged that clinical guideline 42 was generally only being referenced in practice and was not being used as much as it should be.

This report sets out eight recommendations to enhance the arrangements for implementation of NICE clinical guidelines.

Section 1 – Introduction

1.1 Context for the Review

Dementia is not a specific disease. It is an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills, severe enough to reduce a person's ability to perform everyday activities. It is not a clinical diagnosis itself until an underlying disease or disorder has been identified.

Dementia is a progressive condition and symptoms will gradually get worse over time. This progression will vary for each individual, and people living with dementia will experience it in different and unique ways.

Dementia is caused by damage to brain cells which interferes with the ability of brain cells to communicate with each other. There are a number of types of dementia associated with different conditions, and damage to particular types of brain cell, in particular regions of the brain.

The most common types of dementia are:

- Alzheimer's disease – the most common cause of dementia caused by brain cells being surrounded by an abnormal protein, which leads to chemical connections between brain cells being lost, leading eventually to cell death.
- Vascular dementia – if the oxygen supply to the brain is reduced because of narrowing or blockage of blood vessels, some brain cells become damaged or die. This causes vascular dementia. The symptoms can occur either suddenly following one large stroke or gradually through a series of small strokes or damage to small vessels deep in the brain.
- Mixed dementia – this is where a person has more than one type of dementia, and a mixture of symptoms. It is common to have Alzheimer's disease and vascular dementia together.
- Dementia with Lewy Bodies – this type of dementia involves tiny abnormal structures (Lewy bodies) developing inside brain cells. They disrupt the normal cell chemistry leading to cell death.
- Frontotemporal dementia – the frontal and temporal lobes of the brain become damaged over time due to the production of an abnormal protein within nerve cells leading to cell death.

Although many people living with dementia retain normal personality traits and personal attributes, as their condition progresses they can experience some or all of the following problems:

- memory loss
- language impairment
- disorientation
- changes in personality, such as mood swings or aggressiveness
- difficulties with activities of daily living
- self-neglect
- psychiatric symptoms

- out-of-character behaviour
- loss of initiative

There are approximately 19,000 people living with dementia in Northern Ireland and this is expected to rise to 61,000 by 2051[1]. The risk of developing dementia increases with increasing age. The condition most commonly occurs in people over the age of 65 and it is estimated that there are fewer than 1000[2] people under 65 in Northern Ireland living with dementia. Most types of dementia are incurable, but if it is detected early there may be ways to slow its progression helping people maintain a normal lifestyle.

In the care of people living with dementia, health professionals often complement their knowledge and skills with clinical guidelines. Clinical guidelines are recommendations outlining the appropriate treatment and care of people with specific diseases and conditions. They are based on the best available evidence.

In 2011, the National Institute for Health and Care Excellence (NICE)[3] published updated clinical guidelines[4] that offer best-practice advice on the care of people living with dementia and support for their carers. These guidelines make recommendations for specific types of dementia as well as recommendations that apply to all types of dementia.

NICE provides national guidance and advice to improve health and social care. NICE was established in 1999 as the National Institute for Clinical Excellence, a special health authority, with the remit of promoting clinical excellence and the effective use of resources to reduce variation in the availability and quality of treatments and care.

NICE publishes guidance in various categories:

- Technology Appraisals
- Clinical Guidelines
- Public Health Guidance
- Interventional Procedures
- Medical Technologies
- Diagnostics

NICE publications were primarily intended for people using the National Health Service (NHS) in England and Wales and, prior to 2006, the guidance did not automatically apply in Northern Ireland.

On 1 July 2006 the Department of Health Social Services and Public Safety (DHSSPS) established formal links with NICE. From this date new guidance

[1] Northern Ireland Dementia Services Development Centre (DSDCNI) - http://dementiacentreni.org/dementia-northern-ireland
[2] http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf
[3] The National Institute for Health and Care Excellence (NICE) http://www.nice.org.uk/
[4] NICE clinical guideline 42: Dementia: Supporting people with dementia and their carers in health and social care http://guidance.nice.org.uk/CG42

published by the Institute would be locally reviewed for applicability to Northern Ireland, and where appropriate, endorsed for implementation in HSC organisations. This link has ensured that Northern Ireland has access to up-to-date, independent and professional evidence based guidance on the value of health care interventions.

In September 2011, the Chief Medical Officer (CMO) issued Circular HSC (SQSD) 04/11[5], to improve the process for implementation of NICE guidelines. This circular informed the HSC sector of the new process for endorsement, implementation, monitoring and assurance of NICE guidance in Northern Ireland. This Circular also established new arrangements for RQIA to provide assurance in relation to the implementation of NICE clinical guidelines.

To ensure on-going assurance, DHSSPS incorporated commissioned reviews of the implementation of NICE clinical guidelines into the RQIA review programme. It was not specified which NICE clinical guidelines were to be reviewed, as this is subject to annual discussion between RQIA and DHSSPS. During RQIA's public consultation on its review programme, the theme of dementia was highlighted as an area of particular concern. Subsequently the associated NICE clinical guideline 42 on dementia was selected as the theme for the review.

On 27 September 2011, the CMO issued Circular HSC (SQSD) (NICE) 31/2011[6] to the HSC sector. This circular related to NICE clinical guideline 42: Dementia, with the expectation that HSC organisations would use the guidelines in the planning and delivery of dementia care services.

In November 2011, DHSSPS released the Northern Ireland Dementia Strategy[7]. It made recommendations aimed at improving the current services and support arrangements for people living with dementia, their families and their carers. The information and recommendations from NICE clinical guideline 42 were used to inform the development of the dementia strategy.

[5] DHSSPS Circular HSC (SQSD) 04/11 - http://www.dhsspsni.gov.uk/circular_hsc_sqsd_04_11_nice_guidelines_8211_new_process.pdf

[6] DHSSPS Circular HSC (SQSD) (NICE) 31/2011 - http://www.dhsspsni.gov.uk/hsc_sqsd_nice_31_2011_-_nice_clinical_guideline_cg42_-_dementia.pdf

[7] Improving Dementia Services in Northern Ireland - A Regional Strategy - http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf

1.2 Terms of Reference

This review assessed the implementation of NICE clinical guideline 42: Dementia by HSC organisations and assessed how the guidelines were being utilised for the planning and delivery of dementia care services.

The terms of reference for this review were:

1. To review the actions taken by HSC organisations in response to circular HSC (SQSD) (NICE) 31/2011.
2. To review the implementation of NICE clinical guideline 42: Dementia to inform the planning and delivery of dementia services.
3. To identify any relevant learning as to how the effectiveness of the implementation process for NICE guidelines could be enhanced and make recommendations where appropriate.
4. To obtain the experiences of service users and their carers, in relation to dementia care services provided by the HSC trusts.
5. To report on the findings, identify areas of good practice and, where appropriate, make recommendations for improvements.

The review did not focus directly on dementia care services, in terms of their effectiveness or quality, but rather the implementation of NICE clinical guideline 42: Dementia, and its use in the planning and delivery of those services.

1.3 Exclusions

The review did not consider the implementation of NICE Quality Standards as they are not specifically approved for implementation in Northern Ireland. The NICE Quality Standards are a concise set of statements designed to drive and measure priority quality improvements within a particular area of care. They are derived from the best available evidence such as NICE guidelines and other evidence sources accredited by NICE. They are developed independently by NICE, in collaboration with NHS and social care professionals, their partners and service users.

Circulars, guidance, standards, reviews and reports which are issued during the course of this review are not assessed as part of this review but will be highlighted for consideration in the future.

1.4 Review Methodology

The review methodology was designed to gather information about the implementation of clinical guideline 42, including the views of staff, people living with dementia, and carers. The methodology included the following steps:

1. An initial information gathering exercise was undertaken to establish the structure of dementia services within each trust. This identified which services and departments were involved with the implementation of clinical guideline 42. Lines of enquiry were then developed to explore the implementation process for the guideline within each organisation.

2. A questionnaire was completed by each trust, which allowed them to outline the actions they had taken following the issue of the DHSSPS circular and clinical guideline 42. In particular the questionnaire sought information regarding the dissemination and communication of the documents and the assessment, implementation and evaluation of the clinical guideline and its recommendations.

3. A series of both individual and group interviews were held with key staff from the trusts and the HSC Board. Seventy five staff participated in the interviews. The aim of this informal engagement process was to allow two-way discussion to gather information on the implementation of clinical guideline 42.

4. The views of both people living with dementia and their carers was a key element of this review. RQIA worked in conjunction with the trusts and Alzheimer's Society to set up focus groups to obtain the views of people living with dementia and their carers in each of the trust areas. Sixty one people living with dementia and 74 carers of people living with dementia participated in the focus groups.

5. The initial findings from the questionnaire, the interviews and the focus groups were collated, and the results used to inform a stakeholder event held in November 2013. At this event, the initial findings were presented and discussed. Possible approaches to enhance the arrangements were then considered. The summit event included representation from each of the trusts, the HSC Board, DHSSPS and other voluntary organisations.

6. Publication of a report, which included the findings from the review and recommendations associated with the implementation of NICE clinical guideline 42.

Section 2 – Findings from the Review

2.1 Background to the Findings

The release of NICE clinical guideline 42: Dementia, on 27 September 2011, came at a time of significant change. Arrangements for a new process for the endorsement, implementation, monitoring and assurance of NICE guidance that applied to all HSC organisations became effective from 28 September 2011. The new regional dementia strategy was also about to be released by DHSSPS.

When planning how dementia services are commissioned and delivered, it is important to take into account all initiatives and policies relating to the clinical areas specified in clinical guideline 42. The timing of the release of the clinical guideline for dementia had been considered by DHSSPS. It was confirmed that the guideline was released prior to the new process for NICE guidance taking effect, to ensure it was distributed to trusts in advance of the dementia strategy.

Under the new process for implementation of NICE guidance, the HSC Board is required to produce a draft service notification, which is subsequently approved by DHSSPS. This process could have taken up to 15 weeks and potentially could have delayed the dissemination of clinical guideline 42 to the trusts, until after the release of the dementia strategy. Therefore the clinical guideline for dementia did not fall within the scope of the new process for NICE guidance.

These are important factors that must be taken into account when considering the responses from the trusts, in relation to their management and implementation of clinical guideline 42.

2.2 The Actions Taken by HSC Organisations in Response to Circular HSC (SQSD) (NICE) 31/2011

On 27 September 2011, the Chief Medical Officer (CMO) issued Circular HSC (SQSD) (NICE) 31/2011 to all HSC organisations (see Appendix 1). This circular was primarily concerned with NICE clinical guideline 42: Dementia, and outlined DHSSPS expectations in relation to how trusts were to deal with the guideline. In particular, there was a requirement that the HSC sector should take account of the clinical guideline in the planning and delivery of services to people with dementia.

Dissemination of Clinical Guideline 42

RQIA found that all trusts had received the circular and clinical guideline 42 at the time of release, and subsequently circulated them at a senior level within their respective organisations. It was determined that the dissemination was in keeping with each trust's normal distribution process for communications, as, at that time, the trusts had no formal mechanism for dissemination of

clinical guidelines. Trusts had no formal mechanism for the review of the applicability of clinical guidelines and this task was generally carried out by individual directorates or clinical teams.

In the period after release, RQIA found that in most trusts the onward circulation of the clinical guideline to staff, to be limited. Most staff interviewed had not been aware of the clinical guideline for dementia nor could recall receiving any communication about it in 2011.

Staff who were aware of the clinical guideline for dementia in 2011, advised RQIA that this was usually a result of them seeing it through their own practice, through research, or having received it from other sources.

The Northern Health and Social Care Trust (Northern Trust) was able to evidence the dissemination in 2011 of the clinical guideline 42 to selected staff. This was confirmed during interviews, when some staff stated they were asked to comment on the clinical guideline at the time. During the review, the majority of staff interviewed across all trusts, confirmed they had now received information regarding clinical guideline 42.

The situation in relation to dissemination has changed since 2011. Currently, all trusts have organisational policies and formal mechanisms in place for the dissemination, implementation, monitoring and assurance of NICE clinical standards and guidelines. The implementation of clinical guidelines is either described in a specific policy, or is integrated within a wider policy. Each trust now has a multidisciplinary committee which reviews the applicability of the particular clinical guideline for its relevance to the organisation.

At an operational level, clinical guidelines are now being disseminated to relevant clinical leads, who have the responsibility for onward circulation to all staff within their team. In all trusts, staff advised that recent NICE guidance was being communicated to them and discussed during team meetings and sometimes at supervision meetings. The Belfast Health and Social Care Trust (Belfast Trust) is planning to implement a more formal mechanism for communication of clinical guidelines to staff, and responsibility for this task had been passed to a Trust Task and Finish Group.

Staff from the Northern, Western and Southern trusts advised that the clinical guideline for dementia was being held in folders on selected wards, or at a central location for the community teams. Staff further advised that they are now required to familiarise themselves with the clinical guidelines for dementia and a process for sign-off is in place.

RQIA asked trusts to advise on what action they are taking in relation to informing new staff of the clinical guideline for dementia. All trusts have induction programmes in place for new staff. Most make reference to NICE and the guidance it produces; however, the South Eastern and Western trusts were noted to have clinical guidelines for dementia specifically included in their induction programmes. At the time of the review, the Northern Trust was

currently reviewing its induction checklist for new staff, with the aim of including clinical guidelines for dementia.

2.3 The Implementation of NICE Clinical Guideline 42: Dementia, to Inform the Planning and Delivery of Dementia Services

The implementation of NICE clinical guideline 42 can assist HSC organisations in planning and delivering dementia care services. To complement the guideline, NICE has developed associated implementation tools and resources. These are designed to help commissioners and providers of services undertake the initial assessments of services, develop action plans and assist with training, as well as auditing and reporting on progress. Full implementation of the guideline may take several years, due to the complexity of some of the recommendations, particularly in relation to service reconfiguration and delivery.

During the interviews, many practitioners across all trusts stated their current practice was in line with clinical guideline 42. Although this demonstrated the awareness and use of the guideline, no staff were able to submit evidence of any formal assessments or audits carried out to support their position statements.

Baseline Assessment of Services against Clinical Guideline 42

An initial baseline assessment would determine the levels at which current practice is in line with the recommendations from the guideline. Such findings should be used to develop an action plan for taking forward service redesign.

From a trust perspective, the Northern and South Eastern trusts demonstrated that work had been undertaken on a baseline assessment of services upon release of clinical guideline 42. While the other trusts evidenced baseline assessments within the dementia care services, they had not been a direct result of, or initiated by clinical guideline 42. These assessments were a result of work associated with the dementia strategy.

It was noted that in 2010, prior to the release of the DHSSPS circular, the South Eastern Health and Social Care Trust (South Eastern Trust) had completed a baseline assessment against the NICE quality standards for dementia and developed an action plan. The quality standards provide a description of what a high-quality dementia service should look like. Rather than undertake another assessment against clinical guideline 42, the trust continued to work with the action plan derived from the quality standards.

The Northern Trust provided evidence that a baseline assessment had been undertaken against clinical guideline 42, upon release of the DHSSPS circular in 2011. However, the subsequent implementation plan was not fully developed. The changes to dementia services were outlined in the plan for their “New Ways of Working” project.

In 2012, the Western Health and Social Care Trust (Western Trust) appointed a service improvement lead to review service development within the older people's programme of care. A baseline assessment of services was carried out in December 2012, with dementia care representing a significant aspect of the assessment. Services were measured against standards and recommendations from several key strategic drivers, including clinical guideline 42. As part of the review, the trust presented evidence of the action plan which resulted from this service improvement initiative.

The Southern Health and Social Care Trust (Southern Trust) advised of completing a baseline assessment of services against the dementia strategy. A subsequent action plan was developed and they were progressing with work against this plan. They also presented an action plan linked to clinical guideline 42; however, no supporting baseline assessment linked to clinical guideline 42 had been undertaken.

The Belfast Trust advised that service development has been informed by all of the national standards and guidance available. They were progressing with an action plan associated with the dementia strategy.

The current clinical governance arrangements within the trusts ensure that action plans, and progress with the implementation of clinical guideline 42, quality standards or the dementia strategy are being reported back to trust board level.

Priorities for Implementation

Within clinical guideline 42, nine areas were identified as key priorities for implementation, these were:

- Non-discrimination
- Valid consent
- Carers
- Co-ordination
- Memory services
- Structural imaging for diagnosis
- Behaviour that challenges
- Training
- Mental health needs in acute hospitals

Trusts were asked about changes to services that had been implemented or were planned, in relation to these key priorities.

Trusts reported that changes to services had been undertaken in the areas of the nine key priorities, although they stated that none of the changes were specifically implemented as a result of the release of clinical guideline 42. Some trusts did reference that the changes implemented were in line with clinical guideline 42, but did not provide evidence of formal assessment or audit to support this. During staff interviews, the developments in services

were clear, and it was considered that the dementia strategy, rather than clinical guideline 42, was the driver for the changes.

Trusts provided information about planned changes to their dementia care services. Although most changes were being driven by the dementia strategy, some trusts stated that changes were planned that were directly linked to clinical guideline 42. It was evident during interviews that most trusts were now giving clinical guideline 42 more consideration when planning changes to services.

RQIA identified several areas within the key priorities where trusts had advised that no changes to services were planned. These were in the areas of non-discrimination, valid consent and structural imaging for diagnosis. Trusts were asked to clarify why there were no changes planned in these areas.

Non-discrimination

In relation to non-discrimination, clinical guideline 42 states that people living with dementia should not be excluded from any services because of their diagnosis, age or a coexisting learning disability. While all trusts follow the principles of non-discrimination, some advised that there were aspects of their services where they were unable to fully meet this recommendation.

The Belfast Trust advised that they strive to follow the principles of non-discrimination within the dementia care services and had no specific changes planned, as this area was being addressed through other initiatives.

In the Southern Trust, it was advised that people under the age of 65 living with dementia, were currently unable to access some dementia care services. In particular, there was no access to specialist dementia services or day care provision. Their ongoing care was managed by mental health services. However, the dementia services team did provide advice and opinions regarding care upon request and provided expert training to carers. Within existing resources, it was unlikely this service provision would change.

The South Eastern Trust confirmed that people under the age of 65 living with dementia were cared for within dementia care services. However, there was currently no access to cognitive behavioural therapy for people over the age of 65 living with dementia. Staff confirmed this was being explored further to identify how they could ensure good practice in this area.

Staff in the Western Trust stated that services are provided for people under the age of 65 living with dementia. However, staff advised that difficulties had been encountered in relation to age discrimination by some care providers, who were reluctant to accept people over the age of 65 living with dementia.

Trusts were aware of instances of unintended discrimination. However, the current structure and organisation of services within the respective trusts, and

them being unable to easily reconfigure services, were given as the reasons for not meeting this recommendation.

Valid Consent

The area of valid consent was listed by the Belfast Trust as an area where no changes were planned. It was indicated by the trust that they considered the current arrangements to be sufficient. The other trusts advised this was an area where no changes were required, or where changes had been planned.

Structural Imaging for Diagnosis

Clinical guideline 42 recommends that structural imaging should be used to assist in the diagnosis of dementia. Structural imaging aids in the differentiation of the type of dementia and helps to exclude other cerebral pathology. Magnetic resonance imaging (MRI) is the preferred modality to assist with early diagnosis and detect subcortical vascular changes, although computerised tomography (CT) and positron emission tomography (PET) scanning may also be used.

All trusts confirmed that people living with dementia had access to CT scans. With the exception of the Belfast Trust, the other trusts advised they had limited or no access to PET and MRI scanning facilities for the purposes of diagnosing patients with dementia. In these cases, many of the people living with dementia were referred to the Belfast Trust or other locations for such scans, and were sometimes subject to long waiting times.

It was acknowledged that the costs involved in providing PET and MRI scanning facilities were prohibitive for trusts in meeting this recommendation.

All trusts acknowledged that clinical guideline 42 was generally only being referenced in practice, and was not being used as much as it should be.

Use of NICE Implementation Tools

NICE has developed specific implementation tools to assist organisations in the implementation of clinical guideline 42. These tools are available on the NICE website.

In all trusts, there was a general lack of knowledge of NICE implementation tools. In general, people expressed the view that the NICE website was difficult to navigate and felt the implementation tools were not easily accessible. Most trust staff interviewed were not aware that the tools existed. Of the staff that were aware of the tools, they advised they weren't used because they were not familiar with them, they didn't have the time to use them or they had developed their own tool to aid implementation.

References to using the tools were somewhat limited. The Northern Trust reported that they only used certain aspects of the tools during a baseline assessment and the subsequent re-assessment. The South Eastern Trust

confirmed use of some of the implementation tools to take forward their work on the implementation of the quality standards for dementia. In the Western Trust, a consultant confirmed the use of the clinical case scenarios and slide sets as part of a presentation to junior medical staff.

Following the presentation from the NICE Implementation Facilitator for Northern Ireland at the stakeholder event, participants stated they were now more aware of the implementation tools, where to access them and how to use them. They stated they would consider using them in the future.

Training

Raising awareness and education of dementia through training would help to improve recognition, detection and diagnosis of dementia, as well as improving treatment and care for people living with dementia.

During the review, all trusts were able to demonstrate the provision of wide-ranging training programmes in dementia care. While the trusts stated that training was in line with clinical guideline 42, it was clear that the majority of the training had not been developed as a result of clinical guideline 42, but rather emanated from the dementia strategy.

Trusts however, highlighted many planned training initiatives which were more closely aligned with recommendations contained in clinical guideline 42.

- As part of the service improvement project, the Western Trust is delivering training courses on dementia for trust staff in the acute setting, primary and community care, older people's mental health and domiciliary care.
- The Western and South Eastern trusts highlighted planned training in challenging behaviour, based on the Newcastle Support Model, to ward and community based staff, as well as some staff in residential and nursing homes.
- The Belfast, Southern and South Eastern trusts highlighted planned training to skill up dementia champions, who will provide training and advice to other members of staff in the area of dementia care.
- The Northern Trust has incorporated dementia training throughout their New Ways of Working project and structured it around the recommendations contained in clinical guideline 42.

Evaluation of clinical guideline 42

It is considered that the implementation of clinical guideline 42 should be regularly reviewed and monitored, with results fed back to the relevant trust board. One way to monitor the implementation of the guideline is to audit current practice against the guideline. Within the suite of implementation tools, audit criteria are provided to help ensure that practice is in line with the NICE clinical guideline recommendations.

With the limited implementation of clinical guideline 42 by the trusts, the opportunity for evaluation was equally as limited. None of the trusts evaluated

the implementation of clinical guideline 42 directly; however, some evaluations of changes to services were carried out.

- The Belfast and Southern trusts undertook audits of some services in line with the development of the dementia strategy rather than clinical guideline 42.
- The Western Trust audited some services against relevant criteria within clinical guideline 42, although no NICE clinical audits were used as part of this process.
- The South Eastern Trust conducted audits against the NICE quality standards for dementia.
- The Northern Trust conducted a review of its action plan, but no specific evaluation of the changes to services.

Barriers to Implementation of Clinical Guideline 42

From an early stage of the review, it was evident that implementation of clinical guideline 42 was limited in each of the trusts. Trusts were questioned about problems with implementing clinical guideline 42. In response, they described difficulties with implementation of both the overall guideline and some of the specific key priorities.

The main factors that impacted on the overall implementation of clinical guideline 42 were the introduction of the new process for implementing NICE guidance and the release of the dementia strategy. Given the timing of the release of the circular associated with clinical guideline 42, it did not fall within the scope of the new process for implementation of NICE guidance. As a result, there was no requirement for trusts to formally implement clinical guideline 42. Rather, the only requirement was for it to be considered in the planning and delivery of services. Feedback obtained by the review indicated that the wording within the DHSSPS circular for the implementation of clinical guideline 42 was vague and did not direct specific actions which needed to be taken.

The dementia strategy was also released several weeks after the circular for clinical guideline 42 was issued. As the dementia strategy was accompanied by the requirement for direct action by all HSC organisations, this subsequently became the priority for all trusts. Some trusts noted other regional drivers, such as the outcomes from the Bamford Review, being prioritised over the implementation of clinical guideline 42.

Trusts reported that the overall volume of work is increasing for front line staff, who need more help and support if they are to manage the processes for implementation. Due to large case loads and other work pressures, staff advised they had to prioritise their workloads, and on most occasions they had insufficient time to allocate to the implementation of clinical guidelines. Staff indicated their desire to fully implement the clinical guideline 42, as well as their disappointment in being unable to do so, due to lack of capacity in their workload.

Staff in all trusts expressed the view that they had not received enough support from within their organisation to properly implement clinical guideline 42. The specific examples stated were in relation to no additional funding or resources being made available to implement the recommendations within the guideline. These areas were closely linked to staffing levels and availability.

Senior trust staff felt the amount of information, in terms of strategies and guidelines, being simultaneously forwarded for implementation, meant they had to prioritise what they could feasibly do. As there was no formal requirement to implement clinical guideline 42, this was not seen as a priority and subsequently not promoted as a priority within trusts.

2.4 Learning from the Review

Stakeholder Event

In November 2013, as part of the review methodology, RQIA hosted a stakeholder event which was themed 'Sharing Experiences, Improving Care'. It provided an opportunity for a range of HSC staff working in dementia care to: discuss the initial findings from the review; identify learning that may improve the implementation of NICE clinical guidelines; and share areas of good practice linked to clinical guideline 42.

As part of the stakeholder event, three people living with dementia shared their experiences and discussed dementia services within their trust.

The NICE Implementation Facilitator for Northern Ireland provided a presentation outlining the role of NICE, demonstrating how to access clinical guideline 42 and the related implementation tools, and use of other NICE resources.

The Head of Strategy and Delivery (Vulnerable People), NHS Doncaster Clinical Commissioning Group, shared his experiences, supported by practical examples, of implementing clinical guideline 42 to improve dementia services.

The review team also presented the initial findings from the review to the participants, who agreed that the issues identified were an impartial reflection of the current position within the trusts. Participants then had the opportunity to discuss the findings and propose suggestions for improvement, associated with the implementation of NICE clinical guideline 42.

Views and Suggestions Made by Event Participants

Participants were asked to consider two aspects where possible improvements could be made in relation to implementation and use of NICE clinical guidelines. The first was associated with the general release of guidelines and what trusts could do differently to make more use of the guidance. The second was associated with how trusts could make more use

of clinical guideline 42 to support the dementia strategy or the development of dementia services.

General Release of NICE Clinical Guidelines

In relation to the general release of guidelines, participants highlighted suggestions in the following areas:

Awareness - Participants felt there was a need for more awareness raising sessions to inform staff about the availability of NICE clinical guidelines. Raising awareness through staff induction and training was also recommended. They highlighted that there needed to be a supporting document which translates how specific guidelines relate to different people at different levels within their organisation.

Communication - It was suggested that more effective structures and processes needed to be in place for the communication and dissemination of NICE clinical guidelines. Suggestions in this area were: dedicated sections on HSC trusts' intranets for communicating NICE information; simplified links to support access to the information; as well as a specific Northern Ireland section on the NICE website.

Governance - Participants expressed the need for more corporate ownership in relation to the implementation of clinical guidelines. It was suggested that each trust assigns a senior executive as the governance lead for NICE guidelines, with responsibility for updating progress, as a standing agenda item at executive team meetings. It was considered that measurements or indicators relating to implementation should be integrated into governance structures and reported on regularly. Participants felt that implementation groups should be established, with members being assigned specific responsibilities during the implementation of guidelines.

Planning - The need for a planning mechanism was acknowledged. Specifically to try to identify other initiatives in the same area that are ongoing or planned at the same time. Such a mechanism would consider other related guidance or strategies, and identify ways to work collaboratively to achieve implementation.

Culture - Participants recognised that a change in culture associated with NICE guidelines is required, if full implementation of guidelines is to be achieved. It was stated that NICE guidelines had a perceived status within the HSC sector. In particular, NICE information was still perceived as guidance, even though DHSSPS had formally endorsed it as something which was to be implemented and complied with. Participants also felt that NICE champions should be identified to promote the respective guidelines, and that NICE training should become mandatory for staff.

Participants were mindful of the existing challenges associated with the implementation of NICE guidelines, and stressed that investment in resources and time is required for proper implementation.

Issues Specific to NICE Clinical Guideline 42

In relation to making more use of clinical guideline 42, participants considered there were both short and longer term actions that could be taken, and highlighted suggestions in the following areas:

Awareness - Participants felt that raising awareness of clinical guideline 42 would increase its use and made the following proposals:

- hold awareness sessions for staff throughout the trusts, to look at the NICE website and clinical guideline 42
- information regarding clinical guideline 42 should be disseminated to different professional groups, such as social workers and nurses
- to widen the awareness and knowledge of the guideline among other relevant agencies that interact with the dementia care services
- discussion of clinical guideline 42 in team meetings
- incorporate aspects of clinical guideline 42 into personal development plans
- identify aspects of clinical guideline 42 that could be counted towards continuing professional development

Implementation Tools - Following the presentation given by the NICE facilitator at the stakeholder event, participants stated they had a better understanding of the implementation tools. They advised they would explore where they could use the tools within their service, either as part of an evaluation to identify gaps in services or for auditing purposes. It was also suggested that the tools may be used to evidence areas of development within their services.

Integration with the Dementia Strategy - It was noted that clinical guideline 42 was used to inform the dementia strategy; however, during the review it was clear that all staff were not fully aware of this. Participants agreed that both clinical guideline 42 and the dementia strategy should dovetail for the improvement of dementia care services. They suggested that collaborative working may reduce duplication of work. Other suggestions were that:

- trusts discuss the links between clinical guideline 42 and the dementia strategy at team meetings
- clinical guideline 42 be used as guidance and a reference for service improvements
- clinical guideline 42 be used as the evidence base for the work streams of the dementia strategy

At a strategic level, the proposed suggestions were:

- to incorporate clinical guideline 42 into annual service plans
- use the clinical guideline to develop business plans for the development of services
- for DHSSPS to consider the endorsement of the NICE quality standards on dementia and incorporate these into the work streams of the dementia strategy

Other suggestions for using the clinical guideline more effectively, proposed by participants, included: using the guideline as evidence to lobby for additional resources in dementia care services; and updating documentation to incorporate key components of clinical guideline 42.

Sharing Experiences, Improving Care

At the event, the opportunity was provided for trusts to highlight any areas of good practice in dementia care linked to the recommendations from clinical guideline 42.

Each presentation outlined the service/area where clinical guideline 42 was used to promote good practice, a summary of where the guideline was used, and the key improvements to the service as a result of the implementation.

- **Belfast Trust - Dementia Inpatient and Outreach Service**

A Senior Dementia Nurse Specialist from the Belfast Trust outlined the dementia inpatient and outreach service. The aim of the service was to provide an acute inpatient service in conjunction with support and services in the community. The inpatient service provides specialist assessment, treatment and care of people with dementia to enable them to return to the community. The outreach service then provides assistance to enable better care in the community and to prevent unnecessary admission or readmission to hospital.

Inpatient person centred assessments are carried out by a multidisciplinary team, comprising a consultant psychiatrist, a neuro-psychologist, nurses, therapists and social workers. Assessments are evidence based using validated assessment tools, methods and best practice guidance.

The outreach service provides support to nursing and residential homes, follows through on discharged patients, provides support in the community and works closely with the dementia nurse facilitator.

In providing high quality care:

- continuous development and service improvement initiatives are undertaken
- staff are encouraged to maintain a high level of knowledge of dementia and a commitment to the aims of the service
- professional standards are maintained at all times and outcomes are measured in relation to the service being provided
- benefits to patients have included reduced admissions, shorter stays and improved patient and carer experience

- **Northern Trust - Dementia Home Support Team and Inver Model of Care**

A consultant psychiatrist from the Northern Trust outlined the role and benefits derived from the work of the dementia home support team. The team is made up of social workers, behavioural science nurses and support workers, with sessional input from a consultant clinical psychologist. Its aims are to provide comprehensive assessment, providing a better understanding of a person's needs and then to determine how best these needs can be met.

Referencing best practice, the team employs techniques to support people living with dementia to remain at home for as long as possible, reducing hospital admissions and readmissions. The team also provides support to family carers and employed carers. Identified benefits:

- an appropriate level of assessment and intervention
- a better understanding of behaviours that challenge for family carers
- employed carers and all trust staff working with people living with dementia
- the avoidance of unnecessary hospital admissions

The development of the Inver Model of Care was also presented. This outlined how best practice and clinical guideline 42 were used to guide the refurbishment of the ward to become more dementia friendly. The main improvements included:

- themed therapeutic areas
- provision of a more relaxing atmosphere
- enhanced outdoor spaces and additional facilities to improve choice, privacy and dignity
- upgrading lighting and colour signposting, allowing people living with dementia to more confidently mobilise

To complement this, trust guidelines on the use of restraint were updated and implemented, with increased staff training being provided in the areas of management of aggression and challenging behaviour. The trust considered these initiatives as providing a more positive care experience for people living with dementia.

- **South Eastern Trust - Liaison Psychiatry, Mental Health Services for Older People**

A liaison nurse from the South Eastern Trust outlined the development of the liaison psychiatry service within mental health services for older people. This service provides support, education, advice and assessments to departments across all sites, in relation to dementia care.

The team made reference to best practice guidance and the requirements from the NICE quality standards for dementia when developing and delivering its service. They promote a person centred approach to care and champion non-discriminatory practice. By helping to distinguish between dementia, delirium, and depression, the team contributes to the early diagnosis and

treatment of dementia and helps to facilitate follow up by the right people. The advice and support provided in the care of people living with dementia has helped to reduce their length of stay in hospital, and contributed towards their early discharge.

The service also provides education sessions in dementia and delirium awareness and provides information on dementia to staff, people living with dementia and carers. In future, the team plans to overcome some of the obstacles associated with providing dementia care, such as breaking down old habits and attitudes towards dementia, increasing shared care units, and making care units more dementia friendly.

- **Southern Trust - Knowledge is Power - Memory Clinic Information Packs**

The Head of Memory Service from the Southern Trust outlined how best practice was used in the development of a memory clinic information pack. Both service users and practitioners had recognised the fragmented nature of the available information on dementia and how it was shared.

The initial step was to identify all the information currently in use by dementia teams. Staff engaged with people living with dementia and their carers to determine their information needs. Key documents, such as the Northern Ireland Dementia Strategy, Transforming Your Care, the Palliative Care Strategy and other best practice guidance were consulted to identify information requirements and gaps in the provision of information. Various sub-groups were established, which included staff, people living with dementia and their carers, to review the information needs and develop information packs that met those needs.

Two different information packs were developed. A pack for people living with dementia and a pack for carers. The packs contained information on the types of dementia, what happens after diagnosis, practitioners within the dementia care services, and health matters specific to dementia.

At the time of the review, funding had been secured for new information packs, which were being printed. It was planned that all people living with dementia and their carers would be provided with a pack, which could be added to as a person's dementia journey progressed. The packs would ensure that people living with dementia and their carers are better informed and empowered to make decisions about their care.

- **Western Trust - The Memory Assessment Clinic**

A Consultant Clinical Psychologist from the Western Trust presented the memory assessment clinic. The clinic was developed in line with best practice guidance, including clinical guideline 42, the Memory Services National Accreditation Services Programme: Standards (2010), and the regional dementia strategy.

The clinic is staffed by a nurse, social worker, psychiatrist, geriatrician and psychologists, who meet weekly to discuss and assess patients referred to the service.

The clinic aims to comply with the key priorities of clinical guideline 42 by:

- preventing non-discrimination, as all patients have access to the memory assessment service, irrespective of age
- asking all patients for consent prior to the assessment and feedback of results
- identifying a single point of referral for all people with a possible diagnosis of dementia
- requesting neuroimaging to aid diagnosis, when required
- offering carers psychological intervention

The service has facilitated a more focused and streamlined approach by the team, with less overlap between professional roles. There is joint decision making in relation to diagnosis, which delivers prompt decisions, which are unified and more accurate. The result of this teamwork is that people living with dementia have to attend fewer appointments.

The success of the team has seen them win the 'Team of the Year' in the 2012 Northern Ireland Dementia Excellence Awards, and ranked the Western Trust fifth in the UK, in an Alzheimer's study mapping dementia prevalence and diagnosis rates.

2.5 Experiences of People Living with Dementia and their Carers

For people living with dementia, their involvement in the development of services is inherently difficult. Those people who are more able to participate, are likely to be at the start of the dementia journey and likely to have less experience of many of the services. Subsequently their input to any review process would be limited. For those people living with dementia who have progressed further along the dementia journey, although they are likely to have experience of more of the services, they may lack the capacity to fully engage in any review process.

All trusts acknowledged there was no involvement of people living with dementia or their carers, associated with the implementation of clinical guideline 42. However, to varying degrees, there was evidence of involvement from people living with dementia or their carers as part of the dementia strategy or in the local development of services. Some examples included:

- staff consulting with service users in the Belfast and Southern trusts, to obtain their views about the performance of dementia care services
- service users in the South Eastern Trust being involved in a reference group for consultation on the dementia strategy
- the involvement of service users in an audit of the memory clinic and their inclusion in the dementia strategy sub-groups in the Western Trust

- the involvement of service users in the redevelopment of Inver 4 ward in the Northern Trust, and also their involvement in the new ways of working project

The views of people living with dementia and their carers were an integral aspect of the review. The review provided an opportunity for service users and carers to express their views and give their experiences of accessing the dementia care services provided by the trusts. Through focus groups set up by the trusts and Alzheimer's Society, the review team met with people living with dementia and their carers in each of the trust areas.

Sixty one people living with dementia and 74 carers participated in the focus groups to provide information for the review. The following section outlines their personal views expressed on dementia services, which are broadly representative across each trust. RQIA did not validate the views with the trusts during the review.

Diagnosis, monitoring and assessment

An early diagnosis can help people living with dementia get the right treatment and support, and help those people close to them prepare and plan for the future. With treatment and support, many people are able to lead active, fulfilled lives.

Overall, people expressed positive experiences of attending the memory clinics, either for diagnosis, monitoring or assessments. Through attending the clinics, people spoke about getting information and reassurance in relation to their condition, which helped alleviate any concerns or worries. The challenges expressed regarding memory clinics, were more in relation to getting an appropriate referral to the clinic. One example cited, was in relation to the length of time it took for a GP to recognise the need for an assessment.

People reported variations across trusts in relation to the length of time between assessments, which ranged from three to six months and sometimes a lengthier interval. Some carers expressed concern about the number of review assessments and felt they were reducing. Carers felt the follow up assessments should be more frequent.

The biggest area of concern for carers was in relation to their involvement in the assessment process. Many of the carers advised they were not being involved in the assessments. While it was acknowledged there is a need for patient-centred care, many carers felt their relatives lacked the capacity to participate in the assessment alone. Many carers also advised they felt they were not always listened to, especially when they felt they could provide information that would be beneficial to the care of the person living with dementia.

Support after diagnosis

The support provided after diagnosis, is critical to help ensure people are better able to manage their condition. However, from the feedback received, this area had the largest variation between positive and negative experiences. There were instances when people spoke of excellent support from the dementia teams, while others felt there was little or no support available. These comments were common within all trusts.

One area of support that people spoke highly of, were support groups, whether they were organised by the trust or by Alzheimer's Society. People stated they found these groups a pivotal source from which to get information or advice on how to manage dementia, as well as for getting general peer support and help.

Other areas where variations were found were in relation to signposting to other services and the availability of written information about dementia. While some people living with dementia and their carers felt these areas were good, a majority felt they were not adequate, and needed to be improved.

Most people spoke about signposting, and information they received from the Alzheimer's Society and felt it was better than any information received from the trusts. However, it was recognised that some of the trusts have service level agreements in place for the Alzheimer's Society to provide this service.

In relation to the trust provision of services for dementia, people felt they were good but they needed to be more extensive in terms of the number and types of services.

People felt that services and staff were overstretched. However, several people stated they were noticing ongoing improvements within some of the dementia services.

A major issue raised by people in all trusts was in relation to access, availability and quantity of respite and day care. While all carers referred to these services as essential in providing an opportunity for getting a break, they stated they were not readily available. Where respite was available, in all cases, carers advised there were long waiting lists to get access to the arrangements that best suited their needs.

Care in the hospital setting

People living with dementia and their carers also shared their experiences of attending hospital emergency departments and wards. While some people did have a positive experience, the majority of those who attended found the experience to be mostly negative. People told reviewers that staff not being aware a person had dementia was a major contributing factor to the overall negative aspect of their experience. Some people related how staff had seen them as difficult or aggressive, simply because this was how their condition

presented. Staff didn't know about their dementia nor how to manage them or the situation.

Interviewees considered that being made aware of a person's dementia does make a difference. Several people spoke of positive hospital experiences, especially in relation to how staff treated them. In one of these scenarios, it was stated this was as a direct result of the Butterfly Scheme[8].

The butterfly scheme aims to improve the hospital experience for people living with dementia. By placing a butterfly symbol on a person's file, it identifies and prompts staff to follow a special response plan. This will ensure the care provided takes into account the person's dementia and allows staff to apply practical strategies to support the patient in a person centred way.

The Northern, Southern and South Eastern trusts had launched the butterfly scheme in September 2013 and the Belfast trust was about to launch a pilot of the scheme in the Mater hospital. This scheme was proving successful and had gained significant recognition through the Dementia Services Development Centre. The Western Trust already had a similar scheme in operation, known as the Purple Folder scheme.

People expressed the view that simply knowing that someone has dementia is not enough. Staff must also be properly trained in how to interact with and manage someone diagnosed with dementia. The majority of people raised concerns, when speaking about negative experiences. People felt the majority of hospital staff were not properly trained in dementia care. Some of the examples expressed involved staff avoiding the patient, and staff contacting the patient's relatives asking them to come to the hospital to look after the patient.

Care in other settings

A number of people also expressed their views about the care they had received in other settings, such as, their own home or in care homes.
For those people living with dementia, that were living independently or being cared for at home, they referenced home care services. They considered the length of time was not sufficient, and on many occasions it was provided at the wrong time to suit their needs. Some people also felt the help required for emergency situations was not adequate, or just not available.

The feedback regarding people living with dementia, who were in a care home setting, was similar to the experiences expressed in relation to the hospital setting. People stated they felt that staff were not properly trained to interact with and manage someone diagnosed with dementia.

[8] The butterfly scheme provides a system of identification for the care and support of people living with dementia in hospital - http://butterflyscheme.org.uk/

Voluntary sector support

During all meetings conducted as part of the review, people referenced the work of the Alzheimer's Society. They stated that the Alzheimer's Society always made information readily available and were able to signpost them to other services. People also identified the help, support and advice they provided. Many people stated that without the services and support they received from the Alzheimer's Society, they could not have coped with the news of the diagnosis, and the progressive deterioration of their condition.

The key areas where people reflected positive experiences were:

- attending the memory clinics, including receiving reassurance in relation to their condition
- the support groups available
- the trusts' provision of services for dementia, however, they felt there needed to be more
- the support provided by the Alzheimer's Society

The areas where people reflected less positive experiences were:

- getting an appropriate appointment from their GP to the memory clinic
- the carers limited involvement in the assessment process
- signposting to other services and the availability of written information about dementia
- the access, availability and quantity of respite and day care
- hospital staff not being aware a person had dementia
- the lack of staff trained in dementia care
- the lack of nursing and care home staff trained in dementia care

While the views of people living with dementia and their carers are broadly representative of each trust, each individual comment may not directly relate to all trusts.

Section 3 - Conclusion and Recommendations

3.1 Conclusion

The release of the updated NICE clinical guideline in 2011 for dementia came at a time of significant change. Arrangements for a new process for managing NICE guidance were being put into practice and the launch of the regional dementia strategy was imminent. Both of these factors impacted on the implementation of clinical guideline 42.

It is recommended that prior to release of future NICE clinical guidelines, DHSSPS should review and take account of other guidance, strategies or ongoing reviews in the same area, to determine how to maximise the benefit of implementation of clinical guidelines in service improvement.

On 27 September 2011, the CMO issued circular HSC (SQSD) (NICE) 31/2011 to all HSC organisations, which was subsequently circulated at a senior level within the respective organisations. Prior to this, trusts had no formal mechanism for dissemination of clinical guidelines. Until the issue of the DHSSPS circular, dissemination was in keeping with each trusts normal distribution process for communications.

At an operational level, in the period after release, the onward circulation of clinical guideline 42 to staff was limited. However, the current situation is that all trusts now have organisational policies and formal mechanisms in place for the dissemination, implementation, monitoring and assurance of NICE clinical guidelines.

Full implementation of a NICE guideline is not anticipated to happen quickly, and may take several years. Therefore a structured approach to implementation should be adopted.

It is recommended that trusts utilise the appropriate recommendations from NICE clinical guidelines to inform the process of planning future changes to services.

To facilitate implementation of clinical guideline 42, NICE developed associated implementation tools and resources. These are designed to help with initial assessments of services, development of action plans, and associated training, as well as auditing and reporting on progress.

It is recommended that trusts fully utilise the appropriate NICE implementation tools when making changes to services.

Some trusts demonstrated that work had been undertaken on a baseline assessment of services and action plans associated with clinical guideline 42. Other trusts evidenced baseline assessments within dementia care services linked to the dementia strategy.

It is recommended that trusts share their proposed approaches to taking forward the implementation of NICE clinical guidelines and, where appropriate, develop a common approach.

Nine key priorities for implementation are outlined within clinical guideline 42. All trusts reported that changes to services had been undertaken in the areas of the nine key priorities, although they stated that none of the changes were specifically implemented as a result of clinical guideline 42. Some trusts did inform the review team that the changes implemented were in line with clinical guideline 42, but did not provide evidence of formal assessment or audit to support this. During staff interviews, the developments in services were clear, although it was evident that the dementia strategy, rather than clinical guideline 42, was the main driver for the changes.

Areas were identified within the key priorities where trusts had no planned changes to services. These were in the areas of non-discrimination, valid consent and structural imaging for diagnosis. Trusts outlined the reasons and mitigating circumstances that had prevented them from implementing changes in these areas.

In all trusts, there was a general lack of knowledge of NICE implementation tools. Most staff interviewed were not aware that such tools existed. Others were of the view that the NICE website was difficult to navigate and felt the implementation tools were not easily accessible. A reference to using the tools was only expressed on a limited number of occasions. Following the stakeholder event, participants stated they would consider using them in the future.

It is recommended that trusts consider further awareness sessions for staff in relation to clinical guideline 42.

It is also recommended that NICE clinical guidance 42 forms part of the staff induction programme for new staff coming into dementia care services.

Trusts were able to demonstrate the provision of wide-ranging training programmes in dementia care, linked to the dementia strategy.

None of the trusts evaluated the implementation of clinical guideline 42 directly, but some evaluations of changes to services were carried out in line with the dementia strategy.

Trusts referenced barriers to implementation of clinical guideline 42. The main factors that impacted on the overall implementation of clinical guideline 42, at the time it had been released, were the imminent introduction of the new process for the implementation of NICE guidance and the release of the dementia strategy.

Trusts also reported that the overall volume of work for front line staff is increasing, and considered that there was a need for more help and support

to manage the processes for implementation. Staff indicated their desire to fully implement the guidelines, as well as their disappointment in being unable to do so, as they frequently had to prioritise their workload.

Staff in all trusts expressed the view that there was not enough support from within their organisation to properly implement clinical guideline 42, particularly in relation to no additional funding or resources being made available.

In November 2013, as part of the review methodology, RQIA hosted a stakeholder event which was themed 'Sharing Experiences, Improving Care'. It provided an opportunity for a range of HSC staff working in dementia care to discuss the initial findings from the review, identify learning that may improve the implementation of clinical guidelines, and share areas of good practice linked to clinical guideline 42.

Participants at the event were asked to consider the information presented, and propose suggestions where possible improvements could be made in relation to NICE clinical guidelines.

In relation to the general release of NICE guidance, participants suggested improvements in the planning, awareness and communication of guidelines, the governance process, and the culture of organisations in relation to NICE guidelines.

In relation to making more use of clinical guideline 42, participants suggested improvements in raising awareness of the guideline, utilising the implementation tools, and further integration of the guideline with the dementia strategy.

All trusts presented an area of good practice at the event. Each presentation outlined the service/area where clinical guideline 42 was used to create good practice, a summary of where the guideline was used, and the key improvements to the service as a result of the implementation.

It is recommended that trusts develop a mechanism to facilitate the sharing of areas of good practice.

All trusts acknowledged that there was no involvement of people living with dementia or their carers, associated with the implementation of clinical guideline 42. However, to varying degrees, there was evidence of involvement from people living with dementia or their carers in the local development of services.

The views of both people living with dementia and their carers was an important aspect of the review. Through focus groups set up by the trusts and Alzheimer's Society, the review team met with people living with dementia and their carers.

At the meetings, people discussed the positive and negative experiences of using dementia care services for diagnosis, monitoring and assessment, the support they received after diagnosis, the care they received in the hospital setting and in other settings, and the support from voluntary sector organisations.

It is recommended that trusts review the comments made by people living with dementia and their carers, and where applicable, address any concerns raised.

Significant developments are currently being undertaken within dementia care services, which will complement good practice. These developments are linked to the implementation of the dementia strategy. Clinical guideline 42 provides the evidence base which underpins the strategy. The implementation tools can assist organisations to implement both clinical guideline 42 and the dementia strategy to improve services for people living with dementia.

Acknowledgements

RQIA wishes to thank the people living with dementia, their carers and the management and staff from the HSC Board and trusts for their cooperation and invaluable contribution to this review.

3.2 Summary of Recommendations

Recommendations

1. Prior to release of NICE clinical guidelines, the DHSSPS should review and take account of other guidance, strategies or ongoing reviews in the same area, to determine how to maximise the benefit of implementation of clinical guidelines in service improvement.

2. Trusts should utilise the appropriate recommendations from NICE clinical guidelines to inform the process of planning future changes to services.

3. Trusts should fully utilise the appropriate NICE implementation tools when making changes to services.

4. Trusts should share their proposed approaches to taking forward the implementation of NICE clinical guidelines and, where appropriate, develop a common approach.

5. Trusts should consider further awareness sessions for staff in relation to clinical guideline 42.

6. Trusts should include NICE clinical guidance 42 as part of the staff induction programme for new staff coming into dementia care services.

7. Trusts should develop a mechanism to facilitate the sharing of areas of good practice.

8. Trusts should review the comments made by people living with dementia and their carers and where applicable address the concerns raised.

Appendix 1 - DHSSPS Circular HSC (SQSD) (NICE) 31/2011

From the Chief Medical Officer
Dr Michael McBride and the
Chief Social Services Officer
Mr. Sean Holland

Department of Health, Social Services and Public Safety
www.dhsspsni.gov.uk

Circular HSC (SQSD) (NICE) 31/2011

Subject: NICE Clinical Guideline CG 42 – Dementia: Supporting people with dementia, and their carers, in health and social care

Circular Reference: HSC (SQSD) (NICE) 31/2011

Date of Issue: 27 September 2011

For action by:
Chief Executive of HSC Board – **for distribution to:**
Director of Performance Management & Service Improvement
Director of Social Services
Director of Commissioning
Assistant Directors of Commissioning
Head of Pharmacy and Medicines Management
Family Practitioner Services Leads – for cascade to relevant Family Practitioner groups

Chief Executive of Public Health Agency – **for distribution to:**
Director of Public Health
Director of Nursing

Chief Executives of HSC Trusts – **for distribution to:**
Medical Directors – for cascade to relevant staff
Directors of Social Services – for cascade to relevant staff
Directors of Nursing – for cascade to relevant staff
Heads of Pharmaceutical Services – for cascade to relevant staff
Directors of Acute Services – for cascade to relevant staff
HSC Clinical and Social Governance Leads

Chief Executives of HSC Special Agencies and NDPBs

For Information to:
Chair of HSC Board
Chair of Public Health Agency
Chairs of HSC Trusts
Chief Executive, Regulation & Quality Improvement Authority
Chief Executive Patient and Client Council
Chief Executive/Postgraduate Dean, NIMDTA
Chief Executive, NICPLD
Chief Executive, NIPEC
Chair, RMSG

Related documents
See para 7 below

Superseded documents
None

Summary of Contents:

This guideline makes recommendations on supporting people with dementia, and their careers, in health and social care, and it incorporates recommendations from NICE's technology appraisal on donepezil, galantamine, rivastigmine and memantine for treating Alzheimer's disease.

Status of Contents:
Action

Enquiries:
Any enquiries about the content of this Circular should be addressed to:
Standards & Guidelines Quality Unit
DHSSPS
Room D1.4
Castle Buildings
Stormont
BELFAST
BT4 3SQ

SGU-NICEGuidance@dhsspsni.gov.uk

Implementation:
To take account of this guideline in the planning and delivery of services to people with Dementia.

Additional copies:
Available to download from
http://www.dhsspsni.gov.uk/index/phealth/sqs/sqsd-guidance.htm

Working for a Healthier People

Chief Medical Officer Group

Dear Colleagues

NICE Clinical Guideline CG42 – Dementia: Supporting people with dementia, and their carers, in health and social care

This guideline makes specific recommendations on Alzheimer's disease, dementia with Lewy bodies (DLB), frontotemporal dementia, vascular dementia and mixed dementias, as well as recommendations that apply to all types of dementia. Dementia in Parkinson's disease shares a number of similarities with DLB. Although the evidence base for dementia in Parkinson's disease was not examined specifically in the context of this guideline, the recommendations for DLB may be useful when considering treatments for dementia in Parkinson's disease. NICE has also produced a clinical guideline on Parkinson's disease (available from http://www.nice.org.uk/CG035).

The dementia guideline covers both health and social care and was jointly developed by NICE and the Social Care Institute for Excellence (SCIE). It incorporates recommendations from NICE's technology appraisal of donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (http://www.nice.org.uk/TA111).

Amendment March 2011

The clinical guideline has been amended to incorporate the updated NICE technology appraisal of drugs for Alzheimer's disease, published in March 2011.

NICE has amended and reissued the technology appraisal guidance on donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (available from http://www.nice.org.uk/TA217).

The review and re-appraisal of donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease has resulted in a change in the guidance. Specifically:

- donepezil, galantamine and rivastigmine are now recommended as options for managing mild as well as moderate Alzheimer's disease; and
- memantine is now recommended as an option for managing moderate Alzheimer's disease for people who cannot take AChE inhibitors, and as an option for managing severe Alzheimer's disease.

DHSSPS advises that this guidance is valid for Northern Ireland and endorses it for implementation in HSC.

The full NICE guidance is available for download at:
http://www.nice.org.uk/cg42

The HSC sector should also note that:

1. The Department expects the HSC sector to take account of this clinical guideline in the planning and delivery of services to people with Dementia.

2. The cost associated with the implementation of the NICE guideline is unlikely to be significantly additional to the cost of implementing the NI Dementia Strategy.

3. The Mental Capacity Act 2005 and the Department of Health document 'Reference Guide to Consent for Treatment or Examination' do not apply in NI, but work is under way to bring forward similar legislation for NI, incorporating mental capacity

and mental health provisions. The DHSSPS guidance 'Reference Guide to Consent for Examination, Treatment or Care (2003)', which is available on the DHSSPS website, gives advice on determining whether a person has capacity and on what action may be taken where the person lacks capacity. Available from: http://www.dhsspsni.gov.uk/consent-referenceguide.pdf

4. Where the guidance refers to the Mental Health Act, this should be interpreted within the Northern Ireland legal framework of the Mental Health (Northern Ireland) Order 1986. Available from: http://www.opsi.gov.uk/RevisedStatutes/Acts/nisi/1986/cnisi_19860595_en_1

5. This advice does not override or replace the individual responsibility of health professionals to make appropriate decisions in the circumstances of their individual patients, in consultation with the patient and/or guardian or carer. This would, for example, include situations where individual patients have other conditions or complications that need to be taken into account in determining whether the NICE guidance is fully appropriate in their case;

6. NICE has developed tools to help organisations implement this guidance. These are available at http://www.nice.org.uk/cg42 and include costing tools, implementation advice and audit criteria to monitor local practice;

7. NICE has published related guidance listed on page 26 of the NICE Quick Reference Guide which can be accessed at: http://www.nice.org.uk/nicemedia/live/10998/30317/30317.pdf

8. **All NICE guidance endorsed by the Department to date can be accessed on the DHSSPS website at:** http://www.dhsspsni.gov.uk/sqsd-guidance-nice-guidance

Circular HSS (PPMD) (NICE) 01/06 issued on 30 June 2006 provides further information on the Northern Ireland process for reviewing NICE guidance and further details on the local status of the Institute's guidance. This circular can be accessed at: http://www.dhsspsni.gov.uk/nice_guidance_01-06.pdf

DR MICHAEL McBRIDE
Chief Medical Officer

MR SEAN HOLLAND
Chief Social Services Officer

Appendix 2 - Abbreviations

Belfast Health and Social Care Trust (Belfast Trust)

Chief Medical Officer (CMO)

Computerised Tomography (CT)

Department of Health, Social Services and Public Safety (DHSSPS)

Health and Social Care (HSC)

Magnetic Resonance Imaging (MRI)

National Health Service (NHS)

National Institute for Health and Care Excellence (NICE)

Northern Health and Social Care Trust's (Northern Trust)

Positron Emission Tomography (PET)

Regulation and Quality Improvement Authority (RQIA)

South Eastern Health and Social Care Trust (South Eastern Trust)

Southern Health and Social Care Trust (Southern Trust)

Western Health and Social Care Trust (Western Trust)

The **Regulation** and **Quality Improvement** Authority

The Regulation and Quality Improvement Authority
9th Floor
Riverside Tower
5 Lanyon Place
BELFAST
BT1 3BT

Tel: (028) 9051 7500
Fax: (028) 9051 7501
Email: info@rqia.org.uk
Web: www.rqia.org.uk

ISBN 978-1-908660-33-6